Introduction

This paper aims to share the authors' experiences in meeting ethical considerations of conducting collaborative research with people with dementia, supporting them to be more than passive participants in research, but rather encouraging them to have an active role in decisions made during the research process. Collaborative research, is where participants take part in and influence the research process, resulting in shared knowledge production. However, true participation can be realised in different ways (Arnstein, 1969, White 1996) and may include tensions and ethical dilemmas, which require continuous reflection during the research process (Thoft et al. 2018). Through an exploration of some of their positive, and also unexpected experiences, the authors share their learning and challenges they faced.

When conducting collaborative research, there are several ethical considerations when involving people with dementia. These include issues of consent, capacity, support, and worries about meeting research ethics committee requirements, which may prevent researchers from involving people with dementia in research (Carmody et al., 2015). One central barrier is how to give voice to people with dementia in research. Historically, their contribution has been absent in the literature, leading to marginalisation of their voices and experiences in a range of both professional and academic contexts (Cowdell, 2008; Thoft et al., 2018). It is important to include people with dementia in collaborative research so that they may enhance our understanding of what it means to live with dementia and how societies can better support this group, reducing stigma and discrimination in both wider society and research (Thoft et al., 2018; Dewar, 2005). People with dementia are experts by experience and have a unique insight into what it means to live with dementia. There has been a welcome shift from focusing solely on the views of family carers and health professionals, towards more collaborative research. This shift is not only including the person with dementia but is also using research methods and public and patient involvement strategies to design and deliver research, which has the person with dementia at the heart of the research process (Tanner, 2012; Thoft, 2017; Stamou et al., 2018; Ward, 2019; Youell, 2015).

Existing knowledge

Collaborative research

People with dementia are becoming increasingly politically active in matters of their own care, policy and research (Weaks, Wilkinson, Houston & Mckillop, 2012; Bartlett, 2015; Williamson, 2015). This move to a more rights-based approach has also been seen in dementia research, where there is greater demand to include the views of people with dementia (Wilkinson, 2002; Wilkinson & Hubbard, 2003; Mckillop & Wilkinson, 2004). The shift has also come about through personal narratives, which emerge from dementia advocates, such as Kate Swaffer and Christine Bryden (Swaffer, 2015; Bryden, 2015; Bryden, 2018). This

presents a new view of dementia, which shows the need for greater experiential led models of understanding.

People with dementia also want to participate in research (Tanner, 2012), but still face constraints (Bartlett 2015; Rivett, 2017). According to Conder (2011) involvement in research can come in many guises and does not need to include all components of the research process, which can lead to restricted involvement, whereas collaborative research ideally is characterised by a partnership that enables participants to negotiate and engage in trade-offs with traditional powerholders (Arnstein, 1969). However, this is not always seen in praxis. Many people with dementia have the capacity and willingness to contribute to public life post-diagnosis and feel a strong sense of collective strength when they do unite (Bartlett, 2015). Many also want to participate in research so that they can support others living with the condition (Wiersma, 2011; Tanner, 2012; Youell, 2015; Ward, 2019). It is recognised that they can make a valuable contribution to research as active collaborative partners, whilst simultaneously benefitting from their involvement through empowerment and inclusion (Hubbard, Downs & Tester, 2003; Dewing, 2007; Hellström, Nolan & Lundh, 2007; Pipon-Young, Lee, Jones & Guss, 2011; Tanner, 2012). While there is a drive for greater involvement and collaboration in research for people with dementia, this can be a challenging journey for dementia researchers to navigate, particularly in light of the ethical considerations they must address.

Protection of people with dementia in research
Research involving humans raises several ethical, legal and social issues. It is internationally recognized that research involving human participants requires obtaining free and informed consent (World Medical Association, 1964). To protect autonomy, informed consent implies the ability to understand and rationally process relevant information to come to reasoned decisions about participation (World Medical Association, 1964; Bravo, PâQuet & Dubois, 2003). This affects the way research interaction and collaboration is viewed in the West, where we assume it to be based on rational autonomous individuals (Whitehouse, 2000). However, this collaboration can take a different form when working with people with dementia, as they may require support or adaptation.

