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## **The role of peer support in adolescents with type 1 diabetes**

Submitted for the Degree of  
Doctor of Philosophy  
At the University of Northampton

2015

Emily Louise Doe

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### Abbreviations

<b>ADH</b>	Antidiuretic hormone
<b>ANOVA</b>	Analysis of variance
<b>ANS</b>	Autonomic nervous system
<b>AWT1D</b>	Adolescents with type 1 diabetes
<b>BGM</b>	Blood glucose monitoring
<b>BMI</b>	Body mass index
<b>BSSS</b>	Berlin Social Support Scale
<b>CD-RISC 10</b>	10 Item Resilience Scale
<b>CD</b>	Coeliac disease
<b>CGM</b>	Continuous glucose monitoring
<b>CNS</b>	Central nervous system
<b>CSII</b>	Continuous subcutaneous insulin infusion
<b>DAFNE</b>	Dose Adjustment for Normal Eating study
<b>DAWN</b>	Diabetes Attitudes Wishes and Needs study
<b>DCCT</b>	The Diabetes Control and Complications Trial
<b>DKA</b>	Diabetic ketoacidosis
<b>DSSI</b>	Diabetes Social Support Interview
<b>DSSQ-Friends</b>	Diabetes Social Support Questionnaire – Friends Version
<b>GD</b>	Gestational diabetes
<b>HBSC</b>	Health Behaviour in School-Aged Children study
<b>HNS</b>	Hypothalamo-neuropophysial system
<b>HPA</b>	Hypothalamic-pituitary-adrenal
<b>HRQoL</b>	Health-related quality of life
<b>MANCOVA</b>	Multivariate analysis of covariance
<b>MDI</b>	Multiple daily injection
<b>NICE</b>	National Institute for Health and Care Excellence
<b>OT</b>	Oxytocin
<b>OTR</b>	Oxytocin receptor
<b>PVN</b>	Paraventricular nuclei of the hypothalamus
<b>QoL</b>	Quality of life
<b>SDH</b>	Social determinants of health
<b>SES</b>	Socioeconomic status
<b>SON</b>	Supraoptic nuclei of the hypothalamus
<b>STTP</b>	Structured treatment and teaching programme
<b>T1D</b>	Type 1 diabetes
<b>T2D</b>	Type 2 diabetes
<b>VP</b>	Vasopressin
<b>WHO</b>	World Health Organisation
<b>WHO-5</b>	WHO-5 Well-being Index
<b>WHOQoL</b>	World Health Organisation Quality of Life group

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## Abstract

Despite a wealth of research which has taken place aiming to improve self-care in adolescents with type 1 diabetes, a paucity of studies could be identified assessing the utility of support provided by peers. This is in spite of evidence which suggests that, for older adolescents, it is peers who provide the greatest support and are therefore likely to offer a weightier resource towards effective self-care (Cattelino et al., 2014; Choukas-Bradley, Giletta, Widman, Cohen, & Prinstein, 2015; Mercken, Steglich, Sinclair, Holliday, & Moore, 2012; Pezzulo et al., 2013; Visser, de Winter, Veenstra, Verhulst, & Reijneveld, 2013). The current thesis therefore represents a significant attempt to understand the role of peer support in adolescents with type 1 diabetes.

This doctoral research comprises three studies utilising a mixed methods design. Study 1 employs mixed methodology to understand the lived experience of peer support in a clinical sample. Whilst global peer support was found to be positively related to improved psychosocial and diabetes outcomes, diabetes-specific support was found to be higher in those with poorer glycaemic control. Indeed, when diabetes-specific support behaviours were discussed in semi-structured interviews, these behaviours were labelled as unwanted, harrssing and nagging. These findings together indicate the potential for global peer support to offer maintenance of a normal self-concept. Study 2 proposes and assesses an adaptation of the stress-buffering hypothesis (S. Cohen & Wills, 1985) specifically focusing on the psychophysiology of peer support in relation to glycaemic control. Findings suggested that this mechanism was not significant, though limitations with the methodology are acknowledged. Instead, a positive role of stress in relation to improved glycaemic control was found in male, but not female, participants. These results lend support to assertions regarding individualised care plans. Finally, Study 3 assesses the comparability of psychosocial experience between a clinical and reference population of adolescents. Despite differences in peer support, adolescents with and without type 1 diabetes achieve a markedly similar psychosocial profile, minimising the impact of type 1 diabetes on the lives of adolescents. Therefore, the desire for normality outlined in Study 1 seems to be achieved for the most part.

Overall, the findings indicate a role for peer support in the attainment and maintenance of a normative self-concept, separate from the sick role. This thesis suggests that peer support offers a different utility to parental support, and is worthy of further investigation. Taken together, these studies underline the importance of considering the person-centred nature of care, with emphasis on the potential benefit of individualised care plans, and particular attention paid to age and gender differences.

## Chapter 1: Introduction

Adolescence<sup>1</sup> is a period of major physiological and psychological changes, characterised by an effort in young people to establish their identity and independence (Sawyer et al., 2012). Adolescence is a complex maturational and developmental process with great variation across individuals and cultures (Chulani & Gordon, 2014). Successful passage through this portal to adulthood results in biological maturity, a secure sense of self, the ability to enjoy close friendships and group belonging, and the mental capacity to deal with the onslaught of life's challenges. However, establishment of these crucial markers of adult identity during a developmental stage fraught with physical, social and emotional change can result in a particularly difficult period in a young person's life (Smetana, Campione-Barr, & Metzger, 2006; Steinberg & Morris, 2000).

For health psychologists, adolescence poses a particular stage of interest, as it is during adolescence that future patterns of health behaviours<sup>2</sup> are established and reinforced, which will follow through to adulthood and impact prospective actions (Sawyer et al., 2012). In addition, adolescents with a long-term health condition must also engage in self-care<sup>3</sup>. Much like health behaviours, research indicates that the self-care behaviours established during adolescence become habitual and are repeated throughout adulthood (Sawyer, Drew, Yeo, & Britto, 2007). Therefore, it is essential in the management of chronic conditions that effective self-care is established prior to reaching adulthood to positively influence disease trajectory in later life. In addition, it is acknowledged that adolescents with chronic conditions tend to have poorer social outcomes than their healthy peers (D. Stewart, Antle, Healy, Law, & Young, 2007). It is increasingly recognised that the social correlates of health may play an important part in effective self-care (Emerson & Hatton, 2007), with some studies indicating that adolescents with chronic conditions are less likely to receive adequate social support, potentially due to a sense of isolation and difference (Gannon & Nolan, 2006; Jenkins & Rigg, 2003; Wolman, Resnick, Harris, & Blum, 1994). Overall, the social outcomes of adolescents with a chronic health condition are particularly poor, with literature indicating they receive less social support, social contact with friends, and are less satisfied with their spare time activities (Emerson, Honey, Madden, & Llewellyn, 2009).

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<sup>1</sup> Young people aged 10-19 (World Health Organisation, 2001).

<sup>2</sup> Actions which could be considered health-promoting (e.g. exercise) or health-compromising (e.g. smoking) (Conner & Norman, 2005).

<sup>3</sup> The medical and psychological monitoring, control and minimisation of the impact of a disease on health and functioning (Clark et al., 1991; Lorig & Holman, 2003).

Researchers agree that social support<sup>4</sup> has long-term consequences for a range of well-being measures, and specifically with respect to health, including reduced risk to illness and improved recovery from it (Holt-Lunstad, Smith, & Layton, 2010). In adolescence, this concept is more complex, as evidence suggests that for those aged 15 and over, it is peers, as opposed to family members, who provide the greatest social support and are therefore a greater influence in health behaviour, such as self-care (Cattelino et al., 2014; Choukas-Bradley et al., 2015; Mercken et al., 2012; Pezzulo et al., 2013; Visser et al., 2013). Literature suggests that peer influence in long-term health conditions is not always positive, with implicit and overt peer pressure to avoid self-care prevalent (Thomas, Peterson, & Goldstein, 1997). Thus, during adolescence, the greatest source of social support may not always be beneficial in terms of health outcomes. Despite this, a paucity of research has investigated the role played by peer support in adolescents with long-term health conditions (Palladino & Helgeson, 2012).

The prevalence of chronic conditions in adolescence is difficult to determine, though data suggests the most common conditions include obesity, asthma and type 1 diabetes (Michaud, Suris, & Viner, 2007). Type 1 diabetes (T1D) is a lifelong metabolic disorder that is treated with a complex regime of insulin replacement and lifestyle adjustments, and can greatly affect the lives of the adolescent and his/her family (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009). Glycaemic control usually deteriorates during adolescence (Wallander, Fradkin, & Scott, 2013; Wherrett, Huot, Mitchell, & Pacaud, 2013). Although this deterioration is partly related to the hormonal changes of puberty, and to psychosocial and behavioural changes, non self-management behaviours are also a contributing factor, as is lack of knowledge regarding the illness and its treatment (Du Pasquier-Fediaevsky, Chwalow, & Tubiana-Rufi, 2005). With findings suggesting that mortality in young females with T1D is approximately 9 times higher than the population rate, and 4 times higher in males, research into improving diabetes care is a major public health concern (National Health Service, 2011).

The American Diabetes Association (ADA) has stated that the assessment of social situations is an integral part of the on-going management of diabetes, with screening for sufficient social resources a specific recommendation for optimal care (American Diabetes Association, 2010). Indeed, recent guidance from The National Institute for Health and Care Excellence (NICE) in paediatric diabetes care also calls for further research into the efficacy of peer support interventions in adolescents (National Institute for Health and Care Excellence, 2015). However, the mechanisms of operation through which peer support can impact on glycaemic control is less clear and it is likely that it may rely on multiple mechanisms. For example, the mechanism of operation may be social, emotional or biological in nature. Previous

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<sup>4</sup> The assistance and protection given to others. Assistance can be tangible, such as financial aid, or intangible, as in emotional support (Wills, 1985).

research has stated that social networks are a significant source of informational support regarding diagnoses, treatment, expectations and complications in diabetes (Palladino & Helgeson, 2012). It has also been stated that social networks diminish the stress elicited by the disease through offering emotional support (S. Cohen, Gottlieb, & Underwood, 2000). A third explanation points to coping strategies enabled by peer support, providing improved likelihood that the patient will successfully endure stressful events through maintaining effectual self-care and thereby reducing the likelihood that the event will result in poor health (Sarason, Sarason, & Gurung, 1997). Whether the support provided is emotional, instrumental or functional, what is clear is that peer support is strongly related to diabetes outcomes in this at-risk group.

This thesis, therefore, will utilise quantitative, qualitative and biological measures to better understand the role of peer support in glycaemic control, and investigate the possible mechanisms through which peer support is related to improved psychosocial and health outcomes in adolescents with type 1 diabetes (AWT1D). The data presented in this thesis reflects the complexity and specificity of peer support, and will consider this multifaceted concept from an affective as well as biological standpoint. This will identify the facets of peer support most beneficial to AWT1D, which would serve as promising candidates for the target of support interventions aiming to improve psychosocial and health outcomes during this difficult developmental stage.



## Chapter 2: Health in Adolescence

### 2. Overview

This chapter will contextualise the developmental stage of adolescence from a health perspective. Within this, the biological, hormonal, neural and cognitive changes which typify this period are outlined. Pertinently, the social development of adolescents will then be discussed, with particular focus as to how the aforementioned biological and social changes are related to health outcomes. Finally, the concept of adolescence as a foundation for future health will be addressed, providing rationale as to why this developmental stage is seen amongst healthcare professionals as a crucial intervention point with the hope of instilling health-promoting<sup>5</sup> behaviours that last into adulthood.

### 2.1. Introduction

The current generation of adolescents is the largest in history, with 1.8 billion people aged between 10-24 years; a quarter of the world's population (World Health Organization, 2014). Definitions of adolescence are typically concerned with age and social roles, though little consistency exists between countries (Sawyer et al., 2012). In academia, researchers tend to characterise adolescents as those aged 10-19 years; this group encompass most going through the biological and social transitions and changes associated with puberty that have historically defined adolescence. This intentionally broad definition encompasses cultural and legal differences in definitions of adolescence seen in other fields (World Health Organisation, 2001).

Adoption of a life-course perspective suggests that health behaviours and health outcomes in adolescence are able to enact a long-lasting effect on the future health of young people (Sawyer et al., 2012). Within this life-course approach, adolescence presents a critical period of prevention in which opportunities for avoidance of non-communicable diseases, mental disorders, injuries and the proper management of chronic conditions are elicited from risk-processing established during adolescence (Lawrence et al., 2008; Temin & Levine, 2009). The reasons for the sensitivity of this time include social embedding of health risks and biological development occurring before, during and beyond puberty (Sawyer et al., 2012).

### 2.2. Biological development

Puberty is a highly programmed and biologically determined process able to affect behaviour, well-being and health in intricate interactions. Puberty is associated with increasing health-related behaviours and mental health states during adolescence (G. C. Patton & Viner, 2007). These adaptations in behaviour during puberty may be partly caused by changes in the regulation of oxytocin in females and vasopressin in males, which are linked to social

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<sup>5</sup> Routines and habits aiming to promote health and prevent illness. These range from engagement with exercise and maintaining an appropriate BMI, to achieving the appropriate amount of sleep (Belloc & Breslow, 1972; Ford, Bergmann, Boeing, Li, & Capewell, 2012; Frech, 2012).

attachment, pair-bonding and parental behaviours (Insel, 1997). Puberty, therefore, has been categorised as a crucial initiator in the establishment of health behaviours which last throughout adolescence and are typically carried into adulthood (Michaud et al., 2007; Suris, Michaud, Akre, & Sawyer, 2008; Viner et al., 2012).

### **2.2.1. Puberty**

Puberty is defined as the biological timeframe in which a juvenile's gonads (testes or ovaries) are activated, causing distinct hormonal changes. These hormones (oestrogens and progesterone for females, androgens for males) initiate physical and psychological changes with the aim of achieving reproductive competence. Puberty precedes adolescence, with the typical age of onset at 7-12 years for females, and between 8-13 years for males (Cohen & Ball, 2007). Adolescence denotes the period in which puberty has begun, but due to the sociocultural factors of society, the individual is not accepted as mature (Gluckman, Low, & Franko, 2011). This discrepancy has been termed the 'mismatch of puberty' and research has suggested that it is a major driver of adolescent morbidity (Hales & Barker, 2013). In females, the completion of puberty is considered as the onset of menarche. An earlier occurrence of menarche, and therefore a greater pubertal mismatch, is associated with an increased likelihood of engagement in health-compromising behaviours<sup>6</sup>, such as early onset of sexual activity, smoking, alcohol consumption, drug use, aggression and eating disorders (Hales & Barker, 2013; Law, Barker, Osmond, Fall, & Simmonds, 1992; Ong, Ahmed, Emmett, Preece, & Dunger, 2000). This risk is significantly increased when age of menarche is below 11 years of age (Gluckman et al., 2011). In males, an early onset of puberty has also been related to an increased risk of health-compromising behaviours including increased aggression, substance abuse, sexual activity, depression, anxiety and suicidality (Mendle & Ferrero, 2012). Previous research has, therefore, indicated that early onset of puberty is associated with an increase in adolescent morbidity and overall poorer health decisions (Eriksson, 2006; Mendle & Ferrero, 2012; Mendle, Turkheimer, & Emery, 2010).

The physical changes associated with puberty are reflected in the increased sex hormones present in the circulation. As well as impacting appearance and sexual function, puberty also affects the brain, aiding cellular signalling pathways and increasing numbers of vascular cells (Krause, Duckles, & Pelligrino, 2006). Therefore, puberty is also associated with brain development, and in particular enhanced cognitive function.

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<sup>6</sup> Acts which increase the risk of poor health, such as smoking and excess alcohol consumption (Gallant, 2014).

### 2.2.2. Neural and cognitive development

A growing interest is noted in understanding how puberty affects a developing brain (Blakemore, 2012). Animal research suggests pubertal hormone events exert influence over brain maturation and behaviour, able to alter perception, motivation, independence and enable reproductive behaviours (Blakemore, Burnett, & Dahl, 2010). Researchers have, therefore, tentatively suggested that hormonal events during puberty may also affect the structure and function of the human brain (Blakemore et al., 2010).

The prefrontal cortex<sup>7</sup> - where executive control is observed including planning, emotional regulation, decision making, multitasking and self-awareness – undergoes the most extended development. These changes may be able to explain the gradual increase in self-control as an adolescent approaches adulthood (Shaw et al., 2008). Conversely, the limbic system<sup>8</sup>, responsible for reward processing, appetite and pleasure seeking, develops far earlier (B. J. Casey, Getz, & Galvan, 2008). The disproportion in development of the prefrontal cortex and limbic system occurs during adolescence. The observed increase in risk-taking behaviours, some of which may be health-compromising, may be attributable to a discrepancy that would favour emotion and reward over rational decision (B. J. Casey et al., 2008; Herman-Stahl et al., 2008).

Poor decision-making in relation to health during adolescence was previously blamed on a lack of intellectual maturity. However, research has suggested that adolescents are fully aware of the risk to their health. Adolescents would appear to be more influenced by exciting or stressful situations when making decisions than adults, especially in the presence of peers (Steinberg, 2008). Increased activity in the nucleus accumbens<sup>9</sup>, associated with reward, pleasure and emotion, is suggested as linked to these behaviours (Galvan et al., 2006). These findings are consistent with sensation-seeking; a willingness to engage in risky behaviours to attain stimulating experiences (Zuckerman, 2009). This is an important mediator for risk-taking behaviour which increases between 10-15 years old, suggesting an influence of puberty in this heightened orientation towards the opinions and actions of peers (Galvan et al., 2006). It may therefore be suggested that adolescents may be biologically predisposed by neural processing towards being influenced by their social networks to a greater extent than in childhood, or as an adult (Galvan et al., 2006).

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<sup>7</sup> The section of the cerebral cortex covering the anterior of the frontal lobe, typically associated with personality (DeYoung et al., 2010).

<sup>8</sup> A complex set of brain structures located under the cerebrum, alongside the thalamus. It is a collection of structures including the olfactory bulbs, hippocampus and amygdala, among others. The limbic system functions via the endocrine and autonomic nervous systems (Marieb & Hoehn, 2014).

<sup>9</sup> A region in the basal forebrain and a part of the basal ganglia. The nucleus accumbens plays a significant role in the cognitive processing of pleasure, impulsivity and fear; thus its involvement in risk (Marieb & Hoehn, 2014).

### **2.3. Social development**

Adolescent progression to adulthood occurs within a complex network of familial and peer relationships operating at a community, societal and cultural level (Viner et al., 2012). In recent years, focus on adolescent health has shifted upstream from the individual to the social patterns and structures that are able to influence health. Known as social determinants of health (SDH), these theories focus on social contexts and conditions which translate into health effects (Commission on Social Determinants of Health, 2008). SDH will contribute to a person's health across their lifetime, though some are particularly salient during adolescence. At the forefront of SDH are risk and protective factors. These operate at a peer, school and community level. These risk and protective factors are able to interact with structural determinants to positively and negatively influence adolescents' health-related behaviours (Catalano et al., 2012). This can be seen in the individual domain, wherein intelligence, sexual orientation or personality has been found to lead to negative peer relationships including bullying, which has in turn been found to increase the likelihood of engagement in health-compromising behaviours such as substance misuse, unsafe sex, depression, antisocial behaviour and neglect of pre-existing health conditions (Bond, Carlin, Thomas, & Patton, 2001; Herrenkohl et al., 2000). Thus, adolescence can be seen as a crucial time able to promote or hinder peer relationships, emotional control and health. Recently, research has moved beyond risk factors to focus on what may protect adolescents from harm (Viner et al., 2012). These resiliency-based approaches highlight the importance of family and peer relationships, whilst emphasising promotion of positive social and emotional development including avoidance of poor health choices (Catalano et al., 2012). Within the scope of this thesis, the proximal SDH in adolescence are reviewed, including romantic, family and peer relationships.

#### **2.3.1. Proximal determinants**

Adolescents live in a social world, from family and peers through school and community environments. The life-course model of SDH has identified high-quality support from parents and access to education in early childhood as critical factors in later emergence of health outcomes (Commission on Social Determinants of Health, 2008). However, novel factors highly relevant during adolescence are minimised or ignored by these models, such as peer influence, neighbourhood factors and school connectedness. Strong evidence exists suggesting that the social environments of adolescents, including emerging romantic relationships, familial and peer networks predispose them to health-promoting or health-compromising behaviours (Jaccard, Blanton, & Dodge, 2005; Viner et al., 2012). This evidence will be reviewed in the subsequent sections.

### ***2.3.2.a. Romantic relationships***

Literature has consistently demonstrated that being involved in a committed relationship has a positive effect on physical and psychological health in adults, including an overall decrease in mortality (Berge, MacLehose, Eisenberg, Laska, & Neumark-Sztainer, 2012; House, Landus, & Umberson, 1988). Family systems theory attempts to explain this phenomena, and states that these relationships are reciprocal (Minuchin, 1974). Partners are able to shape each other's actions via support and modelling. This explanation may be particularly pertinent to young people, due to the increasing influence of relationship and connectedness factors in the determination of behaviour in this age-group (Berge et al., 2012; Carli, 2001).

Little research has focused on whether the health behaviour benefits of having a partner apply to young people and adolescents. Of those that have been conducted, the majority focus on diet and exercise behaviours, which are important health-promoting behaviours in diabetes (see Section 5.6.). From these, it has been determined that entering into a romantic relationship is associated with weight gain in the early stages (The & Gordon-Larsen, 2009), though once stability is determined, young people in a romantic relationship are less likely to be overweight/obese (Berge et al., 2012; Braithwaite, Delevi, & Fincham, 2010). Berge and colleagues (2012) explain this association as experiencing the partner's health-promoting behaviour as supportive and encouraging. Similarly, the increased orientation towards the opinions and attitudes of a partner during adolescence is able to promote behaviour change, particularly in young females (Berge et al., 2012). However, whilst it is not unusual for an older adolescent to have a romantic partner, it is uncommon for that relationship to be stable and long-lasting under the age of 18. This can be seen in the living arrangement of older adolescents, where they are still likely to live in a family home, and not with a partner (Gluckman et al., 2011). Therefore the influence of the familial network is also an important consideration in terms of the influence over health.

### ***2.3.2.b. Family relationships***

Cross-culturally, familial relationships have consistently been found as a determinant of health throughout the life-course. Families are established as the primary influence on child development (Irwin, Siddiqui, & Hertzman, 2007), and have been identified as a crucial target for improving global health (Commission on Social Determinants of Health, 2008). Adolescence, however, is characterised by an effort on the part of the young person to establish identity and autonomy outside of the family. Despite this lessening of the family influence, extensive research has found that family level factors continue to impact health during adolescence and beyond (Barber, Stolz, & Olsen, 2005; Frech, 2012; Michele Herzer, Vesco, Ingerski, Dolan, & Hood, 2011; Mackey et al., 2011; Rapley, Babel, Kaye, & Brown, 2013).

Presence of high quality social relationships serve to protect adolescents from negative health outcomes, with family connectedness of primary influence, despite ethnicity, income or family structure (Blum et al., 2000). Adolescents with high quality family relationships are less likely to engage in health-compromising behaviours, such as underage sex, smoking, alcohol consumption and drug use (Borowsky, Ireland, & Resnick, 2002; Viner et al., 2006). This has been attributed to high levels of parental monitoring, with parents who remain engaged and knowledgeable about their adolescent's activities less likely to have a child who engages in health-compromising behaviours (Fletcher, Steinberg, & Williams-Wheeler, 2004). Familial norms and attitudes have also been found to yield important influence over engagement with health-compromising behaviours (Bonnie & O'Connell, 2004; C. A. Ford et al., 2005). Like young children, adolescents have also been found to model parents' behaviour directly (Gavin, Catalano, David-Ferdon, Gloppen, & Markham, 2010). Parents exhibiting positive aspects of these behaviours (parental monitoring, health-positive attitudes and healthy role models) have been referred to as authoritative parents, able to promote prosocial behaviours, academic excellence and improved self-confidence, in addition to encouraging health-promoting behaviours in adolescence (Lohaus, Vierhaus, & Ball, 2009). However, adolescents can misconstrue these behaviours as "nagging" and an attempt by the parent to stifle their search for autonomy. Qualitative data suggests that, when this occurs, adolescents are more likely to seek influence from peers, where the influence on health is more variable (Gallant, Spitze, & Prohaska, 2007).

### ***2.3.2.c. Peer relationships***

Emerging strong peer relationships are a hallmark of adolescence, and a key developmental change. It has been proposed that the biological changes outlined in Section 2.2. make adolescents particularly susceptible to peer socialisation (Crone & Dahl, 2012; Peper & Dahl, 2013). Adolescents re-orientate their social network so that the opinions of peers take precedence over those of family members (Larson & Richards, 1991; Larson, Richards, Moneta, Holmbeck, & Duckett, 1996). These peers are able to encourage health-promoting and health-compromising behaviours (Jaccard et al., 2005). High quality relationships with prosocial peers are able to support health, protecting against a broad range of poor health outcomes cross-culturally (Anteghini, Fonseca, Ireland, & Blum, 2001). Much like the family, peer modelling and peer norms are particularly influential in engagement with health behaviours (DiClemente, Santelli, & Crosby, 2009). As a result, peer relationships are also able to increase risk of health-compromising behaviours, particularly in regard to smoking, alcohol consumption, risky sexual behaviour and violence (DiClemente et al., 2009). In addition, the pervasiveness of social media such as Facebook®, Twitter® and Instagram®, has opened new platforms for peers to influence health, the long-lasting impact of which will not be known for some time (Strasburger, Jordan, &

Donnerstein, 2010). Peer factors are said to operate as a counterpoint to the declining influence of parents, as family factors decline in relation to peer influence across domains (Collins & Steinberg, 2006).

The literature would suggest that the influence of family, romantic partners, peers, school and community are influential and important in improving health in adolescents. Appearing to impact at all levels of social support (see Section 3.2.), these social networks are highly influential in encouraging adolescents to engage in health-promoting and compromising behaviours (Viner et al., 2012). Whilst important for this developmental stage, the life-course perspective would suggest the influence of these factors reaches well beyond adolescence. The World Health Organisation (WHO) has estimated that two-thirds of premature deaths can be traced back to health behaviours initiated during adolescence (World Health Organisation, 2011c), suggesting a far wider impact of the biological and psychosocial changes that occur during this developmental stage.

#### **2.4. A foundation for future health: chronic conditions**

In addition to the behaviours which may promote or compromise general health, adolescents with chronic conditions must also engage in self-care. During mid-late adolescence, individuals seek to attain autonomy, including responsibility for and management of chronic conditions (Viner, 2012). The literature suggests that the self-management of health behaviours formed in adolescence become habitual and are repeated throughout adulthood (Sawyer, Drew, Yeo, & Britto, 2007). Therefore, it is essential in the management of chronic conditions that effectual self-care is established prior to reaching adulthood to positively influence disease trajectory in later life.

Due to the rapid physical and psychological changes present during puberty, adolescence sees a host of additional health conditions typically emerging at this time (Michaud et al., 2007). The prevalence of chronic conditions in adolescence is difficult to determine, due to differences in methodology, definitions and access to hard-to-reach populations (Michaud et al., 2007). In-school adolescents in developed countries provide the basis for most estimates of prevalence, providing limited information for those out of education or accessing it via alternative means. The data available suggests worldwide chronic condition prevalence in adolescents exists between 7-11.3% (Michaud et al., 2007). Results from the latest Health Behaviour in School-aged Children (HBSC) study concluded that 15% of adolescents in England have been diagnosed with a chronic condition (Brooks, Magnusson, Klemra, Spencer, & Morgan, 2011). This prevalence is considered high in comparison to other developed countries, and has led to increased attention on chronic conditions in adolescents. Indeed, the most recent NHS Outcomes Framework includes action for reduction of unplanned hospital admissions in under-19s for asthma, diabetes and epilepsy (Department of Health, 2013).

Males in rural areas with low socioeconomic status (SES) appear most at risk of a chronic condition. In addition, the data suggests the most common conditions include obesity, asthma and T1D (Brooks et al., 2011; Michaud et al., 2007; National Paediatric Diabetes Audit, 2012). Obesity differs from other chronic conditions in terms of its pathogenesis largely being caused by factors central to the patient. Asthma, too, may offer skewed results in terms of prevalence as spontaneous recovery is common in child and adolescent patients. Only 10% of asthma cases are carried into adulthood. T1D is, therefore, the most common chronic condition in adolescents that will last throughout the life-course (Kepreotes, Keatinge, & Stone, 2010; Seiffge-Krenke, 2001b).

Indeed, for a condition categorised as paediatric, T1D is predominantly a disease of adolescence; a recent report from the National Paediatric Diabetes Audit (2012) suggested that 70% of those in paediatric diabetes services were 12-19 years old. In addition, the majority of emergency hospital admissions for diabetes are in this at-risk age group. The complexities of being an AWT1D are further explored in Chapter 5, however it is important to note that outcomes for those with diabetes are poorer in adolescence than in childhood. This is particularly pertinent in Britain, where not only are markers of glycaemic control poorer during adolescence than childhood, they are the worst in Europe (National Paediatric Diabetes Audit, 2012). These poorer outcomes typically reflect biological and psychosocial factors related to engagement with self-care behaviours and adherence. Most worryingly, those not achieving effective self-care during adolescence will typically continue to fail to do so in later life and ultimately suffer poorer health outcomes, including mortality (Jacobson et al., 2013). Given this strong association between health behaviours in adolescence and adulthood, adolescence has been categorised as a final opportunity for intervention to encourage health promotion and protection (Frech, 2012; Suris et al., 2008; Viner et al., 2012).

## **2.5. Summary of Chapter 2**

Adolescence encompasses the transition from childhood to adulthood, and is comprised of biological, cognitive and social development. Recent research has established that adolescence is a critical period when health behaviours are established and likely to become entrenched, which may lead to adverse health outcomes in middle and late adulthood (Sawyer et al., 2012). Whilst this encompasses health-promoting and compromising behaviours, the impact on those with chronic conditions is particularly of note. Research into diseases which typically emerge during adolescence, such as T1D, has suggested that self-care behaviours in adulthood can be traced back to adolescence (Sawyer et al., 2007). These findings highlight adolescence as a final point for intervention in encouraging effective self-care (Frech, 2012; Suris et al., 2008; Viner et al., 2012).



During adolescence, the influence of the social network increases, allowing for increased impact on behaviour from the thoughts and opinions of those in the peer social network. Effective peer support could therefore hold the key to establishing health-promoting behaviours in adolescence, which may last throughout the life-course (Sawyer et al., 2012; Viner et al., 2012). This concept, and the influence of social support on health, is explored in Chapter 3.

## Chapter 3: Social Support and Health

### 3. Overview

The aim of this chapter is to provide a summary of the mechanisms through which social support influences health outcomes, focusing on adolescents. Due to the vast amount of literature that has been established concerning this topic, this chapter is by no means an exhaustive review. Instead, it addresses current theoretical positions and highlights the key empirical literature illustrating the association between social support and health outcomes, with particular attention to T1D. As such, social support is defined, before being specifically related to health in adolescence, health conditions in general and in T1D. In order to contextualise the issues encountered in social support in T1D, a section on social support and other health conditions prevalent during adolescence is provided. Finally, theories outlining proposed mechanisms of influence of social support are reviewed. Together, this chapter offers convincing justification for the investigation of peer support in AWT1D.

### 3.1. Introduction

Since the seminal research of Berkman and Syme (1979), when a relationship between social ties<sup>10</sup> and mortality first became evident, an impressive body of literature has investigated the relationship between social factors and health outcomes (Gallant, 2014). It is apparent that social support influences health via physiological, psychological and behavioural mechanisms (Taylor, 2011). The health benefits associated with social support have been recognised in a diverse range of disease and injury states, via both reduced risk to illness and improved recovery from it (Karelina & DeVries, 2011).

### 3.2. Definitions of social support

Social support refers to the material and psychological resources afforded by interpersonal relationships (Rodriguez & Cohen, 1998). This intentionally broad definition encompasses the multidimensional concept of the characteristics and functions of integration<sup>11</sup> within a social network<sup>12</sup> (Lourel, Hartmann, Closon, Mouda, & Petric-Tatu, 2013). Social support itself has been defined as the reciprocal provision of being loved, cared for and esteemed (Cobb, 1976; Gallant, 2014; Wills, 1991), and can be considered a primary function of the social network (Cobb, 1976; Cohen & Wills, 1985). This multidimensional concept is delineated into four distinct subtypes (House, 1981):

- Emotional support; expression of love and caring.
- Instrumental support; practical, tangible assistance.

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<sup>10</sup> Information-carrying connections between people, characterised as strong, weak, or absent (Wuchty, 2009).

<sup>11</sup> The extent to which one has social ties with others (Brisette, Cohen, & Seeman, 2000).

<sup>12</sup> The structure or pattern formed by social ties (Cohen & Syme, 1985). Can be defined in terms of overall network characteristics (size, density, etc.) , or individual links within the network (frequency, reciprocity, duration, etc.) (Heaney & Israel, 2008b).

- Appraisal support; feedback allowing for self-evaluation.
- Informational support; provision of information or advice.

Research still refers to social support in this manner, and draws upon this early literature for much of the definitions still used in current work (Cohen, Gottlieb, & Underwood, 2000; Gallant, 2014).

More recently, research has attempted to conceptualise the difference between received or enacted support, in which support is passed between social network members, and perceived support, where the network member believes support is available should it be required (Gallant, 2014). Both have been found to be influential in health, but are not interchangeable. Perceived support has been found to be most strongly linked to health outcomes (Uchino, 2009), with received support often associated with negative associations of obligation, discomfort and dependence (Thoits, 2011). Despite the good intentions of the support provider, there are also acknowledged negative consequences of support transactions. With this in mind, the matching hypothesis suggests the social support is most beneficial when the category and quantity of support received is congruent with the recipient's needs and desires (Cohen & McKay, 1984; Cutrona & Russell, 1990). Contemporary research has investigated the benefits of invisible support, wherein support is provided without the awareness or acknowledgement of the support receiver (Bolger, Zuckerman, & Kessler, 2000), achieved via ignorance on the part of the receiver, or subtle and skilled support provision (Howland & Simpson, 2010). Studies have indicated that provision of invisible support is able to negate the negative impact of enacted support, with receivers reporting the smallest increases in distress when unaware of accepting social support (Bolger et al., 2000).

### **3.3. Social support and health**

There are three main health behaviours that social support has been found to influence (Kasl & Cobb, 1966); preventative behaviours, adherence and self-care. Preventative, or health-promoting, behaviours involve acts to encourage a healthy lifestyle; routines and habits aiming to promote health and prevent illness. These range from engagement with exercise and maintaining an appropriate BMI, to achieving the appropriate amount of sleep (Belloc & Breslow, 1972; Ford, Bergmann, Boeing, Li, & Capewell, 2012; Frech, 2012). Conversely, engagement in lifestyle choices which increase risk of poor health are termed as risky or health-compromising behaviours, such as smoking and excess alcohol consumption. A wealth of research has been accumulated demonstrating the importance of such behaviours in health outcomes, including mortality (Gallant, 2014).

Most relevant to the participant sample in the present research are disease management behaviours. These were separated by Kasl and Cobb (1966) into two subcategories. The first,

adherence, concerns the acceptance of and faithfulness to a healthcare professional-prescribed treatment and management plan. This can refer to a range of behaviours including taking a medication as prescribed, through to enacting lifestyle changes, and can be applied in both acute and chronic illness (DiMatteo, 2004b). Adherence is associated with improved health outcomes, though rates of adherence to treatment across illnesses remains low (DiMatteo, Haskard-Zolnierrek, & Martin, 2012). The second sub-category is termed self-management or self-care, and is strongly related to adherence. Self-care denotes the monitoring, control and minimisation of the impact of a disease on health and functioning. This encompasses an individual's ability to cope with the psychosocial consequences of diagnosis and management (Clark et al., 1991; Lorig & Holman, 2003). Self-care differs from adherence as it is far more proactive. Here, the patient has a greater level of control, autonomy for care plan adjustment and engagement in decision-making and problem solving. Self-care can be further broken down into three activities:

- Disease management; adherence to a treatment regime.
- Decision-making; adjustment of the treatment regime and communication with healthcare professionals.
- Psychosocial coping; adjustment to the sick role<sup>13</sup> and maintenance of well-being (N. Clark et al., 1991; Henry & Schor, 2015).

Self-care in the National Health Service is guided via increased health information, health technologies (or “telehealths”) and both community-based and healthcare professional-led interventions (Panagioti et al., 2014). Social support is often included in models of self-care as an external influence on knowledge, attitudes and beliefs regarding the disease (N. Clark & Houle, 2009). Successful self-care is associated with improved physical and psychological health, though rates of effective self-care remain poor (Cloninger, 2013). It is important to note that the types and subcategories of support most influential on health will vary and adapt over the lifespan, with times of developmental changes associated with a similar change in support sought and received (Umberson, Crosnoe, & Reczek, 2011).

### **3.3.1. Social support and health research**

Early research linking social support and health utilised mathematical sociological methods to study social networks and practicing health-promoting behaviours. Pioneers in the field such as Langlie (1977) and Hibbard (1988) found that frequency of interactions and number of social network ties were related to health-promotion, with social isolation associated with health-

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<sup>13</sup> The sick role is an adjustment to the self-concept in which the identity is no longer one of a healthy individual, but one who is ill. The sick role is associated with behaviour involving seeking treatment, withdrawal from behaviours which may prolong or exacerbate ill health and taking medication (Kasl & Cobb, 1966).

compromising behaviours. As this research area was adopted into psychology, studies sought to differentiate between the types of relationship providing support and their impact on health. For example, Broman (1993) demonstrated that marriage was associated with reduced alcohol consumption, whilst friendships reduced the likelihood of smoking.

The ‘second generation’ of research into social relationships and health moved away from social network structures, and focused more on the support they provide. A persuasive body of literature exists documenting the importance of social support in facilitating health. Taken together, this evidence suggests that social support has a positive influence on a variety of health behaviours, disease management, health outcomes and mortality (Gallant, 2014). These findings have been demonstrated in the general population (Ng & Jeffrey, 2003) as well as in specific subsets such as adolescents (Kelly, Melnyk, Jacobson, & O’Haver, 2011) and people with diabetes (Brody, Kogan, Murry, Chen, & Brown, 2008; Nakahara et al., 2006).

When considering chronic conditions such as T1D, a large literature examines the relationship between social support and adherence, with a meta-analysis finding 122 studies published between 1948 and 2001 (DiMatteo, 2004a). This meta-analysis found average effect sizes consistently suggesting a positive influence of instrumental ( $r=.31$ ; medium effect according to J. Cohen, 1988), emotional ( $r=.15$ ; small effect, J. Cohen, 1988), and unidimensional social support ( $r=.21$ ; small effect, J. Cohen, 1988), with functional support more powerful than structural support. This prompted DiMatteo (2004a) to suggest that the quality of the social relationship was more important than the quantity of available social ties. Gallant (2003) also concluded, in a review of 29 studies, that social support does enact a positive effect on self-care, with evidence strongest for T1D.

As outlined in the previous chapter, health behaviours formed in adolescence have been found to reach into adulthood (see Section 2.4.). This is a particularly important issue given the onset of a host of long-term health conditions in this already vulnerable age-group (Michaud et al., 2007; Suris et al., 2008).

### **3.3.2. Social support and health during adolescence**

Mounting evidence points towards the “*long arm of childhood*” (Hayward & Gorman, 2004, p. 87) in health research. As outlined in Section 2.4., research suggests that experiences in childhood and adolescence establish social and health trajectory, and are able to act lasting effects in later life (Frech, 2012; Haas, 2008). Adolescence is characterised by a rapid expansion of the social network and the gradual transfer of responsibility for health from parents to self (see Section 2.3.). Umberson and colleagues (2011) suggest that these milestones are related. During childhood, health behaviours are mostly directed by parents, such as eating well, whilst others are prohibited, like alcohol consumption. As children approach adolescence, they assume

greater responsibility for their behaviours, in conjunction with health-compromising behaviours becoming more normative. Therefore, the mechanisms through which social networks are able to influence health behaviours coincide with an increase in the size of this network (Ennett et al., 2006; Umberson et al., 2011). It is therefore agreed that, in terms of the influence of social support on health, adolescence indicates a significant and crucial period in which habits are cemented that are likely to continue throughout the life course (Frech, 2012; Suris et al., 2008; Viner et al., 2012).

Substantial evidence suggests that peers hold the strongest influence in predicting adolescent health behaviour (Cattelino et al., 2014; Choukas-Bradley et al., 2015; Mercken et al., 2012; Pezzulo et al., 2013; Visser et al., 2013). The social standing of the adolescent within their network and the norms and values of that network are significant predictors of engagement with health-promoting and compromising behaviours (Viner et al., 2012). Whilst parents are able to maintain influence over the young person, the health aspect of the relationship is inter-linked and out-weighed by the peer influence once the adolescent becomes more independent (Steinberg & Morris, 2000). Although the relative strength of the social tie to the parent is, for the majority, most important, the collective strength of the peer network matters more than any single tie in the action of health behaviour, and lays the foundations for healthy and unhealthy behaviours in adulthood (Umberson et al., 2011). Adolescence, therefore, represents a key stage in which a support network in flux is accompanied by crucial developmental tasks. The adolescent with a chronic condition is presented with the multiple tasks of attaining an operative support network and achieving developmental milestones, whilst also seeking to maintain effective self-care.

### **3.3.3. Social support and type 1 diabetes**

Research into social support in AWT1D is dominated by research into family support (Ashraff, Siddiqui, & Carline, 2013; Wallander & Varni, 1998). As seen in the previous section, literature may therefore offer consideration of family support and health behaviours which is disproportionate to its influence. The understanding of the relationship between other sources of support, such as romantic relationships and friendships, is therefore limited in AWT1D.

#### ***3.3.3.a. Romantic relationships***

As identified by Helgeson and colleagues (2014), few studies could be found addressing romantic relationships. AWT1D have been found to be no different to the general population regarding attitudes to dating, and experience comparable psychosexual maturity (Pacaud et al., 2007). Some differences in their romantic relationships do occur, with AWT1D typically focusing less on intimacy than their healthy peers. They tend to seek greater security, support and assistance in romantic relationships, and engage in more long-lasting and stable

attachments (Beyers & Seiffe-Krenke, 2007). However, AWT1D have been found to experience less trust and sense of intimate friendship in romantic relationships than healthy adolescents, which would suggest a lack of self-worth and self-esteem, particularly in social relationships (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Intimate relationships too have been found to represent somewhat of a dichotomy of support, with a romantic partner offering benefits on some indices of health, whilst being troublesome in others (Helgeson et al., 2014). Indeed, this is a trend not isolated to romantic relationships, and is a quality present in both family and peer support, as discussed below.

### ***3.3.3.b. Family relationships***

Family support has been stated as consisting of the perception of availability and receipt of caregiving from family that allows for development of resilience and well-being when confronted with stress-inducing events (Baptista, Neves, & Baptista, 2008). Family support typically includes displays of affection, sensitivity, cooperation and trust, whilst acknowledging and encouraging autonomy and independence (Baptista et al., 2010). Where chronic disease occurs, family support has been found to be an important resource in achieving optimal self-care for an adolescent, with a direct correlation existing between the perception of a supportive family, an increase in motivation to self-care effectively, and in health outcomes (Baptista, 2007).

T1D has been described as a burdensome illness, able to enact influence over everyday life, including familial relationships (Ayala & Murphy, 2011). Successful management of T1D requires integration into the lifestyle of the family, resulting in impact on every family member. It has been found that parents remain involved in dimensions of the life of the adolescent that they would otherwise have long ignored (Karlsson, Arman, & Wikblad, 2008). The demands of care have been found to result in increased parent-child conflicts and may hinder the adolescent's emerging sense of autonomy (Law, Walsh, Queral, & Nouwen, 2013).

An imperative task of adolescence requires the development of autonomy and a sense of personal identity (Sales & Irwin Jr, 2013). This has been found to be stalled by the complex tasks of T1D during adolescence, with not only adolescent development suffering, but also self-care as glycaemic control and adherence are likely to deteriorate at this time (Wallander et al., 2013; Wherrett et al., 2013). Maintenance of parental involvement in self-care is related to improved health outcomes (Beveridge, Berg, Wiebe, & Palmer, 2006; Lewin et al., 2006). Likewise, adolescents whose parents are less involved display reduced adherence and poorer self-care (Almeida, Pereira, & Leandro, 2013). However, research has also found that this amplified parental involvement in diabetes management also facilitates diabetes-related conflicts (Gray, Dolan, & Hood, 2013). Indeed, it has been suggested that more frequent family conflicts with

low family cohesion and support are related to poorer self-care (Neylon, O'Connell, Skinner, & Cameron, 2013). Parental involvement in diabetes care is, therefore, complex. Research suggests parents should strive to continue a degree of presence in diabetes management, whilst allowing the adolescent to develop a sense of self (Heleno, Vizzotto, Mazzotti, Cressoni-Gomes, & Modesto, 2009). Identification of the point at which harmonious family support becomes provoking is necessary but problematic, as it is likely that this will be highly individualised.

It is not only adolescents who are stressed by their parents continued involvement in their diabetes management. Parents, too, have been found to feel a burden of stress and worry for the well-being of their affected child (Edmonds-Myles, Tamborlane, & Grey, 2010). This stress is often expressed through intrusive behaviours including nagging, scolding, questioning and giving orders (Luyckx et al., 2013). Nagging has been defined as behaviour annoying to the receiver, and is often centred around a miscommunication (Tannen, 1990). Nagging is characterised by persistent communication of the same message without escalation, and is typically thought of as a female behaviour (Soule, 2001). Parents have been stated to question the adherence and self-care of the adolescent, resulting in disrupted communication and feelings of resentment (J. Spencer, Cooper, & Milton, 2010). Conflict also stems from a perceived lack of understanding displayed by parents, leading to intrusive and blaming behaviours (Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013). Thus, as a parent interferes in a misguided attempt to improve self-care, the adolescent misinterprets this as an accusation that they are incapable of managing their T1D effectively (Seiffge-Krenke et al., 2013). Adolescents appraise this behaviour as *"annoying"*, accusing them of *"losing sight of them as people"* and seeing them exclusively as *"having diabetes"* (Weinger, O'Donnell, & Ritholz, 2001, p. 333). Findings have suggested that this may result from feelings of frustration and guilt over the impact their diabetes has on their parents, and the additional strain it places on the family (Gray et al., 2013). Parents, therefore, may need to seek to engage in effective, balanced communication expressing acceptance of the complexities of self-care. Indeed, research has found that engaging in balanced communication, such as effective problem solving and flexibility, is an essential parental skill in aiding an adolescent to achieve optimal self-care (Barros, 2003). Findings such as these imply that social support from family members towards diabetes management influences health and psychosocial outcomes in both a positive and negative manner.

Parents are considered to be the major providers of support in younger adolescents, with this responsibility transferring to peers as the adolescent nears young adulthood (Almeida et al., 2013). Despite the importance of peers as a source of support in adolescence peer relationships have not been investigated to the same extent as the family, and typically focus on adherence as opposed to glycaemic control as the outcome measure (Helgeson et al., 2009).



### **3.3.3.c. Peer relationships**

When speaking in healthcare terms, peer support is defined as “*assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population*” (Dennis, 2003, p. 321). Peer support has been found to be an important variable in determining disease outcomes for a number of reasons. The facilitation of non-hierarchical, reciprocal relationships based on shared experiences, disease-related or otherwise, can promote mastery over self-management behaviours and thus improve outcomes (Brownson & Heisler, 2009). Greater homogeneity of peers is more likely to lead to this acceptance of help, and enable understanding and empathy (Dennis, 2003). These assertions are consistent with findings of the benefits of support groups and group therapy as improving psychosocial outcomes in chronic conditions. Peers have been cited as providing support that is different from, but complimentary to, the support provided by healthcare professionals and family members (Brownson & Heisler, 2009). Despite this, it has been noted that far greater attention has been focused on family relationships than those provided by peers in T1D. As such, a call for greater focus on the role of peers in self-care has been voiced, particularly given growing importance of peers in an adolescent’s life (Ashraff et al., 2013).

The distinction between friends and peers with diabetes is a difficult one at this developmental stage (Palladino & Helgeson, 2012). Although some research has recommended a division between the two (La Greca, Bearman, & Moore, 2002), only one study could be found which actively investigated the two as separate entities (Hains et al., 2007). Classifying a peer as a friend implied trust, someone whom the adolescent enjoyed spending time with and liked. Importantly, the participants did not differentiate between their peers with or without diabetes in terms of the nature of their relationship (Hains et al., 2007). Palladino and Helgeson (2012) highlighted the changeable nature of adolescent friendships and, as such, state that it is difficult to determine peers from friends over a period of time. As such, in this thesis, the term peers denotes someone of the same approximate age, school year group or social status as the adolescent, who appears within their social network, and includes peers both with and without T1D.

Little is known about how T1D may impact on the support received in AWT1D. It is suggested by some that AWT1D may struggle to establish and maintain relationships due to the constraints their disease may place on social activities (Beck & Smith, 1988), potentially mediated by disease severity (Alderfer, Wiebe, & Hartmann, 2002). Of the limited research conducted, a consensus is far from reached. Research indicates that AWT1D report similar size social networks to their healthy peers (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007), but a lack of intimacy and affection in their affiliations (Seiffge-Krenke, 1997). Other studies support this, concluding that AWT1D are subject to poorer social competence, and struggle to

establish a supportive peer network (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007). This has been interpreted as due to AWT1D perceiving a fundamental difference between themselves and their healthy peers due to living with T1D. Through this lens, they struggle to assimilate with peers, further compounding isolation and loneliness (Helgeson, Snyder, et al., 2007). Conversely, more recent data suggests a larger social network and closer friendships in comparison to a reference group, potentially due to a greater need for supportive relationships in self-care (Helgeson, Palladino, et al., 2014). This may draw peers into the social network to a greater extent, and may even initiate new friendships more readily (Helgeson, Reynolds, Shestak, & Wei, 2006). Little agreement, therefore, is seen in literature concerning the potential impact of T1D on peer support. During adolescence, appealing peers may become more important than maintaining self-care (Palladino & Helgeson, 2012). It is unlikely to be a coincidence that as peer pressure peaks (Berndt, 1979; Blakemore & Mills, 2014), AWT1D display decreasing adherence in exchange for peer acceptability (Palladino & Helgeson, 2012). As interest in achieving peer acceptance mounts, so does a desire for independence from parental influence. Previous research has shown that this combination of aspirations can influence daily choices in disease management including BGM (BGM), diet and insulin administration (Wysocki & Greco, 2006).

Qualitative evidence certainly suggests that AWT1D believe peers impact their disease management (Palladino & Helgeson, 2012). Peers are an important source of emotional support, with this support associated with a belief of improved adherence, glycaemic control, and well-being (Ashraff et al., 2013). However, as with family members, this support may not always be positive. Dovey-Pearce and colleagues (2007) found that adolescents reported well-intentioned peers seeking to offer instrumental or informational support actually reinforced a sense of stigma in AWT1D. Peer-monitoring, buying sugar-free foods and drawing attention to diabetes care behaviours were all stated as threats to the self-concept<sup>14</sup> of the adolescent in question. By calling attention to T1D, participants felt peers were highlighting the differences between them, creating associations of stigma. This feeling of being different has been found key to an adolescent's engagement with self-care behaviours, with those feeling less threatened and different more likely to embrace their disease management (Dovey-Pearce et al., 2007). Ethnographic research has found that people of all ages with T1D are strongly influenced in their self-care by their desire to "keep face" in their social group. Hinder and Greenhalgh (2012) highlight the role of the social environment in what they term "*non self-management behaviours*," or times in which participants actively disengaged from adherence. Social acceptability of self-care at the time and place it is required appeared highly influential on

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<sup>14</sup> The habitual set of emotions, thoughts and behavioural reactions that form identity (Charmaz, 1991)

whether or not the behaviour was performed. For example, social events were considered ‘treats’ or ‘special occasions’ in which participants were far less likely to engage with self-care, no matter how often said social events occurred. Hinder and Greenhalgh draw these conclusions back to the same notion of a desire for normality which outpaces the need for self-care (Hinder & Greenhalgh, 2012).

When considering if these reports of support impact health outcomes, the quantitative evidence is more unclear. Where an impact has been found, the mechanism through which peer relationships influence diabetes outcomes is uncertain. Lehmkuhl (2009) asked AWT1D how peers influenced self-care. Participants stated that they did not offer specific self-care support, but would prefer an increase in reminders for self-care behaviours, monitoring of hyper/hypoglycaemic symptoms and not calling attention to their condition (Lehmkuhl et al., 2009). Emotional support in the form of companionship is the most common form of support reported, with instrumental support only requested for diabetes-related emergencies (Palladino & Helgeson, 2012). Taken together, these findings appear to indicate that although adolescents receive emotional social support, they would prefer additional specific, diabetes-orientated support. These findings raise the question of comparison between diabetes-specific and global peer support. Diabetes-specific support behaviours refer to support specifically targeted at improving self-care, such as monitoring for hypoglycaemia or reminders to test blood glucose (Palladino & Helgeson, 2012). Global social support refers to the definition by House (1981) outlined in Section 3.2., and is support provided entirely independently of T1D.

Despite adolescents reporting more global support, no relationship could be identified between global peer support and self-care behaviours cross-sectionally or longitudinally (Helgeson, Reynolds, et al., 2007), though ecological momentary assessment<sup>15</sup> of interactions with peers aggregated over 4 days was related to increased self-care, particularly in females (Helgeson, Lopez, & Kamarck, 2009). When taking glycaemic control as the outcome measure, the picture remains unclear. Helgeson and colleagues (2007) found no association between global peer support and glycaemic control. A 4-year follow-up suggested global peer support was found to decrease glycaemic control long-term, though this was eliminated when controlling for confounding variables (Helgeson, Siminerio, et al., 2009). In general, studies fail to distinguish between the various types of global social support so it is difficult to determine which area of support is most effective. Indeed, this is a confounding factor of the body of existing literature, and has been stated as potentially providing explanation for the lack of expected relationships (Palladino & Helgeson, 2012) However, when a relationship is found between global peer support and health outcomes, that relationship is positive.

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<sup>15</sup> Ecological momentary assessment strives to collect self-report data as close in time to its occurrence as possible to reduce reliance on memory and improve accuracy (Moskowitz & Young, 2006).

Diabetes-specific peer support appears to produce more mixed results. Several studies have found no association between diabetes-specific support and self-care (Greco, Shroff Pendley, McDonnell, & Reeves, 2001; Hains et al., 2007; Naar-King, Podolski, Ellis, Frey, & Templin, 2006; Pendley et al., 2002), whilst others have found evidence for a relationship. Peer support for BGM is predictive of improved adherence (Kyngäs, 2000), and may be associated with well-being and disease adaptation (Bearman & La Greca, 2002). If adolescents felt that their peers were supportive of their self-care, they were twice as likely to adhere to their care plan (Kyngäs, 2000). However, not all studies showed a positive outcome. Diabetes-specific support has been found to moderate the relationship between diabetes-related stress and glycaemic control; as support increased, the relationship between stress and poor control grew stronger (Hains et al., 2007). This may be due to problematic support provided by peers lacking knowledge concerning T1D and the importance of self-care. They may therefore not provide regular or consistent diabetes-related support, or may even have an influence that is detrimental to self-care (Thomas et al., 1997). This is reflected in the association between conflict and self-care, in which social conflict negatively impacted self-management behaviours (Palladino & Helgeson, 2012). Thus, it is difficult to conclude that peer involvement in specific self-care behaviours is beneficial in terms of health outcomes. It may be that just as parents fall prey to being perceived as nagging (Seiffge-Krenke et al., 2013), peer involvement may be misinterpreted as calling attention to their diabetes, something which findings suggested is an unwanted consequence of social support (Dovey-Pearce et al., 2007; Lehmkuhl et al., 2009).

Alternative explanations as to the inconsistency of findings in extant research lie in the lack of agreement amongst researchers regarding appropriate measurement and methodology. Indeed, particularly when considering the paucity of studies conducted in this field, a wide range of methods have been adopted, including semi-structured interview (Lehmkuhl et al., 2009), ethnography (Hinder & Greenhalgh, 2012), questionnaires (Hains et al., 2009), ecological momentary assessment (Helgeson, Lopez, et al., 2009), longitudinal survey (Helgeson, Siminerio, et al., 2009) and vignettes (Thomas et al., 1997). Such discrepancy in findings may be attributed to the varying methodologies adopted by research purporting to study the same phenomena. With differing operationalisations it is likely to come different results (Coolican, 2013). Even within studies using the same methodological approach, variation in measures adopted is noted. As shall be seen in Section 8.4., a wide variety of measures are in existence, particularly when considering the variables of global social support and self-care. Inconsistency in the conceptualisation of these variables across measures may also impact the findings, and as such, it is important that consensus is achieved in the research community as to which definitions and measures are most appropriate to enable truly comparable results across studies. Furthermore, individual differences in participant groups are likely to play a significant

role in the differing findings of these studies. Taking the study by Lehmkuhl and colleagues (2009) as an example, it is likely that the participants providing qualitative responses in this study have the same experiences of living as an AWT1D as those taking part in research by Gee *et al.* (2007). The work of Lehmkuhl and colleagues (2009) uses a diabetes camp for recruitment, presenting sampling bias in participants which is acknowledged by the authors. Participants attending diabetes camps tend to be better engaged with their self-care and are more likely to prioritise T1D, as is demonstrated in the average glycaemic control of participants (7.88; Lehmkuhl *et al.*, 2009). The study by Gee *et al.* (2007), however, assesses young people from high-risk populations, specifically those from underserved ethnic minorities and of low socioeconomic status. These groups have specific clinical and psychosocial needs, including financial and medical insurance concerns, and the socially problematic nature of disclosure (Gee *et al.*, 2007), which are likely to be very different to the Caucasian sample studied by Lehmkuhl *et al.* (2009). Therefore, despite using the same method, the results of these studies are not comparable. Furthermore, whilst this example presents an extreme case, social support is recognised to be a highly fluid, individualised experience (Lourel *et al.*, 2013), and therefore interpretation of data gathered from multiple groups is unlikely to be valid. The present thesis seeks to address these issues.

What does appear to be evident, however, is the impact of gender. Numerous studies in healthy populations have noted gender differences in peer support, with females reporting greater intimacy in friendships than males (Camarena, Sarigiani, & Petersen, 1990; Golombok & Fivush, 1994; Kuttler, 1999). This is also noted in AWT1D (Helgeson, Reynolds, *et al.*, 2007; Kuttler, 1999), in which a longitudinal 4 year study found that healthy adolescents had closer friendships at the study outset, though this changed over the research period. Over time, the females with T1D grew closer in their friendships, reporting similar levels of intimacy with their peers to their healthy counterparts at the close of the study. In contrast, the relationships reported by male participants with T1D remained distant throughout the duration of the research (Seiffge-Krenke, 1997). This may be due to gender role differences, in which males perceive illness as a weakness, incongruent with the male gender identity. As such, males with T1D may struggle with illness disclosure and therefore may not conduct close friendships (Helgeson, Reynolds, *et al.*, 2007).

Gender also appears to play a major role in how peer support impacts on self-care. Helgeson, Lopez and Kamarck (2009) support the aforementioned finding that conflict is more influential in psychosocial outcomes than support, but particularly among girls. This susceptibility to conflict was more associated with poor glycaemic control in females than males. Findings such as these suggest that young females are especially responsive to peer relationships, both to their potential negative and positive influences. Indeed, it has long been

accepted that social relationships can prove a double-edged sword for females (Belle, 1987). Although relationships have been found to be both a resource and a stressor in girls, boys report lower levels of peer support overall (Helgeson et al., 2007). Helgeson and colleagues (2007) hypothesised that this may be due to illness implying weakness, which is incongruent with the male gender role. Therefore, boys may not disclose their diagnosis to friends, and therefore not receive the level of support experienced by their female counterparts. Indeed, non-disclosure to friends has been associated with poorer adjustment and self-care (Greco et al., 2003). Further research is warranted to investigate the premise that males do not inform friends of their diabetes status. If found to be correct, males may benefit from facilitation of disclosure to peers, which has been stated as particularly problematic (Lehmkuhl et al., 2009). Age, too, is likely to impact on the utility of social support, with previous literature finding that despite older adolescents having greater problem-focused coping skills (see Section 6.4.1.), they are more susceptible to health-compromising choices when facing peer pressure (Thomas et al., 1997).

As is evident here, a significant amount of research has assessed the impact of social support in T1D. This thesis will add to that body of work by addressing potential mechanisms through which that occurs. However, if the nature of the social support sought and received by AWT1D holds commonalities with other conditions prevalent in adolescence, it may be that the findings are generalisable to other health conditions. As such, the nature of social support in other conditions prevalent in adolescence is presented.

### **3.3.4. Social support and other adolescent health conditions**

Obesity is the most common chronic condition presenting in adolescence globally (Michaud et al., 2007). However, it differs significantly from the other conditions with high prevalence in its pathogenesis, and as such shall be given limited attention here. Obesity is defined as a body mass index (BMI) of 30 or over (World Health Organisation, 2011a). Obesity is seen from the medical perspective as due to factors ranging from lack of will-power to organic disorders independent of self-control, though all agree that in its most basic form, obesity is the result of excessive consumption of calories (Rosengren & Lissner, 2008). Although subsequent co-morbid disorders may require medication, obesity itself does not require a self-care regime and, most importantly, is ultimately curable via behaviour change or medical intervention (Reilly & Kelly, 2011).

Of the other chronic conditions seen as prevalent in adolescence, a paucity of research could be found highlighting the role of peer support in self-care. Asthma, coeliac disease, Addison's disease and HIV were all considered, though little research could be found. Asthma prevalence has increased dramatically over the past decade, contributing to negative impacts on health, quality of life (QoL), psychosocial well-being, hospitalisations and seeking emergency

treatment (Stewart et al., 2012). Like T1D, asthma control relies on lifestyle behaviours alongside medication (Yang, Sylva, & Lunt, 2010). The majority of research into social support and asthma focused on parental and family support over that provided by peers. As with T1D (Baptista et al., 2010), families appear to play a significant role in ensuring adherence (Kaugars, Klinnert, & Bender, 2004). Families with increased functioning and less conflict offered more effective management of and coping with asthma, reflected in improved health outcomes (Fiese, Winter, Anbar, Howell, & Poltrock, 2008; Wood et al., 2007) and similar to results seen in T1D (Gray et al., 2013). Family support achieves this by ameliorating barriers to adherence, particularly regarding negative attitudes and cognitive challenges (Rhee, Belyea, & Brasch, 2010). Despite this, just like their counterparts with T1D (Seiffge-Krenke et al., 2013), adolescents reported feeling 'nagged' by parental support, and expressed a desire for increased involvement from peers (Stewart et al., 2012).

Of what has been found in peer-based research, adolescents have expressed concern about their peers' perceptions of them (Couriel, 2003). Adolescents with asthma have been said to be at risk of poorer health outcomes due to denial of the severity of their condition, and desire for social conformity and normality, expressed through neglect of self-care when in the presence of peers (Rhee, Wenzel, & Steeves, 2007). They have expressed desire to share their experiences with peers regarding self-care, feeling "normal," and their future, and have highlighted the importance of the instrumental support provided by parents, peers and teachers (Knight, 2005). Indeed, socialisation, emotional support, information-sharing, and instrumental support have all been found to improve coping and self-care in adolescents with asthma and increase symptom-free days (Conn, Swanson, McQuaid, Douthit, & Fisher, 2015; Letourneau et al., 2012; Rhee, Wyatt, & Wenzel, 2006; M. Stewart et al., 2012; Yang et al., 2010). This characterisation of peer support shows marked similarity to that of AWT1D (see Section 3.3.3.c.) and offers plausibility to the suggestion that any findings presented in this thesis are generalisable to adolescents with similar health conditions.

A lack of research could be found addressing other conditions which could be said to be comparable to T1D. Of other autoimmune conditions typically presenting during adolescence, only coeliac disease (CD) was felt to be prevalent enough to warrant comparison. However, limited studies could be identified considering the social support of adolescents with CD. CD, also known as gluten intolerance, is a chronic autoimmune condition manifesting in fatigue, abdominal pain, weight loss and anaemia (Rosén et al., 2011). Treatment involves lifestyle adaptations to avoid gluten, which resolves symptoms (Di Sabatino & Corazza, 2009). Adolescents with CD have expressed a similar desire for normality and perceptions of stigma (Rosén et al., 2011) as both those with asthma (Rhee et al., 2007) and T1D (Dovey-Pearce et al., 2007; Hinder & Greenhalgh, 2012). Whilst females actively sought out emotional and practical

support, males sought support for normalisation only. They expressed a desire to conceal their CD, and did not incorporate the disease into their social identity, resulting in neglect of their self-care in the presence of peers (Olsson, Hörnell, Ivarsson, & Sydner, 2008; Rosén et al., 2011). Females embraced the sick role more readily, but expressed concerns regarding the burden it placed on family and friends (Rosén et al., 2011). This is similar to the T1D findings outlined by Helgeson et al. (2007), in which males hid their diagnosis to avoid being seen as weak, whilst females found social support to be both a source of help and stress. Like asthma and T1D (Rosland et al., 2008), social setting is key for adherence to a gluten-free diet (Olsson et al., 2008).

Encouragingly, these chronic conditions all appear to show discernible similarities in the way that adolescents access and use peer support in their self-care. Across the three conditions, issues around perception of normality, parental involvement and the social setting of self-care behaviours appear to be influential in self-care, all associated with health outcomes. This suggests that, although the present thesis will focus on T1D, the results may be generalisable to self-care behaviours beyond this population.

Despite these indications of a relationship between support and health outcomes, the mechanisms through which social support is able to influence health behaviours is still unclear, with multiple theories positing both direct and indirect influence of support typologies.

### **3.4. Mechanisms of influence**

Two main theories persist attempting to explain how social support is able to enact influence on health-promoting and self-care behaviours. It is suggested that social support is able to effect health outcomes via direct, or main effects, influence and also via indirect, stress-buffering effects (Cohen & Wills, 1985). Main effects theories state that social support has a direct independent positive effect on health via relational regulation theory (Lakey & Orehek, 2011) or a life-span perspective (Uchino, 2009). The stress-buffering hypothesis suggests that social support is able to moderate the negative impact of stress on health (Gallant, 2014), operating via stress and coping theory (Lazarus & Folkman, 1984a). Evidence supports both mechanisms, and it is widely accepted that social support is able to influence health via both routes independently. However, these effects appear to alter according to structural, over functional, aspects of the support provided. The literature has suggested that structural aspects of social networks directly influence mental and physical health outcomes. Perceptions of availability of support enact both a direct and stress-buffering effect on health (Taylor, 2011).

Multiple theories posit a specific indirect mechanism between social support and health behaviours. The stress-buffering hypothesis (Cohen & Wills, 1985) states that social support buffers against the negative impact of stress, evidenced by mediation of the negative association



between health and stress when high perceived support is noted (Cohen & Wills, 1985). This is said to operate via the stress and coping theory (Lazarus & Folkman, 1984a) in which social support allows for adaptive coping via appraisal, emotional, instrumental and informational support.

What these contrasting theories agree on, is that social support is the main mechanism through which social networks are able to influence health outcomes, including health-promoting behaviours, adherence and self-care (Thoits, 2011). Although the literature generally supports these theories, and thus a positive influence of social support on health, the results are occasionally conflicting. Inconsistent findings may stem from disagreement in the conceptualisation and operationalisation of the concept of social support. Conflicting results may also reflect differences across the subtypes of social support; a plausible explanation is that some subcategories of support are more effective at influencing health behaviours than others, as seen in Section 3.3.3.c. (Taylor, 2011). Additionally, although social support is able to facilitate improved health, the literature also suggests too much support can have a negative impact on health behaviours, most commonly through a backlash against feelings of overprotection and misconstruing the support as nagging (Gallant et al., 2007). The understanding of the mechanisms through which social support influences health would, therefore, be greatly enhanced by a better understanding of how different sources and subtypes of support are able to influence health. A refined understanding of this would allow for the development of targeted interventions to enhance social support, rooted in a strong conceptual foundation (Gallant, 2014).

### **3.5. Summary of Chapter 3**

The current evidence unequivocally suggests that social support impacts health outcomes, via influence on health-promoting behaviours, adherence and self-care (Gallant, 2014). However, the precise mechanism through how this is achieved is contested (Karelina & DeVries, 2011). Evidence for both the direct and indirect social mechanisms outlined has been provided in this chapter, and most researchers agree that a combination of these processes is at work (Gallant, 2014). However, precisely how these psychosocial influences are related to health outcomes is still not fully understood; be that via separate pathways or through interaction with one another. Complex neuroendocrine responses pose a likely candidate (Uchino, Bowen, Carlisle, & Birmingham, 2012), with the role of the neurohormone oxytocin explored in the subsequent chapter.

## Chapter 4: Oxytocin

### 4. Overview

This chapter introduces the neurohormone oxytocin (OT). The structure, synthesis and action of OT is presented, though within the scope of this health psychology thesis, to a limited degree. What is most relevant is the relation between OT and affiliation, or social bonding. Therefore, the role of OT in romantic and filial attachment is outlined, with exclusive regard to adolescents. As such, the role of OT in lactation and parturition is not considered relevant, and therefore discounted. Finally, the proposed role of OT in health is outlined, concluding with the framework of a novel theory applying the psychophysiological underpinnings of the stress-buffering hypothesis of social support to T1D. Overall, this chapter provides a clear foundation on which the use of OT in this thesis is based.

### 4.1. Introduction

Until recently, OT research mostly concerned the role of this influential neuropeptide in female reproduction, specifically in lactation and uterine contractions during parturition (Churchland & Winkielman, 2012). Following the discoveries that exogenous OT induced full maternal behaviour towards fostered offspring in female rats (Pedersen & Prange, 1979), mating behaviour in prairie voles (Carter, 1998; Williams, Insel, Harbaugh, & Carter, 1994), and social recognition in mice (Ferguson et al., 2000), the social role of OT has become a focus in research in the understanding of social behaviours and bonding. It is important to note that social bonds differ in their definitions from those of social support discussed in the previous chapter. While social support is affective in nature, bonds refer to the neurobiology of social attachment to a group member, be they familial, friend or partner (Carter & Porges, 2010).

### 4.2. Structure of oxytocin

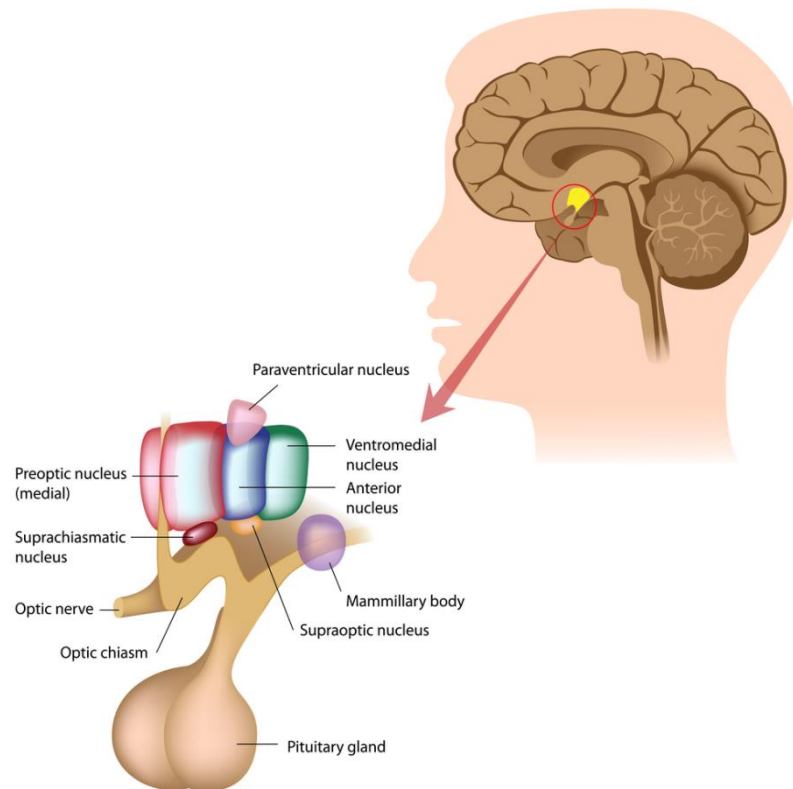
OT is a peptide chain of nine amino acids very similar in structure to vasopressin (VP) (Caldwell, Lee, Macbeth, & Young, 2008). Together, OT and VP constitute a substantial part of the hypothalamo-neurophysiological system (HNS)<sup>16</sup>, able to regulate physiological and behavioural functioning through peripheral and central actions, including the hypothalamic-pituitary-adrenal (HPA) axis (Engelmann & Landgraf, 2013; Neumann & van den Burg, 2013). Despite their structural similarity, their primary functions differ greatly. VP, also known as antidiuretic hormone (ADH) controls the absorption of water by the kidneys and regulates the osmotic content of blood. OT, on the other hand, stimulates contraction of uterine smooth muscle. It is secreted during labour to effect delivery of the foetus. OT also stimulates contraction of smooth muscle in the mammary glands to effect lactation (Messer, 2000).

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<sup>16</sup> Consists of the supraoptic and paraventricular nuclei of the hypothalamus (SON and PVN), and their axons which run towards the posterior pituitary (or neurohypophysis) (Swaab & Lucassen, 2009).

### 4.3. Synthesis and release

OT and VP are both synthesised as part of a larger preprohormone<sup>17</sup>. The preprohormone of OT consists of the signal peptide, nanopeptide (OT) and neuropeptide<sup>18</sup> (Lee, Macbeth, Pagani, & Young, 2009). OT and VP are predominantly produced by the paraventricular (PVN) and supraoptic nuclei (SON) of the hypothalamus (see Figure 1).



*Figure 1.* The location of the paraventricular and supraoptic nuclei of the hypothalamus.

The hypothalamus serves many purposes, but primarily functions to link the nervous system to the endocrine system via the pituitary gland. Through this, the hypothalamus is able to convert external stimuli into the appropriate neuroendocrine response, thus modulating behaviour (Marieb & Hoehn, 2014). The axons of these neurons in the PVN and SON are directed to the posterior pituitary, where OT and VP are ultimately released into the bloodstream to enact its peripheral effects (Dhakar, Stevenson, & Caldwell, 2013). The pituitary synthesises, stores and secretes various hormones, with the posterior pituitary solely concerned with the storage and release of VP and OT (Marieb & Hoehn, 2014).

<sup>17</sup> A precursor protein to prohormones, which are in turn precursors to peptide hormones. Usually, the preprohormone consists of the amino acid chain created by the hormone-secreting cell. It contains a signal peptide, the hormone itself, and amino acids. Before the hormone is released, the signal peptide and amino acids are removed (Voet & Voet, 2010).

<sup>18</sup> A carrier protein which transports OT and VP to the posterior pituitary from the paraventricular and supraoptic nucleus of the hypothalamus (Marieb & Hoehn, 2014).

In addition to the PVN and SON, OT and VP fibres can be located within the central nervous system (CNS) and originate from neurons outside of the PVN and SON (see Figure 2). The action of OT and VP in these subcortical areas are chiefly concerned with the regulation of social and sexual behaviour (Dhakar et al., 2013).

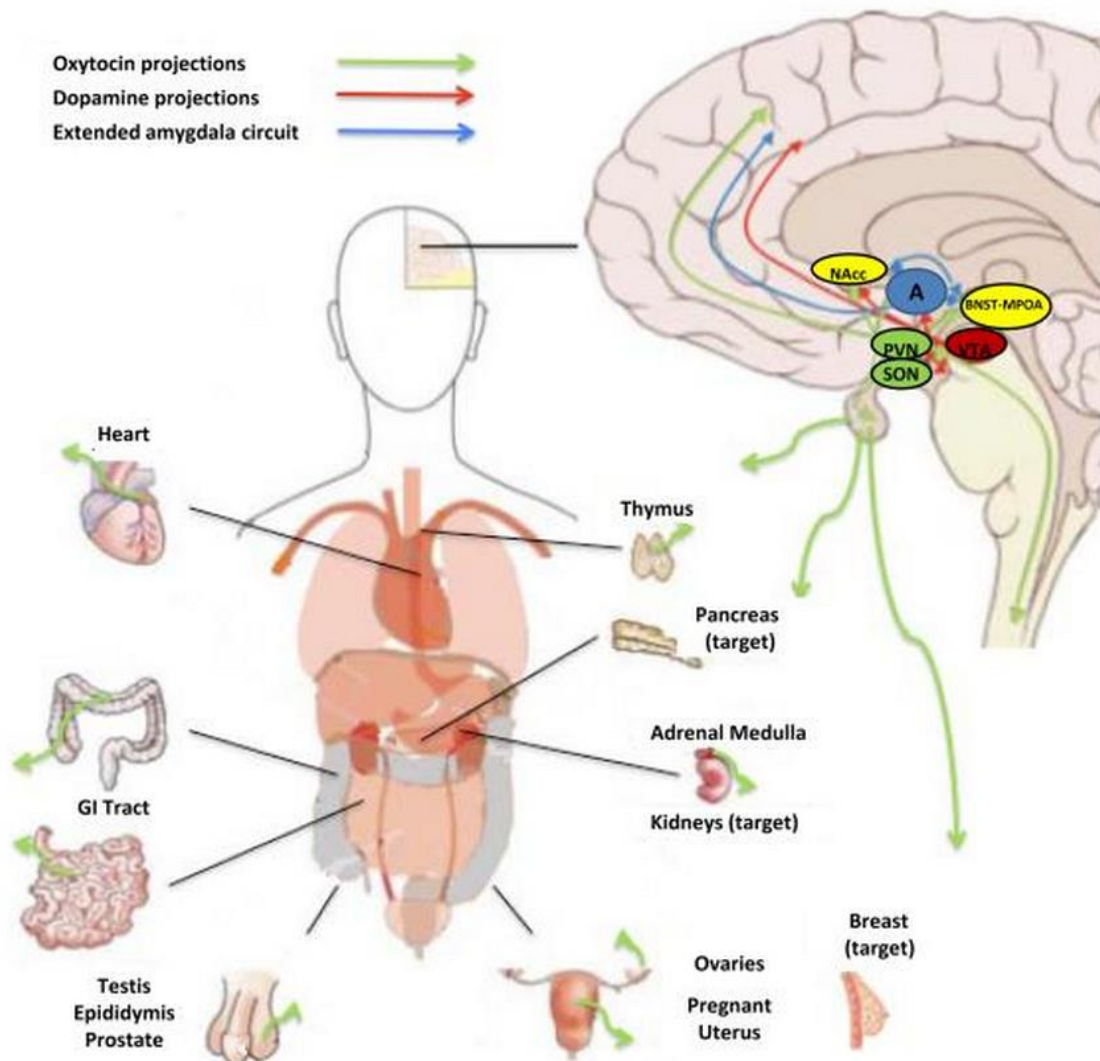


Figure 2. Central and peripheral sites of oxytocin release. Source: Gordon, et al. (2011), p. 40.

*OT is released primarily from the PVN and SON in the brain. Additional central sources of OT are the nucleus of the stria terminalis, spinal cord and anterior commissural nucleus. Central OT sources are shown in green. Peripheral sources of OT release include the pituitary, heart, thymus, gastrointestinal tract, testis, epididymis, prostate, pregnant intrauterine tissue, ovaries and adrenal medulla. The breast, pancreas and kidney are peripheral targets of OT.*

Only one OT receptor (OTR) has been identified. The OTR is located throughout the CNS. In rats, OTRs are located in areas that may be associated with social behaviours, such as the

olfactory bulb and amygdala<sup>19</sup> (Choleris, Kavaliers, & Pfaff, 2004). The correlation between the sites of release and location of OTR suggests a physiological relevance of OT. The OTR has a far wider distribution than OT release; Yoshida and colleagues (2009) have demonstrated OTR locality in cortical, limbic, hypothalamic and brain stem regions in mice, though the distribution of the OTR varies greatly across species. These differences correlate with distinct behavioural properties. For example, in two species of singing mice, who have a prominent vocal capacity for communication, VP receptors are most dense in areas important for vocal sounds (periacqueductal grey and anterior hypothalamus) in the more communicative species. Equally, VP and OT receptors are located in areas required for social and spatial memory in groups of lower density (anterior and laterodorsal hypothalamus, hippocampus and medial amygdala) (P. Campbell, Ophir, & Phelps, 2009). Together, this demonstrates a pattern in which OT and VP receptor locations are specific to the social behaviours of that species (Neumann & van den Burg, 2013). Similarly, research has found that release and binding is also gender specific, thought to aid in reproduction (Carter, 2007).

#### **4.3.1. Sex differences in expression of oxytocin**

OT expression has been found to be consistently higher in females (Carter, 2007; Zingg & Laporte, 2003). The central role of OT on behaviour and physiology has been shown to be dependent on steroid hormones, such as oestrogen, with distribution of OT in the brain differing according to sex (Carter, 2007). Haussler and colleagues (1990) demonstrated that the amount of OT in females far exceeded the amount in males. Sexually dimorphic release of OT has been found in brain regions where OT is able to have a behavioural impact, while areas without a behavioural role do not vary according to sex (Uhl-Bronner, Waltisperger, Martinez-Lorenzana, Condes Lara, & Freund-Mercier, 2005), suggesting a sex-specific behavioural role of OT.

#### **4.4. Action of oxytocin**

OT is a behavioural hormone regulating a wide-range of both social and non-social actions. Often, these behaviours are highly related, such as social species tending towards monogamous pair bonds and bi-parenting (Lee et al., 2009). The particular roles that OT has in regulating both social and non-social behaviour is summarised in Table 1. It is noted that while OT is often discussed in conjunction with VP, within the scope of this doctoral thesis the coverage of the role of VP on these same behaviours is limited. It is also important to recognise that the majority of OT research has taken place in rodents, and consequently its application to human populations is somewhat limited due to their differing social behaviours. Research into endogenous OT in humans is sparser still (Choleris, Pfaff, & Kavaliers, 2013; Neumann &

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<sup>19</sup> The amygdala performs a primary role in the processing of memory, decision-making, and emotional reactions, the amygdalae are considered part of the limbic system (Marieb & Hoehn, 2014).

Landgraf, 2008). It is crucial, therefore, to establish a greater base of research into the regulatory roles of OT in human samples

Table 1. *Summary of the behavioural effects of OT. Adapted from Lee, et al. (2009).*

Behavioural classes	Behaviours	Effects of OT in humans
<i>Social behaviours</i>		
Social memory	Social recognition	↓ amygdala activation to social stimuli ↑ facial recognition
Affiliation	Sexual behaviour	↑ sexual arousal ↑ uterine contractions at parturition
Aggression	Male aggression	↑ plasma OT in males with conduct disorder
<i>Non-social behaviours</i>		
Learning and memory	Non-spatial memory	↓ episodic memory ↓ verbal recall of words
Anxiety & depression	Anxiety	↓ amygdala response to threat ↓ anxiety to social stress
	Depression	↓ plasma OT in major depression

It is important to note that although social stimuli are of particular importance in OT release and action, differentiation between reproductive/physiological and social stimuli is required due to differences in cascade events and subsequent neurophysiological changes (Neumann & van den Burg, 2013). As such, and within the scope of this thesis, this chapter will focus on the social role of OT, though its crucial role in reproduction, parturition and breastfeeding is recognised.

#### 4.5. Affiliation

Affiliation, also known as forming social bonds, is a crucial social behaviour, as the formation of a social group has been found to neutralise the stress and anxiety caused by isolation (Grippe et al., 2007). As with social memory, affiliative behaviours are highly species-specific, though the majority of research has taken place in rodents. In mice and prairie voles, the two most commonly used rodents in OT research, the primary affiliative behaviours are sexual in nature (Carter, 1998). This limits its application to human populations and so, as before, this limitation must be acknowledged. The following section, therefore, shall focus on human research. The affiliative function of OT is often understood within the bio-behavioural synchrony model of affiliation, which attempts to align biological and social processes in order to understand the physiological benefits of social groups (Feldman, 2012).

#### **4.5.1. Bio-behavioural synchrony model of affiliation**

Affiliation consists of two essential elements. It contains both a close interpersonal bond, such as that seen between partners, friends or parent-child, and is initiated by an action or process (Feldman, 2012). Affiliative bonds have been defined by seminal researchers such as Bowlby (1958), Harlow (1958) and Spitz (1946) as selective and enduring attachments, allowing us to form intimate bonds with non-kin group members and eventually create and develop future generations. Ethological research has determined that affiliative bonds should be viewed in three key ways. Firstly, that bonding is expressed through reciprocal care-giving and care-receiving behaviours, most often unique to the species. Secondly, that bond formation is facilitated by neuroendocrine systems, reflecting the relationship between biology and behaviour in bond formation. Finally, that bond formation is a lifelong process, and that the three types of affiliative bonds in mammals (parental, pair and filial) share both physiological and behavioural mechanisms. This is supported by bio-behavioural mechanisms established in infancy that will impact on the social functioning of the individual in their various bonds throughout their lifetime (Feldman, 2012).

This attachment-ethological perspective has been supported by numerous research programs over the last half-century, specifically regarding the biological basis for affiliation. This culminated with the work of researchers such as Carter (1998) and Meaney (2001) specifying the relationship between OT and maternal bonding. Since then, researchers have sought to describe and establish the role of OT in human social adaptation and the formation of affiliative bonds. This has included the identification of the associations between OT and parenting behaviour, the cross-generation transmission of OT, and consistency in OT-related behavioural processes across the three prototypical mammalian affiliative bonds; parental, pair and filial (Feldman, 2012). In humans, these refer to parental bonds, romantic relationships and friends, respectively. Regarding the present thesis, patients with children are excluded due to the impact of parenthood on OT production (Rollins, Martin, Morgan, & Vawter, 2010). Therefore, within the scope of this thesis, this chapter shall focus on the role of OT in the two bonds most likely to be encountered in the participant population; pair and filial.

#### **4.5.2. Oxytocin and romantic attachment**

Romantic attachment across age-groups has been found to impact on well-being and health, while the inability to find a lasting pair bond has been found to worsen psychological distress (August & Rook, 2013), yet little research has sought to identify the neuroendocrine basis of romantic relationships in humans.

In the limited human research that has taken place, OT has been highlighted as a crucial facilitator of pair bonding. Exogenous nasal OT administration has been found to increase

positive communication in romantic partners (Ditzen et al., 2009), with endogenous plasma OT indicative of positive communication, affiliation and emotional support (Gonzanga, Turner, Keltner, Campos, & Altemus, 2006; Grewen, Girdler, Amico, & Light, 2005). However, few studies have identified relationships between OT and negative emotions, such as anxiety and distress (Holt-Lunstad, Birmingham, & Light, 2008; Tabak, McCullough, Szeto, Mendez, & McCabe, 2010; Taylor, Saphire-Bernstein, & Seeman, 2010).

Aside from direct measures of OT, neuroimaging studies of romantic partners displayed greater activation in OT and dopamine<sup>20</sup>-specific brain areas during the early stages of forming a pair bond. Activity is then noted in the cortical regions involved in cognitive functioning and emotion in long-term romantic relationships (Aron et al., 2005; Bartels & Zeki, 2004; Kim et al., 2009). These findings highlight the associations between OT and dopamine which have been proposed as a possible mechanism that mediates the role of OT in bond formation (Feldman, 2012).

Interestingly, the brain areas associated with maternal attachment have also been found as active in long-term pair bonds (Acevedo, Aron, Fisher, & Brown, 2012), consistent with the bio-behavioural model position that differing relationships share biological mechanisms. Comparing the differences between bonding in pair and parental relationships, Schneiderman and colleagues (2012) compared plasma OT in couples compared to non-attached singles and parents. Results suggested that plasma OT was observed in significantly higher proportions in new romantic relationships (>3 months) compared to single participants, indicating a surge of OT when first falling in love. In comparison with new parents, new couples and singles, the newly formed pair bonds displayed the highest concentration of plasma OT, emphasising the initial phase of romantic attachment and its associated euphoria as related to the greatest level of OT release. After six months, the observed plasma OT had not decreased and could be considered stable. The concentration of OT was found to correlate with sociality, positive affect, displays of affection and synchronicity, as well as negatively correlating with preoccupations and worries regarding the relationship (Schneiderman et al., 2012). These findings display similarity to parental bonding, lending further support to the proposed similarity across forms of affiliation, and corroborate the proposition that similar OT-based neuroendocrine mechanisms support across types of bond. For this theory to be further supported, the remaining type of bond, filial attachment, must also be investigated.

#### **4.5.3. Oxytocin and filial attachment**

Close friendship, or filial attachment, is typically expressed via intimate familiarity with pace, rhythms, jokes, movements, behavioural mannerisms and verbal idiosyncrasies with each group

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<sup>20</sup> A neurotransmitter most commonly associated with reward-behaviour (Schultz, 2007).



member (Feldman, 2012). Despite this importance in the lives of individuals, and their positive influence on well-being and social adaptation (Kawachi, Subramanian, & Kim, 2008), little research has focused on the attachments between friends and the physiological mechanisms associated with this. Some research has recognised the processes of young children's formation of social groups at pre-school, and documented the evolution of these friendships as they attend formal education (Asher & Gottman, 1981; Hartup, 1989; Schneider, Attili, Nadel, & Weissberg, 1989), though these studies lacked a biological perspective and would now be considered out-dated. No studies could be found examining filial attachment from this affiliative perspective; to observe interactions and assess their reciprocity, engagement and interpersonal sensitivity in context of their neuroendocrine correlates.

Two longitudinal studies, however, were identified examining children's filial attachment, and one of which focused on OT. In the first (Feldman, 2012), parental OT and synchronous interaction were assessed when children were aged one month and again at six months. At three years, they were recorded interacting with their parents and a close friend, their first selective attachment, with baseline and reactive measurements of salivary OT taken. Children experiencing synchronous parenting engaged in higher quality interactions with their filial affiliation, including display of emotional involvement and affective attunement. The OT measurements in each parent were stable across time. These findings describe a three-year OT stability, and support the bio-behavioural synchrony model, suggesting that OT reactivity is determined in early childhood via parental attachment, and is stable over the life course (Feldman, 2012). These results imply a bi-directional bio-behavioural response in which a child's OT expression is influenced by parental attachment.

In the second study (Feldman, Bamberger, & Kanat-Maymon, 2013), multiple affiliative bonds were examined from infancy through to adolescence. Participants were recorded at five months, three and thirteen years during an interaction with a parent. At three years, children were observed during childcare to assess interaction with peers. At thirteen years, children were again observed, now during positive and negative communication with a same-sex close friend. It was found that the reciprocity of the parental attachment was stable over the thirteen years and was bi-directional; reciprocity between mother and father relationships were found to be inter-related at each stage of the study. Children with high levels of reciprocity between parents displayed enhanced social adaptation at childcare, expressing friendlier, cooperative communication with peers and adults, displayed leadership skills, self-regulation, social involvement and sought mutually beneficial conflict solutions. Adolescents with reciprocal parents expressed greater communication skills, opinions and emotions, empathy, maintained positive affect during conflict and engaged in mutual, assured, fluent dialogue whilst preserving autonomy (Feldman, Bamberger, et al., 2013). Despite OT not being assessed in this study,

previous research has proposed that administration of exogenous nasal OT increases trust and empathy (Bartz, Zaki, Bolger, & Ochsner, 2011), suggesting that attachment and empathy are related. This develops to include non-kin social group members in infancy, progressing through to adolescence, when children typically form life-long friendships (Hartup, 1989), culminating in a capacity to create and maintain a romantic partner attachment, providing the resources needed to nurture the next generation (Lee et al., 2009). Overall, these findings support the notion of biological commonality between the three affiliative bonds – parents, partner and friend – and demonstrate the related nature of behavioural response and neuroendocrine substrates in the formation and maintenance of affiliative bonds.

The ability to construct, maintain and live as social creatures typifies the apex of humanity, according to some evolutionary perspectives (Feldman, 2012). The bio-behavioural synchrony model stresses the physiological building blocks of bonding and its behavioural manifestation, and how these combine to procedure affiliative bonds with a specific pace, rhythm, patterns and focus, beginning in infancy. It is able to account for how affiliations differ but preserve uniformity in expression and neurobiology across multiple relationship types. However, the impact of OT is not isolated to behavioural expression and affiliative bonds. This social neuropeptide has also been found to be beneficial in health, providing a biological basis for the stress-buffering hypothesis of social support (Cohen & Wills, 1985).

#### **4.6. Oxytocin and health**

As well as the modulation of behavioural processes, OT has been found to strongly influence physiological functioning. OT moderates health processes related to inflammation (Clodi et al., 2008; Iseri et al., 2005), ischemic injury (Ondrejčáková, Ravingerová, Bakos, Pancza, & Jezová, 2009; Tugtepe et al., 2007) and atherosclerosis (Szeto et al., 2008), suggesting that OT may be a candidate mediator for the association between social factors and health (G.J Norman, Hawkley, Cole, Berntson, & Cacioppo, 2012; Uchino et al., 2012).

OT has been found to up-regulate immunofunction in human populations. Administration of lipopolysaccharide (LPS), an immunostimulant, works to cause escalation of circulating pro-inflammatory cytokines and glucocorticoids. However, when LPS is administered alongside OT, levels of pro-inflammatory cytokines and glucocorticoids are diminished, potentially via the action of OT on autonomic nervous system function (ANS) (Clodi et al., 2008). This suggests that OT acts to down-regulate the action of the ANS, and supports the assertion that OT function may modulate the association between bonding and health.

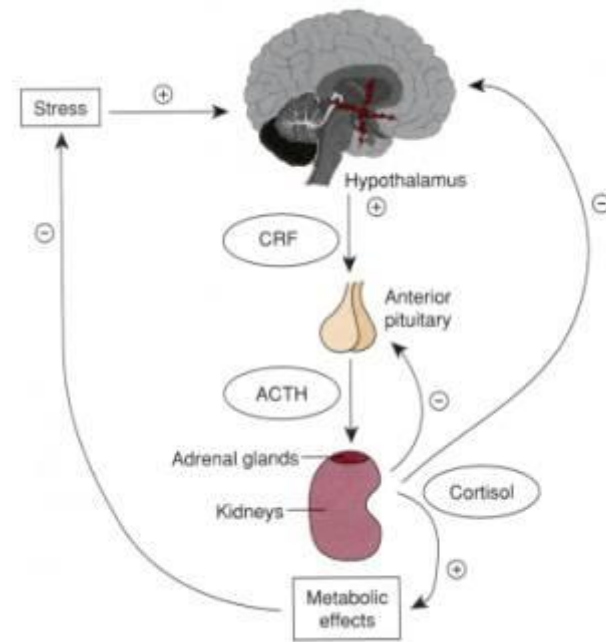
In animal models, OT has been found to moderate pathophysiological responses. Central delivery of OT was found to correct the negative impact of isolation and loneliness on autonomic cardiac control and social behaviours in voles (Grippe, Trahanas, Zimmerman,

Porges, & Carter, 2009). It has been noted that OT can significantly reduce blood pressure in rats with hypertension (Petersson & Uvnas-Moberg, 2007) and is able to moderate the negative impact of social isolation on vascular oxidative stress, atherosclerosis and adipose tissue inflammation in mice (Szeto et al., 2008). Conversely, pharmacological inhibition of OT in mice increases depressive behaviour and cytokine circulation to similar levels to that seen in socially isolated comparisons (Norman et al., 2010). It can therefore be concluded that OT is able to moderate various pathophysiological processes linked to social influences, in addition to the previously noted impacts on behaviour. One of the most likely mechanisms through which OT is able to achieve this is through its action on the ANS and, by extension, the stress response (Norman, Hawkley, Cole, Berntson, & Cacioppo, 2012).

#### **4.6.1. Social buffering of the hypothalamic-pituitary-adrenal axis**

Numerous studies have investigated social buffering of the stress-response. Both human and animal research has identified down-regulation of the HPA axis by social support as a convincing mechanism for the benefits of high quality social interaction (Hostinar, Sullivan, & Gunnar, 2014). Evidence has suggested that OT attenuates stress, fear and anxiety. It is hypothesised that it achieves this via two pathways; modulation of the HPA axis (Neumann, 2002) and facilitation of pro-social behaviours associated with diminishing the neural systems responsible for fear and anxiety (Carter, 2007). Both pathways provide a sound rationale for the role of OT in the stress-buffering hypothesis of social support (Cohen & Wills, 1985).

Stress is typically defined as having insufficient resources to effectively cope with internal or external demands (Lazarus & Folkman, 1984b). This challenge results in a neuroendocrine cascade causing the production of cortisol via the activation of the HPA axis (Cone, Low, Elmquist, & Cameron, 2003). Neurons in the PVN secrete corticotrophin-releasing hormone (CRH) and VP. These act on the anterior pituitary to release adrenocorticotrophic hormone (ACTH) (Gunnar & Vazquez, 2006). ACTH then binds to its receptors in the cortex of the adrenal glands, allowing the release of cortisol. Circulating cortisol binds to receptors in the PVN and creates a negative feedback loop such that the axis can shut down when sufficient cortisol has been released (Cone et al., 2003) (see Figure 3).



*Figure 3.* The hypothalamic-pituitary-adrenal (HPA) axis. Adapted from Papadopoulos and Cleare (2012),

Release of cortisol has various effects on the body, such as enhanced transport of energy to muscles, increased cardiovascular activity, stimulation of immunofunction, improved cognition and increased glucose utilisation (Sapolsky, Romero, & Munck, 2000), allowing the body to effectively respond to the stressor. However, prolonged cortisol secretion can cause significant physiological changes (Hostinar et al., 2014). Pertinent to T1D, cortisol is known to increase gluconeogenesis and decrease glycogenolysis, resulting in hyperglycaemia (Khani & Tayek, 2001). As is acknowledged in Section 5.7., the long-term effects of hyperglycaemia in T1D are numerous and damaging, and would make maintaining optimal glycaemic control an even greater task (Bilous, Williams, & Donnelly, 2010).