How a researcher plans for and responds in situ to such situations could have an impact on the way that the person with dementia engages in the research. This response will in part be led by legislation but is also the result of personal morals and ethics (Hellström et al., 2007). Legislation designed to protect adults who lack sufficient capacity seeks to balance the preservation of autonomy and social commitment to advance knowledge (Bravo, PâQuet & Dubois, 2003; Mental Capacity Act, 2005). However, multiple ethical

frameworks, guidelines and systems of protection around people with dementia might reduce rather than increase their opportunities to have a voice in research (Burns, Hyde, Killett, Poland & Gray, 2014). By excluding people with dementia in research, their sense of autonomy may be eroded and could contribute towards a process of infantilisation (Hellström et al., 2007) or paternalism (Orb, Eisenhauer & Wynaden, 2004). This may increase stigmatisation of people with dementia as it can disempower, devalue and demean the person. Thus, leading to beliefs that people with dementia cannot speak up for themselves, and do not have the right to do so (Swaffer 2015). To reduce any sense of stigma that dementia may have by lay people, it is therefore important to address the ethical issues concerning collaborative research with people with dementia to enable their participation in a constructive and productive way.

In this article, the authors share experiences they encountered on their PhD journeys of conducting research with people with dementia, as participants and/or collaborative partners, involved in designing and running research projects. Drawing on their experiences, this paper highlights some of the key ethical considerations that may support researchers who are, or want to, work collaboratively with people with dementia. This paper addresses some of the issues which may be encountered as they plan and deliver their research, providing practical and methodological approaches which the authors found to have supported their own research. This article seeks to identify and discuss formal and practical ethical issues related to involving people with dementia in collaborative research. Issues related to setting, recruitment and consent are presented and discussed together with suggestions on how to prepare and conduct the study. The paper concludes with a rationale for involving people with dementia in research.

Methodology
All three PhD studies were conducted at the same university between 2012-2018 and included people with dementia in their research projects. Through this period all three authors regularly met and discussed ethical issues related to their projects, which led to the idea for this paper. As all three projects are based upon qualitative participatory methodology, on discussing how the use of such methods were encountered, the authors related several similarities and differences in their approach, which led to shared learning and understanding of working collaboratively with people with dementia. As a result, the authors felt this learning had relevance for other researchers and present their experiences through this paper. To give context to these experiences, a brief overview of each study is presented:
Youell's (2015) qualitative research aimed to better understand the relational impact of living with dementia, particularly the experience of intimacy and sexuality. Her study was conducted in the south of England with community-dwelling older couples living with a dementia diagnosis. Ward (2019) and Thoft's

(2017) studies were undertaken at a school for people with dementia, in the northern part of Denmark, which provides lifelong learning for people with dementia focusing on compensatory learning. Thoft's project aimed to develop a participatory research model for involving people with dementia in research. People with dementia collaborated with the researcher in peer-researcher led projects, deciding on their project aims, collecting data and participating in the data analysis and dissemination of results. Ward's (2019) study explored the use of participatory creative research methods that could support people with dementia to have a voice within the research process. Using photography and storytelling, Ward worked with her participants to explore their experiences of being students at the school and of their home lives. In the article both existing literature and own project quotes are used to support the learning and knowledge gained in collaboration with people with dementia. All names used in the article are pseudonyms.

The setting of the study

One of the first challenges, the authors faced, when planning collaborative research with people with dementia was how best to contact participants. Multiple layers of protection may surround people especially where 'vulnerability' is perceived. This means it can be difficult to allow each potential participant an opportunity to choose independently whether they wish to take part in your project (Youell, 2015).

Building a relationship with gatekeepers

Gatekeepers, who can support access to people with dementia, might be family caregivers, professionals or volunteers in dementia services. The authors found that gatekeepers can enhance or hinder the research process, therefore, developing good relationships can impact how, or even if, the research takes place. A finding reflected in Brooks, et al. (2017) study when recruiting participants where initial contact was made by hospital and care homes staff to comply with data protection regulation. Gatekeepers may feel that refusing participation is a way to protect the person with dementia from situations that might be upsetting or too difficult (Fisk & Wigley, 2000). Building trust with the gatekeepers may therefore be essential even before the consent process starts (Bull, Boaz & Sjostedt, 2014). Otherwise, different systems of protection may reduce rather than increase the opportunities for people with dementia to have a voice in research (Burns et al., 2014), which in turn can act to disempower and reduce our understanding of their embodied experience (Bartlett & Martin, 2002; Robinson, 2002; Orb et al., 2004). The authors found it can take time to identify the right gatekeepers and build a collaborative relationship, which can support a positive and constructive approach to engagement.

To elucidate this point, Youell experienced very different attitudes towards her research by two branches of local dementia charities. One branch was supportive whilst the other refused access because, as a professional researcher, her presence might alter the dynamics of the group and affect the levels of disclosure and peer support which was perceived by staff working with the group (Youell, 2015). Ward, on recruiting for her research project, was informed by a dementia service that she was not able to speak directly with people with dementia about her project and that while the service staff thought the project valuable and interesting, they could not think of anyone who would want to take part. This led to a change in project focus, time spent developing new relationships, ethical applications and project planning. This was a steep learning curve on the importance of managing and developing relationships with gatekeepers (Ward, 2019).

When developing the relationship, it is also important to be aware that gatekeepers might have their own agenda. Thoft experienced how the gatekeepers involved in her research were very supportive in establishing a positive contact with people with dementia but at the same time asked her not to include the spouses of the participants as they had previously experienced that they could take over, not allowing the voice of people with dementia to be heard. This became a restriction, which was managed by providing relatives with comprehensive project information, so they still felt included, and which supported participants to talk about the research project at home (Thoft, 2017). These examples show that researchers need to be flexible to the needs and procedures of gatekeepers, potentially having to compromise on the original study design or doing additional work to maintain positive relationships. This can take time and energy, which many researchers may not have factored into their projects.

Choosing the right setting
The authors found a good way to choose the right setting was to identify places/services where people with dementia regularly attend. These spaces represent a safe and supportive atmosphere in which to conduct a study and to work within an established organisation, an important factor which was supported by Robillard and Feng (2017). Furthermore, it gives the advantage that the participants already know each other, which in turn can support opportunities for successful collaboration. Researchers can also recruit a number of participants in a relatively short period of time, which can otherwise be challenging with vulnerable groups (Dewar, 2005). However, there is a caveat here, as choosing a place/service where people with dementia already attend might only give access to certain groups of people with the risk of excluding those who are not as outgoing, have more advanced dementia or have limited access to

transport (McKeown, Clarke, Ingleton, Ryan & Repper, 2010; Roy, 2012). The authors recognise there is also a paucity of representation from the Black, Asian and minority ethnic or lesbian, gay, bisexual, transgender, intersex and queer/questioning community (McGovern, 2014). This means only some people with dementia get the opportunity to be involved in research while other, perhaps more vulnerable people, remain stigmatised and marginalised (Roy, 2012). Future initiatives for including different groups of people with dementia are therefore needed.

Youell found that working with the local Memory Assessment Service enhanced her ability to recruit participants. She was allowed access to a monthly post diagnostic support meeting where those who had been recently diagnosed were asked to attend an information day. Youell was offered a ten-minute slot to promote her research. The majority of her participants were recruited through this approach. However, in order to attend these meetings, Youell was required to hold a temporary contract with the NHS, which involved further ethical procedures. It is important for organisations, such as the NHS, to involve researchers from outside the service, as this can bring new ways of seeing and understanding processes and systems. It may be useful for researchers and organisations to be aware that meeting further ethical procedures may add time to already pressured deadlines.

Building a relationship with the potential participants
The authors identified that a particularly important aspect of working with people with dementia, is the participant research relationship. This relationship starts before any contact is made with potential participants, is a way to support participation, and can continue after completion of the study (Barnett, 2000; Dewing, 2002; Dewing, 2007). This can be a person-centered way of conducting research, giving the researcher a greater understanding of the participants, and enabling them to be more responsive to participant's needs (Swinnen & de Medeiros, 2018). Empathy and listening skills were identified as important by the authors, as a way to support collaboration with people with dementia, who can often feel that they are no longer heard or included in decision-making (Alzheimer´s Society, 2010). Emma explains how being involved in Thoft's research challenged the negative feeling of having dementia, suddenly Emma felt part of a team, instead of being excluded from society:

> … do not feel put aside with a dementia but feel that you can begin that I can do that then, and I can use for something … you, you get on the team in a way … yes even though you may feel more and more outside because you could not be picked up or otherwise (Thoft, 2017)

A further learning point was the importance of giving time to establish these constructive research relations. However, this can be challenging as there is limited good practice guidance and a one-fits-all approach is not suitable (Staniszewska, 2009; Dupuis, Gillies & Carson, 2012). Thoft spent time with her potential participants prior to starting her study, giving the opportunity to familiarise themselves with each other in an informal way, and to explain the study in a sensitive and unhurried manner. It could be argued that such a relationship can make it difficult to refuse to participate. This was not the case in Thoft´s study, where three participants declined to participate, stating they felt they could be honest in expressing their decision due to their familiarity with Thoft. Ward and Youell similarly found that attending meetings and liaising with the professionals running the service, led to a shared trusting relationship developing between themselves, the service and potential participants. This face-to-face contact prior to formal participation proved invaluable for all three authors, it was a way to allay fears or concerns from potential participants and supported decision making as to whether to participate. Spending time with potential participants prior to recruitment also enabled the researchers to develop knowledge about the participants´ competences, all of which was thought to work to form a constructive start of the research projects. This approach is supported by Robillard and Feng (2017) whose feedback to an exploratory session with people living with dementia and the general public suggested that potential participants preferred research coordinators to obtain consent as opposed to clinicians. This suggests that researchers can dedicate more time to discuss research projects and are unbiased in terms of medical care provision.