A vast resource has been established examining the role of social support in the modulation of the HPA axis during infancy and early childhood (Gunnar & Donzella, 2002; Gunnar, 2006). However, a paucity of studies can be found examining the impact of bonding in older children and adolescents. Of the few that have investigated this age group, social buffering of the HPA axis is supported. Research has found that, in girls aged 7-12 years, a telephone conversation with their mother after a laboratory-based stress test is able to dampen salivary cortisol levels and elevate urinary OT post-stressor. Having their mother present during the stress test elicited even greater diminishment of cortisol (Seltzer, Ziegler, & Pollak, 2010). In 10-11 year olds, diary-reports of stressful events were associated with a lower cortisol response if the child had a “best friend” present at the time (Adams, Santos, & Bukowski, 2011).

Despite the evidence for the HPA-buffering effect, little is known about the neuroendocrine processes which underlie the effect of social behaviour. The working model proposed by Hostinar and colleagues (2014) postulates that parental social behaviour experienced in infancy shape the efficacy of social support in the down-regulation of the HPA axis in response to stress and that, as a direct result, an impulse to utilise social support in times of stress is developed. Hostinar, *et al.* (2014) go on to propose that two biological mechanisms underpin this process; neural priming of attachment figures and OT function, namely OT release, receptor expression and the binding of OT in the brain (see Figure 4).

These findings support the assertion that OT acts as a biological intermediary, able to translate social factors into physiological processes directly linked to health, including autonomic, neuroendocrine and immune functioning. Variation within endogenous OT may, therefore, be able to mediate the compelling impact of social factors on morbidity and mortality in humans (Norman et al., 2012). Pertinent to the present study, however, little research has looked specifically at the impact of OT on disease management in T1D.

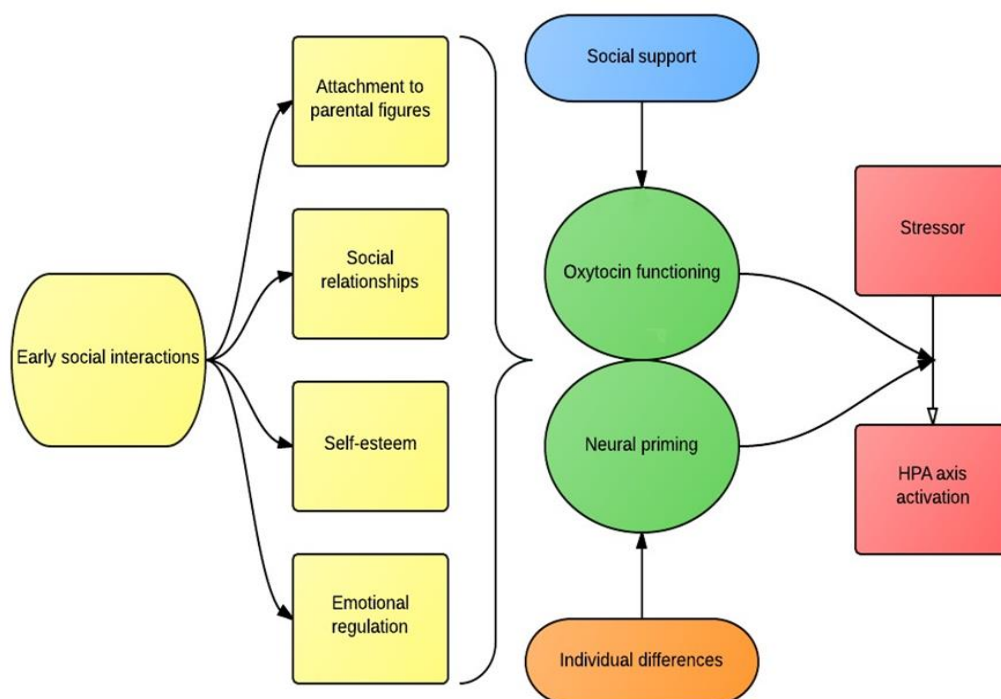


Figure 4. A developmental working model of social buffering of the hypothalamic–pituitary–adrenocortical (HPA) axis. Adapted from Hostinar, Sullivan & Gunnar (2014), p.257.

#### 4.6.2. Oxytocin and diabetes

Although OT is currently attracting considerable attention for its potential role in the action of the social environment on health, no studies could be found examining the relationship between OT and T1D. Considerable research has taken place examining the role of OT in gestational diabetes, due to the previously recognised role of OT in reproductive and birthing behaviours

(Churchland & Winkielman, 2012). However, this research is outside the scope of this thesis. Similarly, research has looked at the benefits of OT as a treatment for T2D, due to its capacity for increasing energy expenditure, satiety signals, adiposity and decreasing food consumption (Cai & Purkayastha, 2013). Again, such research sits beyond the constraints of this thesis.

The potential role of OT in T1D, therefore, is based on speculative theory which this doctoral research aims to investigate. As a stress hormone crucial to the fight-flight-or-freeze stress response, a vital role of cortisol is the increase in the enhanced transport of energy to muscles. This is achieved via heightened gluconeogenesis and glycogenolysis (Khani & Tayek, 2001). Gluconeogenesis is a metabolic pathway wherein glucose is generated from non-carbohydrate carbon substrates such as glycerol, glucogenic amino acids, and fatty acids (Glew, 2010). Glycogenolysis is the breakdown of glycogen, allowing the release of glucose into the bloodstream for uptake by other cells. Both of these pathways act to increase the circulating blood glucose, enabling greater energy for cell uptake should a fight-flight-or-freeze response be required (Marieb & Hoehn, 2014). However, for someone with diabetes, chronically elevated blood glucose will contribute towards hyperglycaemia. As is outlined in Section 5.7., hyperglycaemia is noted as a precursor of microvascular complications, including retinopathy, neuropathy and nephropathy (Fowler, 2008). Those with chronically increased stress, therefore, are at greater risk of poor glycaemic control and, in the long-run, diabetic complications (Giacco & Brownlee, 2010).

As stated in Section 4.6.1., it is acknowledged that OT is able to down-regulate this response via its action on the HPA axis. It is therefore hypothesised that social support, as measured via OT, is able to moderate the stress response, as measured via cortisol, and thereby aid improved glycaemic control and decrease the likelihood of developing microvascular complications in T1D.

#### **4.7. Summary of Chapter 4**

Social relationships are essential to the well-being of humans, with social bonds able to influence both mental and physical health (Uchino et al., 2012). As discussed in Section 3.3., social support can improve recovery rates from disease and modify the physiological pathways that modulate health (Karelina & DeVries, 2011). The findings outlined in this chapter indicate that the association between social factors and health is not simply down to peer-encouraged change in health behaviour, but rather the social bonds and the resultant modulation of physiological processes that play a role in both the promotion and reduction of health and well-being (Norman et al., 2012). As positive social interactions are essential to promote social groups (Smith & Wang, 2012), it is feasible that the neuroendocrine systems responsible for these social behaviours, such as the OT system (Snowdon et al., 2010), were crucial in reducing

stress via their action on the HPA axis. OT, promoted via social support and other social cues, provides various mechanisms in which social bonds can buffer against stress, leading to an improvement in health (Meyer-Lindenberg, Domes, Kirsch, & Heinrichs, 2011). With regard to T1D, OT offers a plausible mechanism through which social support may moderate stress, and thereby mitigate its negative effects on glycaemic control. The intricacies of T1D management, and how they may be impacted by social factors, are explored in the subsequent chapters.

## Chapter 5: Type 1 Diabetes

### 5. Overview

This chapter presents and discusses key information about T1D. Firstly, it gives a clear definition of what T1D is, identifies the prevalence of the illness and considers the different aetiological theories put forward to explain why individuals develop the condition. In addition, this chapter examines the diagnostic criteria and highlights the practicalities of management of T1D. Finally, it provides information regarding the various types of complications which can occur from poor glycaemic control. Overall, this chapter serves as an introduction to T1D essential for understanding the development, design and implementation of this research.

#### 5.1. Introduction

Diabetes is a metabolic disorder in which blood glucose concentrations are chronically raised. The fundamental underlying abnormality is a net deficiency of the hormone insulin. Insulin facilitates the entry of glucose into cells. Without it, glucose cannot leave the bloodstream and will continue to accumulate there, rendering the individual unable to access this energy source. As insulin is the only hormone capable of lowering blood glucose concentrations, its absence or inefficiency results in the patient lacking an endogenous ability to regulate blood sugars (Bilous et al., 2010).

At the end of 2013, diabetes was stated to have caused 5.1 million deaths worldwide and cost USD 548 billion in healthcare spending. It is predicted that in less than 25 years, an estimated 592 million people will be living with diabetes, the majority of which would be preventable with concerted action from healthcare providers and policy makers (International Diabetes Federation, 2013). Diabetes is therefore considered to be a major public health problem from both the short and long-term effects which will be discussed in this chapter.

#### 5.2. Disease classification

The current classification of diabetes is based on the aetiology of the disease. The four main categories of diabetes are:

- Gestational diabetes (GD).
- 'Other specific types of diabetes.'
- Type 2 diabetes (T2D).
- Type 1 diabetes (T1D).

These classifications replace the previous categories of insulin-dependent (IDD) and non-insulin-dependent diabetes (NIDD), based on the need for insulin replacement. IDD is seen as equivalent to T1D, and NIDD as equivalent to T2D (Bilous et al., 2010).



### **5.2.1. Gestational and ‘other specific types of diabetes’**

The classification of ‘other specific types of diabetes’ refers to conditions including endocrinopathies, diseases of the pancreas and genetic syndromes, which cause diabetes as a by-product of their actions on other areas of the body. These include conditions such as genetic deficiency in insulin secretion or inaction, pancreatitis, or hormone-secreting tumours such as Cushing’s syndrome<sup>21</sup> (Bilous et al., 2010).

GD occurs during pregnancy, typically during the second or third trimesters. GD occurs when the body is unable to produce enough insulin to meet the extra needs of pregnancy. Typically, GD will resolve after birth (Dinneen, 2006).

### **5.2.2. Type 2 diabetes**

T2D is caused by insulin resistance and a  $\beta$  cell insulin secretory dysfunction. Here, the pancreas is still able to produce insulin, though it is insufficient or ineffective. Around 80% of patients with T2D are obese, with rising levels of obesity said to be responsible for increasing incidence of T2D (Craig, Hattersley, & Donaghue, 2009). T2D typically occurs in those aged over 40, though increasingly is seen in children and adolescents. T2D accounts for 85-95% of all diabetes cases (Dinneen, 2006).

### **5.2.3. Type 1 diabetes**

The WHO defines T1D as being caused by pancreatic islet cell destruction, wherein the body is no longer able to produce insulin. Autoimmune pathogenesis is indicated in most patients (Thrower & Bingley, 2010). T1D accounts for 5-10% of diabetes cases and can develop at any age but typically appears in childhood, the most common age of diagnosis being 10-14 years old (Dinneen, 2006).

Due to the higher prevalence of T1D in adolescents, the participant group of this research will be drawn from T1D patients. Within the scope of this doctoral thesis, this chapter will focus on the epidemiology, pathophysiology, diagnosis and management of T1D.

## **5.3. Epidemiology**

The most recent National Diabetes Audit suggests that the UK prevalence of all types of diabetes is 6.0%. or 2,703,044 people, in comparison to a global prevalence of 9%. Of these, 10% have T1D (National Diabetes Audit, 2014). When considering paediatric T1D, prevalence is considered to be one in 430-530 in those aged under 19 (National Diabetes Audit, 2014).

In Europe, overall prevalence is increasing by 3.4% per year (Patterson, Dahlquist, Gyürüs, Green, & Soltész, 2009). Recent findings from the EURODIAB epidemiological study have suggested an overall global increase in the incidence of T1D in children below 15 years of

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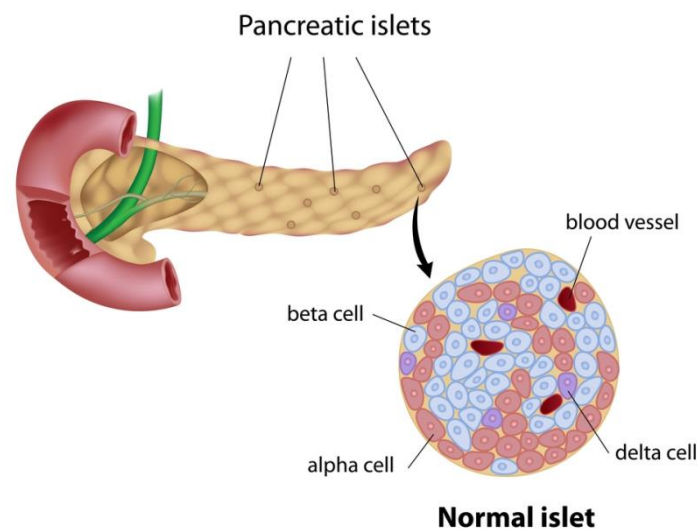
<sup>21</sup> A metabolic disorder caused by overproduction of corticosteroid hormones by the adrenal cortex and often involving obesity and high blood pressure (NHS, 2011).

age, with incidence set to rise from 94,000 to 160,000 by 2020 in Europe alone (Patterson et al., 2009). Several explanations have been posited for such an increase, though none has been truly accepted. These theories include early growth spurts, environmental changes and reduced pathogen exposure in infancy (Gale, 2002). Such findings would indicate a growing problem of established T1D in adolescents, highlighting the need for further research in this at-risk group.

If these predictions prove accurate, the prevalence of T1D would be 70% higher in 2020 than in 1989. Increases of such extreme nature would take several generations should genetic influences be the culprit. This suggests that changing environmental factors in early life are responsible for the rapidly increasing incidence of T1D (Patterson et al., 2009). In order to better understand how this may be occurring, it must first be established how the metabolism of glucose in a healthy individual occurs in comparison to the disordered process underpinning T1D.

#### 5.4. Pathophysiology

In a healthy individual, insulin is produced in the pancreas by  $\beta$  cells. Of the cells of the pancreas,  $\beta$  cells are the most numerous and can be found in the core of the islet of Langerhans (see Figure 5). Parasympathetic innervation is responsible for the stimulation of insulin release, with adrenergic sympathetic nerves serving to inhibit insulin and stimulate glucagon secretion (Hancock, 2010).



*Figure 5.* Structure of a pancreatic islet.

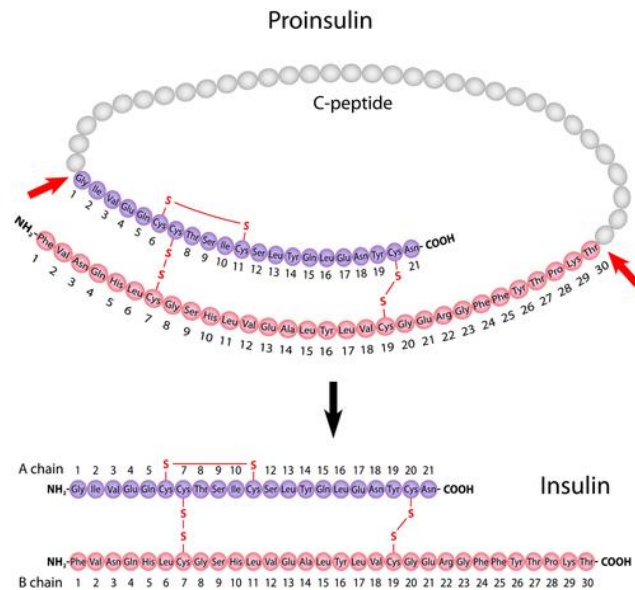


Figure 6. Insulin biosynthesis and processing.

Insulin is produced in  $\beta$  cells in a single amino acid chain precursor molecule; preproinsulin. Preproinsulin is then cleaved and shortened, resulting in peptide chain known as proinsulin. Proinsulin is then further cleaved into insulin and connecting peptide, or C-peptide (see Figure 6; Holt, Watkins, & Kumar, 2010).

Insulin is released from the  $\beta$  cell in response to the metabolism of glucose. Glucose enters the  $\beta$  cells, where it is converted to glucose-6 phosphate by the addition of a phosphate group. This conversion is catalysed by the enzyme glucokinase. This acts as a trigger for insulin secretion. Release occurs in a biphasic pattern, with an acute primary phase persisting for mere minutes, followed by a sustained secondary phase (see Figure 7a). Blood glucose levels below approximately 21mmol/mol fail to stimulate insulin, with half-maximal release occurring at 49mmol/mol (see Figure 7b) (Chew & Leslie, 2006; Hancock, 2010).

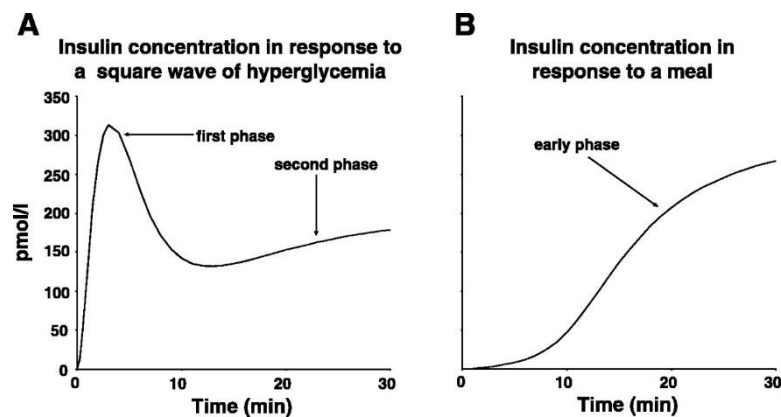


Figure 7. (a) The biphasic glucose-stimulated release of insulin from pancreatic islets. (b) The glucose–insulin dose–response curve. Source: (Caumo & Luzi, 2004).

Glucose is transported into cells via specialised transporter proteins, known as glucose transporters, or GLUTs, such as (see Figure 8):

- GLUT-1; responsible for basal, non-insulin-mediated glucose uptake.
- GLUT-2; constitutes part of the  $\beta$  cell's glucose sensor, and allows glucose uptake in a proportional rate to the extracellular glucose level.
- GLUT-3; responsible for non-insulin-mediated glucose uptake in the brain.
- GLUT-4; allows insulin-stimulated glucose uptake into muscle and adipose tissue.

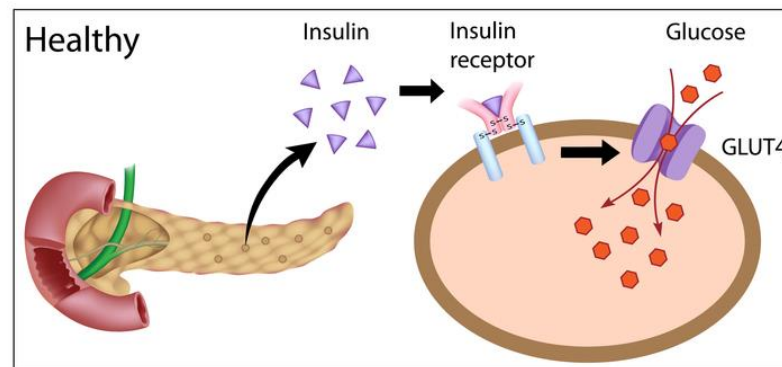


Figure 8. Insulin regulation of glucose transport into cells.

Most GLUTs are present at the cell surface, with the exception of GLUT-4, which is found in the vesicles of the cytoplasm. Insulin is responsible for the translocation of the vesicles to the cell surface, where they are able to fuse with the cell membrane. The GLUT-4 is then able to function as a transporter to allow glucose to enter the cell (see Figure 9) (Chew & Leslie, 2006; Hancock, 2010).

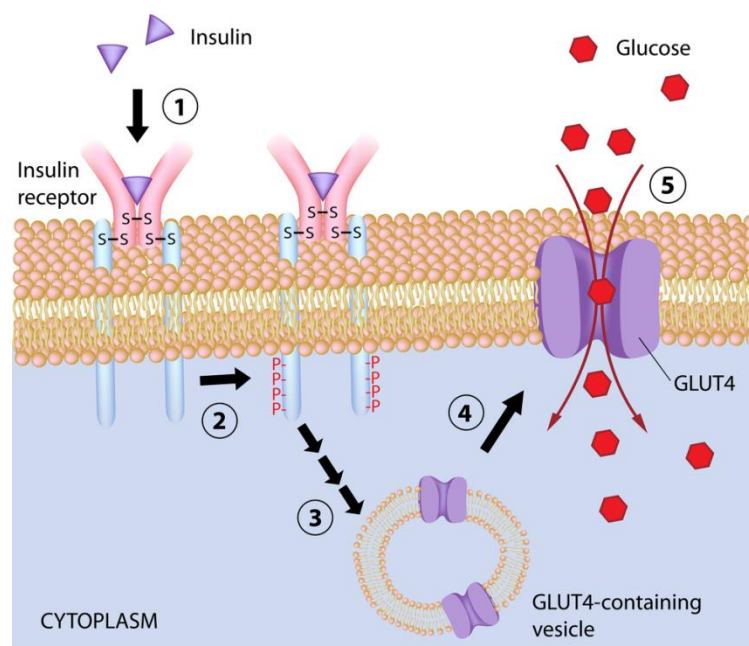
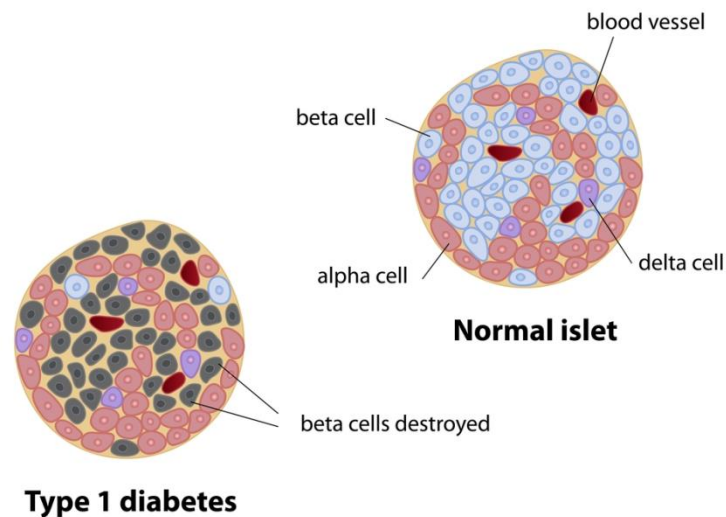


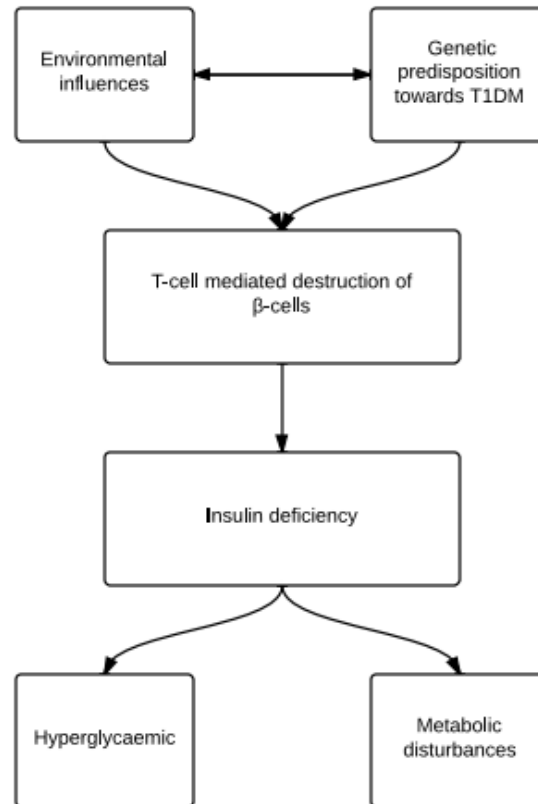
Figure 9. The action of GLUT-4 in the transport of glucose into cells.

In the absence of diabetes, blood glucose concentrations are maintained through this process within narrow limits, typically 28-42mmol/mol (Holt et al., 2010). Glucose entry into circulation occurs through stores in the liver, intestinal absorption whilst uptake occurs in peripheral tissues, including muscle and adipose cells. Therefore, in a person without diabetes, insulin is secreted at low, basal levels with additional stimulation when food is consumed. Insulin is able to reduce blood glucose circulation via suppression of the output from the liver, through glycogenolysis and gluconeogenesis. When this functions correctly, relatively limited insulin is needed to suppress hepatic glucose output, using basal insulin secretion (Bilous et al., 2010; Hancock, 2010).

T1D is most often attributed to autoimmune destruction of the islet  $\beta$  cell (see Figure 10). This is the case in over 90% of T1D. The exact aetiology is still imperfectly understood, though it has been suggested that environmental factors are the most likely culprit for a trigger of an inherent predisposition towards T1D, as seen in Figure 11 (Thrower & Bingley, 2010).

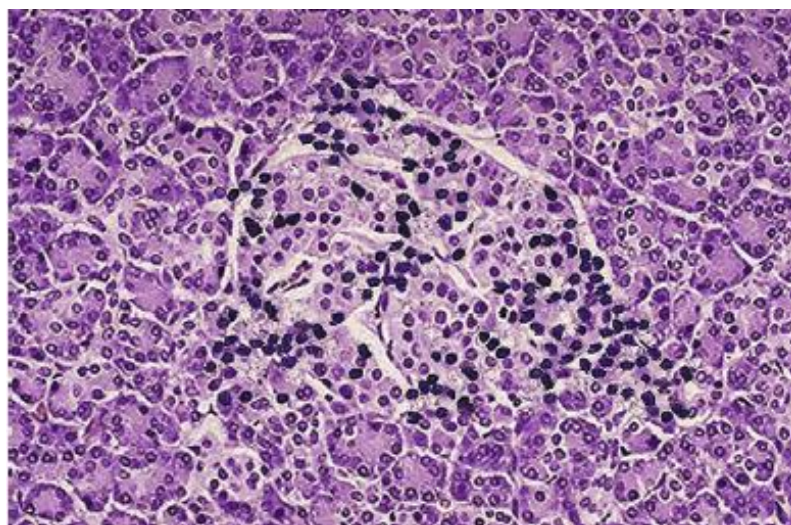


*Figure 10.* Autoimmune destruction of the  $\beta$  cell in type 1 diabetes.



*Figure 11.* The proposed aetiology of type 1 diabetes.

It has been proposed that one or more environmental factors, including viruses, diet, toxins, and a stressful environment, may initiate the autoimmune destruction of  $\beta$ -cells in genetically susceptible individuals. Autoimmunity is indicated by the presence of specific antibodies. In recently diagnosed T1D patients, a chronic inflammatory mononuclear cell infiltrate, or insulitis, is present in the remaining  $\beta$ -cells (see Figure 12). Insulitis gradually destroys  $\beta$ -cells and will ultimately lead to overt T1D (Eizirik, Colli, & Ortis, 2009).



*Figure 12.* Insulitis of the islet cell. Source: Thrower & Bingley (2010), p.593. The islet (centre) is infiltrated with mononuclear cells; macrophages and T-lymphocytes.

Multiple genes have been found to be associated with increased susceptibility to T1D (Barrett, Clayton, & Concannon, 2009). The risk of development of T1D is 5% if a first-degree relative also has T1D, and has an additional risk if the affected parent is the father. Trials attempting to delay onset in those with genetic predisposition have failed, indicating an overriding, dominant role of genes in the pathogenesis of T1D (Wherrett & Daneman, 2009).

Alternatively, prolonged interaction between genetic susceptibility, cumulative exposure to environmental triggers and immune regulatory processes leads to a critical point of  $\beta$  cell damage, resulting in insulin deficiency and hyperglycaemia. It is assumed that this response transpires more rapidly in the young (Thrower & Bingley, 2010)

Hormonal and nervous system signals associated with psychological mechanisms are known to change insulin sensitivity and impair immunity. Stress, in particular, has been indicated as an environmental factor associated with an increased risk of developing T1D (Peng & Hagopian, 2006). However, due to the retrospective nature of these studies, the association between life stress and T1D cannot be relied upon due to recall bias. Prospective studies including measures of stress biomarkers, such as cortisol, would be more methodologically sound but have yet to be carried out. Findings such as these indicate the influence of psychological processes on the pathogenesis and progression of this disease, with particular regard to the impact of stress.

### **5.5. Symptoms and diagnosis**

Symptoms of diabetes occur due to an accumulation of glucose in the blood that the body is unable to use for energy. According to the WHO and International Diabetes Federation (IDF) (2006), the main symptoms of undiagnosed diabetes include:

- frequent urination (polyuria).
- increased thirst, due to more frequent urine production (polydipsia).
- extreme tiredness as glucose is not being effectively used for energy.
- unexplained weight loss as the body digests fat stores in order to access energy not being gained through glucose.
- genital itching or regular episodes of thrush due to the high sugar concentrations present in the urine creating an environment susceptible to infection.
- slow healing of wounds, as high blood glucose allows growth of bacteria.
- blurred vision due to an accumulation of glucose in the lens of the eye.

When two or more of these symptoms are present, NICE recommend a test for diabetes. Diabetes is diagnosed by identifying chronically elevated blood glucose levels, known as hyperglycaemia (World Health Organisation & International Diabetes Federation, 2006). The WHO recommends three possible methods of diagnosis:



- random venous plasma glucose concentration  $\geq 70\text{mmol/mol}$ .
- a fasting plasma glucose concentration  $\geq 42\text{mmol/mol}$  (whole blood  $\geq 36\text{mmol/mol}$ ) or
- two hour plasma glucose concentration  $\geq 70\text{mmol/mol}$  two hours after 75g anhydrous glucose in an oral glucose tolerance test (OGTT).

In addition, a 2011 addendum to the original diagnostic criteria allowed for the use of glycated haemoglobin, or HbA<sub>1c</sub>, in diagnosis of diabetes. Glycated haemoglobin is formed in a non-enzymatic glycation pathway by haemoglobin's exposure to plasma glucose. Normal blood glucose levels are associated with a normal amount of HbA<sub>1c</sub>. As the average amount of plasma glucose increases, the fraction of HbA<sub>1c</sub> increases. When hyperglycaemia occurs, glucose is able to attach to haemoglobin in red blood cells. The longer the period for which hyperglycaemia continues, the greater the glucose binding to the haemoglobin, and therefore the higher the glycated haemoglobin. This process is irreversible and, as such, once haemoglobin become glycated, they remain as such. Glycated haemoglobin is therefore able to accumulate within the red blood cell, and is able to reflect the amount of glucose to which the cell has been exposed throughout its lifecycle (120 days). For this reason, glycated haemoglobin serves as a marker for average blood glucose levels over the two-three previous months prior to the measurement (Crean & Maggs, 2006). Currently, the WHO recommend an HbA<sub>1c</sub> of 48mmol/mol as the cut point for diagnosing diabetes (World Health Organisation, 2011b).

Advancement to T1D is indicated by a deficit of the first-phase insulin response to glucose. Tolerance to oral glucose consumption and serum C-peptide have been found to decline over at least 2 years before clinical T1D is diagnosed (Sosenko, Palmer, & Greenbaum, 2006). Over the life course of the diabetes, whilst some  $\beta$  cell function may remain, up to 99% of  $\beta$  cells will have been destroyed (Thrower & Bingley, 2010). Typically, symptoms in T1D will present rapidly due to a critical loss of  $\beta$  cells. However, rates of progression can vary, so a clinical spectrum of disease presentation is seen (see Figure 13).

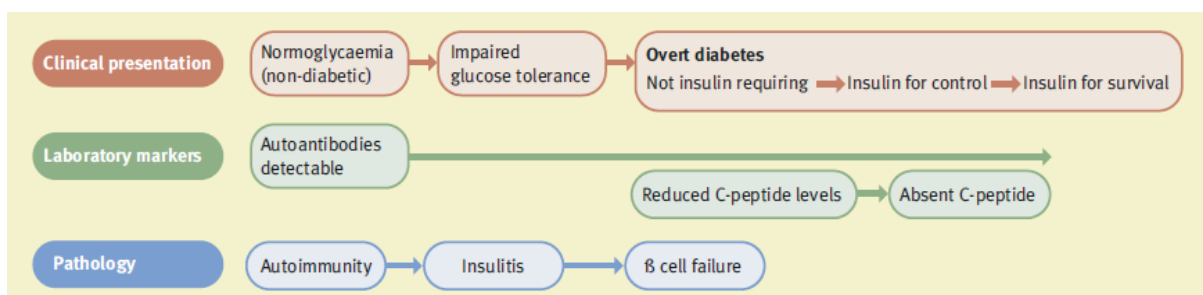


Figure 13. The clinical spectrum of type 1 diabetes. Source: Thrower & Bingley (2010),p.595.

In children and adolescents, presentation of T1D can vary greatly from a clinically stable patient with polyuria, polydipsia, enuresis and weight loss through to diabetic ketoacidosis



(DKA) and severe dehydration. When such convincing physical symptoms are noted, a single blood glucose test of  $>70\text{mmol/mol}$  will result in a diagnosis. It is a rare occurrence for multiple blood glucose measurements or oral glucose tolerance tests to be required for a diagnosis of T1D in young people (“Diagnosis and classification of diabetes mellitus,” 2010). Once a diagnosis is established, the diabetes care team will devise a care plan in order to artificially maintain the insulin-glucose response.

## 5.6. Management

Diabetes is a chronic condition, without cure. Although the disease cannot be reversed, it can be managed through a combination of lifestyle modifications and medication. How well a patient adheres to their care plan will determine their glycaemic control (Jacobson et al., 2013). Glycaemic control is defined as *“the extent to which the metabolism in the person with diabetes differs from that in the person without diabetes”* (Bilous et al., 2010, p. 61). Management of the disease, therefore, seeks to allow the patient to maintain their blood glucose in an acceptable, healthy margin in order to minimise the short and long term effects of hyper and hypoglycaemia (National Institute for Health and Care Excellence, 2015).

The extent to which a patient can be said to have glycaemic control is measured most commonly through blood glucose measurement. Other disordered metabolites, such as ketone bodies, are clinically useful for measurement during times of acute illness or poor glycaemic control. In addition, long term glycaemic control can be assessed using  $\text{HbA}_{1c}$  or fructosamine concentrations (see *Table 2*) (Atkinson & Eisenbarth, 2001).

Table 2. *Indicators of glycaemic control.*

Indicator	Main clinical use
Urine glucose	Poor indication of diabetic control.
Blood glucose	
Fasting	Correlates with mean daily blood glucose and $\text{HbA}_{1c}$ in T2D
Diurnal/circadian profile	Used in self-monitoring and clinical assessment of blood glucose
Glycated haemoglobin	Indicates mean glycaemic control over previous $>3$ months
Glycated serum protein, e.g. fructosamine	Indicates mean glycaemic control over previous 2 weeks
Ketone bodies	Signals insulin deficiency and warns of diabetic ketoacidosis. Monitored during illness or poor diabetic control
Other metabolites/hormones	
Cholesterol & triglyceride	Cardiovascular risk

### 5.6.1. Lifestyle

The foundation and pillar of diabetes management, as well as the treatment most patients struggle with, is lifestyle modification. Typical adjustments will include changes to diet, exercise regime and stopping smoking (Kela, Srinivasan, & Davies, 2010).

The approach towards diet in T1D has changed greatly in the last few decades, with a current emphasis on a low fat diet and use of the glycaemic index of foods or carbohydrate counting to be used when adjusting insulin intake. This was in response to the Dose Adjustment for Normal Eating (DAFNE) study (DAFNE Study Group, 2002) which introduced the structured treatment and teaching programme (STTP) approach to dietary management allowing more freedom in eating habits, and thus increasing QoL (Shearer, Bagust, Sanderson, Heller, & Roberts, 2004). Carbohydrate counting is most common and encourages an understanding of the grams of carbohydrate contained in foods, and the impact those carbohydrates will have on the glucose response (National Institute for Health and Care Excellence, 2015). This allows for a relatively 'free' diet and is therefore a popular approach to nutrition in T1D, particular in adolescents seeking to establish independence from parental meal times and menus (Dennedy & Dinneen, 2010; R. M. Shulman & Daneman, 2010).

Exercise is a problematic prospect for T1D. Any unplanned exercise can result in rising counter-regulatory hormone release. As the body cannot alter circulating insulin, the glucose response to exercise will be reliant on the exogenous dose of insulin. If this has been excessive, hypoglycaemia will occur. With too little, hyperglycaemia will be the result. Patients must, therefore, learn their 'safety zone' for mild to vigorous exercise (National Institute for Health and Care Excellence, 2015). This can be particularly problematic for adolescents during school physical education lessons and extra-curricular activities, where they must seek to establish this balance relatively independently (R. M. Shulman & Daneman, 2010). Other considerations include delayed hypoglycaemia as glycogen is replenished, avoiding injection in exercised limbs due to increased blood flow and greater insulin absorption, and the importance of planning exercise including reducing insulin dose and carrying treatment for hypoglycaemia (National Institute for Health and Care Excellence, 2015).

Healthcare providers seek to address the increased risks of hypoglycaemia associated with adolescent lifestyle, including unpredictable daily activity schedule, alcohol, drug use, smoking, and intensification of the insulin regime, through additional support and counselling when necessary. Older adolescents hoping to hold a driving license require vigilance of hypoglycaemia whilst driving, and to test blood glucose before a driving lesson. They should be made aware that poor glycaemic control will impact their ability to gain and maintain a driving license. In addition, sexual health and contraception advice must also be given, as poor glycaemic control can impact both maternal and foetal health (National Institute for Health and Care Excellence,

2015). Finally, depression, body image concerns and high BMI have all been associated with the onset of eating disorders in adolescents, and must therefore be monitored in the T1D population. The increasing incidence of diabetic bulimia in adolescents, through which a T1D patient controls weight through omission of insulin doses, highlights this growing need (Olmsted, Colton, Daneman, Rydall, & Rodin, 2008).

The lifestyle adjustments required in T1D can, therefore, be deemed considerable for an adolescent, requiring constant effort and self-monitoring. It is perhaps unsurprising that these adjustments are considered the most difficult and emotionally taxing aspects of self-care in T1D patients (Davies, 2010). However, unlike some cases of T2D, T1D cannot be managed with lifestyle adjustments alone. Due to the absence of endogenous insulin, medication is required to replace what the body cannot produce.

### 5.6.2. Medication

Without insulin replacement, patients with T1D would develop hyperglycaemia, ketosis<sup>22</sup>, ketoacidosis<sup>23</sup>, coma and eventual death. Insulin therapy is therefore essential to the life of a T1D patient. The main aim of insulin therapy is to mimic the naturally occurring cycles of insulin release that would occur from the pancreas. This is most commonly attempted via a multiple daily injection (MDI) regime combining basal and bolus insulin doses throughout the day and taken at specified times (see Figure 14).

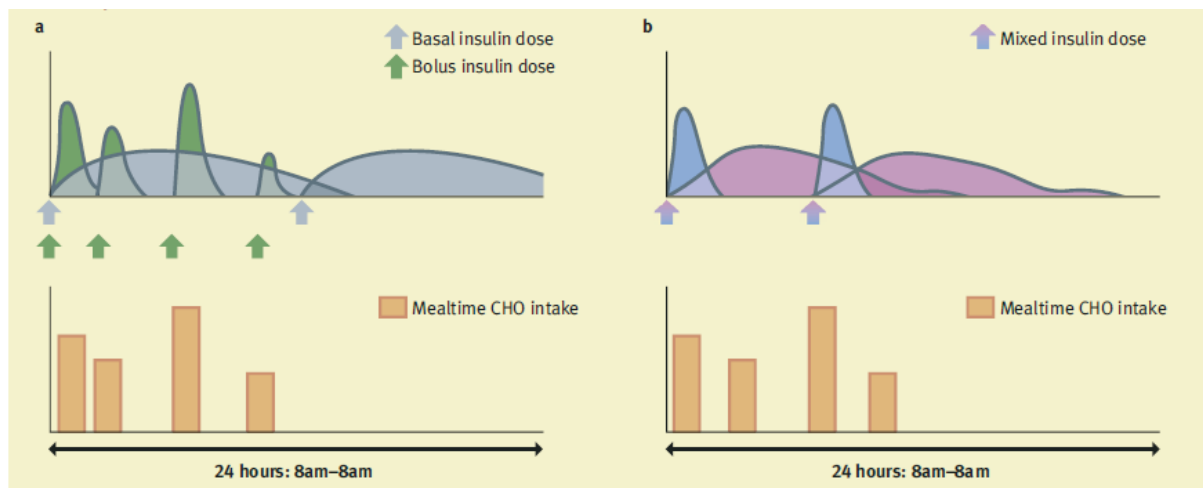


Figure 14. Representative diagrams of insulin administration programmes over a 24-hour period. Source: Dennedy & Dinneen (2010), p.611.

\*CHO: Carbohydrate

<sup>22</sup> A metabolic state where the body's energy supply comes from ketone bodies over blood glucose. Ketone bodies are formed by ketogenesis when liver glycogen stores are depleted (Bach, Schirardin, Weryha, & Bauer, 1977).

<sup>23</sup> A pathological metabolic state marked by extreme and uncontrolled ketosis. The body fails to adequately regulate ketone production, causing such a severe accumulation of keto acids that the pH of the blood is substantially decreased. In extreme cases ketoacidosis can be fatal (Bilous et al., 2010). See Section 5.7.1.

MDI requires administration of bolus insulin (short-acting) and once or twice daily injection of basal insulin (long-acting). Basal insulin regulates hepatic glucose output, whilst bolus insulin adjusts glucose fluctuations. A mixture of both basal and bolus insulin is available as an alternative to the MDI regime (see Figure 14b). However, these methods fail to replicate precisely the *in vivo* regulation of plasma glucose. Insulin is administered to the peripheral circulation, as opposed to portal circulation. Adjustments to insulin dose also occur crudely and at set time points, as opposed to the constant flow managed by a functioning pancreas (Dennedy & Dinneen, 2010). Insulin doses following diagnosis vary greatly across centres, but will typically consist of 2-4 injections per day in adolescents. Starting doses will typically be 0.4-0.6 units/body weight (kg)/day, lower in younger children, and will be continually monitored and adjusted until optimal glucose management is achieved (National Institute for Health and Care Excellence, 2015).

Pertinent to administration of insulin is the monitoring of plasma glucose. Capillary glucose monitors are the standard care, whereby a droplet of blood is obtained from a finger prick is measured in a small, accurate device. However, patient adherence to capillary monitoring can vary, due to the discomfort generated by repeated finger-pricking (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2005).

Insulin delivery has moved beyond syringe and vial insulin administration in recent years. The standard of care device in the UK is the use of an insulin pen. Pre-filled pens allow an easy-to-use 'dial up' of the insulin and convenient, precise, pain-free dosing (Asakura et al., 2009). Alternatively, insulin pump devices (continuous subcutaneous insulin infusion; CSII) are growing in popularity as the CSIIs become more compact and functional. Here, insulin is delivered via a cannula placed subcutaneously in the abdomen. A continuous basal dose is then programmed into the pump, with boluses administered by the patient as necessary via a button press. The more sophisticated smart pumps facilitate administration of a correction bolus should a high plasma glucose reading be entered into the pump, and administer the appropriate bolus dose when the grams of carbohydrate consumed are entered into the 'bolus wizard' (Dennedy & Dinneen, 2010). A meta-analysis of pump vs pen modality demonstrated a 0.5% reduction in HbA<sub>1c</sub> and clinically relevant hypoglycaemia, without an increase in BMI (Pankowska, Blazik, Dziechciarz, Szpowska, & Szajewska, 2009). An internationally agreed consensus statement of the use of pumps in children and adolescents has established guidelines on their prescription, shown in *Table 3* (Phillip, Battelino, Rodriguez, Danne, & Kaufman, 2007), resulting in a growing presence of CSII pump use in adolescents over traditional pre-filled pen use.

Table 3. *Indications for use of continuous subcutaneous insulin infusion (CSII) in paediatrics. From Phillip et al. (2007).*

Conditions when CSII should be considered	Conditions when CSII may be beneficial
Recurrent severe hypoglycaemia	Young children, especially infants/neonates
Wide fluctuations in plasma glucose, regardless of HbA <sub>1c</sub>	Presence of eating disorders
Suboptimal diabetes control	Pronounced dawn phenomenon
Presence of microvascular complications and/or risk of macrovascular complications	Needle phobia
Insulin regime compromising quality of life	Pregnancy
	Ketosis-prone patients
	Competitive athletes

Pumps, however, are not without their limitations. When questioned, adolescents have described multiple liabilities associated with CSII use, including accidents damaging the pump, CSII malfunctions causing embarrassing alarms, and poorer adherence due to convenience. One study found 28% of participants reported 'forgetting' their diabetes, resulting in missed bolus doses and BGM. In this study, the participants stated that CSII therapy enhanced social interactions and normalcy of group activities, with minimal stigma associated with wearing the device. Clothing and fashion, however, were cited as being problematic for the females in the sample and induced feelings of isolation and being different. Common problems included bathing suits, prom dresses and a necessity of wearing clothing with a waistband or pockets to attach the pump. Those who participated in sports reported concerns including disconnecting the CSII during activities, problematic location of the pump, and concerns regarding damaging the device. The most pertinent concerns regarded use of the pump at school. Half of the adolescent sample were required by the school to manage their diabetes in the nurses' office, with others informed they would be unable to attend school with the pump due to unfamiliarity of school nurses with pump technology. This resulted in substantial conflict with the schools over management issues, though social stigma with classmates was not found (Low, Massa, Lehman, & Olshan, 2005).

With the growing use of CSII comes continuous glucose monitoring (CGM) systems. Here, a subcutaneous, glucose oxidase-coated sensor monitors interstitial fluid glucose concentrations and translates this into an estimation of blood glucose concentration. A plot of plasma glucose over a 24 hour period can be produced and used to identify regularly occurring episodes of hyper and hypoglycaemia (Cooke et al., 2009). Newer devices allow this to occur in real-time, and are equipped with alarms to alert patients to hypoglycaemia (Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group, 2009; Tamborlane et al., 2008). In the most advanced devices, real-time CGM has been combined with CSII technology to create an 'artificial pancreas,' which is as close as medical advancement has come to recreating

the naturally occurring insulin cycle produced by a healthy pancreas (Mastrototaro & Lee, 2009; Sherr, Cengiz, & Tamborlane, 2009). A prospective trial of these devices has demonstrated a 0.5% reduction in HbA<sub>1c</sub> and overall reduction in hypoglycaemia in comparison to traditional self-monitoring (Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group, 2009; Tamborlane et al., 2008).

Whatever modality insulin is delivered through, it will continue to be required for the remainder of the patient's life. This, in conjunction with lifestyle adjustments, will involve periods of success and failure, which can be corrected and managed with the correct support offered by healthcare providers (Barnard, Peyrot, & Holt, 2012).

### **5.6.3 Support**

Initial diabetes education and amendments to lifestyle are important steps in aiding achievement of optimal glycaemic control in T1D. Typically, patients will receive 'survival skills' training once diagnosed, so that they may increase their knowledge related to their disease and avoid symptomatic hyper and hypoglycaemia. This will include information on:

- diabetes and insulin.
- the practicalities of BGM and administration of insulin.
- the symptoms of hypoglycaemia and how it is treated.
- the role of diet and exercise.

This will initiate a programme of lifelong learning in how to manage T1D. Effective self-management cannot be attained after one education session, it is expected to last for the remainder of the patient's life, with peaks and troughs of commitment to self-care (Dennedy & Dinneen, 2010). After initial education and stabilisation of blood glucose, adolescents and their families will begin the long-term management of their T1D. This will require regular clinic visits, surveillance for common co-morbid conditions, psychosocial problems and complications. Extra vigilance is required by healthcare providers when caring for adolescents with greatest difficulty meeting the demands of their care routine, where further support is necessary (National Institute for Health and Care Excellence, 2015).

This combination of lifestyle adjustment, medication and support programmes aims to aid the patient in effective management of the disease, through maintaining their blood glucose in an acceptable, healthy margin (National Institute for Health and Care Excellence, 2015). Should the individual fail adequately to maintain this self-care regime, they leave themselves open to the short and long term complications resulting from poor glycaemic control.

### **5.7. Complications**

The Diabetes Control and Complications Trial demonstrated that intensive glycaemic control reduced the risk of complications occurring in diabetes (Jacobson et al., 2013). However,

complications continue to present a significant cause of morbidity and mortality in the disease (Maahs, West, Lawrence, & Mayer-David, 2010). Diabetic complications includes those which present an immediate risk to life, such as diabetic ketoacidosis, or from the development of tissue damage through either micro or macrovascular disease (Bilous et al., 2010).

### **5.7.1. Diabetic emergencies**

Diabetic emergencies are conditions resulting from poor glycaemic control which result in an immediate risk to life. These include diabetic ketoacidosis and hypoglycaemia, as discussed here.

#### **5.7.1.a. Diabetic ketoacidosis**

Diabetic ketoacidosis (DKA) occurs when the patient is in a state of severe insulin deficiency. It is typified by hyperglycaemia, hyperketonaemia<sup>24</sup> and ketoacidosis, and is categorised according to mild, moderate and severe states based on biomedical and clinical criteria. Worldwide incidence rates of 1-5% occur, and are more common in the young and in females. Various studies have reported DKA as present at diagnosis in between 15-67% of T1D cases in children and adolescents, with incidence inversely related to the local prevalence (Levy-Marchal, Patterson, Green, & EURODIAB ACE Study Group, 2001). DKA mortality is low in the UK at around 2%, though each of these represents an avoidable death (Savage et al., 2011). Risk of DKA therefore can be said to be an important complication to consider when studying adolescents.

DKA is caused by relative or absolute deficiency of insulin, in conjunction with counter-regulatory stress hormones such as glucagon and cortisol (see Figure 15). This leads to hepatic overproduction of glucose and ketones, in addition to lipolysis from lack of insulin, where fatty acids in the liver are oxidised to ketone bodies. Hyperglycaemia is caused by glycogenolysis, gluconeogenesis, weakened peripheral uptake of glucose and consumption of ketone bodies over glucose as a source of energy (Savage et al., 2011). Hyperglycaemia results in osmotic diuresis<sup>25</sup>, leading to dehydration. Sodium depletion resulting from dehydration is then deteriorated by reduced renal sodium reabsorption due to the lack of insulin. High circulating plasma potassium is typically seen in DKA due to loss of potassium from cells. Physical symptoms will include progressive polyuria, dehydration, weight loss, weakness, drowsiness, hypotension, tachycardia, hypothermia, concluding with coma (Bilous et al., 2010).

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<sup>24</sup> An elevated level of ketone bodies in the blood throughout the body (Bach et al., 1977).

<sup>25</sup> Increase of urination rate caused by glucose in the kidneys. The glucose cannot be reabsorbed (due to a pathological state or the normal nature of the substance), causing an increase in the osmotic pressure within the tubule and water retention, increasing urine output (i.e. diuresis) (Marieb & Hoehn, 2014).

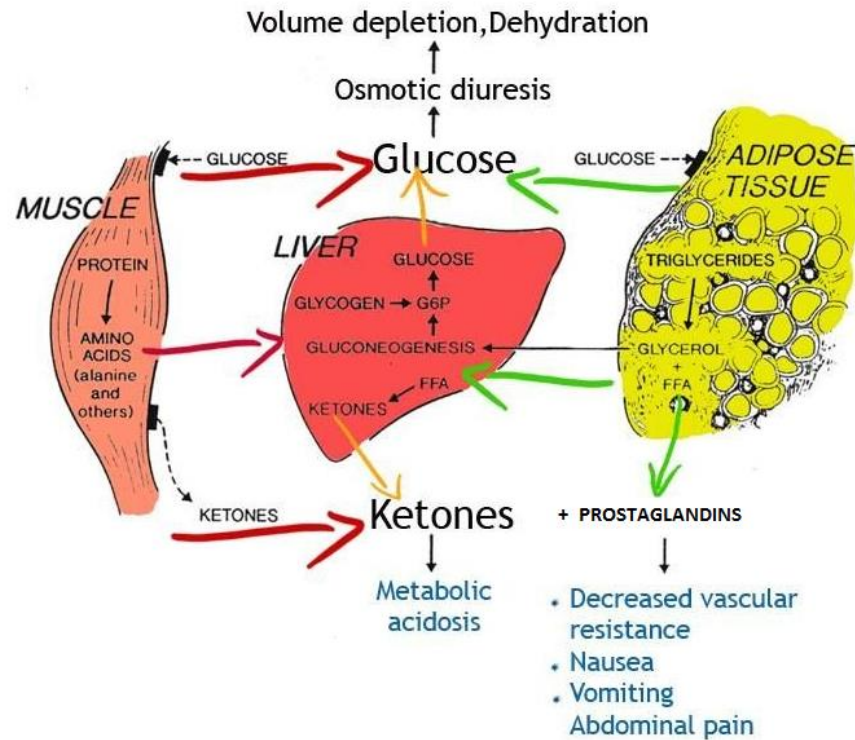


Figure 15. Mechanisms of ketoacidosis. Adapted from: Bilous, & Donnelly (2010), p.89.

DKA requires admission to a hospital emergency department. Treatment necessitates rehydration and administration of insulin to correct serum potassium and ketoacidosis. The overall goal of the treatment is the normalisation of plasma glucose concentration and osmolality<sup>26</sup> (National Institute for Health and Care Excellence, 2015). Complications arising as a result of DKA vary in severity. In children and adolescents, cerebral oedema is common as a result of rapid rehydration, wherein the brain swells within the skull, forcing the medulla and brainstem to herniate and resulting in cardiorespiratory arrest. This accounts for 50% of deaths in occurrences of DKA in young people (Bilous et al., 2010).

#### 5.7.1.b. Hypoglycaemia.

Contrary to DKA, hypoglycaemia is an emergency requiring immediate treatment but will not typically result in hospital admission. Hypoglycaemia is a common consequence of insulin therapy, wherein excess insulin is administered. The brain is incapable of synthesising glucose or storing glycogen for more than five minutes, and is therefore dependent on a constant supply of glucose. An interruption of more than a few minutes can result in dysfunction of the central nervous system, impaired cognition and eventual coma (Holt et al., 2010).

Symptoms of hypoglycaemia are autonomic; they result from activation of the sympathetic or parasympathetic nervous system such as tremors or palpitations, or neuroglycopenic; resulting from a glucose deficiency in the brain, seen in drowsiness or

<sup>26</sup> Normalisation of all chemical particles in the blood (NHS, 2011).



confusion. In T1D, hypoglycaemia is common. Patients can be expected to experience two moderate hypoglycaemia episodes per week, with one severe disabling episode per year. Indeed, T1D patients can experience mild, asymptomatic hypoglycaemia (15-20mmol/mol) for up to 10% of their lives. Autonomic symptoms appear at 20mmol/mol with cognitive function deteriorating at 20mmol/mol. As a result, patients retain awareness of symptoms before cognitive impairment occurs. However, with hypoglycaemia unawareness affecting up to 25% of T1D patients, between 2-4% of deaths in T1D can be attributed to hypoglycaemia (Thrower & Bingley, 2010). Hypoglycaemia can be considered into two classifications; mild and severe. The majority of hypoglycaemia is mild, and can be self-treated through the consumption of quick-acting carbohydrate or administration of glucose to counteract the excess insulin. In a severe hypoglycaemia episode, third party assistance is required (UK Hypoglycaemia Study Group, 2007).

Hypoglycaemia and DKA typically occur due to relatively short-lived poor glycaemic control. Should this lack of appropriate self-care continue over an extended period of time, the patient becomes at greater risk of long-term problems such as micro and macrovascular complications.

### **5.7.2. Microvascular complications**

Microvascular complications are those which occur in tissues due to hyperglycaemia, where the cell is unable to limit glucose transport. This occurs in particular in the retina, kidney and Schwann cells<sup>27</sup>. Convincing evidence of the relationship between microvascular complications and the intensity and duration of hyperglycaemia exists. As the duration of diabetes increases, incidence of retinopathy, nephropathy and neuropathy has been found to be greatest in those with the poorest glycaemic control (see Table 4) (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2000).

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<sup>27</sup> Principal glia of the peripheral nervous system (PNS). Glial cells function to support neurons (Marieb & Hoehn, 2014).

Table 4. *The microvascular complications of diabetes.*

Microvascular complication	Aetiology	Symptoms	Diagnosis	Treatment
Retinopathy - eye disease	Small blood vessel damage to the retina causing progressive loss of vision.	Blurred vision.	Regular eye examination.	Good control will delay onset. Early detection delays blindness.
Neuropathy – nerve damage	Directly via hyperglycaemia, and indirectly via decreased blood flow to nerves through damage to small blood vessels. Leads to sensory loss, limb damage and impotence. Most common complication.	Symptoms vary depending on nerves damage, but include numbness, pain and impotence.	Regular examination by clinician.	Good glycaemic control will delay and prevent neuropathy.
Nephropathy – kidney disease	Small blood vessel damage to kidneys causes organ failure & eventual death. Leading cause of dialysis and kidney transplant in developed world.	Lethargy, anaemia, cognitive impairment, electrolyte imbalances.	Urine test for protein, blood test for kidney function.	Control of hyperglycaemia & hypertension. Medication. Restriction of dietary protein. Eventual requirement of dialysis and transplant.

Several metabolic pathways have been indicated in the mechanism through how this occurs. The commonality of all of these mechanisms is the promotion of reactive oxygen species, resulting in increasing oxidative stress. Researchers have concluded that this may be the common path through which hyperglycaemia causes microvascular complications (Fowler, 2008).

Suboptimal glycaemic control has been found to increase risk of development and progression of microvascular complications, even if disease management improves in later life, known as metabolic memory (White et al., 2001). This phenomenon instils the importance of achieving and maintaining glycaemic control as early in life as possible. Indeed, additional risk factors for development of microvascular complications in later life include younger age of onset and longer disease duration (R. M. Shulman & Daneman, 2010), highlighting the increased risks already attributed to presentation of the disease during and prior to adolescence. This, in combination with poor self-care, puts adolescents with diabetes at risk of developing both micro and macrovascular complications in later life.

### 5.7.3. Macrovascular complications

In macrovascular complications, hyperglycaemia induces atherosclerosis of major blood vessels, leading to a narrowing of arteries. This results in decreased blood flow to extremities, heart muscle and the brain, which can result in diabetic foot disease, heart attack and stroke, respectively (Fowler, 2008).

HbA<sub>1c</sub> has an accepted and continuous relationship with macrovascular disease in both diabetic and general populations (Khaw et al., 2001). Despite this, the UK Prospective Diabetes Study (UKPDS) was unable to find a statistically significant impact of effective glycaemic control on macrovascular complications in T2D (Turnbull et al., 2009). It is speculated that this discrepancy results from the complex pathogenesis of macrovascular complications in comparison to microvascular complications. Retinopathy, nephropathy and neuropathy are most commonly seen in diabetic patients, whilst macrovascular complications such as atherosclerosis are also highly prevalent in the general population (Bilous et al., 2010). Therefore, the pathogenesis of these is multifactorial and, although plasma glucose concentration is clearly important, it is just one factor in a host which result in the development of these health problems (Fowler, 2008).

Trials are currently ongoing to determine if pharmacological interventions could be combined with the standard model of care for at-risk AWT1D to protect from cardiovascular and renal disease in later life (Marcovecchio, Tossavanien, & Dunger, 2009).

## 5.8. Summary of Chapter 5

Epidemiological data suggests that the worldwide incidence of diabetes is rising rapidly, and will soon reach epidemic proportions (Maahs et al., 2010). Whilst biomedical and technological advancement has meant that improvements in clinical care of individuals with diabetes has vastly improved over the past few decades, the commitment required to achieve and maintain near-normal plasma glucose over the lifespan is vast (Barnard et al., 2012). It requires daily attention to lifestyle, diet, exercise, BGM and administration of insulin. Patients with diabetes can now expect to live a long life, but this is achieved at a price (Jacobson, 2004). It is complex and requires effortful self-care, and is considered by patients to have an emotional influence in their lives (Davies, 2010). It is perhaps unsurprising then that patients with T1D have a high co-morbidity with psychosocial disorders, the most pertinent of which are discussed in Chapter 6. Intensive control is achievable with the appropriate skills. It is the challenge of diabetes care teams to provide these tools in order to equip their patients with the best chance of achieving and maintaining diabetes control, and therefore delaying and preventing complications (National Institute for Health and Care Excellence, 2015).

## Chapter 6: Psychosocial Aspects of Type 1 Diabetes

### 6. Overview

The following sections provide information regarding the experience of living as an AWT1D. As such, specific health issues related to T1D are outlined, namely those of self-care, transition to adult health services and striving for autonomy in self-management. The psychosocial functioning of AWT1D is then addressed with regard to QoL, stress and resilience. Taken together, this chapter serves to summarise the psychosocial impact of the biological facts of the preceding chapter, and provide context as to why the psychosocial lives of AWT1D is of such relevance to the present thesis and beyond.

### 6.1. Introduction

Adherence to a care plan is the best way to reduce diabetic complications (Jacobson et al., 2013). Previous research has suggested that appropriate glycaemic control and clinic attendance lowers the risk of microvascular complications by 25% (UKPDS, 1998), maintained at 10 year follow-up (Holman, Paul, Bethel, Matthews, & Neil, 2008). However, diabetes is a disease with recognised low levels of adherence, with a 50 year meta-analysis of research finding that diabetes has the second lowest rate of optimum self-care across 17 chronic conditions, achieving just 67.5% (DiMatteo, 2004b). Current recommendations assure that regular clinic attendance is key to maintaining optimal self-care (National Institute for Health and Care Excellence, 2015), but research has found that frequent physician visits do not have such effect (Martin, Williams, Haskard, & DiMatteo, 2005). It has, therefore, been concluded that diabetes outcomes are more closely related to patient characteristics and decisions than physicians or clinics (O'Connor et al., 2008). Despite this, access to psychological support is poor, with only 31% of outpatient clinics providing psychological services and only 2.6% adhering to the relevant NICE guidelines on support (Diabetes UK, 2008; Nicholson, Taylor, Gosden, Trigwell, & Ismail, 2009).

The Diabetes Attitudes Wishes and Needs (DAWN) survey stated that diabetes causes a variety of psychosocial problems which act as barriers towards achieving optimal glycaemic control, with current healthcare services ill-equipped to provide the necessary support to overcome these factors (Funnell, 2006). DAWN therefore stipulated a number of goals in order to promote effective self-care, improved provision of psychological services and better communication between patients and healthcare providers. Sufficient understanding of the individual differences and psychosocial aspects of diabetes in order to provide these improvements has, however, yet to be achieved (Barnard et al., 2012) and could prove a significant tool in the improvement of adherence and reduction in diabetes complications, particularly in vulnerable groups such as adolescents.

## **6.2. Diabetes in adolescence**

Deterioration in glycaemic control is not uncommon in AWT1D (Wallander et al., 2013; Wherrett et al., 2013) and is often attributed to an erratic meal or exercise schedule (Court et al., 2009), poor adherence (Hood, Peterson, Rohan, & Drotar, 2009a), an increase in hazardous and risk-taking behaviour (S. S. Jaser, Yates, Dumser, & Whittemore, 2011), increased risk of eating disorders (Larranaga, Docet, & Garcia-Mayor, 2011) and the hormonal changes associated with puberty, which have been found to lead to greater resistance to insulin (Danielson, Drum, Estrada, & Lipton, 2010).

In addition to the deterioration in metabolic control, the risk of psychological illness also increases during adolescence (Kakleas et al., 2009; Wherrett et al., 2013). Adolescents present significant increased risk for problems including depression, anxiety, eating disorders and externalising disorders (Fogel & Weissberg-Benchell, 2010). Associated with these is a further deterioration in glycaemic control (M. Herzer & Hood, 2010) and diabetes outcomes (Chida & Hamer, 2008). As glycaemic control worsens, so does the psychological illness, creating a negative feedback loop worsening both physical and mental health (Hassan, Loar, Anderson, & Heptulla, 2006). Findings such as these highlight the importance of research in this at-risk population.

### **6.2.1. Self-care**

Adolescence is a particularly crucial time for young people with diabetes. Whether diagnosed in childhood or adolescence, it is during the adolescent years that the individual learns to take increasing responsibility for the management of their diabetes. As they start to integrate their diabetes management tasks into their emerging lifestyles, adolescents directly experience the relationship between their actions and results of BGM. This may in turn influence their beliefs about diabetes, its treatment and how they will manage it. Therefore these are formative years in the developments of such beliefs, which, once fully integrated and accepted by the young person, may prove difficult to change (Skinner, Murphy, & Huws-Thomas, 2005).

As outlined in Section 5.6, T1D management entails a complex routine of self-care activities (National Institute for Health and Care Excellence, 2015), though only 30-50% of glycaemic control has been found to be attributable to adherence to these guidelines (Hood, Peterson, Rohan, & Drotar, 2009b). Indeed, it has long been known that the majority of adolescents fail to adhere strictly to care plans (Austin, Senecal, Guay, & Nouwen, 2011). As adolescents not achieving optimal diabetes management may endure diabetes complications at a young age (Savage et al., 2011), it is important to identify the causes of not following a self-care routine.

Crucial non-modifiable variables impacting diabetes management include age, gender and duration of disease. Specifically, older adolescents and a longer disease duration predict poorer glycaemic control (Chao, Whittlemore, Minges, Murphy, & Grey, 2014; Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group, 2011). Previous research has revealed conflicting results concerning the impact of gender on self-care. Studies have indicated poor self-care in females (Austin et al., 2011; Bryden et al., 2001; La Greca, Swales, Klemp, Madigan, & Skyler, 1995), with others stating worse self-care in males (Naar-King, Idalski, Ellis, Frey, & Templin, 2005; Perwien, Johnson, Dymtrow, & Silverstein, 2000). However, this contested evidence may be due to a lack of provision for age or disease duration. For example, when time since diagnosis is taken into account, the picture is far clearer, with females usually reporting poorer self-care (Austin et al., 2011; Huang, Palta, Allen, LeCaire, & D'Alessio, 2004; Rewers et al., 2002). In addition, the method of insulin delivery also has been found to impact self-care. CSII pumps tend to facilitate better glycaemic control (Pihoker et al., 2013), self-care (Phillip et al., 2007) and QoL (Lawrence et al., 2012). Therefore, although previous research suggests that older, female adolescents with a longer disease duration using MDI enact poor self-care behaviours, this cannot be conclusively stated as, to date, no research has systematically addressed these interaction effects (Naranjo, Mulvaney, McGrath, Garner, & Hood, 2014). However, as these fixed variables are not easily changed, the majority of research has focused on modifiable factors.

Many external variables have also been found to be influential in non self-management. Systematic reviews of self-care in adolescents have demonstrated that executive function (McNally, Rohan, Pendley, Delamater, & Drotar, 2010; Viklund & Wikblad, 2009), support provided by family members (Borus & Laffel, 2010; Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010; Pereira, Berg-Cross, Almeida, & Machado, 2008; Pyatak, Florindez, & Weigensberg, 2013), peer pressure (Borus & Laffel, 2010; Hains et al., 2007), unawareness of the symptoms of hypoglycaemia (C. B. Smith, Choudhary, Pernet, Hopkins, & Amiel, 2009), depression (Katon, Russo, & Lin, 2009) and alcohol consumption (Ahmed, Karter, & Liu, 2006) have all been found to contribute to non self-management. Despite this, no single variable has been found to consistently account for the variation in self-care behaviours among adolescents (Vermeire et al., 2007).

Most research into non self-management behaviour investigates facets of self-care which are of importance to healthcare providers and researchers. The first-person perspectives of the adolescent are rarely taken into account (Anderson & Funnell, 2000; Pyatak et al., 2013). Patients' view of what constitutes appropriate self-care often differs vastly from that of healthcare providers. Diabetes care teams typically view good self-care as the prioritisation of optimal glycaemic control and an absence of diabetes complications. Conversely, patients see

maintaining a balance between the needs of their diabetes with their “*physical, social, psychological, cultural and economic life circumstances*” (Pyatak et al., 2013, p. 710) as typifying ideal self-care (Anderson & Funnell, 2010; Vermiere, Van Royen, Coenen, Wens, & Denekens, 2003). Self-care can therefore be seen as a series of decisions where the patient must balance their diabetic self with all other aspects of their everyday living, in pursuit of QoL (Hortensius et al., 2012; Vermiere et al., 2003). This may be reflected in the findings outlined in Section 3.3.3.c., in which Hinder and Greenhalgh (2012) highlight the role of the social environment in non self-management behaviours. This active decision to disengage with self-care, particularly at social events, may be seen as a route to achieving life-diabetes balance, though further research is required to confirm this supposition.

Findings such as these represent a striking discordance between the priorities of patients and healthcare teams. While diabetes clinics view poor self-care as negligence, patients view it as merely the balance achieved when being concerned with the whole self. This under-researched phenomena is not well understood (Anderson & Funnell, 2010), and it may be that interventions aiming to aid adolescents in integrating diabetes into their physical, social and psychological life more effectively would improve self-care, and thereby glycaemic control.

Research has found that patients feel their diabetes care team does not appreciate the frustrations and challenges intrinsic in diabetes management (Anderson & Funnell, 2010; Matthews, Peden, & Rowles, 2009; Vermeire et al., 2007), and that many adolescents may be incapable of the high standard and unrealistic goals set for them by healthcare providers (Hood et al., 2009b). With the move from authoritarian healthcare to a patient-centred approach, true collaboration between patients a diabetes care teams is required in order to produce improved outcomes (Pyatak et al., 2013). In order for this to occur, further research is needed to truly understand what the patient considers good self-management, and of the daily influences that may result in success or failure to maintain the care routine.

### **6.2.2. Transition**

In healthcare, a transition implies “*purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults...as they grow up learning to live with their lifelong health condition*” (Dovey-Pearce & Christie, 2013, p. 175). Specific to this thesis, it refers to the transfer from paediatric to adult healthcare settings. The age at which transfer from paediatric to adult services occurs varies according to individual’s maturity, the availability of services specific to the adult clinic, and may rely on hospital, clinic or local government regulations. Research by Garvey and colleagues (2012) states that the most common reasons for transition include feeling too old to attend a paediatric clinic, at the suggestion of the clinician, and attending university. Suffice to say, the appropriate age of

transfer is not agreed upon, even by young people themselves (Michaud, Suris, & Viner, 2004; National Institute for Health and Care Excellence, 2014; Suris, Michaud, & Viner, 2004).

A recent study by Garvey and colleagues (2013) highlighted that 29% of participants felt unprepared for transition, and 26% reported gaps exceeding six months in uptake of adult services. Specific to the UK, Kipps and colleagues found that 20% of participants were unsatisfied with their experiences of transition (Kipps, Bahu, & Ong, 2002). Indeed, some chose to opt out of regular attendance altogether, only to resurface when preventable diabetes complications emerge (de Beaufort, Jarosz-Chobot, Frank, de Bart, & Deja, 2010). Findings such as these highlight the non-purposeful, and potentially premature, nature of transition leading to withdrawal from services, even if only temporarily. When patients feel sufficiently prepared for transition, their outcomes are much improved with a far lower likelihood of a gap greater than 6 months in uptake of adult services (odds ratio 0.47) (Garvey, Wolpert, et al., 2012), highlighting the need for research identifying processes through which successful transition may be achieved.

There is a recognised danger of adolescents becoming 'lost' during transition to adult care, and withdraw from attendance at outpatient clinics (Sheehan, While, & Coyne, 2015). This withdrawal is likely to be followed by poor adherence (Busse et al., 2007; Channon, Smith, Alcolado, & Gregory, 2003; Kipps et al., 2002; Sparud-Lundin, Ohrn, Danielson, & Forsander, 2008), resulting in adverse diabetes outcomes such as acute and chronic complications and early mortality (Kipps et al., 2002; Rollo et al., 2014). Reasons for this feeling of prematurity of transition could include being ill-prepared for assuming sole responsibility for the complex self-care behaviours expected by adult healthcare providers. The adolescent may, therefore, feel unsupported and vulnerable whilst also attempting to maintain effective self-care. It may then be seen as easier to avoid engaging with clinic visits and focus on more typical age-appropriate activities, which may be of a higher priority to the adolescent (Garvey, Markowitz, & Laffel, 2012). Developmental psychology theory has suggested that transition should include a stepping stone of emerging young adulthood care, and not move directly to adult status (Weissberg-Benchell, Wolpert, & Anderson, 2007). This is compounded by qualitative research which identifies staff consistency through transition, navigable clinic structures so as not to be overwhelming, and provision of emotional and social support in addition to medical care as the most influential variables in creating a "smooth" transition (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005; Jones & Hamilton, 2008). Karlsson and colleagues (2008, p. 566) cited "*growth through confirmation of others*" as a key superordinate theme in transition, with both parental encouragement and peer acceptance playing a salient role in facilitating autonomy. Becoming autonomous clearly does not involve a separation from existing relationships, but a widening of



existing networks to embrace self-care. The inclusion of a social element to transition could, therefore, be a method through which self-care may be maintained across service providers.

Research into improving the transition from paediatric to adult services is merited. Current advice is that the change should not be sudden and unanticipated, but a smooth transfer including thorough preparation and adaptation. The process should work alongside high quality diabetes services and should be a collaborative effort with family, so that the two different care systems can be integrated and the expectations of those receiving and providing the service can be addressed (Sheehan et al., 2015).

### **6.3.3. Autonomy**

Transition for an AWT1D is not isolated to the diabetic clinic. Autonomy in decision-making and self-care is foundational in diabetes management (Price et al., 2011), with achieving volitional autonomy a key task for adolescents independent of diabetes (Soenens et al., 2007). In order to achieve this, parents must maintain their emotional and instrumental support whilst also reducing their involvement in the adolescent's diabetes-related decision-making and self-care (Rapley et al., 2013). Adherence in adolescents is dependent on shifting this responsibility effectively, including shared decision-making between the adolescent and parent (Allen, Channon, Lowes, Atwell, & Lane, 2011). Unfortunately, recent research reveals that transition is related to an increase in discordance between parent-child dyads, not the hoped for decrease. This is associated with an increasing number of diabetes-related tasks for which no one believes themselves to be responsible (Rapley et al., 2013), highlighting a serious problem in self-care resulting from transfer of responsibility.

AWT1D often struggle to gain and maintain autonomy, and are forced to confront the limitations caused by their illness. Price *et al.* (2011) stated that transfer of responsibility, like transition in healthcare services, needs to occur gradually and with full support from parents. The process of transfer of responsibility has been found to be related to age, psychological and physical maturity, in addition to minimising hassle and conflict in the parental relationship (Gee et al., 2007). Adolescent demands for increasing independence should be attended to, although support for positive decision-making should also remain clear (Karlsson et al., 2008). Parents must be responsive to the adolescent's perspectives and needs, offer choices in decision-making, encourage initiative and be reasonable regarding their expectations of initial success (Lekes, Gingras, Phillippe, Koestner, & Fang, 2010).

Adolescents and their parents, however, tend not to agree on what achieving autonomy involves (Butner et al., 2009; Hanna, Dashiff, Stump, & Weaver, 2013). Adolescents seeking autonomy are likely to perceive demands from parents as a potential threat to their independence and, therefore, as non-helpful. Family conflict (Lancaster et al., 2010) and

discordance related to assumption of responsibility for diabetes tasks have been found to be predictors of poor glycaemic control (Ritholz et al., 2013). Conversely, improved vigilance was associated with better glycaemic control when mothers were seen by the adolescent as collaborating with them, as opposed to controlling, on problems with self-care (Allen et al., 2011). In an interview study of adolescent females with T1D, Dickinson and O'Reilly (2004) found that they became frustrated when they felt nagged by their parents, and stated that their parents were over-involved in their self-care. Despite this, they were aware that their parents continued involvement was due to feelings of love and caring, and was not malicious. Adolescents have stated that this frustration tended to stem from a divergence of priorities, such as embarrassing them through discussing their diabetes with others, not understanding or denying food cravings, and not feeling listened to (Mulvaney et al., 2008). It can therefore be suggested that understanding the right type and amount of support is necessary to create a smooth transition of responsibility as the adolescent grows.

These findings suggest that achieving autonomy is a double-edged sword. Although it is an important and necessary task for self-care, it appears to be associated with negative diabetes consequences including poorer glycaemic control. Research into interventions aiming to smooth the transfer of responsibility and maintain effective self-care throughout the process is therefore warranted.

### **6.3. Quality of life and well-being**

The WHO QoL group define QoL as *"an individuals' perception of their position in life in context of the culture and the value system in which they live and in relation to their goals, expectation, standards and concerns."* (The WHOQOL Group, 1995, p. 1403). Different conceptualisations of QoL are routinely used, ranging from general to more specific constructs, such as specific health-related QoL (Suurmeijer, Reuvekamp, & Aldenkamp, 2001). Global definitions of QoL refer to it as the perception of well-being in general and are theoretically different from health-related QoL, which focuses on health-related concepts across life domains. Health-related QoL (HRQoL) can address disease-specific issues, such as those unique to diabetes, and more general health-related issues that could be encountered by a healthy individual (Frisch, 2000). HRQoL is defined as *"the physical, emotional and social aspects of an individual's disease and/or its treatment"* (Peterson et al., 2006, p.51). Strongly related to these concepts is well-being. Conceptualisation of well-being has proven problematic in research, which *"has given rise to blurred and overly broad definitions of well-being"* (Forgeard, Jayawickreme, Kern, & Seligman 2011, p. 81). Dodge and colleagues (2012) have proposed a definition of well-being in which it is a state of equilibrium between resources and challenges. This conceptualisation has the advantage of being concise, universal and easily operationalised. Dodge *et al.* (2012) go on to

state that QoL is a dimension of well-being, and as such these concepts are therefore very closely related.

The QoL of AWT1D compared to their healthy peers is contested. Faulkner (2003) stated that T1D patients frequently perceive their QoL as significantly lower. However, several other studies have found that their QoL is not significantly different from non-affected adolescents (Hoey et al., 2001; Laffel et al., 2003; McMillan, Honeyford, Datta, Madge, & Bradley, 2004). A recent meta-analysis of studies comparing the psychosocial profiles of children with T1D in comparison to healthy peers found that, overall, children appear to show similar levels of QoL to their healthy counterparts. However, age differences are noted in which older adolescents view themselves as having worse QoL over time (K. A. Reynolds & Helgeson, 2011). It therefore remains unclear how a diagnosis of T1D impacts on QoL in adolescents. McMillan and colleagues (2004) found that 70% of adolescents rated their QoL as satisfactory, though 60% of participants found living with diabetes to be restrictive in their daily life. This paradox is potentially explained by research which states that, when assessing general as opposed to HRQoL, the diabetes is not the dominating factor. Family, friends and school life are all found to be more important predictors of QoL than the disease itself (de Wit et al., 2007). Findings such as these indicate the importance of social networks in impacting personal well-being; that good quality relationships have more bearing on QoL than suffering from a life-long illness.

Instead, QoL in AWT1D is particularly affected by glycaemic control (Hassan et al., 2006) and social interactions. Findings that poor self-management and high levels of family conflict result in low QoL are common (Lawrence et al., 2012; Matziou et al., 2011). Valenzuela and colleagues (2006) have stated that variables related to family are more impactful than demographics or clinical influences such as treatment type. Non-diabetic factors such as social interactions and family conflict has long been seen as significant predictors of QoL in adolescent populations in comparison to disease duration or treatment intensity (G. Urquhart Law, Walsh, Queralt, & Nouwen, 2013). As QoL is now seen as an important treatment outcome (Valenzuela et al., 2006), interventions aimed at improving psychosocial adjustment via social influences, and therefore QoL, could be considered as an important aspect of disease management if offered alongside standard care.

Further research is warranted into the constructs most influential in HRQoL *“...because the adherence to self-management that ultimately leads to good glycaemic control requires good self-preparation to integrate the experience of the chronic disease, it is essential to explore the HRQOL of children and adolescents with T1D”* (Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011, p.37). Although QoL is now considered a key treatment outcome, little is known about how HRQoL interacts with other significant constructs specifically within diabetes. Ravens-Sieberer and colleagues (2007) studied a paediatric obesity group and found that 37% of variance in

HRQoL was accounted for by coping strategies, lack of emotional support and poor physical health. Coping strategies were also found to be a key determinant in chronic conditions in general (C. Peterson et al., 2006). Of the minimal research into T1D, early disease onset and longer disease duration (Matziou et al., 2011) in conjunction with poor glycaemic control (Debono & Cachia, 2007) have been associated with poor HRQoL, indicating the burdensome nature of diabetes. Gender differences in HRQoL have also been noted in diabetes, with females demonstrating poor HRQoL, increased worry regarding diabetes, poor health satisfaction and poorer health self-concept than their male peers (Hanberger, Ludvigsson, & Nordfeldt, 2009; Lawrence et al., 2012). Female adolescents may, therefore, most benefit from an intervention targeting psychosocial adjustment. In addition, age differences have also been acknowledged. Younger children tend to achieve higher global and HRQoL when compared to older adolescents (Matziou et al., 2011) attributed to the stress associated with puberty and teenage life (Debono & Cachia, 2007). QoL across age groups appears to be influenced by different factors, with younger children rating school as most influential, whereas well-being is the most salient factor for adolescents (Wagner, Müller-Godeffroy, Von Sengbusch, Häger, & Thyen, 2005), signifying differences in the appraisal of QoL depending on developmental stage. As children age, different dimensions become more important, as others fade in significance (Harding, 2001).

If, as indicated here, clinical factors such as treatment style have little impact on QoL, the question still remains as to the influence of QoL on disease management. Recent research by Hilliard and colleagues (2013) indicates that QoL may act as a quantitative predictor of diabetes management, as well as a treatment outcome. A deficit in both global and HRQoL predicted poorer self-care behaviours including reduced BGM. Hilliard *et al.* (2013) posit that this may be due to an increased likelihood that adolescents with poor QoL encounter known barriers to self-care, such as distress, academic problems and poor social support. Each of these dimensions of QoL have been acknowledged in influencing disease management in adolescents (Grey, Whittemore, & Tamborlane, 2002; Hains et al., 2007, 2009; Herzer & Hood, 2010; Polonsky, 1999), and are indicated by Hilliard (2013) as having long-term impact leading to poorer diabetes outcomes.

Importantly, recent research indicates that this relationship is bidirectional (Hilliard et al., 2013). Medical and psychosocial influences impact on QoL, as in turn QoL influences self-care behaviours and metabolic control. Further research is needed to identify the items influencing the subjective burden of symptoms as well as objectively identified outcomes. Once this is achieved, important dimensions can be prioritised and appropriate intervention design becomes possible.

#### 6.4. Stress

Stress is usually defined from a 'demand-perception response' perspective (Bartlett, 1998). Lazarus and Folkman (1984b) incorporate this into a seminal cognitive theory. Stress relates to both an individual's perception of the demands made on them and their perception of their ability to meet those needs. A discrepancy between those two factors will result in the demand-perception threshold being exceeded and will trigger a stress response. The stress threshold is dependent on individual characteristics, past experiences and coping resources, as well as the circumstances in which the demands are made (Langley & Adams, 2007). Research has long shown that stress has an adverse impact on health (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002) in addition to negative psychosocial outcomes (Kanner, Feldman, Weinberger, & Ford, 1987).

Specific to diabetes, research has also shown that stress is a significant correlate of glycaemic control. Studies of significant stressful life events have found a negative impact on glycaemic control in adolescent populations (Nygren, Carstensen, Koch, Ludvigsson, & Frostell, 2015). Everyday stressors, too, have been found to have significant associations with higher blood glucose in adolescents both around diabetes-specific daily stressors (Baucom et al., 2015) and those relevant to adolescent life (Helgeson, Escobar, Siminerio, & Becker, 2010). Everyday stressors have the potential to be problematic for late adolescents in particular. Research suggests that older adolescents are less likely to engage in health-promoting behaviours as a method of stress management, and instead enact behaviours which are typically problematic for those with T1D, such as skipping meals (Baucom et al., 2015). Understanding the role of stress and coping in the daily life of AWT1D therefore has important implications for their long-term health.

Stress may impact on glycaemic control and self-care through a variety of ways. There is evidence that stress has a direct physiological impact by increasing hepatic glycogen production and insulin resistance (Mortensen et al., 1998). Research has also found that stress impacts on disease management indirectly through impeding an individual's ability to conduct self-care activities (Helgeson et al., 2010). Studies have indicated that the typical negative affect and emotionality associated with adolescence (Larson, Moneta, Richards, & Wilson, 2002) may be aggravated by diabetes-related stressors, which would in turn result in active non self-management behaviours (de Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Holmes et al., 2006). There are, however, significant individual differences in this indirect relationship. A review analysing the strength and direction of the association concluded that stress may not adversely impact glycaemic control in all individuals. Although a weak association was found between stress and blood glucose levels, the direction of the relationship was inconclusive (Kramer, Ledolter, Manos, & Bayless, 2000). This suggests that although stress may cue some

individuals to engage in health-compromising behaviours such as avoidance of self-care, leading to poorer glycaemic control, others may cope with stress via participating in self-care behaviours more effectively (Berlin, Rabideau, & Hains, 2012).

The social-ecological context of the stressor and individual must, therefore, play a significant role in the processing of stress to predict glycaemic control (Gonder-Frederick, Cox, & Ritterband, 2002; Johnson, 1995). If the relationship between stress and glycaemic control is considered from a social-ecological approach (Steele & Aylward, 2009) in conjunction with a stress-coping model (Wallander & Varni, 1998), a possible explanation is provided. These models would suggest that stress reaction depends on how the stress is processed, impacted by stress appraisal and coping mechanisms, in addition to the source of the stress, such as social support, school or peers (Berlin et al., 2012). Stress and its impact on glycaemic control is, therefore, differentially affected by factors such as environment, familial support and peer interactions. The aspect of the adolescent's life in which the stress occurs may thereby mediate the relationship between stress and health outcomes, with each stressor capable of affecting self-care and glycaemic control differently, with familial stress the most likely to result in poor glycaemic control (Berlin et al., 2012). Previous research has indicated that non-disease focused care offered routinely, such as individualised and non-judgemental support from a social network, is crucial in minimising the impact of stress on diabetes outcomes (Davidson, Penney, Muller, & Grey, 2004). This suggests that facilitation of effective coping mechanisms, such as social support, is a viable method through which clinics can reduce the impact of stressors on disease management, and thereby poor diabetes outcomes.

#### **6.4.1. Coping**

Lazarus and Folkman (1984a, p. 141) defined coping as *"constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."* They divided coping into two main strategies: problem and emotion-focused coping. Speaking generally, research has suggested that avoidant (or emotion-focused) coping strategies are associated with poor psychosocial variables, adherence, and health outcomes. Conversely, problem-focused strategies have been found to be related to improved psychosocial and health outcomes (Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010). However, researchers have noted this coping dichotomy is neither exclusive nor exhaustive (Skinner, Edge, Altman, & Sherwood, 2003). Illness-specific coping strategies, too, have been investigated in the context of T1D (Luyckx et al., 2010). 'Tackling spirit' assesses to what extent an adolescent is active in their self-care with a positive attitude, often making use of problem-focused coping strategies as a direct result. 'Illness integration' involves the degree a participant accepts and integrates diabetes into their self-concept (Felton & Revenson, 1984).

These strategies, in particular, have been found to be related to improved self-care, glycaemic control, and adjustment (Luyckx et al., 2010). However, not all patients are active in their coping. 'Avoidance' concerns distraction from self-care, with 'passive resignation' representing a sense of helplessness in the face of diabetes (Seiffge-Krenke, 2001a), resulting in lower competence and poorer glycaemic control (Jaser & White, 2011).

Whether or not AWT1D differ from their peers in response to stress is a question which remains largely unanswered. Previous research is inconclusive, with studies finding no difference in coping (Hema et al., 2009), while others identify variance (Olson, Johansen, Powers, Pope, & Klein, 1993), particularly when concerning a dissimilarity between diabetes and other health conditions (Petersen, Schmidt, Bullringer, & DISABKIDS Group, 2006). Likewise, whether or not AWT1D differ in terms of their coping strategies according to gender is also unclear (Frydenberg & Lewis, 2009), though research has indicated that adolescent girls are more likely to employ social and spiritual support than their male counterparts (Pisula & Czaplinska, 2010). Low socioeconomic status, however, is frequently cited as a precursor of poor coping skills and glycaemic control (Jaser et al., 2012), highlighting an obvious at-risk group and potential target for coping skills-related intervention.

Effective coping has previously been found to be enhanced by active engagement from social networks (Berg et al., 2009). In adolescents, collaborative coping with others has been found to be associated with improved glycaemic control, adherence (Wiebe et al., 2005), and fewer depressive symptoms (Berg, Wiebe, Beveridge, Palmer, & Korbel, 2007). This is likely due to the impact of others on stress appraisal (Berg & Upchurch, 2007). Evidence has shown that collaborative coping often results in the appraisal of the stress of diabetes being seen as shared among the network, as opposed to the adolescent's burden alone (Acitelli & Badr, 2005; Berg et al., 2009). Coping skills training incorporating a social element is, therefore, a viable method through which the adverse impact of diabetes stress on health outcomes may be mediated.

### **6.5. Resilience**

Increasingly, research is focusing on factors which protect against the negative consequences of T1D. Resilience has been found to improve health behaviours and outcomes across populations (Yi-Frazier et al., 2013). Resilience encapsulates a capacity to maintain well-being in the face of stress (Burton, Pakenham, & Brown, 2010). Whilst it is noted that both coping resources and resilience are intrinsically associated with stress, these concepts are distinct. Coping style refers to the cognitive and behavioural resources employed to manage the demands of stress. As such, coping can be both adaptive and maladaptive, depending on the strategy employed (Folkman & Moskowitz, 2004). Conversely, resilience specifically refers to an adaptive response to challenge. Maladaptive coping styles cannot be considered resilient, as they do not lead to

positive outcomes for the individual (Beasley, Thompson, & Davidson, 2003; Campbell-Sills et al., 2006; Glennie, 2010). Positive outcomes such as good QoL and achieving optimal glycaemic control are possible, and could be considered as indicators of resilience. Resilient patients can be categorised as those who overcome the challenges which lead to negative outcomes, demonstrating competence exceeding expected functioning (Masten, 2001, 2007).

The conceptualisation of resilience has proven problematic in research, with three current definitions widely used; trait, outcome and process (Hu, Zhang, & Wang, 2015). Trait oriented research suggests that resilience is an intrinsic personality trait. As such, the overarching definition of personality applies, in which traits are internal, innate and stable over time (Burger, 1997). Researchers who support this conceptualisation view resilience as a fundamental aspect of the individual, which is able to inoculate them against the negative aspects of challenge (Connor & Davidson, 2003; A. D. Ong, Bergeman, Bisconti, & Wallace, 2006). An outcome definition suggests that resilience is an adaptive behavioural response to adversity, much like successful coping (Harvey & Delfabbro, 2004; Masten, 2001). Finally, a process conceptualisation states that resilience is a dynamic experience in which a continual re-appraisal is engaged with in response to challenge, so that active adaptation is assisted by protective factors, such as social support (Fergus & Zimmerman, 2005; S.S. Luthar, Cicchetti, & Becker, 2000). The lack of consensus regarding the conceptualisation of resilience is problematic; such a discrepancy hinders effective comparison of research findings and limits operationalisation of the construct within measures (Davydov, Stewart, Ritchie, & Chaudieu, 2010).

It is perhaps for this reason that research into resilience and T1D is limited, and tends to adopt a protective factors perspective (Yi-Frazier et al., 2013). Of the small number of studies addressing these concepts in an adolescent population, resilience has been shown to offer some protection against the negative effects of the disease. Previous research has identified that increased stress was only associated with poor glycaemic control in those with low or moderate resilience (Yi, Vitaliano, Smith, Yi, & Weinger, 2008). Protective assets associated with resilience include a good sense of humour, high intelligence, family support (Masten, 2001), acceptance, emotional support and pragmatism (Yi-Frazier, Smith, Vitaliano, & Yi, 2010). However, in order for a protective factor to influence outcomes, it must be actively engaged with in conjunction with the risk factor (M. Rutter, 2012). Unsurprisingly then, it is the protective factors most closely related to the challenge that have the most impact. Similarly, protective processes that provide opportunity for other protective factors to come into play are also of importance (Masten, 2011).

The influence of resilience as a whole appears to offer protection from depressive symptoms, stress, family conflict and improves coping and QoL (Laffel et al., 2003; Sousa,



Zauszniewski, Musil, Price Lea, & Davis, 2005; Whittemore, D'Eramo Melkus, & Grey, 2005; Yifrazier, Hilliard, Cochrane, & Hood, 2012). No literature could be identified comparing the resilience of those with T1D in comparison to healthy populations, and therefore the question remains as to whether or not the resilience experienced by AWT1D is normative. It is suggested that the increased adversity of living with T1D is likely to impact on resilience.

Resilience occurs at the individual, interpersonal and environmental (e.g. social, contextual) level. Resilience must therefore be multi-systemic and multifactorial (Burt & Paysnick, 2012; Kia-Keating, Dowdy, Morgan, & Noam, 2011; Vanderbilt-Adriance & Shaw, 2008), incorporating influences that are not only limited to the adolescent alone. Indeed, research has indicated that social support acts as a facilitator for resilience, through increased self-esteem and improved coping skills (Helgeson, Palladino, et al., 2014). Several models of how factors interact to produce resilience in patients have been produced over the last decade (Haase, 2004; Koinis-Mitchell et al., 2012; Koinis-Mitchell, Murdock, & McQuid, 2004; Rolland & Walsh, 2006; Whittemore, Jaser, Guo, & Grey, 2010). These models identify the risks and assets related to resiliency on both an individual and social level. Whittemore and colleagues (2010) designed a model of resilience specific to T1D, based on a stress-adaptation approach. In it, demographic characteristics and treatment modality interact with psychosocial responses and family characteristics to produce resilience. The model is recursive, in that a change in one element of resilience is likely to impact on others. This model was updated by Hilliard and colleagues (2012). Here, diabetes-specific and global protective factors interact to create resilience risks and assets. These impact on both diabetes and general competence (social, developmental, academic), which then interact to impact on health outcomes. This model provides diabetes-specific insight into how some adolescents achieve optimal glycaemic control, self-care behaviours and psychosocial outcomes, whilst others struggle, and offers a potential indirect mechanism in which social support is a contributory factor towards resilience.

## **6.6. Summary of Chapter 6**

Rates of adherence in diabetes care are particularly low, with optimal self-care widely reported at below 50% (Naranjo et al., 2014). It has been concluded that engagement with self-care is closely related to both non-modifiable (Naranjo et al., 2014) and psychosocial characteristics of the patients (Vermeire et al., 2007).

Although the majority of adolescents adapt well to the difficult changes of puberty, it must be recognised that their healthcare and emotional needs are distinctly different from those of younger children or older adults (Hanna, Dashiff, et al., 2013). Key psychosocial characteristics appear to be highly related to this relationship between developmental stage and self-care behaviours and within themselves, including well-being, stress, coping mechanisms

and resilience (Yi-Frazier et al., 2013), suggesting a multi-faceted, highly-complex mechanism through which psychosocial factors are associated with health outcomes in AWT1D. Taken together, these findings suggest that research assessing the health outcomes of AWT1D should take into account the complex nature of their psychosocial world in addition to known and directly predictive factors, such as self-care, in order to gain better perspective.

## Chapter 7: Rationale and Methodology

### 7. Overview

The aim of this chapter is to summarise the rationale behind the current doctorate. Firstly, it gives an overview of the background theory and research presented in the first six chapters. Based on the previous research findings (Chapters 1-6), a number of key research questions are proposed and the overall aim of the present research is discussed. Furthermore, specific issues related to the design of a mixed methods study is presented, including details of the philosophical paradigm and implementation of such research.

#### 7.1. Introduction

As has been reinforced in previous chapters, adolescence has been characterised as a “last chance for intervention” in health behaviours (Sawyer, Drew, Yeo, & Britto, 2007). Research has suggested that the self-care behaviours formed in adolescence become habitual and are carried into adulthood. Instilling appropriate self-care in adolescence has, therefore, been suggested essential for lifelong health when living with a chronic health condition (World Health Organisation, 2009). This is particularly of concern in T1D, which is not only prevalent in adolescence (National Paediatric Diabetes Audit, 2012), but also presents great risk to young people. Findings have suggested that mortality in young females with T1D is approximately nine times higher than the population rate, and four times higher in males (National Health Service, 2011). For a disease with such heightened risk to mortality, instilling effective self-care in adolescence becomes all the more important.

It has long been seen in health psychology that social support is an important determinant of health and well-being (Gallant, 2014). A defining characteristic of adolescence is the adaptation of the social network. Adolescents re-orientate their social network so that the opinions of peers take precedence over those of family members (Viner, 2012). This flux creates changes in social support sought and in health behaviours, due to the gradual transfer of responsibility for health from parents to self. Umberson and colleagues (2011) suggest that these milestones are related, with Skinner and Cameron (2010) further linking this to the deterioration in glycaemic control typically seen during adolescence (Wallander et al., 2013; Wherrett et al., 2013). Although researchers appear to agree that social support plays an influential role in the deterioration of glycaemic control in adolescence, the precise mechanism through which it is able to achieve this has yet to be established. A possible explanation can be found in OT. Evidence suggests that OT is able to provide a stress-buffering response, potentially leading to indirect downregulation of the HPA axis and thus cortisol release; a hormone known to have negative health effects (Norman et al., 2012) and associated with increased blood glucose (Khani & Tayek, 2001). These considerations are explored in light of

this in the present thesis, and specifically addressed in the aims and objectives of this doctoral research.

### **7.1.1. Research aim and objectives**

An important concept to consider in the challenge to improve glycaemic control, and thus health outcomes, is social support. The current research body lacks mixed methods evidence derived from an AWT1D population, particularly when considering peer support networks and OT as a biomarker of social bonding. The present thesis will, therefore, build upon the work of previous studies to achieve a more holistic understanding of peer support in AWT1D, in order to make recommendations as to how this may be targeted and improved in the current clinical guidelines.

The aim of this thesis is therefore to understand the role of peer support in health and psychosocial outcomes in AWT1D.