The use of an ethical framework can be helpful in working through some of these ethical decisions when working with people with dementia. Often the first consideration researchers have when exploring the ethics of their study, is those of principalist (Wiles et al., 2008; Wiles, 2015) or procedural ethics (Guillemin & Gillam, 2004). This is perhaps most often referred to in terms of the principles which inform the practical and early stages of the research design (Ellis, 2007; Wiles, 2015). In essence these principles, although not universal, are acknowledged as good practice by research ethics committees, such as doing no harm, respecting anonymity and confidentiality, and informed consent (Wiles et al., 2008). This paper seeks to shine light on the challenges of conducting dementia focused research whilst navigating ethical principles (Beauchamp & Childress, 2001) and ethics in practice (Guillemin & Gillam, 2004) as these interact and inform each other. A focus solely on principalist ethics may not support a researcher during the conduct of the research where unforeseen circumstances may arise. This requires the researcher not only to draw upon their knowledge of ethics more widely to guide their actions, but also own their own moral code and values, and how they perceive care and support to be given to participants. The authors found that giving time to reflect regularly on their practice in terms of ethics helped them to manage their projects in a way

they thought would best meet the needs of their participants and ethical standards. Therefore, the authors referred back to their original aims and processes, considered these in light of their own values and in how these had or could impact on the welfare of the participants.

Here consideration of ethics of care was important (Held, 2006; Ellis, 2007; Wiles et al., 2008; Wiles, 2015); ethics of care takes into consideration how we care for participants within the research and how our own moral values as researchers may have an impact. Held (2006) argues that ethics of care focuses on 'caring relations'.

Developing a research relationship draws on this ethics of care framework, as it requires consideration in the early planning of a project but also is reliant on the researcher's own moral compass and what they consider is 'care' for their participants (Ward, 2019). This illustrates the importance of moral sensitivity (Heggestad, Nortvedt, & Slettebø, 2012) when collaborating with people with dementia. Moral sensitivity is shown by listening to the participants´ opinions and understandings throughout the research process (Heggestad et al., 2012), and through an open and honest dialogue (McKeown et al., 2010). The Danish philosopher, Løgstrup (1905–1981), argued that the way you meet another person is important as your attitude for the person may shape his or her world in a positive or negative way as trust is not of our own making - it is given. By not caring, we might create pain and mistrust.

> Our life is so constituted that it cannot be lived except as one person lays him or herself open to another person and puts her or himself into that person's hands either by showing or claiming trust. By our very attitude to one another we help shape the another´s world. By our attitude to the other person we help to determine the scope and hue of his or her world; we can make it large or small, bright or drab, rich or dull, threatening or secure. We help to shape his or her world not by theories and views but by our attitude towards him or her. Herein lies the unarticulated and one might say anonymous demand that we take care of the life which trust has placed in our hands (Løgstrup, 1997).

However, it may not always be possible or appropriate to spend time in a setting or with participants prior to conducting the research. Youell felt that visiting each participant only once to conduct an interview enabled participation in her study. Due to the sensitive nature of the interview topic, that of sexuality and intimacy, it was appreciated by the participants that the relationship would be short-lived. The authors

reflect that decisions as to the most appropriate method of engagement may be dependent on the topic in question, method and ethical framework of the research.

Developing the research relationship in one-off interviews can come, in part, from the use of well-considered and designed participant information documentation, as the authors learned. The aim needs to ensure participants are fully informed about the study, but also that they can actively decide whether to take part and understand what participation means. In the UK, guidance is provided by the NHS Patient Safety Agency and National Research Ethics Service (2011), which stresses that information documentation should be designed with the participant in mind so that it meets their needs. For people with dementia this can mean looking at the language, length, layout and design, and use of images to support people to understand what is being presented. The authors found that ensuring the information is understood by the person with dementia helped to build their research relationships on trust, respect and empathy at the outset (Orb et al., 2004; Drumm, 2013; Branco, Quental & Ribeiro, 2015). All three authors developed their information and consent documents in collaboration with people with dementia, and independently of each other, to ensure that the materials were understandable and accessible for potential participants (Youell, 2015; Thoft, 2017; Ward, 2019). Working in this collaborative way at the outset of the project helped to ensure that the research started in a positive way that best supported people with dementia to engage in the research.

Recruitment and consent

A further consideration when working with participants living with dementia is that of capacity to consent. The authors' work was based on the model of process consent (Dewing, 2007), which sees capacity as an ongoing process throughout the research, not just at the point of agreeing to participate. This process is undertaken by the person themselves, those who know the person with dementia (e.g. family or service staff) but is also something that occurs through a growing understanding of the individual by the researcher. How this process of consent is carried out will be informed by the ethics framework, partly by practicalities of when and how, but is also informed by the researcher's sense of care for the participant. For Thoft and Ward, the knowledge of their participants grew over weeks and months, through understandings of behavior and verbal and non-verbal cues. For Youell, knowledge of her participants was gained in the open and frank discussions which were encapsulated in the interviews, showing two different ways this approach can be managed.

How a researcher deals with consent and decisions of capacity is a central issue which requires consideration early in the design of a study and on completion of ethical committee documentation. Gaining consent directly from the individual, particularly those who may be vulnerable or under-represented in research, can serve to empower (Prosser, Clark & Wiles, 2008) and provides an opportunity for issues to be discussed openly and inclusively (NICE, 2006). This process can encourage the person with dementia to be taken seriously as an individual with rights and capabilities, as well as providing a sense of purpose in being part of the research (Moody, 1985; Kapp, 1998). The Mental Capacity Act (2005), in the UK, provides guidance to determine capacity to consent, principally to ensure the individual is not assumed or treated to be incapable of making a decision to consent and that decision making is supported, for example through appropriate language and visual cues (Slaughter, Cole, Jennings & Reimer, 2007). Support may come from family or staff who can talk through consent forms with the person with dementia, or as the authors decided, can be through carefully designed information and consent forms which are talked through with the person with dementia directly. This approach was in line with Dewing's (2007) model of process consent and did not rely solely on others to provide presumed consent. How consent is gained may vary dependent on the research, however, ethical committees often require written consent, which is sought at each data collection point. All three researchers found it was possible for people with dementia to give their own consent when designing the consent process in an appropriate way. However, Thoft observed that many of the participants became critical towards the need of a renewed consent in the project and joked about it. This shows the balance researchers may face in meeting ethical requirements set by research ethics committees and conducting these in situ. All the authors experienced this challenge where the ethical process was difficult to execute in the practice of the research, such as getting written consent. For Thoft's participants, a continually renewed consent almost seemed 'unethical' because it questioned the participant's ability to decide and stay with a decision. Thoft perceived that her participants were 'negatively' affected by this repeated consent. Consequently, some began to consent before she asked for it to get it over with, showing they remembered it was required and felt some frustration in being asked (Thoft, 2017).

Youell recalls similar attitudes from some of her participants. On presenting carefully considered consent forms and highlighting the important aspects of freedom to withdraw, anonymity and confidentiality she often heard comments such as:

> Oh my goodness, I'm 85, what do I care who knows what now?
> Does anyone really check all this dear? (Youell, 2015)

Youell felt it was important to record verbal as opposed to written consent, thereby acknowledging the difficulties sometimes experienced around visual tracking (Alzheimer's Society, 2016), selective attention (Fernandez-Duque & Black, 2008) and manual dexterity and ability to write for people living with dementia (Martyr & Clare, 2017). However, this decision was overturned by the regional NHS ethics board, who reviewed her project, and required that written consent was obtained from each participant. In practice, this was adhered to, but watching participants struggle to sign consent forms felt uncomfortable – another example of the pragmatics researchers face in meeting ethical committee requirements in practice. It is important to recognize that research ethics committees can impose safeguards on the research process and researchers may need to navigate these with skill to reach a successful outcome. The research relationship can support decisions about capacity by enabling a growing understanding of the person with dementia in relation to these issues.