#### **7.1.1.a. Research questions**

In order to achieve this aim, the following research questions were developed:

##### ***Question 1. What is the relationship between peer support and diabetes outcomes in AWT1D?***

Existing literature lacks consensus regarding the relationship between peer support and diabetes outcomes. Peer support has been found to predict adherence (Kyngäs, 2000), well-being and disease adaptation (Bearman & La Greca, 2002), with some findings indicating AWT1D are more likely to self-care appropriately if they receive peer support (Kyngäs, 2000). However, not all outcomes are positive. Peer support has also been found to enhance the relationship between increased stress and poor control (Hains et al., 2007). Peers have been criticised for lacking accurate knowledge, and providing poor diabetes-specific support (Thomas et al., 1997). As such, this thesis will seek to clarify the relationship between peer support and diabetes outcomes (Study 1) by adopting a single cohort mixed methods approach to account for individual differences across groups (see Section 3.3.3.c.).

##### ***Question 2. What is the relationship between peer support and psychosocial outcomes in AWT1D?***

Quantitatively, increased peer support has been stated as a contributory factor towards important psychosocial outcomes, such as enhanced QoL (G. Urquhart Law et al., 2013), resilience (Yi-Frazier, Smith, Vitaliano, & Yi, 2010), and reduced stress (Berlin et al., 2012). However, qualitative data has associated diabetes-specific peer support with poor outcomes including damage to the self-concept (Dovey-Pearce et al., 2007) via increased stigma (Hinder & Greenhalgh, 2012). Therefore, the present research will assess the role of peer support in the

psychosocial profile of AWT1D using a mixed methods approach in order to overcome the clear disparity between methodologies in the literature (Studies 1 and 3).

***Question 3. Do the facets of peer support differ in their relationship to psychosocial and diabetes outcomes?***

Global and diabetes-specific support appear to have differing relationships to both psychosocial and diabetes outcomes. Qualitatively, studies have stated that AWT1D believe emotional support to be beneficial when provided by peers (Dovey-Pearce & Christie, 2013; Hinder & Greenhalgh, 2012), whilst quantitative evidence suggests otherwise, as no relationship could be identified between global social support and self-care behaviours in the few studies which have investigated this relationship (Helgeson, Reynolds, et al., 2007). In general, studies fail to distinguish between the various types of global social support, acting as a potential caveat to their findings. This thesis will therefore attempt to distinguish between the facets of peer support in all analyses, in an attempt to identify specific areas of interest (Study 1).

***Question 4. What is the meaning and experience of peer support in AWT1D?***

What is apparent from literature assessing peer support in AWT1D is the lack of consensus between quantitative and qualitative findings. Qualitative studies tend to espouse the benefits of peer support in outcome measures (Dovey-Pearce & Christie, 2013; Hinder & Greenhalgh, 2012), whilst quantitative evidence is unclear, suggesting differing impact of global social support and diabetes-specific support (Palladino & Helgeson, 2012). The research into peer support and health outcomes in AWT1D is, therefore, inconclusive. What is lacking currently is rigorous mixed methods research. No studies have been identified in which a mixed methodology is adopted to expand knowledge of peer support in AWT1D. Therefore, a qualitative research question is included to illustrate and explain the quantitative findings (Study 1).

***Question 5. How are well-intentioned support behaviours perceived as nagging in some AWT1D?***

Due to the lack of consensus in literature highlighted in the preceding sections, it is difficult to conclude that peer involvement in self-care is warranted. It is suggested that, just as parental support is occasionally perceived as “nagging” (Seiffge-Krenke et al., 2013), peer involvement may too be construed as interference and stigmatising, both of which have been stated as an unwanted consequence of social support (Dovey-Pearce et al., 2007; Lehmkuhl et al., 2009). However, no research could be identified assessing the potential for nagging behaviours from peers, with studies focusing on parent and familial involvement in this field. As such, this thesis also attempts to assess whether nagging behaviours are isolated to familial support, or if such misinterpretation of well-intentioned behaviours is also present in peer relationships (Study 1).

***Question 6. Through what mechanism is peer support related to diabetes outcomes?***

Whilst literature does appear in agreement that a relationship between social support and diabetes outcomes exists, though a direction is undetermined, exactly how such relationship may operate is unknown. Several potential mechanisms, therefore, are to be examined in the present thesis, including the potential mediating roles of QoL (Hilliard et al., 2013) and resilience (Whittemore et al., 2010) in Study 1. In addition, a novel mechanism is proposed (see Section 4.6.2.), assessing the psychophysiological effects of the stress-buffering hypothesis (S. Cohen & Wills, 1985), evaluated in Study 2.

***Question 7. Is oxytocin a valid biomarker of peer support?***

Literature suggests OT has a highly prosocial function (Carter et al., 2007; DeVries, Glasper, & Detillion, 2003; Ditzen et al., 2009; Jurek, 2013; Schneiderman et al., 2012). OT has been suggested to enhance social motivation, seeking of social interaction and experiencing rewards as a result of social behaviours (Depue & Morrone-Strupinsky, 2005), and is therefore suggested as a marker of perceived social support (A. Campbell, 2008). However, perhaps due to the relative infancy of ELISA kits allowing for assessment of OT (Carter, 2007), only one study could be identified assessing the association between OT and filial attachment (Feldman, 2012). Thus, this thesis will build on this paucity of knowledge and assess the efficacy of OT as a biomarker of peer support in AWT1D (Study 2).

***Question 8. Is the psychosocial experience of being an AWT1D comparable to healthy peers?***

Research both supports and refutes the assertion that living with T1D impacts on social support (Helgeson, Palladino, et al., 2014), QoL (Hoey et al., 2001; Laffel et al., 2003; McMillan et al., 2004) and resilience (Yi-Frazier, Smith, Vitaliano, & Yi, 2010), and evidence of how any relationship identified may operate is lacking. Determination of whether or not living with T1D impacts the psychosocial functioning of adolescents will help to shape knowledge of whether or not experiences of AWT1D are normative for this tumultuous developmental stage (Viner et al., 2012). Currently, a lack of acknowledgement of the difficulties of adolescence within literature concerning AWT1D may be perpetuating a falsehood that living with T1D is adversely impacting social functioning, whilst in reality an altered psychosocial profile may be expected for this age group. As such, use of a comparison cohort of healthy adolescents will allow for such frame of reference (Study 3).

***Question 9. Does psychosocial experience vary according to gender and age within AWT1D and healthy peers?***

As assessment of psychosocial functioning in healthy adolescents has indicated a presence of gender and age differences in social support (Camarena et al., 1990; Golombok & Fivush, 1994;

Kuttler, 1999), QoL (Kalyva et al., 2011; Lukacs, Varga, Kiss-Toth, Soos, & Barkai, 2014; Naughton et al., 2014) and resilience (Boardman, Blalock, & Button, 2008; Leadbeater, Kuperminc, Blatt, & Hertzog, 1999; Matud, 2004), it is important to consider such moderating factors in assessment of the psychosocial profile of AWT1D. This will allow for comparison of adolescents across health status and important modifying demographic variables (Study 3).

***Question 10. What recommendations for healthcare professionals can be made in order to improve the psychosocial experience of AWT1D?***

Current NICE guidance makes few specific mentions of the psychosocial experience of AWT1D. Most concern diabetes-specific support behaviours, with emotional support only recommended immediately post-diagnosis (National Institute for Health and Care Excellence, 2015). Adolescents, too, do not receive specific recommendations, with blanket guidance for children and young people made together, without consideration for developmental stage. This is despite the unique psychosocial and diabetes-related experiences of AWT1D (Wallander et al., 2013; Wherrett et al., 2013). As such, it is advisable that this thesis provide clinical implications of findings for the care of AWT1D, in order to offer applicable value to this doctoral thesis (Study 1, 2 and 3).

***7.1.2.b. Research objectives***

This aim and research questions of the present thesis will be evaluated using the following research objectives:

1. To explore the relationship between peer support, self-care and glycaemic control in AWT1D (Study 1; Research questions 1, 2, 3, 4, 5 and 10).
2. To explore the effects of social bonding, as indicated by oxytocin, on the cortisol-based stress response, and assess if this is associated with glycaemic control in AWT1D (Study 2; Research questions 6, 7 and 10).
3. To assess whether the psychosocial experience of AWT1D is comparable to that reported by their healthy peers (Study 3; Research questions 1, 7, 8, 9 and 10).

Investigation of these aims, research questions and objectives will not only present an original contribution to knowledge, but also impact treatment opportunities. Current NICE guidelines recommend psychosocial support of AWT1D regarding anxiety, depression, well-being, behavioural and conduct disorders, but no mention is made of peer support, ignoring the social world in which adolescents exist. Formalised support interventions are only recommended for increasing exercise or in instances of diabetes-related family conflict in young people, whilst being recommended far more extensively in adult populations (National Institute for Health and Care Excellence, 2015). A more informed inclusion of social support in paediatric care may have significant patient benefit by increasing psychological well-being, in addition to

improving the serious health outcomes related to poor glycaemic control. Adolescents, in particular, are under-represented within the guidance, with one single stipulation separating adolescent from paediatric care:

*“Be aware that adolescence can be a period of worsening blood glucose control in young people with type 1 diabetes, which may in part be due to non-adherence to therapy.”* (National Institute for Health and Care Excellence, 2015, p. 26)

Given that it is widely acknowledged that the medical and psychosocial needs of adolescents and children differ, with unique vulnerabilities and patient safety risks (Sales & Irwin Jr, 2013), it is perhaps neglectful that current NICE guidelines fail to address the distinctive challenges of self-care during adolescence. This thesis attends to both the provision of social support services in paediatric care, and the failure to tackle the distinctive guidance required for appropriate self-care in adolescence. Through these aims and objectives, an original contribution to research is presented.

## **7.2. Original contribution to knowledge**

In order for this thesis to be considered at doctoral level, an original contribution to knowledge must be made. As such, this purpose is built into the study design. For clarity, the overarching original contributions are outlined here. These will subsequently be addressed within each respective chapter, with conclusions drawn about the implications of that original contribution brought together in the General Discussion (see Section 12.5.)

### **7.2.1. Application of mixed methodology**

A paucity of studies has used a mixed methods approach to understand peer support in AWT1D. Although few studies exist examining this concept in single-methods studies (Section 3.3.3.c.), none could be located rigorously applying a mixed methods approach in AWT1D. Therefore, this study presents a more three dimensional understanding of the experience of peer support in AWT1D than has previously been offered (Study 1).

### **7.2.2. Provision of an in-depth analysis of the facets of peer support**

In general, studies investigating social support in AWT1D fail to distinguish between the various types of global social support, leaving it difficult to determine potential variation between the facets of social support outlined in Section 3.2., and both diabetes and psychosocial outcomes. In addition, studies tend to investigate either global or diabetes-specific support, rarely addressing both in conjunction (Palladino & Helgeson, 2012). As a result, this thesis will offer an original, indepth analysis of a comparison between global or diabetes-specific support, whilst additionally considering the subtypes of support present within the measures at all times. As such, it is hoped differences in the action of the typologies of peer support will be identified and compared.



### **7.2.3. Consideration of the impact of social bonding**

This thesis investigates the role of social bonding, indicated by oxytocin, on glycaemic control in T1D. Although a small number of studies have investigated the role of oxytocin on health in human populations, none could be found examining its role in T1D (Section 4.6.). Thus, this thesis presents an original theory, outlined in Section 4.6.2, clarifying a potential indirect benefit of social support via the down-regulation of the HPA axis by oxytocin, explored in Study 2.

### **7.2.4. Generation of reference data for use of measures of salivary oxytocin in adolescents**

Finally, the current research body lacks evidence derived from an adolescent population when considering oxytocin. Research on oxytocin, as outlined in Section 4.5., has focused primarily on attachment in adults and young children. Given the importance of adolescence in establishing health behaviours in later life (see Section 2.4.), and fluctuations within the social network (see Section 2.3.), it is of consequence that factors found to be influential on health in adult and childhood are likewise investigated in this age group.

A three-study research design has, therefore, been used to address the above aims and objectives, each of which is able to present an original contribution to knowledge.

## **7.3. Research design**

The research aims, research questions and objectives determined the design of this thesis, and thereby the development of the three-study approach which is applied to explore the outlined objectives.

### **7.3.1. Study 1: *“They think it’s helpful, but it’s not”*: The experience of peer support in adolescents with type 1 diabetes**

The first study (Chapter 9) seeks to explore and better understand the relationship between peer support and both psychosocial and health outcomes in AWT1D. In response to the knowledge that social support is a multidimensional, fluid concept (Lourel et al., 2013), it was determined that a mixed methods study would best capture the full lived experience of peer support. For this study, where the objective is to explore the relationship between peer support and self-care in T1D, social support is analysed using both quantitative and qualitative methods to deepen the understanding of an experience as complex as peer support. Quantitative questionnaire measures of global and diabetes-specific support and self-care are therefore analysed and outlined, supported by findings from semi-structured interviews with participants. The qualitative research question allows further exploration of the experience of social support than can be provided by the quantitative data alone, and is used in a supporting capacity to increase understanding of the quantitative results. The mechanisms underpinning this approach are fully explored in Section 7.4.

### **7.3.2. Study 2: Exploring the biological effects of social bonding on glycaemic control in adolescents with type 1 diabetes**

In order to substantiate and expand on the findings of this first study, a second was designed (Chapter 10). This utilises biological methods to assess whether or not the stress-buffering hypothesis of social support (Cohen & Wills, 1985) is applicable to T1D via the measurement of OT and cortisol. It was anticipated that this study would greater illuminate the findings of Study 1, through exploring the physiological responses to a psychosocial experience. Biomarkers of social support (OT) and HPA axis activity (cortisol) were therefore analysed. By combining biological and psychosocial approaches, it is believed that a more comprehensive, holistic view of the experience of peer support will be achieved.

### **7.3.3. Study 3: A comparison of adolescents with and without type 1 diabetes on peer support and psychosocial functioning**

Finally, given that much of the reference data is derived from measures typically used in adults, the expected scores are also taken from this population. It was therefore decided that, given the psychological and biological changes which typify adolescence (Sawyer et al., 2012), comparison to an adult population would be methodologically flawed. In order to explore whether or not the peer support experiences of AWT1D can be considered normative, a sample of their healthy peers would be required for comparison (Chapter 11). Using global, non-diabetes-specific measures, the psychosocial profiles of AWT1D were assessed and compared to a comparison group. Global quantitative instruments of social support, well-being and resilience are compared and contrasted. As demonstrated in Section 6.5., these three concepts are highly related to diabetes outcomes in this population (Perfect & Jaramillo, 2012).

It was concluded that through these three studies and combinations of methodology, the fullest understanding of the role of peer support in health and psychosocial outcomes in AWT1D could be gathered. However, use of such a complex three-study mixed methods approach requires a solid methodological foundation in order to be successful.

## **7.4. Methodology**

The demand for research that informs policy, directs intervention development and improves care through use of both qualitative and quantitative methods is growing (Ritchie & Lewis, 2003). For this reason, research using a mixed methods approach is increasingly seen and well-received in applied settings such as health (O’Cathain, Murphy, & Nicholl, 2007; O’Cathain, 2009; Tashakkori & Teddlie, 2003), including diabetes (Casey et al., 2014; Teddlie & Tashakkori, 2009), adolescent health (Frøisland, Årsand, & Skårderud, 2012; Hilliard et al., 2014), and in social support (Rankin et al., 2014; Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011).

#### 7.4.1. Mixed methods research

Empirically-derived measures allow comparison of samples and generalisation to a population. However, their ability to capture lived experience of a multifaceted concept such as social support is limited (Scott & Bisconti, 2013). Interviews, in contrast, allow participants to input their personal experience and direct the topic of inquiry. This enables the researcher to identify additional aspects of social support limited by quantitative instruments, and view experience through context that may not be found in theory, research or clinical practice (Scott & Bisconti, 2013); a stipulation of particular use when a paucity of studies exists, as is found here. In contrast, purely qualitative inquiry may not permit the generalisability of findings crucial for audiences such as policy makers, practitioners and applied fields, such as healthcare. These audiences, all of which are targeted by the present thesis, require multiple forms of evidence to document and inform their work (Creswell & Plano Clark, 2011b). Relying on either method alone may constrain the breadth and depth of ideas and data available. Use of both allows the researcher to gain perspective and nuance. A mixed methods approach facilitates an original contribution to knowledge by exploring meaning at particular, general and theoretical levels (Scott & Bisconti, 2013). This methodology was therefore chosen to allow as deep and holistic an understanding of experience as possible.

The discussion of inclusion of multiple methodologies in academic research began as early as 1978 (Denzin, 1978) and proponents of quantitative research have long advocated for the inclusion of qualitative findings to support and explain quantitative experimental findings (Campbell, 1974; Cronbach, 1975). Multiple definitions for mixed methods research have emerged since its inception. These definitions conceptualise the core characteristics of methods, research processes, philosophy and research design in various ways. Creswell and Clark (2007) posit one of the most inclusive definitions. Termed the ‘core characteristics’ approach, they assert that:

*“Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone.”* (Creswell & Plano Clark, 2007, p. 5).

Around the time of the initiation of mixed methodologies, a debate began when qualitative researchers became adamant that the different philosophical assumptions of quantitative and qualitative research made their combination untenable (Bryman, 1988; Guba & Lincoln, 1988; Smith, 1983). The issue of reconciling paradigms is still apparent (Giddings, 2006; C. Holmes,

2006), though it is now widely accepted that pragmatism offers the “gold standard” philosophical foundation for a mixed methods approach (Tashakkori & Teddlie, 2003) which allows the use of different theories in mixed methods research providing that each is honoured and explicitly stated when used (Greene & Caracelli, 1997).

#### **7.4.2. Philosophical paradigm**

Pragmatism draws on the primary assumptions of practicality in research and the value of both subjective and objective knowledge, with the research question of primary importance in all decisions (Creswell & Plano Clark, 2011b). Pioneered by Charles Sanders Peirce and William James, the approach was later adopted and modified by John Dewey (Hookway & Zalta, 2013). Deweyan pragmatism is to be understood as a scientific activity. Dewey insisted on the value of science in the understanding of society (Cochran, 2002), and is therefore well suited to this thesis and its assertions of scientific methods in the study of lived experience. Dewey stated that scientific methods allow us to shape the social world in line with personal goals. The term ‘control’ was used, in the sense that science enables us to objectively ‘control’ social interactions (Dewey, 1985). Control is stated as the means through which individuals cope with the world around them; a means of action available through understanding relationships and resolving problematic situations. Dewey’s concept of control should be understood as synonymous with knowledge (Manicas, 1998). Control does not regard determination; it is the temporary and contingent goal of inquiry. Due to the complexity of social worlds and the pace of change to which they are subjected, nothing is ever permanently known or controlled. Truth, therefore, is a transient solution that will eventually be dislodged by a new truth, forcing inquiry to begin once more (Dewey, 1985). This focus of what is important in the moment is well-suited to the present enquiry, which seeks to address the lack of acknowledgement of the adolescent experience in current NICE guidance. With this in mind, Deweyan pragmatism concerns people directing their social existence and working towards personal goals, not truth, which is reflected well in the aims and objectives of the present study to understand how social factors are associated with goals related to health and self-care. Similarly, Dewey stated inquiry must seek to better social situations (Dewey, 1985); a primary goal of this thesis.

Control of one’s social world provides comfort (Cochran, 2002). For Dewey, experience is a process of interaction between the surroundings and the desire to obtain information to meet needs. Dewey rejects the philosophy of the mind-brain dichotomy present in other worldviews, and states that to separate the phenomena of experience is to misunderstand the social world. Under Dewey’s approach *“the quest for certainty by means of exact possession in mind of immutable reality is exchanged for security by means of active control of the changing course of events”* (Dewey, 1984, p. 163). Dewey rejects the search for ‘reality’ and instead

embraces experience as it is lived. Given Dewey's rejection of ontology and assertion that lived experience is truth, the present thesis acknowledges that such ontological measures as questionnaires and biomarkers will reveal a limited component of social support. In order to understand this complex concept, qualitative investigation is required to uncover lived experience and gain a fuller knowledge regarding the truths of the participants. Equally, given Dewey's rejection of philosophy of dichotomy (Dewey, 1984), separation of biological and social processes is similarly rejected in this thesis, giving rise to the investigation of both the biological and psychosocial relationships to peer support. Here it is understood that both biological and psychosocial factors are related to health, either separately or through complex mechanisms which the present thesis endeavours to uncover.

Crotty (1998) emphasised a philosophical paradigm should be supported by a theoretical standpoint that provides direction for the body of work. Operating at a sublevel to the paradigm, the theoretical lens informs the design and aims of the mixed methods approach (Crotty, 1998). As championed by Deweyan pragmatism, multiple theories may be adopted for each study within a programme of research, under the stipulation of practicality and the primary importance of the research question (Tashakkori & Teddlie, 2003). With this in mind, multiple theories inform the present thesis.

#### ***7.4.2.a. Theoretical lens***

As outlined in Section 4.6.1., Study 2 utilises the stress-buffering hypothesis of social support (Cohen & Wills, 1985). This theory has been identified as a framework to develop a novel theoretical understanding of social bonding in glycaemic control. The perspective is outlined in full in Section 4.6.2. In sum, it is acknowledged in research that OT is able to down-regulate the cortisol response via its action on the HPA axis. It is therefore hypothesised that social bonding (OT) is able to moderate the stress response (cortisol), and thereby aid improved glycaemic control (HbA<sub>1c</sub>), by decreasing the likelihood of persistent hyperglycaemia (see Figure 16). Use of biomarkers of these responses (OT & cortisol) are therefore compared and contrasted to a biological indicator of glycaemic control (HbA<sub>1c</sub>) in Study 2, in order for this theory to be examined.

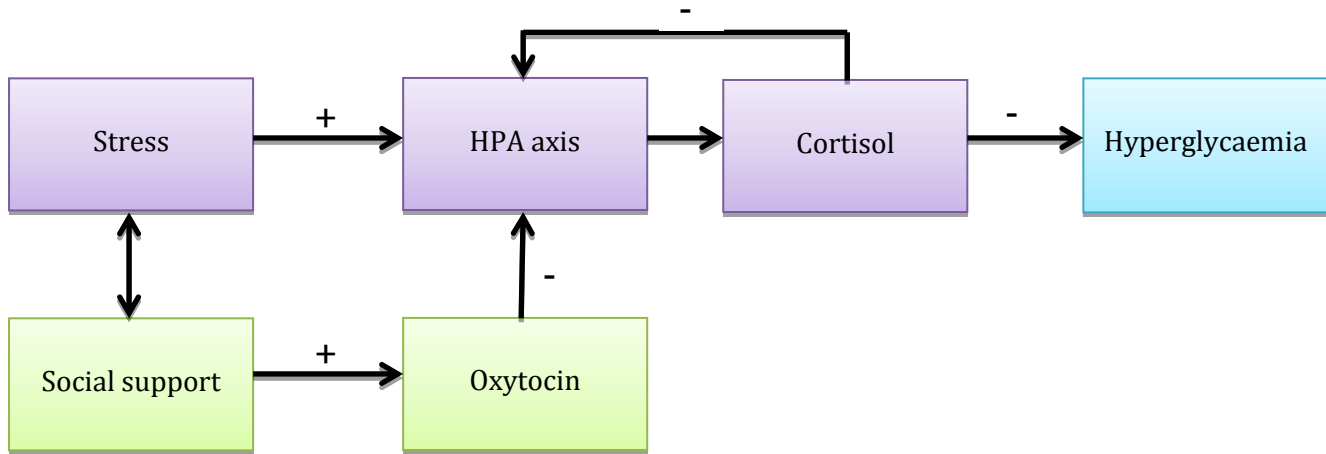


Figure 16. The proposed model of the relationship between stress and social support in glycaemic control.

The combination of studies in this thesis as a whole will utilise mixed methodology in order to fully explore social support from a three dimensional, holistic perspective. With this in mind, a solid foundation of a thorough mixed methods design is required to ensure rigour of application.

#### 7.4.3. Mixed methods design

Creswell and Plano Clark (2011a) highlight five key steps in the design of a mixed methods study due to the inherent complexity of such an approach, which this thesis endeavours to adhere to. Here, a fixed methods design has been used in which inclusion of both qualitative and quantitative measures is predetermined. The complexity of social support and its role in health has been well explored in multiple conditions (Scott et al., 2007), thereby justifying the use of a predetermined design over an exploratory model.

##### 7.3.3.a. Interaction

The level of interaction is defined by Greene (2007) as the extent to which the quantitative and qualitative research strands are intertwined. Greene (2007) states that there are two possible options for relationship; independent and interactive. This thesis uses an independent level of interaction, reflected at the point of interface of the two methodologies. An independent interaction allows for each strand to remain separate until interpretation. As the qualitative research question aims to explain and understand the quantitative results, it was felt that this method best fit the purpose of the qualitative research strand.

##### 7.3.3.b. Priority

Researchers are also required to infer the importance of each strand of research methodology (Creswell & Plano Clark, 2011a). The three studies which comprise this thesis are primarily quantitative, with the qualitative research question aiming to explore the experience of peer support as understood by the participants. This, therefore, best suits a quantitative priority stance, with the qualitative research question taking an explanatory role.

### ***7.3.3.c. Implementation***

Implementation denotes the point at which each strand of data is collected (Creswell & Plano Clark, 2011a). This is reflected in the priority of each methodology. With the primacy of the quantitative approach in mind, sequential data collection was chosen. Participants were firstly approached for the quantitative studies, and then completed qualitative research as follow-up when amenable to this. Participants therefore remain the same across studies, with a smaller subset providing qualitative interpretation. This allowed for recall of quantitative answers provided by that participant, and ask the participant to provide further information on their responses, fulfilling the aim of the qualitative research to explore and illustrate.

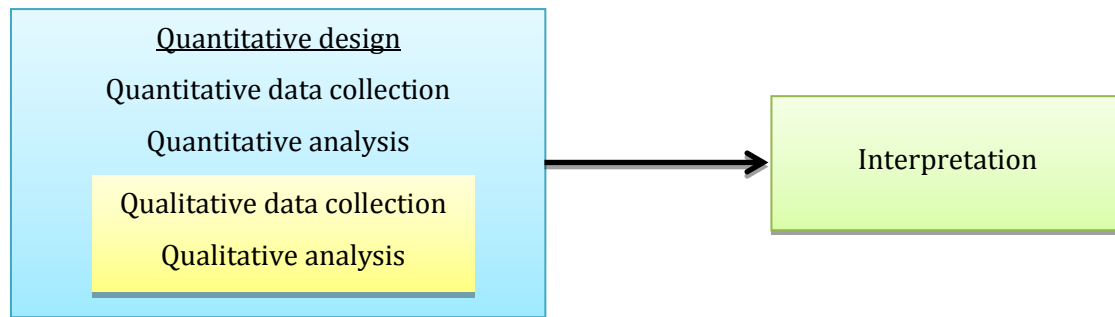
### ***7.3.3.d. Integration***

Integration is the process through which the author combines the data in order to gain understanding from the two research strands (Morse & Niehaus, 2009). The point of interface was chosen as the level of interpretation. The data was therefore collected and analysed separately, with conclusions occurring via the comparison and synthesising of the two strands. This point of interface was selected as it allows the researcher to fully consider and understand each dataset prior to comparison, permitting full interpretation of each individually before they are compared. Other methods have been stated as a 'limiting factor' as categorisation of qualitative findings into a quantitative format often places constraints on the interpretation that is allowed (Bazeley, 2009). This is of particular importance when the qualitative research question is used to explain and explore the quantitative findings.

### ***7.3.3.e. Design***

Reflecting the interaction, priority, implementation and integration strategies of the present thesis is an important consideration in the selection of a mixed methods design. By selecting a typology-based design, an advantageous framework and logic is provided that ensures rigour, persuasiveness and quality (Creswell & Plano Clark, 2011a). Of the typology-based designs that are commonly used in mixed methods research, the embedded design best reflects the aims of this thesis. This design allows primacy of the quantitative research question, with the addition of a supplementary qualitative research question, and is depicted in Figure 17. In an embedded design, this supplemental strand is used by the researcher to enhance the understanding and interpretation of the quantitative study (Creswell & Plano Clark, 2011a). Given the use of the qualitative research question as illustrative and explanatory, an embedded design was chosen to best reflect the dominance of the quantitative work. The embedded design differs from the convergent design in that the purposes for including the secondary data are tied to, but different from, the original research question. This is appropriate for the current approach, wherein the

quantitative data addresses amount of peer support provided, whilst the qualitative research question aims to explore the meaning and experience of peer support.



*Figure 17.* The use of an embedded mixed methods design in the present thesis. Adapted from Creswell and Plano Clark (2011a, p. 70).

In the present thesis, the embedded design is administered in a two-phased approach, reflecting the sequential style of implementation. This design was chosen for feasibility purposes, as quantitative data was to be collected at outpatient clinics. Whilst this enables contact with a high proportion of potential participants, time was also a necessary consideration in order to minimise disruption to hospital appointments. The time and participant inclination for a lengthy qualitative interview in this setting was not appropriate, and therefore a two-phased, sequential design was used in order to minimise the impact of participation, in accordance with ethical procedures (British Psychological Society, 2009). The embedded design is advantageous in the present thesis as the supplemental qualitative research question allows improvement and explanation of the quantitative findings, which is of importance in a multifaceted concept such as social support (Scott & Bisconti, 2013). In addition, it allows for lack of time or resources to extensively commit to both datasets, appropriate for the constraints of doctoral study (Creswell & Plano Clark, 2011a).

Through effective, rigorous use of the aforementioned research design, it is hoped that this thesis will present an in-depth analysis of the role of peer support. This thesis has been planned with methodology at the forefront of consideration, with the hope of designing a thorough, rounded research methodology which may be applied to diverse disease states where a universal view of social support is desired, beyond AWT1D. As found in Section 3.3.4., the reporting of social support in other health conditions prevalent in adolescence was markedly similar, offering credence to this aim. However, with the present thesis in mind, this three-study design, mixed methods approach aims to understand the role of peer support in psychosocial and health outcomes in AWT1D. The practical elements of the data collection process are fully explored in the subsequent chapter, with supplementary information included in the relevant study chapter when required.



## Chapter 8: Quantitative Methods

### 8. Overview

Firstly, an outline of the design of the thesis is provided. In addition, this chapter presents information about the individuals who took part in the research, including details of their recruitment and the inclusion/exclusion criteria on which their selection for research was based. The ethical considerations addressed when carrying out the current research are then presented. Furthermore, it discusses each of the quantitative questionnaire measures employed alongside salivary biomarkers. Finally, this chapter also gives an outline of the overall procedure used and provides information as to the analysis of the biodata.

As outlined in Section 7.3.3.e., a two-phased, sequential approach was implemented for data collection for feasibility and ethical purposes (British Psychological Society, 2009). In order to minimise disruption to both the outpatient clinics and participants, the same participant group was used for all studies outlined in this thesis. Participants were first approached for the quantitative studies, with a smaller subset taking part in the subsequent qualitative study at a later time point. As a result, the practical methods of quantitative data collection remain the same across studies, and can be found here (see Figure 18). Study 3 utilised a group of healthy peers for comparison of social support, and supplemental information regarding their data collection process can be found in Chapter 11, whilst the embedded qualitative research of Study 1 will be outlined in Chapter 9.

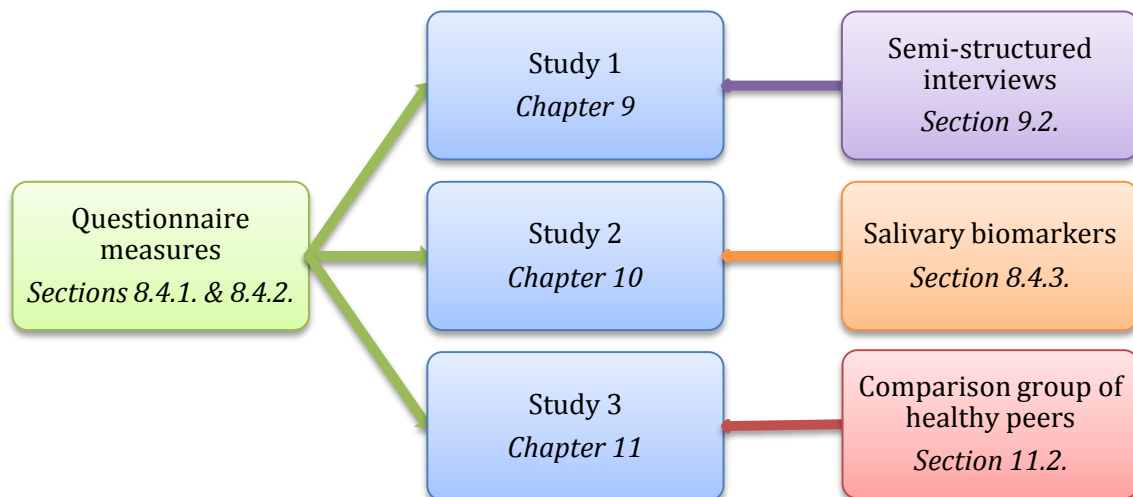


Figure 18. Sources of data for the respective studies within the present thesis.

### 8.1. Design and setting

The quantitative aspects of data collection utilise a cross-sectional research design. In order to ensure a diverse sample, participants were recruited from two general hospitals in the East Midlands of England. These hospitals were located in areas of differing socioeconomic status and ethnic diversity, in two separate NHS Trusts. The participants were recruited via collaboration with the paediatric outpatient clinics located at each site, allowing for the study of a clinical population.

### 8.2. Participants

Participants were aged 15-18, as previous research has indicated older adolescents report qualitatively different social support (Dovey-Pearce et al., 2007; Hanna, Weaver, et al., 2013), QoL (V. M. Wagner et al., 2005) and resilience (Whittemore et al., 2010) than their younger counterparts, or emerging adults. This is the age-group most likely to have re-orientated the support network from one centred around family to peer support, and for which peer influence has become more important in enacting health behaviours (Umberson et al., 2011). The average age of participants was 16.59 ( $SD=.96$ ). Regarding treatment modality, 81 participants used MDI and 10 had CSII pumps for insulin administration.

The inclusion criteria for the research stipulated that participants must have been diagnosed with T1D longer than 18 months ago in order to control for the fluctuations in glycaemic control that typically occur in the first year post-diagnosis (National Institute for Health and Care Excellence, 2015). Female participants must be in the midluteal phase of the menstrual cycle (third-fourth week of the cycle) or on oral contraceptives, due to the fluctuating nature of OT release during the menstrual cycle. Previous research stipulates that in order to minimise the confounding effects of this, research must take place when OT is at its lowest (midluteal phase), or when on oral contraceptives, as this stabilises OT across the menstrual cycle (Bhandari et al., 2014; Kanat, Heinrichs, & Domes, 2013; Pierrehumbert, Torrisi, Ansermet, Borghini, & Halfon, 2012). For the reasons outlined in Section 4.4., potential participants who were parents were also excluded due to the impact this poses on OT (Rollins et al., 2010). Finally, due to the resource constraints of doctoral research, only patients fluent in English were approached for possible participation. Participants must not be diagnosed with other major chronic diseases (including psychiatric diagnosis), cognitive or developmental impairments, and not experienced foster care or residential psychiatric treatment. Previous research has found that each of these interfere with both diabetes care and social support (Wysocki et al., 2000). Patients meeting these criteria were identified by the diabetes care team at each respective outpatient clinic, and therefore not referred in to the study.

An *a priori* sample size calculation was conducted to provide an estimation of how many participants would be required to protect against the possibility of type II error. Using Di Matteo' effect size estimation of  $r=.21$  for unidimensional social support (DiMatteo, 2004a), alpha of .05 and power of .80, as recommended by Cohen (1988), a sample size of 138 was intended for the primary research questions. Through the process outlined above, 91 participants were recruited to the study, 38 male and 53 female. This is significantly below the minimum number to achieve acceptable statistical power, reaching only 64% chance of correctly rejecting the null hypothesis. Therefore, the likelihood of a type II error must be considered when reviewing the results and as such effect size estimations and confidence intervals will be provided for all quantitative findings.

### **8.3. Ethical considerations**

The studies were conducted in accordance with the British Psychological Society and NHS guidelines for ethical research. Ethical approval was received from the University of Northampton ethics committee and the NHS research ethics board (see Appendix A). A detailed account of the ethical considerations of the research can be found in Table 5. During the research, it was essential to be ethically reflexive to ensure that the considerations identified below were continually reviewed and that any potential consequences of participating in the research were minimised.

Table 5. The ethical considerations of the present thesis

Ethical Considerations	Strategies
Informed consent	To achieve informed consent, participants were provided with both written and verbal information (see Appendices B and D) including the purpose and nature of the research. The participants were informed of the aims of the research and the criteria from which they were selected, communicated in a manner reflecting the participant's age. For those aged under 16, this information was also given to parents in order to achieve informed parental consent (see Appendices C and D). Participants and parents provided informed consent with the knowledge that access to the most recent HbA1c result would be provided, but no other data from medical records. Consent, therefore, included disclosure of participation to the diabetes care team so that this information could be securely provided.
Confidentiality	Confidentiality was assured at each stage of the research. All efforts were made throughout the research to remove identifying features from the data. Participants were identifiable only by an ID number allocated at the time of consent. Participants were reminded not to mark questionnaires with their names. Participants were allocated a pseudonym during qualitative transcriptions, which are also used in this thesis. All data generated in the research was coded, and stored on a password-protected computer in a secure office. The participants were informed that the disclosure of information to senior colleagues would only occur if illegal activities were confessed, or their emotional or physical well-being was felt to be compromised.
Psychological Harm	The risks of the research were minimised as far as practically possible and participants were able to withdraw from the research without reason at any given time within the research schedule. The recruitment technique (with clinical support) was designed in order to give a choice to participants as to whether or not they wished to be involved. Comfortable methods of saying no to questions and situations were provided.
Physical Harm	It was not anticipated that participants in the research would reasonably be exposed to potential physical harm. Training was sought in the use of Salivettes® prior to commencement of data collection, with consent provided only with the full tissue sampling procedure in mind.
Right to Withdraw	Participants were reminded of the right to withdraw from the research both prior to and after data collection at each stage. After the conclusion of the research, participants were given a two week "cooling off" period in which they were able to request their data be removed from the study. Participants were made aware that they did not have to provide a reason for withdrawing from the study, and that doing so did not affect their current treatment in any way.
Respect	The wishes, beliefs and ethical views of the participants were respected throughout the research. Discussion of social support has the potential to be an emotional experience and, as such, care and respect for each participant was paramount, particularly during the qualitative interviews. Participants were made aware that emotional or clinical support could not be provided via the research. They would have been provided with the contact numbers of appropriate support organisations should they have requested it, though no participants sought additional support during or after this study.

## 8.4. Materials

The materials provided to participants began with a series of questions designed to capture demographic information, including age and gender, together with more specific information related to T1D, such as treatment modality (i.e. CSII pump or MDI). Subsequent to this, a questionnaire battery was provided. The battery comprised existing psychosocial measures designed to capture participants' global peer support, resilience and QoL, as well as diabetes-specific measures including self-care behaviours and diabetes-specific peer support. The following existing measures were chosen due to their demonstrated high reliability and validity in an adolescent population.

### 8.4.1. Questionnaire measures

The questionnaires used can be separated into two categories; global and diabetes-specific measures. Global measures were required to compare diabetes-specific experiences with normative adolescent experiences, and are utilised in Study 3 to compare to a healthy adolescent participant cohort. Within the AWT1D sample, they also assess the mediating properties of resilience (Whittemore et al., 2010) and QoL (Hilliard et al., 2013) in the relationship between peer support and diabetes outcomes (see Study 1). The target variables assessed by these measures are therefore global peer support (Berlin Social Support Scale), QoL (WHO-5 Well-being Index) and resilience (10-item Resilience Scale).

#### 8.4.1.a. Berlin Social Support Scale

In order to provide comparison between the perceived quality of peer support received independent to that pertinent to T1D, a scale of global peer support was required. The emotional and instrumental aspects of the Berlin Social Support Scale (BSSS; Schulz & Schwarzer, 2003) was chosen, due to its widespread use in studies with healthy participants, individuals with chronic illness and in adolescents (Pinquart & Pfeiffer, 2011). In addition, reliability scores of the perceived social support section of the scale are high, with Schulz & Schwarzer (2003b) reporting a Cronbach's  $\alpha$  of .85, well above the .70 threshold of acceptability (Nunnally, 1978) but below the .90 limit stated as indicating item redundancy (Boyle, 1991).

The perceived support sections of the BSSS consist of eight items assessing availability of emotional and instrumental support. Items include *"There are some people who truly like me"* and *"There are people who offer me help when I need it"*. A four-point Likert scale is used to indicate agreement to the items, ranging from strongly disagree (1) to strongly agree (4) (see Appendix F). The emotional and instrumental items are typically found to load onto a common factor and have highly correlated subscales (U. Schulz & Schwarzer, 2003b) so the sum of perceived availability of support is used as a total score. In the present study, Cronbach's  $\alpha$  for the total scale was .89. As the facets of peer support measured by the BSSS are assessed as

separate variables, it is additionally important to consider the reliability of the subscales. As such, the emotional support subscale of the BSSS received an alpha of  $\alpha=.83$ , and the instrumental subscale  $\alpha=.88$ .

Although not exclusively related to peers, participants were instructed to only include perceptions regarding peer support in their responses to the BSSS. The possibility of participants failing to adhere to this instruction is discussed as a potential limitation in the relevant study chapters.

#### **8.4.1.b. WHO-5 Well-being Index**

Recent research by Hilliard and colleagues (2013) indicates that general QoL may function as a mediator of treatment outcome and self-care behaviours, intrinsically linked to social support. Thus, it was important to consider in the present thesis. In addition, as QoL is a life experience-based concept, it serves as a measure of happiness and satisfaction outside of T1D, allowing for comparison to other groups, essential for Study 3 (Pollard & Lee, 2003). Two well recognised instruments were considered, namely the QoL measure developed by the WHO (WHOQoL; World Health Organisation, 1998a) and the WHO-5 well-being scale (WHO-5; World Health Organisation, 1998b). The decision to use the WHO-5 instrument was made based on feedback from subject experts in T1D, in addition to recent research indicating the use of the WHO-5 as a possible measure of depression (Hochberg, Pucheu, Kleinebreil, Halimi, & Fructuoso-Voisin, 2012; Krieger et al., 2014). Given the commonly found association between depression and diabetes (W. Gillibrand & Holdrich, 2010; K. A. Reynolds & Helgeson, 2011) it was felt that this measure would be advantageous for participants by eliminating the need for an additional depression screening scale. In addition, this scale has been validated for use in AWT1D, with a Cronbach's  $\alpha$  score of .82 (De Wit, Pouwer, Gemke, Delemarre-Van De Waal, & Snoek, 2007).

The WHO-5 consists of five statements regarding the participants' feelings over the preceding two weeks. Item examples include "*I have felt cheerful and in good spirits*" and "*My daily life has been filled with things that interest me.*" Items are rated on a six point scale from all of the time (5) to at no time (0), with that raw score totalled to a range of 0-25 (see Appendix G). The WHO states that a total score of 0 represents the worst possible and 25 represents the best possible well-being. In the current research, a reliability score of  $\alpha = .82$ .

#### **8.4.1.c. 10 Item Resilience Scale**

Resilience has been found to be of particular relevance in diabetes outcomes, with AWT1D found to be at greater risk of poor glycaemic control and self-care when stressed; a risk not found to be present when high in resilience (Yi-Frazier et al., 2010). Social support has also been indicated as a precursor for resilience in response to a diagnosis of T1D and greater adjustment

(Whittemore et al., 2010), and therefore provides a potential indirect mechanism for the relationship between social support and diabetes outcomes.

A methodological review of resilience measures found that only adult-designed scales produced high quality assessment scores (Windle, Bennett, & Noyes, 2011). Therefore, the adult 10 Item Resilience Scale (CD-RISC 10; Campbell-Sills & Stein, 2007) was selected, as it was found in the review to be one of the few highly valid, reliable resilience scales ( $\alpha=.85$ ) (see Appendix H). In addition, the CD-RISC 10 is widely used in adolescents (Rosenberg et al., 2015), despite being designed for adult populations.

The CDRISC-10 is a 10 item measure consisting of items such as *"I am able to adapt when changes occur"* and *"Under pressure, I stay focused and think clearly"* and relates specifically to the previous month. These statements are scored on a five point Likert scale rating from not true at all (0) to true nearly all the time (4), with a higher total score representing a higher level of resilience. A Cronbach's alpha of  $\alpha = .83$  was found in the present thesis.

Alongside global measures applied to both clinical and healthy samples, ones which directly assess the impact of T1D were also utilised. These measures provide a picture of the specific disease-related behaviours engaged in by AWT1D, in the hope that precisely where peer support is required can be pinpointed, together with any potential effect on health and psychosocial outcomes. The target variables assessed by the diabetes-specific measure include diabetes-specific peer support (DSSQ-Friends; Diabetes Social Support Questionnaire – Friends Version). The remaining two diabetes-specific variables serve as outcome measures; self-care (SCI-R: Self-Care Inventory – Revised Version) and glycaemic control (HbA<sub>1c</sub>; glycated haemoglobin).

#### ***8.4.1.d. Diabetes Social Support Questionnaire – Friends Version***

Diabetes-specific support differs from global social support in that it encompasses behaviours explicitly targeted at improving and easing self-care (Palladino & Helgeson, 2012). Research findings of diabetes-specific support are mixed, with studies indicating that this type of support improves (Kyngäs, 2000; La Greca et al., 2002), decreases (Hains et al., 2007; Palladino & Helgeson, 2012; Thomas et al., 1997), and has no impact on self-care (Greco et al., 2001; Naar-King et al., 2006; Pendley et al., 2002). It is therefore likely that individual differences occur within samples as to the usefulness of diabetes-specific support (Heleno et al., 2009), resulting in it being an essential factor to assess in the present clinical sample.

Seven measures of diabetes-specific support for use in AWT1D currently exist, only one of which takes into account peer-support, reflecting the dominance of family support research within the field (Hanna, 2006). The Diabetes Social Support Questionnaire – Friends Version (DSSQ-Friends; Bearman & La Greca, 2002) specifically assesses perceived and enacted

diabetes-specific support behaviours provided by peers. The measure is widely used in research in this area, perhaps due to its uniqueness in the field, but this has allowed for it to be successfully validated (Hanna, 2006). In addition, the scale has been found to be highly reliable ( $\alpha = .94$ ) (Bearman & La Greca, 2002). This is well above the threshold for acceptability (Nunnally, 1978), but may have redundant items (Boyle, 1991). However, it must be considered that this measure was developed prior to the DAFNE study (DAFNE Study Group, 2002) which introduced the STTP or “carb-counting” approach to dietary management in diabetes care (Shearer et al., 2004). As such, many of the items present in the DSSQ-Friends are now redundant under current NICE Guidance (National Institute for Health and Care Excellence, 2015). When items relating to prescriptive eating habits are removed, the reliability of the scale is reduced to  $\alpha=.76$ , indicating a reliable scale (Nunnally, 1978) without the possibility of item redundancy (Boyle, 1991). As with the BSSS, because the subscales of the DSSQ-Friends are to be analysed as separate variables, the reliability of the sub-scales are as follows. *Insulin Shots* has a Cronbach’s alpha of  $\alpha=.67$ , *Blood Testing*  $\alpha=.85$ , *Exercise*  $\alpha=.89$  and *General Items*  $\alpha=.88$ .

The original DSSQ-Friends (see Appendix I) is a 28 item-scale covering support behaviours including aiding insulin delivery, glucose monitoring, diet, exercise and diabetes-specific emotional support. With the removal of items relating to diet, the scale is reduced to 16 items. Each item has two parts. Participants are first asked to rate the frequency of the support behaviour from “*never*” to “*daily*” scored on a Likert scale from 0-5 accordingly, and then to rate how supportive that specific behaviour is from “*not supportive*” to “*very supportive*” scored from -1 to 3. Items include “*How often do your friends watch you for signs that your blood sugar is low?*” and “*How does this make you feel?*” The scoring of the DSSQ-Friends requires calculating a combined score for each item, taking into account both the frequency and supportiveness of behaviours, creating an item score ranging from -5 (an unsupportive behaviour occurring infrequently) to 15 (a highly supportive behaviour often perceived). An average score is then calculated for each specific behaviour type, with the total score a sum of these averages. It is considered that the higher the total score, the greater the level of support perceived (Bearman & La Greca, 2002).

#### **8.4.2. Outcome measures**

##### ***8.4.2.a. Self-Care Inventory – Revised Version***

Successful engagement with a care plan has been found to be the greatest predictor of diabetes outcomes (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2005). Due to the complex nature of effective self-care (Barnard et al., 2012), a measure of engagement with these behaviours was required. Use of this measure allows for assessment of how and where peer support may influence specific health behaviours, impacting a change in health outcomes.



Several scales were considered for the assessment of self-care. Of those questionnaires which have been validated in an AWT1D population, the Diabetes Behaviour Rating Scale (DBRS; McNabb, Quinn, Murphy, Thorp, & Cook, 1994), Summary of Diabetes Self-Care Activities (SDSCA; Toobert, Hampson, & Glasgow, 2000) and Self-Care Inventory-Revised Version (SCI-R; Weinger, Butler, Welch, & La Greca, 2005) were considered. A review of self-care measures in AWT1D indicated that the SDSCA did not cover collaborative self-care (Schilling, Grey, & Knafl, 2002). Given the focus of peer support in the present study, it was thus eliminated from consideration. This review indicated strong similarities between the SCI and DBRS in terms of their validity, reliability, complexity and correlation with other health outcomes (Schilling et al., 2002). As such, the SCI-R was considered favourable in the name of parsimony, with 15 items in comparison to the 36 items of the DBRS. Research has also indicated a stronger relationship between the SCI-R and glycated haemoglobin than other self-care measures (Kichler, Kaugars, Maglio, & Alemzadeh, 2012).

The SCI-R (see Appendix J) is an updated version of the Self-Care Inventory (La Greca, Swales, Klemp, & Madigan, 1988). Unlike the aforementioned self-care scales, the SCI has been updated to reflect changes in diabetes care guidance, creating the SCI-R (Weinger et al., 2005). The SCI-R is a 15-item scale assessing blood glucose regulation, insulin administration, dietary consideration, exercise, and emergency precautions (La Greca, 2004). Unlike the DSSQ-Friends, the SCI-R items regarding diet consider the recommendations of the DAFNE study and reflect current NICE guidance, concerning items such as “*eat the correct food portions*” and “*read food labels*”, all of which are considered part of the STTP model (Shearer et al., 2004), and so remain in the analysis. The scale requires respondents to estimate frequency of engagement with specific self-care behaviours over the previous two months. Items are rated on a 5-point Likert scale ranging from “*never*” (1) to “*always*” (5). To create a total score, items are averaged and converted to lie on a 0-100 point scale. It is considered that the higher the total score, the greater the self-care (Weinger et al., 2005). A satisfactory Cronbach’s alpha was achieved with the current participant sample ( $\alpha = .72$ ).

#### **8.4.2.b. Glycated Haemoglobin**

Due to the widely-acknowledged problems with reliance on self-report measures, including issues such as response bias and demand characteristics (Prince et al., 2008), an objective measure of engagement with self-care was required to validate responses to the SCI-R. In addition, use of a biological health outcome variable allows the application of results from a clinical perspective, as well as behavioural. Thus, a measure of glycated haemoglobin (HbA<sub>1c</sub>, see Section 5.5.) was provided to assess glycaemic control over the preceding 2-3 months.

Currently, NICE recommend an HbA<sub>1c</sub> of 48mmol/mol (National Institute for Health and Care Excellence, 2015) as an indicator of good glycaemic control, with an increasing HbA<sub>1c</sub> indicating worsening control. However, the most recent National Diabetes Audit states that only 35.2% of people with T1D in England achieve this target, with 17% of people with an “exceptionally high” HbA<sub>1c</sub> of 85mmol/mol or above (National Diabetes Audit, 2014). Indeed, in the present study, the average HbA<sub>1c</sub> result was 72mmol/mol, reflecting the current state of self-care.

#### **8.4.3. Salivary biomarkers**

Although some concerns have been raised regarding the limitations of measurement of hormones in saliva over plasma, particularly regarding OT (McCullough, Churchland, & Mendez, 2013), and the use of cotton-based collection methods including Salivettes® (Shirtcliff & Granger, 2001), it was considered the most advantageous option here. Salivary collection of hormones has multitudinous advantages over plasma, given that it is non-invasive, less stressful and more acceptable to participants. As such, it is the standard method for collection of all hormones in behavioural endocrinology and psychology for ethical, methodological and participant recruitment reasons (Schultheiss & Stanton, 2009). In addition, research has indicated that plain cotton-based saliva collection methods, such as the ones used in the present thesis, have minimal impact on the hormones in question (OT & cortisol; Gallagher, Leitch, Massey, McAllister-Williams, & Young, 2006; Wong et al., 2008). Given the participant preference for cotton-based devices over passive drool methods, due to a perception of unpleasantness and embarrassment (Bosch, Veerman, de Geus, & Proctor, 2011), Salivettes® were selected to aid participant recruitment.

Due to the diurnal cortisol curve (Fries, Dettenborn, & Kirschbaum, 2009) it was essential to minimise the confounding variable of naturally fluctuating cortisol throughout the day. Whilst it was impractical to ensure data collection at the identical time since waking for all participants, minimisation of natural variation in cortisol was achieved via the exclusive inclusion of morning outpatient clinics. Thereby, all participants will have been within a similar phase of the circadian rhythm, minimising variation due to the cortisol awakening response.

#### **8.5. Procedure**

The diabetes care teams at paediatric outpatient clinics in the East Midlands were contacted, with two hospitals able to recommend suitable patients to the study. Patients conforming to the inclusion criteria were provided with an information sheet (see Appendix B) by a member of the diabetes care team, most frequently the diabetes nurse, at their regularly scheduled clinic appointment. If potential participants displayed interest in taking part, the diabetes nurse referred them to the researcher in a private room. They were then provided with verbal

information regarding the study and allowed to ask any questions they had regarding the research. This information included the questionnaire, biomarker and qualitative aspects of the research. Participants were provided with a consent form (see Appendix D), and required to return it within one week should they wish to take part. This procedure included additional parental information (see Appendix C) and consent (see Appendix E) if the participant was aged under 16, in accordance with NHS guidance (General Medical Council, 2013).

All participants who chose to consent did so during the initial meeting at the hospital, and thus all data collection took place at the outpatient clinics. Participants were first given the opportunity to ask any questions regarding the research and reminded of their right to withdraw.

Firstly, participants were asked to provide a saliva sample. Participants were required to thoroughly rinse their mouth and lips with water to remove food and cosmetic residue. Participants were provided with two Salivettes®, one for each biomarker, and asked to chew each for 120 seconds, one immediately after the other, in accordance with the guidance given by the manufacturer and detailed by Carter (2007). Participants were then asked to complete a number of quantitative questionnaires (see Section 8.4.). The researcher left the room during this time to minimise demand characteristics, and returned after all questionnaires were completed.

Once finished, participants were thanked for taking part and informed that if they wished to withdraw from the research, they must make contact within two weeks from the date of participation, after which all data was anonymised. After this point specific data files could not be distinguished and removed from the research. Those expressing interest in the follow-up qualitative study were provided with a letter inviting them to participate, requiring additional consent (see Appendix L). Procedures for the qualitative data collection are fully outlined in the pertinent study chapter (see Section 9.2.3.).

Post-participation, the diabetes care team at the respective outpatient clinic was informed, who then provided the participants' most recent HbA<sub>1c</sub> result through the NHS SecureSend service. These details were kept in anonymised form through the participants' ID code on a password-protected computer in a secure office.

#### **8.5.1. Procedures for analysis of biomarkers**

Once collected (see Section 8.5.), the Salivettes® were transported to the laboratory in a cool box, where they were centrifuged at 4°C, 4000rpm for 5 minutes (Jouan CR3i Centrifuge, T40 rotor). This removes cells and aids in the preservation of the sample (Bosch et al., 2011). Samples were then transferred to Eppendorf tubes® and were stored at -20°C until a batch assay procedure could be used, as recommended by Bhandari *et al.* (2014). This procedure minimises the influence of external, potentially confounding variables. Samples were only

subjected to one freeze/thaw cycle to preserve their quality; repeated freezing/thawing has been found to degrade cells and enzymes necessary for effective use of immunoassays (Bosch et al., 2011).

Once all samples had been collected, extraction was performed to concentrate the sample and increase the precision of measurement. The samples were transferred to a lyophilizer (Christ Alpha 1-4 LSC Freeze Dryer) where they were freeze-dried at -40°C with a vacuum for 24 hours. Samples were assayed using Enzyme Immuno Assay (EIA) kits (OT: ADI-900-153, ENZO Life Sciences, Cortisol: ADI-900-071, ENZO Life Sciences; (Bhandari et al., 2014; Cohn et al., 2013; Grewen et al., 2005; Holt-Lunstad et al., 2008; van Ijzendoorn, Bhandari, van der Veen, Grewen, & Bakermans-Kranenburg, 2012). Prior to performing the assay, the freeze-dried residues were reconstituted in 250µl of the relevant assay buffer. Measures were performed in duplicate as recommended by the ELISA manufacturer and publications (Carter et al., 2007).

The manufacturer's procedures for analysis were followed in each case for OT (ENZO Life Sciences, 2015b) and cortisol (ENZO Life Sciences, 2015a), respectively. For OT, diluted standards were prepared and reconstituted samples were mixed with conjugate and antibody in a 96-well plate. The plate was then incubated at 4°C overnight. Excess reagents were removed and the bound OT was incubated at 4°C with a substrate for 1 hour for enzyme reaction, producing a yellow colour. The reaction was then stopped and the optical density of the colour was measured using a Bio Rad 680 XR plate reader. Precise OT levels were calculated using an immunoassay software package utilizing a 4 parameter logistic (4PL) curve fitting program (see Appendix M; My Assays, 2015).

Diluted cortisol standards were prepared in accordance with manufacturer's instructions (ENZO Life Sciences, 2015b) and pipetted into a 96-well plate. 100µl of reconstituted samples were pipetted into the appropriate wells and mixed with conjugate and antibody. The plate was covered and incubated at room temperature on a plate shaker for 2 hours at ~500rpm using the Bio Rad 680 XR plate reader. The reagents were then removed and bound cortisol was incubated with substrate for 1 hour at room temperature, without use of a plate shaker. The reaction with then ceased and the plate was read immediately, with the plate reader blanked against the assigned wells. As with OT, a 4PL curve fitting program (My Assays, 2015) was used to calculate precise cortisol levels (see Appendix N).

## **8.6. Summary of Chapter 8**

Through these methods, the quantitative data which contributes to all three studies comprising this thesis were collected. Additional data was collected for Study 1 (Chapter 9; semi-structured interviews) and Study 3 (Chapter 11; a healthy peer comparison group), with the specific

methods used outlined in their respective sections. The analysis, results and discussion of these studies can be found in the subsequent chapters.

## Chapter 9: Study 1

### *“They think it’s helpful, but it’s not”*: The experience of peer support in adolescents with type 1 diabetes

#### 9. Overview

This chapter discusses the first study carried out as part of the current doctoral research. This study was designed and implemented to explore and better understand the relationship between peer support and both psychosocial and health outcomes in AWT1D. A mixed methods design was used to provide a holistic approach to this multidimensional construct, and seeks to provide illumination of the disagreement between quantitative and qualitative data in the literature. The first part of this chapter defines the rationale behind Study 1 and, based on this, a number of hypotheses are formed, in conjunction with a qualitative research question. The qualitative methodology is then discussed, expanding on the quantitative information provided in Chapter 8. The findings of Study 1 are then presented and discussed. Due to the embedded nature of the qualitative research question, the quantitative data takes priority, with qualitative findings used to illuminate and explain the statistical analysis. Finally, the limitations and clinical implications of these findings are summarised.

#### 9.1. Introduction

The role played by peer support in health outcomes in AWT1D remains decidedly ambiguous. As outlined in Section 3.3.3.c, whilst qualitative studies have found that adolescents assert an influence of peers in their self-care (Dovey-Pearce & Christie, 2013; Hinder & Greenhalgh, 2012), quantitative evidence is unclear, suggesting differing impact of global peer support and diabetes-specific support (Palladino & Helgeson, 2012). The research into peer support and health outcomes in AWT1D is, therefore, inconclusive. Equal numbers of studies have found that diabetes-specific support is both positive and negative (Palladino & Helgeson, 2012), whilst significant findings point to a beneficial aspect of emotional global support in self-care (Helgeson, Lopez, et al., 2009; T. C. Skinner, Hampson, John, & Hampson, 1998; T. C. Skinner, John, & Hampson, 2000). Due to the mixed findings, conclusions cannot be convincingly drawn as to the impact of peer support, leading the way for further in-depth investigation, such as the present study. It is suggested in Section 3.3.3.c that possible explanations for this lack of consensus can be found in variation in adopted methodologies and use of measurement tools. As such, a single cohort mixed methods approach is utilised here.

Whilst it is clear that an association between peer support and diabetes outcomes exists, be it positive or negative, the mechanism through which this relationship operates remains undiscovered. The potential mediating role of additional psychosocial variables is outlined in Chapter 6. Well-being and QoL have been found to be highly related to health outcomes in AWT1D (Hassan et al., 2006; J. Lawrence et al., 2012; Matziou et al., 2011; Valenzuela et al.,

2006). As outlined in Section 6.3., Hilliard and colleagues (2013) went on to suggest that poor QoL acts as a barrier to accessing factors known to enhance self-care, including social support. Hilliard *et al.* (2013) suggest that this relationship is bidirectional; that medical and psychosocial influences impact on QoL, as in turn QoL influences self-care behaviours and glycaemic control. Further research is needed to confirm these suppositions, such that QoL may be considered as a target for intervention should it be revealed as a mediator of the relationship between peer support and outcome variables. As such, it is an important variable to consider in the present study.

A further variable of interest is suggested in Section 6.5.; resilience. Whilst poor QoL may be the lens through which social support is accessed (Hilliard *et al.*, 2013), resilience is seen as a potential psychosocial mechanism through which support behaviours perceived as beneficial enact their influence. In a model posited by Whittemore and colleagues (2010), later updated by Hilliard *et al.* (2012), a recursive model of resilience is presented in which a host of psychosocial variables, including social support and QoL, interact with demographic, medical and family characteristics to produce resilience. Resilience is then seen as a moderator of disease acceptance and adaptation; a key factor in engagement with self-care (Yi *et al.*, 2008). Social support is, therefore, seen as one of many contributory factors which together create resiliency, and thereby improve health outcomes (Whittemore *et al.*, 2010). The assumption has yet to be empirically validated in AWT1D, and thus as a potential mediator of the relationship between peer support and diabetes outcomes, is an essential variable for consideration in the present study.

Peer support, QoL and resilience, therefore, can be seen as potentially contributory factors towards self-care and glycaemic control, and should be considered as inter-related concepts. This study, therefore will address each of these variables quantitatively, and present these alongside qualitative explanations of peer support with the aim of determining if peer support is related to health outcomes in the present participant group, and if so, posit potential mediators of this relationship.

What is particularly intriguing is the difference between qualitative and quantitative findings in previous research. Whilst adolescents have qualitatively reported a request for additional instrumental support (Lehmkuhl *et al.*, 2009), the quantitative findings suggest that this is not positively received when it is provided (Hains *et al.*, 2007; Helgeson, Reynolds, *et al.*, 2007; Helgeson, Siminerio, *et al.*, 2009; Thomas *et al.*, 1997). It is possible that this may be due to individual differences existing in the studied groups; that there is a fundamental personal difference between those requesting additional support and those rejecting it when it is provided. It is suggested that an explanation for this discrepancy lies in the individualised nature of the experience of social support (Lourel *et al.*, 2013) making comparison across

samples problematic. It was therefore determined that a single cohort mixed methods approach may best account for variation between groups in the utility and experience of peer support (see Section 3.3.3.c.).

#### **9.1.1. Aims and objectives**

This study seeks to explore the potential relationship between peer support and diabetes outcomes in AWT1D, in response to the inconclusive findings of previous research. Findings have suggested that peer support may hold both a positive and negative association with health outcomes, and as such this study aims to address how the well-intentioned, supportive behaviours of peers may be accepted or misconstrued by the receiver. The objectives of the present study are, therefore:

1. To identify relationships between peer support and diabetes outcomes. *Hypothesis 1.*
2. To identify any variation between peer support and diabetes outcomes dependent on the type of support provided. *Hypotheses 1 and 2.*
3. To determine whether or not these relationships differ according to the level of glycaemic control present in participants. *Hypothesis 3.*
4. To assess the accuracy of the mechanisms of social support proposed by Hilliard *et al.* (QoL; 2013) and Whittemore *et al.* (resilience; 2010). *Hypotheses 1, 2, 4 and 5.*
5. To explore these relationships using a mixed methods approach. *Qualitative research question.*

#### **9.1.2. Hypotheses**

Due to the findings of previous research, it is hypothesised that:

##### **9.1.2.a Hypothesis 1: Global peer support**

- i. Global peer support will be positively associated with self-care, but not glycaemic control.
- ii. That emotional support will have a stronger relationship with self-care than instrumental support.

##### **9.1.2.b. Hypothesis 2: Diabetes-specific support**

- i. A relationship between diabetes-specific support and self-care will be found, though a direction cannot be determined from previous literature.
- ii. A relationship between diabetes-specific support and glycaemic control will be found, though a direction cannot be determined from previous literature.



### **9.1.2.c. Hypothesis 3: Glycaemic control**

- i. Those with better glycaemic control (below average HbA1c) will report higher QoL and resilience.
- ii. Social support will differ, though a direction cannot be determined from previous literature.

### **9.1.2.d. Hypothesis 4: Quality of Life**

Quality of life mediates the relationship between social support and diabetes outcomes.

### **9.1.2.e. Hypothesis 5: Resilience**

Resilience mediates the relationship between social support and diabetes outcomes.

### **9.1.3. Qualitative research question**

Due to the embedded nature of the mixed methods design (see Section 7.4.3.), the qualitative research question is exploratory in nature. The qualitative research question is illustrative and explanatory of the quantitative findings, and as such is “what is the meaning and experience of peer support in AWT1D?”

## **9.2. Method**

The research mechanisms underpinning this approach are outlined in Section 7.4. The methods of quantitative data collection have been outlined in depth in the previous chapter. As such, this section will focus on the qualitative methodology.

Semi-structured interviews were selected, as this method allows the researcher and respondent more flexibility than a conventional structured interview (Creswell & Plano Clark, 2011a; J. A. Smith, 1995). As this stream of research is exploratory, it was felt that this was vital to allow free expression of new information. Semi-structured interviews allow for exploration of complex experience reduced and simplified by quantitative methods, and permit a more complete understanding of experience whilst allowing for pre-determined lines of enquiry (M. Patton, 2002).

### **9.2.1. Participants**

After completion of the quantitative data (see Chapter 8), participants were invited to take part in the qualitative aspect of the research. Due to time constraints and the in-depth nature of qualitative interviewing, it was expected that not all participants would wish to consent to both streams of the mixed methods research. Twelve of the original 91 participants elected to be interviewed, outlined in Table 6. In the name of anonymity, participants were allocated a pseudonym, used in Table 6 and throughout this thesis. Recruitment for the qualitative research stream continued until data saturation was reached and no new themes were achieved during the interview process, as recommended by Smith (1995). Data saturation was suspected at ten participants, and confirmed in a further two interviews.

Table 6. *Qualitative participant demographic information and short biography.*

Participant	Age	Insulin	Short biography
Philip	17	CSII Pump	Philip has had T1D since he was 4 years old and reported having held responsibility for his care for some time. He takes pride in having excellent control of his diabetes, even apologising for having recently been ill and therefore reporting a “worse than usual” HbA <sub>1c</sub> of 55mmol/mol. Philip wished to study engineering at a top university, and was in preparation for his A level exams at the time of interview. He plays rugby and cricket in his spare time, citing this as his main reason for requesting pump over MDI therapy.
Lewis	16	MDI	Lewis was adopted at the age of 5 into his family. Coincidentally, his adopted mother also has T1D and expressed surprise when Lewis was diagnosed at 14. Lewis is shy and took time to open up during interview. He enjoys playing football, and expressed frustration when he felt his diabetes prevented him from “being normal.” He was the only participant who expressed a desire to have a companion present during interview, and thus his mother was in attendance. The interview therefore became more of a three-way focus, as Lewis’ mother (Angela) contributed to his narrative.
Nathan	15	MDI	Nathan is very mature for his age. He was very funny during the interview, and frequently made jokes both about his diabetes and in general. He is the only member of his immediate family with T1D, though his grandmother had also had T1D before she passed away. Nathan enjoyed spending time with his friends, typically spending a few hours at a friend’s house after school before returning home. He enjoyed playing computer games and football, and admitted to having a sweet tooth he frequently indulged without his mother’s knowledge.
Paul	15	MDI	Paul had not long been diagnosed with T1D, having only recently complied with the inclusion criteria of 18 months post diagnosis. He was quiet during the interview, and took some time to relax. His parents had expressed concern about his adjustment to his diagnosis, whilst Paul himself stated that he was frustrated by his parents’ level of involvement in his care. Paul disclosed that he had few friends at school and frequently felt lonely. He expressed that he felt as if his diabetes had worsened this situation, marking him out as different.
Panvi	15	MDI	Panvi’s diagnosis did not come as a shock to his family. Diagnosed 2 years ago, he has a brother, father and grandmother, all of whom had been diagnosed at a similar age. He expressed acceptance of his T1D, stating that he knew so many people in his family and community with T1D that it did not appear unusual. His family already considered T1D in their activities and meals due to its prevalence in the household and as such he believed he had already lived a “diabetic life” before his diagnosis. Panvi is aspiring to be a doctor, so that he may further treatment opportunities and influence the care of others with T1D.
Catherine	18	MDI	Catherine is very interested in biology, initiating her desire to be included in this study. She is very ambitious and had aspirations to attend a top class university at the time of interview, though wished to stay at home so that she may continue to have parental support for her self-care. Catherine’s diagnoses of T1D had been traumatic. She had suffered a coma brought on by severe diabetic ketoacidosis, and since recovering had suffered significant memory loss. She relied on her diaries to remind her of her past, and on her mother for practical reminders. As such, she was still limited in terms of the responsibility she took for her self-care.

Charlotte	17	MDI	Charlotte is outgoing, funny and honest. She expressed her thoughts and opinions in an unguarded, direct way. She had never fully adjusted to her diagnosis, and admitted herself to being in denial. Her control was poor, with HbA <sub>1c</sub> of 89mmo/mol. Her father also has T1D, and had recently had his foot amputated as a result of complications. He used himself as an example to her, stating that she should be dissuaded from poor self-care by being directly exposed to the consequences of such behaviours. Charlotte, however, was very determined to live life with her T1D taking a backseat.
Jessa	16	MDI	Jessa is extraverted, straight-talking and witty, describing herself as a “handful” at school. Her father and younger brother also have T1D, and she felt very much at ease with her diabetes. Her adjustment and coping were excellent. She espoused a philosophy of flexibility, instilled in her by her parents, in which she felt she could truly be “normal” as long as she managed her T1D efficiently. She plays basketball in her spare time and was applying to Sixth Form Colleges at the time of interview.
Isabelle	16	MDI	Isabelle was three when she was diagnosed with T1D. Her mother is a nurse, and as such had grown up with a care routine strictly adhering to the guidance. Now beginning to take responsibility for her own care, Isabelle expressed some resentment about the strict routine. She has school friends also with T1D, and stated that she believed they were allowed to be far more relaxed in their self-care. Isabelle plays guitar and enjoyed music, playing in a band in her spare time.
Puja	15	MDI	Puja is assertive and academic. She aspires to be a lawyer, and believes that she should not let her T1D “get in her way.” She is fiercely ambitious. She believes herself to have few friends at school, and spends most of her spare time reading. Having been diagnosed at 11, she stated that she was always autonomous in her care. However, her self-reported self-care rating of 66 was at odds with her HbA <sub>1c</sub> of 80mmol/mol.
Idimma	15	MDI	Idimma is spirited and egocentric. She disclosed her attitude towards her T1D was poor, corroborated by her HbA <sub>1c</sub> of 108mmol/mol. As a result of her neglect of self-care, she received additional support from the diabetes care team at her outpatient clinic. She resented this additional attention openly, and stated that she hoped her taking part in this study would be seen as evidence of improved engagement by the care team. Popular at school, Idimma enjoys spending time with friends and shopping in her spare time.
Claire	15	MDI	Claire had been diagnosed with T1D at the age of 9. Approaching her 16 <sup>th</sup> birthday, Claire was beginning the process of transferring to adult services at the clinic, an early decision due to her excellent self-care (46mmol/mol). Claire is the only member of her family with T1D, and disclosed that she felt a responsibility to achieve and maintain excellent self-care so that family life may continue as normal, as much as possible. Shy and diligent, she has a small circle of close friends. She enjoys reading and art in her spare time.

### 9.2.2. Interview Schedule

Considering the embedded nature of the qualitative research question, an interview schedule which complemented the quantitative questionnaires was considered essential. As such, the Diabetes Social Support Interview (DSSI; La Greca et al., 1995) was selected. In addition to being considered highly reliable, valid, and widely-used (Malik & Koot, 2011), the interview schedule was used by the research team in their design of the DSSQ-Friends (see Section 8.4.2.a.), and so together should create a coherent narrative of peer support.

The DSSI (see Appendix K) consists of 10 questions, such as *“in what ways do your friends help you to feel good about your diabetes?”* and *“in what way do your friends help you or provide support for glucose testing?”* The interview schedule consists of the same set of questions for family and friends. Despite the focus of the current study being peer-support, it was felt that by keeping the family questions present, a more holistic view of the support network and the support provided would be gained, so that differences may be identified in their operation and utility. In addition, these questions served to validate the assumption that older adolescents no longer rely on family members for support.

### 9.2.3. Procedure

Once the quantitative data collection process had been completed (see Section 8.5.), participants were reminded of the possibility of taking part in a follow-up interview. If this was amenable, the contact details of participants were noted and they were provided with an invitation to participate requiring further consent for the qualitative study (see Appendix L). This enabled participants a comfortable way of declining participation, both in person and then again in written form. Those who responded positively were contacted using their preferred method (most chose email) to arrange a mutually convenient time and location for participation to take place.

The location and timing of the semi-structured interview was determined by participants to maximise their comfort and free expression. If the participant wished, they were able to select a parent or companion to be present during the interview. All but one of the participants chose to be interviewed without the presence of a parent or companion, and all but one was interviewed in their home in order to minimise disruption to their routine and maximise participant comfort. The interview schedule was memorised in advance to allow full appreciation of the participants' replies, as recommended by Smith (1995).

Participants were invited to re-read the information sheet initially provided to them during the quantitative study should they wish, and were able to ask questions regarding the study. They were assured of their anonymity and informed that they may withdraw at any time until the anonymisation of their data, which occurred two weeks after interview. Participants

were assured that all names would be pseudonymised and place names removed from transcripts to guarantee their anonymity. Each participant was asked to provide additional consent to that offered earlier. Interview audio was recorded on a Dictaphone. The interviews were transcribed by the same researcher to maintain anonymity, and the transcripts kept in a secure office on a password-protected computer.

#### 9.2.4. Analytic framework

One of the key debates in mixed methods research is the use of theory. Due to the paradigm differences between the quantitative and qualitative perspectives, the combination of their results can prove problematic (Tashakkori & Teddlie, 2003). One of the reasons for this is the use of a theoretical standpoint adopted by most analytic frameworks in qualitative study (Creswell & Plano Clark, 2011b). Even within pragmatic research such as the present thesis, the issues of reconciling theoretical standpoints of quantitative and qualitative analysis are problematic (Giddings, 2006; Holes, 2006). As such, a theoretically neutral analytical framework is adopted here, to ease the amalgamation and interpretation of the results. Thematic Analysis is considered a highly flexible, popular, theoretically neutral framework, following a systematised process (Braun & Clarke, 2006), and so was chosen for the current analysis.

Braun and Clarke (2006) recommend a six phase procedure when using Thematic Analysis, which was adhered to. The approach utilises an idiographic method. This begins with isolating noteworthy findings in one transcript, and attempting to locate them in subsequent transcripts until generalisations can be made. The process is outlined in the Table 7 in full.

Table 7. *Phases of Thematic Analysis, taken from Braun and Clarke (2006).*

Phase	Description of the process
1 Familiarising yourself with your data	Transcribing data, reading & re-reading, noting down initial ideas.
2 Generating initial codes	Coding interesting data features in a systematic fashion across the entire dataset, collating data relevant to each code.
3 Searching for themes	Collating codes into potential themes, gathering all relevant data to each theme
4 Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire dataset, generating a thematic 'map.'
5 Defining and naming themes	Ongoing analysis to refine the specifics of each theme, generating clear definitions and names for each theme.
6 Producing the report	Final analysis. Selection of vivid, compelling quotes, relating the analysis to the research question.

Phase one: Each interview was transcribed and analysed. An example transcript is provided in Appendix O. As recommended by Braun and Clarke (2006), transcripts were read

repeatedly to allow for intimacy with the data; each was read actively and repetitively, with anything considered significant noted.

Phase two: Codes were identified through the use of hand-written notations. Any data which were considered of interest to the research question were highlighted. These codes served to organise the data into meaningful groups, which were to become themes in the subsequent phase. An inductive approach is utilised here, in which codes and emerging themes are data driven (M. Patton, 2002). Due to the exploratory nature of the research question, the codes and themes selected were those which occurred naturally within the transcripts; no predetermined theoretical framework, categories or assumptions were imposed on the data.

Phase three: Emerging theme titles were collated. The wording used was not definitive, but sought to capture the recurring concepts being acknowledged in the coding groups. As recommended by Braun and Clarke (2006), the codes were organised using visual representations; codes were written on separate note cards and organised into theme-piles.

Phase four: All emerging themes were scrutinised so that less coherent themes may be discarded or absorbed into larger superordinate themes. Other, more diverse themes were broken into smaller sub-themes. Key to the decision process were the number of times codes appeared within a theme, and the significance of the subject matter. These themes were then allied with the whole dataset in order to establish the fit of the thematic map to the primary source material.

Phase five: Once a fitting thematic map had been established, the process of defining and refining themes began in order to establish and capture the *“essence of what each theme is about”* (Braun & Clarke, 2006, p. 92). This was achieved through the organisation of coherent and consistent data codes comprising the themes. For each theme, a detailed analysis was performed, focusing on the ‘story’ of the theme and how each contributed to the research question. The master theme map was then created (see Figure 24, p.126). Themes which did not fit the overall structure were discarded. In addition to those analysed in Section 9.3.5., themes of *Negotiation*, *Acceptance*, *Distrust of the Clinic* and *Fear of Transition* were also identified, but discarded as they were not pertinent to the research question (Braun & Clarke, 2006) (see Appendix S).

Phase six: The writing of thematic analysis is achieved during this phase and can be found in Section 9.3.5. and beyond. Braun and Clarke (2006) stipulate a *“concise, coherent, logical, non-repetitive and interesting account of the story the data tell – within and across themes”* (Braun & Clarke, 2006, p. 93). This is achieved through selective use of quotations providing compelling evidence of themes, embedded within the analytic narrative. Braun and Clarke (2006) state that the successful application of this systematic approach to thematic analysis allows for a convincing, data-driven answer to the research question at hand.

Qualitative research seeks to understand meaning, but it is not assumed that meaningful truth is stable (see Section 7.4.2.). Truth is interactively and socially constructed. Social actors are placed within environments structured dependent on gender, class, race, age and other ascribed descriptors. Social actors' multitudinous, changing settings shape the construction of truth within its context (M. Patton, 2002). Qualitative researchers must therefore recognise that the research setting itself as one such context of interactive truth-making. Therefore, interpreting qualitative data requires reflection on the research context, particularly regarding the biases of the researcher, and the impact this may have had on the production of knowledge (Etherington, 2004).

### **9.2.5. Reflexivity**

Considering the impact of the researcher on the data quality and interpretation is an essential component of qualitative research (Etherington, 2004), and thus an account of the potential impact my personal history, value system and culture may have had is provided.

Having conducted qualitative research previously, the researcher was familiar with the practices and procedures of qualitative research and, as such, was able to confidently conduct the interviews. However, the author was unprepared for the difficulties encountered and the challenges presented by interviewing adolescents. Some participants took time to relax and offer more complex answers, and as such much of their initial transcripts are sparse with rich data. Conversely, some of the participants were extremely conversational and the researcher struggled to keep them from disclosing continual tangential narratives. The researcher was unprepared for the challenges of interviews with adolescents and, as such, this may have affected the interview quality.

In terms of the personal narrative of the author, no direct experience of T1D is acknowledged. However, a close childhood friend was diagnosed with T1D very young; possible around 3 years old. As a result, the researcher has some experience of being a peer to someone with T1D during adolescence, and knows something of the challenge of providing support that is effective, whilst not harassing. These experiences may have tainted the researcher's perception of the problem at hand, and any interpretation and analysis of the transcripts must be viewed through this lens. In addition, as an adult, white female, the author's interpretation of the data of adolescent males and females of differing ethnicity must be considered limited, as is knowledge and understanding of their life experiences. As such, the researcher's interpretation exists within the confines of her own life experience and should be considered imperfect.

### 9.3. Results

Due to the complex nature of the research design, several analyses were undertaken. Graphical representation of the analysis of the various hypotheses, and how these relate to the qualitative research question is pictured in Figure 19.

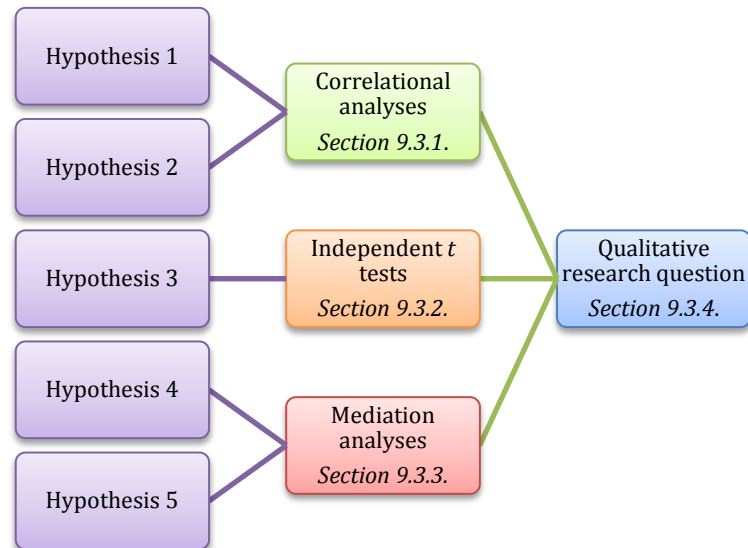


Figure 19. *Methods of analysis applied in Study 1.*

Pearson's Product Moment Correlational analyses were used to identify the relationships between the various categories peer support and diabetes outcomes (hypotheses 1 & 2; Sections 9.1.2.a. and b). Independent samples *t* tests were utilised to assess the psychosocial differences between those with above or below average glycaemic control (hypothesis 3; Section 9.1.2.c.) The correlations then informed the use of mediation analyses, in order to investigate potential mediating effects of QoL (hypothesis 4; Section 9.1.2.d.) and resilience (hypothesis 5; Section 9.1.2.e.) on the relationships between peer support and the outcome variables. These were confirmed using the Sobel test. For all statistical tests an alpha of .05 was used. Descriptive statistics for these data are presented in Table 8.

Table 8. *Descriptive statistics of participants' reported emotional support, instrumental support, diabetes-specific support, quality of life, resilience, self-care and glycaemic control.*

	<i>n</i>	M	SD	Min	Max
Emotional support	90	13.36	2.98	0	16
Instrumental support	90	13.43	3.28	0	16
Diabetes-specific support	86	74.16	79.34	-10	301
Quality of life	86	15	4.85	3	23
Resilience	86	26.52	6.32	3	41
Self-care	86	52.65	8.12	29	67
Glycaemic control (mmol/mol)	86	72.1	7.87	36.6	129.5



The data for all peer support measures was found to be highly positively skewed (see Appendix P), therefore bootstrapping was used to allow for use of parametric measures. This was seen as preferable over non-parametric equivalents due to the enhanced robustness of the test and to ensure comparability of results across studies (Kowalski, 1972; Kraatz, 2011), and offers a more accurate analysis of true to life data than that offered by transformation (Wright, 2011).

No significant differences were noted between age of participants or treatment modality. However, as indicated by previous research, gender-specific differences were noted. Due to non-equality of variance, *t*-tests were interpreted using Welch's correction. This indicated that males reported significantly higher resilience ( $M_{\text{males}} = 28.95$ ,  $M_{\text{females}} = 24.92$ ;  $t(85)=3.21$ ,  $p=.002$ ,  $d=.68$ , 95% CI [.03, 1.12]) and QoL ( $M_{\text{males}} = 16.27$ ,  $M_{\text{females}} = 13.92$ ;  $t(85)=2.36$ ,  $p=.021$ ,  $d=.50$ , 95% CI [.07, .94]) than their female counterparts. This difference is discussed alongside the pertinent hypotheses in Study 3 (see Section 11.4.4.). No other gender differences were noted.

### 9.3.1. Correlational analyses

In order to investigate hypotheses 1 and 2, which refer to the relationships between social support and diabetes outcomes, correlation analyses were conducted between the subscales of the BSSS, DSSQ-Friends, SCI-R and HbA<sub>1c</sub>. It must be remembered when interpreting the correlations that high HbA<sub>1c</sub> values indicate poorer glycaemic control. Appropriate plots accompanied by simple linear model-fitting statistics for the analyses can be viewed in Appendix Q, as recommended by Weatherall *et al.* (2004) to appropriately manage multiple correlation analysis, and reduce risk of Type I error. Interpretation of *r* as a natural effect size was assessed using Cohen's guidelines (J. Cohen, 1988), available in Table 9.

Table 9. *Interpretation of r as a natural effect size, according to Cohen (1988).*

<i>r</i>	Effect size
>.1	Small
>.3	Medium
>.5	Large

#### 9.3.1.a. Hypothesis 1: Global peer support

- i. *Global peer support will be positively associated with self-care, but not glycaemic control.*

Pearson's correlations revealed that increased overall global peer support is positively related with increased self-care, as  $r(84)=.30$ ,  $p=.005$ , 95% CI [.07, .47], indicating a small-medium effect according to Cohen's guidelines (J. Cohen, 1988). However, contrary to the literature, this increased self-care is translated into an improved HbA<sub>1c</sub>, as  $r(84)=-.22$ ,  $p=.041$ , 95% CI [-.43, -.02], suggesting a small negative effect (J. Cohen, 1988), and thereby an improvement in

glycaemic control. Therefore, hypothesis 1.i is only partially supported; global peer support is related to self-care and glycaemic control, whilst only self-care was hypothesised.

- ii. *That emotional support will have a stronger relationship with self-care than instrumental support.*

When the BSSS is split into its component subscales of emotional and instrumental support, differences between the functioning of these subtypes are indicated. As predicted, both emotional ( $r(84)=.29, p=.004, 95\% \text{ CI } [.08, .47]$ ) and instrumental support ( $r(84)=.28, p=.005, 95\% \text{ CI } [.07, .46]$ ) were found to be positively associated with increased self-care behaviours with small-medium effect (J. Cohen, 1988), with a only slightly stronger association with emotional over instrumental support. Nevertheless, hypothesis 1.ii can be accepted, though the effect size difference is negligible.

Due to the unexpected relationship with  $\text{HbA}_{1c}$  indicated by the results of hypothesis 1.i, it was decided to extend hypothesis 1.ii to include the relationship between the subtypes of global peer support and glycaemic control. Interesting differences are noted. A non-significant association between emotional support and  $\text{HbA}_{1c}$  was indicated ( $r(84)=-.18, p=.053, 95\% \text{ CI } [-.04, .37]$ ). However, the relationship between instrumental support and  $\text{HbA}_{1c}$  is significant, as  $r(84)=-.24, p=.013, 95\% \text{ CI } [.03, .43]$ , suggesting a small negative effect (J. Cohen, 1988). This finding suggests that instrumental support has a greater association with health outcomes than emotional support.

### **9.3.1.b. Hypothesis 2: Diabetes-specific support**

- i. *A relationship between diabetes-specific support and self-care will be found, though a direction cannot be determined from previous literature.*
- ii. *A relationship between diabetes-specific support and glycaemic control will be found, though a direction cannot be determined from previous literature.*

Neither hypothesis 2.i, nor hypothesis 2.ii can be accepted, as non-significant relationships were identified between the DSSQ-Friends and SCI-R ( $r(84)=.00, p=.972, 95\% \text{ CI } [-.21, .22]$ ) and  $\text{HbA}_{1c}$  ( $r(84)=.17, p=.121, 95\% \text{ CI } [-.04, .37]$ ). The DSSQ-Friends can be further broken down into its component supportive behaviours; *Insulin Shots, Blood Testing, Exercise and General Items*. To assess if differences existed between the component supportive behaviours and diabetes outcomes, further correlational analyses were performed (see Table 10). Only *General Items* were found to be significantly related to  $\text{HbA}_{1c}$  ( $r(84)=.25, p=.022, 95\% \text{ CI } [.04, .44]$ ) with a small effect size (J. Cohen, 1988). The *General Items* component refers to three statements, namely “Are available to listen to concerns or worries about your diabetes care,” “Encourage you to do a good job of taking care of your diabetes” and “Understand when you sometimes make mistakes in taking care of your diabetes.”

Table 10. *Correlations among the component behaviours of diabetes-specific support, self-care and glycaemic control.*

	Insulin Shots	Blood Test	Exercise	General Items
Glycaemic control	.120	.137	.176	.247*
Self-care	.155	.027	-.045	-.058

\* $p < .05$

### 9.3.2. Independent $t$ tests

It was decided to compare the diabetes-specific support of those with poorer or enhanced glycaemic control to assess for differences between the psychosocial profiles of those with or without optimal glycaemic control. Whilst correlational analyses are most appropriate for continuous variables such as these scale measures, group comparison was felt to be of value in this instance given the detrimental outcomes of poor glycaemic control (see Section 5.7.). In addition, as outlined in Section 8.4.2.b., NICE and the WHO recommend a HbA<sub>1c</sub> of 48mmol/mol (National Institute for Health and Care Excellence, 2015), thereby imposing a group on this continuous measure, and creating a dichotomous comparison. However, only 35.2% of people achieve this goal of glycaemic control in the UK (National Diabetes Audit, 2014). Therefore, in order to reflect the difficulties seen in achieving optimal control, the mean value of HbA<sub>1c</sub> found within the participant sample was used as a mid-way point to calculate those with above or below average HbA<sub>1c</sub> for the present group. As seen in Table 8, this was 72mmol/mol. This creates two groups, the descriptive statistics for which can be seen in Table 12. Those with above average glycaemic control ( $\leq 72.1$ mmol/mol) comprised 21 males and 18 females, 34 using MDI and 5 using CSII pump for insulin delivery. Those with below average glycaemic control ( $\geq 72.2$ mmol/mol) consisted of 16 males and 31 females, with 43 using MDI and 3 using CSII pumps.

Application of multiple  $t$  tests increases the chances of Type I error, which must be eliminated in order to present accurate results. Whilst the Bonferroni correction is the standard procedure for managing such risk, many have criticised this method as being overly conservative (Moran, 2003; Narum, 2006; Perneger, 1998; Rice, 1989). The Bonferroni procedure dramatically increases the risk of committing Type II error, and to reach the recommended 80% statistical power, requires prohibitively large sample sizes to detect medium effects (e.g.,  $n=128$  per group for independent samples  $t$  test). As such, application of the Bonferroni correction was rejected in the present study. Instead, effect sizes and corresponding confidence intervals; approaches unencumbered by issues with statistical power and error, will be presented and interpreted alongside traditional hypothesis testing methods in

order to manage risk of Type I error (Garamszegi, 2006; Hedges, 2008). Interpretation of the effect size of Cohen's  $d$  was assessed using Cohen's guidelines (J. Cohen, 1988) (see Table 11).

Table 11. *Interpretation of the effect size of Cohen's  $d$  (1988).*

$d$	Effect size
>.2	Small
>.5	Medium
>.8	Large

Table 12. *Descriptive statistics of demographic characteristics and psychosocial variables of those with above ( $\leq 72.1$ mmol/mol) or below ( $\geq 72.2$ mmol/mol) average glycaemic control in Study 1.*

Variable	Group (HbA <sub>1c</sub> )	$n$	M	SD	Min	Max
Age	<72.1mmol/mol	48	16.69	.99	15	18
	>72.2mmol/mol	38	16.42	.92	15	18
Self-care	<72.1mmol/mol	48	54.13	8.09	29	67
	>72.2mmol/mol	38	50.79	7.88	38	65
QoL	<72.1mmol/mol	48	15.29	4.93	3	23
	>72.2mmol/mol	38	14.63	4.80	3	23
Resilience	<72.1mmol/mol	48	27.27	5.56	14	41
	>72.2mmol/mol	38	25.58	7.12	3	38
Diabetes-specific support	<72.1mmol/mol	48	48.73	59.11	-10	224
	>72.2mmol/mol	38	106.29	90.13	0	301
Overall global peer support	<72.1mmol/mol	48	27.60	4.50	16	32
	>72.2mmol/mol	38	26.97	4.76	14	32

Those with below average HbA<sub>1c</sub> were more likely to be female and marginally younger, though the prevalence of females within the participant sample skews this result. As before, due to non-equality of variance,  $t$  tests were interpreted using Welch's correction. Unsurprisingly given the established link between adherence and glycaemic control (see Section 6.2.1.), a significant difference in the self-care of those with above ( $M=54.13$ ) or below ( $M=50.79$ ) average HbA<sub>1c</sub> was noted, as  $t(80)=2.79, p=.007, d=.61, 95\% \text{ CI } [.17, 1.06]$ , indicating a large effect (J. Cohen, 1988). Such a difference is in line with the assertions of the DCCT (Jacobson et al., 2013), and validates the use of the SCI-R as an accurate portrayal of self-care in relation to glycaemic control.

### 9.3.2.a. Hypothesis 3: Glycaemic control

The findings of independent samples  $t$  tests investigating these hypotheses can be seen in Table 13. Due to the unexpected significant findings of hypothesis 1 (see Section 9.3.1.a.), global peer support was also included in the analysis.

Table 13. *Independent samples t tests comparing those with above or below average glycaemic control on QoL, resilience, diabetes-specific and global peer support.*

Variable	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>	95% CI of <i>d</i>
Quality of life	1.32	79	.190	.29	-.15, .73
Resilience	1.31	81	.194	.28	-.15, .72
Diabetes-specific support	-3.62	79	.001	-.78	-1.23, -.33
Global peer support	2.01	82	.048	.44	.00, .88

- i. *Those with better glycaemic control (below average HbA<sub>1c</sub>) will report higher QoL and resilience.*

As can be seen above in Table 13, the results of independent samples *t* tests were non-significant. However, due to the underpowered sample size, type II error must be considered here. As such, when looking at the effect sizes of these results, small-medium effects are noted (J. Cohen, 1988) suggesting a likely Type II error. Nevertheless, hypothesis 3.i is rejected in accordance with the NHST method.

- ii. *Diabetes-specific support will differ, though a direction cannot be determined from previous literature.*

Interesting significant findings are acknowledged here. The statistical analysis suggests that those with above average HbA<sub>1c</sub> report marginally significant greater global peer support ( $M=27.60$ ) than those with below average HbA<sub>1c</sub> ( $M=26.97$ ). However, this relationship is reversed when considering diabetes-specific support. Those with below average HbA<sub>1c</sub> score significantly higher on the DSSQ-Friends ( $M=106.29$ ) than those with above average HbA<sub>1c</sub> ( $M=48.73$ ), suggesting that those with poorer glycaemic control perceive greater diabetes-specific peer support. Therefore, hypothesis 3.ii is accepted.

### 9.3.3. Mediation analyses

Hypotheses 4 & 5 concern potential mediators of the relationship between peer support and diabetes outcomes; namely QoL and resilience, as indicated by the literature (see Sections 6.3. and 6.5.). As such, mediation analysis was conducted between the subscales of the WHO-5, CD-RISC 10, BSSS, DSSQ-Friends, SCI-R and HbA<sub>1c</sub>, to assess whether QoL and resilience meet Baron and Kenny's (1986) conditions for mediation. It must be considered that due to the cross-sectional nature of the present study, diabetes outcome variables cannot be said to truly hold predictive value, however, this terminology is employed for sake of clarity.

According to Baron and Kenny (1986), a mediator must contribute to the explanation of the relationship between the predictor and the outcome variable. In other words, they must relate to the mechanism through which two variables of interest are related. There are two potential mechanisms through which this can occur; either through direct impact of the

predictor variable or via the mediator. The predictor may also affect the mediator. This is represented in Figure 20.

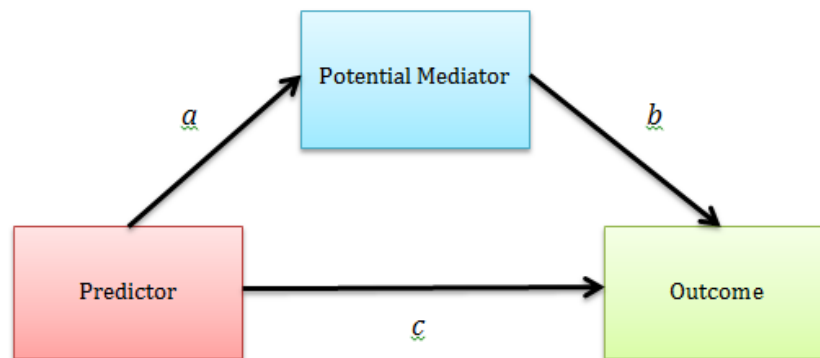


Figure 20. The mediational model, as suggested by Baron & Kenny (1986).

A variable must fulfil certain criteria in order to be considered a mediator. These include:

- Variance in the predictor must be considered to account for variations in the mediator (path a).
- Variance in the mediator must be considered to account for variations in the outcome variable (path b).
- When controlling for paths a and b, the relationship between the predictor and outcome variables is no longer significant. The most convincing evidence of this would be for the relationship to now equal 0, however Baron and Kenny (1986) state that a significant decrease in path c is sufficient for classification as a mediator.

As the mediation models of QoL and resilience proposed by Hilliard and colleagues (2013) and Whitemore *et al.* (2010) respectively have yet to be investigated, this mediation analysis is exploratory and seeks to confirm the status of QoL and resilience as mediators. In order to be considered mediators, the above conditions must be met. When the mediational model is applied to these variables, the relationships depicted in Figure 22 and Figure 23 are suggested.

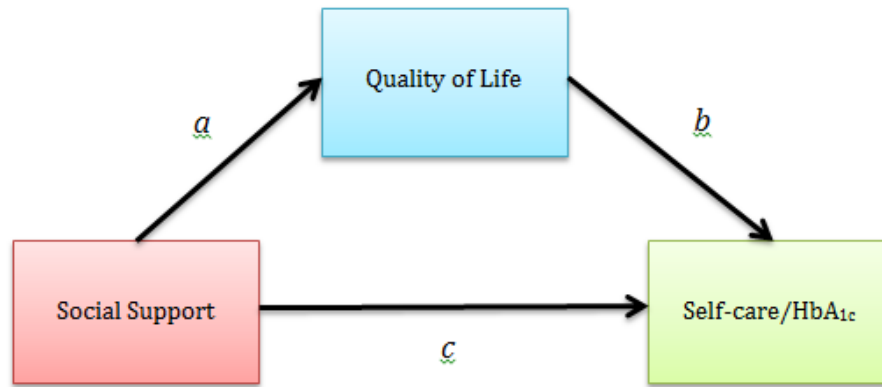


Figure 21. The proposed mediational role of quality of life in the relationship between social support and diabetes outcomes, as suggested by Hilliard et al. (2013).

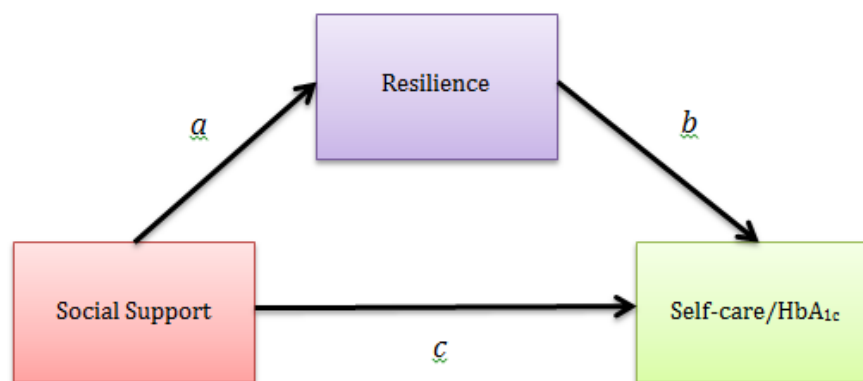


Figure 22. The proposed mediational role of resilience in the relationship between social support and diabetes outcomes, as suggested by Whittemore et al. (2010).

These models suggest that:

- A variation in social support will be met with variation in QoL/resilience (path a).
- A variation in QoL/resilience will be met with variation in self-care and/or HbA<sub>1c</sub> (path b).
- When these relationships are controlled for, the relationship between social support and diabetes outcome variables is no longer significant.

These models will be investigated using formal mediation analysis. This requires a step process model in which several regressions are performed; (i) the predictor (peer support) and mediator (QoL/resilience) and (ii) the predictor (peer support), mediator (QoL/resilience) and outcome variables (self-care/HbA<sub>1c</sub>). The Sobel product of coefficients approach is then used to calculate the indirect effect of the mediator (QoL/resilience). This was preferred over the use of bootstrapping, as bootstrapping requires the assumption that *a* and *b* are uncorrelated, which is violated here (Kenny, 2014). The four step process for formal mediation analysis recommended by Baron and Kenny (1986) can be seen in Table 14, with the addition of the Sobel test of the indirect pathway to ensure full mediation analysis (Sobel, 1982). The method recommended by

Baron and Kenny (1986) was preferred over the PROCESS approach due to the resource constraints of this doctoral thesis.

Table 14. *The procedures for formal mediation analysis as recommended by Baron and Kenny (1986), with the addition of the Sobel test of the indirect pathway (1982).*

Analysis	
Step 1	Linear regression of X (social support) predicting Y (diabetes outcomes) to test the <i>c</i> path
Step 2	Linear regression of X (social support) predicting M (QoL/resilience) to test the <i>a</i> path
Step 3	Linear regression of M (QoL/resilience) predicting Y (diabetes outcomes) to test the <i>b</i> path
Step 4	Multiple regression with X (social support) and M (QoL/resilience) predicting Y (diabetes outcomes) to test for full mediation
Step 5 (Sobel test)	Multiply the unstandardized coefficients from Steps 2 and 4, compare to a critical values table, e.g. those produced by MacKinnon (2008).

Before commencing mediation analyses, correlations between demographic characteristics (age, gender and treatment modality) and diabetes outcome variables (SCI-R and HbA<sub>1c</sub>) were calculated to determine if any should be considered covariates and subsequently controlled for in the mediation analysis. None were found to have significant relationships and so were not considered as covariates. Whilst it was originally hoped to include diabetes-specific alongside global peer support as predictor variables, the results of hypothesis 2 indicate that this is not required (see Section 9.3.1.b.). Appropriate plots alongside simple linear model-fitting statistics can be viewed in Appendix Q.

#### **9.3.3.a. Hypothesis 4: Quality of Life**

*Quality of life mediates the relationship between social support and diabetes outcomes.*

In order to assess if beginning the process of mediation analysis is worthwhile (Kenny, 2014), correlational analyses were conducted between WHO-5, BSSS, SCI-R and HbA<sub>1c</sub>, the results of which are shown in Table 15 below. These correlations also serve to demonstrate the relationship between peer support and psychosocial outcomes, namely QoL and resilience. As the WHO-5 was found to be correlated with each of the predictor and outcome variables, the mediation analysis could proceed. In addition, a positive association with peer support is indicated, in which the BSSS displays significant relationships with the WHO-5 to medium effect (J.Cohen, 1985)

Table 15. *Correlations among quality of life, global peer support, self-care and glycaemic control.*

	Glycaemic control	Global peer support	Quality of life
Self-care	-.37**	.30**	.23*
Glycaemic control	---	-.22*	-.18*
Global peer support	---	---	.41**

\* $p < .05$ , \*\* $p < .01$



A sequence of linear regressions were utilised to investigate the potential mediation effects of QoL on the relationship between global peer support and diabetes outcomes. The results of these regressions are shown in Table 16 below. Overall BSSS significantly predicted results of the SCI-R ( $\beta=.27, p=.011$ ), and subsequently the WHO-5 ( $\beta=.40, p<.001$ ). However, the WHO-5 was not a significant predictor of the SCI-R ( $\beta=.20, p=.056$ ). In accordance with Baron and Kenny's guidelines (1986), the mediation analysis therefore did not progress beyond step 3 and as such, QoL cannot be said to be a mediator of the relationship between peer support and self-care.

Table 16. *Mediation analysis to determine whether quality of life is a mediator of the relationship between peer support and self-care.*

Mediation analysis step	Measurement	$\beta$	$p$	$F$	$R^2$
1	BSSS SCI-R	.27	.011*	6.68	.07
2	BSSS WHO-5	.40	.000***	16.08	.16
3	WHO-5 SCI-R	.20	.056	3.74	.04

\* $p<.05$ , \*\*\* $p<.001$

This process was repeated with HbA<sub>1c</sub> as the outcome variable, the results of which are shown in Table 17. Whilst overall BSSS was found to significantly predict HbA<sub>1c</sub> ( $\beta=-.22, p=.041$ ) and WHO-5 ( $\beta=.40, p<.001$ ), as with self-care, the mediation analysis process was halted at step 3, wherein the WHO-5 was not found to be predictive of HbA<sub>1c</sub> ( $\beta=-.18, p=.096$ ). Therefore, hypothesis 4 is rejected.

Table 17. *Mediation analysis to determine whether quality of life is a mediator of the relationship between peer support and glycaemic control.*

Mediation analysis step	Measurement	$\beta$	$p$	$F$	$R^2$
1	BSSS HbA <sub>1c</sub>	-.22	.041*	4.31	.05
2	BSSS WHO-5	.40	.000***	16.08	.16
3	WHO-5 HbA <sub>1c</sub>	-.18	.096	2.83	.03

\* $p<.05$ , \*\*\* $p<.001$

### 9.3.3.b. Hypothesis 5: Resilience

*Resilience mediates the relationship between social support and diabetes outcomes.*

As with QoL, it was first important to assess if the CD-RISC 10 was associated with the BSSS, SCI-R and HbA<sub>1c</sub> before proceeding. The results of these correlations can be found in Table 18. As with QoL, these correlations also function to assess the psychosocial outcomes of peer support. In this case, a significant relationship was found, suggesting a positive association between peer support and resilience, to a small-medium effect (J.Cohen, 1985). However, whilst the CD-RISC

10 was found to be correlated with BSSS, it was not associated with the SCI-R nor HbA<sub>1c</sub>, as such, mediation analysis for resilience was not carried out. Hypothesis 5 is therefore rejected.

Table 18. *Correlations among resilience, global peer support, self-care and glycaemic control.*

	Self-care	Glycaemic control	Global peer support	Resilience
Self-care	---	-.37**	.30**	.11
Glycaemic control	---	---	-.22*	-.16
Global peer support	---	---	---	.25*

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

#### 9.3.4. Summary of the quantitative findings of Study 1

A summary of the quantitative findings is presented in Table 19. The meaning and interpretation of these findings is uncovered in the subsequent qualitative analysis.

Table 19. *Summary of the quantitative findings of Study 1.*

Hypothesis	Accepted/Rejected	Comment
1.i Global social support will be positively associated with self-care, but not glycaemic control.	Partially accepted ( $r=.30$ )	<i>Additional relationship to glycaemic control noted</i>
1.ii That emotional support will have a stronger relationship with self-care than instrumental support.	Accepted ( $r=.29$ )	<i>Minimal difference in comparison to instrumental support (<math>r=.28</math>)</i>
- <i>Additional hypothesis:</i> emotional support will have a stronger relationship with glycaemic control than instrumental support	Rejected ( $r=-.18$ )	<i>Only the relationship between instrumental support and HbA<sub>1c</sub> was significant</i>
2.i A relationship between diabetes-specific support and self-care will be found, though a direction cannot be determined from previous literature.	Rejected ( $r=.00$ )	
2.ii A relationship between diabetes-specific support and glycaemic control will be found, though a direction cannot be determined from previous literature.	Rejected ( $r=.17$ )	<i>Only 'General Items' subsection significantly related to HbA<sub>1c</sub></i>
3.i Those with better glycaemic control will report higher QoL and resilience	Rejected ( $d=.29$ , $d=.28$ )	
3.ii Diabetes-specific support will differ, though a direction cannot be determined from previous literature.	Accepted ( $d=-.78$ )	<i>Those with poorer glycaemic control reported significantly more diabetes-specific support</i>
4 Quality of life mediates the relationship between social support and diabetes outcomes.	Rejected ( $r^2=.04$ )	
5 Resilience mediates the relationship between social support and diabetes outcomes.	Rejected	<i>Not carried out</i>

#### 9.3.5. Qualitative analysis

Three overarching themes emerged from transcripts when thematic analysis was applied; *Support, Nagging, and Burden*. These are allied with their subthemes in Figure 24. Each theme is described and supported by extracts from the transcripts that are felt to be representative. Additional quotes can be found in the final themes table, with the number of times themes arose

collated in the master themes table (see Appendices R and S). Extracts from the transcript are presented *ad verbatim*. Pauses in speech are shown using the symbol (...), with extractions from text using ... These have been used in order to improve understanding and reduce ambiguity. Words or phrases included to increase comprehension are shown in parentheses.

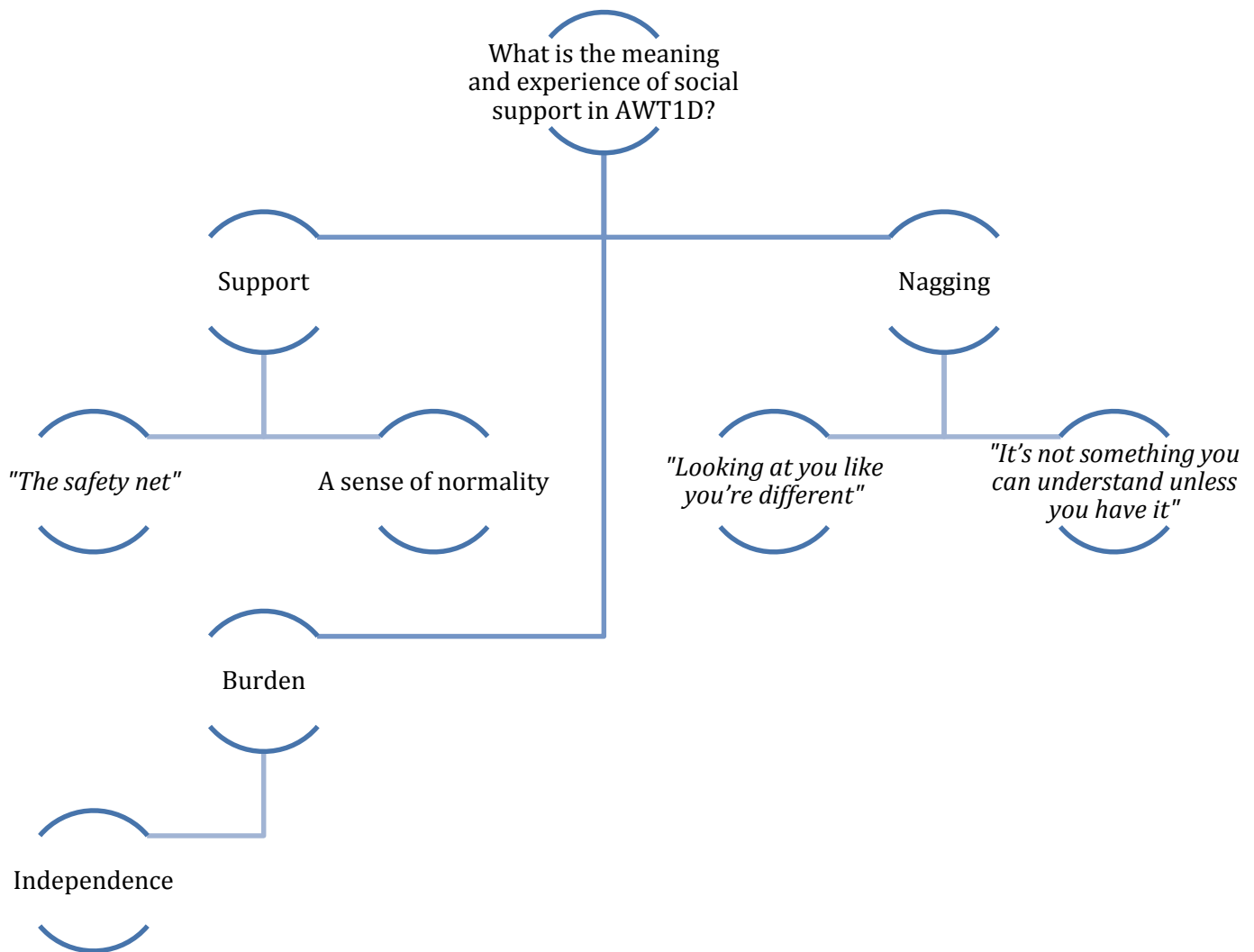


Figure 23. Overarching and subthemes derived from thematic analysis of semi-structured interviews with adolescents with type 1 diabetes.

#### 9.3.5.a. Support

The first overarching theme concerned how participants used and interpreted the support provided to them by their peers. Aligned with the findings of hypotheses 1 & 2, it would appear that global support was preferred over diabetes-specific support:

*"Just listening really. (...) I (...) I, I, I don't know what she says back to me, I don't think she says much, but it's just listening to me moan about it [T1D], and just shrugging her shoulders and saying 'well, that's life, isn't it?'" Catherine: 280.*

This idea of emotional support being more highly valued in their lives was echoed by the majority of participants. The worth and efficacy of peer support is affirmed and explored in two subthemes; *A Sense of Normality* and *The Safety Net*.

*i. A Sense of Normality*

The primary role of peer support appeared to be in the attainment and maintenance of what was perceived as “normal” adolescent behaviours.

*“But my friends, they just (...) were there (...) if I, um, needed to talk or just not be the girl with diabetes for a bit.” Isabelle: 216*

*“...they [peers] never say ‘well you can’t have that, you can’t do that’ and they’ve never, kind of, singled me out because of it...They, they always try to make me feel the same as everyone else.” Jessa: 182*

This sense of normality seemed to be maintained mostly through engagement with what participants stated were typical behaviours perpetuated by their peers, including attending social events such as parties and the cinema. A frequently mentioned source of peer support was seen in the capability of peers to downplay the seriousness of T1D, most often by presenting humour in self-care:

*“...I think the best thing they [peers] do is that they joke about it. I do like it, because it makes everything (...) Just a bit of a joke and a bit of, a bit more funny, because sometimes with diabetes it’s just negatives, and there’s never really positives....The usual joke is ‘Oh, Philip’s doing his heroin’ and stuff like that...” Philip: 233*

Although humour is not actively included in the typologies of support outlined in Section 3.2., the emphasis participants placed was on the capability of humour to soften the impact of self-care. This allies closely with appraisal support (see Section 3.2.), focusing on the re-evaluation of situations, which was not assessed in the quantitative questionnaires. Indeed, potentially the sense of normality maintained through peer relationships may too relate to appraisal support; that engagement in normal adolescent behaviours and conversation allows re-evaluation of the identity to one not centred around T1D. The idea of a “diabetes label” was raised frequently, and was easily dismissed when in the presence of peers:

*“I don’t really want to advertise ‘I’m diabetic! Please make sure that I’m ok!’ all the time...It’s just nice to be (...) normal sometimes, to try to forget about it.” Claire: 649*

*“...not the girl who’s got diabetes (...) the girl who’s got the label on.” Charlotte: 882*

This openly suggests that it is the rejection of this “diabetes label” within peer relationships that AWT1D find fundamentally beneficial and supportive, which they are not able to achieve via other support networks. For some participants, however, this normality was attained simply through ignoring self-care in the presence of peers:

*"Not talking about it [is most helpful]. I think if they always went on about it, and wanted to talk about it, I couldn't cope with that (...) No."* Idimma: 354

As can be seen in this quote, for some participants, a sense of normality was most easily achieved through denial. In the most serious cases, this translated into disengagement with self-care whilst in the presence of peers:

*"...you don't want to go off every lunchtime and do something [diabetes-related], you want to sit with your friends and chill...I still don't test, I don't think I'll ever test in school, ever. I never have."*

Charlotte: 238

This attitude was most frequently seen in participants with particularly poor glycaemic control. When cross-referencing self-reported denial of self-care behaviours with HbA<sub>1c</sub>, it was evident that those with the poorest control (Idimma, Puja, Charlotte, Paul and Lewis, all >80mmol/mol) were those most frequently reporting such avoidance of self-care. This subtheme, therefore, presents a crucial idea in which appraisal support exclusively provided by peers enables realignment of the identity to a "normal" adolescent, reported as supportive. However, this appraisal support may operate on a spectrum in which total immersion in normality may lead to a rejection of the sick role, and thereby self-care behaviours.

Although appraisal support was most often cited, instrumental support and diabetes-specific behaviours were also reported as advantageous and supportive, though in very restricted activities and with specific caveats. These behaviours are outlined in the subtheme *The Safety Net*.

## ii. *The Safety Net*

The title of this subtheme is taken from a quote from Lewis, in which he describes his ideal supportive peer relationship:

*"...they would just let you get on with it and with the safety net of someone around who does know what to do [in a diabetic emergency]."* Lewis: 352

This idea was echoed by almost all participants. Peers appear to have a very specific support role in mind regarding which diabetes-specific behaviours will be accepted by AWT1D. Whilst a clear preference for global support was demonstrated overall, there were a select few diabetes-specific behaviours which participants received and accepted from their peers. These primarily concerned the use of their peers as a "safety net" for when diabetic emergencies occurred:

*"I kind of rely on the (...) friends ...to (...) keep an eye on me. Just 'cause they know me better (...) they know what to look for."* Philip: 126.

*"She knows how I'm like when my sugars are low and when my sugars are high...I can relax a bit more..."* Panvi: 114

Specifically, knowing the procedures to correct hypoglycaemia was highlighted by almost all participants as a key supportive behaviour:

*"...I have got people around me who do know what to do [in the event of hypoglycaemia]...they carry stuff on them, just in case."* Philip: 141

With one in particular believing that not informing peers of the optimal course of action to take in the event of a diabetic emergency would be unwise or unsafe:

*"I think your friends should know. It's like, imagine if you're, I don't know, out with your friends at the weekend, and they don't know anything, I think, I think that's silly. I think you're asking for trouble."* Isabelle: 413

However, this concept of a safety net was finite, and clear limits were imposed on the knowledge that peers needed to have:

*"...they know to give me food [in the event of hypoglycaemia](...)I don't think they need to know much else."* Paul: 276

Participants remain guarded in the amount of information they wished to disclose to peers, and many expressed a desire for a swift return to normality once a diabetic emergency had been successfully dealt with:

*"Once I've told them how to help if I do have a hypo, I kind of (...) don't want to think about it again. I just want to be me and them not to worry..."* Catherine: 582

*The Safety Net* is interpreted as an acceptable level of illness disclosure, divulged only with personal safety in mind. Additional information or explanation strays too far from normality to be tolerable. This concept is demonstrated particularly in the point at which participants stated behaviour became nagging. As expected, this was a highly individualised process, though some commonalities emerged. Even with the current subtheme in mind, a clear line is presented in which support becomes harassment. Primarily, this concerns drawing the attention of others to their 'difference':

*"...they can see that I've gone white and sweaty, but in front of everyone, they're like 'are you ok?' and I'm like 'oh yeah, make everyone look at me why don't you?'"* Charlotte: 263

### **9.3.5.b. Nagging**

How enacted, well-intentioned supportive behaviours become perceived as nagging is not clear in previous research (see Chapter 3). It was, however, extremely salient for the participant group and was discussed at length with each. Many different behaviours could be construed as nagging, and little agreement could be seen on what was or was not interpreted as pestering dependent on individual differences:

*"...it's just having to constantly repeat yourself to different people."* Philip: 185

*"...sometimes it's really, really nice and sometimes it kind of winds you up a bit. It's like, first thing in the morning, it's like 'what's your blood sugar?' and I'm like 'I haven't tested yet!'" Charlotte: 14*  
*"I don't like when they [peers] tell me 'have you done that, have you done this, have you done that?' but when they stop telling me, then I forget, then I feel like complete crap, so it's like a vicious cycle." Catherine: 47*

*"...there has been a couple of times when they'll [peers] be like 'Jessa, are you sure you're allowed that' and at the same time, they kind of just leave me to it, which I expect them to. You know, not treat me like a little kid or something." Jessa: 279*

What is or is not nagging is, therefore, highly individualised and specific behaviours could not be isolated. At its root appears to be a basic assumption that *"...they think it's helpful, but it's not"* (Catherine: 572); participants were aware that behaviours were well-intentioned, but were nevertheless perceived as unsupportive and provocative. Two levels of interpretation of behaviour were highlighted in the transcripts as potential lenses through which benevolent support is misconstrued as nagging; *Looking At You Like You're Different* and *It's Not Something You Can Understand Unless You Have It*.

#### *i. Looking At You Like You're Different*

As with the previous subtheme, here the name is also taken from a direct participant quote. When discussing reasons for her disengagement with self-care, Charlotte stated that:

*"...I don't want people looking at me, like 'why are you doing that?' ...I don't want them knowing, looking at me, looking at you like you're different." Charlotte: 233*

All participants spoke about the social problems presented by being an AWT1D. The participants highlighted an associated label or stigma that came alongside illness disclosure. Illness disclosure to peers was, therefore, a contentious issue. Whilst some participants saw the benefits of peers being aware of diagnosis in order to provide diabetes-specific support in the case of emergencies, this did not automatically result in illness disclosure to peers:

*"Like, if I meet someone new (...) I won't tell them I'm diabetic...I don't like it. I don't want them to think of me as 'Catherine the diabetic' (...) or 'that girl with diabetes.'" Catherine: 643*

*"...it's not anyone else's business, really. [Inaudible] different (...) that's why I don't talk about it. That's why I like the pump.... they don't need to know." Paul: 166*

Potentially, keeping diagnosis confidential enables for ultimate normality when interacting with peers. Whilst most participants achieved a sense of normality through engagement with typical adolescent behaviours, the extremes of this attitude could lead to denial (see *A Sense of Normality*). Possibly, in the case of Paul who did not disclose his illness to any peers, he has employed a strategy to maintain normality in which he engages in total denial in the presence of peers. Through this, he is able to maintain his pre-diagnosis identity and reject the "diabetes

label” he fears; something he is unable to do with family members. This can be seen in other participants who did not exercise such extreme measures, in the reactions of peers after illness disclosure:

*“...and then it all changes [once friends are aware of diagnosis]. Constantly they give you the sympathetic look on their face, and it’s like ‘stop it!’”* Jessa: 514

It is this reaction, the misplaced overt empathy and concern, which participants stated was most likely to cause a disengagement with self-care:

*“...I do feel sometimes like I just wanna (...) like, go out with my friends and she’ll [concerned peer] be like ‘are you ok?’ all the time (...) So, sometimes it does feel tempting to just (...) get away from it all.”* Isabelle: 632

*“...when people stare when you inject and that (...) tell you what you should be doing. That’s the worst.”* Lewis: 207

When probed why this was, participants cited a sense of stigma, of being different, which fuelled a desire to be normal and therefore disengage with self-care. One participant overtly highlights the sick role as a reason for her non self-management:

*“...it’s like they see me as a disabled, ill person all the time, rather than as their friend...”* Catherine: 875

When receiving advice, sympathy and reminders from peers, participants appear to be actively reminded of their sick role. When this is unsolicited, participants find it particularly repellent, and is construed as harassment rather than the support it was intended to be by the provider. It was through this mechanism that participants suggested support became nagging. This was particularly poorly received when the support provider was someone who had no experience of T1D:

*“...the sly comments from people who don’t have a clue what, what it’s about.”* Philip: 349

This concept of insider/outsider knowledge is explored in *It’s Not Something You Can Understand Unless You Have It*.

## ii. *It’s Not Something You Can Understand Unless You Have It*

The title of this subtheme is adapted from a participant quote. When discussing unsolicited advice, Lewis stated:

*“I don’t think it’s something you can [understand] (...) unless you have it.”* Lewis: 181

This subtheme reflects the previous, in that a fundamental “difference” existing between the participants and their peers facilitates an ingroup/outgroup mentality. Participants viewed their T1D as a disparity, which consequently fuels a perception of similarity with others in those who had peers and family members living with the same condition:



*"...there's some other people in my school that are, that are diabetic (...) that I know as well, and I used to go sit with them in a room and do my injections and that was alright because (...) they'd know how it felt to have to inject (...) and that was nice."* Panvi: 215

This similarity seems to be based in shared experiences, and an increased ability to deemphasise the significance of T1D, frequently through the medium of humour:

*"'Cause you walk in and you, it's like you know that person's got diabetes...it's like you share something so big. You've experienced the same things; 'have you done this?' 'yeah, I've done this' and you can have a good old laugh, 'cause you know there's always a funny story that follows a hypo (laughs)."* Jessa: 532

Through her language, Jessa reveals the significance of T1D and the impact it has had on her life. It could be construed that experiencing such a significant part of the self in relative isolation, with a perception of incongruence of experience with peers, would be a decidedly solitary existence. Therefore, it is perhaps unsurprising that adolescents with access to those with shared experience drew on these friendships for support. However, for many of the participants, they were not fortunate enough to know others of their own age living with T1D. For these participants, the same ingroup/outgroup attitude appeared to exist, but manifested itself in a belief that those without T1D could never truly empathise with the experience:

*"Living with it is just different and (...) even if you know all the facts, which a lot of people don't (...) having it is different. Like, even Michelle [girlfriend], even though I know she knows most about me and about diabetes, she still doesn't really know what it's like for me, really."* Philip: 134

This coalesced into an increased resentment at unsolicited advice provided by those inexperienced in T1D. A belief that without personal experience, diabetes-specific advice and support was particularly unwarranted, and typically incorrect or inaccurate:

*"...it's a bit ridiculous, how people react.... 'cause they're like 'oh you're not meant to eat this, not meant to eat that, blah, blah, blah, blah' (...) like misconceptions and things like that."* Catherine:

698

This irritation at support from an inexperienced source was associated with a greater perception of nagging; support appeared to be more readily received and accepted when it was perceived as coming from an ingroup member. When recognised as coming from an outgroup member, the advice was more likely to be dismissed. This was not only associated with general diabetes-specific support, but also for some in the case of diabetic emergencies:

*"Like, you're not listening. Like, they've heard somewhere along the line that you need to give diabetics sugar [when suffering from hypoglycaemia], and that's all they remember, even if I tell them not to. So (...) I'm open with them, but (...) like, I wouldn't necessarily trust them to take care of me if I was proper ill, you know?"* Charlotte: 200

As demonstrated here, this wasn't necessarily the fault of the participants, but of persistent and prevalent misconceptions amongst peers about what constituted appropriate self-care. However, the participants also appeared to be generally unwilling to correct these assumptions. Participants believed that peers were continually repeating questions and presenting the same misapprehensions as those which participants believed they had already corrected:

*"And then, like, different (...) different people had the same questions. So it was like, really repetitive (...) after a while...Like I was answering the same thing all the time. Just boring."* Paul:

260

Both of these central ideas may potentially be linked to the previously discussed idea of stigma. This sense of difference facilitates ingroup mentality which many found beneficial, but consequently also creates an outgroup. This outgroup is rejected when providing diabetes-specific support due to a lack of understanding, both of appropriate self-care and of the experience of T1D:

*"...they [friends] don't understand, sort of, how much work it is to maintain and how much extra work it is...it really annoys me when people are not aware...It's not fair that they can make judgements about you."* Philip: 117

Therefore, well-intentioned support provided by this group is frequently misconstrued as nagging. This nagging, for some, seemed to be based in a highlighting of their perception of this dissimilarity between themselves and their peers, both to them and to others.

Overall, when attempting to uncover the distinction between support and nagging behaviours, a complex picture emerges. Fundamentally, it appears to be drawn from identity. Whilst emotional and appraisal support allow for the pre-diagnosis identity to remain intact, instrumental and diabetes-specific support appear to remind the participants of the sick role, which is ultimately rejected. This rejection is particularly strong when the support provider is perceived as an outgroup member, and therefore lacking in true understanding of the experience of T1D. However, there are clearly other influences which also impact the perception and acceptance or rejection of support. As one participant states:

*"I don't think it's even actually any difference between the two [support & nagging], it's more how I'm feeling when they say it. (...) Like, if I'm feeling like they're getting at me, then even if they said something that was a reminder, I think I take it as nagging."* Charlotte: 71

Nagging is therefore likely to be a multidimensional construct related to factors such as the T1D status of the support provider, the presence of peers or others without T1D to which the stigma of T1D may be revealed, and mood of the support receiver. However, the research question of support experience is not yet fully answered without consideration of what it is to specifically request support. The reluctance to engage in this behaviour is evidenced in the final theme; *Burden*.

### 9.3.5.c. Burden

Despite a commitment to achieving independence in their self-care, many of the participants spoke about occasions where cooperation from others was also required. This ranged from ensuring mealtimes with peers were within their assigned timeslot, through to requesting help with diabetic emergencies. However, participants were notably reluctant to seek support in even simple behaviours which could aid their self-care:

*"I mean, they are aware of it all the time and things, and they do know [eating late at night is problematic for self-care], but I never say anything. I don't want to create problems, I don't want to ruin the evening by being like 'we should have done this earlier, it's too late now' kind of thing."*

Catherine: 461

The reasons provided for this reaction were complex. However, like the previous themes, at its heart appeared to be a sense of isolation in their self-care. The participants frequently used phrases implying that self-care was their responsibility and shouldn't be a shared burden:

*"But I don't want to be demanding, you know? It's not their fault I'm diabetic, is it?"* Jessa: 311

This sense of isolation was seen through the impact they perceived sharing the responsibility would have on their relationships. Some spoke about the impact their T1D had had on parents and siblings:

*"...[If I did not have T1D] I wouldn't have to rely on my mum being there or worry while I was watching the movie. Just to (...) still be on, like, standby in case something did happen, so she wouldn't have to (...) she could just drive off."* Nathan: 246

*"So, we've kind of tailored things round me now really, which I suppose isn't fair on Joseph [brother]."* Catherine: 395

Consequently, they appeared to worry that T1D had the potential to have similar impact on others in their life, and sought to avoid this through managing T1D in isolation and without the support of peers:

*"It's too much (...) I don't think you could ask it [to provide support] of them really, in my opinion."*

Philip: 270

Their main reasoning for this appeared to be that, by coping alone, they could avoid peers being concerned or preoccupied with their T1D:

*"I don't want people to worry about me, that's what I think anyway. If I told someone I was struggling, or didn't like something, in my mind they're going to worry, and I don't want that."*

Charlotte: 365

*"...they're my friends and I, I (...) don't want to rock the boat. It's bad enough that I have to spend every waking minute worrying about it, it's not fair to have them expecting to do that too."*

Catherine: 466

It is through this sense of T1D being their burden to manage that a potential second explanation for the misperception of nagging is conceived. If participants are determined to be responsible and independent in their management, no matter their motivation for doing so, supportive behaviours may therefore be misconstrued as nagging through an assumption that provision and acceptance of help has an implication of failure. This is explored in the subtheme of *Burden; Independence*.

*i. Independence*

Participants regularly emphasised that managing T1D was their responsibility and that they were keen to prove their capability of doing this successfully:

*"I got diabetes when I was 12 and I, sort of, just tried to keep it independent since....it's always been my thing, I just like to keep control of it."* Panvi: 8

This desire to manage T1D successfully appeared to be associated with a sense of maturity and responsibility. Reliance on others appeared to be construed as juvenile and underdeveloped, whilst successful self-care was reflective of their status as emerging adults, particularly in the older adolescents:

*"I, kind of, take responsibility over that...because it's my thing, I guess. It's like (...) I'm not a kid or nothing and (...) I just can take care of it, so I do (...) really."* Lewis: 12

*"...that makes me feel really, really nice and positive about it 'cause it shows I can manage it, I can look after it."* Catherine: 719

It is potentially this determination to prove their worth as capable young adults that leads to a rejection of diabetes-specific support provided by peers. A desire for independence was frequently cited for one of the reasons for reluctance to seek support:

*"I'm very independent, so I don't think, it [talking to friends] doesn't really come into it."* Charlotte:

204

This therefore provides an additional mechanism through which support is perceived as nagging. However, despite assertions that the main motivator for independence was maturity, for some participants, their reasons for achieving self-sufficiency were still related to their rejection of the sick role and a desire to be "normal":

*"...you do it by the books, you get on with it, you've just got to be independent...you can't just rely on other people. It's always been the fact you can't be seen as not being normal and safely keep it to yourself, you keep independent."* Lewis: 16

*"...it's more just being independent and just getting on with it and I don't, I don't, I don't want people to be recognising me as 'diabetic kid' or whatever. It's just literally something I have, have got on with it. That's, that's how I feel about it, anyways."* Philip: 95

Therefore, for some participants, it is possible to conclude that even in striving for independence, a primary motivator is not to prove themselves as capable adults, but as “normal” adolescents.

#### **9.4. Discussion**

As outlined in Section 3.3.3., the understanding of the impact of social support in AWT1D is limited. Thus, in response to this paucity of knowledge, a series of hypotheses and research questions were proposed (Section 9.1.2 and 9.1.3.) which sought to provide a holistic account of the experience of peer support in AWT1D, and consequently make conclusions about the utility and experience of the support provided by peers. Using the results outlined in the previous section, each of the proposed hypotheses is subsequently addressed.

##### **9.4.1. Quantitative findings**

##### **9.4.1.a. Hypothesis 1: Global peer support**

- i. *Global peer support will be positively associated with self-care, but not glycaemic control.*
- ii. *That emotional support will have a stronger relationship with self-care than instrumental support.*

Previous research has offered conflicting findings with regard to global peer support, as seen in Section 3.3.3.c., with much research pointing to non-significant or limited impact of peer support on self-care (Palladino & Helgeson, 2012). This, however, did not appear to be present in the current participant sample and these findings contradict much previous research. Overall global peer support was positively correlated with both self-care and glycaemic control, suggesting a constructive role for non-diabetes related support in health outcomes. These findings build on those previously published by additionally distinguishing between subtypes of social support. Here, interestingly, whilst both emotional and instrumental support were found to be related to self-care, only instrumental support was negatively associated with glycaemic control. Therefore, whilst emotional support is related to engagement with self-care behaviours, only instrumental support is associated with an improved clinically-relevant outcome.

House (1981) defines emotional support as expressions of caring, whilst instrumental support is practical in nature. Emotional support may provide AWT1D with resources which enable effectual coping and increased self-efficacy, which indirectly support engagement with self-care. This has previously been seen in parental support in emerging adults with T1D (Helgeson et al., 2013). Hinder and Greenhalgh (2012) highlight the socially problematic nature of self-care for adolescents, and the importance of maintaining social standing. From this perspective, emotional support may offer a resource which AWT1D may utilise in their choice to engage in self-care in commonly encountered adolescent social situations, for example, at school. If emotional support increases perceptions of self-efficacy, AWT1D may use these beliefs

in their decision to enact appropriate self-care in the presence of their social group, via a belief that it will not damage their social standing as they believed themselves loved and cared for. However, the impact of emotional support is somewhat limited, as the relationship did not extend to glycaemic control. This may be due to emotional support being an expected norm of friendship (Helgeson et al., 2013). Thus, its presence may be less noticeable and influential than support behaviours which are not expected as a condition of friendship, such as instrumental support. However, the recognised problems with self-report information must also be recognised as a possible explanation for this. Whilst participants may have offered an idealised account of their self-care via the self-report measure, this is not seen in their HbA<sub>1c</sub>. Thereby, a simplistic explanation for this finding may be found in response bias.

Instrumental support was, however, related to glycaemic control. It should be remembered here that instrumental support is a facet of global peer support, not diabetes-specific support. Thus, although the support provided within this subtype is practical in nature, it is not necessarily exclusively related to self-care behaviours. Traditionally within research, instrumental support is more acceptable to males than females due to the perception of emotional support as a feminine requirement (Eagly, 2013). In the participant group, males had healthier glycaemic control ( $M=68.3\text{mmol/mol}$ ) in comparison to females ( $M=76\text{mmol/mol}$ ), though this difference was non-significant. This finding therefore may simply reflect support subtype preference within the participants with improved glycaemic control; males.

Alternatively, as with emotional support, instrumental support may operate as a resource for increased self-efficacy, which may bleed into other areas of life including self-care. This has been noted in previous research in participation in physical activity, particularly in males, those of low SES, and minority groups (M. S. Peterson, Lawman, Wilson, Fairchild, & Van Horn, 2012). Due to beliefs that instrumental support is easily accessed and readily available, participants may be more willing to engage in self-care, knowing that assistance is available should it be required.

However, despite the measure of instrumental support referring to global behaviours, participants were not instructed to exclusively recall instances of instrumental support that were unrelated to T1D in order to avoid counter-intentional cues. As such, it is possible that the instances which participants categorised as global instrumental support were actually more closely related to diabetes-specific support. The relationship here is therefore logical, as provision of instrumental support eases self-care. This aligns with previous research in which AWT1D were more than twice as likely to engage in self-care when supported by peers (Kyngäs, 2000). However, whilst the relationship between instrumental support and glycaemic control was significant, the same cannot be said of the findings for hypothesis 2, which lends argument to a fundamental difference between instrumental and diabetes-specific support behaviours.

#### **9.4.1.b. Hypothesis 2: Diabetes-specific support**

- i. *A relationship between diabetes-specific support and self-care will be found, though a direction cannot be determined from previous literature.*
- ii. *A relationship between diabetes-specific support and glycaemic control will be found, though a direction cannot be determined from previous literature.*

The findings in relation to diabetes-specific support produce unclear indications of its role, leading to these non-directional hypotheses (see Section 3.3.3.c.). Whilst the literature indicates an ambiguous relationship between diabetes outcomes and diabetes-specific support, within the present participant population no overall association was indicated. Only one significant relationship between the component behaviours of diabetes-specific support could be found. This group of behaviours, named *General Items*, refers to behaviours which may be considered closely aligned with emotional support, as rather than referring to practical behaviours, they denote encouragement and understanding. Therefore, the interpretations outlined for the results of hypothesis 1 are maintained by this finding.

Only one other study could be located noting a non-significant relationship between overall diabetes-specific support and glycaemic control (M. S. Smith, Maueth, Palmer, Pecoraro, & Wenet, 1991), which they indicated may be due to their small sample size ( $n=37$ ). Similarly here, these surprising findings may be due to Type II error given the underpowered nature of the population (see Section 8.2.), though the small effect sizes would indicate otherwise. A lack of significant findings between diabetes-specific support and self-care is, however, more common (Greco et al., 2001; Hains et al., 2007; La Greca, Auslander, et al., 1995; Naar-King et al., 2006; Pendley et al., 2002).

Several interpretations of this finding are possible. Firstly, it must be remembered that the measure of diabetes-specific support relies upon perceived support. Therefore, it is possible that adolescents' perception of support is simply inaccurate due to recall bias or demand characteristics (Hains et al., 2007). Alternatively, AWT1D may make poor use of the diabetes-specific support available to them from peers, either through ineffective utilisation of support behaviours or through interpreting increased support as aversive (Greco et al., 2001).

Finally, the support provided by peers may too be erroneous. Peers may lack knowledge regarding self-care, or may provide support which is inconsistent or lacking in specificity. The support provided may be neutral, or even encourage behaviours incongruent with self-care guidance (Wysocki & Greco, 2006). This potential for support behaviours which conflict with optimal self-care has been previously seen in interpreting non-significant relationships between diabetes-specific support and self-care (Naar-King et al., 2006; Pendley et al., 2002; Thomas et al., 1997), and may also be extended to glycaemic control in the present study. This growing

body of research indicates that education of peers in T1D may be crucial in aiding AWT1D in attaining optimal self-care, and research into the feasibility of interventions is warranted. This interpretation is supported by the findings of hypothesis 3.

#### **9.4.1.c. Hypothesis 3: Glycaemic control**

- i. Those with better glycaemic control (below average HbA1c) will report higher QoL and resilience.*

Previous research has highlighted the interrelated nature of QoL, glycaemic control and social support, with poor self-management and lack of social support strongly associated with poor QoL (G. Urquhart Law et al., 2013; J. Lawrence et al., 2012; Matziou et al., 2011; Valenzuela et al., 2006). Hypothesis 3.i therefore set out to confirm these findings in the present participant population, so that the role of QoL in the relationship between peer support and diabetes outcomes may be better understood. However, in the present sample, the findings were non-significant. This raises interesting questions about the QoL profile of the participant sample. In their validation of the WHO-5 measure in AWT1D, de Wit and colleagues (2007) cite an average score of 12.68 (63.38%). In the present sample, a mean score of 15 (75%) was found within the participants, suggesting a group above average in QoL. Therefore, the group appear to qualitatively differ from those in the previous studies which report the impact of QoL in the social support-diabetes outcome relationship.

Given the high indication of QoL within the participant sample, it would be logical to conclude that the population would also be high in resilience, and that it is potentially via this variable that participants are able to maintain QoL whilst living with T1D. This is a phenomena noted in the research (Burton et al., 2010; Whittemore et al., 2010; Yi-Frazier et al., 2010) that informed this hypothesis. However, non-significant findings are also acknowledged in the present sample, suggesting that those high and low in glycaemic control did not differ in terms of their resilience. These findings indicate that factors other than QoL and resilience are enacting influence on the observed relationship between peer support and diabetes outcomes, and bring into question the role of these psychosocial variables in terms of their utility in glycaemic control. However, to truly dismiss the influence of QoL and resilience, models proposed by Whittemore *et al.* (2010) and Hilliard *et al.* (Hilliard et al., 2012) were examined. Interpretation of these non-significant results is therefore reserved until these models are investigated in greater depth (see Section 9.4.1.d.).

- ii. Diabetes-specific support will differ, though a direction cannot be determined from previous literature.*

As outlined in Section 3.3.3.c., diabetes-specific support has been found to be highly related to diabetes outcomes, though the findings are ambiguous with the case for both a positive and



negative impact convincingly made (Palladino & Helgeson, 2012). This hypothesis, therefore, sought to identify potential differences in diabetes-specific support across those with above or below average glycaemic control in the present population. Seemingly paradoxically, it was found that those with poorer glycaemic control ( $>72.2\text{mmol/mol}$ ) reported greater diabetes-specific peer support.

Several potential explanations for this finding are outlined. Simply, it may be that those with below average glycaemic control receive greater diabetes-specific peer support due to an awareness of their potential mismanagement of T1D. However, literature indicates low levels of disclosure of poor HbA<sub>1c</sub> to peer groups, suggesting that peers would be unaware of this lack of glycaemic control (Helgeson & Novak, 2007). This interpretation would align with parental support more readily, therefore, than with exclusively peer-based support, as the present measure indicated.

A second interpretation of this finding can be seen in the potential for these diabetes-specific support behaviours provided by peers to be ill-informed. As with hypothesis 2, it could be suggested that the diabetes-specific support behaviours engaged in by peers are inappropriate and not in accordance with current care guidance, or may offer support which is inconsistent and unreliable (Naar-King et al., 2006; Pendley et al., 2002; Thomas et al., 1997). However, the DSSQ-Friends specifically related to behaviours which healthcare professionals recommend as those which will optimise improvement of glycaemic control, and therefore should eliminate potentially erroneous supportive behaviours, such as those regarded as “normal” adolescent behaviour (Pendley et al., 2002).

A third interpretation concerns the potential for the behaviours cited by the DSSQ-Friends, and thereby the healthcare profession, as supportive are construed by AWT1D as harassing. The support behaviours previously identified as perceived as nagging (Luyckx et al., 2013; J. E. Spencer, Cooper, & Milton, 2013) align closely with those detailed by the DSSQ-Friends and NICE guidance as beneficial (National Institute for Health and Care Excellence, 2015). Previous research has highlighted that seemingly innocuous behaviours, such as reminders to check blood glucose levels, have been interpreted as intrusive and an accusation of incapability by adolescents when delivered by parents (Seiffge-Krenke et al., 2013). It is possible that these behaviours elicit the same reaction when conveyed by peers.

This interpretation may operate via several mechanisms. It has been suggested that misconstruing parental support as nagging is related to feelings of burden, guilt and frustration, primarily at the impact that T1D has had on those within the family of the AWT1D (Gray et al., 2013). There is potential for this mechanism to spread to those in the wider social network, given the transfer of social support from family to peer group within adolescence (Galvan et al., 2006). Adolescents may feel that minimal engagement with self-care will allow for the

maintenance of family life as it existed prior to diagnosis, and therefore diabetes-specific support behaviours serve to bring T1D to the forefront of the family dynamic once more, reigniting guilt. This same potential mechanism is one which may be extended to the peer group, in which non self-management behaviours allow for continuation of the social network without alteration.

An alternative, though complimentary, mechanism is highlighted by Dovey-Pearce and colleagues (2007). Qualitatively, these diabetes-specific support behaviours were said to reinforce stigma and difference within the self-concept of the adolescents, which they ultimately rejected. The self-concept is the pattern of personal attributes associated with the sense of self, confirmed in social experience, emotions, thoughts and behaviours (Charmaz, 1983). What adolescents appear to engage in is rejection of the sick role from the self-concept. The sick role is an adjustment to the self-concept in which the identity is no longer one of a healthy individual, but one who is ill. The sick role is associated with behaviour involving seeking treatment, withdrawal from behaviours which may prolong or exacerbate ill health, and taking medication (Kasl & Cobb, 1966). Regarding AWT1D, the behaviours highlighted as nagging reflect those emphasised in the DSSQ-Friends, including peer-monitoring, purchasing low sugar foods, and highlighting self-care behaviours (Dovey-Pearce et al., 2007). Therefore, diabetes-specific behaviours may actually actively encourage non self-management (Hinder & Greenhalgh, 2012) by threatening the self-concept of the adolescent from that of a “normal” adolescent towards the sick role. This interpretation may align well with that of Gray and colleagues (Gray et al., 2013), in which the “normal” adolescent self-concept is one heavily reliant on ordinary social interactions, which are incongruent with self-care behaviours. Therefore, at the root of the interpretation of well-intentioned support behaviours as nagging may lie a desire to be a normal adolescent. This is explored more fully alongside the qualitative findings in Section 9.4.2.

#### **9.4.1.d. Hypothesis 4: Quality of Life**

*Quality of life mediates the relationship between social support and diabetes outcomes.*

Hilliard and colleagues (2013) proposed a model in which QoL predicts engagement with self-care and glycaemic control. Hilliard *et al.* (2013) indicate reduced QoL acts as a barrier to accessing resources such as social support, and thereby indirectly lessens glycaemic control (see Section 6.3.). However, mediation analysis of QoL revealed it to be a non-significant predictor of glycaemic control and self-care, as QoL was not suggested as a predictor of either outcome measure.

Several explanations for this are possible. Firstly, the measure of QoL used was the WHO-5. Primarily, this instrument was designed to assess well-being as opposed to QoL.

Although QoL is considered a determinant of well-being (Dodge et al., 2012), nevertheless these are two separate, though closely related constructs. Use of a QoL measure, such as the WHOQoL, may offer results supportive of the model. However, the use of the WHO-5 was recommended by experts in the field, and allowed for depression screening (Krieger et al., 2014) without inclusion of an additional tool in what may already be considered a relatively laborious questionnaire battery. Therefore the use of the WHO-5 remains warranted.

A second explanation lies in the level of peer support reported by participants. The average global peer support score of the participants was high ( $M=26.79$ ) in comparison to previous uses of the BSSS with long-term health conditions ( $M=24$ , Schulz & Schwarzer, 2003). It is crucial to remember that this model assesses overall QoL, not HRQoL. Whilst HRQoL is primarily concerned with health status (Peterson et al., 2006), QoL is a far broader concept (The WHOQOL Group, 1995). Studies have suggested that general QoL in AWT1D has multitudinous predictors, only few of which are associated with health factors. Other more pertinent factors include demographic characteristics alongside psychosocial factors such as social support, family environment, self-esteem and depression (Abolfotouh, Kamal, El-Bourgy, & Mohamed, 2011). Given the above average peer support reported by participants, these results could suggest that psychosocial factors are a more influential predictor of overall QoL than health status. These findings therefore reflect the conclusions of de Wit *et al.* (2007), who suggested that satisfaction with social support was more influential in the perception of QoL than living with T1D.

A final alternative interpretation for these findings can be seen in response bias. Participants were aware of the purpose of the study from the outset, and may therefore have implicitly felt the need to amplify their perceptions of both their psychosocial experience in order to lessen the apparent impact of T1D.

Overall, however, these findings suggest that the model proposed by Hilliard and colleagues (2013) is simply inaccurate in the present participant sample, and that factors other than QoL serve as the mechanism through which peer support is related to diabetes outcomes. The role of QoL in AWT1D is contested within the literature, with ambiguous findings both supporting (G. Urquhart Law et al., 2013; J. Lawrence et al., 2012; Matziou et al., 2011; Valenzuela et al., 2006) and dismissing (Hoey et al., 2001; Laffel et al., 2003; McMillan et al., 2004) its influence. These findings add to the body of research which indicates the complexity of psychosocial experience of health, and suggests that it is unlikely that one variable is able to serve as a mediator in isolation.

#### **9.4.1.e. Hypothesis 5: Resilience**

*Resilience mediates the relationship between social support and diabetes outcomes.*

Whittemore and colleagues (2010) propose a model of resilience in T1D in which demographic characteristics and treatment modality interact with psychosocial responses and family characteristics to produce resilience. Therefore, the model offers a potential indirect mechanism through which peer support is related to diabetes outcomes via resilience (see Section 6.5.). Like the model of QoL previously, this informed hypothesis 5 and allowed for mediation analysis of the influence of resilience. Similarly, analysis revealed resilience not to be a significant mediator of diabetes outcomes, as it was not found to be significantly related to either self-care or glycaemic control.

A potential explanation for these findings may lie in the level of resilience assessed in participants. The participant group appeared exceptionally low in resilience ( $M=26.52$ ) in comparison to others using the CD-RISC 10 in healthy adolescent populations ( $M=31.78$ , Prince-Embury & Saklofske, 2013). Unfortunately studies using the CD-RISC 10 in AWT1D did not report mean values, and therefore comparison cannot be made (Patel, 2013). Nevertheless, this finding does suggest that participants may be low in resilience in comparison to other samples, though given the limited research assessing resilience in AWT1D (see Section 6.5.) this is difficult to assess. If the participants are low in resilience, their experience may not be able to be considered comparable and therefore not reflective of the wider population, as research has noted significant influence of resilience in AWT1D (Yi et al., 2008). Again though, the paucity of research into the resilience of AWT1D must be noted (Yi-Frazier et al., 2013) and these findings contribute to a growing picture of this psychosocial variable.

These findings may also indicate that the very definition of resilience is incorrect. Resilience is considered in the literature concerning AWT1D using a protective factors model, in which contributory assets, including social support, pragmatism and acceptance (Yi-Frazier, Smith, Vitaliano, & Yi, 2010) produce resiliency. This suggests a conceptualisation of resilience in which it is the sum of the benefits of various psychosocial variables. However, some research has considered resilience as a personality trait (Friborg, Barlaug, Martinussen, Rosenvinge, & Hjemdal, 2005). If this is the case, factors contributing towards the manifestation of personality trait are intrinsic to the individual and not external (Burger, 1997) and thus it is unlikely to be related to factors such as social support. Potentially, then, the model proposed by Whittemore *et al.* (2010) is based on an erroneous conceptualisation of resilience which assumes that external factors are able to influence the formation of a characteristic quality.

Taken together, the results of hypotheses 4 and 5 suggest a difference in the characterisation of social support between family and peers. Family support has been conceptualised as allowing for resilience and well-being when confronted with challenge

(Baptista, Neves, & Baptista, 2008). Whilst this may be the case for family support, the evidence of this study suggests that peer support provides a fundamentally different utility. Whilst the mediating role of QoL and resilience may be seen if research were to focus on family support, they have not been maintained in the present study, suggesting an alternative role for peer relationships in AWT1D. Whilst the utility of peer support has therefore been unable to be uncovered by quantitative results, the qualitative findings provide greater illumination regarding the action of social support in AWT1D.

#### **9.4.2. Qualitative research question**

*“What is the meaning and experience of social support in AWT1D?”*

The results of tests of the quantitative hypotheses indicate a complex role of peer support in disease management. Global peer support appears to be more influential in its association with diabetes outcomes than diabetes-specific support, with those with poorer glycaemic control reporting significantly more diabetes-specific support than their counterparts. The findings also indicate that, contrary to literature, the mechanism of operation for social support does not include a central role for QoL or resilience, leaving the question remaining as to how peer support might be utilised. Due to the embedded nature of the qualitative research question (see Section 7.4.3.), the primary function of the qualitative findings is therefore to explain and provide context to these results.

Contrary to previous research, the quantitative findings do not indicate utility of QoL or resilience in the mechanism of operation of social support. This is potentially explained by the *Support* overarching theme. Participants indicated a central role of appraisal support in their peer relationships, particularly in the form of humour, stating that this allows for normalisation of self-care behaviours. Instrumental support was minimised to the subtheme of *The Safety Net*, in which participants reduced diabetes-specific support behaviours to diabetes emergencies only. This may be explained through symbolic interactionism, in which the self-concept is maintained through social relationships (Charmaz, 1983, 1995). This suggests that AWT1D use peer support for the attainment and maintenance of a “normal” adolescent identity, in which they participate in activities they perceive as ordinary to their developmental stage, as opposed to sick role behaviours related to T1D. This is supported by the research of Dovey-Pearce *et al.* (2007) who consider the impact of diagnosis and self-care on the self-concept of AWT1D, stating that it can have a devastating impact on the self-concept, via integration of the sick role and a life-long impact perceptions within the personal identity. This may be mediated by the maintenance of the pre-diagnosis self through peer relationships, allowing for continuation of normality and sense of self, integrating the findings of Dovey-Pearce *et al.* (2007) with symbolic interactionism (Charmaz, 1983, 1995).

For some, this maintenance of the self-concept led to non self-management, whereby in the presence of peers adolescents neglected self-care in order to maintain normality. This was most strongly seen in those with poorer glycaemic control. This is a consistent finding in literature into AWT1D and is well-supported, though rarely sufficiently explained beyond peer pressure (Borus & Laffel, 2010; Croom et al., 2011; R. Gillibrand & Stevenson, 2007; Glasgow, Toobert, & Gillette, 2001; Hernandez-Tejada et al., 2012; M. Peyrot et al., 2005). Dovey-Pearce *et al.* (2007) highlight the balance in self-care employed by participants, in which both engagement and avoidance are active process allowing for effective coping with the devastating effects of diagnosis and acknowledgement of mortality on the self-concept. This is also reflected in Hinder and Greenhalgh's ethnographic work (2012) in which engagement with self-care was highly dependent on social context, in which the appropriate behaviours were only enacted when perceived as achievable and socially acceptable. The requirement to plan menus, restrict dietary content, adjust medication dosage and keep written records of their progress were said to be particularly problematic in the macro environment of T1D management, and were frequently observed by the researchers as those most likely to be ignored. A need to maintain a coherent identity and a "normal" social life was cited by Hinder and Greenhalgh (2012) as being the most influential factor in the active choice to disengage with self-care.

This same interpretation also allows for explanation of the quantitative findings in which participants did not find diabetes-specific support behaviours effective and, according to the results of hypothesis 3.ii, were associated with poor glycaemic control. The very behaviours outlined in the DSSQ-Friends scale were highlighted by participants as those which constitute *Nagging* and encouraged non self-management. This was explained in depth through the two subthemes *Looking At You Like You're Different* and *It's Not Something You Can Understand Unless You Have It*. Through *Looking At You Like You're Different*, it is seen that at the heart of rejection of supportive behaviour lies a sense of difference. By enacting diabetes-specific support behaviours, peers are reinforcing the sense of difference that research suggests AWT1D have already integrated into their self-concept. Dovey-Pearce *et al.* (2007) highlight that a sense of difference is incorporated into the self-concept almost immediately after diagnosis. AWT1D alter their personal identity in relation to their peers, negatively impacting the self-concept and creating stigma. Thus, even well-intentioned, seemingly innocuous behaviours may reinforce stigma. This phenomena appears to operate cross-culturally, having also been outlined in the USA, where participants have highlighted that peers enquiring after the welfare of AWT1D has felt stigmatising (Buchbinder et al., 2005). This perception of difference may conversely encourage active non self-management, in which AWT1D attempt to regain and prove the "normal" self-concept via increased disengagement with self-care. Thereby, receiving unsolicited diabetes-specific behaviours may contribute towards poor glycaemic control.

This central idea is further examined in *It's Not Something You Can Understand Unless You Have It*. Here, diabetes-specific support behaviours were more likely to be accepted if the provider also had T1D. Indeed, of the few interventions in AWT1D utilising peer mentoring, those receiving group medical appointments (B J Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989), group skills training (Grey, Boland, Davidson, Li, & Tamborlane, 2000), or allocation of a peer mentor (Lu et al., 2014) reported improvement of diabetes outcomes due to increasing acceptability of advice and improvement in health literacy. A further explanation may lie in the phenomena is identity fusion (Swann, Jetten, Gómez, Whitehouse, & Bastian, 2012). Identity fusion is stated to stem from a merging of personal and group identity, in which the boundary between the personal and social self becomes porous, promoting strong relational ties (Swann et al., 2012). According to the principle of extended identity fusion, this can occur with individuals who have no personal relationship, but for whom a salient shared quality presents a sense of cohesion. The extended fusions facilitate pro-group behaviour (Swann et al., 2012). When applied to these findings, AWT1D may experience extended fusion with other people with T1D, and may therefore experience advice and diabetes-specific support provided as in-group behaviours which will serve to better represent the entire group identity, rather than their personal identity. Such experiences have been suggested to exist in ethnic and shared value groups (Swann et al., 2012), and has been investigated in family and military social integration (Sani, Herrera, Wakefield, Boroch, & Gulyas, 2012). It is logical to conclude similar incidents may be present in illness identity. Further research into the concept of identity fusion in AWT1D is warranted.

These findings may also be explained by the utilisation of the self-concept, in which acknowledgement of shared experience reduces stigma and fear of judgement. However, the consequence of this appeared to be increased rejection of diabetes-specific support when provided by healthy peers, particularly when these behaviours were unsolicited. Research has highlighted the need for AWT1D to have mastery over diabetes-related discussions and social resources in peer relationships. Schur *et al.* (1999) acknowledges the potential for peers to provide normative experience, on the condition that the support offered is in line with the requirements of AWT1D. Indeed, Meijer, Sinnema, Bijstra, Mellenbergh, and Wolters (2000) highlight the continual need for renegotiation of friendship boundaries in adolescents with long-term health conditions, reflective of the changing nature of self-care and therefore support needs.

An alternative explanation for the interpretation of diabetes-specific support behaviours lies in the overarching theme of *Burden*. This theme explored the reasons for participants' reticence to engage peers in self-care. Participants expressed concern that adaptation to peer activities and relationships which would ease self-care would be considered troublesome and

create a strain on the friendship. This belief has been seen previously in research (Buchbinder et al., 2005; Peters, Nawijn, & van Kesteren, 2014) and has been associated with supportive behaviours being misconstrued as an infringement on autonomy. This is potentially an expansion of the guilt and frustration expressed by participants at the impact their diabetes management has had on their relationships. This is expressed by participants in terms of family relationships, which too have been found in previous research (Gray et al., 2013). Here, participants also appear to extend these negative emotions to peer relationships, and express a desire to manage diabetes in isolation in order to minimise the impact on peer networks. This is more fully explored in the subtheme of *Independence*, in which participants stated belief that self-care was their responsibility alone.

The emphasis of achieving autonomy in diabetes management is one which older adolescents hear frequently (see Section 6.3.3.). With parental relationships, supportive behaviours during the achievement of autonomy are frequently perceived as nagging (Allen et al., 2011; Lancaster et al., 2010; Ritholz et al., 2013), qualitatively associated with an implication that the adolescent is incapable of achieving optimal self-care alone (Dickinson & O'Reilly, 2004). This has also been seen in one previous study into adolescent support (Peters et al., 2014) though it was not fully explored. These findings would suggest that the same consequences of parental involvement during the transition to autonomy are applicable in peer relationships; that supportive behaviour is perceived as an implication of failure (Allen et al., 2011; Dickinson & O'Reilly, 2004). Indeed, previous research has highlighted that adolescents see self-care as a highly personal construct, which increases perception of support as interference (Karlsson et al., 2008). This association may explain the limiting of acceptable diabetes-specific support to emergency situations only; participants believe that they could and should be able to manage their diabetes without support. This is potentially associated with normative adolescent development. Typically, adolescence is characterised by attaining autonomy and establishing an adult identity (Sawyer et al., 2012). A key element of this is demonstrating capability and responsibility as a maturing young adult. Adolescents will frequently be required to prove their responsibility, both at school and at home (Bukatko, 2007). It is therefore potentially unsurprising that adolescents feel the same pressure to prove themselves as capable in their management of a long-term health condition. However, that is not to say that this desire for total autonomy is not damaging. Indeed, in some participants, it is potentially this desire to achieve independence that influences lack of illness disclosure towards peers, thereby minimising the support available and reducing the likelihood of engagement with self-care. With parental relationships, continued monitoring of self-care was associated with improved glycaemic control when self-care was perceived as a collaboration between parent



and adolescent (Allen et al., 2011). Therefore, if similar collaborative relationships could be conceived with peers, support may continue without the neglect of an autonomous identity.

However, this desire of true autonomy may still relate to the self-concept. In a recent qualitative exploration of the experience of social support in AWT1D living in Holland, Peters *et al.* (2014) attribute the drive for independence to participants not wanted to be seen as ill or helpless. Although the authors fail to attribute this concept to the sick role, these factors clearly align with this concept (Kasl & Cobb, 1966). One participant in the present thesis openly stated that self-sufficiency facilitates comparability of his relationships, and therefore an alternative explanation for the desire for autonomy may be seen in striving for a normative self-concept. Participants do not wish to be viewed as patients. By being seen as successfully managing diabetes and therefore minimising its impact on their lives, they may best achieve the goal of living an ordinary adolescent life whilst also maintaining health. Arguably, this is the adaptive approach, counterbalanced by the denial of self-care in order to achieve normality explored earlier. Although further research is required in order to fully assess this supposition, it may be that by emphasising the minimal impact effective self-care can have on identity would be a greater motivator towards maintaining glycaemic control than the current health discourse.

#### **9.4.3. General discussion**

When taken together, these findings suggest a complex role for peer support in the lives of AWT1D. In the present sample, the role of QoL and resilience were not found to be mediators of the relationship between peer support and diabetes outcomes. Therefore, the question of how psychosocial variables are related to self-care and glycaemic control remains open, and is more fully explored in the subsequent study chapters.

Overall, global peer support has greater association with diabetes outcomes than diabetes-specific support. Whilst an apparently paradoxical finding, this is supported by literature (Buchbinder et al., 2005; Dovey-Pearce et al., 2007; Peters et al., 2014) and qualitative themes, which suggest that diabetes-specific support behaviours constitute nagging. Using symbolic interactionism (Charmaz, 1983, 1995), the qualitative findings suggest that this is related to rejection of sick role behaviours from the self-concept in the presence of peers. Indeed, it is suggested that whilst the measurement of emotional and instrumental facets of social support produced differing results (see hypothesis 1), it is potentially appraisal support which adolescents most often receive from peers. Qualitative findings suggest that humour is essential in peer relationships when confronted with T1D, which is allied more closely to appraisal support than other facets. Whilst one other study could be found discussing the use of humour in peer relationships within AWT1D (Peters et al., 2014), the authors erroneously categorised this behaviour as emotional support. As outlined in Section 3.2., emotional support

is the feeling of being cared for, whilst appraisal support allows for readjustment of the evaluation of a situation. Humour regarding self-care behaviours is, therefore, most closely associated with appraisal support. Few studies have distinguished between the subtypes of global social support in T1D research, and none could be found specifically addressing appraisal support. These findings suggest that appraisal support may be highly related to diabetes outcomes, and therefore warrants further investigation. It is suggested that appraisal support operates by allowing for a normative self-concept, and thereby increasing acceptability of self-care behaviours.

It is also suggested that behaviours perceived by adolescents as nagging may be related to a desire for autonomy. Self-care would appear to be more appealing if the emphasis is placed on the minimal impact T1D places on the social life, if properly managed. Further research is needed to confirm these suppositions.

#### **9.4.4. Limitations**

The present study has various strengths and limitations. The use of a mixed methods approach in the study of social support in AWT1D is novel, and allows for both a holistic approach to the fluid concept of social support (Lourel et al., 2013) and for further illumination of quantitative findings. Limitations lie in the underpowered sample size (see Section 8.2.) and in the potentially skewed levels of psychosocial variables collected (see Section 9.4.1.). Participants appeared above average in global peer support and QoL, whilst low in resilience. In addition, few participants using CSII pump treatment modality were recruited, which has previously been found to be related to both QoL and resilience (Hilliard, Goeke-Morey, Cogen, Henderson, & Streisand, 2009; McMahon et al., 2005; Pihoker et al., 2013; Valenzuela et al., 2006). Therefore, the results presented here may not be representative of the wider population and therefore limited in terms of their generalisability. However, the participant sample present relatively diverse demographic characteristics, including a range of self-care engagement and level of glycaemic control, and thereby the sample is not so limited as to be worth disregarding.

A further limitation lies in the self-report nature of the questionnaires, leaving the data open to response bias. However, given the limitation of the underpowered sample, it is likely that more robust methodology (such as peer-rated confirmatory measures of psychosocial variables) would have further reduced participant numbers. Nonetheless, the cross-sectional nature of this research must also be brought into question due to the limitation that this places on causal relationships. Whilst peer support and outcome measures were ultimately related, it cannot be stated objectively that these variables are influential. To elucidate the direction of this relationship, an intervention designed to improve peer support would be required to assess the impact on diabetes outcomes. Some studies completing such research have found promising

results indicating a causal relationship (Ellis et al., 2005; Greco et al., 2001; Wysocki, Greco, Harris, Bubb, & White, 2001b), lending support to this assumption, though no interventions utilising existing peer relationships could be located in a UK population. Further investigation is therefore warranted, with a full systematic review of intervention studies presented in Appendix T.

Finally, as time since diagnosis was not collected, this cannot be assessed as a variable of interest. Previous research has shown that disease duration is influential in crucial psychosocial variables such as adjustment (Austin et al., 2011; Chao et al., 2014; Lehmkuhl et al., 2009; Matziou et al., 2011), and thereby may also impact on the utility of peer support and its role in diabetes outcomes. Future research should consider disease duration in order to better understand how the association between social support and diabetes outcomes may change over time.

#### **9.4.5. Clinical implications**

Overall, these findings suggest that the current support behaviours outlined in the guidance may need adaptation. Few specific mentions to social support in AWT1D are made within the guidelines, and those that relate explicitly to diabetes-specific behaviours (National Institute for Health and Care Excellence, 2015). These findings suggest that such support is unhelpful, and may even be damaging, in terms of aiding adolescents to reach and maintain optimal self-care and glycaemic control. The person-centred nature of care must also remain central. NICE guidance for the care of those with diabetes has recently been criticised by healthcare professionals for not truly incorporating a person-centred approach (Middleton, 2015), which these findings lend credence to. AWT1D appear to be struggling to assimilate T1D within their self-concepts, with potential that emphasis on the minimal role T1D plays in their social lives if appropriately cared for best associated with achieving and maintaining glycaemic control. A care plan devised with a holistic view towards the adolescent's lifestyle in mind may be beneficial in achieving this attitude. Care plans incorporating education, career aspirations, family and social life, alongside self-care, may best allow for the incorporation of T1D into the self-concept through emphasis of a whole person approach. The care plans should aim to emphasise the minimisation of the impact of T1D on other areas of life in order to promote effective self-care. Such care plans have previously been championed (Dovey-Pearce et al., 2005), and newly introduced guidance highlights the incorporation of life goals into care plans (National Institute for Health and Care Excellence, 2015). Further expansion of guidance may, therefore, be warranted.

Though person-centred approaches within healthcare have existed in the guidance for many years, anecdotally, conversations took place between healthcare professionals and

AWT1D whilst completing data collection that did not comply with such guidance. Conversations often centred around T1D, with the motivator for improving self-care the threat of micro and macrovascular complications in later life. Such use of threat in AWT1D has been found to increase a sense of challenge to the self-concept, leading to withdrawal and non self-management behaviours as a means of protection (Sayer, Hauser, Jacobsen, Willett, & Cole, 1995). Future research should assess current acceptance of clinical guidance within healthcare settings, as if current patient-centred approaches to care are not acceptable to staff, such radical changes to care plans are unlikely to be effectively adopted.

#### **9.4.6. Original contribution**

In addition to clinical implications, the findings presented here offer an important contribution to theoretical knowledge. The quantitative findings offer 3 clarifications. Firstly, whilst the body of previous literature has been unable to determine a relationship between peer support and glycaemic control (Helgeson, Lopez, & Kamarck, 2009; Skinner, Hampson, John, & Hampson, 1998; Skinner, John, & Hampson, 2000), this study presents findings which indicate that instrumental support, specifically, is related to improved HbA<sub>1c</sub> (see Section 9.3.1.a.). This suggests that a neglect in the literature to isolate specific facets of global social support in the analysis (Palladino & Helgeson, 2012) may explain the mixed findings. A further suggestion of the role of appraisal support is indicated by the qualitative findings, which warrants further investigation (see Section 9.4.2.). Secondly, the ambiguous literature in relation to diabetes-specific support is clarified. The failure of previous studies to elucidate a relationship between diabetes-specific support and health outcomes (Palladino & Helgeson, 2012) is suggested to interact with the potential for this support to be associated with behaviours perceived as nagging (see Sections 9.3.2.a. and 9.4.2.). Finally, the investigation of the models of the mediation of social support presented by Hilliard *et al.* (QoL; 2013) and Whittemore *et al.* (resilience; 2010) are suggested as inaccurate in adolescent populations (see Sections 9.3.3. and 9.4.1.).

Qualitative findings also present further contributions to knowledge. Whilst previous research has qualitatively investigated the perception of support as nagging in familial relationships (Luyckx *et al.*, 2013; Seiffge-Krenke *et al.*, 2013; J. Spencer *et al.*, 2010; Weinger *et al.*, 2001), none could be located offering the same explanation in peer relationships. The qualitative findings suggest that the perception of nagging is also present in peer networks, and that it may be related to factors both different (normality within the self-concept; see Section 9.4.2.) and similar to (achievement and maintenance of autonomy (Seiffge-Krenke *et al.*, 2013; see Section 9.4.2.) parental support. Previous literature highlighting the importance of the self-concept within AWT1D (Dovey-Pearce *et al.*, 2007) is also expanded upon to include the

importance of instrumental support in diabetic emergencies, ingroup/outgroup behaviour and the perceived burden of T1D on the social network (see Section 9.4.2.).

#### **9.4.7. Conclusion**

Participants indicate that various types of peer support are received as a matter of course within self-care. Adolescents differed in their attitude towards peer support, particularly in terms of the specific support behaviours enacted and the health status of those providing support. Whilst global peer support appears to be preferred by AWT1D, and most often associated with improved outcome measures, diabetes-specific behaviours are not perceived as supportive, and are misconstrued as a threat to autonomy and the self-concept.

These findings lend support to the adaptation of NICE care plans to a truly person-centred approach, and should incorporate further personal information in order to demonstrate to AWT1D how self-care can fit within a wider social context. As those with the greatest knowledge of theory, health psychologists employed in paediatric wards are thereby best placed to be central to the design and utilisation of such care plans. An essential facet of these may be a peer support intervention. Previous research lends credibility to the value of interventions utilising existing friendships and peers with T1D in self-care (Ellis et al., 2005; Greco et al., 2001; Wysocki et al., 2001b). Such interventions may allow for education regarding accessing appropriate support in view of their need for normalisation of self-concept and autonomy. These findings suggest that skills such as discussing diagnosis, conducting self-care in public and requesting support when required would all be beneficial. At present, AWT1D appear reticent to engage in these behaviours due to a fear of burden and stigmatisation. There is potential that addressing this fear of stigma may increase self-care (Peters et al., 2014). In addition, these results emphasise the acceptability of advice provided by peers with T1D, making mentoring programmes an excellent candidate for future research. Indeed, new NICE guidance makes a specific call for research investigating peer-based education programmes in this age group (National Institute for Health and Care Excellence, 2015).

Ultimately, these findings suggest a convincing association between global peer support and diabetes outcomes in AWT1D. However, the precise mechanism through which peer support achieves this remains questionable. QoL and resilience, mediators proposed by previous research (Hilliard et al., 2013; Whittemore et al., 2010), were not found to be significant predictors of outcomes in the present sample. Therefore, the mechanism of operation of peer support remains undiscovered. Previous research has suggested a role for OT in health outcomes due to its role in the down-regulation of the HPA axis (Norman, Hawkley, Cole, Berntson, & Cacioppo, 2012; Uchino, Bowen, Carlisle, & Birmingham, 2012; see Section 4.6.).

The potential model through which OT may be related to glycaemic control is outlined in Section 4.6.2. and 7.4.2.a. This is empirically investigated in the subsequent study chapter.

## Chapter 10: Study 2

### Exploring the biological effects of social bonding on glycaemic control in adolescents with type 1 diabetes

#### 10. Overview

The following chapter details the second study in this doctoral thesis. The rationale and hypotheses for this research can be found in the subsequent section. The methods employed are also discussed, expanding on the information given in Chapter 8 by providing a systematised review of preceding studies using salivary OT ELISAs so that expected concentrations of this biomarker can be determined. This is followed by details of the statistical analyses applied and the results that were ascertained. The chapter concludes with a discussion of the main findings, methodological limitations of Study 2, and the implications of these for clinical practice and theory.

#### 10.1. Introduction

OT presents an increasingly intriguing potential mechanism by which social bonding may be able to impact on health. Both human and animal studies have cited the ability of OT to down-regulate the HPA axis, and subsequent immunocompromising glucocorticoids, as a convincing hypothesis for such a mechanism (Hostinar et al., 2014). It is perhaps surprising, then, that no studies could be found examining the relationship between OT and T1D. This study chapter, therefore, aims to address a speculative theory outlined in Section 4.6.2. In this theory, the increased circulating blood glucose associated with cortisol release (Khani & Tayek, 2001; Marieb & Hoehn, 2014) is suggested as potentially damaging for effective glycaemic control, given its contribution towards hyperglycaemia (McCowen, Malhotra, & Bistrrian, 2001). Those with increased cortisol levels are therefore suggested as being at greater risk of poor glycaemic control and diabetes complications (Giacco & Brownlee, 2010). Given the acknowledged ability of OT to down-regulate cortisol release via its action on the HPA axis, it is suggested that increased social bonding (as indicated by OT) is able to moderate cortisol and thereby make maintaining optimal glycaemic control an easier and more realistic goal. This speculative theory will be analysed in the present study.

Previous research has also suggested that the neuroendocrine response to stress and social support may be sexually dimorphic (DeVries et al., 2003; Grewen et al., 2005; Clemens Kirschbaum, Klauer, Filipp, & Hellhammer, 1995; Takai et al., 2007). Although unconfirmed in T1D populations, healthy adult studies have suggested that the response of males and females to laboratory stressors and partner provided support is gender specific. Males experience greater cortisol increases to acute psychological laboratory stress, attenuated by support provided by strangers, and to a greater extent, romantic partners (Clemens Kirschbaum et al., 1995). Conversely, females experience a reduced stress response, though salivary cortisol is not

mitigated by the support of strangers, and is increased by the support provided by a romantic partner (Clemens Kirschbaum et al., 1995). Despite this, evidence suggests females are more likely to experience reduced cardiovascular stress-reactivity in response to increased OT (Grewen et al., 2005), though no studies could be identified investigating this effect with respect to cortisol. These findings suggest that females evaluate support provided by partners as more effective than males, and may consider the support behaviours as advantageous even when objectively ineffective, in which social desirability is likely to play a significant role (Day & Livingstone, 2003; Haber, Cohen, Lucas, & Baltes, 2007). Literature, therefore, suggests a sexually dimorphic biological response to both stress and social support, which must be addressed in the present study.

Thirdly, given the results of the previous study (see Chapter 9), it is considered important to assess whether a difference in the psychophysiological response to social support is present in those with above or below average glycaemic control. Previous research has suggested that increased stress is predictive of poorer glycaemic control in AWT1D (Gray et al., 2013; Neylon et al., 2013). As outlined in Section 6.4., life event (Nygren et al., 2015), daily (Baucom et al., 2015) and adolescent-specific stressors (Helgeson et al., 2010) have been found to have a negative effect on glycaemic control in AWT1D. Engaging with peer support as a coping mechanism for stress has been found to be associated with improved glycaemic control, adherence (Wiebe et al., 2005), and fewer depressive symptoms (Berg et al., 2007). As such, it is suggested that differences in glycaemic control will be echoed in differences in both cortisol and OT.

Finally, as outlined in Section 4.5.3., no studies could be found examining filial attachment from an affiliative perspective using OT as a biomarker in adolescents. Whilst one study is acknowledged in which parental OT and synchronous interaction were assessed in children, suggesting that OT reactivity is determined in early childhood via parental attachment (Feldman, 2012). These results are limited in their application to the current population given the variation that is likely to occur in social bonding due to the differing developmental stages and health conditions (see Section 3.3.). Therefore, this study will also assess the efficacy of salivary OT to act as a biomarker of affiliative filial attachment, or peer support, particularly in AWT1D.

This second study was conducted to approach the potential role of peer support in glycaemic control from a biological standpoint. This was considered prudent for two purposes. Firstly, to expand and substantiate the findings of Study 1, in which global peer support was found to be associated with improved self-care and glycaemic control. It is considered important to investigate whether these psychosocial findings translate to a biological consequence, given the poor health outcomes found in this age group (National Diabetes Audit,



2014). Secondly, this study provides an investigation of the use of Cohen & Wills' stress-buffering theory of social support (1985) in this population. The stress-buffering hypothesis (S. Cohen & Wills, 1985) itself was investigated in T1D in the years after its theorisation using psychosocial variables, lending support to the psychosocial role of peer support (Cox et al., 1984; Hanson & Pichert, 1986; M. F. Peyrot & McMurry, 1992). However, due to recent advances in biomarker analysis, this study is able to investigate the stress-buffering role of social support from a psychophysiological standpoint. Whilst the psychosocial effect of social support on cortisol has previously been investigated (Clemens Kirschbaum et al., 1995), the reliable analysis of endogenous OT is a comparatively recent innovation (Carter et al., 2007), and as such no literature investigating the role of OT in the stress-buffering hypothesis (S. Cohen & Wills, 1985) could be located. This chapter describes the analysis of the biomarkers of social support (OT) and cortisol in the clinical participant group, in conjunction with glycaemic control and self-care measures. It will also investigate potential gender and diabetes care differences in the role of peer support in the stress response.

#### **10.1.1. Aims and objectives**

With this in mind, the aim of this study chapter is to explore the effects of social bonding, as indicated by OT, on the cortisol-based stress response, and assess if this is associated with glycaemic control in AWT1D. Whilst previous research has suggested a psychosocial moderation of the stress response by peer support in T1D, this has not been confirmed by biological data. As such, it aims to establish whether a psychophysiological mechanism operates in global peer support, associated with diabetes outcomes in AWT1D.

The objectives of the present study are to:

1. Examine the proposed theory (see Section 4.6.2.) using measures of the biomarkers of peer support (OT) and stress (cortisol). *Hypothesis 1.*
2. Consider variables through which this relationship may be moderated (gender and glycaemic control). *Hypotheses 2 and 3 respectively.*
3. Assess the validity of salivary OT as a biomarker of peer support in AWT1D. *Hypothesis 4.*

#### **10.1.2. Hypotheses**

Due to the findings of previous research, it is hypothesised that:

##### ***10.1.2.a Hypothesis 1: Stress-buffering hypothesis***

- i. Increased salivary OT will be associated with reduced salivary cortisol.
- ii. Increased salivary OT and reduced salivary cortisol will be associated with improved glycaemic control (HbA<sub>1c</sub>) when controlling for self-care behaviours.
- iii. Salivary OT moderates the relationship between social support and glycaemic control.

- iv. Salivary OT moderates the relationship between cortisol and glycaemic control.

**10.1.2.b. Hypothesis 2: Gender differences**

- i. Males will report greater salivary cortisol than females, though a relationship to glycaemic control (HbA<sub>1c</sub>) cannot be determined from previous literature.
- ii. Males will report less salivary OT than females, though a relationship to glycaemic control (HbA<sub>1c</sub>) cannot be determined from previous literature.

**10.1.2.c. Hypothesis 3: Glycaemic control differences**

- i. Those with above average glycaemic control (HbA<sub>1c</sub>) will have less salivary cortisol and increased salivary OT than those with poorer glycaemic control.
- ii. Gender differences will be present within this, though a direction cannot be determined from previous literature.

**10.1.2.d. Hypothesis 4: Oxytocin and peer support**

- i. Salivary OT will be positively related to greater global peer support, QoL and resilience.
- ii. Salivary OT will be negatively related to greater diabetes-specific peer support, due to the findings of Study 1 (see Section 9.4.1.).

## **10.2. Method**

Full methodological procedures for this research can be found in Chapter 8. Details specific to the current study are presented here.

### **10.2.1. Participants**

The number of participants in the present study differs from the previous. It was found during data collection that a small number of participants ( $n=2$ ) were reluctant to provide saliva samples, though happy to provide questionnaire data. As such, a decision was made to allow these participants to opt-out of the biomarker provision, in accordance with ethical guidance (British Psychological Society, 2009). Furthermore, some female participants ( $n=15$ ) were not within the midluteal phase of their menstrual cycle or on oral contraceptives. The majority of these participants were reluctant to reschedule data collection for an appropriate time within their menstrual cycle, and as such provided questionnaire data only. Finally, the volume of saliva provided by some participants proved problematic ( $n=7$ ). Effective measurement of salivary cortisol and OT requires a minimum of 1ml of saliva for the present immunoassay (ENZO Life Sciences, 2015a, 2015b). In addition, up to 450  $\mu$ l of saliva can remain in the Salivette® after centrifuging (de Weerth, Graat, Buitelaar, & Thijssen, 2003). As such, participants would have been required to provide 2.9ml of saliva across the samples in order to provide sufficient tissue for analysis. Not all participants were able to provide such volume, which regrettably could not be identified until post-data collection. Due to these factors, 69 participants provided data for biomarker analysis. The demographic characteristics for these

participants are as follows; 32 male and 37 female, 63 using MDI and 6 using CSII pump, with an average age of 16.81 ( $SD=1.14$ ).

### **10.2.2. Expected concentrations of biomarkers**

Due to the relatively recent innovation of OT ELISAs as a reliable measure of salivary OT, consensus regarding the standard concentrations of OT present in saliva has yet to be established. Recent publications are noted seeking to establish standard concentrations for plasma OT (Christensen, Shiyanov, Estepp, & Schlager, 2014), though none could be located identifying the same for salivary OT. Christensen *et al.* (2014) determined expected plasma OT by conducting a systematised review of previous literature, and so the same method is repeated here.

An initial review of PubMed, PsychInfo and Science Direct databases using the search terms “saliva” and “oxytocin,” limited to human participants, was conducted in January 2015. Publications in English were preferred due to the limited scope of this doctoral study, as were those with full articles available (b, second selection). The third selection (c) was performed by hand, by studying the retrieved publications to ensure the inclusion of a salivary measure of OT, and did not focus on pregnancy, labour or parenthood, or a clinical population, due to the impact of these factors on OT expression. A final hand search (d, fourth selection) was conducted in order to remove duplicate publications, review articles and those not reporting mean OT concentrations. The selected publications were then searched for references to other relevant articles, and attempts to locate follow-ups to prospective research were made. This resulted in eight studies being selected for review. A diagram of the review process can be seen in Figure 24, with a full list of studies available in Appendix U.

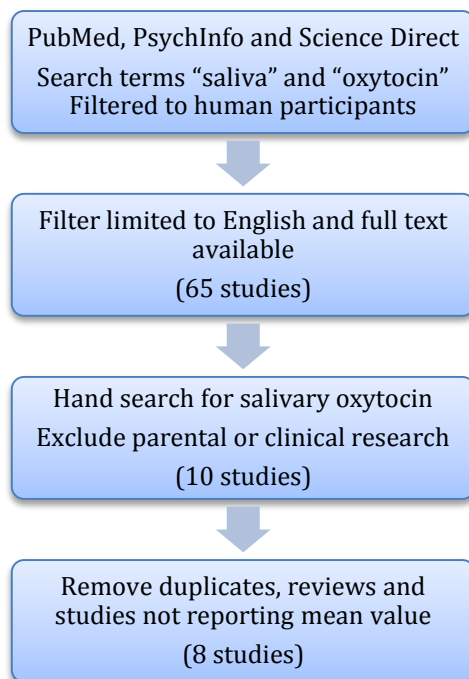


Figure 24. Flow diagram of the oxytocin literature review process and results.

These publications produced a mean concentration of 10.10pg/ml ( $SD=4.48$ ).

Assessment of salivary cortisol is far more established, allowing for the expected concentration of cortisol to be taken from immunoassay manuals (Endocrine Sciences, 2009). This suggests expected morning cortisol >2 hours after waking of <100 – 3300pg/ml.

### 10.3. Results

As outlined in Section 8.5.1., all samples were analysed in duplicate to account for intra-assay variation. Mean scores of the duplicate samples were then calculated to produce a single average cortisol and OT amount for each participant, which was input into the statistical analysis. In accordance with standard practice for duplicate samples, those with greater than 10% variation between the two analyses were discarded (Welsh, Smith, & Nelson, 2014). This occurred in six OT and three cortisol samples, precise values of which can be seen in Appendix V. This further reduced the participant sample, resulting in a sample of 60 participants; 29 male and 39 female, 59 using MDI and 5 using CSII pump, with an average age of 16.65 ( $SD=1.04$ ). Descriptive statistics for this sample are found in Table 20. Average cortisol and OT were within the expected range (see Section 10.2.2.) and as such can be considered valid.

Table 20. *Descriptive statistics of participants' glycaemic control, oxytocin, cortisol and reported self-care.*

	<i>n</i>	M	SD	Min	Max
Glycaemic control (mmol/mol)	58	69.4	8.55	37.7	117.5
Oxytocin (pg/ml)	56	10.15	4.9	2.72	21.17
Cortisol (pg/ml)	60	1205.30	791.77	233.1	4735
Self-care	59	39.66	7.94	0	52

As with Study 1 (see Section 9.3.), the data for OT and cortisol measures was found to be highly skewed and kurtotic (see Appendix W), therefore bootstrapping was applied during statistical analyses to allow for use of parametric measures, as recommended by Kraatz (2011) and Wright *et al.* (2011). Pearson's Product Moment Correlational analyses were used to identify the relationships between biomarkers (hypotheses 1.i), which informed a hierarchical regression to assess the psychophysiological role of OT and cortisol in terms of glycaemic control (hypothesis 1.ii), and mediation analyses concerning the role of OT (hypotheses 1.iii and 1.iv). Multivariate analyses of covariance (MANCOVA) were utilised to assess the gender (hypothesis 2.i and 2.ii) and glycaemic control (hypothesis 3.i and 3.ii) differences in the psychophysiological model of the stress-buffering hypothesis, as indicated by OT and cortisol, whilst controlling for self-care. For all statistical tests an alpha of .05 was used.

### 10.3.1. Hierarchical regression and moderation analyses

In order to investigate hypothesis 1, which assesses the psychophysiology of the stress-buffering hypothesis in AWT1D, correlational analysis between salivary OT and cortisol is first conducted in order to affirm the expected negative relationship, which would indicate down-regulation of the HPA axis by OT (hypothesis 1.i.). Hierarchical regression analysis was then conducted between OT, cortisol, HbA<sub>1c</sub> and the total SCI-R score (hypothesis 1.ii). The moderating role of OT in relationships between peer support (hypothesis 1.iii), cortisol (hypothesis 1.iv) and glycaemic control requires moderation analysis. Moderation analysis differs from the mediation analysis outlined in Section 9.3.3. in that moderator variables impact the direction or strength of the relationship between the predictor and outcome variables. Conversely, a mediator variable accounts for the relationship between the predictor and the outcome (Baron & Kenny, 1986). Therefore, in the case of the present study, moderation analysis will determine the impact variation in the moderator (OT) has on the established relationships between the predictor (peer support/cortisol) and outcome variables (HbA<sub>1c</sub>), using multiple regression.

It is noted that high HbA<sub>1c</sub> values indicate poorer glycaemic control when interpreting results. Appropriate plots accompanied by simple linear model-fitting statistics for the analyses can be viewed in Appendix X, in accordance with guidance for avoiding Type I error provided by Weatherall *et al.* (2004).

### 10.1.2.a Hypothesis 1: Stress-buffering hypothesis

- i. *Increased salivary OT will be associated with reduced salivary cortisol.*

Pearson's correlation reveals the expected negative relationship between OT and cortisol, supporting the potential of OT to downregulate the HPA axis, as  $r(54) = -.34$ ,  $p = .011$ , 95% CI  $[-.55, -.08]$ , indicating a medium negative effect according to Cohen's guidelines (J. Cohen, 1988). Hypothesis 1.i is therefore accepted.

- ii. *Increased salivary OT and reduced salivary cortisol will be associated with improved glycaemic control (HbA<sub>1c</sub>) when controlling for self-care behaviours.*

It is important in nonexperimental research to control for self-care to determine if such behaviour eliminates the relationship between peer support, stress and glycaemic control. Therefore, a hierarchical multiple regression was calculated to predict HbA<sub>1c</sub> based on OT and cortisol, controlling for self-care as measured by the SCI-R, the results of which can be viewed in Table 21. In order to manage potential multicollinearity between cortisol and OT, both were entered within the same block, as recommended by Smolkowski (2004) and Harrell (2001), however, as the collinearity statistics were within accepted limits, the assumption of multicollinearity was met (Field, 2013).

Table 21. *Summary of hierarchical regression analysis for variables predicting glycaemic control*

Variable	$\beta$	95% CI for $\beta$	$t$	$r$	$r^2$	$\Delta r^2$
Step 1				.18	.01	-.01
Self-care	-.12	-.11, .05	-.82			
Step 2				.16	.03	-.03
Self-care	-.13	-.12, .05	-.85			
Oxytocin	.11	-.06, .03	.75			
Cortisol	.02	-.01, .01	.11			

The hierarchical multiple regression revealed that self-care did not contribute significantly to the regression model, as  $F(1,51) = .704$ ,  $p = .405$  and accounted for only 1.4% of variance in glycaemic control. Introducing OT and cortisol explained an additional 3% of variation in glycaemic control, though this was non-significant ( $F(3,49) = .42$ ,  $p = .737$ ) and regarded as a negligible effect (J. Cohen, 1988). As a result, hypothesis 1.ii is rejected.

- iii. *Salivary OT moderates the relationship between social support and glycaemic control.*  
 iv. *Salivary OT moderates the relationship between cortisol and glycaemic control.*

It is prudent to only proceed with moderation analysis if initial exploratory analyses are significant (Kenny, 2014). Due to the non-significant findings of Hypothesis 4.i and 4.ii., it was determined not to proceed with moderation analysis for OT, as it is not a significant predictor of HbA<sub>1c</sub> when controlling for self-care. Hypotheses 1.iii and 1.iv are therefore rejected.

### 10.3.2. Multivariate analyses of covariance (MANCOVA)

Hypotheses 2 and 3 assess variation in the psychophysiology of the stress-buffering hypothesis according to gender and glycaemic control. As such, MANCOVA were required to assess differences in cortisol and OT according to gender (hypothesis 2.i and 2.ii) and level of glycaemic control (hypothesis 3.i and 3.ii), when controlling for self-care. It is noted that 90% confidence intervals are reported in the MANCOVAs over the standard 95%, as recommended by Steiger (2004). This is due to the inability of partial eta-squared to present a negative value, increasing the chances of a 95% confidence interval including 0 despite a  $p < .05$ . A reduced confidence of 90% ensures comparability to 95% CIs for effect sizes which are able to reach negative values (Steiger, 2004).

#### 10.1.2.b. Hypothesis 2: Gender differences

- i. *Males will report greater salivary cortisol than females, though a relationship to glycaemic control ( $HbA_{1c}$ ) cannot be determined from previous literature.*

MANCOVA revealed that there was not a significant difference in salivary cortisol or  $HbA_{1c}$  based on gender, as  $F(2, 49) = .53$ ,  $p = .6$ , Wilk's  $\Lambda = .98$ ,  $\eta_p^2 = .02$ , 90% CI [.00, .09]. However, the small sample size present in the current study poses risk of Type II error. Tabachnick and Fidell (2012) recommend a sample of 92-120 for a MANCOVA of these parameters. As such, the effect size must be acknowledged. The recommendations for interpretation of partial eta-squared can be found in Table 22. According to these guidelines, gender has a small effect on glycaemic control and cortisol (Field, 2013).

Table 22. *Interpretation of partial eta-squared, according to Field (2013)*

$\eta_p^2$	Effect size
.01	Small
.06	Medium
.14	Large

When correlational analyses between cortisol and  $HbA_{1c}$  were conducted for each gender, interesting differences were noted. Whilst females did not experience a relationship between cortisol and  $HbA_{1c}$  ( $r(24) = .01$ ,  $p = .981$ , 95% CI [-.39, .38]), males have a significant positive association between stress and glycaemic control, as  $r(25) = -.44$ ,  $p = .021$ , 95% CI [.18, .68], indicating a medium effect (J. Cohen, 1988). Hypothesis 2.i is therefore only partially accepted; whilst gender differences in cortisol are non-significant, a positive relationship to glycaemic control is found to be significant in males but not females.

- ii. *Males will report less salivary OT than females, though a relationship to glycaemic control (HbA<sub>1c</sub>) cannot be determined from previous literature.*

A statistically significant difference in OT and HbA<sub>1c</sub> based on gender is recognised ( $F(2, 49)=3.65$ ,  $p=.031$ , Wilk's  $\Lambda=0.91$ ,  $\eta_p^2=.090$ , 90% CI [.01, .26]) to a medium effect (Field, 2013). In addition, a statistically significant effect of gender on OT ( $F(2, 49)=6.49$ ,  $p=.013$ ,  $\eta_p^2=.08$ , 90% CI [.05, .34]), suggesting a medium effect (Field, 2013), but not HbA<sub>1c</sub> scores ( $F(2, 49)=3.45$ ,  $p=.288$ , partial  $\eta^2=.02$ , 90% CI [.00, .25]) is acknowledged. However, when correlational comparisons between genders are analysed, neither males nor females suggested a significant association between OT and HbA<sub>1c</sub> (Females:  $r(24)=-.05$ ,  $p=.799$  95% CI [-.43, .34], Males:  $r(25)=-.05$ ,  $p=.802$ , 95% CI [-.41, .32]). Hypothesis 2.ii is partially accepted; whilst gender differences in OT are significant, a relationship between OT and HbA<sub>1c</sub> is not gender dependent.

### 10.1.2.c. Hypothesis 3: Glycaemic control

- i. *Those with above average glycaemic control (HbA<sub>1c</sub>) will have less salivary cortisol and increased salivary OT than those with poorer glycaemic control.*

As with Study 1 (see Chapter 9), it was decided to compare the OT and cortisol of those with above or below average glycaemic control to assess for differences between the psychophysiological mechanism of peer support. The mean value of HbA<sub>1c</sub> within the participant sample for Study 2 was 69.4mmol/mol. The descriptive statistics for the two groups can be seen in Table 23 below.