Working with family/service staff to support the process of consent can also be a relevant approach if the person with dementia feels comfortable with this. Dewing (2007) argues that a person-centered and inclusive way of gaining consent involves all those in the research process. By accessing people in their homes or via a service, the views of the staff and family may become important to include. However, these are not sought at the detriment of the person with dementia, but rather Dewing's model places the person with dementia at the center of the consent process. The ethics of care approach also acknowledges the importance of relationships and these can both promote connection and independence or autonomy in decision making (Dewing, 2007). Youell found that spouses in her study had a significant role agreeing together with their person with dementia that they wanted to participate. Ward and Thoft recruited teacher advocates to have a similar role in their projects. In all three studies, the process of assessing capacity to consent involved an individual who was familiar with the person with dementia to assess their wellbeing at the point of data collection and provide support if any adverse issues arose during the study, such as insecurity, sadness or aggression. While working with family and service staff to support consent is a valuable way of working and ensuring that the person with dementia is supported, it is important to remember that people with dementia can give their own consent if it is designed to meet their needs. This means, those without service or family support can be considered for inclusion in research. However, there is a concern that those without such advocacy may be excluded from research opportunities. It may also hinder the recruitment of participants with severe cognitive impairments (Bravo, PâQuet & Dubois, 2003), as this may be a challenge for ethical committees on grounds of capacity, or the individual may not hear about research opportunities.

There may also be a potential conflict of interest or understanding that family/staff may decline participation on a person with dementia's behalf, by judging what is relevant for people with dementia and considering engagement according to their own agenda (Thoft, 2017), albeit with the aim of being supportive and caring.

In exploring the issues of consent and capacity within each of these projects, an interesting difference was identified between the approvals required in the different countries. Ward found there was limited guidance for how to undertake the research in Denmark, and therefore to ensure that the study and the related documentation was of the highest ethical standards, Ward initially followed the NHS Ethical guidance (National Patient Safety Agency and National Research Ethics Service, 2011). However, to ensure the project was conducted ethically and within the cultural norms of Denmark (Liamputtong, 2008), the documentation was reviewed by an independent Danish researcher and the gatekeepers within her research setting to ensure it was meeting the Danish ethical standards and was suitable for the people with dementia, prior to seeking approval from the Danish Data Protection Agency. Halder, Binder, Stiller, & Gregson (2007) identify that when conducting cross-cultural research, the ethical processes from one country may not equate to another. For the main part, the Danish ethical process, at the time, was similar to the UK. However, the process was simplified, requiring less detailed information for ethical approval and for the participants. With growing cross-cultural research taking place, through European funding streams and wider international collaborations, the authors highlight the importance of understanding not only the legal requirements of the collaborative countries but also how to work within differing cultural norms.

The study - managing the research relationship in situ
The potential power imbalance of the researcher-participant relationship was also considered by the authors. This related to how involved the participants were and how they were treated. Ward and Gahagan (2010) identify trust as a key component of the research relationship, and of the ethics of care. Held (2006, p.15) suggests that researchers need to understand what 'fairness, equality, individual rights' mean and how best to apply these (Held, 2006, p.15), in order to explore the power within a research relationship. The authors found this related to: open communication with participants and use of language; understanding the research setting; encouraging participation and ownership of the process.

However, the relationship between the participants and the researcher is characterised as asymmetric because the researcher is the one who has power, often influenced by factors such as position, age and

disability (Cornwall, 2008; Karnieli-Miller et al, 2009; Schneider, 2010; Tanner, 2012). The authors found that awareness of this power imbalance had implications for their respect for participants' autonomy and reactions. By using an ethics of care model, the authors were able to reflect on how a power balance could be mitigated. This can be challenging when the participants have limited verbal capacity and have challenges with expressing themselves clearly (Heggestad et al., 2012). The development of a research relationship was important here, it supported trust and a shared knowledge of each other as researcher and participant (Heggestad et al., 2012).

Youell found that subconsciously she was trying to reduce her perceived 'expert status'. Due to the limited contact with each participant this was not a relationship that was built-up over time so her approach to the research relationship provides a different perspective. Youell notes:

> It is apparent through my initial comments during the interviews that I wished to play down this assumption [*that of expert*]. I make reference to the fact that I am not very good with technology when setting up the tape recorders. Although, an unconscious tactic, this is a theme which runs throughout the interviews and it is not until analysis that it became obvious that I was attempting to downplay my expert status (Youell, 2015)

Ward perceived that being honest, open, and following through with decisions made during the study were important, an approach recommended by Doucet and Mauthner (2002). This openness was evidenced by responding honestly to the questions posed by the participants, even when this was challenging or personal. For example, during one of Ward's creative sessions, participants had been sharing stories of their home lives. Towards the end of one session, a participant, Helena, asked Ward to share her life story, saying that they had shared their stories and now it was Ward's turn. Ward recalls being surprised that they would want to know about her home life but responded by sharing stories of her husband and cat (Ward, 2019). Thoft's relationship with her participants also developed during the project, and her participants began asking personal questions about her working life and children. One participant even expressed concerns about her succeeding with the PhD on time. This individual also attended the public defense of her PhD, illustrating his engagement in the project at the time of data collection and beyond (Thoft, 2017).