Table 23. *Descriptive statistics of age, oxytocin, cortisol and self-care of those with above ( $\leq 69.4$ mmol/mol) or below ( $\geq 69.5$ mmol/mol) average glycaemic control in Study 2.*

	Group	n	M	SD	Min	Max
Age	<69.4mmol/mol	39	16.74	.993	15	18
	>69.5mmol/mol	47	16.43	.927	15	18
Oxytocin (pg/ml)	<69.4mmol/mol	36	10.87	5.78	3.16	27.20
	>69.5mmol/mol	43	9.10	4.95	2.72	21.17
Cortisol (pg/ml)	<69.4mmol/mol	29	1233.63	627.14	526.6	2907
	>69.5mmol/mol	29	1182.24	962.22	223.1	4735
Self-care	<69.4mmol/mol	38	41.82	5.63	29	52
	>69.5mmol/mol	47	38.91	8.11	00	52

MANCOVA suggests no significant difference in OT and cortisol based on level of glycaemic control, as  $F(2, 49)=.525$ ,  $p=.595$ , Wilk's  $\Lambda=.980$ ,  $\eta_p^2=.132$ , 90% CI [.00, .09]. However, a medium-large effect of glycaemic control on OT and cortisol is indicated (Field, 2013). Hypothesis 3.i is therefore rejected on the basis of the NHST method, though the effect size indicates that this may be due to an underpowered sample. Further research is therefore warranted.



- ii. *Gender differences will be present within this, though a direction cannot be determined from previous literature.*

Due to the non-significant findings of hypothesis 2.i and hypothesis 3.i, hypothesis 3.ii is also rejected.

### 10.3.3. Correlational analyses

Due to the paucity of research using salivary OT as an indicator of social bonding, no studies could be found assessing whether OT is a valid marker of self-reported peer support (see Section 4.5.3.). Hypotheses 4.i and 4.ii therefore seek to determine if salivary OT is related to psychosocial variables, including peer support, diabetes-specific support, QoL and resilience. As such, correlation analyses were conducted between OT, the SCI-R, BSSS, DSSQ-Friends, WHO-5 and CD-RISC 10. Appropriate plots accompanied by simple linear model-fitting statistics for the analyses can be viewed in Appendix X in order to mitigate Type I error (Weatherall, 2004).

#### 10.3.3.a. Hypothesis 4: Oxytocin and peer support

- i. *Salivary OT will be positively related to greater global peer support, QoL and resilience.*
- ii. *Salivary OT will be negatively related to greater diabetes-specific peer support, due to the findings of Study 1.*

Neither Hypothesis 4.i nor 4.ii can be accepted, as non-significant relationships were identified between OT and the psychosocial variables, as seen in Table 24. Hypotheses 4.i and 4.ii are therefore rejected.

Table 24. *Correlations among oxytocin, peer support, quality of life, resilience and diabetes-specific support.*

	Self-care	Peer support	Quality of life	Resilience	Diabetes-specific support
Oxytocin	.04	-.03	.08	.06	-.01

### 10.3.4. Summary of the findings of Study 2

Table 25. *Summary of the findings of Study 2.*

	Hypothesis	Accepted/Rejected	Comment
1.i	Increased salivary OT will be associated with reduced salivary cortisol.	Accepted ( $r=-.34$ )	<i>Negative relationship between OT and cortisol</i>
1.ii	Increased salivary OT and reduced salivary cortisol will be associated with improved glycaemic control (HbA <sub>1c</sub> ) when controlling for self-care behaviours.	Rejected ( $r^2=.03$ )	
1.iii	Salivary OT moderates the relationship between social support and glycaemic control.	Rejected	<i>Not carried out</i>
1.iv	Salivary OT moderates the relationship between cortisol and glycaemic control.	Rejected	<i>Not carried out</i>
2.i	Males will report greater salivary cortisol than females, though a relationship to glycaemic control (HbA <sub>1c</sub> ) cannot be determined from previous literature.	Partially accepted ( $\eta_p^2=.02$ )	<i>Gender difference in cortisol non-significant. Positive relationship to glycaemic control in males but not females</i>
2.ii	Males will report less salivary OT than females, though a relationship to glycaemic control (HbA <sub>1c</sub> ) cannot be determined from previous literature.	Partially accepted ( $\eta_p^2=.09$ )	<i>Gender differences in OT are significant, but relationship between OT and HbA1c is not</i>
3.i	Those with above average glycaemic control (HbA <sub>1c</sub> ) will have less salivary cortisol and increased salivary OT than those with poorer glycaemic control.	Rejected ( $\eta_p^2=.13$ )	
3.ii	Gender differences will be present within this, though a direction cannot be determined from previous literature.	Rejected	<i>Not carried out</i>
4.i	Salivary OT will be positively related to increased global social support, quality of life and resilience.	Rejected ( $r=-.03$ , $r=.08$ , $r=.06$ )	
4.ii	Salivary OT will be negatively related to increased diabetes-specific support, due to the findings of Study 1.	Rejected ( $r=-.01$ )	

### 10.4. Discussion

This section discusses the main findings of Study 2. Based on the stress-buffering hypothesis (S. Cohen & Wills, 1985), a psychophysiological application of this theory was proposed in Section 4.6.2., which included the potential role of OT as the biological mechanism through which social support is related to improved diabetes outcomes. Using a series of hypotheses, Study 2 was designed to test the relationships proposed in this model and the role of OT in AWT1D. Using the results outlined in the previous section, each of the proposed hypotheses is subsequently addressed. In addition to the main findings of this study, the methodological limitations are also discussed and the implications of these are outlined. Finally, the clinical implications and original contributions of this study are reviewed.

#### 10.4.1. Hypothesis 1: Stress-buffering hypothesis

- i. *Increased salivary OT will be associated with reduced salivary cortisol.*

OT has been identified as able to down-regulate the HPA axis in both human and animal research (Hostinar et al., 2014). It was therefore expected that salivary OT would present a negative relationship with salivary cortisol in the present sample, confirmed by the correlational analysis of hypothesis 1.i. These findings therefore support the potential for OT to modulate the stress response (Neumann, 2002). Whilst previous research has established the ability of OT to moderate the HPA axis during infancy and early childhood (Gunnar & Donzella, 2002; Gunnar, 2006), a paucity of studies examined the impact of social bonding in older children and adolescents (Adams et al., 2011; Seltzer et al., 2010). These findings build on this limited body of research, confirming this phenomena in adolescent populations in addition to early childhood. The acceptance of hypothesis 1.i lends support to the assertion that OT acts as a biological intermediary, able to translate social factors into physiological processes directly linked to health, including autonomic, neuroendocrine and immune functioning (Norman et al., 2012). Confirmation of this association lends credence to the validity of the theoretical psychophysiological model of the stress-buffering hypothesis, proposed in Section 4.6.2, and tested in hypothesis 1.ii.

- i. *Increased salivary OT and reduced salivary cortisol will be associated with improved glycaemic control (HbA<sub>1c</sub>) when controlling for self-care behaviours.*
- ii. *Salivary OT moderates the relationship between social support and glycaemic control.*
- iii. *Salivary OT moderates the relationship between cortisol and glycaemic control.*

In Section 4.6.2., the potential role of OT in T1D was outlined. It is based on the assumption that cortisol increases circulatory blood glucose (Khani & Tayek, 2001). In T1D, therefore, chronically elevated cortisol may lead to chronically increased blood glucose, contributing towards hyperglycaemia and making achievement and maintenance of optimal glycaemic control more challenging. As stated in Section 4.6.1., it is acknowledged that OT is able to down-regulate cortisol release via its action on the HPA axis. It was therefore hypothesised that OT is able to moderate the stress response, indicated by cortisol, and thereby aid improved glycaemic control and decrease the likelihood of hyperglycaemia in T1D. However, these findings do not support Cohen and Wills' stress-buffering hypothesis (1985).

There are several potential explanations for this finding. At its most basic, it suggests that the psychophysiological understanding of the stress-buffering hypothesis of social support (S. Cohen & Wills, 1985) is not applicable in peer support in AWT1D. Whilst Study 1 promotes the assertion that improved perceived global peer support is related to improved diabetes outcomes, the findings of Study 2 suggest that this is not achieved through the indirect

psychophysiological mechanism proposed in Section 4.6.2. As outlined in Section 4.6., investigation of the role of OT in health behaviours is still very much in its infancy, and a paucity of research has utilised it as a biomarker of social bonding in clinical populations (G.J Norman et al., 2012; Uchino et al., 2012). It is, however, theorised that OT is related to health behaviours via two pathways; modulation of the HPA axis (Neumann, 2002) and facilitation of prosocial behaviours (Carter, 2007). Whilst the present hypothesis focuses on the HPA axis and rejects such assumption, the remaining pathway remains unanswered. It may be that OT is related to improved health outcomes via a psychosocial pathway, as opposed to a psychophysiological route. Future research may therefore wish to consider the remaining option. Indeed, the stress-buffering hypothesis has been criticised for inadequately capturing the essence of support, regarding recipient acceptance of the support provided and whether it enhances coping (Goldsmith, 2004). However, as OT provides an overall view of social bonding, and is unlikely to be influenced by ineffective support (Feldman, 2012), these issues are overcome in the present study. As such, it is concluded that the psychophysiological stress-buffering model proposed in Section 4.6.2. is potentially inaccurate, though limitations of the current study must also be acknowledged.

With this in mind, the failure to detect stress-buffering effects, which are not uncommon in social support in general, may be attributed to issues regarding sample size and power (Mitchell, Evans, Rees, & Hardy, 2014; Wills & Shinar, 2000). Namely, that a small sample size resulted in an inability to detect the stress-buffering capability of OT. A *post hoc* power calculation revealed that on the basis of the effect size ( $r=.16$ ), an  $n$  of approximately 72 would be required to obtain statistical power at the recommended .80 level (J. Cohen, 1988). Thus, the sample of 60 in the present study is insufficient to accurately reject the null hypothesis. However, interpretation of the effect size (small; J.Cohen, 1988), unencumbered by power requirements, suggests this results is unlikely to be due to Type II error.

Further methodological problems may be attributed to questions related to salivary OT itself. As outlined in Section 8.4.3., criticisms have been levelled at the use of saliva as a reliable bodily fluid in which to detect OT. Salivary assays of OT have typically been criticised as correlating weakly with ELISA estimates taken from plasma, with  $r$  values of .41-.59 (Feldman, Gordon, & Zagoory-Sharon, 2010; Grewen, Davenport, & Light, 2010; McCullough et al., 2013), implying coefficients of determination of between 17-35%, respectively. Conversely, the well-established and widely used measure of salivary cortisol typically correlates with plasma at  $r>.9$ , or >81% shared variance (Kaufman & Lamster, 2002; C Kirschbaum & Hellhammer, 2000; McCullough et al., 2013). Horvat-Gordon *et al.* (2005) concluded that “*measurement of OT in saliva does not yield meaningful indices of individual differences or intra-individual change*” (p. 445); a concern which has yet to be properly addressed ten years on (Gröschl, 2009). Thus, the

non-significant findings of hypothesis 1.ii may be due to an inaccurate assessment of OT, which would have been more truthfully measured in plasma. Further research should compare the results of the present study with a replication using plasma OT, to detect any potential variation between salivary and plasma samples. However, the reasons for choosing a salivary sample outlined in Section 8.4.3. remain valid. Assessment of human plasma necessitates invasive sample collection, and is unappealing to participants (Schultheiss & Stanton, 2009). Given the problematic power outlined above, it is likely collection of plasma would have further limited participant numbers and compounded this issue, constraining the ethicality of conducting this study if it is unable to produce useful knowledge (British Psychological Society, 2009). In addition, plasma OT concentrations are likely to be contaminated by the stress induced in response to a needle stick, requiring an indwelling venous catheter and habituation period prior to sampling in order to reliably assess resting OT and to minimise problems associated with experimental manipulation (Grewen et al., 2010), which is likely to further reduce acceptability of plasma sampling to participants. Recent studies have successfully isolated OT in saliva using ELISA methods (Bhandari et al., 2014; Cohn et al., 2013; Grewen et al., 2005; Holt-Lunstad et al., 2008; van Ijzendoorn et al., 2012). As such, saliva sampling is an attractive alternative to plasma, though further validation of the use of the assay with saliva may be required.

Additionally, it is suggested that isolation of a specific type of social bond within OT may be methodologically impossible. Due to OT offering a biological assessment of overall social bonding (see Section 4.1.), it may be that differences occur between familial and peer support which cannot be isolated within the overarching viewpoint of this biomarker. In order to assess whether or not these results are due to erroneous operationalisation of OT as a marker specifically of peer support, it is important to consider the relationship between self-report and biological measures of peer support. If this interpretation proves correct, it would be expected that results of the self-report peer support would not be related to levels of OT. As such, this is assessed under Hypothesis 4 (see Section 10.4.4.) in order to further investigate this suggestion.

Finally, it is noted that self-care was not found to be a significant predictor of glycaemic control. Whilst this relationship is well-established in literature, with self-care found to be the main predictor of glycaemic control and diabetes complications (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2005), it was not found in the present participant sample. It is logical to conclude that participants succumbed to response bias and demand characteristics, given the clinical setting. Whilst every effort was made to ensure that participants were aware that their data would not be shared with the outpatient clinic, and that the researcher was not a member of the diabetes care team, the setting may have consciously or unconsciously communicated demand characteristics and encouraged response bias, presenting an idealised version regarding self-

care behaviours, potentially for fear of possible consequences to admissions of non self-management.

#### **10.4.2. Hypothesis 2: Gender differences**

- i. Males will report greater salivary cortisol than females, though a relationship to glycaemic control ( $HbA_{1c}$ ) cannot be determined from previous literature.*

The basic neuroendocrine core of stress responses does not seem to vary substantially between males and females. Both sexes experience a cascade of hormonal responses released from the paraventricular nucleus of the hypothalamus, activating the adrenal medulla to trigger release of norepinephrine and epinephrine, and concomitant sympathetic responses, as noted in Section 4.6.1.. Hypothalamic release of CRF and other hormones stimulate the release of ACTH from the anterior pituitary, which then stimulates the adrenal cortex to release corticosteroids, namely cortisol (Jezova, Skultetyova, Tokarev, Bakos, & Vigas, 1995; Taylor et al., 2000). It is therefore unsurprising that gender differences in cortisol were non-significant in the present population. Previous research noting sexual dimorphism in the stress response utilised laboratory-induced stressors (DeVries et al., 2003; Grewen et al., 2005; Clemens Kirschbaum et al., 1995; Takai et al., 2007), and as such differences may be recognised in the gender response to the laboratory environment, rather than a biobehavioural one.

Interestingly, however, sexual dimorphism in the relationship between cortisol and glycaemic control is recognised in the present study. Whilst cortisol is not related to glycaemic control in females, males indicated a medium-large negative effect of cortisol on glycaemic control. This suggests an increase in cortisol is related to improved glycaemic control in male participants. It would therefore appear that males may interpret stress as eustress, as opposed to distress. Eustress is defined as an optimal level of arousal and perceived stress necessary to perform at an optimal level (Lazarus, 1991). As illustrated in Figure 25, a certain amount of physiological arousal is a required motivator towards performance. However, if the stress is perceived as exceeding coping resources, then distress results (Lazarus & Folkman, 1984b; Yerkes & Dodson, 1908).

### The Yerkes-Dodson Law

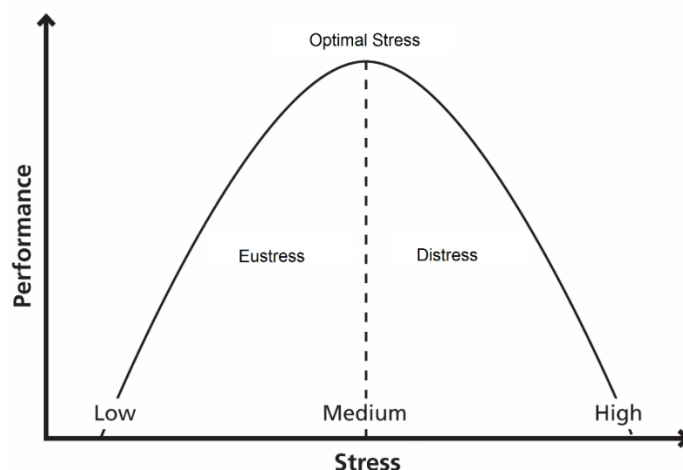


Figure 25. The Yerkes-Dodson curve of arousal (1908).

Therefore, whilst females present no relationship between stress and glycaemic control, males may require sufficient stress regarding their diabetes management in order to effectively self-care. Indeed, whilst much literature has documented the limiting effects of distress on self-care and glycaemic control, review data has concluded that stress may not adversely impact metabolic control in all individuals. Although a weak association was found between stress and blood glucose levels, the direction of the relationship was inconclusive (Kramer et al., 2000). Some people may therefore cope with stress via participating in self-care behaviours more effectively (Berlin et al., 2012). These findings add to this hypothesis by suggestion that this difference in coping may be sexually dimorphic. This may be explained from a social-ecological approach (Steele & Aylward, 2009), alongside a stress-coping model (Wallander & Varni, 1998). These models suggest stress-reactivity depends on the processing of the stressor, impacted by appraisal and coping, in addition to the source of the stressor (Berlin et al., 2012). Males may therefore appraise and cope with stressors adaptively, as motivators towards improved self-care, whilst females do not make such associations. Indeed, previous research has suggested that the aspect of the adolescent's life in which the stress occurs may mediate the relationship between stress and health outcomes, with each stressor capable of affecting self-care and glycaemic control differently. In particular, stress resulting from conflict in the social network is most likely to adversely impact glycaemic control in adolescents (Berlin et al., 2012). Therefore, another explanation for this difference may lie in the sexually dimorphic response to peer support. Helgeson, Lopez and Kamarck (2009) suggest that conflict in the social network is more common in females, whilst males report lower levels of peer support overall (Helgeson et al., 2007). Stressors with the capacity to adversely impact glycaemic control are therefore more likely to occur in young females, and may moderate the positive impact experienced by peer support, thereby mediating the correlation coefficient. Males are less likely to experience

stressors with the capacity to impede their glycaemic control, and may therefore demonstrate greater interpretation of eustress.

- ii. *Males will report less salivary OT than females, though a relationship to glycaemic control (HbA<sub>1c</sub>) cannot be determined from previous literature.*

As outlined in Section 4.3.1., OT expression is known to be sexually dimorphic (Carter, 2007; Zingg & Laporte, 2003), due to dependence on sex-specific steroid hormones, such as oestrogen (Carter, 2007). McCarthy, *et al.* (1996, p. 1206) observe that the OT receptor is “*one of the most strongly oestrogen-regulated systems in the brain...oestrogen-induced increase in oxytocin receptor binding is integral to its behaviour-modifying effects.*” It is therefore expected that females express greater OT, supported by the present findings. OT facilitates social behaviour, particularly that maternal in nature, and therefore presents an evolutionary advantage for mother-child bonding, explaining the greater prevalence in females (Carter, 1998, 2003).

OT can be incorporated in the ‘*tend and befriend*’ biopsychosocial model of female affiliation proposed by Taylor *et al.* (2000). It is argued that females’ evolutionarily role in caring for offspring resulted in a reduction of the fight-flight-or-freeze response to threat, as this may pose additional risk to children in their care. Under threat, oestrogen-potentiated OT will “*calm the female who is physiologically aroused by a stressor and also to promote affiliative behaviour, including maternal behaviour toward offspring*” (Taylor *et al.*, 2000, p. 416). As a result, females do not engage in fight-flight-or-freeze but instead seek out proximity to other females for protection in numbers. The tend and befriend theory is posited to underpin female valuing of interpersonal connectedness and interdependence, whilst males seek autonomy and independence (Cross & Madson, 1997), and female-typical interpersonal personality traits such as empathy, supportiveness and interdependence (Bem, 1974; Spence, 1984). Indeed, female affiliation displays greater trust and self-disclosure than male friendship (Cross & Madson, 1997). This may, therefore, go some way to explaining the findings of hypothesis 2.i, in that female response to stress is to seek out social support as a coping mechanism, which may potentially be damaging to self-care if ineffective, inconsistent or non-adherent (Palladino & Helgeson, 2012; Thomas *et al.*, 1997). Conversely, males may seek self-sufficiency in the face of challenge, thereby improving self-care independently.

Hypothesis 2.ii, however, can only partially be accepted. Whilst OT is sexually dimorphic, non-significant associations between OT and glycaemic control according to gender are recognised. The methodological limitations of this study outlined under hypothesis 2.ii must therefore also be acknowledged here.



### 10.4.3. Hypothesis 3: Glycaemic control

- i. *Those with above average glycaemic control ( $HbA_{1c}$ ) will have less salivary cortisol and increased salivary OT than those with poorer glycaemic control.*
- ii. *Gender differences will be present within this, though a direction cannot be determined from previous literature.*

Previous literature has noted that stress negatively impacts on glycaemic control and self-care through a variety of ways, as outlined in Section 6.4. Stress operates biologically by increasing hepatic glycogen production and insulin resistance (Mortensen et al., 1998), and psychosocially by impeding the ability to self-care effectively (Helgeson et al., 2010). It was therefore hypothesised that those with poor glycaemic control would report greater biological stress, based on the findings of Study 1. Due to the suggestion that the neuroendocrine response to stress is also sexually dimorphic (DeVries et al., 2003; Grewen et al., 2005; Clemens Kirschbaum et al., 1995; Takai et al., 2007), it was suggested gender differences would likely occur within this. However, both hypotheses are rejected in the present sample.

As suggested in Sections 10.4.1. and 10.4.2., significant individual differences are likely to impact the relationship between stress and glycaemic control (Berlin et al., 2012; Kramer et al., 2000). Whilst stress may hinder effective self-care in some, others may employ advantageous coping mechanisms (Berlin et al., 2012). Whilst avoidant, emotion-focused coping strategies are associated with poor health outcomes, problem-focused strategies precede an improved psychosocial and health profile (Luyckx et al., 2010). With respect to T1D, facing challenges with a 'tackling spirit' or positive attitude, has been found to lead to problem-focused coping strategies as a direct result, related to improved self-care, glycaemic control and adjustment (Luyckx et al., 2010). Conversely, avoidant strategies, such as seeking distraction from self-care, or 'passive resignation' and helplessness (Seiffge-Krenke, 2001a) have been related to poorer diabetes outcomes (Jaser & White, 2011). Stress, therefore, is not a conclusive determinant of poor glycaemic control, supported by the present findings. It is noted that the present study did not assess coping strategy, and thereby lacks crucial information which may impact the relationship between stress and glycaemic control. Future studies might address coping style as a potential mediator in this population.

An important finding of this study was the considerable variation between individuals in the nature and extent of the stress-glycaemic control relationship. Overall, participants did not display an association between stress and  $HbA_{1c}$ , though differences are noted both between genders and within individuals in the magnitude and direction of the relationship between glycaemic control and stress, suggesting that an overarching group analysis may be misleading. The recognition of individual differences in stress-reactivity is not restricted to diabetes. There

is evidence of such variance in response to stress in other patient groups, both in laboratory and naturalistic settings (Andersson, Hägnebo, & Yardley, 1997; Roy, Kirschbaum, & Steptoe, 2001; Roy, Steptoe, & Kirschbaum, 1998; Traue & Kosarz, 1999). Previous research has suggested that glycaemic control and stress is predicted by being female, having chronic hyperglycaemia, and high variability of stress and glycaemic control (Kramer et al., 2000; Riazzi, Pickup, & Bradley, 2004). The findings of the present study, however, further contradict this by stipulating that males are more susceptible to stress-reactivity than females. It is therefore suggested that high variation exists in between individuals to the extent of making small-scale group comparison studies such as these difficult to interpret accurately.

Speaking generally, gender differences in coping style have been noted in healthy populations. Females typically employ more emotion-focused and avoidant coping styles than their male counterparts, who typically revert to rational and detachment strategies (Billings & Moos, 1981; Endler & Parker, 1990; Folkman & Lazarus, 1980; Matud, 2004; Ptacek, Smith, & Dodge, 1994). This believed to be explained by a socialisation hypothesis, which states that males are socialised into instrumental, problem-orientated coping behaviours, whilst females are socialised towards passive, emotion-focused strategies due to perceived gender roles (Pearlin & Schooler, 1978; Ptacek, Smith, & Zanas, 1992). Variations in coping strategy may also be due to stressor variation. As outlined in Section 10.4.2., stressor typology also impacts on stress appraisal and coping (Berlin et al., 2012). Typically, females experience more social stressors, whilst males report greater occupational and financial stress (Billings & Moos, 1981; Folkman & Lazarus, 1980) which may require differing coping styles (Banyard & Graham-Bermann, 1993). Extremely limited research, however, could be located specifically assessing coping style in T1D, though research into other groups suggests gender differences should be present by early adolescence due to developmental changes (Frydenberg & Lewis, 2009). Of the single study identified, scarce gender differences are noted. Females employ a style of 'investing in friends' more frequently than males in AWT1D, though otherwise coping strategies do not differ according to gender (Pisula & Czaplinska, 2010). The homogeneity of coping strategies in the limited literature suggests that male AWT1D resort more frequently to female-typical coping styles, such as avoidant coping. This may be due to restrictions placed on their available coping strategies by their T1D, such as physical activity. However, given the unexpected findings noted in the present study, further research into the coping style of AWT1D is warranted.

#### 10.4.4. Hypothesis 4: Oxytocin and peer support

- i. *Salivary OT will be positively related to greater global peer support, QoL and resilience.*
- ii. *Salivary OT will be negatively related to greater diabetes-specific peer support, due to the findings of Study 1.*

Literature suggests OT has a highly prosocial function (Carter et al., 2007; DeVries et al., 2003; Ditzen et al., 2009; Jurek, 2013; Schneiderman et al., 2012). OT has been suggested to enhance social motivation, seeking of social interaction and experiencing rewards as a result of social behaviours (Depue & Morrone-Strupinsky, 2005), and is therefore suggested as a marker of perceived social support (A. Campbell, 2008). However, as outlined in Section 4.5.3., only one study could be identified assessing the ability of OT to associate with filial attachment, or peer support. This study suggested that OT response to social stimuli is dependent on parental attachment, and is stable over the life course (Feldman, 2012). Thus, a mandate to use OT as a marker of peer support in the present study was established. However, the results of hypothesis 4 brings this into question.

OT was not related to measures of peer support, nor any other prosocial behaviours, as would be expected (see Sections 6.3. and 6.5.). This implies that the psychosocial questionnaire measures may be inaccurate, or that salivary OT is not representative of perceived peer support. As with all questionnaire measures, the disadvantages of self-report must be acknowledged. Participants were aware of the purpose of the study, and as with Study 1, may have amplified their psychosocial experience in order to lessen the apparent impact of T1D. This would explain the lack of correlation between self-report psychosocial and biological measures. As with hypothesis 1, potential concerns surrounding the detection of OT in saliva are also acknowledged (see Section 10.4.1.).

However, a second interpretation of these findings lies in the possibility that it is a flawed operationalisation of OT to attempt to assess peer support specifically. It is suggested that, whilst the ability of OT ELISAs to correlate with parent-child and romantic attachment is relatively well-established (Feldman, Gordon, Influx, Gutbir, & Ebstein, 2013; Feldman, 2012; Gordon et al., 2008; Grewen et al., 2010; Schneiderman et al., 2012), the assessment of OT as a marker of peer support in adolescents is novel. The lack of association between OT and the BSSS suggests that OT may not a valid biomarker of perceived support provided by peers in isolation of other bond types. As stated in Section 10.4.2., it is considered that OT provides an overarching viewpoint of social bonding, and is unlikely to have the ability to differentiate between familial and peer support. Therefore, it may be that peer support in isolation is related to improved outcomes (see Study 1), but is mitigated by a potentially negative impact of familial support (see Section 3.3.3.b.). However, the use of OT as a biomarker of support does not allow

for such specific analysis. Unfortunately, it would appear that due to the overall picture of social bonding provided by OT, the specific relationships between peer and familial support and diabetes outcomes cannot be determine, and therefore the psychophysiological impact of these different support networks remains unclear. It is therefore possible that the failure to identify relationships between peer support and OT is down to erroneous operationalisation of this biomarker. Limitations regarding saliva samples may also explain the lack of detection, as discussed in Section 10.4.1, and further outlined below in Section 10.4.5.

Finally, as with hypothesis 10.4.1. and Study 1, concerns regarding sample size and power must be acknowledged. These findings may be due to Type II error given the underpowered nature of the population (see Section 8.2.), though the small effect sizes would indicate otherwise.

#### **10.4.5. Limitations**

There are a number of limitations that need to be considered when interpreting the findings of this study. Firstly, the sample size was underpowered. A *post hoc* power calculation revealed that on the basis of the effect size ( $r=.16$ ), an  $n$  of approximately 72 would be required to obtain statistical power at the recommended .80 level for the most complex analyses (J. Cohen, 1988). Thus, the sample of 60 in the present study is insufficient to accurately reject the null hypothesis. In order to account for this limitation, effect sizes and confidence intervals are reported and interpreted at all levels. For all non-significant analyses, corresponding effect sizes were also small, reaffirming the indication of non-significance.

As outlined in Section 10.4.1., additional criticisms can be located in the methodological validity of salivary OT as a biomarker of social bonding. Whilst the decision to use saliva over plasma was considered in light of participant recruitment and comfort, alongside the practical constraints of doctoral study, the limitations of salivary OT must be considered. Salivary assays of OT correlate weakly with plasma (Feldman et al., 2010; Grewen et al., 2010; McCullough et al., 2013). Thus, the non-significant findings presented in the present study may be due to the inability of current ELISA technology to accurately assess OT in saliva. Future studies may therefore wish to include plasma over salivary measures, whilst considering the limitations this places on recruitment. Indeed, as discussed in Section 10.4.4., the use of OT as a biomarker for peer support is novel in adolescents, and the non-significant results here may be attributed to the inability of the use of OT as a biomarker of support to differentiate between support providers. Use of plasma OT in future studies would aid in locating whether the limitation here lies in the use of saliva, or in the relationship between OT and peer support.

A further limitation can be seen in the lack of data collected regarding participant coping styles. Previous research has indicated that coping styles interact with stress-reactivity to

impact on glycaemic control (S. S. S. Jaser & White, 2011; Luyckx et al., 2010; Seiffge-Krenke, 2001b). Indeed, coping style variation may go some way to explaining the findings of hypothesis 3 (see Section 10.4.3.). As such, future research should consider coping style in assessment of the relationship between stress and glycaemic control, in order to control for its effects on diabetes outcomes.

A final limitation is located in questionnaire measures, which are subject to the constraints of response bias. However, as with Study 1 (see Section 9.4.4.), whilst other more robust was considered, given the present issues with sample size, this would have been further compounded by more complex methodology requiring peer-raters. As such, the choice to use questionnaire assessments of social support and self-care remains a valid one.

#### **10.4.6. Clinical implications**

Whilst the non-significant findings presented in this study shed little light on the mechanism through which social support is associated with improved self-care and glycaemic control (see Chapter 9), some interesting results are presented regarding gender differences in stress. Whilst females do not appear to present a relationship between stress and glycaemic control, males appear to improve glycaemic control as stress increases (see Section 10.4.2.). This has important implications for healthcare professionals.

A large body of research has been amassed asserting that motivational health communication messages leading to shared decision making is the gold standard regarding improved patient adherence in a variety of disease states (Coulter & Ellins, 2007; Edwards et al., 2000; Kreps et al., 2011). However, these results suggest that male AWT1D may benefit from an element of risk communication alongside these motivational messages. It is suggested that additional risk communication may serve to heighten patient stress surrounding T1D, which as the results of the present study suggests, may feed forward into improved glycaemic control. Further research is required to assess if these assumptions are accurate. However, it must be remembered that according to the Yerkes-Dodson curve (1908) too great an emphasis on risk is likely to generate excessive stress, which will result in withdrawal from self-care. Therefore precise amounts of stress generation must be determined in order to protect patient safety, and prevent unintentional worsening of glycaemic control.

#### **10.4.7. Original contribution**

Methodologically, the systematised review of OT studies present in Section 10.2.2. presents a basic indication of expected levels of OT in saliva, which can be utilised for future researchers in the study of this tissue. This has yet to be established in literature, and therefore provides a useful benchmark for future studies. This contribution is attenuated by the findings of the

present study, which suggest further investigation of plasma OT is required to establish the efficacy of salivary measures in the first instance.

Interestingly, as outlined in Section 10.4.2., this study suggests that the relationship between stress and health outcomes is sexually dimorphic. Whilst literature has long established that the psychosocial (Lundbery, 2005, Matud, 2004, Pearlin, Scott Schieman, Elena M. Fazio and Stephen C. Meersman, 2005) and biological response (DeVries et al., 2003; Grewen et al., 2005; Clemens Kirschbaum et al., 1995; Takai et al., 2007) to stress may be sexually dimorphic, none could be located suggesting that the biological response to stressors may differ in terms of health outcomes. These findings suggest that the health consequences of stress are not only gender specific, but also not always negative. Whilst males may benefit from mild stressors in terms of motivation to self-care effectively, thereby improving glycaemic control (see Section 10.4.2.), this has yet to be established in other health conditions. As such, further research may wish to study this phenomenon in other age groups and disease states, so as to establish if these findings are unique to an AWT1D population. Findings in favour of this hypothesis would have significant impact for risk communication in healthcare settings, and may suggest a need for gender-specific care plans.

#### **10.4.8. Conclusion**

Taken together, the results of this study suggest that the psychophysiological aspect of the stress-buffering hypothesis cannot be accurately assessed with the current methodology. Whilst OT is related to a down-regulation of the HPA axis, as indicated by reduced cortisol, the current results suggest that OT is unrelated to glycaemic control. The question remains, therefore as to whether social support and diabetes outcomes are biologically related. As stated in Sections 10.4.1. and 10.4.4., further research is required adopting different methodologies, particularly plasma OT and a larger sample, in order to elucidate any potential psychophysiological relationship between peer support and glycaemic control.

An interesting gender difference is noted in the relationship between stress and glycaemic control, in which diabetes outcomes appear to benefit from increased stress in males. The results here demonstrate a clear need to pursue this avenue of research, as it has the potential to offer a route of significant gain for patients through potential enhanced risk-communication. In conclusion, although most did not display a biological relationship between stress and diabetes outcomes, individual differences in the stress response are noted. Recognising these individual differences in care guidance is a needed step towards optimal management of T1D. Those who respond to stress poorly can be identified and helped to understand, predict and increase their health-promoting behaviours. This education may be reciprocal, and allow healthcare professionals to better understand what differentiates those

who display pro-health responses to stress in comparison to those who do not, so that effective guidance may be designed, or peer mentoring programs advocated.

Overall, the findings of Study 1 and 2 indicate that peer support is associated with improved health in AWT1D, though the means through which it is able to achieve this remains ambiguous from a physiological standpoint. Psychosocially, a main effects model is implicated (see Section 9.4.). What remains unclear, is whether or not the peer support experienced by AWT1D can be considered normative. As outlined in Section 3.3. and Chapter 6, literature is unclear as to whether the psychosocial experiences outlined in this and the previous chapter are impacted by their health conditions, or if tumultuous psychosocial functioning is simply a developmental marker. A comparison study between AWT1D and their healthy peers therefore follows in Study 3.

## Chapter 11

### Study 3: A comparison of adolescents with and without type 1 diabetes on peer support and psychosocial functioning

#### 11. Overview

This chapter describes the final study, carried out as part of the current doctoral thesis. Study 3 was designed to investigate comparability of the psychosocial experience of AWT1D and healthy adolescents of the same age group. The aim of Study 3 was to determine whether or not the psychosocial functioning of AWT1D can be considered normative for this developmental stage, or if living with T1D can be said to have a detrimental impact on their psychosocial life. This chapter, first of all, discusses the rationale behind Study 3. This is followed by an outline of the methods regarding the reference participants, expanding on the information given about the methods in Chapter 8. Finally, the findings of Study 3 are presented and discussed in relation to existing literature and implications for clinical practice.

#### 11.1. Introduction

Whether or not living with T1D impacts on the psychosocial profiles of AWT1D is a contested issue. Research both supports and refutes the assertion that T1D impacts on peer support, QoL and resilience, and evidence of how any relationship identified may operate is lacking. Regarding peer support, it is suggested that the limitations T1D may place on social activities is thought to contribute towards a difficulty in establishing and maintaining friendships (Beck & Smith, 1988). However, it is noted that such assertions significantly pre-date the DAFNE study (DAFNE Study Group, 2002) which introduced the STTP approach to nutrition, allowing for more freedom in eating habits (Shearer et al., 2004). Therefore, this posited mechanism may be vastly outdated.

Whilst research appears to indicate that AWT1D have similar size social networks to comparative peers (Helgeson, Reynolds, et al., 2007), the quality of support provided within the network appears to differ, with AWT1D reporting significantly less high quality peer support (Helgeson, Snyder, et al., 2007; Seiffge-Krenke, 1997). Conversely, findings also suggest that AWT1D have a larger social network, and greater support than their healthy peers, potentially due to a greater need for intimate relationships due to the demands of self-care (Helgeson, Palladino, et al., 2014). This may draw peers into the social network to a greater extent, and may even initiate new friendships more readily (Helgeson et al., 2006). Little agreement, therefore, is seen in literature concerning the potential impact of T1D on peer support.

Gender differences, too, may play a role. Whilst largely agreed upon in healthy populations (Camarena et al., 1990; Golombok & Fivush, 1994; Kuttler, 1999), limited research has investigated this phenomenon in AWT1D. In healthy populations, research appears in agreement that females seek out and engage in a far greater number of intimate relationships,



preferring peer dyads. These relationships are likely to heavily rely on self-disclosure and emotional support (Salomon & Strobel, 1997). Males, however, report significantly less emotional support. They prefer group-based peer relationships and are more likely to maintain friendships through engagement with group activities such as sport (Gabriel & Gardner, 1999; Maccoby, 1990). Little research has investigated such differences in AWT1D, however. Longitudinal investigation suggests that whilst comparative peers reported enhanced peer support at the initiation of the study, females with T1D described increasing support over time, eventually reaching equivalency with their healthy peers after 4 years (Seiffge-Krenke, 1997). Males, however, continued to report a lack of support from peers for the study duration. Seiffge-Krenke (1997) suggests that this is due to the male gender role. Behaviours typically recognised as belonging within the sick role, including appropriate self-care, are often defined as identifiers of weakness within gender studies research (Broom & Lenagh-Maguire, 2010). Indeed, adult males with T1D have been found to have a greater desire to project a masculine identity to peers, particularly within an all-male environment, than a compulsion to appropriately self-care (O'Hara et al., 2013).

QoL is a similarly contested factor. Whilst qualitative research states that AWT1D believe their QoL to be significantly lower than their peers (Faulkner, 2003), quantitative data does not support this assertion (Hoey et al., 2001; Laffel et al., 2003; McMillan et al., 2004). Despite this, researchers assume that general QoL is likely to be impacted amongst AWT1D, simply because of the demands that self-care places on the life of the individual (Barnard et al., 2012). Indeed, this is likely to be true when assessing HRQoL (Hanberger, Ludvigsson, & Nordfeldt, 2009; Lawrence et al., 2012). However, it must be recognised that global QoL should assess life outside of health status. Family, friends and school life are all found to be more important predictors of global QoL than the disease itself (de Wit et al., 2007). Findings such as these indicate the importance of social networks in impacting QoL, and indicate the entwined nature of QoL and the social support research outlined above. As such, it is difficult to assess a direction of difference, should one exist, from literature.

Regarding gender differences, females are more likely to report less QoL than males (Kalyva et al., 2011; Lukacs et al., 2014; Naughton et al., 2014). However, the mechanism through which this occurs is unclear. Research suggests that emotional functioning appears to be at the root of reduced QoL in females (Miller & Eisenberg, 1988; Rosenfield, Vertefuille, & Mcalpine, 2000; Upton et al., 2005). Age differences, too, are abundant in literature in healthy populations, though limited in T1D. Older adolescents report enhanced QoL (Cotton, McGrady, & Rosenthal, 2010; N. Reynolds, Mrug, & Guion, 2013; J. Wagner, Abbott, & Lett, 2004). This is thought to be due to increasing cognitive and social skills, improving throughout this developmental stage (Cotton et al., 2010).

Whilst no studies could be identified comparing the resilience of AWT1D in comparison to healthy populations, it is suggested that differences may occur, due to potential differences in QoL and peer support. Protective assets associated with resilience include a good sense of humour, high intelligence, family support (Masten, 2001), acceptance, emotional support and pragmatism (Yi-Frazier, Smith, Vitaliano, & Yi, 2010). As such, differences in QoL and peer support are therefore likely to lead to differences in resilience, if this protective factors approach is adopted (S.S. Luthar & Zelazo, 2003). However, in order for a protective factor to influence outcomes, it must be actively engaged in conjunction with the risk factor (M. Rutter, 2012). Similarly, protective processes that provide opportunity for other protective factors to come into play are also of importance (Masten, 2011). Exposure to challenge, such as T1D, may therefore enhance resiliency in participants, and produce differences between those who have and have not faced such adversity. Nevertheless, such suggestions are purely assumptions and are not based on literature due to the paucity of research in this area. As such, non-directional hypotheses must be employed.

Gender differences, too, are likely to occur within this, primarily due to differences in coping style. Coping is highly related to resilience, though the two are fundamentally different. Coping refers to skills employed in the face of demand in order to manage resultant stress (Folkman & Moskowitz, 2004). Resilience, however, specifically identifies an adaptive response to such demand (Stratta et al., 2013). As such, not all coping styles can be defined as resilient. Indeed, as discussed in Section 6.4.1., not all coping resources produce positive outcomes, and therefore are not resilient (Beasley, Thompson, & Davidson, 2003; Campbell-Sills, Cohan, & Stein, 2006; Glennie, 2010). As explored in Section 6.4.1., the recognised gender differences in coping style, therefore, are likely to impact on resiliency. Females are far less likely to employ resilient coping styles, instead preferring maladaptive emotion-focused coping (Boardman et al., 2008; Leadbeater et al., 1999; Matud, 2004). If a protective factors approach is adopted (S.S. Luthar & Zelazo, 2003), then such influences are also likely to be sexually dimorphic, given their greater likelihood of investing in intimate relationships (Salomon & Strobel, 1997). However, as above, research in this area applied to T1D is lacking, and therefore direct conclusions regarding these differences are difficult to assume based on literature.

#### **11.1.1. Aims and objectives**

With this in mind, the aim of this study chapter is to explore the impact of T1D on the psychosocial profiles of adolescents. Using generic, non-diabetes-specific measures, psychosocial variables will be assessed and compared to a comparison group of healthy peers. This will be achieved using the following objectives:

1. To identify any differences in peer support between AWT1D and healthy peers.  
*Hypothesis 1.*
2. To identify any differences in QoL between AWT1D and healthy peers.  
*Hypothesis 2.*
3. To identify any differences in resilience between AWT1D and healthy peers.  
*Hypothesis 3.*
4. To account for variables through which these differences may be moderated, namely age and gender. *Hypothesis 4.*

### **11.1.2. Hypotheses**

Due to the findings of previous research outlined in Section 11.1., it is hypothesised that:

#### ***11.1.2.a. Hypothesis 1: Peer support***

AWT1D will differ in their peer support to a healthy peer comparison group, though a direction cannot be determined from previous literature.

#### ***11.1.2.b. Hypothesis 2: Quality of Life***

AWT1D will differ in their QoL to a healthy peer comparison group, though a direction cannot be determined from previous literature.

#### ***11.1.2.c. Hypothesis 3: Resilience***

AWT1D will differ in their resilience to a healthy peer comparison group, though a direction cannot be determined from previous literature.

#### ***11.1.2.d. Hypothesis 4: Age and gender differences***

- i. Older females with T1D will experience peer support comparable to healthy older females.
- ii. Males with T1D will report significantly less peer support than females with T1D and healthy peers, irrespective of age and gender.
- iii. Age and gender differences will occur between groups in QoL, though a direction cannot be determined from previous literature.
- iv. Age and gender differences will occur between groups in resilience, though a direction cannot be determined from previous literature.

## **11.2. Method**

Full methodological procedures for this study can be found in Chapter 8. Details specific to the current study are presented here.

### **11.2.1. Setting**

As this study offers a comparison between adolescents with and without T1D, a sample of healthy participants of the same age range was required in order to explore whether or not the

psychosocial experience of AWT1D can be considered normative. To this end, a sample of healthy adolescents aged 15-18 was recruited. This was achieved in collaboration with a youth club and two secondary schools with attached FE sixth form colleges in the East Midlands of England. The secondary school recruitment was acquired via after school “homework” clubs, specifically for science and psychology A level and GCSE qualifications.

### **11.2.2. Reference participants**

Through this, a further 80 reference participants were recruited, including 17 males and 63 females. The average age of the reference sample was 16.45 (SD=.99), which is comparable to the clinical sample (M=16.59, SD=.96).

An *a priori* power analysis was conducted on the basis of group comparisons between the clinical and reference populations on peer support measures, as this is the primary research question of the present study. Regrettably, only one study could be identified in this field reporting an effect size, and as such  $d=.5$  was used as a benchmark. Using an alpha of .05 and power of .80, as recommended by Cohen (1988), a minimum sample size of 52 per group was established. The present study therefore can be said to have sufficient power to avoid Type II error.

Due to the prevalence of females attending after school clubs, an abundance of female participants were recruited. Such gender disparity was not anticipated, and the lack of male participants must be considered a limitation of the study (see Section 11.4.5.).

### **11.2.3. Materials**

Participants in the reference group completed generic measures of global peer support, resilience and QoL to enable comparison of general life experience with the clinical sample. Therefore, the questionnaires utilised in the present study are the Berlin Social Support Scale (BSSS; see Section 8.4.1.a.), WHO-5 Well-being Index (WHO-5; see Section 8.4.1.b.) and the 10 Item Resilience Scale (CD-RISC 10; see Section 8.4.1.c.). Diabetes-specific measures, applicable only to the clinical sample, were not employed.

### **11.2.4. Procedures**

Local secondary schools and sixth form colleges were approached, through which two establishments in the East Midlands were identified, alongside a local youth club recommended by a member of staff at one school. Both schools preferred use of after school homework clubs as recruitment settings, so as not to disrupt curriculum teaching in these crucial educational year groups. A presentation on the thesis topic was provided during an after school club, through which information sheets and consent forms (see Appendices Y and Z) were provided to potential participants. The subsequent session was then utilised for data collection or to arrange a mutually convenient time and location for participation. As with the clinical sample,

those aged under 16 required parental consent (see Appendices AA and BB). The majority of participants wished to take part during this second session, though 17 chose to take part at a subsequent club meeting. Those who took part during the after school club were required to do so in an empty classroom away from the rest of the group in order to maintain comparability to the clinical sample, and minimise social desirability bias in questionnaire responses. Participants were initially given the opportunity to ask any questions regarding the research and reminded of their right to withdraw.

Participants were then asked to complete a number of questionnaires (see Section 8.4.) As with AWT1D, the researcher left the room during this time to minimise demand characteristics, and returned after all questionnaires were completed. Once finished, participants were thanked for taking part and informed that if they wished to withdraw from the study, they must make contact within two weeks from the date of participation, after which all data was anonymised.

### 11.3. Results

The analysis of the hypotheses outlined in Section 11.1.2. required application of various tests of difference. Independent samples *t* tests are utilised to analyse fundamental differences between the clinical and reference groups according to peer support, QoL and resilience (hypotheses 1, 2 and 3). Assessment of demographic variables which may modify this difference require application of three-way analysis of variance (ANOVA) (hypothesis 4). Descriptive statistics for the data are presented in Table 26.

Table 26. *Descriptive statistics of participants' reported emotional support, instrumental support, quality of life and resilience.*

	Group	<i>n</i>	M	SD	Min	Max
Global peer support	Clinical	90	27.51	4.53	14	32
	Reference	80	27.71	4.173	14	32
Emotional support	Clinical	90	13.70	2.24	6	16
	Reference	80	13.71	2.18	6	16
Instrumental support	Clinical	90	13.83	2.55	6	16
	Reference	80	14.00	2.18	8	16
Quality of life	Clinical	86	15.06	4.77	3	23
	Reference	80	14.70	3.41	7	21
Resilience	Clinical	86	26.64	6.05	3	38
	Reference	80	26.41	4.90	14	38

As with Studies 1 and 2, the data for all measures was found to be highly skewed (see Appendix CC), and therefore bootstrapping was used to allow for use of parametric measures and to ensure comparability of results across studies (Kowalski, 1972; Kraatz, 2011).

No significant differences were noted between the age of participants with or without T1D ( $t(164)=-.93$ ,  $p=.680$ ,  $d=-.14$ , 95% CI  $[-.45,.16]$ ). However, as noted in Section 11.2.1, there were significantly more females in the reference than clinical group ( $t(167)=2.86$ ,  $p<.001$ ,  $d=.44$ ,

95% CI [.13,.75]). As such, this inequality may serve to significantly alter results and must be considered a limitation of the findings subsequently presented. This limitation is discussed further in Section 11.4.5.

### 11.3.1. Independent *t* Tests

To reduce risk of Type I error generated by producing multiple tests, effect sizes and corresponding confidence intervals will be presented and interpreted alongside traditional hypothesis testing methods (Garamszegi, 2006; Hedges, 2008). Interpretations of effect sizes are in accordance with Cohen's guidelines (see Table 11, p.119, J. Cohen, 1988). Due to non-equality of variance, *t* tests were interpreted using Welch's correction.

#### 11.3.1.a. Hypothesis 1: Peer support

The findings of independent samples *t* tests investigating hypothesis 1 can be seen in Table 27.

Table 27. *Independent samples t tests comparing those with or without diabetes on facets of peer support*

Variable	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>	95% CI of <i>d</i>
Global peer support	.28	146	.782	.05	-.28, .37
Emotional support	.03	145	.978	.00	-.32, .33
Instrumental support	.45	147	.652	.07	-.25, .40

*AWT1D will differ in their peer support to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

As can be seen from Table 27, differences are not recognised between those with or without diabetes on either the total BSSS score, or its component facets of emotional or instrumental support, with negligible effect sizes (J. Cohen, 1988). As such, hypothesis 1.i is rejected.

#### 11.3.1.b. Hypothesis 2: Quality of Life

*AWT1D will differ in their QoL to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

Independent samples *t* tests suggest that adolescents with and without T1D do not differ in terms of their QoL as  $t(162)=.04$ ,  $p=.967$ ,  $d=.01$ , 95%CI [-.30,.31]. Therefore hypothesis 2 is rejected.

#### 11.3.1.c. Hypothesis 3: Resilience

*AWT1D will differ in their resilience to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

Finally, analysis also reveals that the clinical and reference participants do not differ in their resiliency, as  $t(163)=.08$ ,  $p=.937$ ,  $d=.01$ , 95% CI [-.29, .32]. Hypothesis 3 is thereby also rejected.

### 11.3.2. Analysis of Variance (ANOVA)

Three-way ANOVA were utilised in order to assess variance in the psychosocial variables of interest dependent on health status, gender and age, as indicated by previous literature (see Section 11.1.). Age differences were compared for those  $\leq 16$  and  $\geq 17$ , given the mean age in the samples (clinical  $M=16.59$ , reference  $M=16.45$ ).

In order to control for the increased likelihood of Type I error generated by multiple applications of ANOVA, all calculations are presented alongside appropriate effect size estimates and corresponding confidence intervals. Interpretations of effect sizes are consistent with Field's recommendations (see Table 22, p.173, Field, 2013). Appropriate plots are offered alongside statistical tests to allow for ease of interpretation. As with Study 2, 90% confidence intervals are reported in the ANOVAs to ensure comparability to 95% CIs for effect sizes which are able to reach negative values (Steiger, 2004).

#### 11.3.2.a. Hypothesis 4: Age and gender differences

- i. *Older females with T1D will experience peer support comparable to healthy older females.*
- ii. *Males with T1D will report significantly less peer support than females with T1D and healthy peers, irrespective of age and gender.*

ANOVA reveals a significant three-way interaction of health status, gender and age on global peer support, as  $F(1, 159)=4$ ,  $p=.047$ ,  $\eta_p^2=.03$ , 90% CI [.05, .71], to a small effect (Field, 2013). Analysis supports the assumption that older females report global peer support of a comparable level to the healthy reference group (see Figure 26). Interestingly, males with T1D appear to begin with greater peer support than their healthy counterparts, only to reduce the peer support they receive over time, eventually reaching the level of support reported by the younger healthy males (see Figure 28). Therefore, whilst females with T1D and the healthy peer comparison group appear to report greater peer support with age, these results suggest that males with T1D receive less peer support as they grow older.

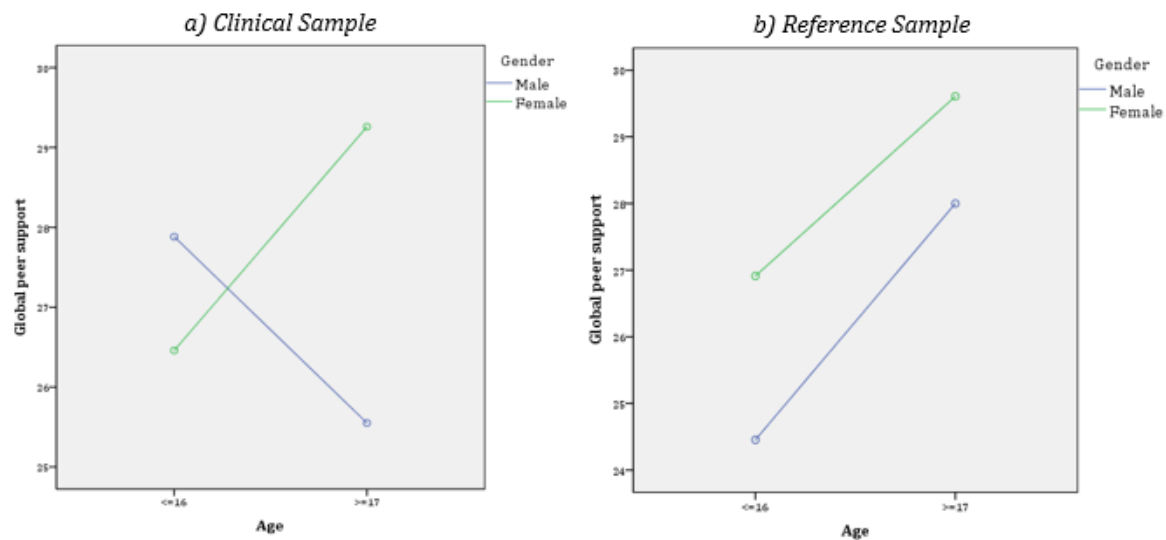


Figure 26. Three-way interaction of the effect gender and age on those with (a) and without (b) type 1 diabetes on global peer support.

No significant two-way interactions were noted in the analysis. However, a significant main effect of age ( $F(1, 159)=5.03, p=.026, \eta_p^2=.03, 90\% \text{ CI } [.04, .71]$ ) and gender ( $F(1, 159)=4.5, p=.035, \eta_p^2=.03, 90\% \text{ CI } [.05, .72]$ ) is also acknowledged. These findings suggest that older participants report greater global peer support (see Figure 29), and that females report significantly more peer support than males (see Figure 28).

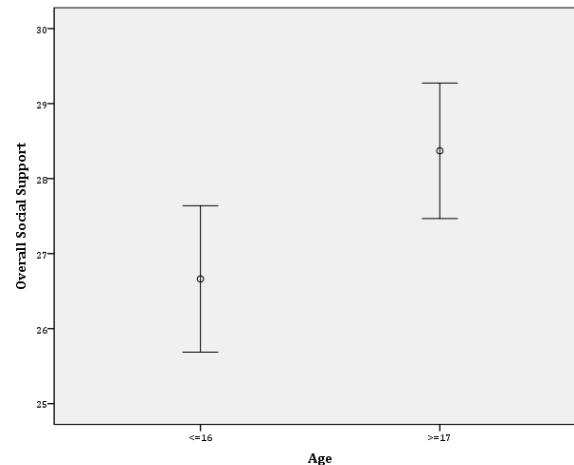


Figure 27. Mean global peer support of those aged ≤16 in comparison to participants ≥17, with 95% confidence intervals.



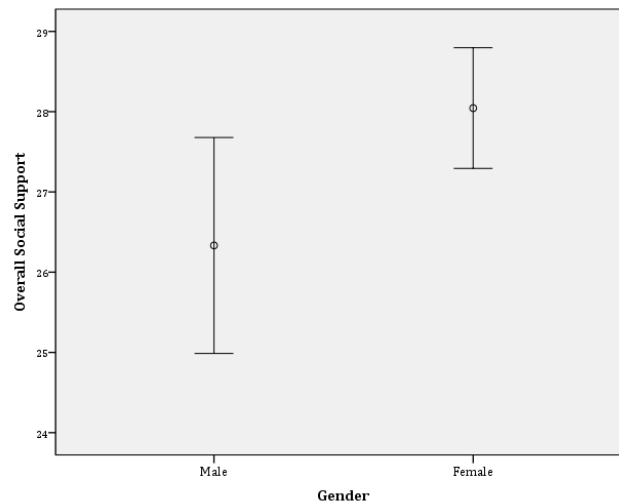


Figure 28. Mean global peer support of males and females, with 95% confidence intervals.

Therefore, whilst hypothesis 4.i can be accepted, hypothesis 4.ii can only be partially accepted, as whilst males do report worse peer support than females overall, age does appear to have significant impact. Younger males with T1D report significantly more peer support than females with T1D, or healthy peers of the same age group.

- iii. *Age and gender differences will occur between groups in QoL, though a direction cannot be determined from previous literature.*

No interactions were noted between age, gender and health status as  $F(1, 159)=3.05$ ,  $p=.083$ ,  $\eta_p^2=.02$ , 90% CI [.02, .45]. However, significant main effects of both age ( $F(1, 159)=12.81$ ,  $p<.001$ ,  $\eta_p^2=.08$ , 90% CI [.17, .55]) and gender ( $F(1, 159)=6.31$ ,  $p=.013$ ,  $\eta_p^2=.04$ , 90% CI [.09, .59]) are recognised, to a medium and medium-large effect, respectively (Field, 2013). These findings suggest that older adolescents have improved assessments of their QoL (see Figure 29), and that males have better QoL than females, as seen in Figure 30.

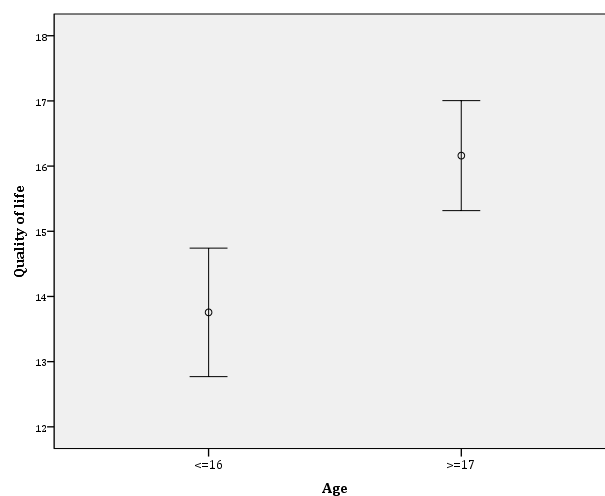


Figure 29. Mean quality of life of those aged  $\leq 16$  in comparison to participants  $\geq 17$ , with 95% confidence intervals.

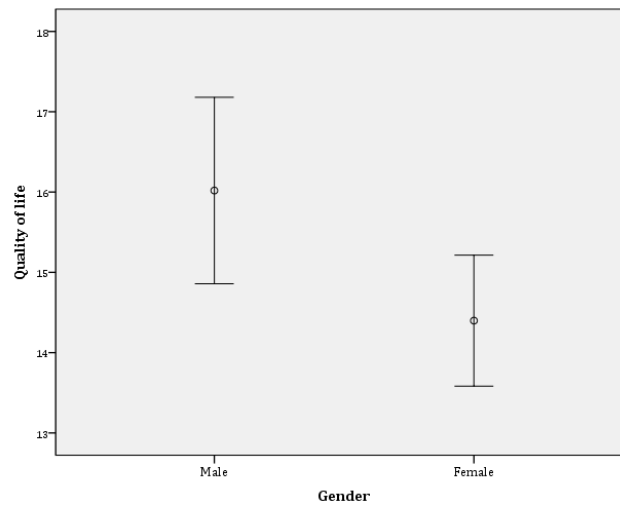
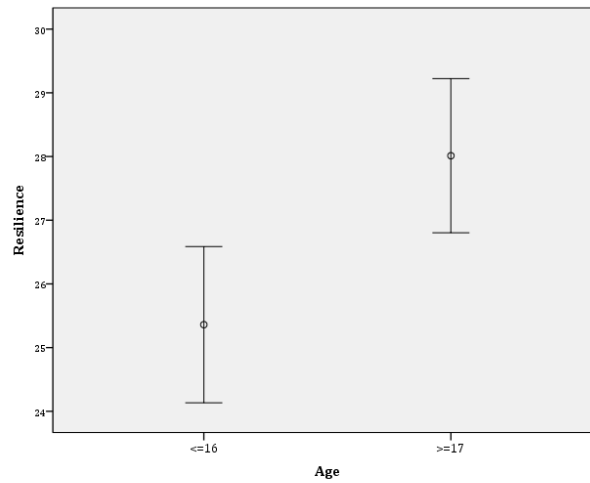


Figure 30. Mean quality of life of males and females, with 95% confidence intervals.

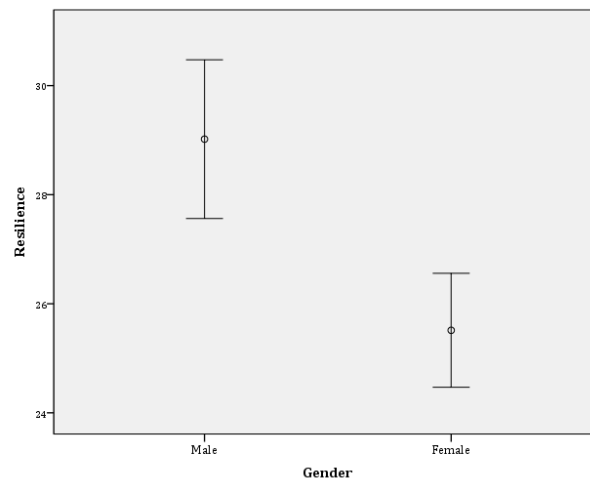
These findings suggest that health status does not impact on perception of QoL, whilst age and gender have independent effects. Therefore, hypothesis 4.iii can be partially accepted, as age and gender differences are noted, regardless of health.

- iv. *Age and gender differences will occur between groups in resilience though a direction cannot be determined from previous literature.*

Finally, a three-way interaction between health status, gender and age in resilience is non-significant, as  $F(1, 159)=.009$ ,  $p=.925$ ,  $\eta_p^2=.00$ , 90% CI [.31, .97]. No two-way interactions were acknowledged, either. However, as with hypothesis 4.iii, significant main effects of both age and gender are recognised, as  $F(1, 159)=8.69$ ,  $p=.004$ ,  $\eta_p^2=.05$ , 90% CI [.02, .36] and  $F(1, 159)=15.65$ ,  $p<.001$ ,  $\eta_p^2=.09$ , 90% CI [.17, .55], respectively. These results suggest medium effects of these demographic characteristics on resilience (Field, 2013). As can be seen in Figure 31, it is apparent that older participants reported significantly more resilience than those aged  $\leq 16$ . Figure 32 demonstrates that males experience significantly greater resilience than females, regardless of T1D.



*Figure 31.* Mean resilience of those aged  $\leq 16$  in comparison to participants  $\geq 17$ , with 95% confidence intervals.



*Figure 32.* Mean resilience of males and females, with 95% confidence intervals.

As with QoL, these findings minimise the impact of T1D on psychosocial experience. Whilst differences between those with and without T1D were not located, significant impact of both age and gender were noted independently. Therefore, hypothesis 4.iv can be partially accepted.

### 11.3.3. Summary of the findings of Study 3

A summary of the findings of Study 3 can be located in Table 28.

Table 28. *Summary of the findings of Study 3.*

	Hypothesis	Accepted/Rejected	Comment
1.	AWT1D will differ in their social support to a healthy peer comparison group, though a direction cannot be determined from previous literature.	Rejected ( $d=.05$ )	
2	AWT1D will differ in their QoL to a healthy peer comparison group, though a direction cannot be determined from previous literature.	Rejected ( $d=.01$ )	
3	AWT1D will differ in their resilience to a healthy peer comparison group, though a direction cannot be determined from previous literature.	Rejected ( $d=.01$ )	
4.i	Older females with T1D will experience social support comparable to healthy older females.	Accepted ( $\eta_p^2=.03$ )	
4.ii	Males with T1D will report significantly less social support than females with T1D and healthy peers, irrespective of age and gender.	Partially accepted ( $\eta_p^2=.03$ )	<i>Younger males with T1D report significantly more social support than females with T1D, or healthy peers of the same age group.</i>
4.iii	Age and gender differences will occur between groups in QoL, though a direction cannot be determined from previous literature	Partially accepted ( $\eta_p^2=.02$ )	<i>No impact of T1D on QoL. Main effects of age and gender are recognised.</i>
4.iv	Age and gender differences will occur between groups in resilience, though a direction cannot be determined from previous literature	Partially accepted ( $\eta_p^2=.00$ )	<i>No impact of T1D on resilience, whilst age and gender represented significant main effects.</i>

### 11.4. Discussion

As outlined in Chapter 6, the psychosocial experience of AWT1D is contested. Whether or not T1D impacts on the lives of adolescents significantly enough to alter their perceptions of peer support, QoL and resilience is not agreed upon in literature. The question, therefore, remains as to whether AWT1D have life experiences which can be considered normative for a person of their age. Thus, in response to this paucity of knowledge, a series of hypotheses were offered (Section 11.1.2.) which sought to account for potential psychosocial differences between AWT1D and a healthy peer comparison group. Using the results outlined in Section 11.3., each of these hypotheses is consequently explored.

#### 11.4.1. Hypothesis 1: Peer support

*AWT1D will differ in their peer support to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

Whether or not the peer support received by AWT1D differs from healthy adolescents appears disputed. Whilst literature has found peer support to be both lessened (Helgeson, Snyder, et al., 2007; Seiffge-Krenke, 1997), and enhanced (Helgeson et al., 2006; Helgeson, Palladino, et al.,

2014), neither is supported by the present findings. As can be seen in Table 27, differences are not recognised between the clinical and reference group on global peer support, nor emotional or instrumental support. As such, it can reasonably be concluded in this population that the peer support experienced by adolescents with or without T1D is comparable.

These findings are illuminated greatly by the discussion of Study 1. Whilst no previous research could be located highlighting such lack of difference, when presented in consideration of Section 9.4., interpretation can be found. As highlighted in Section 9.4., adolescents seek the normality from peer relationships that they struggle to locate in familial support. With this in mind, AWT1D expressed reticence to discuss management of T1D with their peers, due to a perceived sense of difference that this facilitates (see Section 9.4.2.). As such, T1D is unlikely to be the central focus of peer relationships, and may be deliberately minimised in its potential impact. This interpretation reflects other dominating factors in the relationship outlined in the qualitative data of Study 1, including social activities and educational concerns (see Section 9.3.5.). Such explanation has previously been seen in research reflecting a lack of difference in global QoL between groups of adolescents with or without T1D. Research by de Wit and colleagues (2007) suggests that diabetes is not a leading consideration in assessment of global, rather than health-related, QoL. Family, friends and school life were all more predictive of general QoL than health status (de Wit et al., 2007). Thus, similar processes may be involved in the assessment of peer support.

It is important to recognise that a central aspect of the interpretation of Study 1 is the role played by peers who share a diagnosis of T1D. Unfortunately, quantitative data on these support network members was not collected and so cannot be analysed for correlates. However, given the importance placed on such group members in Chapter 9, it is logical to assume such relationships may also impact on the global peer support received and reported here. A three-way group comparison may offer some further interpretation, had the data available allowed it. It may be that healthy peers and AWT1D with peers with T1D may experience similar levels of social support, due to a sense of belonging and interpretation of similarity between the self and members of the peer network. AWT1D who lack friends with T1D may conversely demonstrate a group with impaired peer support, as they interpret a fundamental difference between themselves and their peers, concordant with a lack of understanding. Such findings would offer explanation for the lack of consensus amongst literature in terms of the experience of peer support reported by AWT1D populations and in the present study, as composition of the peer network is as yet unconsidered in research. Future studies may wish to direct attention to this deficit of knowledge.

A final interpretation of this finding lies in response bias. It may be that due to a desire to appear “normal” and to minimise the impact of their T1D, AWT1D may have offered an

exaggerated estimation of their peer support. Ethnographic research has found that people of all ages with T1D are strongly influenced by a desire to “keep face” and “prove themselves” (Hinder & Greenhalgh, 2012), which, in the present research, may have influenced a desire to inflate their psychosocial profile to one they perceive as normative. Such interpretation would, therefore, explain a lack of difference in self-report measures. This acts as a fundamental limitation of the present study, and must be remembered in interpretation of all self-report measures.

#### **11.4.2. Hypothesis 2: Quality of life**

*AWT1D will differ in their QoL to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

Literature concerning perceived global QoL of AWT1D is inconclusive. Adolescents appear to believe that their QoL is negatively impacted by T1D (Faulkner, 2003), though this is not supported by quantitative findings (Hoey et al., 2001; Laffel et al., 2003; McMillan et al., 2004). The results of the present study support such findings, suggesting that the psychosocial distress experience by AWT1D is similar to peers. It is remarkable that AWT1D do not experience reduced QoL in response to T1D, given the vast impact that self-care can have on the social, emotional and physical life of the adolescent (Barnard et al., 2012). Previous research has suggested that such findings indicate successful application of coping resources in the adolescent population, due to enhanced management, education and social care provided by diabetes care teams (V. M. Wagner et al., 2005). Indeed, the participant sample has access to a multidisciplinary care team including a diverse range of healthcare professionals caring for various aspects of their physical and emotional well-being. This enhanced support may be responsible for the positive perception of QoL seen in AWT1D (V. M. Wagner et al., 2005). These results may, therefore, not be applicable to those unengaged with or unable to access the diabetes care team. Undeniably, a limitation of this and all other studies using clinical settings to access participants is that the research is limited to patients who engage with healthcare. In the UK, outpatient clinic attendance rates vary widely, from 75% to 1.4% non-attendance (Hardy, O'Brien, & Furlong, 2001; Masding et al., 2010). Specific to the outpatient clinics in the present study, 22% and 34% non-attendance was reported within the data collection cycles. Should diabetes care teams be responsible for this enhanced perception of QoL, it would be expected that participants with chronic non-attendance at clinic would report significantly lower QoL than those who are engaged with healthcare. Further research is therefore required in order to support this assertion, though the difficulties with accessing this hard-to-reach population make such studies prohibitive.

Another explanation may be found in the influence of personal factors such as coping resources, personality traits and peer support, all of which are known to impact on psychosocial outcomes (Acitelli & Badr, 2005; Berg et al., 2009). The relatively enhanced QoL reported in the clinical sample may represent improved adaptation and coping skills due to sufficient resources, such as peer support. Indeed, it is logical to conclude that if social support is a significant contributor to QoL, then normative levels of peer support found in Section 11.4.1. will feed into a QoL similarly comparable to peers. AWT1D may, therefore, perceive their QoL to be similar to that of their peers due to comparable support. It is noted that literature has identified an association between poor QoL and the prevalence of complications and comorbid illness (Edelman, Olsen, Dudley, Harris, & Oddone, 2002). As this study utilises adolescents, who will typically have lived far less time with T1D than adults, participants were unlikely to have been diagnosed with a comorbidity and, as such, potentially bypass the main determinant of poorer QoL in this health condition (Edelman et al., 2002).

Alternatively, even when psychosocial distress is present, the questionnaire may not be felt to be the appropriate place to describe such emotions. Adolescents are likely to avoid reporting distress (Wake, Hesketh, & Cameron, 2000), or may find that alternative dimensions of QoL are not captured by the WHO-5. Indeed, research has indicated that specific facets of QoL such as acceptance, coping resources, lifestyle and future expectations are those most likely to be impacted by T1D (Olsson, Toumbourou, & Bowes, 1998), none of which are accurately assessed by the WHO-5. However, the scale has been validated for use in AWT1D (De Wit et al., 2007) and as such the decision to use the questionnaire remains appropriate.

### **11.4.3. Hypothesis 3: Resilience**

*AWT1D will differ in their resilience to a healthy peer comparison group, though a direction cannot be determined from previous literature.*

A paucity of literature exists assessing resilience in T1D (Yi-Frazier et al., 2013), with no studies located which compared the resilience of AWT1D to peers. However, research has suggested that resiliency must be actively engaged with in order to effect outcomes (M. Rutter, 2012). It is therefore suggested that differences in resilience are likely to occur between the clinical and reference samples, simply as AWT1D may consider living with T1D as an adversity, enabling them to practice resiliency. Similarly, factors said to be contributing towards resilience include sense of humour, high intelligence, family support (Masten, 2001), acceptance, emotional support and pragmatism (Yi-Frazier, Smith, Vitaliano, & Yi, 2010). Therefore, it was suggested that hypothesised differences in peer support and QoL were likely to lead to perceived differences in resiliency. However, *t* test analysis suggests that no such difference exists.

There are several possible explanations for this finding. Firstly, if the assumption that resiliency is produced by a series of protective factors (S.S. Luthar & Zelazo, 2003) is assumed, as stated by Masten (2001) and Yi-Frazier and colleagues (2010), then it is unsurprising that resilience does not differ, as neither did QoL and peer support. Social support, in particular, has been found as an influential factor in a sense of resiliency (Yi-Frazier, Smith, Vitaliano, & Yi, 2010). Therefore, if no difference is perceived in the amount of social support received between adolescents with or without T1D, it is logical that they would also not differ in resilience.

A further interpretation of this result lies in the application of cognitive adaptation theory. Helgeson *et al.* (2014) use this theory as their conceptualisation of resilience in emerging adults with T1D aged 18-25, in comparison to peers. According to cognitive adaptation theory, encountering adverse life events acts as a threat to beliefs regarding the self. Specifically, conceptualisations of a sense of mastery over the life course, self-esteem and the belief that positive outcomes are possible are unfavourably impacted by such negative events (Taylor & Brown, 1988). Adaptation to and acceptance of such occurrences is achieved through regaining these qualities, suggesting that intrinsically linked to resiliency are equivalent constructs of high self-esteem, internal locus of control and optimism (Taylor & Brown, 1988). Cognitive adaptation theory has been widely used in the field of health psychology to explain differences in reaction to health conditions (DuBois *et al.*, 2015; Ranchor *et al.*, 2010; T. Schulz *et al.*, 2012). This may be due to research which suggests successful adoption of these constructs are particularly adaptive when faced with severe threat, such as diagnosis of a life altering or limiting condition (Helgeson, 1992, 1999). Such research suggests that the more serious the threat, the greater the influence of optimism, self-esteem and locus of control (Helgeson, Reynolds, *et al.*, 2014).

Some have characterised T1D as a severe health threat (Helgeson, Reynolds, *et al.*, 2014) and, as such, it is assumed that indicators of resilience, conceptualised as successful cognitive adaptation, are more likely to be present in those with T1D than their healthy counterparts, due to greater exposure to challenge (Helgeson, Reynolds, *et al.*, 2014). This would be consistent with research in other health conditions that shows cognitive adaption indicators reveal stronger relations to good health outcomes under conditions of more severe threat (Helgeson, 1992, 1999). However, Helgeson *et al.* (2014) was unable to fully support such hypothesis. Whilst indicators of cognitive adaptation predicted lower levels of bulimic symptoms, conflict, breakup of romantic relationships, and alcohol for those with T1D, this only occurred in the older emerging adults. No differences were observed between 18-19 year olds with or without T1D in cognitive adaptation. This suggests that the resiliency-based advantages of encountering challenge only develop in adulthood. Helgeson *et al.* (2014) suggest that this may be due to those with T1D experiencing greater adversity in adulthood than their peers. There may simply



be more for those with T1D to adapt to, as they face challenges such as transition to adult services in healthcare and total autonomy in self-care. This is in addition to the life changes also occurring during this developmental stage independent of T1D, including leaving home and encountering higher education or employment for the first time. These life events are also likely to be made more complex by T1D (Helgeson, Reynolds, et al., 2014). Nevertheless, with the present study in mind, this suggests that the adversity presented by T1D alone is not sufficient enough to produce changes in cognitive adaptation, leading to increased resiliency, in older adolescents. It is likely that additional life challenges are required in order for the beneficial effects of adversity to emerge. As such, the resilience experienced by AWT1D is considered normative.

#### **11.4.4. Hypothesis 4: Age and gender differences**

- i. *Older females with T1D will experience peer support comparable to healthy older females.*
- ii. *Males with T1D will report significantly less peer support than females with T1D and healthy peers, irrespective of age and gender.*

Research assessing gender differences in peer support is lacking with concern to T1D, specifically. Amongst healthy adolescents, gender differences are well investigated (Camarena et al., 1990; Golombok & Fivush, 1994; Kuttler, 1999; Zhang, Gao, Fokkema, Alterman, & Liu, 2015). Research indicates that females prefer to establish dyadic, intimate relationships based on self-disclosure and emotional support. Conversely, males prefer group-based friendships, grounded in companionship and group activities (Gabriel & Gardner, 1999; Maccoby, 1990). Similarly, females seek and attain emotional support more readily than males (Salomon & Strobel, 1997). Regarding T1D, of the limited literature that could be identified, age appears to also play a significant role in assessment of social support. Younger AWT1D appear to perceive impaired social support, which for females, gradually increases with age, reaching a comparable level after 4 years. Males with T1D, however, report impaired social support, across age groups and in comparison to males without T1D (Seiffge-Krenke, 1997). Such findings are supported in the present study, in which a three-way interaction of health status, age and gender is noted. As can be seen in Figure 29 (see p.187) and Figure 28 (see p.188), males appear to report significantly less peer support than females overall. However, when age and gender are taken into consideration, it is noted that males with T1D report less peer support over time having initially reported the greatest support, whilst females with T1D reach comparability with their peers in those aged 17 and over. Indeed, in the older age bracket, males with T1D report significantly less peer support than males without T1D, and females overall.

Although initially low, peer support increased dramatically with age for all except males with T1D. This upward trend in peer support has been noted in previous research in a similar

age group (Liu, Mei, Tian, & Huebner, 2015; McNelles & Connolly, 1999; Seiffge-Krenke, 1997; Vaux, 1985), though would appear to be poorly understood. It is suggested that such increases in perceived peer support are related to differing conceptualisations of support with increasing age. As is noted by McNelles and Connolly (1999) self-rated intimacy in relationships also increase with age, suggesting that friendships may have lasted longer by this developmental stage, if one assumes that most friendships are made in school. Therefore, if a participant perceives that those within their social network simply know them better having spent increasing time in each other's company, it follows logically that the perceived support would subsequently increase.

In addition, irrespective of health status, females reported greater peer support than males. Moreover, an increasing discrepancy is noted between males and females with T1D, in which females increase in their peer support at a rate similar to their healthy counterparts, whilst males with T1D decrease almost as rapidly, with far less peer support than males without T1D in the older age group. Firstly, it is noted in previous research that male adolescents prefer peer support provided via accessing shared activities, particularly sport and exercise (Gabriel & Gardner, 1999; McNelles & Connolly, 1999). Given the inherent limitation T1D can place on prolonged participation in such activities (see Section 5.6.1.), it is suggested that requirement to withdraw from or limit exercise may consequently adversely impact male friendships. This may worsen with age, in which feelings of difference and lack of participation may become compounded, particularly during stressful life changes occurring in those aged  $\geq 17$ , such as transition to adult healthcare services.

Interpretation of similar findings have highlighted the potential for the involvement of the male gender role (Seiffge-Krenke, 1997). Research into adult males with T1D has highlighted the problematic nature of illness-related behaviours in traditionally male environments. The workplace, in particular, has proven challenging. Within these settings, acceptable behaviour norms are set by non-diabetic male colleagues and will rarely involve emotional support or conversations concerning health (Broom & Lenagh-Maguire, 2010). The desire to be identified as masculine has been stated to override compulsion to appropriately self-care, instead striving to achieve an external identity of a 'normal' male (O'Hara et al., 2013). This is likely to be a particularly crucial goal for adolescent males, as they endeavour to establish an adult self (Viner et al., 2012). Indeed, adolescents who ascribe to traditional ideas of male gender roles are less likely to engage with health-promoting behaviours (Mahalik, Burns, & Syzdek, 2007). Therefore, males with T1D may be adopting an external identity in order to portray what they perceive as an ideal, masculine self, thereby ignoring health concerns, in order to achieve acceptance (Hinder & Greenhalgh, 2012). As such, peer relationships may lack intimacy and thereby provide impaired support.

Research into adults with T1D may also serve to offer some explanation. Women with T1D have been found to focus on well-being and social support in their self-care, whilst males are concerned by sexual functioning and affordability of healthcare (Hjelm & Nambozi, 2008). Female adolescents may, therefore, hold social support more centrally within management of their T1D, and therefore prioritise it. Males place less emphasis on such support. Indeed, males are consistently noted as reporting less social support than females (Enzlin, Mathieu, & Demyttenaere, 2002) but no research could be identified assessing their satisfaction with the support available. It may be the case that both males generally, and specifically with T1D, are merely accessing the optimal amount of social support for their requirements, and as such have adequate individualised support available. Whilst satisfaction is not investigated in the present study, it may be surmised that low satisfaction with peer support would adversely affect QoL and resilience, investigated in the subsequent hypotheses, due to the interrelated nature of these concepts. As males report overall increased QoL and resilience than females (see Section 11.3.2.), it is suggested that they are potentially satisfied with the support available, and as such do not perceive this as a disadvantage. Indeed, as explored in Section 11.4.3., the increased adversity posed by living with T1D may have instilled independence in the males with T1D, aligned with cognitive adaptation theory. Therefore, they simply require less peer support than females, or males without T1D.

*iii. Age and gender differences will occur between groups in QoL, though a direction cannot be determined from previous literature.*

QoL has become an increasingly crucial outcome measure in diabetes (J. Wagner et al., 2004). Generally, living with diabetes has been demonstrated as having a negative impact on QoL, though the relationship between QoL and diabetes is thought to be complex and multifactorial (Bradley & Speight, 2002; Upton et al., 2005; J. Wagner et al., 2004). Whilst differences in QoL between those with and without T1D were investigated, and subsequently dismissed in hypothesis 2, the focus of the present research question concerns the potential for age and gender differences within this relationship. In the present study, interactions between health status, age and gender were not found. However, significant main effects of both age and gender are noted, to medium effect (Field, 2013). These findings suggest that, independent of T1D, older adolescents have enhanced QoL (see Figure 29, p.188), whilst males report significantly greater QoL than females (see Figure 30, p.189).

It is a common finding for females to report lower QoL than males, both amongst people with T1D (Kalyva et al., 2011; Lukacs et al., 2014; Naughton et al., 2014) and their healthy counterparts (Bisegger et al., 2005; Michel, Bisegger, Fuhr, & Abel, 2009) though the reasons for this phenomenon remains unclear. It has been suggested that psychosocial and emotional

concerns prove a greater hurdle to QoL for females than males (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). Indeed, when measures of QoL are analysed by their component facets, the gender difference tends to be most overtly evident in the emotional functioning sub-scale (Miller & Eisenberg, 1988; Rosenfield et al., 2000; Upton et al., 2005). This is supported by recent work by Naughton and colleagues (2014), who state that psychological and social concerns have greater influence in the adolescent female's perception of QoL than males. Such findings, supported by the present research, go some way to explain why females are at greater risk of emotional health problems such as anxiety and depression than males (Upton et al., 2005).

Similarly, age differences are also abundant in literature, with QoL likely to increase with age (Cotton et al., 2010; N. Reynolds et al., 2013; J. Wagner et al., 2004). This has been explained as a reflection of more developed cognitive skills and enhanced ability to identify positive outcomes from undesirable situations (Cotton et al., 2010). Piagetian theory states that formal cognitive operations propagate during adolescence. Formal operations allow for complex and abstract thought, relying on fewer concrete objects and events (Piaget & Cook, 1954). This shift from the real to the abstract may thus impact on QoL, with particular attention to T1D. QoL may succumb to a conceptual shift in which it becomes a matter of 'living well' and 'overall health' rather than 'diabetes' and 'self-care' (J. Wagner et al., 2004). This would reflect the developmental stages of understanding illness, corresponding to Piaget (Berry, Hayford, Ross, Pachman, & Lavigne, 1993; Perrin & Gerrity, 1981). In addition, the potential impact of broadened life experience must be acknowledged. Conceptualisation of QoL is individualised, and increased exposure to those with poorer experiences than their own may produce a gradual re-evaluation of personal QoL. Similarly, older adolescents may have concluded that strict adherence to a care plan precedes an inflexible lifestyle, leading to a prioritisation of QoL over self-care. Consequently, compromises in self-care may become more abundant, as older adolescents seek and achieve autonomy in self-management for the first time. (Soenens et al., 2007). This may thereby explain the acknowledged worsening of glycaemic control with age (Wallander et al., 2013; Wherrett et al., 2013).

Finally, the normalisation of identity, and thus experience, may also play a contributory role. Identifying their QoL in terms of relative health and living well, as opposed to T1D and self-care, serves to create comparability with peers. This change in personal conceptualisation may serve an adaptive function, or to encourage non self-management behaviours, as noted in Study 1 (see Section 9.4.2.). However, there is potential for psychological adjustment to diabetes to influence this interpretation. This variable was not measured in the present study, nevertheless, it is likely that such conceptual change in relation to QoL is related to adjustment (Luyckx et al., 2010), though the direction of such relationship would require investigation. This conceptual

shift may, therefore, be a result of relationships between other unacknowledged variables. It is possible that AWT1D with better quality adjustment to T1D may experience attitudinal change towards QoL as a result of assimilation of diabetes within the self-concept.

- iv. *Age and gender differences will occur in resilience though a direction cannot be determined from previous literature.*

Coping and resilience are two highly related, but distinct concepts. Coping skills are not always adaptive; not all will lead to positive outcomes in response to stress, and therefore not all can be defined as resilient (Beasley et al., 2003; Campbell-Sills et al., 2006; Glennie, 2010). Acknowledged gender differences in coping style (see Section 6.4.1.), then, are likely to also impact on resilience (Stratta et al., 2013). Females tend to score higher on measures of distress and emotion-focused coping; both of which can be classed as maladaptive, and therefore non-resilient (Boardman et al., 2008; Leadbeater et al., 1999; Matud, 2004). Protective factors contributing towards overall resilience are also likely to differ according to sex. Females are more likely to invest in intimate relationships with a social network, whilst males engage in problem-focused coping (Bernard, 1995). It would seem, therefore, that females are at a distinct disadvantage in terms of investing in coping resources which are known to lead to resiliency. It is unsurprising then that, in the present study, females report significantly less resilience than males, to a medium effect (Field, 2013) and independent of health status.

Before discussing the implications of such a finding, an important theoretical dichotomy must be noted. Research frequently conceptualises a protective model of resilience, which is activated when adversity is presented (S.S. Luthar & Zelazo, 2003). However, the present findings support a compensatory model of resiliency by reporting statistical main effects and no interaction effects, which suggests that resilience operates irrespective of challenge (Hjemdal, Aune, Reinfjell, Stiles, & Friborg, 2007). This raises an important theoretical issue regarding theories of resilience, which has previously been acknowledged (see Sections 6.5. and 9.4.1.e.). The findings of the present study supports such conclusions; that a trait definition of resilience is likely to operate within this age group, in which resilience operates as a fixed personality trait that enables effective coping and adjustment when presented with adversity. Such a trait is considered a type of stress inoculation, insulating individuals against negative outcomes when confronted with trauma, and operating irrespective of such adversity (Connor & Davidson, 2003; A. D. Ong et al., 2006).

No research could be located investigating gender differences in resilience with respect to AWT1D. Indeed, within such an age group, only one study could be identified. Stratta *et al.* (2013) investigated the impact of the 2009 earthquake in L'Aquila, Italy, on resilience of adolescents in the area. Males seemed to most benefit from a protective mechanism model of

resilience, whilst females seemed to be more traumatised by the challenge, and lack resiliency (Dell'Osso et al., 2011; Stratta et al., 2013). This is supported by the present findings, as females reported significantly less resilience than their male counterparts, regardless of health status. Specifically, males adolescents in the study by Stratta *et al.* (2013) were more likely to engage in problem-focused coping. In general, literature espouses the benefits of such a coping style (Carver, 1997; Coyne, Aldwin, & Lazarus, 1981), with some associating these coping resources as contributory to resiliency (Campbell-Sills et al., 2006; Dumont & Provost, 1999). Although resilience and coping are inter-related, but conceptually different, constructs, it is possible to gain insight into such findings through gender differences in coping style. Some view coping style as a protective factor contributing towards resilience (Campbell-Sills et al., 2006; Stratta et al., 2013), however, given the trait approach adopted in the present study, it is suggested that coping style may be a lens through which resiliency is viewed. It may be that, due to trait resiliency, those who are highly resilient are more likely to adopt adaptive coping styles, and recognise the problematic nature of avoidant coping.

Lending further support to the trait definition of resilience is an alternative interpretation of the present findings. Research has identified genetic factors which may explain individual differences in resiliency (Boardman et al., 2008; Caspi et al., 2003; Michael Rutter, 2003; Silberg, Rutter, Neale, & Eaves, 2001). Few studies could be located assessing whether the heritability of resilience was sexually dimorphic. However, of those that could be identified, there is support for the theory that genetic expression of resiliency is constrained in females, but enabled in males (Shanahan & Hofer, 2005). This is said to be achieved through a gene-environment interaction, in which sex is defined as an environmental moderator due to differing socialisation, gender roles and access to resources, dependent on biological sex (Boardman et al., 2008; Walters, 2002). Such research suggests that genetic heritability of resilience has greater expression amongst males than females, dependent on environmental processes specifically noted in two measures of psychological functioning. Self-acceptance is an important moderator of expression of resilience for both males and females, whilst environmental mastery is an important moderator for males only (Boardman et al., 2008). These findings are supported by the present research, in which males reported significantly greater resilience than females. Such conclusions also go some way to explain the age differences present in this study. Namely, older adolescents reporting increased resilience than their younger counterparts, independent of health status. Given that self-acceptance is known to increase with age (Negovan, Bagana, & Dinca, 2011; Vasile, 2013) this too would explain an overall increase in resilience in the older participant grouping, regardless of gender or health. Alternative interpretations of the age difference present in the sample may be found in the impact of QoL. Recent literature supports the assertion that QoL is a significant predictor of

resilience (Sagone & Caroli, 2014) and therefore age differences in QoL are likely to thus impact overall resilience. The finding that older adolescents have greater QoL (see hypothesis 4.iii in Section 11.4.4.) is thereby also seen in the greater presence of resilience in older adolescents. Such differences in QoL are fully explored in the preceding section. Taken together, these studies advocate a compensatory model of resilience (Hjemdal et al., 2007), and argue for the adoption of a trait definition over the protective model.

#### **11.4.5. Limitations**

Before concluding, several limitations of this research are acknowledged alongside suggestions for future research. Firstly, as stated in Section 11.2.2., it is recognised that there was a significant lack of male participants in the reference group. Whilst the overall power of the study was sufficient, *post hoc* analysis of the data reveals that for gender analysis, the ability of the data to successfully reject the null hypothesis is severely diminished at only 43%. As such, the ability of the present study to assess the psychosocial profiles of healthy adolescent males is impaired. Such gender disparity in attendance at afterschool homework clubs was not anticipated. However, discussions with teachers at the schools revealed that this was not unusual, and not unique to the academic disciplines targeted. With this in mind, it is recommended that future researchers wishing to use such recruitment settings consider whether such an unbalanced demographic profile is suitable for the aims of that study. Regarding the present research, the lack of males in the reference population may have impacted results. Particularly when considering the results of hypothesis 1.i and 1.ii, in which males with and without T1D significantly differed in their peer support (see Section 11.4.1.), another interpretation of this finding may lie in the lack of sufficient male participants to provide an accurate frame of reference. It is possible that this study recruited healthy males unusually high in peer support, and that a larger, more representative sample may have embodied a similar decrease in support to those in the clinical group.

Furthermore, the utilisation of a generic measure of QoL may have impaired the ability of the research to detect facets of self-care which adversely affect QoL. Whilst the global measure allowed for comparability between the clinical and reference samples, it is possible that using such a measure in isolation does not provide a full picture of the QoL of AWT1D. With this in mind, it is possible that the reason for the lack of difference between the clinical and reference groups is due to the limitations of the measure. However, using a diabetes-specific assessment of QoL would not have fulfilled the aims of the present research, and as such the decision to use the WHO-5 remains valid.

Finally, the questionnaire assessments were administered in very different settings for each group. Whilst the reference participants completed the questionnaire battery in an

afterschool club; an environment they are familiar with and have chosen to attend by choice, the environment for AWT1D was less comforting. AWT1D completed questionnaires during visits to the outpatient clinic at the hospital. Such an environment is likely to induce a certain degree of stress in participants, and is one in which participants may feel they are obliged to attend. As such, the state of mind of each participant group is likely to be very different. AWT1D may have been more susceptible to demand characteristics, due to the clinical setting. Despite being assured that the hospital was not affiliated with the research in any way, clinical participants may, consciously or otherwise, have dismissed such information. This may have led to an inflation of their psychosocial profile. It may be that due to a desire to appear “normal” and to minimise the impact of their T1D, AWT1D may have offered an exaggerated estimation of psychosocial measures. Ethnographic research has found that people of all ages with T1D are strongly influenced by a desire to “keep face” and “prove themselves” (Hinder & Greenhalgh, 2012), which, in the present research, may have influenced a desire to inflate their psychosocial profile to one they perceive as normative. Such interpretation would, therefore, explain a lack of difference in self-report measures. This acts as a fundamental limitation of the present study, and must be remembered in interpretation of all self-report measures.

#### **11.4.6. Clinical implications**

Taken together, these results suggest that AWT1D not only believe themselves to be ‘normal’ (see Study 1), but also appear to have a psychosocial profile that would suggest this belief is accurate. As such, it would be prudent for healthcare providers to remember such beliefs when discussing self-care with adolescents. As alluded to in Study 1 (see Section 9.4.5.), discussions between diabetes care teams and adolescents which emphasised a centrality of T1D within the lifestyle, contrary to the person-centred guidance recommended by NICE, were observed during the data collection process. The findings of the present study lend support to these recommendations; that emphasising a difference between patients and the general public is not only ineffective (Sayer et al., 1995), but also fundamentally false. These results provide further support to the recommendations of Study 1 (see Section 9.4.5.), and suggest that holistic care plans incorporating education, career aspirations, family and social life, alongside self-care, may best reflect the normative view of AWT1D, and thereby may be more effective. Furthermore, these results provide evidence for diabetes care teams that the time, effort and cost they invest into AWT1D results in excellent psychosocial outcomes that can be considered normative for the adolescent population.

The one area where specific alterations to current practice may require further investigation is the peer support of male AWT1D. As outlined in Section 11.4.4., males with T1D reported significant less peer support than both females and males without T1D (see Figure 29,



p.187) and Figure 28, p.188). As such, it may be that this population may benefit from a support intervention. However, it must be remembered that whilst peer support is significantly reduced in this group, particularly in comparison to males without T1D, an impact on QoL and resilience is not observed. Therefore, it is possible, as outlined in Section 11.4.4., that male AWT1D simply require less peer support than other groups due to enhanced independence in their self-care. Further research is required into the satisfaction of male AWT1D with their peer support provision before such recommendations can be persuasively made. To simply recommend an intervention without being able to determine the impact of this reduced peer support would be reductionist. Indeed, given that males and females with T1D did not report significant differences in self-care nor HbA<sub>1c</sub>, an impact on health outcomes is also not observed. The impact of this reduced peer support is, therefore, likely to be minimal, lending further support to the observation in Section 11.4.4. that satisfaction with support is a key under-researched variable.

#### **11.4.7. Original contribution**

Age and gender differences in resilience in adolescents is not something that has previously been investigated. As such, this study provides important insight into how resilience changes, not only across developmental stages, but also between genders. The gender differences noted in adults in resilience are now suggested to also be prevalent in adolescents, and raise questions about when such differences might emerge. Future studies may wish to investigate resilience in young adolescents and children, to establish the point at which interventions to increase resilience may be most effective. The results outlined here and discussed in Section 11.4.4. support the trait-based, compensatory model of resilience (Hjemdal et al., 2007) over the protective factors model. This suggests future researchers working with this population may wish to consider the conceptualisation of resilience in their research design, as it would appear to differ in adolescents and adults.

#### **11.4.8. Conclusion**

Overall, this study suggests that AWT1D and their healthy peers do not fundamentally differ in their psychosocial profile. These findings minimise the impact of T1D on the life of the adolescent, and suggest that the desire for normality explored in Study 1 is a successful endeavour. Understanding this perception of normality should help clinicians refocus attention from T1D and on to truly person-centred care.

Taken collectively, the gender and age differences highlighted here underscore the usefulness of a individualised approach to adolescent health. It may be important for care plans to incorporate both gender and age, within the person-centred approach. Males and females, older and younger adolescents appear to have very different psychosocial profiles, and

therefore are likely to have different needs. As such, an individualised approach to holistic care plans will allow for focus on particular areas within the psychosocial profile of the adolescent.

Finally, it must be remembered that whilst other studies investigating AWT1D have highlighted concerns within psychosocial outcomes of this population, the unique experiences of adolescence must be borne in mind. Whilst inflated distress and depression have been found in this age group (Helgeson, Reynolds, et al., 2007) without comparison to a reference sample, it is difficult to assess whether such results are due specifically to living with T1D, or are simply a normative adolescent experience. Researchers must, therefore, be mindful in their interpretations of results in this population.