Youell found that one-off interviews also enabled honest, open and frank discussions. This seemed beneficial to the participants as emphasised by Betty:

Perfectly happy with everything and I feel very comfortable with you and in fact I've enjoyed you coming. Sometimes it helps to speak with someone who you feel you can release your emotions and not feel, you know, feel like you're being over the top because, you know, I didn't feel ashamed to cry in front of you whereas others you feel as though, you know, sometimes it's very difficult (Youell, 2015)

The researcher perceived this quote demonstrated the cathartic impact that research can have, particularly where the topic is sensitive and personal. It also shows the trust placed in Youell as the researcher, demonstrating the importance of the researcher's own moral values to care for her participants and their stories.

While our participants are the core focus of ethical frameworks, it is also important to recognize the impact on the researcher. When conducting research and hearing people's stories, it is important to understand how, as researchers, we cope when participants are emotional or if stories are reflective of our own personal experiences. In an earlier project, Youell, realised the emotional impact that such disclosures can have, and subsequently ensured that appropriate clinical supervision was in place for her own wellbeing. Such considerations are important for researchers to make when designing their studies (Youell, 2015).

The authors found that they learned from their participants, not only in relation to the topic of the respective studies, but also about their lives and about what it means to live with dementia. The authors learned from the way their participants spoke and reacted to one another. Ward reflects that her participants were patient of each other's dementia, that they listened to stories that were repeated and often asked questions to encourage these stories, rather than saying they had been said before. This led to her participants taking on the role of a researcher in many ways, a role she tried to encourage. Their use of language also had an impact as it was found to be inclusive, this style was adopted by Researcher's 2 and 3. This acknowledges the potential for language to impact on the research relationship, helping or hindering participation and accentuating inequalities between researcher and participant, or even participant and participant. The authors found that careful consideration of verbal and nonverbal communication, with a focus on reminiscence and emotional questions, rather than factual, helped with their studies. The aim was to ensure participants were involved in discussions and to reduce stress by: reducing the use of questions; not contradicting or interrupting (Alzheimer's Society, 2016); giving time for people to speak and listening (Kitwood, 1997; Care UK, 2014); focusing on skills and interests; reducing technical language or slang.

The authors learned the importance of use of language, and perceived that positive use of language can support participants to feel comfortable and engaged in the research. Researchers 2 and 3 found the use of 'we' and 'together' could act to bond the group, and could be used to include the researcher. The language used was also perceived as a way to reassure when concerns were expressed. In the example below, Thoft offered Johan reassurance about a clapping exercise used as a warm-up in their first session. Thoft's use of language plays down the potential difficulty of the exercise by saying it will be fun and 'a small thing'. In the same session, she also told Theresa that she did not 'need to pay much attention to it', while Ward mirrored the language of the school environment to help make the task familiar, but also by reducing potential worries by saying the task was 'not an assignment'. Analysis of the sessions (which were video recorded) noted non-verbal signs which suggested participants were relaxed by the use of language, for example with smiles or leaning back in the chair, and was perceived to minimise concerns or anxieties the participants may have felt:

> Johan: We need to be aware of our fun and have to concentrate.
>
> Thoft: This is nothing serious, we are just doing this for fun. It's just a small thing.
>
> John: This is long time we have been sitting around in a circle.
>
> Thoft: Ward said this is just to have fun and relax, this is not an assignment.
>
> (Johan was observed to smile and clapped along with the game, laughing with the other participants) (Ward, 2019)

However, language can be a barrier, particularly in the type of questions asked. The authors learned that people with dementia often responded better to questions which focus on emotional connections, which draw out memories and experiences. The use of language was also found to be quite poetic at times, providing insights into life with dementia, with the participants using metaphors to explain how they experienced their dementia, describing the brain as a dusty place or feeling as if the door step gets higher preventing social connections. This use of language by the people with dementia may suggest that as researchers we can also consider using more poetic language, and is perhaps an area for further investigation.

However, it is inevitable that factual questions will be asked. Ward experienced that participants found such questions confusing to answer and highlighted their dementia. For example, asking the age of a daughter (see extract below). Ward found that when her participants asked each other questions, they could also use language that hindered communication, such as focusing on factual questions, or

contradicting another person's comment. The authors found that such questions needed careful considered.

> Ward: How old is she?
>
> Helena: Oh…she was three months when we got her, oh no that is the memory again.
>
> Thoft: That is not important, but she has grown up hasn't she?
>
> Helena: Yes, around 30.
>
> Thoft: Oh yes 30.
>
> Helena: 24.
>
> Thoft: It is difficult to remember the age around 30 and maybe 24. (Ward, 2019)

If meeting with participants over several sessions, the authors found a structured approach was useful. The authors found that the use of repetition could be a positive way of working, be this through verbal or written communication, for example, by using a folder for storage papers related to the research process (Mckillop 2004, Wilkinson 2002). The authors drew on evidence from cognitive training on the use of structure and repetition, which suggests that activities that are well practiced may be transferred to the long-term memory (Mogensen 2013), and that repetitive training may improve or maintain cognitive function for people with dementia (Bach-y-Rita 2003, Yu 2009). Ward and Thoft reported the use of repetition supported their participants' ability to be involved and contribute to the research. However, the use of repeated questions over time may annoy participants. Ward found that two of her participants, Johan and Ernst, were aware that she had asked similar questions about the service they attend over several sessions. This use of repeated questioning is referred to as 'narrative quilting' in lifestory work and can be a way to elicit further information (McKeown et al., 2010). People with dementia can often only give small or fragmented details as a result of their memory, so this technique may allow development of fuller answers over time (McKeown et al., 2010). However, Johan and Ernst found the process repetitive. In the extract below, Ernst comments that Ward had to know what items were made in the woodwork class, suggesting he recalled having previously shared this information. While such questioning can elicit further details, Ward found that knowing how and when to use a repeated question required thought when working with people with dementia.

> Thoft: Ward also wants to know how important it is for you to go to the woodcraft?
>
> Ernst: That is… I do other things than oiling benches!
>
> Thoft: I do more than just making the benches.

Ernst: She must know that we make chopping boards, and rolling pins... (Ward, 2019)

When working over a longer period, the authors suggest that a researcher can maintain a close relationship with the participants throughout the study. However, this may result in the persons´ stories and experiences being cast in the researcher's terms and meanings to gain an understanding of their mental constructions of situations and contexts (Keady, Williams & Hughes-Robets, 2005), therefore having a potential influence on the participants' attitudes and actions. The authors found that it was important to take care of the trust participants show, so they feel safe and supported. This awareness includes being morally sensitive and acting trustfully, putting the relationship and the participants' well-being above the research. As an example, Ward was asked by one participant not to show the photographs taken by her participants outside of the research setting. This participant was worried that she would be recognised by friends and she did not want them to know she had dementia. This request was adhered to and no photographs were used in the resultant thesis or will be used in future work. However, this did have an impact as one of Ward's aims had been to address a gap in visual methods approaches with people with dementia, that the images taken by participants are often not used in the analysis or write up process. This example is provided because it highlights that the participant's needs are at the forefront of the research process. Ward had to re-think her aims in light of this change, which occurred in situ, and was responded to and agreed with the participants in the moment (Ward, 2019). While Ward found ways to compensate for this, it highlights the need to be responsive to participants' wishes and concerns, and shows how in situ challenges can arise which require the researcher to respond in a way which puts the participant at the forefront.

Conclusion

There is a growing move to involve people with dementia in research, be this as participants or as collaborative partners. The authors have shared their experiences of working collaboratively with people with dementia, highlighting the importance of the research relationship with both the participants and gatekeepers to reach successful outcomes of the research. The authors acknowledge that involving people with dementia in research is nuanced and skilled work for which specific training and support would be beneficial. There is no one size fits all to conducting research with people with dementia, but by sharing some of the positive and unexpected experiences from their own research, the authors share ways of managing and working through some of the ethical considerations. The authors found use of an ethical framework enabled engagement with people living with dementia. The authors found this places ethics at the heart of all decision making in the project, from initial design, ethical documentation to meeting those

unexpected moments. Importantly, it asks the researcher to regularly consider, and to reflect on their place in the research, how they will manage power dynamics, how their language is being used and how they respond to the needs of the participants. However, this does not imply that their participants are passive in the process, but rather sees them as active partners and aiming for greater equality and collaboration in the process. The aim of this paper is to share these experiences to inform future dementia research and establish good practice.

The ethos of our research is that people with dementia can contribute to the research process, with the aim to understand the embodied experiences of living with dementia. It is therefore important to make every effort to design the research, so it allows full participation and collaboration. We can learn from those who are living with dementia to become more inclusive in research and in society and to develop more appropriate services for people living with dementia if we are willing to listen to what they have to say, and find ways of conducting research in a collaborative way.

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