## Chapter 12: General Discussion

### 12. Overview

The final chapter of this thesis discusses the research questions which shaped the design of the research and the implications of the findings for the role of peer support in AWT1D. Resultant limitations are acknowledged, alongside proposed future directions for research. Finally, the implications for healthcare professionals working within paediatric diabetes care are outlined, in addition to the original contribution to knowledge presented by this thesis. Together, these findings are presented with the purpose of meeting the overall aim of this thesis; to understand the role of peer support in health and psychosocial outcomes in AWT1D.

### 12.1. Discussion of emergent findings

In order to achieve this aim, a series of research questions were proposed (see Section 7.1.1.) based on the findings and limitations of previous research. The research aim, questions and objectives determined the design of this thesis, and thereby the development of the three-study approach. Study 1 was designed specifically to address the lack of mixed methods approaches in the literature, through which it was believed the lack of consensus between quantitative and qualitative findings prevalent in research could be clarified. In addition, this mixed methods study allowed for assessment of the utility, experience and acceptance of peer support in AWT1D. Study 2 allowed for assessment of the psychophysiological underpinning of the stress-buffering hypothesis, with assessment of an original theory of mechanism of influence through which peer support may operate. Finally, Study 3 assessed the comparability of the psychosocial functioning of AWT1D in comparison to a reference population of healthy adolescents, so that the impact of living with T1D might be better understood. Based on the results from these studies, this chapter addresses each of the proposed research questions (see Section 7.1.1.), in order that answers may be drawn from the data presented in the preceding chapters with an overarching viewpoint.

#### 12.1.1. Question 1. What is the relationship between peer support and diabetes outcomes in AWT1D?

The relationship between peer support and diabetes outcomes has limited literature when considering an AWT1D population. Of the paucity of research investigating this relationship, consensus is far from reached. Studies report both positive (Bearman & La Greca, 2002; Kyngäs, 2000) and negative (Hains et al., 2007; Thomas et al., 1997) consequences of enhanced perceived support from those outside of the family during adolescence. The findings of Study 1 suggest that the reasons for this disparity may lie in the conceptualisation of peer support itself. Whilst global peer support was related to improved self-care and glycaemic control, diabetes-specific support behaviours were not related to diabetes outcomes (see Section 9.3.1.). Indeed, within these relationships, differences also occurred between the facets of the various

measures. As such, the lack of clarity in literature may in some part be due to a failure of authors to distinguish between the various typologies of support in their research (see Section 3.3.3.c.). In addition, participants with greater diabetes-specific support reported poorer glycaemic control in comparison to participants with greater global support (see Section 9.4.1.c.), lending further evidence to the assertion of a beneficial outcome to global peer support.

The finding that global support has greater association with diabetes outcomes than diabetes-specific support initially appears contradictory. However, when previous literature (Buchbinder et al., 2005; Dovey-Pearce et al., 2007; Peters et al., 2014) is combined with the qualitative interview data of Study 1, potential interpretations are acknowledged. The possible explanations underlying the various relationships between facets of global support are outlined under Question 3 (Section 12.1.3.). However, overall, a prospective explanation for the lack of association between diabetes-specific support and diabetes outcomes may lie in erroneous advice provided by peers. Previous research has highlighted the lack of accurate knowledge regarding self-care prevalent amongst healthy adolescents (Naar-King et al., 2006; Pendley et al., 2002; Thomas et al., 1997), in addition to the possibility that the support provided is inconsistent or lacking in specificity (Wysocki & Greco, 2006). Therefore, the need for education of peers of AWT1D may be an important step in assisting patients to achieve optimal self-care, and research into the feasibility of interventions is warranted. However, as the measure used specifically addresses behaviours which are recommended by healthcare professionals as those which will improve glycaemic control, ill-informed and non self-management support behaviours should have been eliminated.

An additional interpretation of this difference can be found in the qualitative interview data, in which application of symbolic interactionism (Charmaz, 1983, 1995) suggests AWT1D reject diabetes-specific behaviours due to a desire to maintain normality. Indeed, as highlighted in Study 3, the finding that older adolescents have a greater perception of QoL suggests that older AWT1D may decide that strict adherence to a care plan leads to an inflexible lifestyle, and therefore prioritise QoL over self-care. Older AWT1D may therefore seek a balance in self-care, in which both engagement and avoidance are active process allowing for effective coping with living with T1D (Dovey-Pearce et al., 2007). A need to maintain a coherent identity and a “normal” social life was cited by Hinder and Greenhalgh (2012) as being the most influential factor in the active choice to disengage with self-care. Therefore, diabetes-specific support may be rejected due to unacceptability of the demands of self-care within this balance. Additional interpretation of such findings can be found under Question 5 (see Section 12.1.5.). Overall, these findings suggest that global peer support offers a positive relationship to diabetes outcome measures.

### **12.1.2. Question 2. What is the relationship between peer support and psychosocial outcomes in AWT1D?**

Amongst the limited research investigating peer support in AWT1D, a disparity was acknowledged between quantitative and qualitative studies. Whilst peer support was associated with improved outcomes, such as QoL (G. Urquhart Law et al., 2013) and resilience (Yi-Frazier, Smith, Vitaliano, & Yi, 2010), qualitative interviews highlighted a potentially damaging psychosocial effect of diabetes-specific peer support (Dovey-Pearce et al., 2007). As hypothesised, the results of Studies 1 and 3 were consistent with this. However, it is important to acknowledge that, whilst peer support was related to improved psychosocial variables, QoL and resilience were not considered mediators of the relationship between peer support and diabetes outcomes. Therefore, whilst these factors are inter-related, QoL and resilience cannot be considered mechanisms through which peer support is related to diabetes outcomes. The possible explanations for such findings are explored in Sections 9.4.1.d. and e., however, when taken together, these findings suggest that factors other than QoL and resilience explain the relationship between social support and diabetes outcomes. Indeed, the role of both of these concepts is contested in the literature, with studies both advocating (G. Urquhart Law et al., 2013; J. Lawrence et al., 2012; Matziou et al., 2011; Valenzuela et al., 2006) and rejecting (Hoey et al., 2001; Laffel et al., 2003; McMillan et al., 2004) the importance of QoL and resilience. Therefore, the findings of this thesis contribute to the literature indicating a complexity of psychosocial experience of health. Indeed, due to this intricacy, it is unlikely one variable in isolation would act as a sole mediator, and as such multidimensional models present more likely candidates. This is discussed further under Question 6 (see Section 12.1.6.).

The current research found that increased markers of global peer support were associated with improved QoL and resilience (see Section 9.3.3.), to a level that was comparable to peers without T1D (see Section 11.4.2. and 11.4.3.). The mixed methods nature of the present thesis allowed for further exploration of the reasons for this through qualitative interview. It is suggested that, via symbolic interactionism (Charmaz, 1983, 1995), engagement in intimate peer relationships allows AWT1D a sense of normality, which is not as easily accessed through familial support. During qualitative interviews, participants spoke at length about the centrality of illness to their personal identity, and the difficulty of maintaining what they perceived to be “normal” adolescent activity in familial environments, where living with T1D is a constant presence. These findings, therefore, suggest that peer support is associated with improved psychosocial functioning in relation to the self-concept. This supports the findings of Dovey-Pearce *et al.* (2007), who have stated that the maintenance of the pre-diagnosis self-concept via peer relationships allows for continuation of this sense of normality and self. As such, improved psychosocial outcomes may be directly related to an improved psychosocial profile due to a

belief that, despite diagnosis of T1D being considered a major event (Helgeson, Reynolds, et al., 2014), life is able to continue in much the same way it did previously, with some minor adaptations. It may, therefore, be considered that peer relationships allow for significant appraisal support, in which living with T1D is no longer considered a devastating experience. This possibility is explored further under Question 4 (Section 12.1.4). Taken together, this thesis highlights the positive relationship between improved peer support and psychosocial functioning in AWT1D.

### **12.1.3. Question 3. Do the facets of peer support differ in their relationship to psychosocial and diabetes outcomes?**

Not only was a fundamental difference noted between the impact of global and diabetes-specific support on psychosocial and diabetes outcomes (see Section 12.1.1.), but within these overarching concepts, differences were also noted between the facets. This finding contributed significantly to the literature, in which a paucity of studies separating social support into its underlying factors is acknowledged (Palladino & Helgeson, 2012). Whilst both emotional and instrumental support were found to be related to self-care, only instrumental support was associated with improved glycaemic control. Therefore, only instrumental support is related to a clinically-relevant outcome.

When interpreting these findings in light of qualitative interviews, it is noted that appraisal support is a hitherto unconsidered variable in research, which may offer additional important explanation. The interviews with participants revealed a central role of humour in peer support, particularly overtly related to T1D (see Section 9.3.5.a.), and was stated to be the most supportive element that participants received from peers and no other social network. Humour can be classified as appraisal support, as it allows for reconsideration of life-altering self-care (Helgeson, Reynolds, et al., 2014) as less damaging to the self-concept, thereby increasing acceptability of self-care behaviours to the AWT1D. As a result, a recommendation for future research considering appraisal support is made so that these hypotheses may be academically investigated.

In answer to the present research question, this thesis highlights interesting differences in the type of support provided and the relationship to both diabetes and psychosocial outcomes. Overall, facets of global peer support appear to offer benefits for self-care, glycaemic control and psychosocial functioning, whilst diabetes-specific support would appear to be unrelated to such effects. As a result, the usefulness of diabetes-specific support in aiding improved health is called in to question.

#### **12.1.4. Question 4. What is the meaning and experience of peer support in AWT1D?**

An additional qualitative research question is included and explored in Study 1 so that quantitative findings may be better explained and contextualised. When viewed together, the results to the questions outlined in the preceding sections lend support to the utilisation of the self-concept within interpretation of the quantitative findings. These results suggest that the primary function of peer support in AWT1D is the attainment of a “normal” adolescent identity, whilst living with T1D. As outlined in Section 9.3.5.a, this is something participants believed was unique to their peer support; it could not be drawn from family relationships, which they stated to be shaped around their health. Dovey-Pearce *et al.* (2007) stipulates the usefulness of peers in allowing adolescents to engage in what they perceive to be typical adolescent activities, thus maintaining normalcy alongside their sick role. Such interpretation allows for acknowledgement of the positive impact of global peer support highlighted in Section 12.1.1. and 12.1.3., whilst the lack of association between diabetes-specific support and outcome variables may be due to rejection of these sick role behaviours. Indeed, ignoring the demands of self-care is not an uncommon finding in research (Borus & Laffel, 2010; Croom *et al.*, 2011; R. Gillibrand & Stevenson, 2007; Glasgow *et al.*, 2001; Hernandez-Tejada *et al.*, 2012; M. Peyrot *et al.*, 2005), though has previously been attributed to peer pressure. Instead, this interpretation suggests that active non self-management may be due to a desire to maintain normality and a coherent identity over the demands of self-care.

Recent research has highlighted the drive for independence in self-care as being attributed to a wish to not be seen as helpless by peers (Peters *et al.*, 2014); an idea strongly allied to the sick role (Kasl & Cobb, 1966). Therefore, even in the drive for autonomy in self-care, it is possible to see the desire for normality. Being seen by others to be successfully independently managing their T1D may be important for AWT1D in order to establish their identity as a functioning adult. Indeed, this desire may be seen as an adaptive one. Successful management of T1D minimises the impact of the condition on the life of the adolescent (Jacobson *et al.*, 2013). Therefore, if a wish to achieve normality results in improved self-care, this may be an aspiration that could be better incorporated into care guidance. This may help AWT1D to understand that denial of self-care will not lead to a normal self-concept in the long-term due to prevalence of complications (see Section 5.7.), whilst effective self-care may do.

Taken together, this interpretation suggests that the meaning and experience of peer support in AWT1D is related primarily to attainment and maintenance of a normal adolescent identity, independent of the demands of self-care. This experience appears to be unique to peer support, thus suggesting that the utility of support provided by various social networks differs.

The usefulness of a variety of social networks, therefore, should be emphasised in research and clinical practice.

#### **12.1.5. Question 5. How are well-intentioned support behaviours perceived as nagging in some AWT1D?**

Research suggests that, whilst social support is able to facilitate improved health, too much or unnecessary support can have a negative association with health and psychosocial outcomes via a sense of overprotection and interference, commonly referred to as “nagging” (Gallant et al., 2007). Whilst this concept has been thoroughly investigated in parental relationships with AWT1D (Luyckx et al., 2013; Seiffge-Krenke et al., 2013; Weinger et al., 2001), no studies have assessed this phenomena in peer support. Similarly, though the damaging effects of nagging are well known (see Section 3.3.3.b.), studies have failed for the most part to determine how well-intentioned support behaviours are misconstrued as intrusive. Our understanding of the mechanism through which this occurs would greatly enhance health communication within family and peer support.

Quantitative data from Study 1 suggests that the diabetes-specific support behaviours highlighted in the DSSQ-Friends are not associated with psychosocial nor health outcome measures, and that participants with poorer glycaemic control report greater diabetes-specific support and worse psychosocial outcomes. One potential interpretation of these findings is that the behaviours outlined in the DSSQ-Friends are those which AWT1D believe to be nagging. Specific items highlighted within the measure align closely with those stated to be nagging in previous literature, including reminders from parents to test blood glucose (Luyckx et al., 2013; Seiffge-Krenke et al., 2013; J. E. Spencer et al., 2013). Such interpretation may too be present when the reminder is provided by a peer group member.

There is suggestion in research that misconstruing support as nagging is associated with a drain on the family of AWT1D (Gray et al., 2013). Potentially, that same mechanism is present in peer relationships. A key theme of the qualitative interviews of Study 1 was *Burden*, in which participants’ explored their reticence to allow peer involvement in self-care. Participants perceived their self-care to be their problem alone, and stated that they were concerned that involving peers may make them appear troublesome. This may be an experience which is unique to adolescence, and may explain the consistent finding of worsening glycaemic control during this developmental stage (Wallander et al., 2013; Wherrett et al., 2013). This is suggested to be related to the emphasis of autonomy placed on AWT1D (see Section 6.3.3.). As a result of the prominence of independence in self-care, AWT1D may misinterpret diabetes-specific support behaviours as an accusation of failure or interference. Potentially, this is to be expected for this developmental stage, given that establishment of a responsible adult identity is



one of the key tasks of adolescence (Sawyer et al., 2012). Participants may, therefore, seek autonomy in their self-care in order to prove their ability to cope independently, and thereby reject support.

Alternatively, further illumination is provided by the research of Dovey-Pearce and colleagues (2007). Her work highlights the reinforcement of stigma and difference within the self-concept of AWT1D, and the effort AWT1D make to accept or reject the sick role into their identity. Through this interpretation, diabetes-specific support behaviours are actively rejected as they threaten the “normal” self-concept the adolescent desires (Dovey-Pearce et al., 2007). Literature has highlighted the importance of normative social interactions and activities in AWT1D, with the aim of maintaining an identity separate from the sick role (Gray et al., 2013). As such, nagging behaviours may be those which may remind adolescents of the demands of self-care, which are rejected in the pursuit of normative adolescent experience.

This sense of difference is further supported in the theme *It's Not Something You Can Understand Unless You Have It*, in which diabetes-specific support behaviours are seen as acceptable when provided by another AWT1D. It is possible that these support behaviours are not interpreted as nagging when a shared identity is seen with the support provider. This is explored in identity fusion (Swann et al., 2012), in which the boundary between the personal and group identities of the individual become blurred. AWT1D may experience extended identity fusion with others with T1D, and therefore do not perceive diabetes-specific support behaviours as nagging due to shared identity and positive in-group behaviours. In addition, a reduction in sense of stigma and fear of judgement may too occur when diabetes-specific support is provided by an individual able to convey advice based on personal experience. Such findings highlight the potential utility of peer mentoring programs, in which AWT1D may receive diabetes-specific support from other AWT1D. Indeed, of the few interventions in AWT1D utilising peer mentoring, those receiving group medical appointments (B J Anderson et al., 1989), group skills training (Grey et al., 2000), or allocation of a peer mentor (Lu et al., 2014) reported high levels of acceptability of advice and improvement in health literacy. As such, a recent call from NICE for research into peer-based interventions amongst AWT1D is warranted, and the results from the present thesis would indicate a likely success of such findings (National Institute for Health and Care Excellence, 2015).

In answer to the pertinent research question, nagging is indeed present in peer, as well as familial, relationships. This finding is novel in literature, and suggests that the mechanism through which support behaviours are construed as harassing may be linked to the self-concept and the same attainment of normality outlined in answer to Question 4 (see Section 12.1.4.). The ability of AWT1D to live a life comparable to that of their peers, therefore, is of primary

importance to them, with diabetes-specific support behaviours appearing to pose a threat to this identity.

#### **12.1.6. Question 6. Through what mechanism is peer support related to diabetes outcomes?**

It is suggested that social support is able to effect health outcomes via direct, or main effects, influence (Gallant, 2014) and also via indirect, stress-buffering effects (Cohen & Wills, 1985). Evidence supports both mechanisms, and it is widely accepted that social support is able to influence health via both routes independently (Taylor, 2011). However, no research could be identified explicitly assessing mechanisms of influence in AWT1D regarding peer support. Whilst literature has suggested a relationship between peer support and diabetes outcomes, none has highlighted a model specifically addressing how such a relationship may operate. Several candidates were therefore assessed in the present thesis, with the most likely candidate determined via a process of elimination.

Firstly, the mediating factors of QoL (Hilliard et al., 2013) and resilience (Whittemore et al., 2010) were assessed. Hilliard and colleagues (2013) suggested that reduced overall QoL prevents effective accessing of coping resources, such as social support, and therefore mediates the relationship between peer support and diabetes outcomes (see Section 6.3.). However, mediation analysis revealed that QoL was not a significant predictor of self-care nor glycaemic control, and as such, this model is dismissed in the present sample. Potential explanations for this are explored in Section 9.4.1.d., however, overall, the results suggest that factors other than QoL serve as a model of operation for the relationship between peer support and diabetes outcomes. Indeed, the role of QoL is far from agreed in literature (Hoey et al., 2001; Laffel et al., 2003; G.U. Law et al., 2013; J. Lawrence et al., 2012; Matziou et al., 2011; McMillan et al., 2004; Valenzuela et al., 2006) and, as such, it is undetermined how QoL is involved in the operation of social support.

Secondly, Whittemore *et al.* (2010) suggest an indirect mechanism through which social support is related to diabetes outcomes via resilience (see Section 6.5.), through a protective factors model in which effective support is seen as a contributory feature towards resilience (S.S. Luthar & Zelazo, 2003). As such, resilience was suggested to mediate the relationship between resilience and diabetes outcomes. However, resilience was not found to be correlated with self-care nor glycaemic control, and as such this model is rejected in the present sample. Interpretations of this rejection and the implication for resilience is fully explored in Section 9.4.1.e. However, when combined with the above non-significant predictor of QoL, these findings suggest a fundamental difference in the operation of family and peer support. Whilst family support has been conceptualised as enabling resilience and QoL when managing T1D

(Baptista, Neves, & Baptista, 2008), these variables do not appear to be of primary importance in peer support. Further exploration of the mechanism of influence of peer support in AWT1D is therefore provided.

In Study 2, the psychophysiological function of the stress-buffering hypothesis is explored via a model proposed in Section 4.6.2. This model is based on the knowledge that OT is able to down-regulate cortisol release, and thereby may help to reduce blood glucose (Khani & Tayek, 2001). However, the findings of Study 2 do not support this hypothesis, and therefore the model proposed cannot be accepted. Alternative explanations for this finding are outlined in Section 10.4.1. Overall, however, the methodological limitations of Study 2 means that conclusions regarding the psychophysiological model cannot be drawn, and further research is required. Literature has suggested that up-regulated OT is related to improved health via two pathways; modulation of the HPA axis (Neumann, 2002) and facilitation of prosocial behaviours (Carter, 2007). The present study investigates the first in AWT1D, though due to methodological constraints cannot draw convincing conclusions. Additionally, the second remains an unanswered question. Further research is required to assess the validity of Carter's (2007) hypothesis, alongside the psychophysiological model proposed herein.

#### **12.1.7. Question 7. Is oxytocin a valid biomarker of peer support?**

Whilst OT is considered to be a neurohormone with a highly prosocial function (Carter et al., 2007; DeVries et al., 2003; Ditzen et al., 2009; Jurek, 2013; Schneiderman et al., 2012), and has been successfully noted as a biomarker of parental (Carter, 1998; Meaney, 2001) and romantic relationships (Ditzen et al., 2009; Gonzanga et al., 2006; Grewen et al., 2005), only one study could be identified which assessed the ability of OT to act as a biomarker for filial attachment. The results of this study imply a bi-directional bio-behavioural response in which OT expression in filial affiliation is influenced by parental attachment (Feldman, 2012). As such, assessment of the usefulness of OT as a biomarker of filial attachment, or peer support, in adolescents is currently lacking, with limited research elsewhere in the field.

In AWT1D, OT was not related to peer support. Whilst it is possible that the questionnaire results are inaccurate due to response bias (see Section 11.4.1.), an alternative interpretation is that salivary OT is not a valid biomarker of peer support alone. The lack of congruence between the self-report measure of peer support and OT suggests that OT is not a valid representation of perceived peer support. There are several possible explanation for this. Familial and peer support may be unable to be differentiated within OT. As such, it is logical that participants may have had differing results on self-report and biomarker measures, as the questionnaire specifically requested information reporting peer support, whilst OT would provide an overarching view of social bonding in general. Indeed, as highlighted in Section 4.1.,

OT is a biomarker of social bonding, not social support. Although these concepts are interlinked (see Section 4.1.), it is possible that they are conceptually too different to be accurately differentiated within OT. As such, the use of this biomarker is able to provide an overarching view of a participant's total social bonding, but cannot determine from which social network such attachment is obtained. This is therefore potentially an erroneous operationalisation of peer support specifically, instead producing a measure of total social support.

An alternative explanation is possible regarding the ability of OT to be accurately detected in saliva with current ELISA technology. As is outlined in Section 8.4.3. and 10.4.1., some researchers have questioned the capability of ELISAs to achieve an accurate representation of OT when extracting from saliva. This is based on literature which has highlighted weak correlations between plasma and salivary OT (Feldman et al., 2010; Grewen et al., 2010; McCullough et al., 2013). Therefore, in order for true dismissal of the psychophysiological underpinnings of the stress-buffering hypothesis to be assessed, future research should utilise plasma over salivary OT. However, due to the acknowledged participant recruitment problems presented by research using plasma samples (Schultheiss & Stanton, 2009), achieving this alongside sufficient participants for statistical power may prove challenging. Overall, the findings of the present thesis call into question the ability of current ELISAs to accurately assess peer support in isolation from salivary OT. Therefore, further research is needed in order to determine whether or not the psychophysiological model of support proposed in Study 2 is accurate, namely with an increased sample size sufficient for statistical power and use of plasma OT.

#### **12.1.8. Question 8. Is the psychosocial experience of being an AWT1D comparable to healthy peers?**

Comparability of the psychosocial experience of AWT1D to healthy peers appears to be of primary importance to them (Questions 5 and 6; see Sections 12.1.5. and 12.1.6.). It is pertinent, therefore, for literature to assess the differences, or lack thereof, in the psychosocial profile of AWT1D and comparable peers. As can be seen in Study 3, this thesis supports the assertion that, not only do AWT1D desire normality, they also appear to achieve it, for the most part. AWT1D do not differ from their peers in terms of global peer support (see Section 11.4.1.), QoL (see Section 11.4.2.), or resilience (see Section 11.4.3.).

When considered in line with the qualitative findings of Study 1, an interpretation in line with normalisation of the self-concept is achieved. In interviews, participants spoke of their reticence to discuss and engage in self-care around peers. Active engagement of peers in management was only acceptable to participants during diabetic emergencies, but was otherwise not sought, and actively rejected by some (see Section 9.4.2.). As a result, T1D does

not occupy a central role in the lives and peer relationships of AWT1D. Research regarding QoL has highlighted the minimal function of T1D in the assessment of general QoL, as opposed to HRQoL. Other dominating factors included family, friends and school life (de Wit et al., 2007). This assertion is supported by the present findings, and suggests that the lack of dominance of T1D extends to other crucial psychosocial variables. As a result, the psychosocial profile of AWT1D is comparable to their healthy peers, as they do not consider T1D to dominate their lives. However, it must be noted that the present clinical sample had poor glycaemic control, with an average HbA<sub>1c</sub> of 72mmol/mol, well above the NICE guidance of 48mmol/mol (National Institute for Health and Care Excellence, 2015). As suggested in Section 9.4.2., seeking normality may not always produce beneficial health outcomes. For some participants, a desire for normative adolescent experience can lead to active non self-management in the presence of peers (Hinder & Greenhalgh, 2012); a finding that is well established in research (Borus & Laffel, 2010; Croom et al., 2011; R. Gillibrand & Stevenson, 2007; Glasgow et al., 2001; Hernandez-Tejada et al., 2012; M. Peyrot et al., 2005) and is supported by this thesis. As such, the drive for normality, whilst it can be considered successful due to the comparability to healthy peers, may be considered a driving factor towards the average poor glycaemic control seen in the sample. Seeking normality may, therefore, not always produce adaptive outcomes when health is considered.

#### **12.1.9. Question 9. Does psychosocial experience vary according to gender and age within AWT1D and healthy peers?**

Literature suggests that psychosocial profiles of adolescents is likely to vary according to both gender and age, regarding social support (Camarena et al., 1990; Golombok & Fivush, 1994; Kuttler, 1999; Seiffge-Krenke, 1997), QoL (Kalyva et al., 2011; Lukacs et al., 2014; Naughton et al., 2014) and resilience (Boardman et al., 2008; Leadbeater et al., 1999; Matud, 2004). However, no research could be identified assessing whether such demographic characteristics interacted with T1D to produce variation in psychosocial experience. The findings of Studies 2 and 3 suggest that a disparity of experience is noted across genders, ages and health status.

Study 2 highlights the gender differences within AWT1D regarding the association of cortisol and glycaemic control. Whilst no such relationship was recognised in females, male AWT1D indicated a significant negative relationship, suggesting that increased stress results in improved glycaemic control in this group. As noted in Section 10.4.2., it is suggested, therefore, that males may experience a small degree of stress as eustress, in which an amount of physiological arousal, as indicated by cortisol, is required in order to motivate towards optimal self-care. Further research, however, is required to determine at what level this arousal ceases to be eustress and becomes distress (Lazarus & Folkman, 1984b; Yerkes & Dodson, 1908). This

thesis, therefore, supports the findings of Berlin *et al.* (2012), who suggested that it was reductionist to suggest that all individuals respond to stress by withdrawing from self-care, and that, for some, immersion in self-care may act as an adaptive coping mechanism. This thesis adds to this hypothesis by suggesting that such coping actions may be sexually dimorphic, perhaps explained by gender differences in appraisal (Berlin *et al.*, 2012), as stated by a social-ecological model of coping (Steele & Aylward, 2009).

The findings of Study 3 suggest that a particular area of interest lies in the interaction between health status, gender and age in peer support. As can be seen in Figure 29 and Figure 28 (see p.187 and p.188), males with T1D were likely to report less peer support with age, having started from a place of significantly greater support over other groups. In comparison, healthy peers and females with T1D reported increased peer support in the older age groups. Females with T1D aged 17 and over could be considered to have comparable peer support to their counterparts in the reference group. Such a finding has not previously been noted in literature, and several explanations are offered in Section 11.4.4. However, overall, involvement of the male gender role appears to be of significant influence here. Findings of poor male support in AWT1D have previously highlighted the problematic nature of a masculine identity regarding support and diabetes outcomes (Broom & Lenagh-Maguire, 2010; O'Hara *et al.*, 2013; Seiffge-Krenke, 1997). Male adolescents may be at particular risk of poor self-care as a result of reticence to seek out emotional support (Broom & Lenagh-Maguire, 2010), due to the establishment of adult identity which typifies this developmental stage (Viner, 2012). As suggested by the findings of Questions 1 (see Section 12.1.1.) and 3 (see Section 12.1.3.); emotional support is related to improvements in self-care and can be considered an adaptive resource in striving to achieve optimal glycaemic control. Research into healthy adolescent males has highlighted the negative impact of a masculine identity on health-promoting behaviours (Mahalik *et al.*, 2007), perhaps due to a lack of emotional support. This thesis suggests this gender role is also likely problematic in AWT1D, and indicate that, in combination for the findings of Study 2 highlighted above, gender-specific personalised care plans may serve to target specific areas of vulnerability according to sex. This recommendation is further explored in Question 10 (see Section 12.1.10.).

Interaction effects of health status, gender and age were not noted within QoL and resilience. However, significant main effects of both gender and age are acknowledged in Study 3 (see Section 11.3.2.). Both differences indicated a significant benefit of being older and male regarding these variables. These findings are fully discussed in Section 11.4.4. Overall, this thesis suggests that specific contributory factors towards the conceptualisation of QoL and resilience differ according to these demographic characteristics, including emotional functioning (Miller & Eisenberg, 1988; Rosenfield *et al.*, 2000; Upton *et al.*, 2005), age

differences in cognitive ability (Cotton et al., 2010), and coping resources (Boardman et al., 2008; Leadbeater et al., 1999; Matud, 2004).

In answer to the research question, when taken together these findings suggest that psychosocial experience of AWT1D differs according to age and gender. However, with the exception of peer support, these differences are largely in line with the developmental changes found in healthy peers. As such, for the most part, these findings serve to underline the statements made in answer to Question 8 (see Section 12.1.9); that AWT1D have a largely normative adolescent experience, minimising the impact of T1D on their lives. Where differences are noted, most pertinently in male peer support and the association between stress and glycaemic control, recommendations towards gender-specific care plans can be made on the basis of this thesis. As such, Question 10 is discussed forthwith.

#### **12.1.10 Question 10. What recommendations for healthcare professionals can be made in order to improve the psychosocial experience of AWT1D?**

The findings outlined in answer to Question 9 (see Section 12.1.9.) suggest that male and female AWT1D experience differing psychosocial profiles, with some impact of age. Together, these suggest that care plans adapted according to gender and age may be of benefit in terms of health outcomes. Particularly regarding the association of stress and glycaemic control in males, these findings suggest that some element of risk communication alongside standard motivational messages may improve self-care in this at-risk group (National Paediatric Diabetes Audit, 2012). Additional risk communication may heighten stress regarding self-care, and the findings of Study 2 in combination with previous literature (Berlin et al., 2012) suggest that this may act as a motivator towards adherence. Similarly, whilst an association with health outcomes has not been determined in the present thesis, the findings of Study 3 suggest that older male AWT1D experience significantly lessened peer support. With this in mind, it may be that additional consideration of emotional support may be of benefit in care plans for this vulnerable population, potentially in the form of a support intervention. As has been previously noted, recent NICE guidance has called for research into support programmes for paediatric diabetes care (National Institute for Health and Care Excellence, 2015). These findings suggest that not only is such research warranted, but that gender-specificity within these interventions may be required. Further research is therefore warranted into the association between stress, peer support and diabetes outcomes in male AWT1D, with a view to adapt care plans and interventions in mind.

Additionally, the age differences noted within the psychosocial profiles of AWT1D highlight the importance of developmental stage considerations within care plans. Current NICE guidance fails to specifically address adolescent concerns for the most part, instead considering

child and adolescent care together as paediatric guidance (National Institute for Health and Care Excellence, 2015). This indicates that such umbrella care may be erroneous, and may be a contributory factor towards the reduction in glycaemic control typically seen in this age group (Wallander et al., 2013; Wherrett et al., 2013). These findings suggest that significant differences occur within the psychosocial functioning of older adolescents, and as such it can be extrapolated to assume that differences may also occur between the profiles of children and adolescents. Guidance which specifically addresses adolescent experience may therefore be of benefit to specifically target the unique challenges posed by this developmental stage.

Overall, this thesis highlights the importance of normality to AWT1D. Interpretation of Studies 1, 2 and 3 in combination allows for the centrality of a normative adolescent identity to be seen within this population. According to current NICE guidance, diabetes-specific support behaviours take precedence in the psychosocial care offered to AWT1D. These findings would suggest that such an aim is unhelpful, and potentially damaging, in terms of diabetes outcomes (see Study 1). The inclusion of life goals within newly proposed NICE guidance (National Institute for Health and Care Excellence, 2015) go some way to recognising the need for person-centred view of AWT1D. However, the findings of this thesis also suggest that emphasis of how effective self-care can minimise the impact of T1D on the psychosocial experience may be beneficial, seeing as it appears to be a primary goal of AWT1D. Such centralisation of normality within care plans has previously been championed (Dovey-Pearce et al., 2005), but has yet to be placed within guidance. Indeed, the findings of this thesis suggest that, not only do adolescents seek normality of experience (Study 1), for the most part, they also appear to achieve it (Study 3). Therefore, communication regarding an emphasis of normality may be pertinent. As such, further adaptation of guidance may be warranted.

## **12.2. Limitations**

There were a number of limitations that have been noted throughout the course of this doctoral study. Many of these were reviewed individually within each respective study. These are now revisited and summarised with an overarching view regarding the impact on the overall thesis.

One of the main criticisms of the current research is the homogeneity of the sample. The participants were largely Caucasian, which limits the generalisability of the findings. Every effort was made to ensure a diverse sample, including the use of two NHS trusts with differing socioeconomic and ethnic diversity. However, participant recruitment was largely limited to Caucasian patients, in part due to issues encountered regarding the limitation of clinic attendance which will be addressed subsequently. As such, the interpretations of the findings outlined in the preceding sections are limited to a relatively homogenous group of Caucasian adolescents. It may be that a more diverse sample would have produced different results due to



cultural, ethnic, racial and socioeconomic differences in both health and psychosocial factors. To ensure generalisability, a more varied group of AWT1D would be required, particularly with regard to race, ethnicity and social status. Such a sample would demonstrate whether or not the associations outlined in Section 12.1. vary across subgroups and circumstances.

As previously alluded to, a further limitation is noted in the use of outpatient clinics as a recruitment site. Research utilising this design is fundamentally limited to those who engage with clinic attendance. In itself, attendance at clinic appointments is a recognised problem within this at-risk population (Hardy et al., 2001; Masding et al., 2010). Within the clinics used in the present study, 22% and 34% non-attendance was recorded within the 3 month recruitment cycles. This would constitute a significant proportion of the potential population from which the eventual sample was drawn. As such, the interpretations of these findings are limited to those who are engaged with healthcare. It is therefore likely that selection bias was present within both the participants who volunteered to take part in the research and those who attended their clinic appointments. Consequently, the sample may have been better adjusted to T1D than those who did not attend their clinic appointment during the recruitment cycle. It may be that those who do not attend clinic have varying health and psychosocial profiles which would have impacted on the results and discussion outlined above. However, accessing such a hard-to-reach population could be considered prohibitive. Innovative methodology such as respondent-driven or indigenous field worker sampling may be more effective at recruiting from this difficult to access group (Shaghaghi, Bhopal, & Sheikh, 2011). However, given that no detail regarding the number of other AWT1D within the social network was collected alongside questionnaire data, it is difficult to assess how effective such a strategy might be. An alternative approach could utilise digital technology, which has been stated to be an effective strategy for overcoming issues related to hard-to-reach populations (DeMartini, Beck, Klein, & Kahn, 2013). However, given the requirement of physical samples of saliva to be provided alongside questionnaire data, such recruitment methods would not have been appropriate for the aims of the present thesis. Therefore, whilst a limited view of the role of peer support can be offered by the present participant group, the sampling methods selected for this thesis remain valid. The limitations related to the decision to use salivary measures of OT have already been extensively addressed in Sections 10.4.1. and 10.4.5., and are summarised in answer to Question 7 (see Section 12.1.7.). However, it is acknowledged that despite the limitations related to the use of salivary biomarkers is defended with regard to the issues with participant recruitment raised by the use of plasma (Schultheiss & Stanton, 2009).

Additionally, as this thesis utilises a cross-sectional design, causality cannot be demonstrated effectively. As such, the interpretation of the findings outlined in Section 12.1. is limited by the inability of the study to definitively defend against spurious correlations and

extraneous confounding variables. It may be that additional, unaccounted for variables may impact upon the statistical results, and thereby the interpretation of findings. Indeed, in individual studies missing variables which may have impacted on the relationships outlined are included within limitations, including adjustment (Study 1) and coping styles (Studies 2 and 3). As a result, the interpretation of these findings is not conclusive regarding causal relationships. Randomised controlled trials of the statements made in the current chapter would be required in order to state causality. However, given that manipulation of peer support would be difficult to produce ethically, such methods would pose significant prohibitive factors towards achieving this aim.

There was some concern regarding the methods used to operationalise QoL. The choice to use the WHO-5 Well-being Index as an indicator of QoL proved problematic in the differentiation in conceptualisation between QoL and well-being. Whilst well-being is determined to be a contributory factor of QoL (Schallock, 2004), they are separate constructs. Therefore the use of the WHO-5 may have offered a limited view of QoL and influenced the results, particularly when considering unexpected findings such as the lack of relationship between QoL and diabetes outcomes (see Study 1). However, the decision to use the WHO-5 was done in conjunction with experts in the field, and had an additional benefit as a screening tool for depressive symptoms (Krieger et al., 2014). This reduced the size of the questionnaire battery, which may be considered a benefit as boredom, lethargy and disinterest with a lengthy questionnaire pack would likely have affected the results provided by participants. The use of the WHO-5 therefore remains acceptable.

Indeed, the reliance on self-report measures within this thesis is in itself a limitation. Whilst validation of key self-report variables was obtained with biomarkers where possible (social support by OT, and self-care by HbA<sub>1c</sub>), the potential for response bias in questionnaire data must always be acknowledged. Whilst a more robust methodology such as peer-rated confirmatory measures would have increased the reliability of the data provided by participants, it is likely that this would have further impacted on sample size due to difficulties recruiting willing peers. Given the underpowered nature of the study on the whole (see Section 8.2.), adoption of such methodology may have further reduced the ability of the thesis to avoid Type II error. Indeed, the underpowered nature of the study itself must be remembered when interpreting results and, as such, this calls in to question the ability of the research to accurately reject the null hypothesis. Surprising non-significant findings, such as the lack of relationship between QoL and diabetes outcomes (see Section 9.3.3.), may simply be due to an underpowered sample.

Finally, the study is limited in its wider view of T1D by the utilisation of a relatively narrow age group over a cross-sectional design. It cannot be stated on the basis of these findings

whether or not these interpretations impact beyond this developmental stage and can truly be considered long-lasting. Indeed, the findings outlined in Section 12.1. may be a transient episode related to this difficult developmental stage. Whilst research indicates that health behaviours outlined during adolescence are likely to last into adulthood (see Section 2.4.), further longitudinal research would be required in order to assess the potential impact of these associations beyond the age of 18. Such research would be able to prove or refute the usefulness of the assumptions made herein regarding a long-term impact.

### **12.3. Clinical implications of the thesis**

The implications for clinical guidance are outlined in full in answer to Question 10 (see Section 12.1.10.). By way of summary, recommendations for individualised care plans incorporating factors such as gender and age, alongside education, career aspirations, family and social life, in addition to self-care, may best allow for the incorporation of T1D into the self-concept through emphasis of a holistic view of individuals. Whilst newly released NICE guidance includes life goals within care plans in paediatric settings (National Institute for Health and Care Excellence, 2015), indicating an acknowledgement within healthcare that a holistic approach is preferable, it is suggested that further additions would best enable a truly person-centred approach of care.

### **12.4. Future directions**

Most theories of health behaviour change include a social component (Ajzen, 1980; Bandura, 1986; Brug, Schaalma, Kok, Meertens, & van der Molen, 2000; Lazarus & Folkman, 1984a; Rosenstock, 1974; Ruggiero & Prochaska, 1993; Vallis et al., 2003). In the majority of these models, social norms and support are considered a direct determinant of the resulting health behaviour. In addition to the specific call for support interventions from NICE (National Institute for Health and Care Excellence, 2015), the American Diabetes Association (ADA) has stated that the assessment of social situations is an integral part of the on-going management of diabetes, with screening for sufficient social resources a specific recommendation for optimal care (American Diabetes Association, 2010). It can therefore be stated that investigation of the efficacy of social support focused interventions is warranted.

As highlighted in the systematic review of intervention studies found in Appendix T, support interventions targeted at AWT1D are relatively scarce, but have been studied in greater number in adult populations. Qualitative reports have repeatedly cited a supportive social network as key to maintaining self-care, with companionship and camaraderie particularly pertinent in adults (Rosenbek Minet, Lønvg, Henriksen, & Wagner, 2011). Indeed, a recent investigation by Markowitz and Laffel (2012) found that participation in a support group was associated with a significant decrease in diabetes burden for young adults (age 18-30). Most positively, participation was associated with an increase in self-care behaviours and a decrease

in HbA<sub>1c</sub>. Findings such as these indicate that young adults greatly value peer support and translate this into improved glycaemic control. It can reasonably be concluded that the same may be true of adolescent populations.

With this in mind, and in line with the findings of the present thesis, the design of a peer support intervention presents an interesting future direction for research. Success in this area would naturally lead to further investigation in other adolescent health conditions. As outlined in Section 3.3.4., the experiences of peer support highlighted in AWT1D bear striking resemblance to those reported in research into adolescents with asthma and coeliac disease (see Section 3.3.4.). As a result, it is possible that theories and interventions found to be effective in AWT1D may be of benefit to other populations. Further research would clarify this assumption and elucidate potential causal relationships.

## **12.5. Original contribution of the thesis**

The original contributions to knowledge of this doctoral thesis are outlined at the close of each study chapter, with the overarching and most pertinent findings revisited here. For clarity, these contributions align with the original aims that were offered during the design of the programme of study, outlined in Section 7.2., and are discussed in turn.

### **12.5.1. Application of mixed methodology**

No studies have previously investigated peer support in AWT1D using a rigorous mixed methods approach. This gap in literature resulted in an unexplained disparity between quantitative and qualitative findings (see Section 3.3.3.), which the present thesis has sought to qualify. This thesis therefore presents a more three-dimensional approach of peer support than has previously been found in literature.

Such an approach has allowed for interesting findings to emerge around the role played by peer support in the lives of AWT1D, and suggests that nagging behaviours present in familial support are also likely to occur in peer networks. This nagging is suggested to be specifically related to diabetes-specific support, and factors which are both different (normality within the self-concept; see Section 9.4.2.) and similar to (achievement and maintenance of autonomy; Seiffge-Krenke et al., 2013; see Section 9.4.2.) parental support. In addition, research which has espoused the importance of the self-concept in AWT1D (Dovey-Pearce et al., 2007) is also expanded upon with the inclusion of instrumental support, in-group/out-group behaviour and the perceived burden of T1D on the social network (see Section 9.4.2.).

### **12.5.2. Provision of an in-depth analysis of the facets of peer support**

A criticism of previous literature assessing peer support in AWT1D was the neglect of consideration of variation between the actions of the facets of social support (Palladino & Helgeson, 2012). As such, potential differences between the overarching aspects of global peer

support and diabetes-specific support, as well as the facets of instrumental and emotional support. Such consideration of a range of support provided by peers is novel in literature, and indicates interesting variation between the efficacy of global and diabetes-specific support, as well as between instrumental and emotional support. The findings of this thesis suggests that it is specifically general instrumental support which is associated with improved glycaemic control, whilst emotional support is related mostly to self-care (see Section 9.3.1.a.). A further indication of potential for appraisal support to act as a key factor in peer support is suggested by the qualitative interviews, but requires further investigation (see Section 9.4.2.). Finally, the potential for diabetes-specific support behaviours to be related this type of support being associated with nagging. Indeed, the only facet of diabetes-specific support with a beneficial relationship to diabetes outcomes appeared to be “general items,” which aligned closely with global emotional support (see Sections 9.3.2.a. and 9.4.2.).

### **12.5.3. Consideration of the impact of social bonding**

The inclusion of OT as a biomarker of social bonding in AWT1D is innovative in the field. Although a small number of studies have investigated the role of OT on health in human populations, none could be found examining its role in T1D (Section 4.6.). Indeed, this thesis presented an original theory suggesting a psychophysiological underpinning to the stress-buffering hypothesis that was outlined in Section 4.6.2, clarifying a potential indirect benefit of social support via the down-regulation of the HPA axis. This potential mechanism of influence of support in AWT1D was novel in literature, though it was found to be non-significant in Study 2. The conclusive nature of this finding is questioned in Section 10.4.5., and it is suggested that further research is required addressing these limitations before this hypothesis is dismissed.

### **12.5.4. Generation of reference data for use of measures of salivary oxytocin in adolescents**

Due to the relative infancy of OT ELISAs (Carter, 2007), no research could be identified previously assessing salivary OT in adolescents, independent of a pre-existing health condition. As such, a key task of this thesis was to establish expected concentrations of saliva for use not only in interpretation of the presenting findings, but also for other researchers. A systematised review of studies using salivary OT in adults in presented in Section 10.2.2., which is used as basic reference data. This, in itself, appeared to be novel, though other studies using a similar technique for plasma OT in healthy adults are noted (Christensen et al., 2014). Pertinently, the findings of Study 2 allows for an established indicator of salivary OT in AWT1D (10.15pg/ml, SD=4.9). These findings can therefore be used by future researchers as reference data for expected concentrations of salivary OT in adolescents. Additionally, unexpectedly, the findings also call in to question the validity of such methodology, given the disparity of similarity

between self-report and OT indicators of peer support. This is fully explored in Question 7 (see Section 12.1.7.). As such, whilst a benchmark is established, researchers wishing to use this measurement should proceed with caution. Further research is required to assess the efficacy of salivary OT as a biomarker of peer support in isolation, perhaps utilising plasma OT alongside saliva to validate the findings.

## **12.6. Conclusion**

To conclude, the overall findings of this thesis suggest that the role of peer support in AWT1D is tied to normative adolescent experience. Whilst familial support is crucial in terms of explicit diabetes outcomes (Beveridge et al., 2006; Lewin et al., 2006), peer support is less involved in T1D, with the exception of diabetic emergencies. Instead, peers provide important contextualisation of managing T1D within normal adolescent life, via improved global emotional and instrumental support, but not diabetes-specific support. The findings indicate that this is achieved through assimilation of T1D within a self-concept that orientates around normative experience, over the sick role. It is suggested that through this, AWT1D are able to experience a comparable level of psychosocial functioning to healthy peers. As such, the normative adolescent experience of AWT1D is paramount, and emphasis of the minimisation of the impact of T1D on this experience may be a beneficial communication to them during care plan design. Therefore, this goal should be incorporated into care plans via a greater emphasis on the person-centred approach, potentially through individualised care plans, particularly according to age and gender. Due to the comparability of the psychosocial functioning of AWT1D to healthy peers, and adolescents with asthma and coeliac disease, it is believed that such adaptations may also be of benefit to wider paediatric practice. What is now required is the utilisation of these findings in informing the design of peer-based support interventions for AWT1D, in line with current NICE guidance, so that these findings may contribute towards evidence-based clinical practice for paediatric diabetes care and beyond.

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## **APPENDICES**



## Appendix A: NHS Ethical Approval



**Health Research Authority**

**National Research Ethics Service**

**NRES Committee West Midlands - Staffordshire**

HRA NRES Centre Manchester  
3rd Floor  
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Telephone: 0161 625 7835

06 March 2013

Miss Emily Doe  
Mobile X03 Park Campus  
University of Northampton  
Boughton Green Road  
NN2 7AL

Dear Miss Doe,

**Study title:** The influence of social support on disease management  
in adolescents with Type 1 Diabetes Mellitus  
**REC reference:** 13/WM/0053  
**IRAS project ID:** 115698

Thank you for your letter of 05 March 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair and the lead reviewer of the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Rinat Jibli, [nrescommittee.westmidlands-staffordshire@nhs.net](mailto:nrescommittee.westmidlands-staffordshire@nhs.net).

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

A Research Ethics Committee established by the Health Research Authority

## Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		25 January 2013
Evidence of insurance or indemnity	AON	02 August 2013
GP/Consultant Information Sheets	1	11 January 2013
Interview Schedules/Topic Guides	Diabetes Social Support Interview	
Investigator CV	Emily Doe	
Investigator CV	Jorg Huber	
Investigator CV	Mary Dobson	
Investigator CV	Stuart Allen	
Letter from Statistician		15 January 2013
Letter of invitation to participant	2	21 February 2013
Other: Sources of Help	1	11 January 2013
Other: Presentation to Participants	1	11 January 2013
Participant Consent Form: Parent	2	21 February 2013
Participant Consent Form: Participant	2	21 February 2013

A Research Ethics Committee established by the Health Research Authority

Participant Information Sheet: Participant	1	11 January 2013
Participant Information Sheet: Participants	2	21 February 2013
Protocol	1	11 January 2013
Questionnaire: Self-Care Inventory	Validated	
Questionnaire: Berlin Social Support Scale	Validated	
Questionnaire: Diabetes Social Support Questionnaire	Validated	
Questionnaire: WHO-5 Wellbeing Scale	Validated	
Questionnaire: 10 Item Resilience Scale	Validated	
REC application	3.4	28 January 2013
Response to Request for Further Information		05 March 2013

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

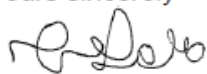
Further information is available at National Research Ethics Service website > After Review

<b>13/WM/0053</b>	<b>Please quote this number on all correspondence</b>
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



**Signed on behalf of:**

**Mr Victor Scofield**

**Alternate Vice-Chair**

Email: [nrescommittee.westmidlands-staffordshire@nhs.net](mailto:nrescommittee.westmidlands-staffordshire@nhs.net)

*Enclosures:* "After ethical review – guidance for  
researchers"

*Copy to:* *Prof Carol Phillips*

*Mrs Julie Wilson, Northampton General Hospital NHS Trust*



## Appendix B: Clinical participant information sheet



### **Research Project:**

### **The influence of social support on disease management in adolescents with Type 1 Diabetes**

We are asking if you would like to join in a research project to find out more about how people your age with Type 1 Diabetes use support from their friends and family to manage their Diabetes. Before you decide if you want to take part, it's important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. If you want to, you can talk to your family, friends, doctor or anyone else whose advice you would like.

#### **Why are we doing this research?**

Being a teenager involves a lot of physical and emotional change. It is also a time when young people establish their identity and independence. Teenagers with diabetes have the additional problem of having to manage their illness. Control of their blood sugar sometimes gets worse, partly due to a lack support from family and friends.

#### **What do we want to do?**

The research team want design an intervention for teenagers to improve the quality of the support they receive from friends, and therefore hopefully the control of their Diabetes. For this intervention to be effective, it is important that teenagers in our target groups are involved in the design of the study. Because of this, we are inviting you to take part in the pilot study to help make decisions about how this intervention should work.

#### **Why have I been invited to take part?**

You have been invited to participate in the study because you have Type 1 Diabetes and are in our target age group, age 15-18.

#### **Do I have to take part?**

No. It is up to you. We will ask you for your consent and to sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect your care.

#### **What will happen to me if I take part?**

You will be asked to name a convenient and suitable time and location to meet with the researcher. You will only meet with the researcher once, and will be asked to complete two tasks:

1. You will be asked to provide two samples of saliva, one immediately after the other. These saliva samples will be analysed for hormones we associate with behaviour, called oxytocin and cortisol. Saliva sampling is quick and painless, and involves chewing on a piece of foam called a Salivette for 60 seconds. Your sample will only be tested for level of oxytocin and cortisol; no other tests will be performed on your saliva.
2. Participants will then be asked to complete some questionnaires. This will take 15-20 minutes and will help us to get a better picture of the type of social support you currently experience and what you find most helpful.

It is expected that taking part would take 10-20 minutes in total. We will also contact the clinic and ask for your most recent HbA<sub>1c</sub> measure so that we know about your glycaemic control. This will help us to know how well you manage your Diabetes. The researchers will not have access to your medical records; it will be securely sent to us by the Diabetes Care Team. Your medical care will not be affected in any way.

If you are a girl, we will need to make sure that your saliva samples are taken at a certain time of the month, as your hormones are affected by your menstrual cycle. If you are on the contraceptive pill

this won't matter, as The Pill stops this change from happening. You will be asked about this when arranging a time to take part in the research.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get might help young people with Type 1 Diabetes in the future. If you wish, you can also take part in the larger trial later on, where your thoughts and opinions will have helped us design an intervention aimed at improving social support.

**Will anyone know I am doing this?**

We will keep your information in confidence. This means we will only tell those who have a need or right to know.

You will be allocated an ID code which will be used to identify all of your data. Your name or other personal details will not be written on anything of your measures. This will be the only way of identifying you, so your results will be completely anonymous.

The clinic will be informed that you have chosen to take part in the research so that they can send us your latest HbA<sub>1c</sub> result, but will not be told about your personal data. A summary of all of the participants' results will be made available to the clinic, parents and participants, but this will be anonymous and no participants will be identified.

**Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by NHS West Midlands Research Ethics Committee and the University of Northampton Ethics Committee. The researcher has been cleared to conduct research by the NHS and has passed a Criminal Records Bureau check.

**Who do I contact if I have any questions?**

Miss Emily Doe  
MX5 Park Campus  
University of Northampton  
Northampton  
NN2 7AL  
Phone: 01604 892537  
Email: emily.doe@northampton.ac.uk

**Thank you for reading this – please ask any questions if you need to**

## Appendix C: Clinical participant parent information sheet



### **Research Project:**

### **The influence of social support on disease management in adolescents with Type 1 Diabetes**

#### **Information for Parents**

We are asking if you would permit your son/daughter to join in a research project to find out more about how adolescents with Type 1 Diabetes use support from their friends to manage their Diabetes. Before you decide if you will allow your son/daughter to participate, it's important to understand why the research is being done and what it will involve for participants. Please consider this information sheet carefully and feel free to discuss it with your son/daughter and others.

#### **Why are we doing this research?**

Adolescence is a period of major physiological and psychological changes, and is also characterised by an effort in young people to establish their identity and independence. Teenagers with diabetes have the additional burden of illness management. Glycaemic control can deteriorate during adolescence, partially due to the lack of quality social support. Studies have also found that those at greatest risk of poor psychological adjustment to diabetes during adolescence include girls, older adolescents, children lacking in social support, and those with higher HbA<sub>1c</sub>.

#### **What do we want to do?**

The research team are aiming to design an intervention for adolescents to improve the quality of the support they receive from friends, and therefore hopefully their glycaemic control. For this intervention to be effective, it is vital that adolescents in our target groups are involved in the design of the study. Therefore, we are inviting your son/daughter to take part in the pilot study to help contribute to the making of this intervention.

#### **Why has my child been invited to take part?**

Your son/daughter has been invited to participate in the study because they have Type 1 Diabetes and are in our target age group, age 15-18. We are looking for twelve participants at this stage as this is a pilot study. If your child participates, they will help design the intervention study through their thoughts and opinions.

#### **Do they have to take part?**

No. It is up to you and your child to decide. We will ask you for your consent and then ask if you would sign a form, and the same for your son/daughter. You can be given a copy of this information sheet and signed consent forms to keep. Your child is free to stop taking part at any time during the research without giving a reason. If they decide to stop, this will not affect the care they receive.

#### **What will happen to them if they take part?**

Participants will be asked to name a convenient and suitable time and location to meet with the researcher if they are unable to take part during their clinic visit. They will only meet with the researcher once, and will be asked to complete two tasks during this time:

3. They will be asked to provide two samples of saliva, one immediately after the other. These saliva samples will be analysed for two hormones. One, oxytocin, is hormone released during social bonding. The second is indicative of the amount of stress your child is experiencing, called cortisol. Saliva sampling is quick and painless, and involves chewing on a piece of foam called a Salivette for 120 seconds. Samples will only be tested for levels of oxytocin and cortisol, no other analysis will be performed on samples provided by your child.
4. Participants will then be asked to complete some questionnaires. This will take 15-20 minutes and will enable us to gain a better picture of the type of social support participants currently experience and what they find most beneficial.

It is expected that participation would take between 10-20 minutes in total, depending on how quickly participants work through the questionnaires. In addition to these tasks, we will also contact the clinic to gain access to participants' most recent HbA<sub>1c</sub> measure to assess glycaemic control. This will enable us to put participants' opinions about social support in context with their Diabetes management. The research team will not have access to this data themselves; it will be securely sent to the researchers by a member of the Diabetes Care Team. The researchers will not have access to medical records.

Participants' medical care will not be affected in any way.

**What are the possible benefits of taking part?**

We cannot promise the study will help your child, but the information we get might help young people with Type 1 Diabetes in the future. If they wish, your son/daughter can also take part in the intervention trial later on, where participants' thoughts and opinions will have helped us design an intervention aimed at improving social support and disease management. We will contact you later about this second study if you wish.

**Who do I contact if I have any questions?**

Miss Emily Doe  
 School of Health  
 MX5 Park Campus  
 University of Northampton  
 Northampton  
 NN2 7AL  
 Phone: 01604 892537  
 Email: emily.doe@northampton.ac.uk

**Thank you for reading so far – if you are still interested, please go to Part 2**

## Part 2

This section contains more detailed information if you wish your child to participate.

### **What happens when the research project stops?**

Nothing will change in your son/daughter's medical care. After the second study has been designed, your child will be invited to take part in that if they have indicated interest in receiving the intervention.

### **Will anyone know that they are doing this?**

Your son/daughter's information will remain private and confidential. The Diabetes Care Team at the outpatient clinic will be notified that they have chosen to take part so that the team can send your son/daughter's latest HbA<sub>1c</sub> result to the research team. Any information they receive back from us about participant results will be completely anonymised.

Participants will be allocated an ID code which will be used to identify them to the research team. This will be the only identification used on any data held about them, so results will be entirely anonymous.

The clinic will be informed that participants have chosen to take part in the research, but will not be informed of any results relating to specific participants. A summary of the results and will be made available to participants, parents and members of the Diabetes Care Team.

### **What will happen to any samples given?**

Your son/daughter will be asked to give two saliva samples if they choose to participate in the study. These will be allocated an ID code used to identify them to the research team, so that name and details will not be written on the sample. They will be stored in a locked refrigerator in a secure laboratory at the University of Northampton, which only members of the research team will have access to. After the samples have been analysed and the results have been recorded, they will be destroyed in accordance with government guidance.

As the samples will only be analysed for levels of hormones associated with behaviour, oxytocin and cortisol, nothing medically relevant will be found from the study. Therefore the results will remain confidential.

### **Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by NHS Staffordshire Research Ethics Committee and University of Northampton Ethics Committee. The researcher has been cleared to conduct research by the NHS and has passed a Criminal Records Bureau check.

**Thank you for reading this – please ask any questions if you need to**

If you are unhappy with the service being offered, The Patient Advice and Liaison Service (PALS) at NUH is available to guide you in any complaint.

PALS operates a drop-in service from 9.30am to 4.30pm every weekday except bank holidays. The office is located close to the Main Reception (Derby Road entrance), on the central corridor, opposite X-ray.

Alternatively, you can contact PALS on:

pals@nuh.nhs.uk

0800 183 0204 (free from a landline) or 0115 924 9924 ext 65412 or ext 62301

NUH NHS Trust, c/o PALS, Freepost, NEA 14614, Nottingham NG7 1BR

## Appendix D: Clinical participant consent



### Research Project:

### The influence of social support on disease management in adolescents with Type 1 Diabetes

#### Participant Consent Form

Circle yes or no for each statement:

Have you received information about this project?

YES / NO

Have you asked all the questions you want?

YES / NO

Have you had your questions answered in a way you understand?

YES / NO

Do you understand that if you change your mind, you can withdraw from the study?

YES / NO

Are you happy to take part?

YES / NO

If any of the answers are NO or you DO NOT wish to take part **DO NOT SIGN YOUR NAME**. By signing you confirm that:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that participation will involve the taking of saliva samples and the answering of questionnaires.
4. I agree to the Diabetes Care Team at Nottingham Children's Hospital being informed of my participation in the study.
5. I understand that relevant sections of my medical notes (most recent HbA1c result) and data collected during the study, may be looked at by individuals from University of Northampton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
6. I agree to take part in the above study.

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix E: Clinical participant parent consent form**

*Date*

Dear Parent/Guardian,

**Research Project:**

**The influence of social support on disease management in adolescents with Type 1 Diabetes**

We are writing to you to ask if you would like your child to take part in a research project.

The research is a study being conducted by the Centre for Health and Wellbeing Research at the University of Northampton in conjunction with *Hospital*. The study will investigate how influential social support is in glycaemic control in adolescents with type 1 diabetes. Your child is invited to participate in the pilot study, and will therefore have the opportunity to help design an intervention to improve social support in adolescents with type 1 diabetes and thereby glycaemic control.

In order to achieve this, taking part in the research will involve several different measures, which are laid out in the attached information sheet. If you would like to see a copy of the questionnaires then please use the contact details attached. Participation in the research is voluntary and it is up to you to choose whether or not you would like your child to take part. If you choose not to participate then your child's care will not be affected in any way.

If you are happy for your child to participate, then please return the attached slip in the enclosed stamped addressed envelope to the research team by September 2014. Without the receipt of this consent form, your child will not be able to participate in the research. If you do not wish for your child to participate, then you do not need to do anything.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Emily Doe'. The signature is fluid and cursive, with the first letter 'E' being particularly large and stylized.

Miss Emily Doe  
PhD Researcher  
University of Northampton



**Research Project:**

**The influence of social support on disease management in adolescents with Type 1 Diabetes**

**Parent Consent Form**

Please initial boxes

- |   |   |
|---|---|
| 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.   | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |
| 2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without their medical care or legal rights being affected.   | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |
| 3. I understand that my child's participation involves the collection of two saliva samples and the answering of questionnaires.  | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |
| 4. I agree to the Diabetes Care Team at Nottingham Children's Hospital being informed of my child's participation in the study.   | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |
| 5. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from University of Northampton, from regulatory authorities or from the NHS Trust, where it is relevant to their taking part in this research. I give permission for these individuals to have access to their records. | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |
| 6. I agree for my child to take part in the above study.  | <div style="border: 1px solid black; width: 80px; height: 30px; margin: 0 auto;"></div> |

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Child: \_\_\_\_\_



## Appendix F: Berlin Social Support Scale

### Berlin Social-Support Scales (BSSS)

Ralf Schwarzer & Ute Schulz, 2000

#### Perceived Available Support

Please indicate for each of the statements which is closest to how you feel about the support you receive from your friends.

		Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
	<i>Emotional</i>				
1	There are some people who truly like me.				
2	Whenever I am not feeling well, other people show me that they are fond of me.				
3	Whenever I am sad, there are people who cheer me up.				
4	There is always someone there for me when I need comforting.				
	<i>Instrumental</i>				
5	I know some people upon whom I can always rely.				
6	When I am worried, there is someone who helps me.				
7	There are people who offer me help when I need it.				
8	When everything becomes too much for me to handle, others are there to help me.				

## Appendix G: WHO-5 Wellbeing Index



**Psychiatric Research Unit**  
WHO Collaborating Centre in Mental Health

### WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	<i>Over the last two weeks</i>	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<b>1</b>	<b>I have felt cheerful and in good spirits</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>2</b>	<b>I have felt calm and relaxed</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>3</b>	<b>I have felt active and vigorous</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>4</b>	<b>I woke up feeling fresh and rested</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>5</b>	<b>My daily life has been filled with things that interest me</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

## Appendix H: 10 item resilience scale

## Connor-Davidson Resilience Scale 10 (CD-RISC 10)

**initials**    **date**   /   /   **visit**   **age**

**marital status** ☐ married ☐ separated ☐ widowed ☐ never married ☐ divorced ☐ refused

**gender** ☐ male ☐ female

**race or ethnic origin** ☐ White, not Hispanic origin ☐ black, not Hispanic origin ☐ Hispanic  
☐ Asian ☐ Native American or Alaskan native ☐ other ☐ unsure

Please indicate how much you agree with the following statements as they apply to you over the last **month**.  
If a particular situation has not occurred recently, answer according to how you think you would have felt.

	not true at all	rarely true	Sometimes true	Often true	True nearly all the time
1. I am able to adapt when changes occur.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
2. I can deal with whatever comes my way.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
3. I try to see the humorous side of things when I am faced with problems.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
4. Having to cope with stress can make me stronger.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
5. I tend to bounce back after illness, injury, or other hardships.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
6. I believe I can achieve my goals, even if there are obstacles.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
7. Under pressure, I stay focused and think clearly.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
8. I am not easily discouraged by failure.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
9. I think of myself as a strong person when dealing with life's challenges and difficulties.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
10. I am able to handle unpleasant or painful feelings like sadness, fear and anger.	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4

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We acknowledge contributions as works made for hire by Laura Campbell-Sills, Ph.D. and Murray Stein, M.D.

10/15/08

## Appendix I: Diabetes social support questionnaire – Friends version

### DSSQ: FRIENDS

We want to know **how often** your friends do things to **help or support your diabetes**. There are no right or wrong answers. Just circle the number that indicates how often these things happen with your friends.

We also want to know how you feel about your friends' behaviors. Everyone has different ideas about what is helpful and supportive. **We want to know what is helpful and supportive for you.** Circle the number that shows how supportive each behavior is for **YOU**.

---

These are the scales to use in answering the questions:

How often does this happen?	<u>0</u> Never	<u>1</u> Less Than 2x a month	<u>2</u> Twice a Month	<u>3</u> Once a Week	<u>4</u> Several times a Week	<u>5</u> At least once a day
When this happens, how do you feel about it?	<u>-1</u> Unhelpful Or NOT Supportive	<u>0</u> Neutral	<u>1</u> A little Helpful or Supportive	<u>2</u> Helpful/ Supportive	<u>3</u> Very Supportive	

**Note:** If a behavior listed never happens, circle "0" for "never". Please try to rate how you think you would feel if this did happen.

How Often Do Your Friends.....

How does this make you feel?.....  
or How would you feel?

#### INSULIN SHOTS

3. Remind you to take your insulin.

How often? 0 1 2 3 4 5  
(circle one)

It feels: -1 0 1 2 3  
(circle one)

10. Let you know they appreciate how difficult it is to take insulin injections.

How often? 0 1 2 3 4 5  
(circle one)

It feels: -1 0 1 2 3  
(circle one)

#### BLOOD TESTING

11. Ask you about the results of your blood tests.

How often? 0 1 2 3 4 5  
(circle one)

It feels: -1 0 1 2 3  
(circle one)

12. Watch you test your blood sugars to see what the values are.

How often? 0 1 2 3 4 5  
(circle one)

It feels: -1 0 1 2 3  
(circle one)

16. Remind you to test your blood sugar.

How often? 0 1 2 3 4 5  
(circle one)

It feels: -1 0 1 2 3  
(circle one)

18. Let you know that they appreciate how hard it is to test blood sugars every day.

How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

23. Watch you for signs that your blood sugar is low.

How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

24. Help out when you might be having a reaction.

How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

**Exercise**

45. Suggest ways you can get exercise.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3
47. Invite you to join in exercising with them.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3
51. Encourage you to join an organized sports activity (e.g., little league, gymnastics).  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3
53. Exercise with you.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

**General Items**

54. Are available to listen to concerns or worries about your diabetes care.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3
57. Encourage you to do a good job of taking care of your diabetes.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3
58. Understand when you sometimes make mistakes in taking care of your diabetes.  
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

---

Note that the numbers of the items are not sequential. The original numbering was retained, so that items can be matched to those on the Family Version of the DSSQ.

This scale is copyrighted, and may not be used without the written permission of the author:  
Annette M. La Greca.

## Appendix J: Self-care inventory – Revised version

### Self Care Inventory-Revised Version (SCI-R)

This survey measures what you actually do, not what you are advised to do. How have you followed your diabetes treatment plan in the past 1-2 months?

	Never ▼	Rarely ▼	Sometimes ▼	Usually ▼	Always ▼	
1. Check blood glucose with monitor	1	2	3	4	5	
2. Record blood glucose results	1	2	3	4	5	
3. If type 1: Check ketones when glucose level is high	1	2	3	4	5	Have type 2 diabetes
4. Take the correct dose of diabetes pills or insulin	1	2	3	4	5	Not taking diabetes pills or insulin
5. Take diabetes pills or insulin at the right time	1	2	3	4	5	Not taking diabetes pills or insulin
6. Eat the correct food portions	1	2	3	4	5	
7. Eat meals/snacks on time	1	2	3	4	5	
8. Keep food records	1	2	3	4	5	
9. Read food labels	1	2	3	4	5	
10. Treat low blood glucose with just the recommended amount of carbohydrate	1	2	3	4	5	Never had low blood glucose
11. Carry quick acting sugar to treat low blood glucose	1	2	3	4	5	
12. Come in for clinic appointments	1	2	3	4	5	
13. Wear a Medic Alert ID	1	2	3	4	5	
14. Exercise	1	2	3	4	5	
15. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	1	2	3	4	5	Not on insulin

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## **Appendix K: Diabetes social support interview**

### **Diabetes Social Support Interview (DSSI) Schedule**

Annette M. La Greca, Wendy F. Auslander, Peggy Greco, Dante Spetter, Edwin B. Fisher

Jnr. & Julio V. Santiago

*Journal of Pediatric Psychology. Vol. 20, No. 4, 1995, pp. 449-476*

- 1) In what way does your family help you or provide support for insulin shots?
- 2) In what way does your family help you or provide support for glucose testing?
- 3) In what way does your family help you or provide support for sticking to a meal plan or diet?
- 4) In what way does your family help you or provide support for exercising regularly?
- 5) In what ways does your family help you to feel good about your diabetes?
- 6) In what way do your friends help you or provide support for insulin shots?
- 7) In what way do your friends help you or provide support for glucose testing?
- 8) In what way do your friends help you or provide support for sticking to a meal plan or diet?
- 9) In what way do your friends help you or provide support for exercising regularly?
- 10) In what ways do your friends help you to feel good about your diabetes?

## Appendix L: Invitation to interview

Address

Date



Dear Name,

### Research Project:

### The influence of social support on disease management in adolescents with Type 1 Diabetes

At your recent appointment at the diabetes clinic, you kindly took part in research being conducted by *Hospital* in conjunction with University of Northampton into the well-being of adolescents with Type 1 Diabetes. Thank you for your participation. We are now writing to you to invite you to the second part of the research, which involves being interviewed by the lead researcher, who you will have met in the clinic when you gave your questionnaire responses and saliva samples.

The interview will ask you questions regarding your diabetes management and how you cope fit it in with your social and school or work life. We want to know how diabetes affects the lives of teenagers and young adults so that we can better adjust the treatment you receive and offer you services which can help to make your diabetes easier to manage. We can only do this by asking adolescents with diabetes, such as yourself, what they'd like to change.

We anticipate that the interview will last from 30 minutes to an hour, and will take place in a suitable location of your choosing, such as your home or a cafe. We regret that we would not be able to conduct the interview at school or college. Those who participate in the interview will be entered into a draw to win £50 of shopping vouchers.

Participation in the research is voluntary and it is up to you to choose whether or not you would like to take part. If you choose not to participate then your care will not be affected in any way.

If you are happy to participate, then please return the attached slip in the enclosed stamped addressed envelope to the research team before *date*. Alternatively, you can get in contact with the lead researcher via email (emily.doe@northampton.ac.uk) or telephone (01604 892537) to register your interest in taking part. Please do not hesitate to get in contact if you have any questions regarding the research. If you do not wish to participate, then you do not need to do anything. Thank you once again for your earlier part in the research.

Yours sincerely,

A handwritten signature in black ink that reads "Emily Doe".

Emily Doe  
PhD Researcher - University of Northampton

X-----

### The influence of social support on disease management in adolescents with Type 1 Diabetes

I would be interested in being interviewed as part of the above research project.

### **PLEASE RETURN BY DATE**

Name: \_\_\_\_\_

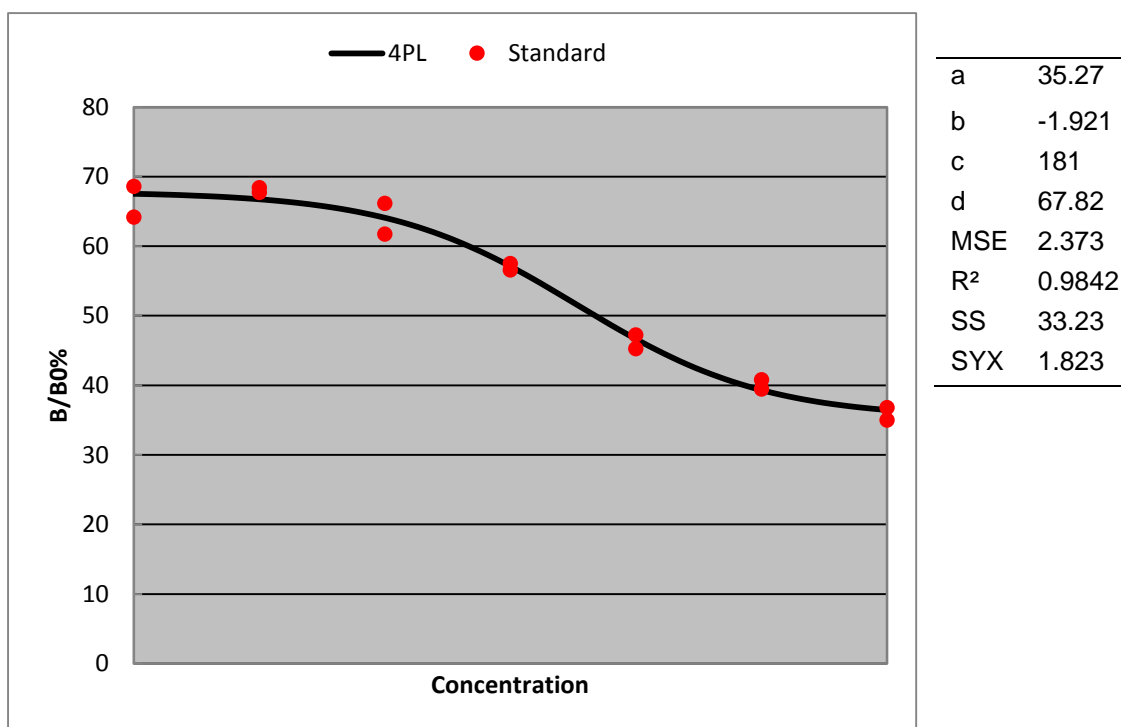
Email address/Phone number: \_\_\_\_\_

Any preferred day/time of interview: \_\_\_\_\_

Signature: \_\_\_\_\_

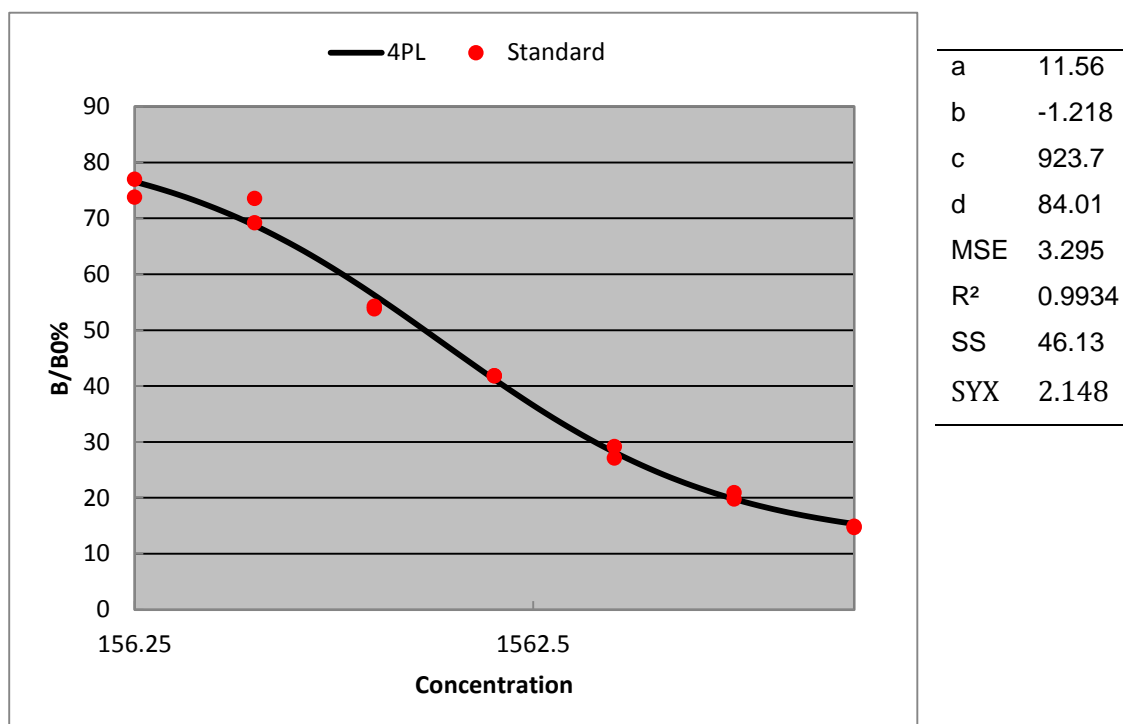


### Appendix M: Example 4PL for oxytocin analysis



	Calibrator	Wells	Conc.	B/B0%	SEM	Backfit	Recovery %
●	Standard1	A2 B2	1000	36.8 35	0.89	861 < Curve	86.1 -
●	Standard2	C2 D2	500	39.5 40.8	0.667	487.7 412.2	97.55 82.44
●	Standard3	E2 F2	250	45.3 47.3	1	276.3 239.4	110.5 95.76
●	Standard4	G2 H2	125	57.5 56.6	0.445	121.3 129.4	97.05 103.5
●	Standard5	A3 B3	62.5	61.7 66.2	2.22	84.2 39.18	134.7 62.69
●	Standard6	C3 D3	31.25	68.4 67.7	0.334	> Curve 7.828	- 25.05
●	Standard7	E3 F3	15.63	64.2 68.6	2.22	61.52 > Curve	393.7 -

### Appendix N: Example 4PL for cortisol analysis



Calibrator	Wells	Conc.	B/B0%	SEM	Backfit	Recovery %
Standard1	A2	10000	14.7	0.115	11680	116.8
	B2		14.9		10990	109.9
Standard2	C2	5000	19.8	0.575	5001	100
	D2		20.9		4425	88.5
Standard3	E2	2500	29.2	1.03	2344	93.74
	F2		27.1		2677	107.1
Standard4	G2	1250	41.8	0	1212	96.98
	H2		41.8		1212	96.98
Standard5	A3	625	53.8	0.23	701.6	112.3
	B3		54.3		686.7	109.9
Standard6	C3	312.5	73.6	2.18	214	68.48
	D3		69.2		302.7	96.87
Standard7	E3	156.3	77	1.61	147.3	94.28
	F3		73.8		209.5	134.1

## Appendix O: Example interview transcript

- 1
- 2
- 3 Participant 029710
- 4 Interviewer: So thinking specifically about your family (...) how would you say that
- 5 help you in terms of, like, the practicalities of your diabetes management? So your,
- 6 like, blood glucose testing, your injections or pump if you're on that, or anything like
- 7 that?
- 8 Participant: I'm on injection.
- 9 I: Mmmhmm.
- 10 P: Yeah, they help a lot, 'cause, like, I've got a memory like a fish, even after 10 years
- 11 of being diabetic. I'm like, I'll eat my dinner and I'll, like, completely and utterly
- 12 forget, like, thinking I've already done it, I'm fine. But then my dad will come and
- 13 "Jessa, have you done your insulin?" and I'm like "oops, no!" (laughs)
- 14 I: (laughs)
- 15 P: I'll always, I will always get reminded, I constantly get asked, before I've gone bed
- 16 I get 'have you done your bloods, how was your bloods?' stuff like that. So they do
- 17 help a lot.
- 18 I: And how do you find that?
- 19 P: Them helping?
- 20 I: Yeah, like, do you find that helpful or would you prefer to deal with it on your own,
- 21 type thing.
- 22 P: (...) I prefer (...) it to be, like, by myself, but I know if it was my control wouldn't
- 23 be anywhere near as good as it is. And it's not even that like, it could be improved
- 24 quite a lot, like, now so (...)
- 25 I: So, it's kind of a necessary evil at this point? (laughs)
- 26 P: (laughs) Yeah, yeah.
- 27 I: OK, so you've been diagnosed 10 years?

- 28 P: Yeah.
- 29 I: So quite a while then. How did you find it when you were diagnosed?
- 30 P: To be honest, I like, 'cause obviously my older brother is diabetic so I kind of like
- 31 'well, he's alright, I'll be alright' type thing.
- 32 I: Yeah?
- 33 P: Yeah, 'cause obviously like, 'cause my mum, like (...) she knew, like, instantly,
- 34 'cause obviously I lost a lot of weight, I was constantly going toilet and everything
- 35 like that, and so she was like 'right, you're diabetic, don't, don't even have to go to
- 36 hospital' (laughs)
- 37 I: (laughs)
- 38 P: It's like she's telling the hospital 'she's diabetic.' But yeah, I was like, when I, like,
- 39 found out, I was like, I was quite (...) not to grips, but I was familiar with the terms
- 40 and everything, so I was like 'oh, my big brother's got it, it'll be alright.'
- 41 I: Did you find that reassuring to have him?
- 42 P: Yeah, yeah.
- 43 I: How do you find it managing your diabetes with your brother about?
- 44 P: Um, not different really (...) quite independent.
- 45 I: Yeah? (...) How olds your brother?
- 46 P: Err, I know this one (laughs) 20, 21, I think. Something like that.
- 47 I: OK, so he's quite a bit older than you. Proper big brother. Do you find that you talk
- 48 to each other about it?
- 49 P: Yeah, yeah, we do have a chat now and then, like, comparing almost, don't we?
- 50 Because, like, we can relate, obviously, and then, um (...) yeah, it's more my parents
- 51 that (...) do the whole practical stuff, like, not even that, like, my dad, he'll come in
- 52 now and then "Jess, have you got everything in your bag for school? Do you have,
- 53 like, carbs and that? Jessa, make sure you take your lunch. Jessa, make sure you do
- 54 this. Jessa, make sure you do that." I was like "Yes dad. Yes dad. Yes dad. Yes dad."

55 (laughs) So it's, annoying, but I don't think it's any different to, like, how he would be  
56 if I weren't diabetic. 'Cause obviously, like, he's like it with my little brother too and  
57 that so, with me and Adam it's just, like, the extra nag of watching out for our  
58 diabetes too (...). He'd always be pestering me about something, it just happens to be  
59 my diabetes (laughs).

60 I: (laughs) So it just kind of blends into everyday life?

61 P: Yeah, 'cause I'm like, I know he's asking something about diabetes so I'm just  
62 gonna nod and smile (laughs)

63 I: (laughs) Make sure you're on it! (...) So what about your diet and that? Obviously,  
64 having someone else in the house who's diabetic, I imagine that helps a lot.

65 P: Yeah, like (...) I do, I am, I do keep my restrictions but, at the same time (...) even  
66 my parents, they're like, they try to make it as if I'm, like, not diabetic, if that makes  
67 sense. So it's like, it's not every weekend, but every now and then they'll come home,  
68 like, with loads of sweets and loads of pop and we'll have like a nice little, like, family  
69 thing. And then, um (...) they'll just tell me "Jessa, you need this much extra." Or they  
70 used to anyway, now they ask me "Jessa, how much do you think you need to do"  
71 'cause obviously I'm getting to that age where now, aren't I? Like, yeah, so like, I'll do  
72 extra, to like (...) going, to make sure I'm not going high or low.

73 I: How does that make you feel?

74 P: (...) It used to be, like (...) I remember, like, one time (...) in, like, a very long time  
75 ago, we always used to have pudding after dinner, but we don't any more. The  
76 amount of times they'd be sat there with like, their sugary donut or something  
77 chocolatey, and I'm sitting there with a banana or something (...) 'it's good for you  
78 Jessa, it's good for you!' (...) and I'd be like, 'yeah right, I'd rather be having what  
79 you're having!' (laughs)

80 I: (laughs)

81 P: But yeah, um, nah. It's (...) it's changed a lot now, 'cause within the past, I'd say  
 82 just under a year, my dad and mum, they've been switching it around, so like, they've  
 83 been asking me instead of telling me what I need to do, so I've been becoming slowly  
 84 more and more independent with it. So like, yeah, like I said, they'd ask me 'what do  
 85 you think you need to do?' instead of telling me 'Jessa, your bloods are this, you need  
 86 to do this much' so, yeah.

87 I: How have you found that?

88 P: Yeah, good, because I am, like, eventually going to be moving out and stuff (...) so I  
 89 think it's good to, like, start doing it now. Especially, like, gradually rather than just  
 90 dumping it all on me, you know, like 'bye!' (laughs) 2 minutes later 'dad, what am I  
 91 meant to do? (laughs)

92 I: (laughs) So it sounds like everyone, kind of, is all inclusive with the diet and that.  
 93 How does that make you feel?

94 P: Yeah, it's good! I don't feel, like, singled out or anything. I feel (...) I know it  
 95 sounds really silly, and kind of stupid in a way, but I forget I'm a diabetic half the  
 96 time! (laughs)

97 I: (laughs) Some may say that's a good thing though.

98 P: Yeah, I know. It's like, at school my, my mates will be eating something and I'll be  
 99 like "Oh, wait, I can't have that." (laughs)

100 I: (laughs)

101 P: But, yeah, it's like, it's not (...) I feel normal. I guess that's a good thing.

102 I: That's a good thing, that's definitely a good thing. So what would you say it is that  
 103 your family does that makes you feel best, feel most supported, about your diabetes?

104 P: Um (...) I'd say the times I feel best about my diabetes is when I've just been to a  
 105 hospital appointment and my HbA<sub>1c</sub> come down a bit more, and my mum's like 'I'm  
 106 so proud of you baby!' (laughs) I'm like 'stop it, you'll make me blush!' (laughs)

107 I: (laughs)

- 108 P: It's like, yeah, 'cause like (...) I don't know, it's like they (...) ugh, I'm like, they, it's  
 109 something I have no choice of, I need to do it, and they make it sound like I've just  
 110 done something massively (...) contributing to like world peace or something  
 111 (laughs)
- 112 I: (laughs)
- 113 P: It's like, I just do what I need to do.
- 114 I: What about them being supportive? What is it that they do that makes you feel like  
 115 (...) you don't have diabetes, as you put it, or that you can rely on them?
- 116 P: Well, 'cause like I say, I have got a memory like a fish and if I do like, I eat my  
 117 dinner, I go back to my room, do what I was doing before I had my tea, and then like  
 118 5 minutes later, knock knock knock 'Jessa?' 'Yeah?' 'Do your insulin.' 'Oh! Thanks!'  
 119 (laughs). Yeah (...) I always know that (...) even if I don't remember, I know they will,  
 120 and I know that, like, 'cause you do have some, well, you're not diabetic, so you  
 121 probably don't have them days (laughs) but I do have them days where I'm like 'I  
 122 don't need to do bloods, I don't need to do this, I'll just do it later, I don't need to do  
 123 that.' But they'll be like 'Jessa, no, do it.' (laughs) So yeah, I do, I do feel (...) they do,  
 124 my parents do support me a but lot, like, but yeah, it's mainly my parents 'cause I've  
 125 got older brothers and sisters, I've got a younger brother, but they're off doing their  
 126 own thing. It's my parents more than anyone.
- 127 I: Yeah? What about (...) how do I put it, if you're having a really bad day with it?
- 128 P: Yeah, yeah. I mean, myself I've got a pretty big, abnormally big appetite but there  
 129 are days when I'm just like 'I don't want to eat, I don't want to do this, I just want to  
 130 stay in bed, and sleep and chill, why, why do I have to get up and do stuff?' (laughs)
- 131 I: (laughs)
- 132 P: But yeah, it's like, I don't know, it's like you have them days but you know you'll  
 133 get over it eventually.
- 134 I: How is it that you get over it? Who do you talk to?

- 135 P: I don't know, in my opinion, I'm pretty independent when it comes to things like  
 136 that, because I think to myself, I'm like 'I know I'm not going to feel like this 24/7.' If  
 137 I, if I do feel like that for like, like 2 days or something then, and that has happened  
 138 before, I do go talk to mum and say like 'mum, I don't want to do this, I feel like (...)'  
 139 and she'll be keeping more of an eye on my blood sugar levels, make sure I'm doing  
 140 everything properly and looking after myself, you know. So I know that if I'm being,  
 141 like, a total fail when it comes to managing it properly, I have that back up. 'Cause  
 142 it's, like, part of being a teenager as well, isn't it, like having days where you just  
 143 don't want to do anything! (laughs)
- 144 I: (laughs) Definitely! I think half my teenage life was spent in my room, like, I don't  
 145 want to leave! (laughs)
- 146 P: (laughs)
- 147 I: So what about your friends (...) how do you find (...) managing the practicalities of  
 148 your diabetes with them?
- 149 P: Um (...) I'd say (...) not all of them. I'd say mainly Hannah (...) and Charlie, really,  
 150 because they, I spend more time with them more than anyone else, so like, say if I'm  
 151 going low, they'll notice it like that. Say, like, if my words start slurring or I starting  
 152 to sweat when I shouldn't be or like if I'm just going, bouncing off the walls because  
 153 I'm high. They're like 'Jessa (...) and give me the look and I'm just like 'Oh, I didn't  
 154 even know I was!' (laughs)
- 155 I: (laughs) Do you feel they'd know what to do if you had a hypo or anything like  
 156 that?
- 157 P: Yeah! I haven't even been with them that long and they know everything, they  
 158 know more than me! (laughs) It's like 'What has happened here?' (laughs) And it's  
 159 good, it's like, I find it quite funny, but other people find it quite bad; Hannah brings  
 160 sugar to school for me just in case I forget. (laughs) And it's like, I, I d- I have got a  
 161 memory like a, a (...) idiot (laughs), but yeah, like, I've gone to school, like, in a rush



- 162 or something, I've arrived and I'm looking at my bag like 'right, I've got everything I  
 163 need educational-wise, diabetic-wise just missing a couple of things!' But yeah, like,  
 164 Hannah, she's always got a couple of chocolate bars in her bag for me, so like if I'm  
 165 low, she's like 'here you are.' (laughs)
- 166 I: (laughs) That's amazing.
- 167 P: (laughs) Yeah. And then Charlie usually lets me have, like, a sausage roll or  
 168 something if I'm, need it. (laughs) If I need it (laughs).
- 169 I: (laughs) Even when you don't need it?
- 170 P: (laughs) Sometimes!
- 171 I: How does it make you feel, having people in your life like that who-?
- 172 P: I feel quite relaxed! But the same time I know I shouldn't do to a (...) great degree  
 173 of it. (...) Because, like (...) they're not going to be there everyday (...) they have sick  
 174 days, they, like, you know (...)so I know that I need to (...) do it by myself, but to use,  
 175 like, they are gonna be there, but obviously not forever, so if it's, like, a last resort  
 176 type thing. That's what I need to keep that in my frame of mind, otherwise I'll get too  
 177 relaxed with it all, start slipping.
- 178 I: How do you find it, managing you diabetes around them? (...) Like, are you  
 179 comfortable doing your injections around them, or-?
- 180 P: Yeah, they've seen me do plenty of injections, I'm just like 'Cover me!' PSSSH, you  
 181 know? (laughs) Yeah, um (...) Hannah and Charlie, they've both put the needle on  
 182 and everything, they both prep and give it to me (...) um, Charlie wanted to inject me  
 183 once but he was sha-he was shaking too much so I was like 'nah, you're alright  
 184 darling!' (laughs)
- 185 I: (laughs) Yeah, no shaky hands!
- 186 P: (laughs) But yeah, um (...) yeah (...) 'cause Hannah's slept round quite a bit. So  
 187 she's seen me, like, wake up during the middle of the night shaking and sweating  
 188 and she's gone to get me food and everything (...) during the middle of the night

189 because I was having a low, and then um (...) But yeah, but like, it was quite funny,  
190 obviously with your mate you're like laughing and joking and everything, the second  
191 they find out I'm having a low they're like 'You ok Jessa? You ok Jessa? You ok Jessa?  
192 Jessa, you ok?' Yeah (laughs) they are quite supportive, 'cause (...) but obviously like,  
193 it's just 'cause I spend so much of my time with them personally, everyone is just,  
194 like, casual. Yeah.

195 I: How does it work with those casual people?

196 P: (...) How do you mean?

197 I: Like, do you hide it more? Are you as open with them? Or?

198 P: I'm very open with everyone, but (...) it's just, like, do (...) everyone, everyone has  
199 like a rough idea what diabetes is, so if I was to say, if I was with someone other than  
200 Hannah and Charlie, and I go 'oh, I feel a bit low' they'll go 'oh, do you need sugar?'  
201 It's like (...) yeah. It's like, 'oh, I'm feeling a bit hyper' and they're like 'oh, do you  
202 need sugar?' and I'm like 'no, that'll make it worse.' (laughs) But they'll still go  
203 galloping off, and I'm like 'eurgh.' Like, you're not listening. Like, they've heard  
204 somewhere along the line that you need to give diabetics sugar, and that'll all they  
205 remember, even if I tell them not to. So (...) I'm open with them, but (...) like, I  
206 wouldn't necessarily trust them to take care of me if I was proper ill, you know?

207 I: Just because they don't know enough?

208 P: Mmm, yeah.

209 I: How do you find it at school? Like, with classmates and teachers and that?

210 P: (laughs) I actually get away with so much. Sometimes, I shouldn't really admit  
211 this, but I do, kind of, milk it just a tad bit, but then I think 'I have to inject myself 4  
212 times a day for the rest of my life, so I'm gonna milk it!' (laughs) But yeah, but my  
213 mates at school, 'cause when I have a hyper I go a bit, you know, loopy and I'm like  
214 jumpy and I'm like, and it's like (...) it's, it's weird, the time when I shouldn't feel  
215 energetic and I'll feel so energ-energetic it's unbelievable. And it's like, everyone

- 216 thinks it's funny, and I'm like 'don't!' And I'm like, I can't remember afterwards, and  
 217 everyone's like 'you did this, this, this, this and this' and I'm like 'oh, for Christ's  
 218 sake.' (laughs)
- 219 I: (laughs)
- 220 P: Literally, one, one of my mates was like 'it's like your flip a switch,' and I'm just  
 221 like 'oh, dear.' It's like, yeah, 'cause they said that you can tell when I'm about to go  
 222 because my knees start bouncing and I start sweating and I go giggly, like, basically, I  
 223 look high (laughs).
- 224 I: (laughs)
- 225 P: But yeah, I'm just like [bounces knees] yeah (laughs)
- 226 I: (laughs) So, it sounds like (...) you've got lots of thing in place at school to, like,  
 227 stop you feeling embarrassed or anything?
- 228 P: Yeah (...) just, kind of, cope with it. If anyone has a problem with me and my  
 229 diabetes, I kind of just stick two fingers up at them and be like 'cool mate.' No (...)  
 230 'cause people have been like 'Oh, you do this, this just 'cause you're diabetic' and I'm  
 231 like 'Erm, no!' 'Cause I just, I'm like, I'm very one of them people (...) I don't keep my  
 232 opinions to myself (laughs) But yeah (...) I haven't come across many people who've  
 233 been like that, like 'oh, you just do this,' but I've found like, when I, 'cause it has  
 234 happened when I've talked to someone afterwards and, you know when it starts out  
 235 and argument but it turns into a friendship? (laughs) Yeah, I've talked to them and  
 236 afterwards found out they've got no one in their family whatsoever or been friends  
 237 or anything with anyone who's diabetic, so when I tell them what it's actually like to  
 238 be diabetic, they're like 'Oh my gosh, I'm so sorry!' and I'm just like 'Mmmhmm'
- 239 I: So would you say it's about them understanding?
- 240 P: Yeah, but obviously, not everyone, it's not like a necessity to know about diabetes,  
 241 but (...) I don't mind telling them about it. Especially 'cause, like I say, when they  
 242 know it's different.

243 I: You don't mind that?

244 P: No, no. I'm just like 'I can pass on my wisdom' (laughs)

245 I: How does that make you feel about your diabetes?

246 P: It's like, I do, I do feel a lot more comfortable (...) say, like, I'm in class, I'm having  
 247 a high or a low and I'm like 'Sir, I need to go outside' and I, like, turnaround and I'm,  
 248 like, giggling or something and people are like 'she's having a bloody low again.' And  
 249 I'm just like (laughs). Even the teacher knows, it's like, like, we, even the sub. We had  
 250 a sub the other day, and I'm just sitting there and I was giggling to myself and he was  
 251 like 'You've had an energy drink haven't you?' and I was like 'no, honestly!' (laughs).  
 252 Yeah, it's like, even the sub knew, 'cause he's a diabetic as well. It's like everyone, not  
 253 everyone, just like (...) I don't know, like (...) I just take it in my stride, and be like 'oh  
 254 yeah, cool mate.' I know some people be like 'Oh, this, this, this, this' but I'm just like  
 255 'cool' you know? (laughs) Like, go, be gone, type thing. I don't let it bother me.

256 I: That's a good way to be, I think. Better than letting it get to you.

257 P: Yeah. 'Cause in my old school I had a, um, a mate that got diagnosed when she was  
 258 12 years old, so obviously she was more emotional to dealing with it and stuff. I'm  
 259 like sitting there going 'la la la la la' and she's like 'how do you do that?' (...) I was  
 260 like 'right' so I had to sit her down and be like 'this is what you do.' (laughs) Oh,  
 261 gosh. It's so funny though.

262 I: (laughs) Mmm. So what about in terms of, like (...) going out with your friends and  
 263 stuff, like, outside of school. How do you manage your diabetes in those (...)   
 264 situations?

265 P: Um (...) I don't know, um (...) obviously, they know I'm diabetic and I suppose in  
 266 that sense they, they do, like, there has been a couple of times when they'll be like  
 267 'Jessa, are you sure you're allowed that' and at the same time, they kind of just leave  
 268 me to it, which I expect them to. You know, not treat me like a little kid or  
 269 something.

- 270 I: No, absolutely.
- 271 P: But yeah, it's like they, they are aware, like sometimes (...) if I go up, like, and get  
 272 something really sugary, I'll sit back down and Charlie will be like 'make sure you do  
 273 some extra if you need it' (...) or, like, when Hannah sleeps round, we'll get, like,  
 274 loads of sugar in to eat and everything, and she'll be like, she'll make sure, no, she'll  
 275 be like 'I'll eat this, you can have that' (laughs) 'You can have this cube, I'll have the  
 276 rest.' Yeah, they're understanding, and it helps a lot because if I didn't have friends  
 277 that were understanding I probably wouldn't be as good with it as I am.
- 278 I: That's really good. Do you feel (...) do you feel there are any negatives to it, like,  
 279 any limitations on what you can and can't do with them?
- 280 P: No, 'cause (...) I don't know (...) I'm a very (...) I'm a, a, I don't know, I'm very easy  
 281 going, so like if people try, I mean, I know my limits so I will stop (laughs) now and  
 282 then at the limit. But, like, if they want to, like, eat that extra bit of sugar, I'm just like,  
 283 just sit there or something, you know? Like I don't know, I just, I keep it in my head,  
 284 like, I know I'm not allowed it and I just keep in my head that feeling I get when I've,  
 285 when I'm really, really high and I'm just like 'That's not happening' (...) because it  
 286 don't feel good. If I just, if I keep that in my head, it, it gives me, like (...) more  
 287 motivation to, like, not do that. I just make sure I do my insulin.
- 288 I: How does that make you feel to, to have to (...) keep that in your head and say no  
 289 to things?
- 290 P: I just like (...) you know, you want to eat it, you want to be able to have that, that,  
 291 whatever it is (...) but you can't (...). It's only a bit of food at the end of the day.
- 292 I: Yeah.
- 293 P: And there's plenty of nice savoury stuff you can have (laughs). Sometime,  
 294 sometimes, you know when you're having a bad day, and I'm just like [sighs] 'do you  
 295 mind?' you know? Like, not eating it around me. But I don't want to be demanding,  
 296 you know? It's not their fault I'm diabetic, is it? If they want to eat, it's like, if

297 anything I'll walk away if it's one of them days. I'd rather just go stand by myself for  
298 a while, till the chocolate's gone, rather than ask them to put it away (...) 'Sorry, I'm  
299 allergic' (laughs)

300 I: Is that what you say?

301 P: Sometimes (...) to strangers more than anything though, just 'cause it's easier.

302 Like on a day to day basis.

303 I: Easier?

304 P: Yeah (...) than explaining about diabetes, like, having too much and stuff. It's just  
305 easier to say I'm allergic.

306 I: Less questions?

307 P: Definitely.

308 I: So (...) what about in terms of exercise, how do you find incorporating that into  
309 your life?

310 P: I love sport.

311 I: Yeah?

312 P: Yeah!

313 I: What do you do?

314 P: I dance, I play basketball and I do badminton.

315 I: Oh wow.

316 P: (laughs) And I work out quite a bit.

317 I: Is that something that you do because of your diabetes or is it something that you  
318 would do anyway, do you think?

319 P: I'd do it anyway. I can't just stand sitting there. If I'm not doing school work, I  
320 doing that, or I'm just (...) sleeping. (laughs)

321 I: (laughs)

322 P: Yeah, yeah, dance, basketball, badminton and work out a lot. Yeah (...) just double  
323 checking that is it! (laughs)

324 I: So are these things you did before your diabetes, or?

325 P: Um (...) wait, dance was (...) mates, 'cause I was mucking about and they said I  
 326 was good (...) (laughs) so I was like, 'yeah, I'll go for a few classes' (laughs), um,  
 327 badminton is a school thing and basketball is wherever, whenever, yeah (...) and  
 328 workout is just by myself, really. (...) I think, in all honesty, I'd probably do it more if  
 329 I didn't have diabetes. 'Cause, like, you have days where you just (...) like, I've got  
 330 lumps in my arms where, I've like, I've done it and then it's not worked or  
 331 something, and I haven't realised what's happened. So sometimes I'm like, I don't  
 332 want to do anything, I really don't. Whereas I think if I didn't have diabetes I'd be  
 333 like 'let's go!' (laughs). 'Cause say, like, if I'm having a high, then, I do (...) I'm like, I  
 334 go, if I'm in I'll have to go to my room for a bit and dance around for ages, come back  
 335 out and just be like [sighs] and like (...) I just, 'cause like, even in my old school - this,  
 336 this is amazing, can't do this in my new school, I'm well gutted - but in my old  
 337 school, yeah, 'cause they knew how much I liked basketball, if I was high, they'd take  
 338 me for the rest of the lesson, go and play basketball with the gym teacher.

339 I: Oh my gosh.

340 P: I know, right? So good. But they won't do that at my new school (...) it's well  
 341 depressing (laughs). And then at my primary school I used to have to go round,  
 342 running round the field, massive field, and it'd just be like in the middle of class, and  
 343 you'd see this child running across the field (laughs) me! And I'd be like 'coo-ee!'  
 344 (laughs)

345 I: (laughs)

346 P: I even remember, Mrs Rowntree, she'd stand there like, she'd get her shades out,  
 347 she'd sit on the grass and casually tell me to run another lap. And every now and  
 348 then you'd hear like 'Come on Jessa, you can do it!' (laughs) So I was like 'Cheers  
 349 miss!' (laughs)

350 I: (laughs)

- 351 P: So, yeah, I did that for like, what, about 10 minutes in primary school and my  
352 bloods would come down by, like, 5 mmol.
- 353 I: Wow.
- 354 P: Yeah, and obviously 'cause basketballs like a lot more fast-paced, 'cause you've got  
355 all defence and that going on, so a lot more heart raising, heart pulse raising,  
356 whatever you call it. And so that worked a lot too. But, but, yeah, my new school's a  
357 bit of a bummer and won't let me do it. It's like 'you're high, go back to class.' So  
358 yeah, now it's much more for fun, whereas I guess it used to be actually for my  
359 diabetes. (...) It made it more, in my opinion, I loved it, 'cause it helped out, it linked  
360 in, it helped me out, showed me, like, what my sugars did when I exercised and stuff  
361 (...) and how to control it and that, but now it's just 'cause it's fun.
- 362 I: I can see how that'd be helpful for sure (...) I guess now it's GCSEs and stuff they're  
363 like 'no, stay in class.'
- 364 P: Exactly, I walked, I was, like, having a really bad high, I was sitting there like,  
365 literally like this going [giggles, bounces knees]. Miss was like 'you're high again  
366 aren't you?' and I was like 'yeah' she was like 'right' and she sat down, and I was like  
367 'miss, can I go for a run for a bit or something?' and she was like, she looked at me as  
368 if I'd, like, grown a second head, like 'NOOOO!' and I was like 'well then.' (laughs)  
369 And I was like 'it'd help' and she was like 'the only place you can go is for a walk to  
370 the toilet if you need it' I was like 'ooo, sassy!' (laughs)
- 371 I: (laughs)
- 372 P: It's quite funny though, 'cause like, my dad doesn't know about this, but I stole the  
373 wheelchair and I was wheeling it up and down the corridor when she went to the  
374 toilet herself. She came back and she was like 'JESSA!' and I was like 'I feel better  
375 now.' (laughs)



- 376 I: (laughs) Can that be frustrating? That (...) the teachers don't necessarily know  
377 how (...) that that could potentially be better to let you have 5 minutes in the long  
378 run?
- 379 P: Exactly, I'm like 'miss, give me like 5 minutes to have like a (...) speed walk round  
380 the school and I'll feel 10 times better' and she's like 'that's ridiculous' and I'm like  
381 'it's not(...) it's basic science' (laughs)
- 382 I: (laughs)
- 383 P: That's what I'm thinking! And I would say that, but then I'd get done for back  
384 chatting. I can't be bothered. (laughs)
- 385 I: Would it be helpful if (...) someone, like, parents or nurses or someone, went into  
386 the school and told them that it'd be better for you to have 5 minutes out?
- 387 P: Probably, yeah (...) 'cause that's the main problem, that's the one main thing that I  
388 can't do when I'm high (...) it's like, I see every little thing, apart from my  
389 concentration, what I'm supposed to be concentrating on. 'Cause like, they'll be  
390 sitting there, like, 'cause, like I had a high, I had a test, I had an exam, rather, last  
391 Thursday and I went high and I done a paragraph, put my head down, look back up  
392 and I was, like, looking at every line on the ceiling tiles, all that like. Then I look back  
393 down and I start looking at everyone else (laughs). I was like 'I need to do this, but I  
394 just can't.'
- 395 I: Yeah (...). How have you found (...) managing your diabetes with exams?
- 396 P: Err (...) I think, difficult, difficult. Because obviously I've been more concentrating  
397 on that, like, I need to revise for this, I need to make sure this works, I need to do  
398 this, this and this, and this, this, and this. And then, with all that going on, it's like, 'oh  
399 yeah, I need to eat.' And perhaps do some insulin too, you know, make sure I survive  
400 for the day (laughs).
- 401 I: Has it gone down your priority list a bit?

402 P: Yeah, yeah, 'cause obviously, I've had it for such a long time, I'm just like, it's not  
 403 as a blinker in your head, going 'you need to do this, you need to do this.' So I don't  
 404 feel like I need to do it until an hour later, when I should have done my insulin, and  
 405 I'm sitting there going 'why am I feeling so weird for?' It's like 'oh, yeah.'

406 I: Have you found (...) because we know that, actually, stress is really bad for your  
 407 control because the hormones that you release when you're stressed impact on you  
 408 blood glucose so, no matter how well you're controlling, no matter how on top of  
 409 your injections you are, you find that your sugars are shooting up anyway. Um (...)   
 410 have you, have you found anything like that yet?

411 P: Um, yeah, because, it's like a delayed reaction almost, because I'll be sitting there,  
 412 like (...). 'Cause I had the final part to my exam today and I was preparing for it  
 413 during my lunch, all fine, going like 'right, I feel good, I feel good.' Got in there,  
 414 started writing and I'm feeling shaky and like 'why am I shaking? What am I shaking  
 415 for?' I had to go out for 5 minutes to, like, drink a bit of water, and make sure I was  
 416 all alright, and then go back in and then start my test (sighs). I hated it so much  
 417 though, 'cause it was like, it was during my, I've spent my whole lunchtime, I felt  
 418 good, I felt prepared, I felt 'let's do this one, mate' and I got in there and, literally, I  
 419 picked the pen up and I could see my hand shaking and I'm like 'what am I shaking  
 420 for?' And it's like, so I put my hand up, and sir was like 'you alright?' and it's like 'can  
 421 I go outside for a minute please?' I hate it so much when things like that happen.

422 I: How come?

423 P: (...) It's just like, embarrassing, you know? Like, 'cause like, I remember sitting a  
 424 mock last year, right, and this girl who was sat behind me was ill and she had to go  
 425 out. It was proper bad. 'Cause like, I don't know if it was nerves or what but she  
 426 completely threw up outside the room, and everyone heard it (laughs). It was so  
 427 rough. But, like, everyone was proper judging her, like afterwards 'oh my god, did  
 428 you hear that girl vom? So sick!' and whatever, I, like, felt proper sorry for her. (...)

- 429 But, yeah, I guess, that might be me too, you know? Like, I don't know if they say  
 430 stuff like that about me when I have to go outside, or whatever. And, I know it's  
 431 different, but (...) I don't know if they know. I shouldn't let it get to me. (...) Plus I  
 432 don't know what happens if I have to leave in a big test, you know, to eat or take  
 433 some insulin or whatever.
- 434 I: I think you should get some kind of additional help (...)
- 435 P: I'll ask, I, I don't know (...) I don't have loads, I just have, like, weird ones, but, I  
 436 don't know. I'll ask, and if they say no, I just, kind of, eat anyway.
- 437 I: I can't see them not letting you; I don't think they're allowed because (...) it's for  
 438 medical reasons.
- 439 P: No, 'cause I asked, yeah, I had this Spanish exam (...) Wednes - yesterday, and I  
 440 was like 'miss, can I take my water, bottle of water to the desk?' and she was like 'no,  
 441 get your bum on your seat.' And I was like 'how rude!' so I got my water and was like  
 442 [mimes swigging overdramatically from bottle] (laughs) and went to go sit down  
 443 then. (laughs) I got evils for that one, but yeah. (...) But, but yeah, I don't know, I'd  
 444 just eat or whatever anyway, even if they said no.
- 445 I: Yeah, there must be, they must have something in place, 'cause like, it's literally  
 446 your life.
- 447 P: 'Cause like, if anything, that's the time for it to go (...) naughty word up, you know?  
 448 (laughs). That is the time for it to go all wonkified and stuff. That's the time when it's  
 449 most likely going to happen. But, I've (...) I've had, I've gone high during exams but,  
 450 but I've never had a low (...) I don't think (laughs) I haven't had many exams yet.
- 451 I: Yeah, like, like I say (...) it's the stress hormones, they mean there's more sugar in  
 452 your blood so (...) always hyper, rarely hypo, from what I know.
- 453 P: Yeah, I've had older mates who've already sat their exams, and she told me, um,  
 454 she didn't ask, she didn't do nothing, she went and took a big bottle of water. Beside  
 455 that big bottle of water was a wrapped up sausage roll, beside the sausage roll was a

- 456 big can of coke, and she was like 'you don't ask, you just do.' I was like 'fair enough!'  
457 (laughs). 'Cause she said, she was like, she started laughing, 'cause, you know, like, at  
458 the beginning they're like 'make sure you have one 2b pencil, a ruler a calculator'  
459 and then she said that he actually, like, looked at her and said 'your coke, your  
460 sausage roll' (laughs) like that and everyone started laughing. (laughs)  
461 I: (laughs) Every eventuality.  
462 P: Yeah, I think I'll just, like, take a little goodie bag with me!  
463 I: OK, so um, (...) what is it about school life that (...) makes you feel best about your  
464 diabetes?  
465 P: Teachers not so much! (laughs) But, um, yeah, my mates, they, they're good, yeah  
466 (...). 'Cause, I don't know, it's just (...) without, I forget about it, but at the same time I  
467 know it's there, if that makes sense. I only remember, it only, like, comes into my  
468 mind when I need to do something with me diabetes. 'Cause obviously, it's not  
469 constant, it's only when you eat or when you, you're feeling low, or high, or  
470 whatever. It's like, any other time, it's like (...) normal. Normal, normal, you need to  
471 inject yourself, normal, normal, eat. Yeah, it's just, it's the attitude I take. I'm like 'I  
472 want that chocolate cake, and I'll worry about it later.' (laughs)  
473 I: (laughs) One of the nurses was saying that to me the other day that, like (...) the  
474 attitude that some of the other staff at the clinic have annoys her 'cause it's (...)   
475 you're a teenager, you know, a bit of chocolate cake on occasion isn't going to kill  
476 you! (laughs)  
477 P: Oh it's not on occasion, it's every day mate! (laughs) I'll just worry about it later.  
478 (laughs)  
479 I: (laughs) Using up those 3-4 hypers a week are we? (laughs)  
480 P: I'm doing good! (laughs)

481 I: (laughs) (...) So, um (...) if, god forbid, your little brother was diagnosed tomorrow,  
482 and you could sit his friends down and, kind of, say 'look, this is the one thing that's  
483 going to make him feel the best,' what would that thing be?

484 P: One thing that'd make him feel good (...) um (...) just treat him like he's normal,  
485 'cause the one thing, it has happened a couple of times, where, like, say I've met and  
486 new person and straight away they're not going to know I'm a diabetic, and so, like,  
487 things, like, when I'm with them I'll have a low and I'm like 'I'm having a low' and  
488 they're like 'what's a low?' 'I'm diabetic.' 'OH!' and then it all changes. Constantly  
489 they give you the sympathetic look on their face, and it's like 'stop it!' It's just, like,  
490 just to make him feel as normal as you possibly can, because, 'cause obviously, in a  
491 way he will and in a way he won't be, because he's always got to have that, he's  
492 always got to have the injection, he's always got to go to hospital he's always got to  
493 make sure he's doing this, got to make sure he's eating this, got to make sure he's  
494 checking blood if he's doing sport, he's always got to be doing something, but it's just  
495 (...) make it seem like it's (...) normal. Just part of life. That's what I try and do.

496 I: I think that (...) I mean, you seem to be doing really well with it, so I think that's  
497 pretty good advice. So (...) what this will hopefully eventually lead to is (...)  
498 something in place at the clinic, be it some sort of group (...) for, that, err, all the  
499 older adolescents, where you can just, kind of, get together and talk to other people,  
500 who (...) are going through similar things at similar times-

501 P: I think that would be great.

502 I: Yeah?

503 P: 'Cause you walk in and you're like, you've got diabetes, we're automatically  
504 friends (laughs).

505 I: (laughs)

506 P: 'Cause you walk in and you, it's like you know that person's got diabetes, you like  
507 (...) I might just be, like, the only one feeling it, but it's like you share something so

508 big. You've experiences the same things; 'have you done this?' 'yeah, I've done this'  
 509 and you can have a good old laugh, 'cause you know there's always a funny story  
 510 that follows a hypo (laughs).

511 I: (laughs)

512 P: Especially the ones that happen in public! (laughs) The amount of strangers I've  
 513 ended up talking to, it's unreal. (laughs) I'm not good to socialise with when I'm  
 514 having a low.

515 I: So if that was in place, would that be something you'd be interested in doing?

516 P: Yeah, I mean I'd love to do that.

517 I: Fab. The other thing we were thinking about would be to (...) get some good  
 518 friends involved –

519 P: Yeah, a boy at my school, he was like walking past, walking with his buddies, and  
 520 he was like 'yeah I need to do this, I need to do that' and I was like 'he's not diabetic,  
 521 is he?' so I went, like, running up to him; 'are you diabetic?' (laughs), like 'we're  
 522 friends now!' (laughs)

523 I: (laughs)

524 P: And I was literally with him for all the way up the stairs, right through the school  
 525 to the cafeteria talking about pure diabetes. I was like 'this happened, has that ever  
 526 happened to you?' (laughs) and he was like 'yeah, then this happened to me, has that  
 527 ever happened to you?' it was just, like, back and forth, back and forth. (laughs) I  
 528 know, 'cause my friends were, I literally, literally was like 'has he got diabetes?'  
 529 (laughs) It's like, it's great. I blame my weirdness on my diabetes quite a lot (...) I'm  
 530 pretty sure it's just natural, but we'll go with the diabetes (laughs)

531 I: (laughs)

532 P: 'Cause I'll be bouncing, and people will be like 'Jessa, what you bouncing for?' and  
 533 I'll just be like 'errr...I'm having a high?' (laughs), 'Jessa, what you doing that for?'  
 534 'errr, diabetes?' (laughs)

535 I: (laughs)

536 P: It's like (...) if I've got it, I may as well use it.

537 I: May as well get something out of it! (...) So, um, for the group, would you prefer

538 bringing your friends along or just meeting people who go through it naturally?

539 P: Just meeting people, 'cause I know people at my school that have it, but we don't

540 exactly communicate, like I, there've been a couple of times when I've gone to them,

541 or they've gone to me, and it's like 'have you got your insulin? I've forgot mine' (...)

542 type thing, I'll be like 'yeah, here you go love' but (...) other than that, it's like, we

543 don't, we don't exactly, like, see each other through school, like 'oh, what's your

544 bloods this morning?' it's like, I don't know, one of them things, but, yeah, it'd be

545 great, we'd like (...). 'Cause in, when I was in, where I used to live I was in, I had so

546 many, like, I had Tara, I had Anna, I had loads of people (...) 'cause, it's like, it was

547 actually like, 'cause, um, 'cause we'd always go to the medical room at the same time

548 to do our insulin, and we're sitting there, like, '5, 4, 3, 2, 1' and all say what our

549 bloods were at the same time, and then, like, whoever was the highest had to lock

550 away everything, 'cause obviously it's needles and stuff, so we all had to, it all had to

551 get locked away, they had to lock it away and we, and we got to go. It's like (...) it was

552 quite funny, but I don't get to do it anymore, 'cause everyone's boring up here

553 (laughs). They're no fun (laughs).

554 I: So would you find the opportunity to talk to, um, other people useful?

555 P: Yeah, I'd love it, I really would.

556 I: Great. The, um, the other thing I've been thinking about that you might found

557 useful is the adult, well, the young adult clinic that's also at the hospital to be

558 someone who you could go to and be, like, 'when you went to uni, how did you

559 cope?' so it's kind of like a source of information from someone who's actually gone

560 through it, who can give you some real answers. How would you, how would you

561 find that?

562 P: Yeah, 'cause I, I've been, I have, when my dad decides to appear, I'm gonna go for  
 563 me, my application for college tonight, and I was thinking about it today 'cause I  
 564 knew we were gonna do it tonight, I was like, I know for a fact my bloods are gonna  
 565 be everywhere when we get back 'cause they already are when I've been away,  
 566 'cause the times change, and when I go from doing my morning insulin from, like, 11  
 567 o'clock when I wake up to 6 o'clock in the morning it's that, it changes so much, and  
 568 with the added stress of starting college, I know I'm just going to be everywhere. It's  
 569 like, walking to class, stop, eat. I'd be behind everything, but, I know, I know I'd be  
 570 alright after a while but, but I'm just kind of scared about them first few weeks.

571 I: Why scary?

572 P: It's just, it's just that whole thing about going to a new place all over again with  
 573 new people, and having that conversation, like 'hi, I'm a diabetic, if I look like this I  
 574 need to be eating this' (laughs), and I've seen the site as well, and it's huge, it's huge,  
 575 like 'oh crap!' (laughs) so there's also non-diabetic scary there too, just, like, big new  
 576 college and that.

577 I: Are Hannah and Charlie coming with you?

578 P: Charlie is, Hannah's not (...) so that's good. Having someone there who, um, who  
 579 knows me.

580 I: From a diabetes perspective or just in general?

581 P: Both, really.

582 I: Have you thought much about uni or, what, what it would be like if you were  
 583 going somewhere where you knew literally nobody? How would you think about  
 584 your diabetes then?

585 P: (...) I'm quite, (...) without trying to sound vain, I'm quite, I like to think I'm quite  
 586 easy to get along with. So I just don't mind being like 'hey, do you mind helping me a  
 587 bit?' (laughs) It's like, make myself, make them feel sorry for me, like 'yeah, you sit



588 there, while I do this.' (laughs) 'I need someone with me, I'm having a low' (laughs)  
 589 'if I die, it's gonna be on your conscience!' (laughs)  
 590 I: (laughs)  
 591 P: The amount of times I've been sitting in public, my mum hates it, 'cause I'm  
 592 usually with her when it happens, it'll be like 'mum, I'm having a low' 'right, you sit  
 593 on that bench, I'm gonna be in that shop' she'll come out and I'll be talking to  
 594 someone, and she'll be like, they'll go away, she'll be like 'Jessa, who was that?' 'no  
 595 bloody clue.' (laughs) It's like 'I've made a new friend!' (laughs) I'm not even joking,  
 596 'cause I was in town one time and some dude just kind of walked past and smiled at  
 597 me and I was like 'what?' and then my mum was like 'you don't remember him, do  
 598 you?' and I was like 'no!' she said, I 'do you remember about 6 months ago, you had a  
 599 low.' 'Oh dear, did, did I?' 'you just started talking to him out of the blue.' 'Oh.'  
 600 (laughs) It's like getting drunk, always a good story follows a hypo, and I've got a few  
 601 of them (laughs). That's what I don't get though, 'cause sometimes I'll be, like, I'll  
 602 have a low and it'll be like 'right, I'm shaking, I'm going to stop here, everyone else  
 603 can fend for me, like, I need food.' (laughs) But then, other times, I'll be like bouncing  
 604 off, and I can feel myself shaking, but I still have that energy there to move but I  
 605 know like [clicks fingers] it's gone, and then I'll be, like, worse than my worst low, if  
 606 that makes sense. Like, I, I literally, I can't move. I can't eat as well, I, I (sighs). But  
 607 my, my mum says the, the difference, she can tell because of my eyes and stuff. So  
 608 (...) as long as other people can tell, I'm good! The amount of times, yeah, I've been  
 609 told to check my bloods and I feel fine, I look and it's like, 3.2 or something and I'm  
 610 like 'Oh! Chocolate!' (laughs). 'Cause I remember in my primary school, like, literally,  
 611 on the induction day, this teacher's going to be doing this today, and they'll come on,  
 612 and they get through the day, and then they'll get the Jessa speech, like 'class, you  
 613 have a girl in your class, and she's a diabetic' and it's just (sigh) it's like 'don't touch  
 614 her box, you will die' (laughs). The thing is, they always did anyway, 'cause they saw,

615 like, the Chewee bars, not the needles inside. I'm not even joking, the school I'm  
 616 going to now, someone, 'cause it's in the (...) um, medical room, but it's not locked  
 617 away, and someone stole the Chewee bars from there. I was like 'what if I need it?' so  
 618 I told miss, and she was like 'oh don't worry love, I'll get you another one' and it's  
 619 like 'that's not the point!' And I (...) I actually started to get really worried, like 'oh  
 620 my god, what if someone is stupid enough to take my insulin, what if they did this?'  
 621 'cause it's, it's like, I feel rude, saying 'be stupid enough to do it' but someone who  
 622 didn't understand or something, I would feel so horrible, but then (...) I'd be like 'it's  
 623 your fault!' (...) But then, the teacher came in and she, she was like, it was quite  
 624 funny though, because she was the Head and she kind of looked at me, and she was  
 625 like 'have you told miss?' and I was like 'yeah' and she gave her such a dirty look and  
 626 I was like 'Oooh, beef.' (laughs) And she took my box out of my hands and was kind  
 627 of like on tip toes, put it on the highest one she possibly could (...). I feel bad, you  
 628 know, if, like, anyone took it. I've told my mates, like, it's fine for me, but you, you  
 629 can't touch it or you'll end up in a coma or dead but, but they don't believe me. I'm  
 630 like 'you wanna try it?' (laughs). They laugh at me like 'hahahaha, you're so funny'  
 631 but they, they don't understand, if you take an overdose of basal, it is, it's an  
 632 overdose. They think I'm joking, but I'm not. Because, like, obviously I keep some in  
 633 my bag and, joking around at school, people will take my bag and I'm like 'don't go  
 634 near my bag, because of what's in it. If you crack it, I'm screwed, if you take it, you're  
 635 screwed.'

636 I: It's true. I'm shocked that they, they don't keep it locked away.

637 P: I know (...) and I'm not even thinking about now, I'm thinking about in the future,  
 638 in the very, very late future, when I have kids and that, I need to always make sure  
 639 it's out of the way. Like, even when I don't have kids 'cause my sister's already got a  
 640 kid and has another on the way, and when she comes round I need, I need to make  
 641 sure everything's out of reach, 'cause if she had (sigh) I could, I could never, ever  
 642 forgive myself. Even though obviously I didn't do it, it would still be my fault for not

643 putting it away. I'd hate myself for it. I couldn't handle it, I really couldn't. But still,  
644 yeah (...)  
645 I: Yeah it's (...) a big responsibility for you. Um (...) I think that was all I had to ask  
646 you. Is there anything else, like, regarding your diabetes or things that are important  
647 to you in your support network that you'd like to say?  
648 P: (...) Not, not that I can think of.  
649 I: Alright, thank you very much

### Appendix P: Tests of assumptions for Study 1

**Tests of Normality**

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
HbA1c	.090	86	.080	.960	86	.009
TotalCD	.094	86	.056	.974	86	.085
TotalBSSS	.161	86	.000	.876	86	.000
TotalWHO	.105	86	.021	.962	86	.013
TotalSCIR	.117	86	.005	.971	86	.051
TotalDSSQ	.185	86	.000	.849	86	.000

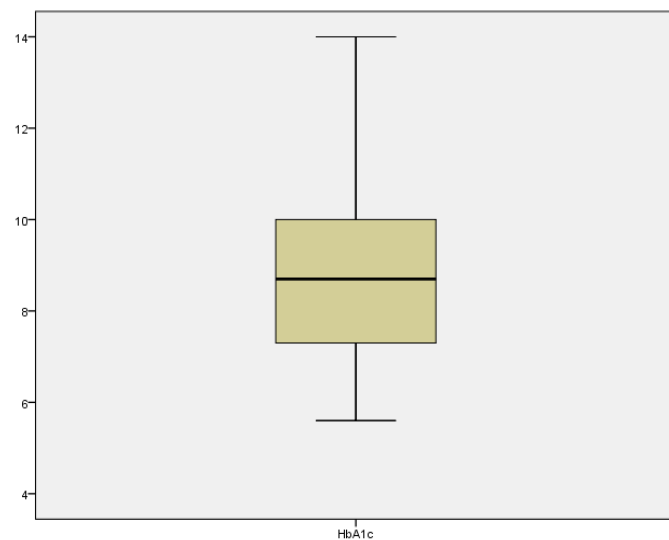
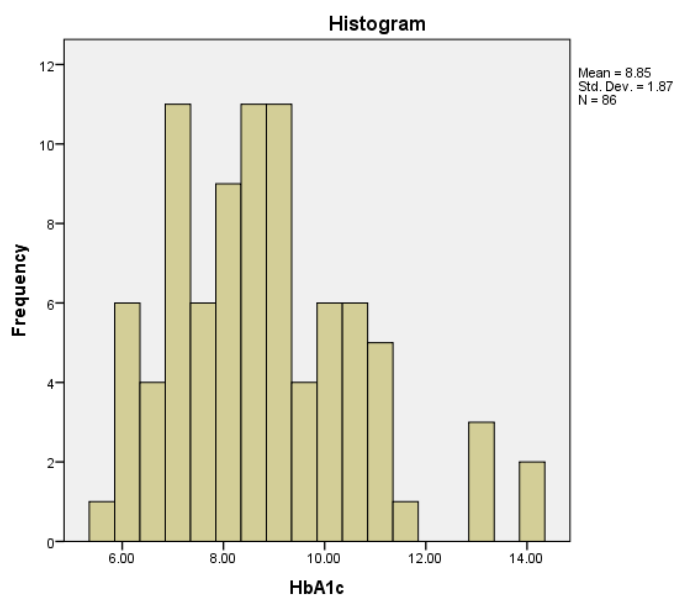
a. Lilliefors Significance Correction

**Tests of Normality**

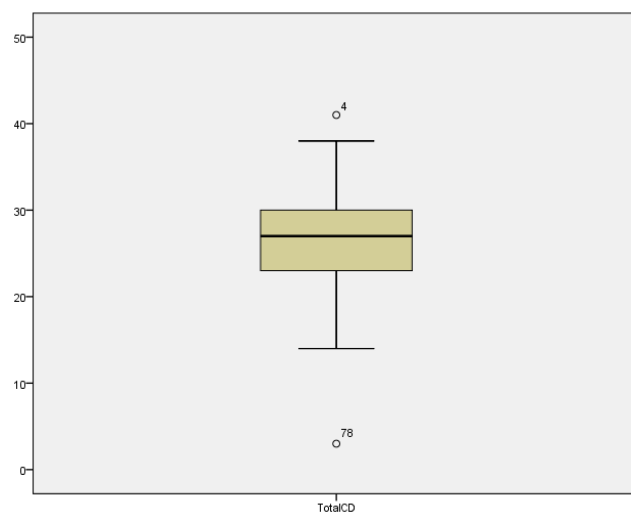
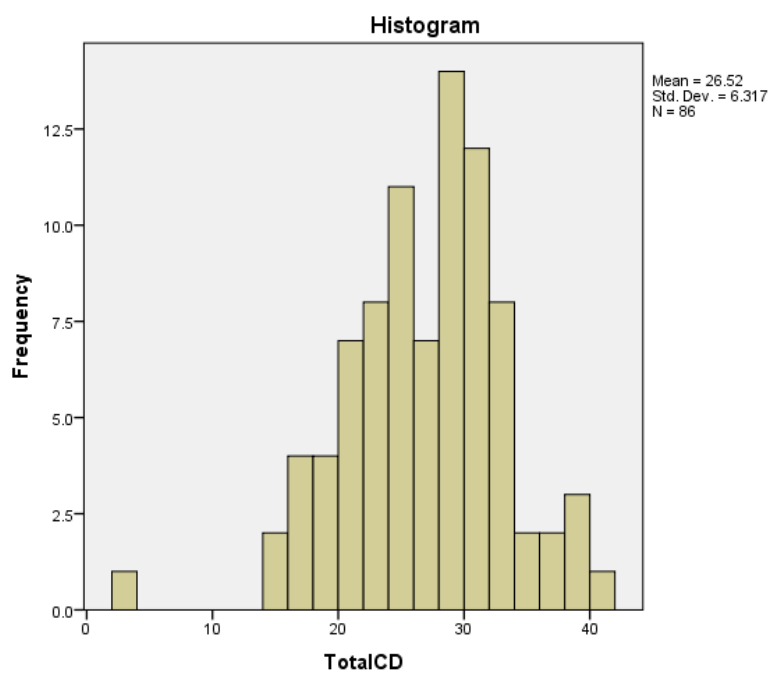
	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
TotalEmo	.188	90	.000	.770	90	.000
TotalInstru	.217	90	.000	.771	90	.000

a. Lilliefors Significance Correction

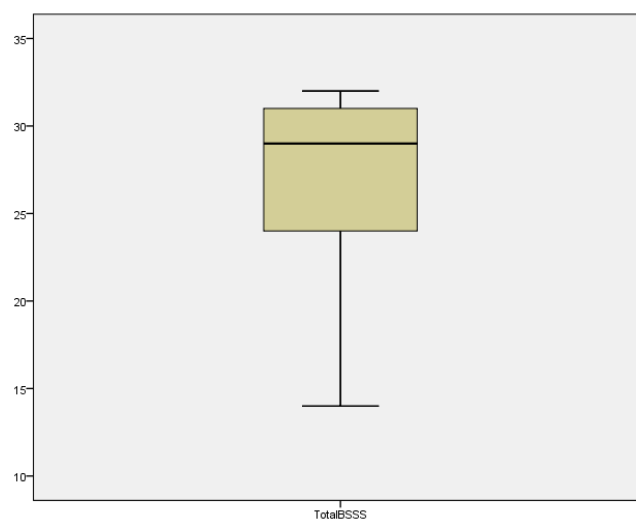
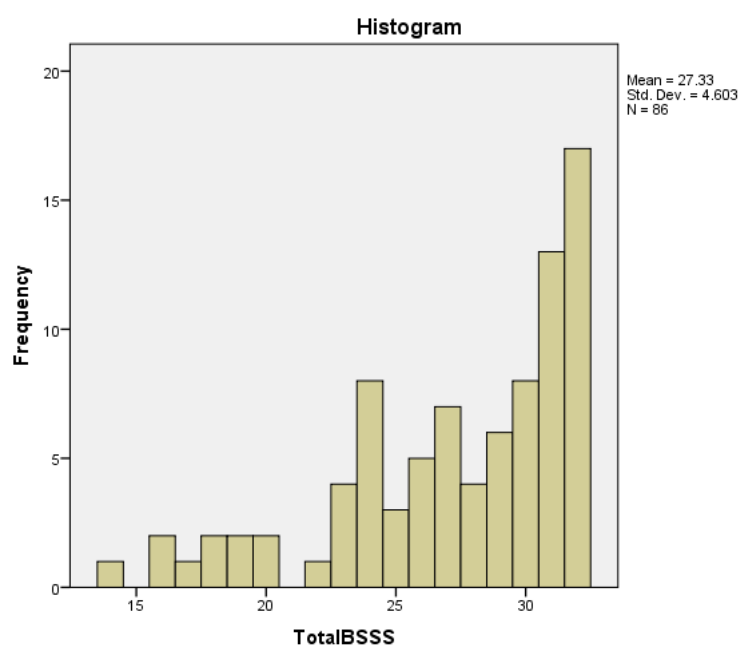
### Glycaemic control (HbA<sub>1c</sub>)



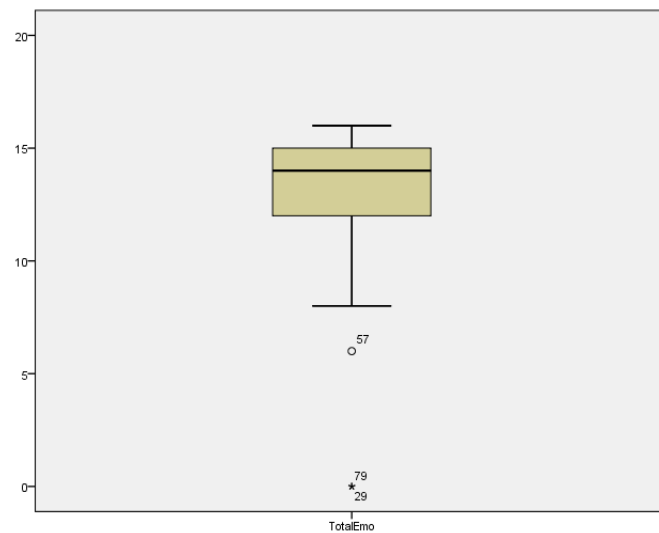
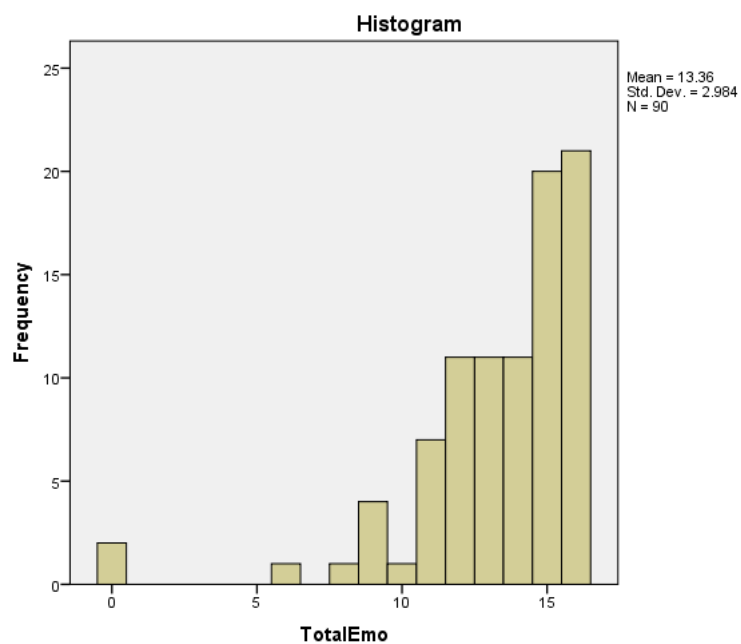
### Resilience (TotalCD)



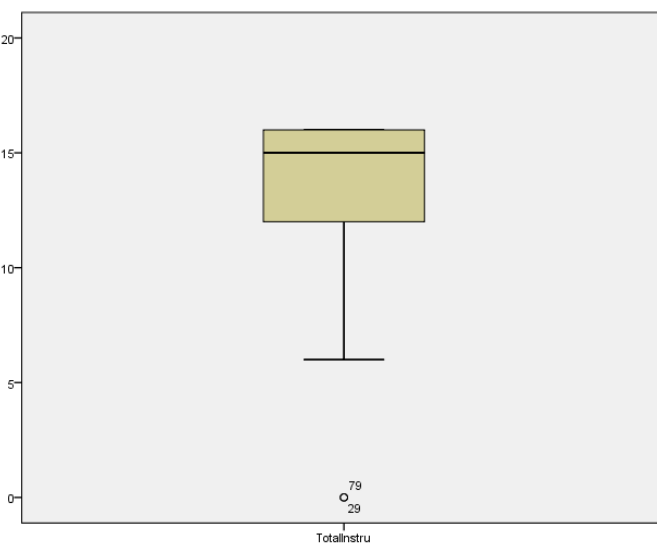
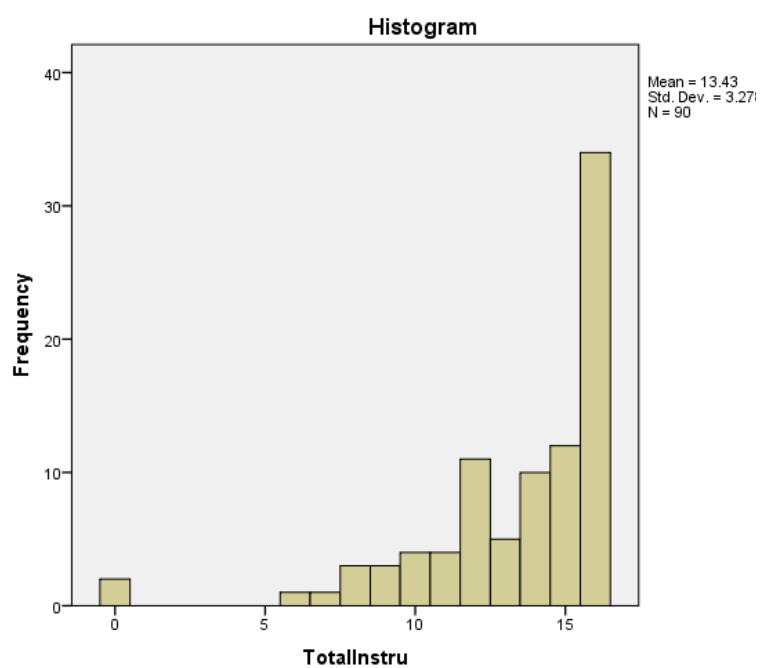
### Global peer support (TotalBSSS)



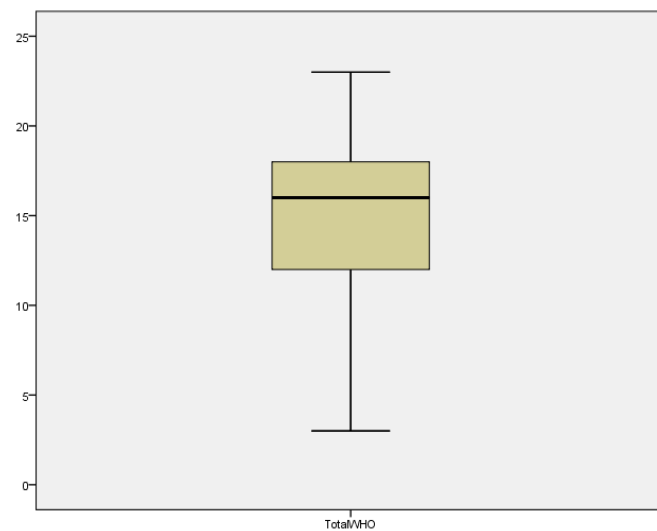
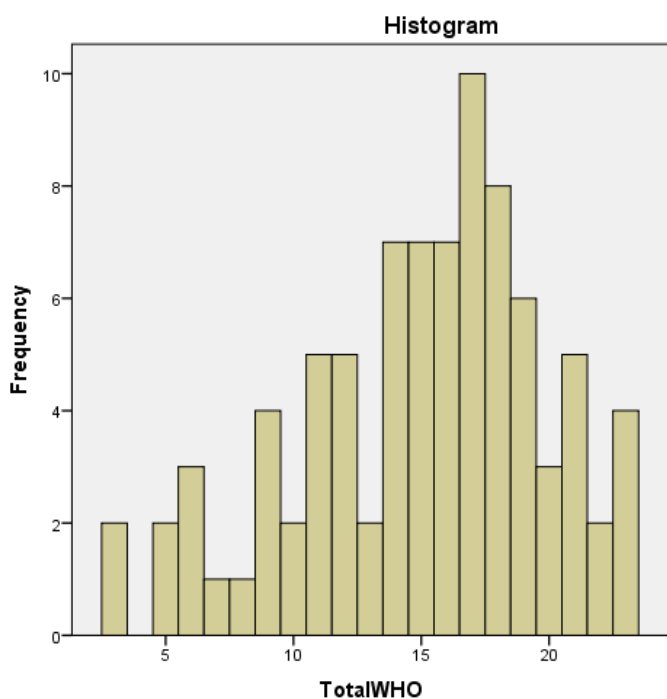
### Emotional peer support (TotalEmo)



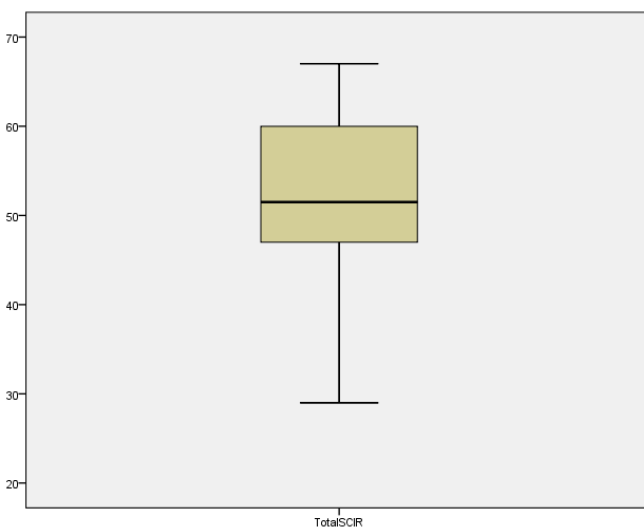
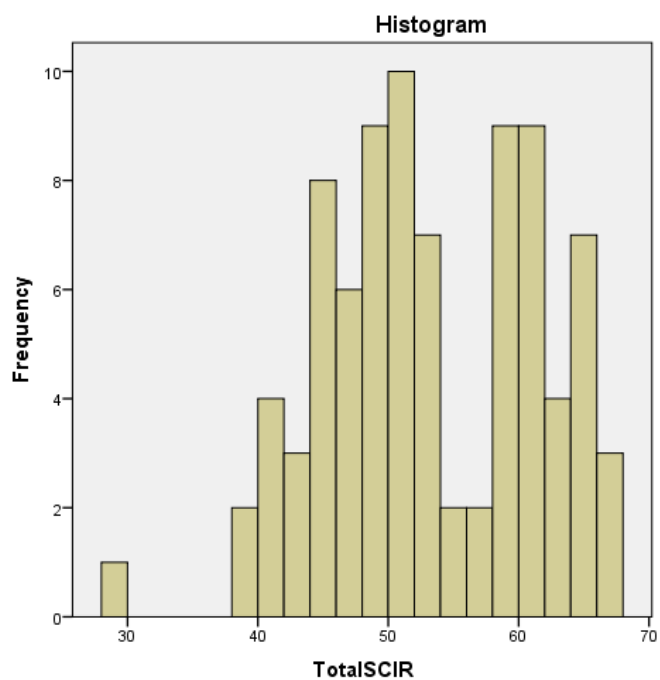
### Instrumental peer support (TotalInstru)



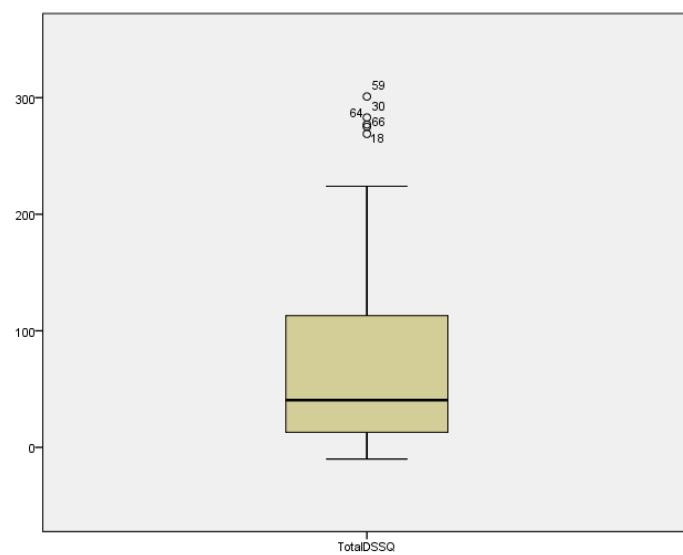
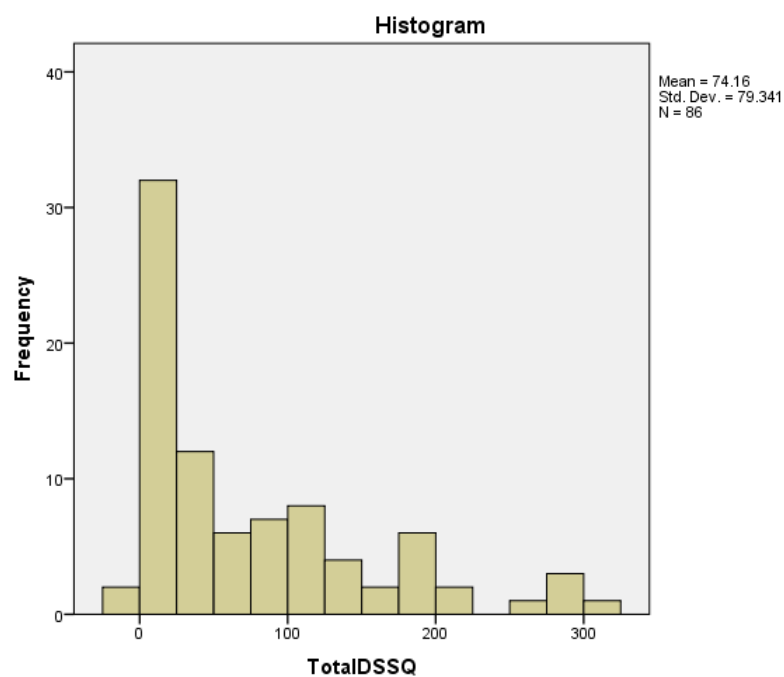
### Quality of life (TotalWHO)



### Self-care (TotalSCIR)



### Diabetes-specific support (TotalDSSQ)

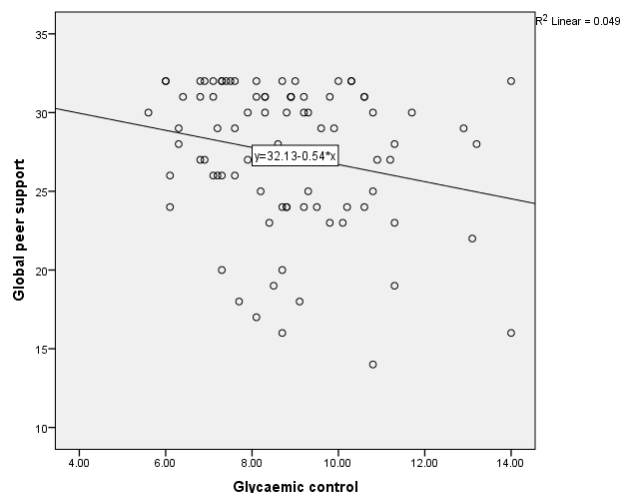
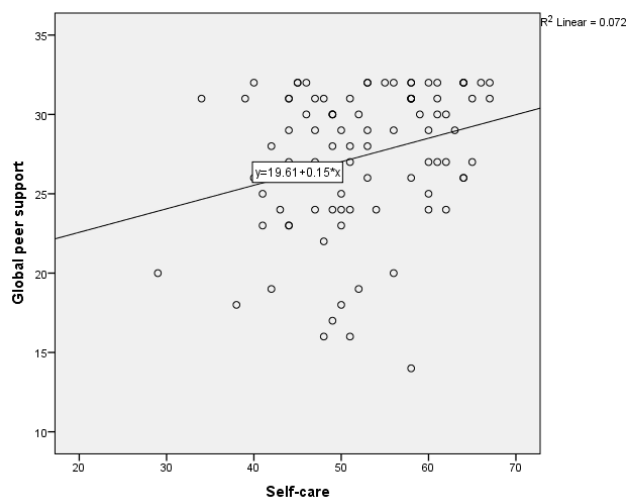




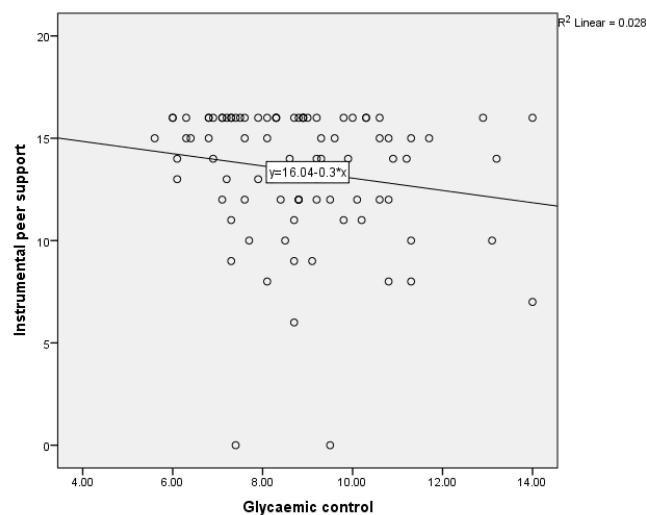
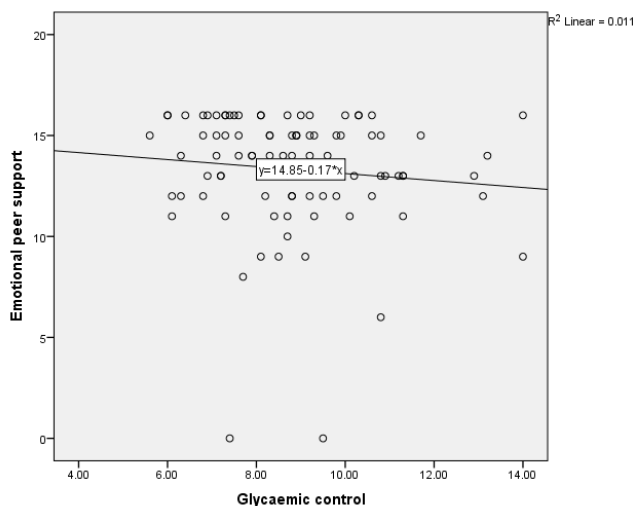
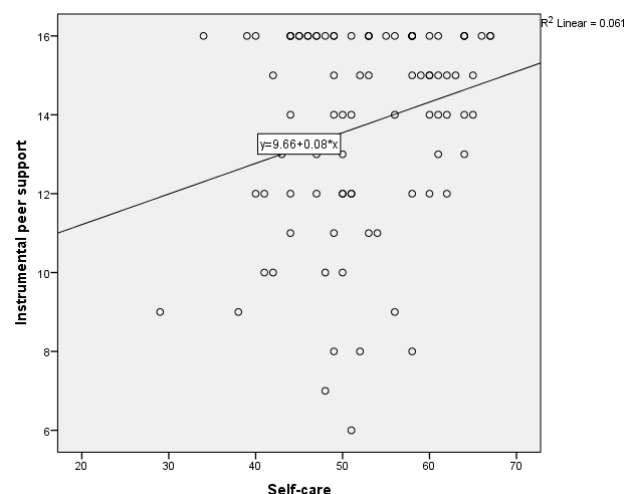
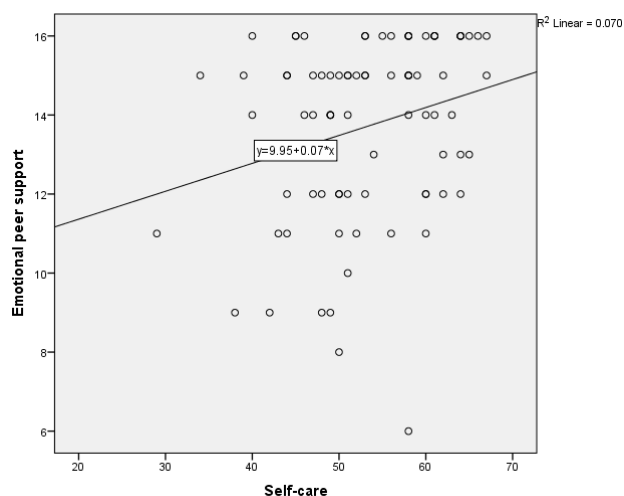
## Appendix Q: Plots for Study 1

### Hypothesis 1: Global peer support

iii. *Global peer support will be positively associated with self-care, but not glycaemic control.*

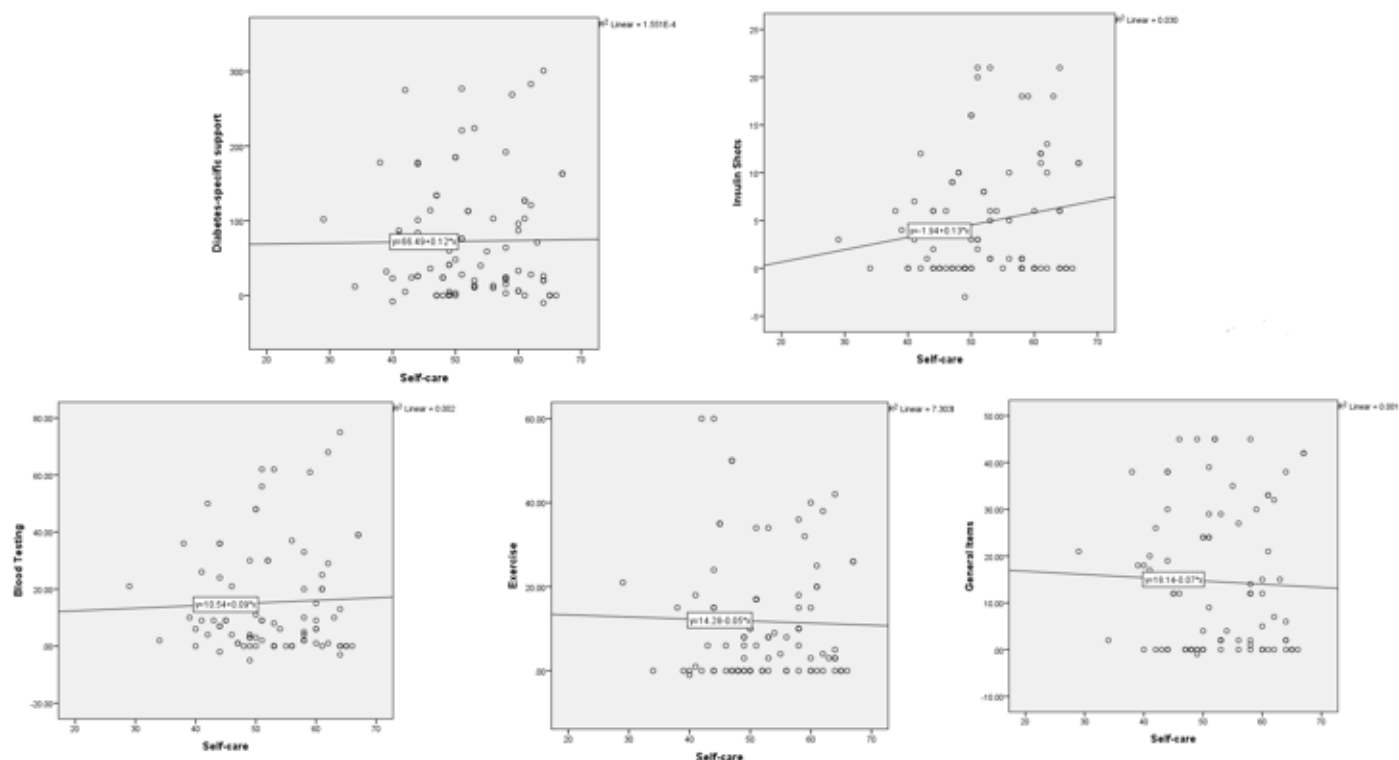


iv. *That emotional support will have a stronger relationship with self-care than instrumental support*

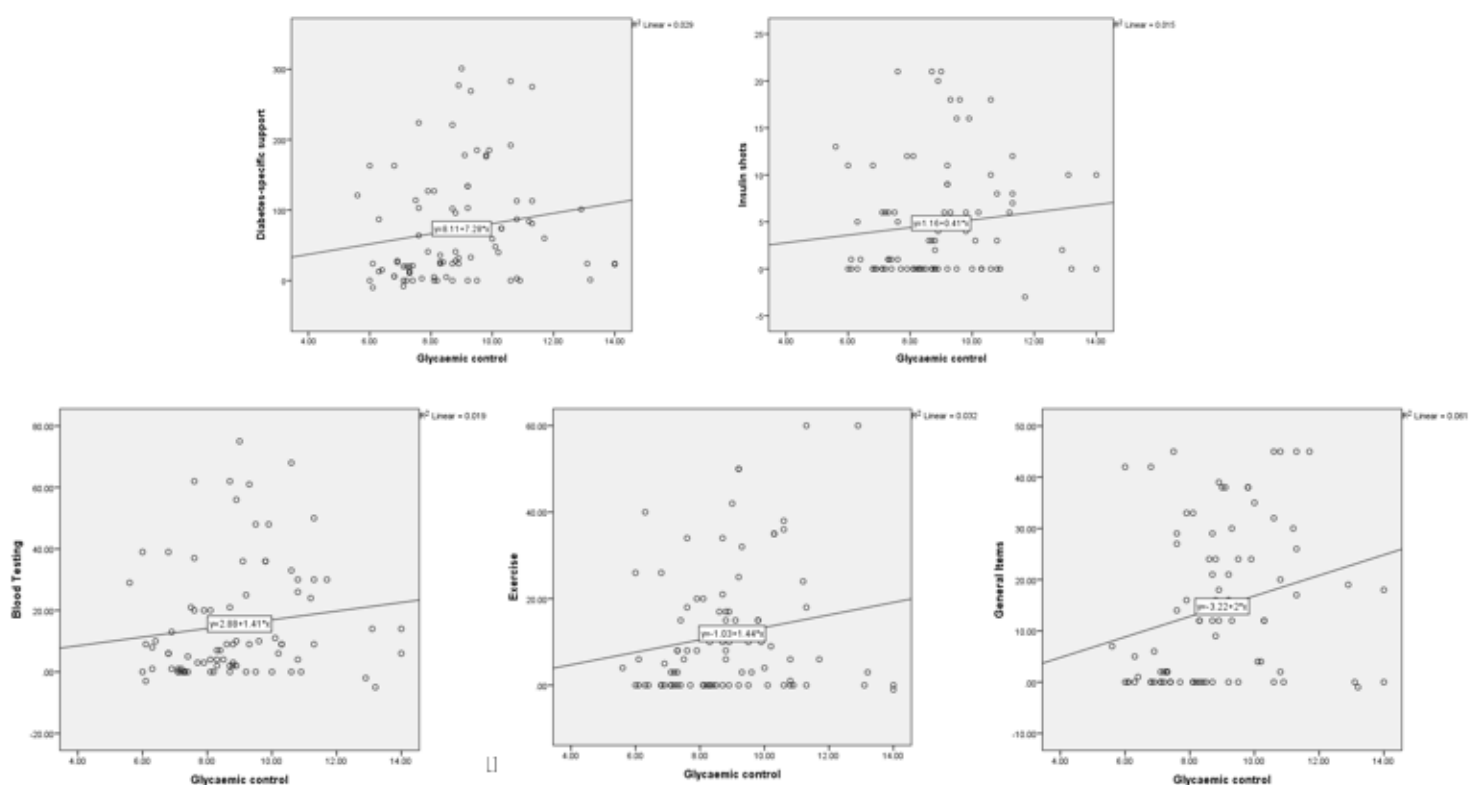


## Hypothesis 2: Diabetes-specific support

- iii. A relationship between diabetes-specific support and self-care will be found, though a direction cannot be determined from previous literature.

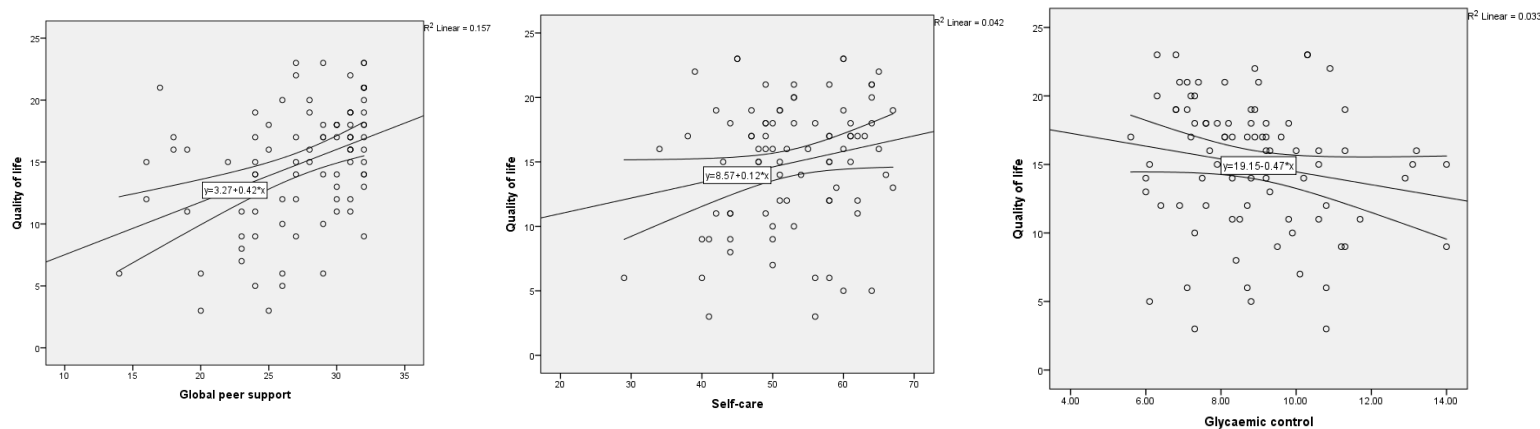


- iv. A relationship between diabetes-specific support and glycaemic control will be found, though a direction cannot be determined from previous literature.



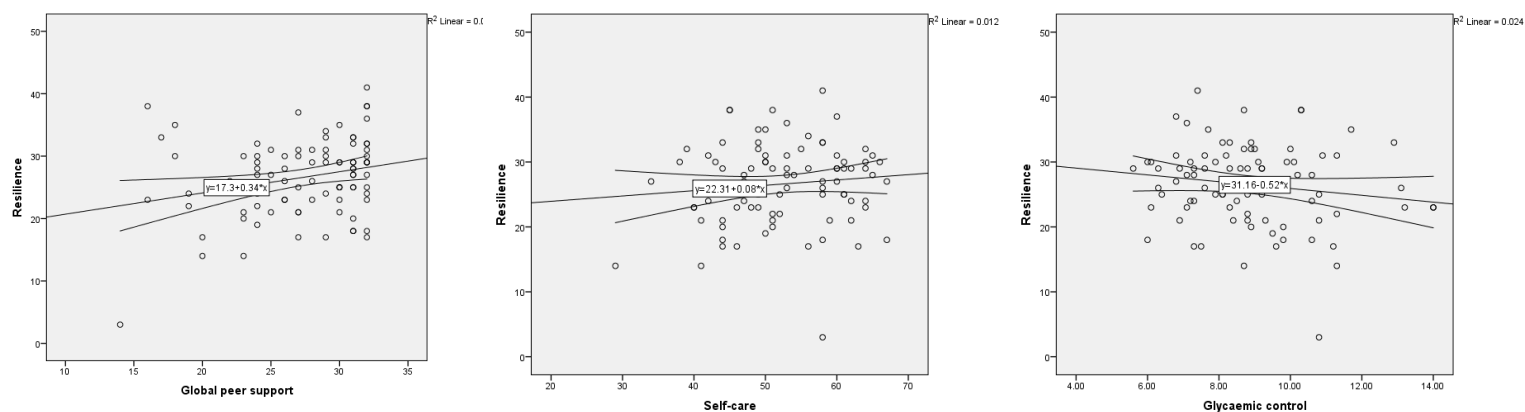
### Hypothesis 4: Quality of Life

*Quality of life mediates the relationship between social support and diabetes outcomes.*



### Hypothesis 5: Resilience

*Resilience mediates the relationship between social support and diabetes outcomes.*



**Appendix R: Master theme list**

Theme	Reference
A sense of normality	019817: 147; 019817: 200; 029507: 255; 019715: 103; 019715: 233; 029710: 631; 019811: 272; 019817: 242; 019817: 262; 019817: 268; 029507: 216; 029507: 649; 029507: 882; 029618: 25; 029618: 182; 029618: 238; 019517: 132; 029710: 96
Acceptance	019811: 452; 019817: 96; 029507: 41; 029507: 188; 029507: 701; 019715: 93 029710: 113; 029710: 222; 029710: 239; 029710: 490; 029710: 520; 029710: 556; 019823: 158; 029507: 405; 029507: 638; 029507: 863; 029618: 419; 019715: 240; 019715: 245; 029710: 664
Being different	019817: 166; 019817: 171; 019817: 175; 029507: 366; 029507: 377; 029507: 419; 029507: 427; 029507: 429; 029507: 438; 029507: 628; 029507: 632; 029507: 643; 029618: 172; 029618: 33; 029618: 233; 019715: 218; 019715: 299; 029710: 78; 029710: 514; 029710: 603; 029710: 644; 019811: 150; 019823: 77; 019823: 89; 019823: 97; 019823: 107; 019811: 162; 019811: 166; 019811: 185; 019811: 276; 019811: 301; 029507: 310; 029507: 613; 029507: 543; 029507: 788; 029507: 830; 029618: 10; 029618: 21; 029618: 263; 019715: 148; 019715: 156; 029507: 261; 019811: 207; 029507: 251; 029507: 267; 029507: 270; 029507: 568; 029507: 875; 029618: 226; 019715: 108; 019715: 349; 029710: 451
Burden	019823: 126; 019817: 246; 029507: 395; 029507: 461; 029507: 466; 029618: 363; 029618: 365; 019715: 259; 019715: 270; 029710: 311; 019823: 5; 019823: 24; 019717: 235; 029507: 8; 029507: 46; 029507: 201; 029507: 593; 029507: 603; 029507: 630; 029507: 610; 029507: 640; 029507: 758; 029710: 20; 029507: 165; 029618: 280
Denial	029507: 38; 029507: 177; 029507: 663; 029618: 12; 029618: 118; 029618: 138; 029618: 354; 029710: 136; 029710: 421
Distrust of the clinic	019823: 181; 029507: 90; 029507: 94; 029507: 107; 029507: 284; 029507: 290; 029618: 386; 029618: 393; 029618: 402; 019715: 288
Independence	019823: 16; 019823: 33; 019811: 12; 029507: 719; 029618: 62; 029618: 204; 019715: 8; 019715: 16; 019715: 95; 019715: 309; 019823: 40; 019817: 108; 019817: 280; 029507: 400; 029507: 666; 029618: 41; 029618: 217; 029710: 70; 029710: 70; 029710: 672
In-group	019823: 83; 019811: 104; 019811: 168; 019811: 181; 019817: 76; 019817: 80; 019817: 142; 019817: 215; 029507: 792; 029507: 818; 029618: 21; 029710: 48; 029710: 532; 029710: 552; 029710: 577
Lack of understanding	019817: 134; 019823: 135; 019811: 177; 019811: 260; 019817: 125; 029507: 698; 029507: 816; 019715: 110; 019715: 117; 019715: 125; 029710: 200; 029710: 227; 029710: 248; 029710: 653; 029710: 662
Nagging	019823: 126; 019811: 212; 029507: 14; 029507: 194; 029507: 209; 029507: 219; 029507: 229; 029507: 233; 029507: 572; 029507: 623; 029618: 47; 029618: 65; 029618: 71; 029618: 129; 029618: 196; 029618: 249; 029618: 254; 019715: 29; 019715: 185; 029710: 54; 029710: 279
Negotiation	019823: 142; 029507: 196; 029507: 350; 029507: 392; 029507: 410; 029507: 668; 029618: 91; 029618: 105; 019715: 49; 029710: 77; 029710: 305; 019823: 12; 019823: 51; 019823: 113; 029507: 356; 029507: 412; 029710: 298; 019811: 56; 029507: 416; 029618: 99; 029618: 114; 029710: 66; 029710: 495
Safety net	019823: 132; 019811: 280 ; 019817: 114; 019817: 126; 029507: 582; 029618: 413; 019715: 141; 019715: 352; 029710: 183; 029507: 504; 029507: 519; 029507: 523; 029710: 409; 029710: 417; 029710: 598; 029710: 437

Support	019817: 182; 029507: 452; 029507: 472; 019715: 166; 019715: 179; 019823: 24; 019823: 65; 019823: 78; 019817: 5; 019817: 14; 019817: 65; 019817: 69; 019817: 152; 019817: 157; 019817: 207; 019817: 214; 019817: 224; 029507: 157; 029507: 212; 029507: 225; 029507: 315; 029507: 259; 029507: 370; 029507: 384; 029507: 575; 029507: 725; 029507: 746; 029507: 752; 029507: 770; 029507: 781; 029618: 155; 029618: 380; 029618: 406; 019715: 91; 019517: 280; 019715: 247; 029710: 9; 029710: 124; 029710: 149; 029710: 160; 029710: 173; 029710: 200; 029710: 289
Transition	029507: 811; 029507: 840; 019715: 316

### Appendix S: Themes and corresponding quotes

Theme	Reference	Quote
A sense of normality	019817: 147	Do my bloods, like, and people crowd round me, guessing what I'm gonna be.
A sense of normality	019817: 200	...when I was on injections my friends used to just sit there and hit me until, we, like he'd start 5 minutes before the end of the lesson, just so I'd do it [inject].
A sense of normality	029507: 255	So there's, like, quite a lot of humour to it, and things like that.
A sense of normality	019715: 103	...I have the constant jokes about it, but I don't really mind...The usual joke is 'Oh, Andrew's doing his heroin' and stuff like that...
A sense of normality	019715: 233	...I think the best thing they [friends] do is that they joke about it. I do like it, because it makes everything (...) Just a bit of a joke and a bit of, a bit more funny, because some fays with diabetes it's just negatives, and there's never really positives.
A sense of normality	029710: 631	It's like getting drunk, always a good story follows a hypo, and I've got a few of them (laughs).
A sense of normality	019811: 272	It's stopped being an issue. No one really asks about it, that much.
A sense of normality	019817: 242	...try to fit me in with what they were eating, what they were doing...
A sense of normality	019817: 262	...try to fit her in with what you're doing. That helps a lot. And like don't eat things, like sweets and chocolate and stuff, in front of her, 'cause that would make her feel...like, not fit in...
A sense of normality	019817: 268	Yeah, being like a (...) normal teenager, doing what your friends do.
A sense of normality	029507: 216	But my friends, they just (...) were there (...) if I, um, needed to talk or just not be the girl with diabetes for a bit.
A sense of normality	029507: 649	I don't really want to advertise 'I'm diabetic! Please make sure that I'm ok!' all the time...It's just nice to be (...) normal sometimes, to try to forget about it.
A sense of normality	029507: 882	...not the girl who's got diabetes (...) the girl who's got the label on.
A sense of normality	029618: 25	...you don't feel like you're on your own. You're not weird, everyone kind of, makes you feel like everyone...
A sense of normality	029618: 182	...they [family] never say 'well you can't have that, you can't do that' and they've never, kind of, singled me out from the others because of it...They, they always try to make me feel the same as everyone else. I, I know deep down I'm not, but (...) they try to make me feel like I am. It doesn't work but...
A sense of normality	029618: 238	...you don't want to go off every lunchtime and do something, you want to sit with your friends and chill...I still don't test, I don't think I'll ever test in school, ever. I never have.
A sense of normality	019517: 132	...they [friends] ask you about it, which gets a bit repetitive, and it really does annoy me, but when they get to know you, it's not a problem anymore. It's just (...) something that's there. Something that they don't care about, and don't ask about any more.
A sense of normality	029710: 96	I don't feel, like, singled out or anything. I feel (...) I know it sounds really silly, and kind of stupid in a way, but I forget I'm a diabetic half the time! (laughs)...I feel normal. I guess that's a good thing.

Acceptance	019811: 452	I've just (...) grown up with it.
Acceptance	019817: 96	I suppose I don't know any different...That's the one advantage of having had it all your life.
Acceptance	029507: 41	...you've got it, you just have to deal with it....we'll just control it, and not let it control you.
Acceptance	029507: 188	...yeah, it sucks but (...) you've just got to deal with it, haven't you? It's not going to go anywhere.
Acceptance	029507: 701	I really do hate having it, but you've got to accept it, haven't you?
Acceptance	019715: 93	...it's something I'm going to have forever, something I've just got to cope with...
Acceptance	029710: 113	...it's something I have no choice of, I need to do it...
Acceptance	029710: 222	...I do, kind of, milk it just a tad bit, but then I think 'I have to inject myself 4 times a day for the rest of my life, so I'm gonna milk it!' (laughs)
Acceptance	029710: 239	Yeah (...) just, kind of, cope with it. If anyone has a problem with me and my diabetes, I kind of just stick two fingers up at them and be like 'cool mate.'
Acceptance	029710: 490	'Cause, I don't know, it's just (...) without, I forget about it, but at the same time I know it's there, if that makes sense. I only remember, it only, like, comes into my mind when I need to do something with me diabetes. 'Cause obviously, it's not constant, it's only when you eat or when you, you're feeling low, or high, or whatever. It's like, any other time, it's like (...) normal. Normal, normal, you need to inject yourself, normal, normal, eat.
Acceptance	029710: 520	...make it seem like it's (...) normal. Just part of life. That's what I try and do.
Acceptance	029710: 556	I blame my weirdness on my diabetes quite a lot (...) I'm pretty sure it's just natural, but we'll go with the diabetes (laughs)...It's like (...) if I've got it, I may as well use it.
Acceptance	019823: 158	I don't know. It just (...) affected how they were (...) made it real.
Acceptance	029507: 405	...now, I can't [eat sugary foods] (...) and then I felt (...) so ill afterwards. I mean, this was at the stage where (...) my eyesight was so bad... 'cause it was blurry all the time...And it would just get worse, and I'd feel really sick...
Acceptance	029507: 638	What if something does happen? What am I going to do? Who are they going to call?
Acceptance	029507: 863	...[talking to friends about diabetes] kind of makes it seem more serious, in a sense, that this is really, really serious and you have to take this really seriously and you can't joke about it at all...
Acceptance	029618: 419	...they're your friends, it's kind of all a joke, and all a bit of fun, and silly, and sometimes it's really hard to have a serious conversation with your friends.
Acceptance	019715: 240	...if you get into the nitty-gritty with your friends, it's not fun. You don't want to scare them.
Acceptance	019715: 245	...this is actually serious stuff and that (...) if I don't look after myself properly, I could really shoot myself in the foot for the rest of my life (...) it's not fun stuff. It's not stuff you want to bring up and bum everyone out.
Acceptance	029710: 664	They laugh at me like 'hahahaha, you're so funny' but they, they don't understand, if you take an overdose of basal, it is, it's an overdose. They think I'm joking, but I'm not.
Being different	019817: 166	...when it's friends are eating stuff that I can't have, or whatever...
Being different	019817: 171	...if we won this teat the teacher would buy us a box of chocolates and it's just like 'er, that's alright, just leave me

		out!' You know? Like, rewards everyone else, but not me. Fine.
Being different	019817: 175	I just sit there and watch them eat (...) (laughs) hate them a little bit.
Being different	029507: 366	...he'll [brother] literally have like 5 packets of Jaffa Cakes, and, like, a massive slab of cake and, like, half a tub of ice cream. I mean, I, I feel a bit like 'why can't I do that now?'
Being different	029507: 377	He'd [brother] get a Jaffa Cake and he'd be like 'mmm, this is delicious!'...And I'd be like 'you're going to die later.'
Being different	029507: 419	When they [friends] used to bring in a massive box of cakes and things like that, they would just look at me, and obviously I can't have any, and they'd be like 'we'll bring you a pack of carrots next time' and although they meant it well, I didn't feel any better because of it...
Being different	029507: 427	Like, it's never going to be as nice to sit down with a carrot as it is a cake, you know?
Being different	029507: 429	...don't bring me a substitute, just don't even let me know it's [eating cakes] happening. It's just (...) not rubbing it in...it's bad enough when you can't have it, but to have everyone eating it in front of you, that, that's (...) it's like (sigh).
Being different	029507: 438	I'd rather just avoid it [temptation to eat sugary foods] 'cause I think, like, my self will, I don't think is as strong (...) as I think it is, sometimes.
Being different	029507: 628	I think I get nagged more than Joseph [brother] ever did.
Being different	029507: 632	...I do feel sometimes like I just wanna (...) like, go out with my friends and she'll [mum] still phone me and text me 'are you ok? When are you coming back? (...) So, sometimes it does feel tempting to just turn off the phone and (...) get away from it all.
Being different	029507: 643	Like, if I meet someone new (...) I won't tell them I'm diabetic...I don't like it. I don't want them to think of me as 'Claire the diabetic' (...) or 'that girl with diabetes.'
Being different	029618: 172	I've never felt 100% well, unless my blood sugars are completely controlled...when you just feel crap all of the time, just can't be bothered.
Being different	029618: 33	I don't think there is any way you can feel normal with it. I don't anyway, I never have...
Being different	029618: 233	...I don't want people looking at me, like 'why are you doing that?' Like, I know that people should know that you have it [diabetes], to help you, if something went wrong, but I don't want them knowing. Looking at me, looking at you like you're different.
Being different	019715: 218	...with sport, it's a lot harder not to talk about diabetes, because it's always, they're always making notes like 'oh, why are you doing this? Why are you doing that?' But it hasn't been the case where I've had to keep monitoring myself or anything like that, so it's been kind of low-key, and they haven't really noticed, so it's been OK.
Being different	019715: 299	...when you're actually diagnosed, it's just the worst thing ever, and you don't have a clue what's going on unless you've got somebody you know who's got diabetes, but then, it's just awful really. You don't know what to do.
Being different	029710: 78	The amount of times they'd be sat there with like, their sugary donut or something chocolatey, and I'm sitting there with a banana or something (...) 'it's good for you Jessa, it's good for you!' (...) and I'd be like, 'yeah right, I'd



		rather be having what you're having!'
Being different	029710: 514	...and then it all changes [once friends are aware of diagnosis]. Constantly they give you the sympathetic look on their face, and it's like 'stop it!'
Being different	029710: 603	...it's just that whole thing about going to a new place all over again with new people, and having that conversation, like 'hi, I'm a diabetic, if I look like this I need to be eating this' (laughs)
Being different	029710: 644	...and then they'll get the Jessa speech, like 'class, you have a girl in your class, and she's a diabetic' and it's just (sigh)
Being different	019811: 150	Just not like (...) doing it in front of people, and stuff.
Being different	019823: 77	I mainly just try to keep to myself, because I'm not really a friendly person...
Being different	019823: 89	...I don't think it's anything to do with them, it's just because I don't really talk about my diabetes much, I don't really seem to let it affect me as much. So I think they kind of forget that I have it...
Being different	019823: 97	They don't completely ignore me, and object to me (...) it's just that I don't talk about my diabetes much.
Being different	019823: 107	...I test in private, like in the toilets or something. With the pump I can be much more (...) discrete. That's why I like it.
Being different	019811: 162	...with the pump they don't see it. I just sort myself out. But (...) when I was injecting it was more difficult to keep private.
Being different	019811: 166	...it's not anyone else's business, really.
Being different	019811: 185	Different (...) that's why I don't talk about it. That's why I like the pump.
Being different	019811: 276	...they know to give me food [in the event of hypoglycaemia]...I don't think they need to know much else.
Being different	019811: 301	Just don't, really (...) they don't need to know.
Being different	029507: 310	...really upset or depressed about it for some reason...I don't feel well, then I don't like explaining why to people.
Being different	029507: 613	It's difficult to have my own space, you know? ...I have to go with her [mum] everywhere.
Being different	029507: 543	Like, if I'm really, really stressed, I won't tell them, which I suppose is not a good thing to go through, really...I try not to talk about things like that with them.
Being different	029507: 788	...if we've just come back from hospital, don't even ask. Never ask what's happened at hospital, cause we don't wanna tell you.
Being different	029507: 830	...I don't advertise it to people, but they don't advertise at all either.
Being different	029618: 10	...we [family] don't really talk about it [diabetes management], it's not like a conversation we have.
Being different	029618: 21	I just keep it myself, get on with it. I don't really like talking to other people about stuff.
Being different	029618: 263	...they can see that I've gone white and sweaty, but in front of everyone, they're like 'are you ok?' and I'm like 'oh yeah, make everyone look at me why don't you?'
Being different	019715: 148	...I would rather risk it than tell people, tell them all this stuff and (...) It might frighten them off a bit, I don't know.

Being different	019715: 156	...when they talk to other people about it, and I don't like that. Because it's like somebody is talking about you, and the fact that you haven't been well or whatever, and I guess it's just been people being unaware.
Being different	029507: 261	...people stare at you if you're in the common room and you take it [insulin], which is not a nice feeling.
Being different	019811: 207	...when people stare when you inject and that (...) tell you what you should be doing.
Being different	029507: 251	People turn around and look at you like (gasps)
Being different	029507: 267	...like they're thinking 'that doesn't look right, that looks a bit fishy and suspicious.' It's a bit (...) weird.
Being different	029507: 270	...you're an adult, like, why is my diabetes that interesting? Go on with your meal, like, leave me alone, you know?
Being different	029507: 568	...they'll try and watch me inject and I'll feel a bit uncomfortable when they do that...
Being different	029507: 875	...they see me as a disabled, ill person all the time, rather than as their friend...
Being different	029618: 226	...I didn't like it [testing at school], because people look at you. It was like 'piss off.' So (...) it was really, really embarrassing at school. So I just, I never, I still don't test at school.
Being different	019715: 108	Take my blood sugar, and the beeps and stuff, and the stares from them [classmates]...
Being different	019715: 349	...the sly comments from people who don't have a clue what, what it's about.
Being different	029710: 451	...I don't know if they say stuff like that about me when I have to go outside [during exams], or whatever. And, I know it's different, but (...) I don't know if they know. I shouldn't let it get to me.
Burden	019823: 126	It's good that they're there and do worry about some things, but I don't want them to over worry about anything...
Burden	019817: 246	...I'd be alright, like, I wouldn't have to rely on my mum being there or worry while I was watching the movie. Just to (...) still be on, like, standby in case something did happen, so she wouldn't have to...Make sure that she could just drive off. I'd like to be alright with friends' 'cause they knew that.
Burden	029507: 395	So, we've kind of tailored dinners and things round me now really, which I suppose isn't fair on Joseph.
Burden	029507: 461	I mean, they are aware of it all the time and things, and they do know [eating late at night is problematic for diabetes management], but I never say anything. I don't want to create problems, I don't want to ruin the evening by being like 'we should have done this earlier, it's too late now' kind of thing.
Burden	029507: 466	...they're my friends and I, I (...) don't want to rock the boat. It's bad enough that I have to spend every waking minute worrying about it, it's not fair to have them expecting to do that too.
Burden	029618: 363	I can't talk to my parents, because then they think something is wrong, and they'll be 'oh my God, is she ok?'
Burden	029618: 365	I don't want people to worry about me, that's what I think anyway. If I told someone I was struggling, or didn't like something, in my mind they're going to worry, and I don't want that.
Burden	019715: 259	I don't want to see anybody else have it, um, because I know how hard it is to treat, and obviously, I've had it OK, my HbA <sub>1c</sub> has been great (...) but to see somebody else get it that I know would be devastating, and I don't, I don't even know what would do at all.
Burden	019715: 270	I don't think you could ask it of them really [friends provide support], in my opinion.

Burden	029710: 311	But I don't want to be demanding, you know? It's not their fault I'm diabetic, is it? If they want to eat, it's like, if anything I'll walk away if it's one of them days. I'd rather just go stand by myself for a while, till the chocolate's gone, rather than ask them to put it away.
Burden	019823: 5	...they can adjust the basal rate on my insulin pump.
Burden	019823: 24	I prefer it, having some help. Right now anyway.
Burden	019717: 235	'Cause I know I would [ignore self-care] if there was no one to give me a push.
Burden	029507: 8	My mum is, um, the important one really...
Burden	029507: 46	She never really leaves my side, she's like my best buddy really, when it comes to that [diabetes management]
Burden	029507: 201	...but it's like, I'm 18, you know? (...) I don't know anyone else my age who has their mum still worrying about this kind of stuff. It can be (...) a bit (...) um, embarrassing at times, and like (...) frustrating. I can't just do something (...) on my own, when I want to. I have to check I have everything and that mum can come too, or whatever.
Burden	029507: 593	...it's just mainly mum, really, who does the practical stuff. That's why I always say, I'm never leaving my mum, she's not getting rid of me!
Burden	029507: 603	...you need the, kind of, like, the all-day support, kind of thing, which (...) I don't like the sound of really, that you're always reliant on someone else. I don't like the idea that I can't by myself go out, really.
Burden	029507: 630	I'm 18. I'm an adult (...) but I'm still reliant on mum.
Burden	029507: 610	...it does feel really restricting sometimes that you always need someone with you, which I don't like.
Burden	029507: 640	...I don't like to draw to the fact (...) that I need constant support and help (...) 'cause it's, it's just (...) it's almost in a sense embarrassing...
Burden	029507: 758	I don't know what I'd do without her, really. If I didn't have my mum, I probably think I'd be back in hospital again, really (...) 'cause I couldn't cope by myself with it.
Burden	029710: 20	I'd prefer (...) it to be, like, by myself, but I know if it was, my control wouldn't be anywhere near as good as it is. And it's not even that like, it could be improved quite a lot, like, now so (...)
Burden	029507: 165	...it's [diabetes] affected them far more than it's affected me, in a sense.
Burden	029618: 280	...she's [friend] been there since I was really bad, so I don't want to push her out, say 'I'm fine, I don't need you.' You don't want that, do you? ...I don't want her to think that I'm not grateful of how, how she's helped and stuff, but it's really hard.
Denial	029507: 38	...when I first got it, obviously you go in to like massive denial, like (...) I don't want to have this anymore!
Denial	029507: 177	It took me about 3 years to get over (...) the denial (...) of it.
Denial	029507: 663	I wish all the time that I didn't have it.
Denial	029618: 12	I just like to forget about it. Just get on with it, not think about it. I don't know.
Denial	029618: 118	You just don't listen [to advice], I didn't want to, I don't like it. It doesn't help...I went through, like, four months

		not doing one blood test...I just hate it, I don't want to. I think sometimes you think 'if I don't do it, I can forget about it' but you don't, and it doesn't help.
Denial	029618: 138	I don't look into the future, I see here and now, today. Like, there's nothing {wrong} with me now, I'm perfectly fine, like, what's, what's the problem?...the nurses, they'll say 'you'll end up in hospital soon, the way you're going' but (...) it'll come to that when it comes, you know? It doesn't, it's not happening now, is it?
Denial	029618: 354	Not talking about it. I think if they always went on about it, and wanted to talk about it, I couldn't cope with that (...) No.
Denial	029710: 136	I do have them days where I'm like 'I don't need to do bloods, I don't need to do this, I'll just do it later, I don't need to do that.' ...there are days when I'm just like 'I don't want to eat, I don't want to do this, I just want to stay in bed, and sleep and chill, why, why do I have to get up and do stuff?' ... it's like you have them days but you know you'll get over it eventually.
Denial	029710: 421	I've had it for such a long time, I'm just like, it's not as a blinker in your head, going 'you need to do this, you need to do this.' So I don't feel like I need to do it until an hour later, when I should have done my insulin, and I'm sitting there going 'why am I feeling so weird for?' It's like 'oh, yeah.'
Distrust of the clinic	019823: 181	...I just think that some doctors don't understand the emotional side of diabetes as well as actually controlling it.
Distrust of the clinic	029507: 90	...I think the best way is that we sort it out, 'cause we know (...) what my body would be best for, really.
Distrust of the clinic	029507: 94	...sometimes they don't really, um (...) know the right thing to do....
Distrust of the clinic	029507: 107	...we're not listening to them, we'll just go back (...) to how we thought it was best...
Distrust of the clinic	029507: 284	...we go to the hospital all the time and it's 'bring it down, take more insulin' which I hate the sound of. I don't like the idea of injecting something foreign into my body...
Distrust of the clinic	029507: 290	There are side effects for everything, but they [healthcare professionals] never tell you.
Distrust of the clinic	029618: 386	...the others [nurses] are kind of patronising I think, like, I'm 17 years old, I don't need to talk to me like a kid, you know? I know some of the stuff, like, I've probably done, if kind of a bit immature and stuff, but she talks to you how you want to be spoken to, you know what I mean?
Distrust of the clinic	029618: 393	...some of the nurses (...) 'So how's she coping with it?' and it's like 'I'm right here! Ask me!'
Distrust of the clinic	029618: 402	...the nurses haven't done that so why would I ask them?
Distrust of the clinic	019715: 288	...I think if people can speak to others and not have to speak to the nurses about different things just to get ideas and get opinions of things...
Independence	019823: 16	...it means I can go to more, more places, do more stuff, eat more food.
Independence	019823: 33	...the insulin pump, it gives me freedom...
Independence	019811: 12	...I, kind of, take Independence over that...because it's my thing, I guess. It's like (...) I'm not a kid or nothing and (...) I just can take care of it, so I do (...) really.
Independence	029507: 719	...that makes me feel really, really nice and positive about it 'cause it shows I can manage it, I can look after it.

Independence	029618: 62	...I've always made it myself, since I was diagnosed. I always did my blood testing, my injections, they've never done anything for me...
Independence	029618: 204	I'm very independent, so I don't think, it [talking to friends] doesn't really come into it.
Independence	019715: 8	I got diabetes when I was 12 and I, sort of, just tried to keep it independent since....it's always been my thing, I just like to keep control of it.
Independence	019715: 16	...you do it by the books, you get on with it, you've just got to be independent...you can't just rely on other people. It's always been the fact you can't be seen as not being normal and safely keep it to yourself, you keep independent.
Independence	019715: 95	...it's more just being independent and just getting on with it and I don't, I don't, I don't want people to be recognising me as 'diabetic kid' or whatever. It's just literally something I have, have got on with it. That's, that's how I feel about it, anyways.
Independence	019715: 309	...I like to be independent, and I don't, I wouldn't want them to be talking about it and know things.
Independence	019823: 40	Well it's taught me to, um (...) ummm, I don't know really, I just feel that it's helped.
Independence	019817: 108	...when I go out with my friends, like, if I go around their house (...) I just have to be careful....Just (...) be more responsible.
Independence	019817: 280	I can't play football as more (...) like, I can still play football, but I can't, like, play it as more, as aggressively as I used to be able to, 'cause, in case it, in case I get hit by the ball (...) or kicked, or something like that.
Independence	029507: 400	I've been made to take Independence for my diet a bit more than I would have previously.
Independence	029507: 666	What's the point in taking this, 'cause I know I'm going to have to take this again later on. I'm going to have to take it again tomorrow.
Independence	029618: 41	...it's when you become a teenager, and you want to go out, and do different things, and your parents aren't always there to back you up and remind you. It's a lot more (...) Independence (...) like for yourself. (...) I think it was easier when I was younger, but that's because I wasn't doing as much.
Independence	029618: 217	I took more Independence, I, I did things better to, so I didn't have so many high blood sugars, whereas before I just really couldn't be bothered, so I wasn't bothering with it.
Independence	029710: 70	And then, um (...) they'll just tell me "Jessa, you need this much extra." Or they used to anyway, now they ask me "Jessa, how much do you think you need to do" 'cause obviously I'm getting to that age where now, aren't I?
Independence	029710: 70	...I'd say just under a year, my dad and mum, they've been switching it around, so like, they've been asking me instead of telling me what I need to do, so I've been becoming slowly more and more independent with it. So like, yeah, like I said, they'd ask me 'what do you think you need to do?' instead of telling me 'Jessa, your bloods are this, you need to do this much' so, yeah.
Independence	029710: 672	I need to always make sure it's [insulin] out of the way. Like, even when I don't have kids 'cause my sister's already got a kid and has another on the way, and when she comes round I need, I need to make sure

		everything's out of reach, 'cause if she had (sigh) I could, I could never, ever forgive myself.
In-group	019823: 83	...I just prefer one or two people to care enough than lots of other people trying to nag me about it.
In-group	019811: 104	...just 'cause she [mum with T1DM] knows more about it.
In-group	019811: 168	...I mean, I talk to mum about it 'cause she has it too...
In-group	019811: 181	I don't think it's something you can [understand] (...) unless you have it.
In-group	019817: 76	...it's nice to have someone around who's, kind of, been through it.
In-group	019817: 80	Sometimes (...) we talk about (...) how it was, like, how it was for her [Grandma with T1DM]. How it was a trial, for her.
In-group	019817: 142	...well, nan has it [T1DM] too, so...she knows most, I think.
In-group	019817: 215	...there's some other people in my school that are, that are diabetic (...) that I know as well, and I used to go sit with them in a room and do my injections and that was alright because (...) they'd know how it felt to have to inject (...) and that was nice.
In-group	029507: 792	...but they do understand and they do (...) empathise with you a bit. I mean, they can't fully understand, in a sense, but, but they do kind of say (...) 'oh, well, I, I can understand why you're angry at the doctor today'
In-group	029507: 818	She's the only one I know who, kind of, like (...) understands more of why it affects you like that.
In-group	029618: 21	...it is easier, because you feel, because you feel like people understand a bit more.
In-group	029710: 48	Yeah, yeah, we [participant & diabetic brother] do have a chat now and then, like, comparing almost, don't we? Because, like, we can relate, obviously...
In-group	029710: 532	'Cause you walk in and you, it's like you know that person's got diabetes...it's like you share something so big. You've experiences the same things; 'have you done this?' 'yeah, I've done this' and you can have a good old laugh, 'cause you know there's always a funny story that follows a hypo (laughs).
In-group	029710: 552	I was like 'this happened, has that ever happened to you?' (laughs) and he was like 'yeah, then this happened to me, has that ever happened to you?' it was just, like, back and forth, back and forth. (laughs)
In-group	029710: 577	...'cause we'd always go to the medical room at the same time to do our insulin, and we're sitting there, like, '5, 4, 3, 2, 1' and all say what our bloods were at the same time, and then, like, whoever was the highest had to lock away everything...
Lack of understanding	019817: 134	Living it is just different and (...) even if you know all the facts, which a lot of people don't (...) having it is different. Like, even Michelle, even though I know she knows most about me and about diabetes, she still doesn't really know what it's like for me. Really.
Lack of understanding	019823: 135	...they openly eat sweets that are really sugary and I can't have, and try to offer one to me, which really annoys me...
Lack of understanding	019811: 177	They [friends] wouldn't get it.
Lack of understanding	019811: 260	And then, like, different (...) different people had the same questions. So it was like, really repetitive (...) after a

		while...Like I was answering the same thing all the time. Just boring.
Lack of understanding	019817: 125	...there's a lot more people that don't (...) quite understand what it's like...
Lack of understanding	029507: 698	And so it's, it's a bit ridiculous, how people react.... 'cause they're like 'oh you're not meant to eat this, not meant to eat that, blah, blah, blah, blah' (...) like misconceptions and things like that
Lack of understanding	029507: 816	'it's not contagious it is? I've not touched you and given it to you?'
Lack of understanding	019715: 110	...they [classmates] don't say anything about it because they're completely unaware of what any of it means, because they've never had to know...
Lack of understanding	019715: 117	...they [friends] don't understand, sort of, how much work it is to maintain and how much extra work it is...it really annoys me when people are not aware...It's not fair that they can make judgements about you, but then they don't know, so I can't snap one back at them, really.
Lack of understanding	019715: 125	...they [friends] don't know the difference between type I and type II which really offends me, and it offends me when I hear it on TV....It's the assumptions people make, especially when I'm meeting new people as well...people make assumptions that you haven't treated yourself right and that's why you're in that situation...
Lack of understanding	029710: 200	Like, you're not listening. Like, they've heard somewhere along the line that you need to give diabetics sugar, and that'll all they remember, even if I tell them not to. So (...) I'm open with them, but (...) like, I wouldn't necessarily trust them to take care of me if I was proper ill, you know?
Lack of understanding	029710: 227	And it's like, everyone thinks it's [hyperglycaemia] funny, and I'm like 'don't!'
Lack of understanding	029710: 248	...they've got no one in their family whatsoever or been friends or anything with anyone who's diabetic, so when I tell them what it's actually like to be diabetic, they're like 'Oh my gosh, I'm so sorry!' and I'm just like 'Mmmhmm'
Lack of understanding	029710: 653	...I actually started to get really worried, like 'oh my god, what if someone is stupid enough to take my insulin, what if they did this?' 'cause it's, it's like, I feel rude, saying 'be stupid enough to do it' but someone who didn't understand or something, I would feel so horrible...
Lack of understanding	029710: 662	I've told my mates, like, it's fine for me [insulin], but you, you can't touch it or you'll end up in a coma or dead but, but they don't believe me.
Nagging	019823: 126	...leaving me alone with it, as I said before, because I don't like people hassling me about it.
Nagging	019811: 212	Angry (...) 'cause it's nothing to do with them.
Nagging	029507: 14	...sometimes it's really, really nice and sometimes it kind of winds you up a bit. It's like, first thing in the morning, it's like "what's your blood sugar?" and I'm like "I haven't tested yet!"
Nagging	029507: 194	...I think she's far more concerned with my health than she would be if I, like, wasn't diabetic.
Nagging	029507: 209	... "are you ok Claire? Are you feeling ok? You look a bit pale" and it's like (sigh) "I'm fine!"
Nagging	029507: 219	...wanted to see what, what I was doing all the time and I'd jab myself and they'd be like "what's that? Why're you doing that? What kind of insulin you using?"

Nagging	029507: 229	...it is helpful, but when it's over the top (...) every 5 minutes 'are you ok? Have you tested? Have you taken?' it's a bit too much...
Nagging	029507: 233	....they'll ask me every 5 minutes afterwards, which...I don't like, because I don't want to be reminded of the fact that I just had a hypo and I didn't feel very well and I don't want to be kept on being reminded about it but (...) it does show that they care.
Nagging	029507: 572	...they think it's helpful, but it's not.
Nagging	029507: 623	...it is, like, full on 'how are you feeling? 'are you ok?' 'do you need lunch now?' 'have you tested your bloods?' and things like that. And there are times where (...) it just gets a bit (...) much.
Nagging	029618: 47	I don't like when my parents tell me 'have you done that, have you done this, have you done that?' but when they stop telling me, then I forget, then I feel like complete crap, so it's like a vicious circle. ..It's like what points are helpful, in what point does it become nagging?
Nagging	029618: 65	They [parents] don't really have anything to do with it, apart from reminding me, well, I class it as nagging. They probably feel it's nice and supportive.
Nagging	029618: 71	I don't think it's even actually any difference between the two [support & nagging], it's more how I'm feeling when they say it. (...) Like, if I'm feeling like they're getting at me, then even if they said something that was a reminder, I think I take it as nagging.
Nagging	029618: 129	The more people tell you, as well, the more you go against it....you're like 'yes, I know' but it, it doesn't change anything...I don't find it helpful, I don't, I don't.
Nagging	029618: 196	I try and look at it from their perspective, they've got a kid that they can see getting poorly and poorly and poorly, when you look at it like that, you kind of think 'oh, I'm not going to moan' but some days you're just like 'shut up and get away from me.'
Nagging	029618: 249	...she's [friend] very good, but can be a bit (...) a bit over controlling at times, a bit in-your-face.
Nagging	029618: 254	...she [friend] feels (...) she still needs to mother me, and that, for me that's just really annoying. I get why she does it (...) but surely she can see that I'm coping better with it now?
Nagging	019715: 29	...it [receiving extra help] has been a bit helpful, but it gets annoying, it really does....because your parents are aware of it, and they keep bringing it back up over and over and over again, and oh, it just gets, it irritates the hell out of me sometimes, but I know that they mean well but I'd just rather keep it to myself.
Nagging	019715: 185	...it's just having to constantly repeat yourself to different people.
Nagging	029710: 54	So it's annoying, but I don't think it's any different to, like, how he would be if I weren't diabetic. 'Cause obviously, like, he's like it with my little brother too and that so, with me and Adam it's just, like, the extra nag of watching out for our diabetes too (...). He'd always be pestering me about something, it just happens to be my diabetes (laughs).
Nagging	029710: 279	...there has been a couple of times when they'll [friends] be like 'Jessa, are you sure you're allowed that' and at



		the same time, they kind of just leave me to it, which I expect them to. You know, not treat me like a little kid or something.
Negotiation	019823: 142	...most of the food there was chocolatey and sugary, had a slice, a slice of cake (...) but then I didn't want to kill myself (...) so I just went away to the library.
Negotiation	029507: 196	...like we have to eat at this time, we have to make sure that we've always got, like, a banana and a bit of juice with us and make sure that this happens, and we've got to make sure that, if the worst happens, we've got a number to call (sigh).
Negotiation	029507: 350	...we've always been healthy (...) but we're, like, even more conscious of it now...
Negotiation	029507: 392	...I used to come home from school and I'd be like Jaffa Cakes and a little pot of those fruity yogurts, the really sweet ones, but now no more.
Negotiation	029507: 410	...you kind of learn that if you want to look after yourself and if you want to feel better then (...) you might as well just avoid it [sugary foods].
Negotiation	029507: 668	...it's going to affect the rest of my life, and I almost feel like (...) I have to plan the rest of my life around it, 'cause as soon as you got it (...) you're not allowed to do...certain things, so I (...) I hate the fact that I can't do that anymore...I have to adapt all the time. I have to do new situations, different things, and (...) it, it does feel kind of like discrimination sometimes.
Negotiation	029618: 91	...I want my dinner and everyone else is eating and I got to be like 'right, I got to work this [insulin] out' before I've even eaten. That's the annoying bit.
Negotiation	029618: 105	It's kind of been in my life as long as I can remember, really.
Negotiation	019715: 49	...I don't drink alcohol, I don't have fizzy drinks and I try to keep away from, um, sort of, less starch and keep away from sugar basically.
Negotiation	029710: 77	...a very long time ago, we always used to have pudding after dinner, but we don't any more.
Negotiation	029710: 305	...you know, you want to eat it, you want to be able to have that, that, whatever it is (...) but you can't (...). It's only a bit of food at the end of the day.
Negotiation	019823: 12	We'll work it out together, but usually, um, they listen to what I think...
Negotiation	019823: 51	Because they still allow me to have some things, like an occasional bar of chocolate at the shops...
Negotiation	019823: 113	I know I shouldn't over eat (laughter) though I do.
Negotiation	029507: 356	...I know you're not meant to have, like, chocolate and, sort of, things like that now, but she'll buy me like, um, the 90% dark, purest stuff.
Negotiation	029507: 412	...I try to stay away from temptation. I mean, you're not perfect, you know sometimes you, you kind of give in to it.
Negotiation	029710: 298	I know I'm not allowed it and I just keep in my head that feeling I get when I've, when I'm really, really high and I'm just like 'That's not happening' (...) because it don't feel good. If I just, if I keep that in my head, it, it gives me,

		like (...) more motivation to, like, not do that. I just make sure I do my insulin.
Negotiation	019811: 56	I just eat what I want, really.
Negotiation	029507: 416	I manage to sneak it [sugary foods] past her [mum] , I'll have it, but (...) I do, I feel like I've almost, in a sense, I've no other choice but to do that. As in, I can't do anything else.
Negotiation	029618: 99	...I go through stages of just guessing. You don't every mealtime think 'oh, how much is it? How much is that?'
Negotiation	029618: 114	I do eat whatever I want to eat (...) because my insulin you just do when, when you eat, but (...) I don't know (...) I've had that attitude before and it doesn't get you anywhere.
Negotiation	029710: 66	I do, I am, I do keep my restrictions but, at the same time (...) even my parents, they're like, they try to make it as if I'm, like, not diabetic, if that makes sense. So it's like, it's not every weekend, but every now and then they'll come home, like, with loads of sweets and loads of pop and we'll have like a nice little, like, family thing. And then, um (...) they'll just tell me "Jessa, you need this much extra."
Negotiation	029710: 495	.Yeah, it's just, it's the attitude I take. I'm like 'I want that chocolate cake, and I'll worry about it later.' ... it's not on occasion, it's every day mate! (laughs) I'll just worry about it later. (laughs)
Safety net	019823: 132	...well if it is urgent, I think most of them know what to do. I feel safe.
Safety net	019811: 280	I can trust them.
Safety net	019817: 114	She knows how I'm like when my sugars are low and when my sugars are high...I can relax a bit more than maybe I can with other people.
Safety net	019817: 126	I kind of rely on the (...) friends that I knew (...) from primary school just to (...) keep an eye on me. Just 'cause they know me better (...) they know what to look for.
Safety net	029507: 582	Once I've told them how to help if I do have a hypo, I kind of (...) don't want to think about it again. I just want to be me and them not to worry...
Safety net	029618: 413	...I think your friends should know. It's like, imagine if you're, I don't know, out with your friends at the weekend, and they don't know anything, I think, I think that's silly.
Safety net	019715: 141	...I have got people around me who do know what to do...they carry stuff on them, just in case...when I go somewhere new, I take more care. Um (...) but I don't, I never feel like I'm at risk around my friends, really, so.
Safety net	019715: 352	...they would just let you get on with it and with the safety net of someone around who does know what to do.
Safety net	029710: 183	...they're [friends] not going to be there every day ... so I know that I need to (...) do it by myself, but to use, like, they are gonna be there, but obviously not forever, so if it's, like, a last resort type thing. That's what I need to keep that in my frame of mind, otherwise I'll get too relaxed with it all, start slipping.
Stress	029507: 504	...school is the main stress (...) that affects my diabetes, 'cause if I'm really, really stressed at school, mum will know because my blood sugars will rocket...
Stress	029507: 519	They [blood glucose results] were, week before exams they were 16 all the time, like background 16, and then the morning just before the exams, they were, like, 20, which is ridiculous.

Stress	029507: 523	You can't concentrate, you can't really write, and so I'd take, like, a massive bucket load of insulin to try and bring them [blood glucose levels] down...my [exam] results were really bad, they reflected that, 'cause I just, I just can't concentrate when they're at 20.
Stress	029710: 409	I had an exam, rather, last Thursday and I went high and I done a paragraph, put my head down, look back up and I was, like, looking at every line on the ceiling tiles, all that like. Then I look back down and I start looking at everyone else (laughs). I was like 'I need to do this, but I just can't.'
Stress	029710: 417	And then, with all that going on [exams], it's like, 'oh yeah, I need to eat.' And perhaps do some insulin too, you know, make sure I survive for the day.
Stress	029710: 598	...and with the added stress of starting college, I know I'm just going to be everywhere.
Stress	029710: 437	I hated it so much though, 'cause it was like, it was during my, I've spent my whole lunchtime, I felt good, I felt prepared, I felt 'let's do this one, mate' and I got in there and, literally, I picked the pen up and I could see my hand shaking and I'm like 'what am I shaking for?'
Support	019817: 182	...the cinema's quite hard, 'cause obviously if I went with my friends, I wouldn't be able to have stuff like popcorn...
Support	029507: 452	...it's really late that they organise it [nights out with friends] and so, 'cause you've got the, the natural rhythm and that you've created then, then when they go out at, like, 8 o'clock to have dinner when I normally have it at half 6, if, kind of, messes up my sugars...I try not to do it too often.
Support	029507: 472	...we'll go somewhere rather than eating out, kind of thing. So we'll go out to a party or something, and things like that. Rather than eating really, really late and messing me up in the mornings...
Support	019715: 166	...the biggest thing socially is now that we're coming to the age people are starting to drink, and they'll say 'oh, why aren't you drinking?' and that question is just the killer...
Support	019715: 179	It's [alcohol] got sugar in it, you go up and down, and when you're drunk you can't actually tell what your blood sugars are, so it's really dangerous, and that's why I don't want to drink.
Support	019823: 24	I prefer it, having some help. Right now anyway.
Support	019823: 65	Moral support. Encouragement, yeah. I think that's important...being there, I guess. Helping me when I need it.
Support	019823: 78	...the ones I do have, they're not really (...) very helpful...one or two friends are quite helpful with it, and, er, if I go visit there, or something, they always get their parents to get Diet Coke or something, so that, that is quite helpful.
Support	019817: 5	...my mum (...) helps a lot in the blood testing because she has to, she tells me to do it, before meals...she tells me to make sure I do my insulin and stuff.
Support	019817: 14	...she writes notes telling me how much carbohydrates I'm having so I can do the right insulin.
Support	019817: 65	...they, like, try to make me feel (...) like it's ok to have it. Like they understand how hard it is to (...) do injections, and test my blood, and stuff.

Support	019817: 69	Like, it doesn't matter when I have bad days or mess up. I know they'll be ok with it.
Support	019817: 152	Some of them are like "oh, it must be really hard, I could never be diabetes because I can't (...) like, I'm afraid of needles" so they know what it's like...
Support	019817: 157	It'd be harder without friends that (...) knew...no one would know what was wrong with me, what (...) happens when I go low...
Support	019817: 207	...it kind of seems nice that, that they're trying to help me (...) and trying to get me to do it when (...) I'd do it, but it'd just take me a while before I would do it, sometimes (...) so (...) they'd, they'd help, a bit.
Support	019817: 214	So it was, it was nice of them to, like (...) have an eye out for me, or whatever.
Support	019817: 224	...it was nice in the fact that they'd (...) like, try to find out what (...) try to ask questions, like, what it feels like (...) what happens (...) if, um, like (...) what happens if you don't treat it properly, um (...) they, they'd just ask. Comment on (...) like "I'd never be able to do that during break" or (...) stuff like that, that would just (...) help me get used to having people around when I did it.
Support	029507: 157	Mum was there, as my support mechanism...
Support	029507: 212	...it, it was really nice of them to show that they cared and they, they really wanted to make sure that I was ok. They were (...) really there for me.
Support	029507: 225	...I think they [friends] did change a bit, like slightly more caring side, really. Just to show that they, they do care, they want to make sure that you are ok, which is really nice.
Support	029507: 315	...it [asking questions] shows that they want to learn about it and that they're interested in the fact that you have it and what that means for you and what that also means for them, in a sense.
Support	029507: 259	...I call her [diabetic friend] my prick partner because (...) we take at the same time and things (...) which is funny.
Support	029507: 370	...he [brother] kind of joins in with our meals and things like and he just, like, supplements it 'cause obviously he needs far more.
Support	029507: 384	...he [brother] kind of thinks about the food and things.
Support	029507: 575	...that's all I'd really expect from my friends (...) really. Just like, be there if I need them, know what to do (...) but not necessarily to (...) remind me or help me inject or something. I don't really need it. And it kind of makes me feel (...) like it emphasises the differences, you know?
Support	029507: 725	...like if I text him saying that I don't feel too well, he'll be like 'right, I'm on my way' ...and that's really nice. It's more the fact that when I'm not feeling too well, and you know you need to do sometime about it, and that they're the kind of rock that you're with.
Support	029507: 746	... 'cause she's [mum] calm, and she sorted the situation out 'cause I can't cope with it at that moment...if I get into a pickle she'll stay calm, she won't panic about it...
Support	029507: 752	...she'll [mum] calm me down, she'll talk me through it...she just calms me down all the time, which I suppose is

		my main (...) my main worry.
Support	029507: 770	...with Shelly [diabetic friend], I know I can say, like 'oh my god, I've just has an HbA <sub>1c</sub> and its rocketed again' ...so I moan with them a lot, really...It's good to have someone you can do that with.
Support	029507: 781	...she'll [diabetic friend] be crying because of something that'd just happened, I'll be like 'it's ok; they did that to me yesterday. I'm OK now, I've stopped crying today' and things like that.
Support	029618: 155	...she's [mum] really supportive, if I said to her 'can you take me swimming?' or 'can you come with me for a run?' she'll come with me...
Support	029618: 380	...she [nurse] rings to make sure you're okay, and I never had anything like that, so I feel very supported from her...she's like a friend...she obviously cares about your diabetes and stuff, but it's not diabetes, diabetes, diabetes, it's more broad, kind of thing...
Support	029618: 406	...just me telling him [newly diagnosed brother] that I've been through the same thing, he's been like 'I'm not a freak!'
Support	019715: 91	...I guess around the time of diagnosis, it was comforting me at the time (...) until we were used to it...
Support	019517: 280	Just listening really. (...) I (...) I, I, I don't know what she [mum] says back to me, I don't think she says much, but it's just listening to me moan about it, and just shrugging her shoulders and saying 'well, that's life, isn't it?'
Support	019715: 247	Really close friends, maybe, like my girlfriend, she knows. Talk about with her, 'cause I know she understands (...) she won't judge me. But mates? Not really.
Support	029710: 9	I'm like, I'll eat my dinner and I'll, like, completely and utterly forget, like, thinking I've already done it, I'm fine. But then my dad will come and "Jessa, have you done your insulin?" and I'm like "oops, no!" (laughs)
Support	029710: 124	I always know that (...) even if I don't remember, I know they will, and I know that, like, 'cause you do have some...them days where I'm like 'I don't need to do bloods, I don't need to do this, I'll just do it later, I don't need to do that.' But they'll be like 'Jessa, no, do it.'
Support	029710: 149	I know that if I'm being, like, a total fail when it comes to managing it properly, I have that back up.
Support	029710: 160	Say, like, if my words start slurring or I starting to sweat when I shouldn't be or like if I'm just going, bouncing off the walls because I'm high. They're like 'Jessa (...)' and give me the look and I'm just like 'Oh, I didn't even know I was!' (laughs)
Support	029710: 173	Hannah, she's always got a couple of chocolate bars in her bag for me, so like if I'm low, she's like 'here you are.'
Support	029710: 200	...obviously with your mate you're like laughing and joking and everything, the second they find out I'm having a low they're like 'You ok Jessa? You ok Jessa? You ok Jessa? Jessa, you ok?'
Support	029710: 289	Yeah, they're understanding, and it helps a lot because if I didn't have friends that were understanding I probably wouldn't be as good with it as I am.
Theme	Participant	Quote
Transition	029507: 811	It feels really sudden, 'cause it's like, you go there for 4 years and all of a sudden you're not allowed to go back

		there anymore. You must go somewhere else.
Transition	029507: 840	'Cause it does feel, like, so sudden and that...all the services are stopping now...So I'm not allowed to see people who I used to be able to see...it's really daunting
Transition	019715: 316	...because it is a big transformation obviously, becoming completely independent in every sense, and then still having to manage your diabetes, but transitioning services and things like that, it's all a big change, all at once.

## **Appendix T:**

### **A systematic review of support intervention studies in adolescents with type 1 diabetes**

#### **Introduction**

Despite the well-established recommendations for optimal diabetes care discussed in Chapters 5 and 6, the quality of care received by patients still requires improvement (Global Guidelines for Type 2 Diabetes, 2006). In England, the International Diabetes Federation state that an estimated 3.1 million people have diabetes, with this figure set to reach 4.6 million by 2030 (International Diabetes Federation, 2011). However, this increasing prevalence has not seen an improvement in diabetes outcomes (Barnard et al., 2012). The National Diabetes Audit reported that only 28.2% of patients with T1D achieved the optimal HbA<sub>1c</sub> of less than 48mmol/mol, with 17% suffering from markedly elevated blood glucose levels (HbA<sub>1c</sub> >86mmol/mol) (National Diabetes Audit, 2010). These findings have remained stable over the previous 3 years, indicating that improvements in care have not been successful in improving diabetes control.

Treatment modalities for patients with diabetes have never been better. Self-blood glucose monitoring (BGM), insulin pumps, insulin analogues and improvements in oral medications have enhanced medical care for millions of diabetes patients. However, this effort to improve healthcare services seem localised to the biomedical aspects of illness (Barnard et al., 2012). Although psychosocial support systems have also seen improvement over the last decade, there is often a discrepancy between optimal care and the availability and delivery of these interventions. Barnard and colleagues (2012) therefore recommended that an improvement in psychosocial outcomes depends upon the accurate assessment of the availability of such interventions in conjunction with the design of programmes to reduce inconsistencies in the availability and delivery of psychosocial interventions.

Many non-pharmacologic interventions exist for diabetes patients, such as patient education services, self-monitoring aids and telemedicine, however, their effectiveness in improving diabetes outcomes remains unclear (Farmer, Gibson, & Tarassenko, 2005; Pimouguet, Le Goff, Thiebaut, Dartigues, & Helmer, 2011; Vermeire, Wens, & Van Royen, 2005) with evidence of poor service provision despite the obvious clinical need (Barnard et al., 2012). In addition, poor quality research evidence has included systematic reviews that have failed to distinguish between psychological and educational interventions, diabetes types, randomised trials and non-randomised trials, or even between adults and children (Hampson et al., 2001; Winkley, Landau, Eisler, & Ismail, 2006), resulting in a lack of high quality evidence of treatment efficacy.

Interventions aimed at promoting diabetes management are often based on the assumption that improved adherence to the care plan leads to better glycaemic control. Hood

and colleagues (2009) provided strong evidence for this assumption in a recent comprehensive meta-analysis of adherence research in paediatric T1D. This research supports previous findings and practice guidelines which have long advocated the importance of striving for adherence to care plans (Silverstein et al., 2005). Furthermore, it has also been found that achieving improved glycaemic control confers reduced risk of the complications associated with T1D (Svoren et al., 2007; White et al., 2001, 2002). Interventions, therefore, typically target adherence-promoting components via the behavioural processes that are directly involved in disease management, or through the indirect processes that can facilitate improved management (Hood et al., 2009a). This may be achieved through an increase in diabetes-related knowledge or via an increase in the skills necessary to complete self-care tasks. Typical outcome measures are, therefore, an increase or improvement in BGM, insulin administration, dietary adherence and physical activity. Others focus on psychosocial outcomes such as coping skills (Grey et al., 2000; Serlachius, Northam, Frydenberg, & Cameron, 2012) or communication (Wysocki, Greco, Harris, Bubb, & White, 2001a). In these studies, an attempt is made to integrate the multiple layers of the life of the patient with effective disease management (Ellis et al., 2005).

Winkley et al. (2006) conducted a meta-analysis of psychological interventions aimed at improving glycaemic control patients with T1DM. The review included ten randomised controlled trials conducted with paediatric, adolescent, and adult populations with T1D and written in any language. Encouragingly, the interventions studying paediatric and adolescent populations were found to be moderately successful ( $r=.46$ ) in improving psychosocial outcomes such as reduction of distress. However, the studies were less successful at improving glycaemic control ( $r=.35$ ), resulting in a reduction of HbA<sub>1c</sub> of .48% across the studies, which fails to achieve clinical relevance. The authors, therefore, concluded that there is an argument to be made for the benefits of such interventions in paediatric and adolescent populations. However, the question remains as to whether such programmes are capable in eliciting an improvement in biomedical outcomes given the variability in efficacy found, and the lack of evidence for improved glycaemic control.

### **Support Interventions**

Most theories of health behaviour change include a social component (Ajzen, 1980; Bandura, 1986; Brug et al., 2000; Lazarus & Folkman, 1984a; Rosenstock, 1974; Ruggiero & Prochaska, 1993; Vallis et al., 2003). In the majority of these models, social norms and support are considered a direct determinant of the resulting health behaviour. In addition, in their most recent position statement the American Diabetes Association (ADA) has stated that the assessment of social situations is an integral part of the on-going management of diabetes, with



screening for sufficient social resources a specific recommendation for optimal care (American Diabetes Association, 2010). It can therefore be stated that investigation of the efficacy of social support focused interventions is warranted.

Social support interventions targeted at adolescents with T1D are relatively scarce, but have been studied in greater number in adult populations. Qualitative reports have repeatedly cited a supportive social network as key to maintaining self-care, with a theme of *“being in it together”* particularly pertinent in adults (Rosenbek Minet et al., 2011). Indeed, a recent investigation by Markowitz and Laffel (2012) found that participation in a support group was associated with a significant decrease in diabetes burden for young adults (age 18-30). Most positively, participation was associated with an increase in self-care behaviours and a decrease in HbA<sub>1c</sub>. Findings such as these indicate that young adults greatly value social support and translate this into improved glycaemic control. It can reasonably be concluded that the same may be true of adolescent populations. Similar results have also been found in online (Armstrong, Koteyko, & Powell, 2012) and telephone-based interventions (Rotheram-Borus et al., 2012).

How social support is implicated in the facilitation of glycaemic control is unclear and may rely on multiple mechanisms. Previous research has stated that social networks are a significant source of information regarding diagnoses, treatment, expectations and complications in diabetes (Wasserman & Trifonova, 2006). It has also been stated that social networks diminish the stress elicited by the disease through offering emotional support. A third explanation points to coping strategies enabled by social support, providing improved likelihood that the patient will successfully endure stressful events through maintaining the treatment regimen and thereby reducing the likelihood that the event will result in poor health (Sarason et al., 1997).

The adoption of social support programmes in diabetes care has been done so from a variety of perspectives including face-to-face management programmes, peer coaching, community health workers (CHWs), telephone and online support (Heisler, 2007):

- Face-to-face group support: involves a single or group of peer supporters delivering education or support in a group setting (Lorig & Gonzales, 2000).
- Peer coaching: also known as mentoring. Concerns peer supporters working one to one with patients on a ‘role model’ basis (Joseph, Griffin, Hall, & Sullivan, 2001).
- Community health workers (CHWs): professionals living in the same community as the patient population. CHWs therefore share subcultural norms and values with the patients, which can prove more advantageous than clinicians. CHWs provide a bridge

between the community and the diabetes clinic, whilst also offering emotional, informational and instrumental support (Albright et al., 2009).

- Telephone and internet-based support: offers support to patients without face-to-face interaction. This model have proven popular with those in rural areas, where geographic boundaries can prove problematic (Philis-Tsimikas et al., 2004).

Each approach shares the common goal of facilitating on-going support to patients in their self-care, though each varies in their exposure to support sources. Their heterogeneity can also be seen in their focus, utilisation of peer knowledge and experience, and in their provision of emotional, appraisal and informational forms of support (Dennis, 2003). It can therefore be stated that the interventions are too diverse to warrant evaluation through meta-analysis, and that further work is necessary in the field to determine a definitive definition of support interventions before such comparisons can be conclusively made. With this in mind, relatively little systematic appraisal of support interventions has taken place. A Cochrane review concluded that telephone-based peer support were of limited use and effectiveness in diabetes (Dale, Caramlau, Lindenmeyer, & Williams, 2009). Others have focused on adult populations (Dale, Williams, & Bowyer, 2012), are culturally specific (Simmons, Voyle, Rush, & Dear, 2010) or lack comprehensive appraisal of the clinical outcomes (Brownson & Heisler, 2009). A recent systematic review of peer support programmes in T1 and T2D concluded that there was inconsistent evidence to definitively state the impact of such interventions, although preliminary findings were promising for the effectiveness of support programmes in improving biomedical and psychosocial outcomes in diabetes (Tang, Ayala, & Rana, 2011).

### **Research Questions**

- Does research provide evidence of positive impact of interventions targeting social support on biomedical and psychosocial outcomes in AWT1D?
- What are these interventions, what outcome measures were used and how did they define social support?

### **Method**

A literature search was conducted to retrieve publications studying interventions for AWT1D, where social support was a primary or secondary outcome measure. As “intervention” is not an internationally agreed term and is rarely included as a key word, it was decided that the first selection would focus on social support in T1D patients. An internet-based literature search was conducted by the researcher in PubMed, Science Direct, PsychInfo and Web of Science, covering 1980-2013 in February 2013. Publications in English were preferred due to the limited scope of this doctoral study. Boolean strand search terms of “social support,” diabetes AND “type 1” were

applied. From these studies, the author selected the LIMIT TO function to restrict results to participants aged 13-19 and those with full articles available (b, second selection), to ensure that only research focusing solely on adolescents was included. The third selection (c) was performed by hand, by studying the retrieved publications for intervention studies and excluding existing reviews. A final hand search (d, fourth selection) was conducted in order to remove duplicate publications and prospective research, so that post-intervention results may be examined and compared. The selected publications were then searched for other relevant references to intervention articles, and follow-ups to prospective research were searched for. This resulted in eight studies being selected for review. A diagram of the review process can be seen in Figure 1.

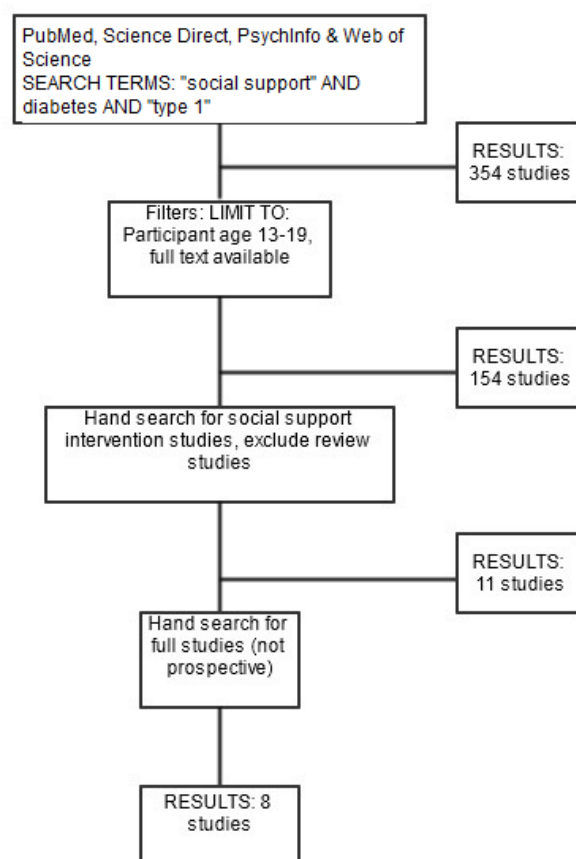
The primary studies were reviewed for methodological quality using the five item, three level Jadad scale (Jadad et al., 1996) as it is an established scale for assessing reliability and external validity, containing items that have been demonstrated as correlated with bias (Halpern & Douglas, 2007), in addition to being the most widely used assessment of methodological quality outside of Cochrane reviews (Moja et al., 2005).

## **Results**

From the initial 354 publications found (a), 154 focused on adolescents aged 13-19 and had full articles available to view (b). From these, 11 studies concerned intervention research (c), with a further 3 excluded for being prospective research (d), leaving 8 in the present review. A flow diagram of the review process can be found in Figure 1.

### **Definitions and measures**

The 8 reviewed studies included 6 RCTs and 2 cross-sectional investigations, each of which studied a different social support intervention model (Table 1), multisystemic therapies, behavioural family systems therapy, pharmacy-based intervention, adolescent-peer paired intervention, summer school programme, online education and support programme, negotiated telephone support and parent-adolescent teamwork support.



*Figure 1.* Flow diagram of the literature review process and results.

The studies measured social support in a variety of ways. Most employed recognised and validated questionnaires (e.g. the Diabetes Social Support Questionnaire), others scored interactions in online support groups, engagement with a telephone support system, or through interviews (e.g. the Diabetes Social Support Interview). Interventions targeting support from family, friends, peers with T1D and formal support from counsellors were studied, reflecting the diverse nature of social networks.

The included studies also used differing outcome measures. Most used biomedical outcomes, such as a change in HbA<sub>1c</sub> or BGM, as the primary measure. Three studies did not use self-care as the primary outcome, but instead focused on an improvement in social support. This was assessed through a variety of questionnaire measures or qualitative interview. None assessed diabetes complications, such as blindness, inpatient admission or incidence of diabetic ketoacidosis, possibly due to the young age of the participants and thus the reduced likelihood of micro or macrovascular complications.

The reviewed studies encompassed a total of 512 participants. The mean number of participants per study was 61 (range 6-127) and had a mean age 14 (range 10-18). Few gave detailed information regarding the duration of diabetes in their participants, except to say that

the majority had been diagnosed for more than one year, with the exception of Greco et al. (2001), who used participants with a duration of less than 18 months. The majority of the studies took place in the USA, with one in Canada and one in the UK. Quantitative pooling of the intervention studies in a meta-analysis proved inappropriate due to the limited number of studies and their heterogeneity. A narrative method was therefore preferred. A brief summary of the eight reviewed studies can be found in Tables 1-3.

The methodological quality of the studies was assessed using the Jadad scale (Jadad et al., 1996). The quality of the studies was found to be very low, with an average score of two out of five on the scale. The individual scores are shown in Table 4. Due to the limited number of studies yielded from the research, the methodological quality of the studies was not used as exclusion criteria.

### **Effects**

Improved support from friends, family and peers with T1D may improve diabetes management and biomedical outcomes in AWT1D (1, 2, 3, 5, 6, 8). Psychosocial and subjective outcomes improved across all but one of the studies, presenting a psychological and well-being value to the interventions with or without a clinically relevant outcome (2, 3, 4, 5, 6, 7, 8). Involving friends and peers with T1D in social support interventions proved particularly effective in improving psychosocial and clinical outcomes (3, 4, 5). However, there was no impact on disease management when support was provided formally from clinicians or strangers (6, 7). Surprisingly, no significant age or gender differences were noted in the reviewed studies.

The impact on glycaemic control was mixed. The majority of studies found that increased support improved self-care, however, Sims & Haines (2011) found a decrease in glycaemic control post-intervention. HbA<sub>1c</sub> increased from 7.6% to 7.8% over the duration of the program, with the peer advocates increasing from 7.9% to 8.6%. The reason behind this increase is unclear, and is further explored in the discussion.

Table 1. Social support intervention studies in adolescents with type 1 diabetes.

Study	Intervention	Study Design	Measures	Results	Discussion	Limitations
1 <i>Social learning intervention to promote metabolic control in T1DM: Pilot experiment results - (Kaplan, Chadwick, &amp; Schimmel, 1985)</i>	Summer school program. Lectures/discussion sessions administered by experts in diabetes care.	RCT. Randomly assigned to a social learning intervention, or a control. The intervention identified social situations where peer influence might lead to non-adherence, and taught appropriate responses. The control group discussed medical information relevant to diabetes.	HbA1c, diabetes knowledge, attitudes and behaviour assessed using scales developed by the Rand Corporation . Sarason Social Support Questionnaire.	Significantly lower HbA1c at follow up for experimental group; control had increased. No correlation between diabetes knowledge and control. Positive correlation between HbA1c and social support satisfaction. Changes in knowledge were not associated with lowered HbA1c. Change in attitudes was not correlated with changes in control. Improved self-care behaviours also enhanced metabolic control.	Diabetes knowledge is unrelated to disease management. The intervention was successful at improving control relative to an education intervention. Those with poor metabolic control were more content with support networks. Bad influence of peers?	Pilot study: small sample size and subjects were self-selected. Not representative of population.
2 <i>Challenges of a pharmacist-directed peer support program among adolescents with diabetes - (Sims &amp; Haines, 2011)</i>	Pharmacists trained peer advocates as facilitators for the education component using the US Diabetes Conversation Map. Other support session activities included BGM, short term	Cross-sectional study; all participants took the 4 week intervention.	HbA1C. Self-care inventory, quality of life for youth.	Only 6 participants attended all sessions and were included in results. HbA1C increased from 7.6% to 7.8% over the duration of the program. Peer advocates increased from 7.9% to 8.6%. Unclear why. Questionnaires revealed improvement in adherence and exercise. Both members and advocates had higher HRQoL. Statistical power prevented further analysis.	Future programme would be better incorporated into an existing diabetes program such as a diabetes camp or after-school program. Would enhance attendance to support sessions and allow opportunity for interaction over an extended period of time. Pharmacists are well equipped to assist in diabetes management programs.	Barriers to recruitment included high prevalence of extracurricular activities consuming time of potential participants and lack of parental support of participation. Duration was also a barrier: only 2

		goals and dialogue relating to diabetes challenges.					sessions focused on social support.
3	<i>Behavior therapy for families of adolescents with diabetes - (Wysocki et al., 2001a)</i>	Behavioural Family Systems Therapy (BFST). Four therapy components used in accordance with each family's treatment needs as identified by psychologists: problem-solving, communication skills, cognitive restructuring, functional & structural family therapy.	RCT. Participants randomised to 3 months of BFST, education support group or current therapy.	Parent-Adolescent Relationship Questionnaire, Teen Adjustment to Diabetes Scale, Diabetes Responsibility & Conflict scale, Self-Care Inventory, HbA1c.	BFST = lasting improvement on PARQ extreme beliefs compared to CT & ES groups. PARQ overt conflict: sig from CT, not ES. Dissipated at 12 months. BFST differed on DRC from CT & ES. At 12 months, still differed from CT. No difference in TADS at any point. BFST showed improved SCI at 6 & 12 months; CT & ES deteriorated. No age/sex differences. No significant HbA1c differences.	BFST showed short-term improvements in relationships, but benefits in diabetic control, treatment adherence and adjustment depended on age & sex. Older girls worst off. Treatment effects were durable, persistence on favouring BFST at 6-12 months. Delayed treatment effect for adherence. None of the immediate post-treatment interactive effects dependent on age or sex persisted at follow-up. Benefit requires prolonged family interaction? Change in HbA1c requires even longer?	RM-ANCOVA: evaluating change in scores when groups differed at baseline - importance of stratification prior to randomisation.
4	<i>A peer group intervention for AWT1D and their best friends - (Greco et al., 2001)</i>	Adolescent-peer pairs attending education and support sessions. Groups were	Cross-sectional study. Parent, adolescent and peer completed baseline measures, then participated in intervention.	DSSI, Diabetes Education and Support Assessment Tool, Teen Adjustment	Significant increase in knowledge & support, as did peers. Global support on DSSI did not improve, however ratio scores indicated peers provided greater support following intervention.	Intervention was effective at improving knowledge & support. Support in the group was higher at baseline than in previous studies; was recognition of improvements in global support therefore	Unknown psychometric properties of the DESAT limited the interpretation of findings. Demand characteristics in

		composed of 3 to 6 pairs. Group leaders followed a detailed treatment manual with didactic presentations, hand-outs, activities and homework for each session.	Second questionnaire completion after intervention.	to Diabetes Scale, Diabetes Responsibility and Conflict Scale, Self-Care Inventory, Peer Interaction Record, Self-Perception Profile.	Parents reported significantly less conflict and improved adjustment. No significant changes in adherence. Peers = improved self-perception, but none in participants. No significant changes on peer or adolescent reports of peer activities.	limited? Improvements in conflict and adjustment – significant association between conflict and poor adherence/metabolic control in previous research. Use of peers alleviates burden of diabetes care experienced by family members?	self-reporting level of support – participants informed of study purpose. Lack of follow-up. DSSI not time-specific: questioning over a set period of time more effective than in general?
5	<i>Use of multisystemic therapy to improve regimen adherence among AWT1Din chronic poor metabolic control – (Ellis et al., 2005)</i>	Multisystemic therapy: intensive home & community-based family therapy. Treatment goals individually designed for each participant. Targets adherence problems in family system, peer network & community.	RCT with repeated measures. Assigned to MST or control condition. MST = 6 months of therapy plus standard care. Control -= standard care only.	Diabetes Family Behaviour Checklist, Family Relationship Index of the Family Environment Scale, frequency of BGM, HbA1c.	Relationships: Effect of treatment on primary caregiver support non-significant, but significant on secondary caregiver compared with control. Adherence: Significant main effect of treatment on BGT & improvement in metabolic control. Controls worsened. SEM: MST improved support in 2 parent, but not single parent families. Primary caregiver support did not mediate the effect of MST on BGT. BGT mediated effect of MST on HbA1c in single but not two parent families.	Sig improvements in relationships as result of MST only in two parent families: increase in support from primary and secondary caregiver. No improvement in relationships/support in single parent families (greater burden?) but improvements in BGT & were the only group to show a clinically relevant improvement in HbA1c. Two-parent families had significant improvements in BGT but not HbA1c. MST strongly associated with improved BGT.	Self-report data, included only a single aspect of adherence (BGT). Only reports outcome at treatment termination. Outcomes just due to attention?
6	<i>A randomized control trial of</i>	Calls made by a specialist	RCT. Randomised to a control,	HbA1c, self-efficacy,	Significant correlations between age and average	Removal of standard care in conjunction with NTS	Not sufficient statistical power to



	<i>the effect of negotiated telephone support on glycaemic control in young people with T1DM - (Howells et al., 2002)</i>	paediatric dietitian trained in counselling. Designed to provide support and assistance. Participants chose subject of the call and did not have to focus on disease management.	continued routine management + NTS, or removal of standard clinical case + NTS.	barriers to adherence, problem solving and diabetes knowledge	length of call and frequency. School and social topics discussed frequently. After 1 year, significant improvement in self-efficacy, no difference in glycaemic control. Barriers to adherence were a significant predictor of HbA1c.	produced no differences – as good as clinic visits? No improvement in HbA1c. Improvements in self-efficacy were observed despite only having diabetes-centred calls if required by participants. Structured but basic counselling about general life problems appears to help participants feel able to overcome the barriers to self-care. Contact, independent of content, appears to be key.	assess change in HbA1c
7	<i>Evaluation of an online education and support intervention for adolescents with diabetes - (Nicholas et al., 2012)</i>	Eight sequential online information modules and an online forum for discussing modules, moderated by a social worker.	RCT. Participants randomly assigned to the intervention or a control group.	Children's inventory of social support (CISS) and post-intervention interviews	Four themes: experiences of diabetes, means of participation, benefits of the intervention and challenges in the intervention. Outcomes indicated interventional gains approaching significance in participant's quality of relationships. Interviews identified beneficial impact of decreased isolation, knowledge gain and normalisation of experience.	Primary gain was online interactivity with peers. Lack of significance in CISS scores may reflect that while the intervention was perceived as beneficial, it was limited in scope regarding overall social support network and sample size. Shift in peer support too nuanced to be detected by a generic measure. Ultimately, the intervention "normalised" experiences = reality of isolation and stigmatisation.	None outlined
8	<i>An office-based intervention to maintain parent-</i>	Four sessions of patient & family education	RCT. Participants randomly assigned to intervention, attention control	Interview, Diabetes Family Conflict	No significant differences in attention control and standard care conditions after 12 months. Intervention group	Parent involvement in self-care can be improved through a low-intensity intervention integrated into outpatient	Sample size of 85 homogenous families results in a lack of

<i>adolescent teamwork in diabetes management</i> – (Anderson, Brackett, Ho, & Laffel, 1999)	sessions on the importance of parent-adolescent responsibility sharing & conflict management. Sessions prior to clinic visits over 12 months, involved active family discussion and negotiated responsibility sharing plan.	of traditional diabetes education or standard care control.	Scale, Diabetes Family Behavior Checklist, HbA <sub>1c</sub>	parents maintained involvement in diabetes management, control parents declined. Teamwork families reported a significantly greater decrease in diabetes-related conflict compared to no change in the control groups. All parents reported a decrease in unsupportive behaviour; intervention group reported a significantly greater decrease in negative behaviours than the controls. Over 24 months, intervention group had 2.4 times greater chance of improving their HbA <sub>1c</sub> than the control.	care. Promisingly, this increased involvement did not result in increased diabetes-specific conflict, as has been shown in previous research. Greater parental support was associated with improved glycaemic control at 24 month follow-up, reinforcing the value of parent-adolescent partnership.	generalisability. No at-risk adolescents (HbA <sub>1c</sub> >8%) were included in the research, which could yield differing results.
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Table 2. Summary of patient characteristics

Study	<i>n</i>	Age	Country	Duration of diabetes	Follow-up time
1. Kaplan, Chadwick, & Schimmel (1985)	21	13-18	USA	No minimum	None
2. Sims & Haines (2011)	6	13-17	USA	No minimum	3-4 months
3. Wysocki et al. (2001)	119	12-17	USA	> 1 year	12 months
4. Greco et al. (2001)	21	10-18	USA	< 18 months	None
5. Ellis et al. (2007)	127	10-17	USA	> 1 year	24 months
6. Howells et al. (2002)	79	12-15	UK	No minimum	12 months
7. Nicholas et al. (2012)	31	12-17	Canada	> 1 year	None
8. Anderson et al. (1999)	85	10-15	USA	> 1 year	24 months

*Table 3.* Interventions and outcomes of reviewed studies.

Study	Intervention	Outcomes			
		Behaviour	Psychosocial	Knowledge	Biomedical
1. Kaplan, Chadwick, & Schimmel (1985)	Summer school	++	NS	NS	+
2. Sims & Haines (2011)	Pharmacy-based	++	+	NA	-
3. Wysocki et al. (2001)	BFST	+	++	NA	NS
4. Greco et al. (2001)	Friend dyad	NS	++	+	NA
5. Ellis et al. (2007)	MST	+	+	NA	++
6. Howells et al. (2002)	Telephone	+	+	NA	NS
7. Nicholas et al. (2012)	Online	NA	++	NA	NA
8. Anderson et al. (1999)	Teamwork	++	++	NA	+

+: Positive effect; ++: Positive effect on multiple measures; -: Negative effect; NS: Non-significant; NA: Not assessed

*Table 4.* Methodological quality of the studies as assessed by the Jadad scale (Jadad et al., 1996)

Study	Quality			
	Randomisation	Blinding	Withdrawal	Total
1. Kaplan, Chadwick, & Schimmel (1985)	1	0	1	2
2. Sims & Haines (2011)	0	0	1	1
3. Wysocki et al. (2001)	1	0	1	2
4. Greco et al. (2001)	0	0	1	1
5. Ellis et al. (2007)	1	0	1	2
6. Howells et al. (2002)	2	1	1	4
7. Nicholas et al. (2012)	1	0	0	1
8. Anderson et al. (1999)	2	0	1	3

## Discussion

The review demonstrates that interventions trials targeting social support in AWT1D are surprisingly scarce. Most of the eight reviewed studies provide evidence supporting the influential role of social support in diabetes management.

The interventions studied were highly heterogeneous and were not considered to be comparable through meta-analysis. As a result, a precise definition of social support could not be derived from the review. The interventions could be classified as those targeting existing support networks including family and friends, and those hoping to facilitate new networks including peers with T1D, counsellors and clinicians. From the results of this study, it could be suggested that those focusing on existing networks show far greater promise in improving psychosocial and diabetic outcomes than creating additional support. This is consistent with previous research which has suggested that fostering new relationships is only of value when current networks are small, overburdened or unable to provide effective support (Heaney & Israel, 2008a).

Surprisingly, biomedical outcomes were assessed in only six of the eight trials, and improved in only three. Only one study showed a decline in disease management post-intervention; the pharmacy-based intervention (Sims & Haines, 2011). The reason for this increase in HbA<sub>1c</sub> is unclear and affirms the challenge in attaining and preserving glycaemic control during adolescence. In addition, changes in HbA<sub>1c</sub> may take more time to be effective than allowed in this study, in which follow-up data was only collected 3-4 months post-intervention. Participation in the support group also did not require a minimum disease duration, so accurate measurement of HbA<sub>1c</sub> is called into question by adjustment to a new care routine. In addition, follow-up data was only collected from six participants, resulting in the analysis lacking in generalisability and statistical power. The potential value, therefore, of social support interventions in improving self-care cannot sufficiently be represented in this study.

Lack of methodological quality, however, was not isolated to Sims & Haines (2011). The quality of the studies was assessed as being particularly low on the Jadad scale (Jadad et al., 1996), with an average score of two out of a possible five. The only studies to display moderate to high methodological quality were Anderson et al. (1999) and Howells et al. (2002). Two of the studies failed to compare their intervention against a control (2,4) suggesting particularly low methodological quality and a basic failure to address the requirements of assessing the efficacy of an intervention. Both fail to provide a rationale for not including a control group. Similarly, only two studies were able to provide sufficient detail in the process of their randomisation to control or intervention groups (6,8), with most simply stating that participants were randomised. In the interests of replicability, this is lacking in information and

is therefore not methodologically sound. Blinding was also lacking in the studies, with only one addressing this source of potential bias in the findings (6). Most of the studies provided appropriate levels of detail concerning participant attrition in their research, except for one (7), which did not appear to lose any participants over the duration of the study, or failed to provide details of any withdrawals. These failures in methodological processes outline a requirement for high quality research assessing the validity of the interventions. All but one study (6) could be stated as succumbing to bias and, therefore, their conclusions cannot be considered reliable. Until high quality research is conducted assessing the efficacy of social support interventions, it remains a challenge for researchers and policy makers to definitively state the value of such programs. This is an obstruction that requires addressing.

Surprisingly, the selected investigations rarely based their interventions on existing models and theories of health behaviour, including the recent developments in the Behaviour Change Taxonomy (Michie, 2008). Even diabetes-specific models such as the Permanent Therapeutic Patient Education Model (World Health Organisation, 1988) or Anderson's patient empowerment model (1995) were not utilised. This demonstrates a specific and concerning oversight by the authors of these trials to employ established psychological theory in their research, and may go some way to explaining the failure of some of the trials in improving outcomes. Any future interventions should ground their research in theory in order to address these concerns. In addition, despite it having been previously found that increased stress and vulnerability result in enhanced benefit from social support in the prevention of diabetic complications (van Dam et al., 2005), neither perceived nor biological stress was assessed in any of the studies. Future research should also apply measures of stress to participants so that the role of social support in the mitigation of stress can be considered as a possible mechanism through which social support is beneficial to patients with diabetes.

A negative impact of social support was also found. Kaplan, Chadwick & Schimmel (1985) found a positive correlation between social support satisfaction and HbA<sub>1c</sub>, indicating that improved support was associated with poorer glycaemic control. Similarly, there was a positive correlation between the Means End Problem Solving Test and disease management. These correlations suggest that those most satisfied with their social support and those with the greatest social skill were actually in the poorest glycaemic control. The authors explained this as the support network providing a negative influence on self-care through the reinforcement of non self-management behaviour (Kaplan et al., 1985). This is not unusual; observational studies have previously suggested that a larger social network may impact negatively on diabetes management, and that greater satisfaction with social support may be related to worse glycaemic control, particularly in males (Glasgow et al., 2001; Song et al., 2012). Receiving more social support than required can be experienced as nagging or harassment, which may impact

negatively on adherence and self-care (Boehm, Schlenk, & Funnell, 1997). Indeed, an excess of instrumental support has been related to depressive symptoms (Wills & Shinar, 2000), with it damaging self-esteem through feelings of dependency. It is therefore reasonable to conclude that so-called “invisible support,” whereby the patient is unaware of receiving support (Maisel & Gable, 2009), may prove to be important in both achieving optimum glycaemic control and maintaining good psychosocial outcomes. Unfortunately, none of the reviewed intervention studies measured this or differentiated between types of support provided. This review cannot, therefore, conclude at what point social support can influence negatively on disease management, nor on the role of invisible support. Conversely, as none of the specific components of social support were measured in isolation, the most effective aspects of support also remain unidentified. Therefore, no optimal size of social network, or valuable mechanisms of it, could be established.

### **Limitations**

Some limitations of this review must be outlined. Firstly, the heterogeneous nature of the reviewed studies makes it difficult to compare findings. However, this served to underscore the review’s main conclusion; that social support is a fluid concept lacking in sufficient research and definition. Secondly, the small number of studies meeting the inclusion criteria of this review makes any conclusions precarious in their generalisability. Instead, the review concludes that the research body is lacking in evidence in order to make generalised statements about the efficacy of social support interventions in the studied population. Finally, the methodological quality of the studies was particularly low. The majority of the studies could be stated as succumbing to bias, which is therefore transferred to the results of this systematic review. Although it was initially hoped that low quality studies could be excluded, the lack of methodologically sound studies has meant that this would have made the review impossible. Instead a recommendation is made that high quality research is needed when assessing social support interventions, so that definitive conclusions regarding their efficacy can be made.

### **Clinical implications**

Actively involving friends and peers with T1D in diabetes management and intervention programmes may be favourable. An open discussion of what social support patients require should be encouraged. Healthcare professionals may wish to consider offering some of these methods of delivering social support such as online interventions, summer school programmes or adolescent-peer dyads. These low-cost methods of improving social support may be easily incorporated into care, and offered to patients to help them make informed decisions and improve adjustment, though further research is needed to determine if these interventions improve adherence and glycaemic control. It was also found that the majority of support

intervention research has taken place in the USA, and that a balance needs to be developed with research in other cultures for results to be conclusively accepted.

### **Conclusion**

None of the reviewed studies assessed the different components of social support in their analysis, which constricts the ability of the present review to identify which aspects of social support could be considered beneficial or limiting for adolescents with T1DM. Further research is therefore warranted to identify these components, and particularly the point at which useful support becomes nagging or harassment, and the potential role of invisible support.

It would appear that involving existing friends and introducing peers with T1D into an intervention is relevant for health and psychosocial outcomes. This particular social network shows promise in both face-to-face and internet settings. The use of clinicians and counsellors, however, does not appear to be effective at improving psychosocial or health outcomes. It could be suggested that these are instead used as an additive to a friend or peer based social network, in order to maintain or enhance formalised diabetes care.

Well-designed trials of interventions targeting social support in the case of AWT1Dare warranted in order to identify the most beneficial components and sources of social support in improving the problem of diabetes management in adolescents with T1DM.

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### Appendix U: Systematised review of salivary OT studies

Article	Participants	Mean OT (pg/ml)
Bhandari R, Bakermans-Kranenburg MJ, van der Veen R, Parsons CE, Young KS, Grewen KM, Stein A, Kringelbach ML, van IJzendoorn MH. Salivary oxytocin mediates the association between emotional maltreatment and responses to emotional infant faces. <i>Physiol Behav.</i> 2014 May 28;131:123-8.	Adult	2.65
Koven NS, Max LK. Basal salivary oxytocin level predicts extra- but not intra-personal dimensions of emotional intelligence. <i>Psychoneuroendocrinology.</i> 2014 Jun;44:20-9.	Adult	9.4
Seltzer LJ, Ziegler T, Connolly MJ, Prososki AR, Pollak SD. Stress-induced elevation of oxytocin in maltreated children: evolution, neurodevelopment, and social behavior. <i>Child Dev.</i> 2014 Mar-Apr;85(2):501-12	Children (8-11.5 years old)	12.37
Apter-Levy Y, Feldman M, Vakart A, Ebstein RP, Feldman R. Impact of maternal depression across the first 6 years of life on the child's mental health, social engagement, and empathy: The moderating role of oxytocin. <i>Am J Psychiatry.</i> 2013 Oct;170(10):1161-8.	Children (M= 6.33 years)	5.9-7.1 (6.5)
Feldman R, Gordon I, Influx M, Gutbir T, Ebstein RP. Parental oxytocin and early caregiving jointly shape children's oxytocin response and social reciprocity. <i>Neuropsychopharmacology.</i> 2013 Jun;38(7):1154-62.	Children (3 years)	7.18
Blagrove M, Fouquet NC, Baird AL, Pace-Schott EF, Davies AC, Neuschaffer JL, Henley-Einion JA, Weidemann CT, Thome J, McNamara P, Turnbull OH. Association of salivary-assessed oxytocin and cortisol levels with time of night and sleep stage. <i>J Neural Transm.</i> 2012 Oct;119(10):1223-32.	Adult	13;16
Holt-Lunstad J, Birmingham W, Light KC. The influence of depressive symptomatology and perceived stress on plasma and salivary oxytocin before, during and after a support enhancement intervention. <i>Psychoneuroendocrinology.</i> 2011 Sep;36(8):1249-56.	Adult	9;16
Feldman R, Gordon I, Zagoory-Sharon O. The cross-generation transmission of oxytocin in humans. <i>Horm Behav.</i> 2010 Sep;58(4):669-76.	Infant	16.37

### Appendix V: Variance in biomarker samples

The following were removed due to discrepancy between the two samples being too large to calculate a reliable average:

#### *OT*

Participant	Sample 1	Sample 2
029711C	15.72	2.73
029836C	20.3	1.64
029677C	.79	13.2
019524	27.18	43.77
029627	10.56	.78
029836	16.9	6.59

#### *Cortisol*

Participant	Sample 1	Sample 2
029714	200.5	410
029836	8925	5919
019870	1636	2397

## Appendix W: Tests of assumptions for Study 2

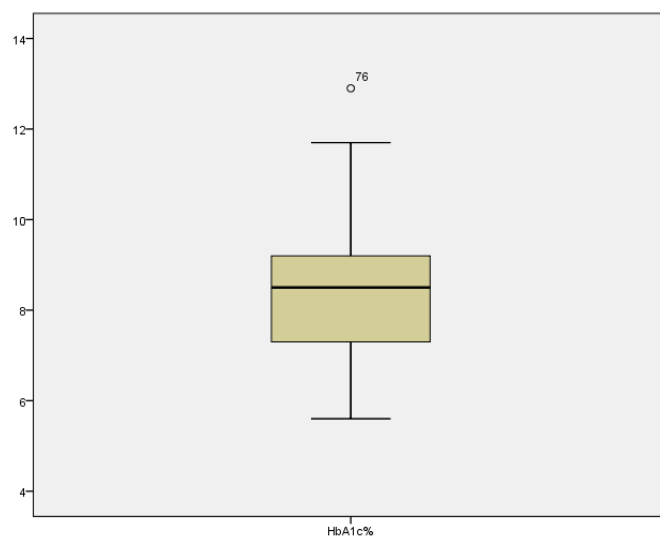
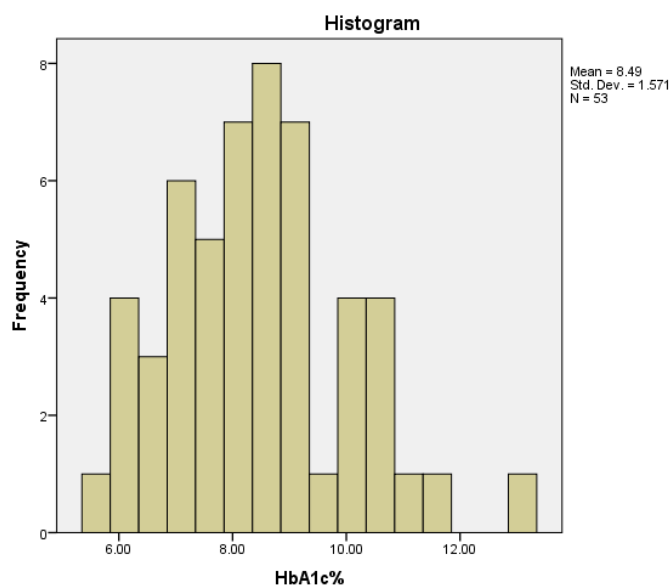
Tests of Normality

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
HbA1c%	.080	53	.200*	.978	53	.425
OTpg/ml	.127	53	.032	.938	53	.009
Cortpg/ml	.144	53	.008	.895	53	.000
TotalSCIR	.068	53	.200*	.982	53	.620

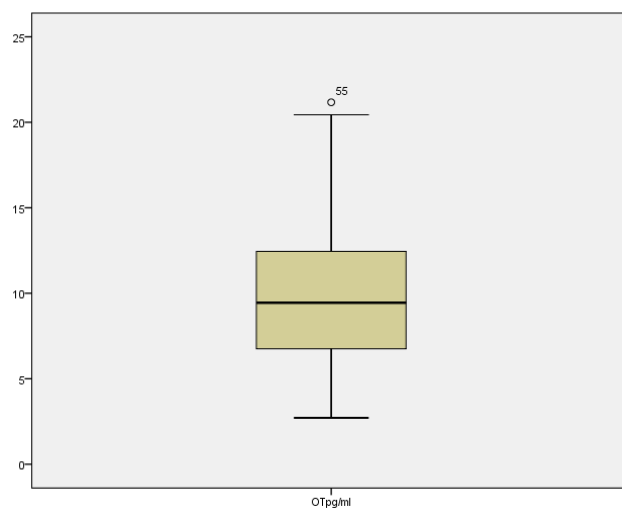
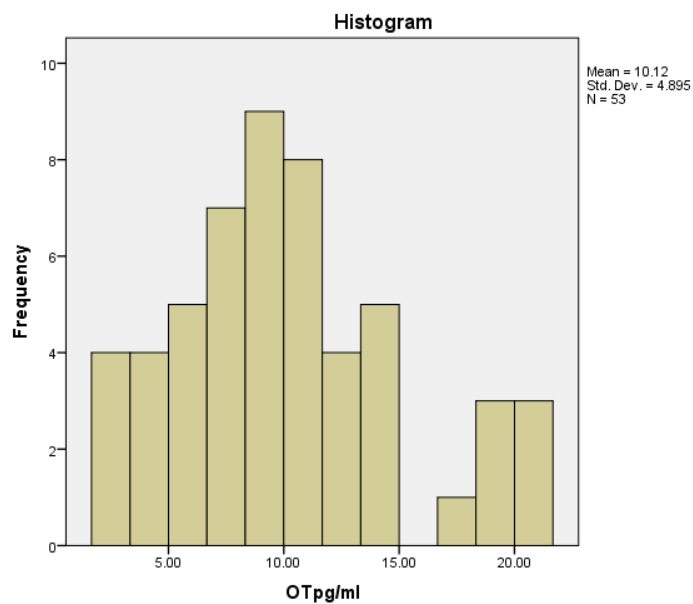
\*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

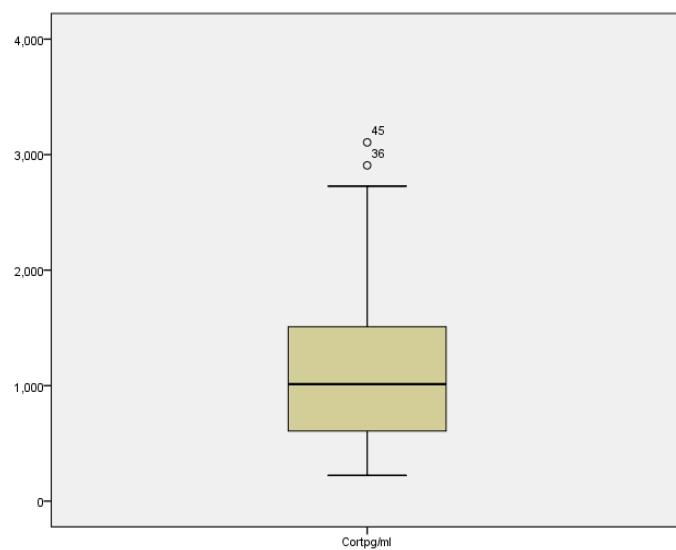
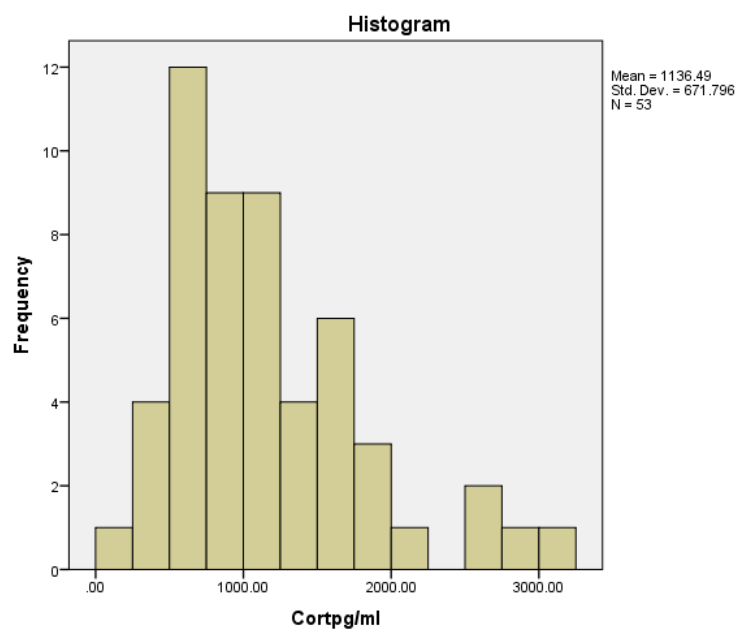
### Glycaemic control (HbA<sub>1c</sub>)



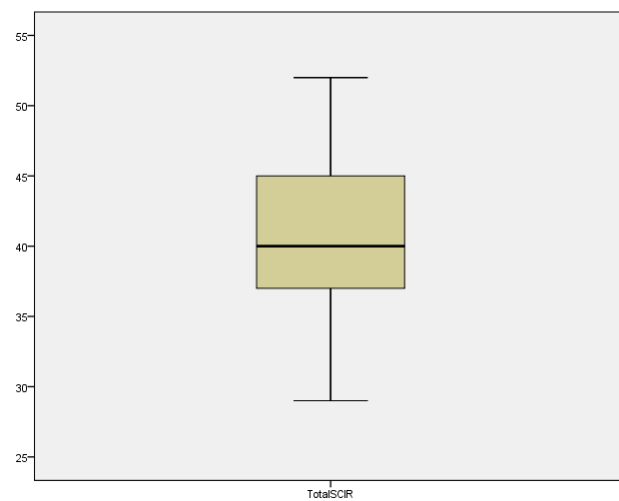
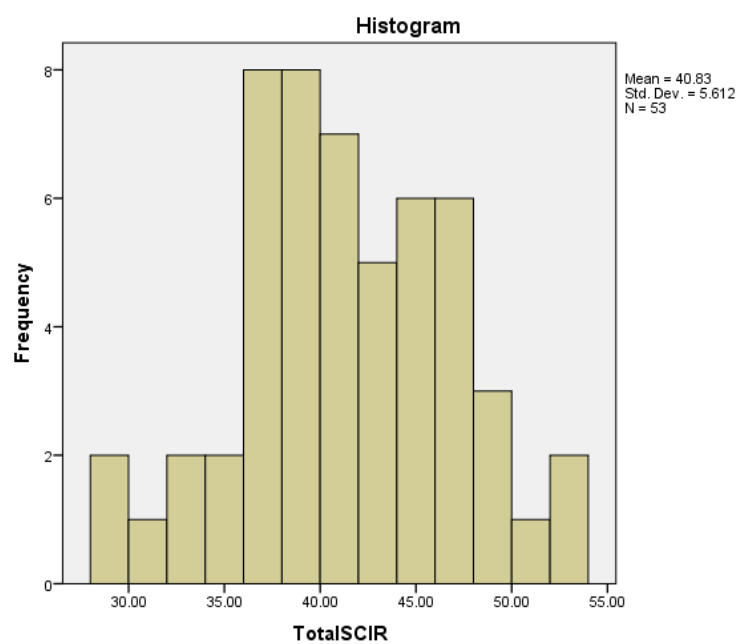
### OT (pg/ml)



### Cortisol (pg/ml)



### Self-care (SCIR)

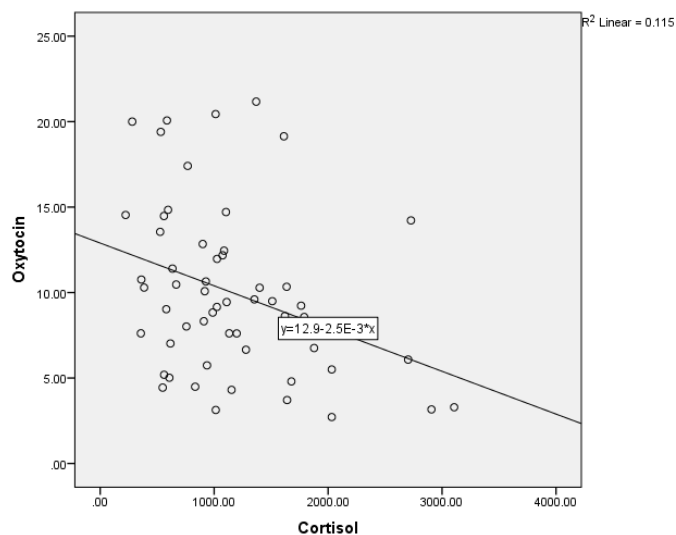




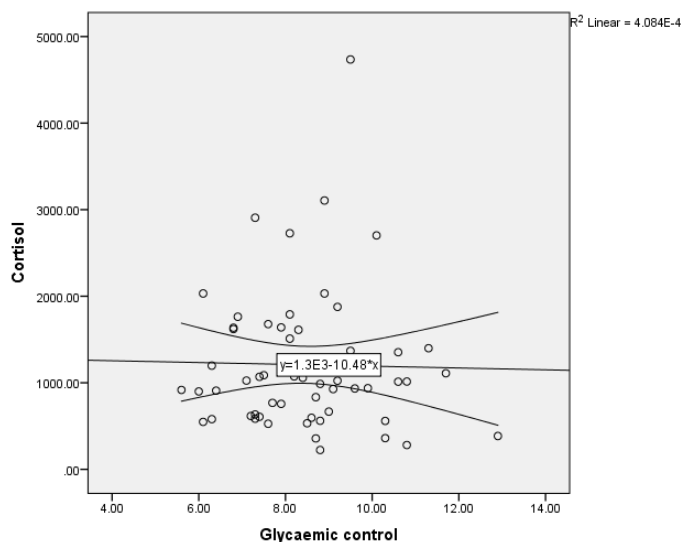
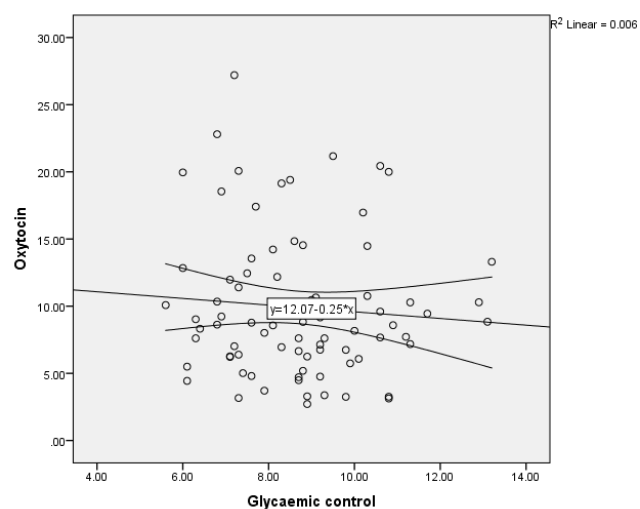
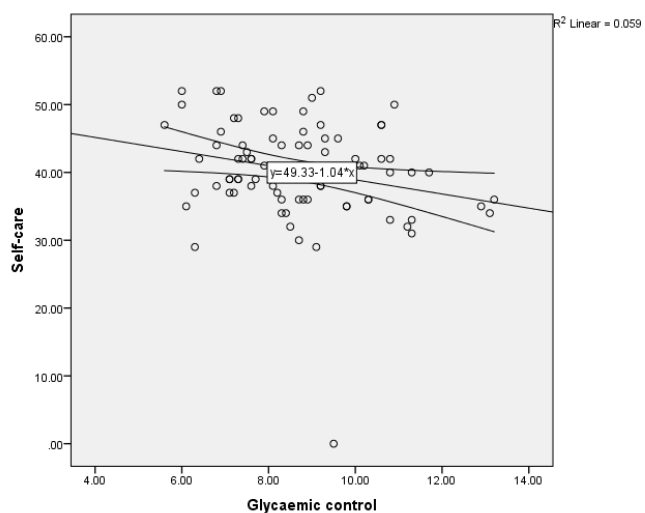
## Appendix X: Plots for Study 2

### Hypothesis 1: Stress-buffering hypothesis

- v. Increased salivary OT will be associated with reduced salivary cortisol.

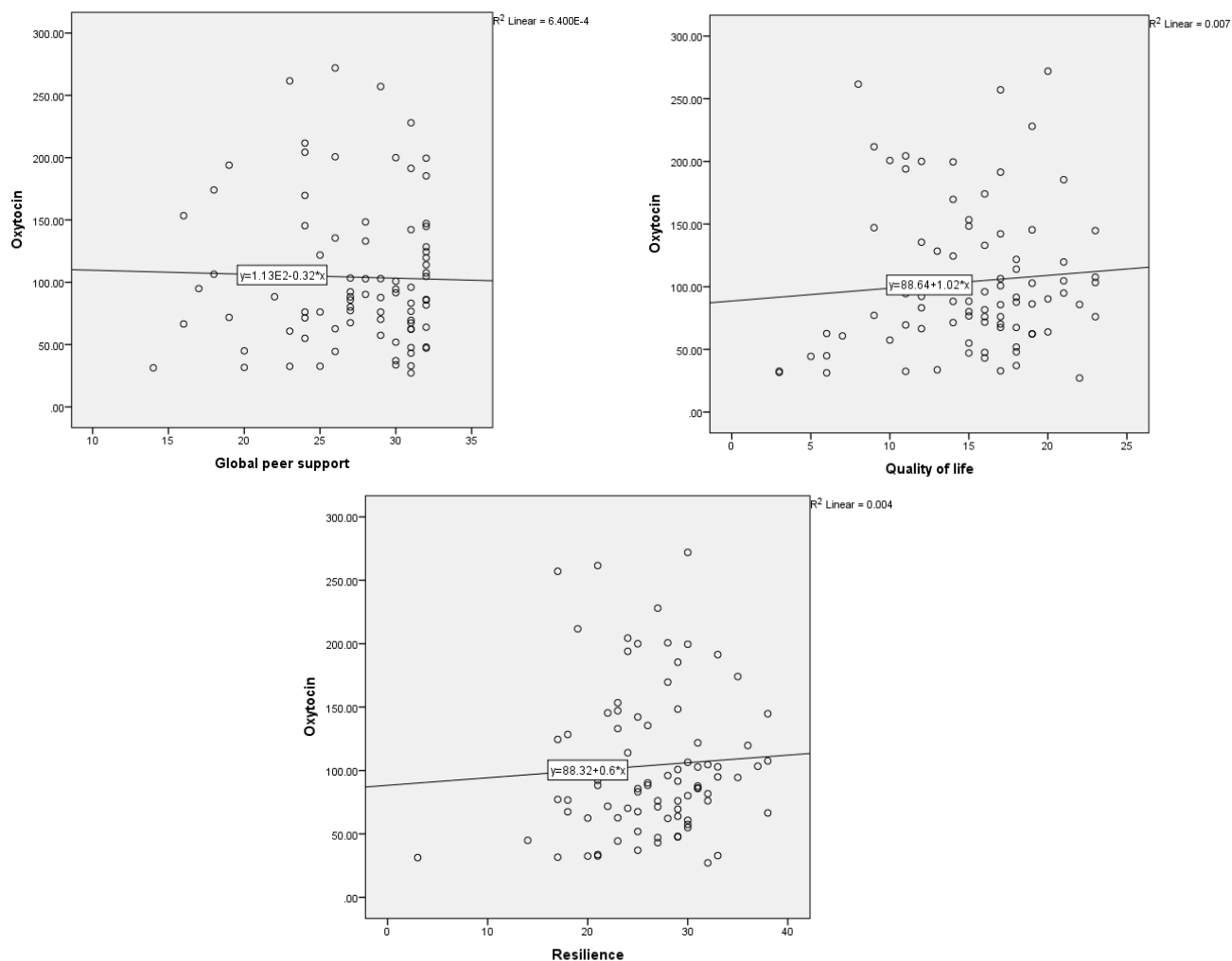


- vi. Increased salivary OT and reduced salivary cortisol will be associated with improved glycaemic control ( $HbA_{1c}$ ) when controlling for self-care behaviours.

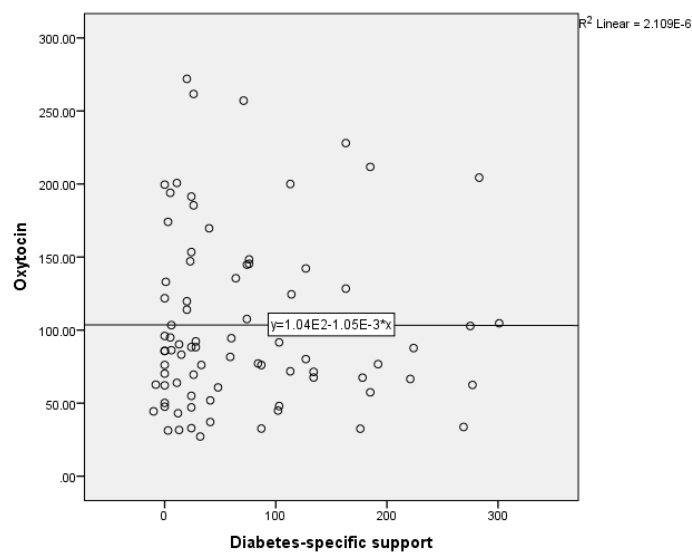


#### Hypothesis 4: Oxytocin and peer support

iii. Salivary OT will be positively related to greater global peer support, QoL and resilience.



iv. Salivary OT will be negatively related to greater diabetes-specific peer support, due to the findings of Study 1.



## Appendix Y: Reference participant information sheet



### **Research Project:**

#### **The influence of social support on disease management in adolescents with type 1 diabetes**

We are asking if you would like to join in a research project to find out more about how people your age with Type 1 Diabetes use support from their friends and family to manage their Diabetes. Before you decide if you want to take part, it's important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. If you want to, you can talk to your family, friends, or anyone else whose advice you would like.

#### **Why are we doing this research?**

Being a teenager involved a lot of physical and emotional change. It is also a time when young people establish their identity and independence. Teenagers with diabetes have the additional problem of having to manage their illness. Control of their blood sugar often gets worse, partly due to a lack support from family and friends. Research has also found that those at higher risk of not coping well with diabetes when they are a teenager include girls, older adolescents (16-18), people lacking in social support, and those with high blood sugar.

#### **What do we want to do?**

The research team want design an intervention for teenagers to improve the quality of the support they receive from friends, and therefore hopefully the control of their Diabetes. For this intervention to be effective, it is important that we compare the support received by teenagers who don't have Diabetes to judge how different it is. Therefore, we are inviting you to take part in the pilot study to help find out how the way you use your family and friends for support is different to someone your age with Type 1 Diabetes.

#### **Why have I been invited to take part?**

You have been invited to participate in the study because you are in our target age group, age 15-18. We are looking for twelve participants at this stage as this is a pilot study, meaning that we are testing out the methods ready for a larger trial later on.

#### **Do I have to take part?**

No. It is up to you. We will ask you for your consent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason.

### **What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get might help young people with Type 1 Diabetes in the future. You will help us to understand the differences between social support in teenagers with and without Diabetes, which might help important new techniques and interventions be designed in future.

### **What will happen to me if I take part?**

You will only meet with the researcher once, and will be asked to complete two tasks during this time:

5. You will be asked to provide two samples of saliva, one immediately after the other. These saliva samples will be analysed for a hormone released for social bonding, called oxytocin. Saliva sampling is quick and painless, and involves chewing on a piece of foam called a Salivette for 60 seconds. Your sample will only be tested for level of oxytocin; no other tests will be performed on your saliva.
6. Participants will then be asked to complete some questionnaires. This will take 15-20 minutes and will enable us to get a better picture of the type of social support you get and what you find best about it.

It is expected that participation would take around 20 minutes in total, depending on how quickly you work through the questionnaires. You will not need your parents to be there to take part, but you can ask for them to be there if you would feel more comfortable.

### **What will happen to the samples I give?**

You will be asked to give two saliva samples if you choose to take part in the study. These will be allocated an ID code used to identify them as yours to the research team, but your name and details will not be written on the sample. They will be stored in a locked refrigerator in a secure laboratory at the University of Northampton, which only members of the research team will have access to. After your samples have been analysed for oxytocin and the results have been recorded, they will be destroyed as instructed by government guidance. The results of your sample will be confidential.

### **Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by NHS West Midlands Research Ethics Committee and the University of Northampton Ethics Committee. The researcher has been cleared to conduct research by the NHS and has passed a Criminal Records Bureau check.

### **Who do I contact if I have any questions?**

Miss Emily Doe

Phone: 01604 892537

Email: [emily.doe@northampton.ac.uk](mailto:emily.doe@northampton.ac.uk)

## Appendix Z: Reference participant consent form



### Research Project:

### The influence of social support on disease management in adolescents with Type 1 Diabetes

#### Participant Consent Form

Circle yes or no for each statement:

Have you received information about this project?

YES / NO

Have you asked all the questions you want?

YES / NO

Have you had your questions answered in a way you understand?

YES / NO

Do you understand that if you change your mind, you can withdraw from the study?

YES / NO

Are you happy to take part?

YES / NO

If any of the answers are NO or you DO NOT wish to take part **DO NOT SIGN YOUR NAME**. By signing you confirm that:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the above study.

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix AA: Reference participant parent information sheet



### **Research Project:**

#### **The influence of social support on disease management in adolescents with Type 1 Diabetes**

#### **Information for Parents**

We are asking if you would permit your son/daughter to join in a research project to find out more about how adolescents with Type 1 Diabetes use social support to manage their Diabetes. Before you decide if you will allow your son/daughter to participate, it's important to understand why the research is being done and what it will involve for participants. Please consider this information sheet carefully and feel free to discuss it with your son/daughter and others.

#### **Why are we doing this research?**

Adolescence is a period of major physiological and psychological changes, and is also characterised by an effort in young people to establish their identity and independence. Teenagers with diabetes have the additional burden of illness management. Glycaemic control can deteriorate during adolescence, partially due to the lack of quality social support. Studies have also found that those at greatest risk of poor psychological adjustment to diabetes during adolescence include girls, older adolescents, children lacking in social support, and those with higher HbA<sub>1c</sub>.

#### **What do we want to do?**

The research team are aiming to design an intervention for adolescents to improve the quality of the support they receive from friends, and therefore hopefully their glycaemic control. For this intervention to be effective, it is important that we compare the social support received by healthy adolescents to see how effective it is. Therefore, we are inviting your son/daughter to take part in the pilot study to analyse how their social support differs from an adolescent with Type 1 Diabetes.

#### **Why has my child been invited to take part?**

Your son/daughter has been invited to participate in the study because they are in our target age group, age 15-18. We are looking for twelve participants at this stage as this is a pilot study.

#### **Do they have to take part?**

No. It is up to you and your child to decide. We will ask you for your consent and then ask if you would sign a form, and the same for your son/daughter. You will be given a copy of this information sheet and signed consent forms to keep. Your child is free to stop taking part at any time during the research without giving a reason.

#### **What will happen to them if they take part?**

They will only meet with the researcher once, and will be asked to complete two tasks during this time:

1. They will be asked to provide two samples of saliva, one immediately after the other. These saliva samples will be analysed for a hormone released during social bonding, called oxytocin. Saliva sampling is quick and painless, and involves chewing on a piece of foam called a Salivette for 60 seconds. Samples will only be tested for levels of oxytocin, no other analysis will be performed on samples provided by your child.
2. Participants will then be asked to complete some questionnaires. This will take 15-20 minutes and will enable us to gain a better picture of the type of social support participants currently experience and what they find most beneficial.

It is expected that participation would take approximately 20 minutes in total, depending on how quickly participants work through the questionnaires. You will not need to be present for the duration of their participation, though can be present if you so wish.

**What are the possible benefits of taking part?**

We cannot promise the study will help your child, but the information we get might help young people with Type 1 Diabetes in the future. Their contribution will help researchers to better understand the differences between social support in adolescents with or without diabetes, which might help important new techniques and interventions be designed in future.

**Who do I contact if I have any questions?**

Miss Emily Doe

Mobile X03 Park Campus

University of Northampton

Northampton

NN2 7AL

Phone: 01604 892537

Email: emily.doe@northampton.ac.uk

OR

Professor Jorg Huber

CHWB Sunley Conference Centre

Northampton

NN2 7AL

Phone: 01604 893633

Email: jorg.huber@northampton.ac.uk

**Thank you for reading so far – if you are still interested, please go to Part 2**

## Part 2

This section contains more detailed information if you wish your child to participate.

### **What happens when the research project stops?**

When the results have been analysed, the research team will invite you to a presentation at the clinic where your child's results will be anonymously presented to the group of participants, parents and members of the Diabetes Care Team. Your child will also be able to request a short report on their results if they wish.

### **Will anyone know that they are doing this?**

Your son/daughter's information will remain private and confidential. Participants will be allocated an ID code which will be used to identify them to the research team. This will be the only identification used on any data held about them, so results will be entirely anonymous.

At the end of the study we will prepare a presentation. This will be a summary of the results and will be made available to participants, parents and members of the Diabetes Care Team that wish to attend. The presentation will be anonymous and no participants will be identified.

### **What will happen to any samples given?**

Your son/daughter will be asked to give two saliva samples if they choose to participate in the study. These will be allocated an ID code used to identify them to the research team, so that name and details will not be written on the sample. They will be stored in a locked refrigerator in a secure laboratory at the University of Northampton, which only members of the research team will have access to. After the samples have been analysed for oxytocin and the results have been recorded, they will be destroyed in accordance with government guidance.

As the samples will only be analysed for levels of the social bonding hormone, oxytocin, nothing medically relevant will be found from the study. Therefore the results will remain confidential.

### **Who is organising or funding the research?**

This research forms the basis of the doctoral study of the lead researcher, Miss Emily Doe. It is funded by the Centre for Health and Wellbeing at the University of Northampton.

### **Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by NHS Staffordshire Research Ethics Committee and the University of Northampton Ethics Committee. The researcher has been cleared to conduct research by the NHS and has passed a Criminal Records Bureau check.

Thank you for reading this information sheet. Please use the above contact details if you have any questions regarding the study.



## Appendix BB: Reference participant parent consent form



### Research Project:

**The influence of social support on disease management in adolescents with Type 1 Diabetes**

### **Parent Consent Form**

Research Centre: University of Northampton

Name of Researcher: Miss Emily Doe

**Please initial in the boxes**

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without their legal rights being affected.

3. I agree for my child to take part in the above study.

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Child: \_\_\_\_\_

### Appendix CC: Tests of assumptions for Study 3

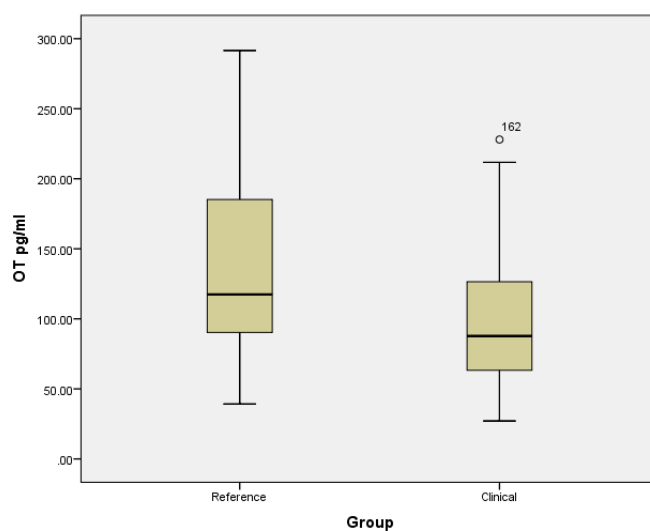
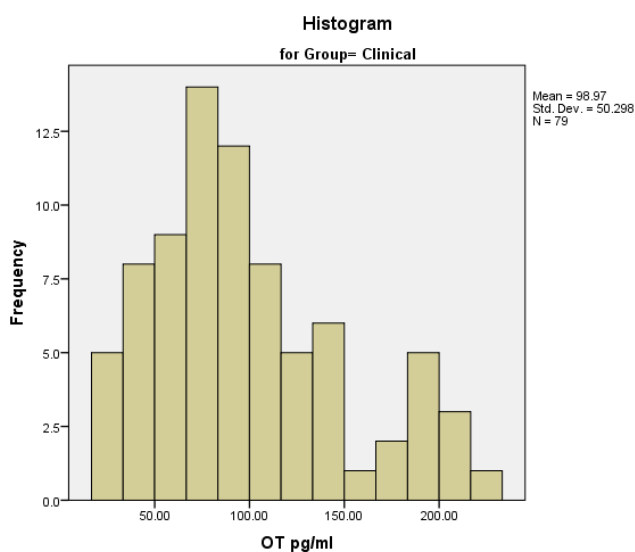
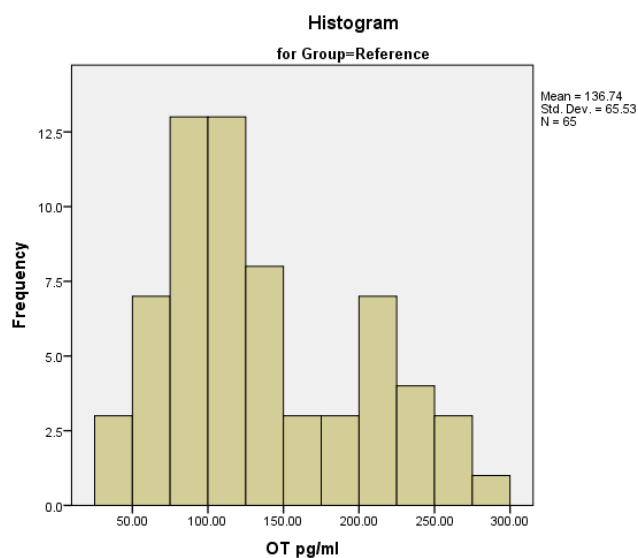
#### Tests of Normality

	Group	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
OT pg/ml	Reference	.148	65	.001	.936	65	.002
	Clinical	.131	79	.002	.924	79	.000
TotalBSSS	Reference	.159	65	.000	.909	65	.000
	Clinical	.174	79	.000	.863	79	.000
TotalWHO	Reference	.103	65	.083	.962	65	.045
	Clinical	.110	79	.019	.962	79	.019
TotalCD	Reference	.082	65	.200*	.978	65	.315
	Clinical	.089	79	.189	.985	79	.480

\*. This is a lower bound of the true significance.

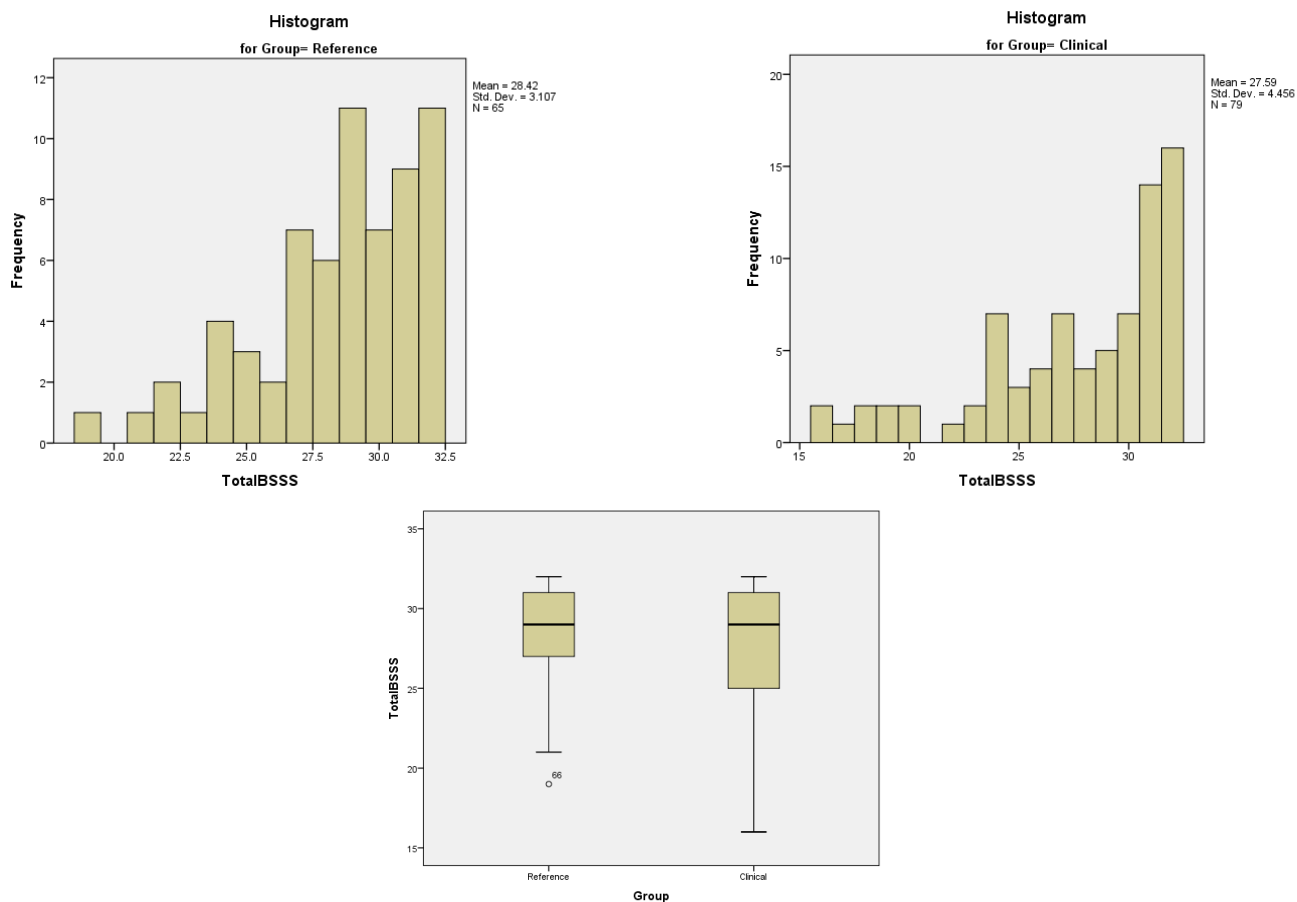
a. Lilliefors Significance Correction

#### Oxytocin (OT pg/ml)

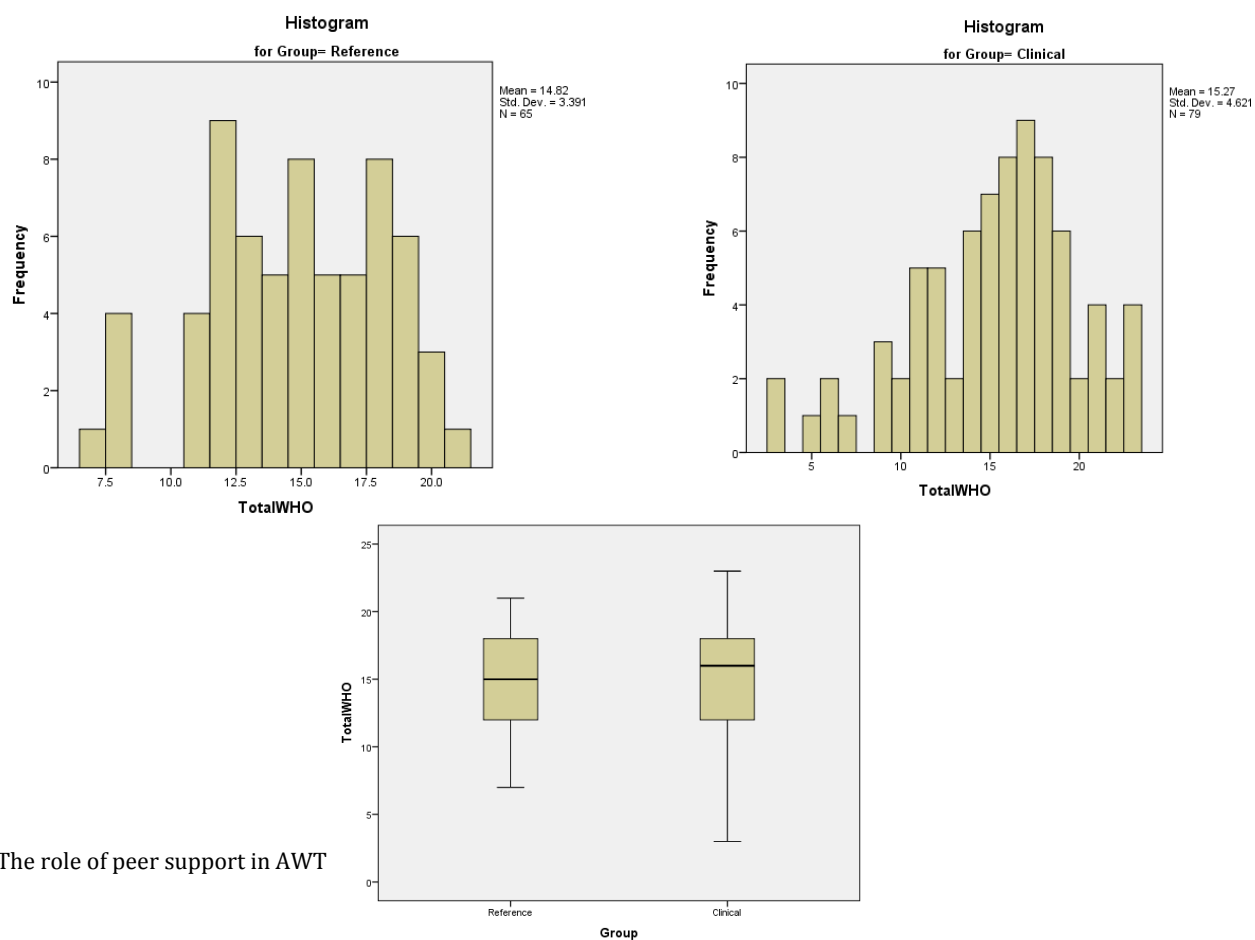


The role of peer :

## Global peer support (TotalBSSS)



## Quality of life (TotalWHO)



The role of peer support in AWT

## Resilience (TotalCD)

