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From Ears to Experience: Insights into Living with Long-Term Glue Ear

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Abstract

Glue Ear is a common childhood condition which causes intermittent hearing loss. It is highly prevalent in children under 7 years, but is rarely discussed in teacher training. It is well understood in a medical rather than an educational context. Most of the research has been quantitative, by healthcare professionals seeking to understand and identify any potential long term effects. This has led to a focus on the 'ears' of the young person rather than the whole person in a life context, their experience. This paper explores how combining Interpretative Phenomenological Analysis (IPA) with a modification to Photovoice enables a mother of a child with long-term Glue Ear to explain its day-to-day impact. The impact of this condition for the child in the classroom and how it can impact learning and relationships with peers is under-researched.

Keywords: Glue Ear, early years' education, photovoice, interpretative phenomenological analysis (IPA), mothers' experiences

"Sometimes I feel ashamed that I can't always hear what others are saying." (Male - history of ongoing Glue Ear, aged 22)

"Even now, as an adult, I remember the teacher growling at me when I was 8 as I hadn't heard the bell. It was unfair." (Female - history of ongoing Glue Ear, aged 34)

1. Background

The intermittent, but distressing and disruptive, nature of Glue Ear, or Otitis Media (OM), is captured in the above quotes by two of those who have had it long term. Glue Ear is a form of conductive hearing loss in which the middle ear is filled with liquid instead of air. The result is hearing loss until the fluid disappears, which can take up to 6-10 weeks. Glue Ear occurs in about 80% of children under the age of 10 years, with peaks at the ages of 2 and 5 years (Bluestone et al., 2002). It is a continuum condition from children at one end having one or two episodes while those at the other end continue to have the condition into adulthood (Gunasekera, Morris, McIntyre & Craig, 2009) with the assumption that most children 'grow out' of it by 7 years of age.

The potential impacts are often trivialised by educational professionals because it is described in medical terms and perceived as 'temporary' and 'common' as it is present in large numbers of children. This can lead to students falling substantially behind at a time when they are starting to use and understand language, learning how to read and write and developing their social skills. About 30% of children spend about a third of their life with intermittent hearing loss up to the age of ten years (Wilson, 2009). Many teachers do not feel adequately trained or understand chronic medical conditions (Nabors, Little, Akin-Little & Iobst, 2008; Bannon, 1995) which means they can be overlooked in the classroom.

The greater proportion of research to date has been on identifying optimum medical treatments to minimise the impact of Glue Ear (Feldman & Paradise, 2009; Paradise et al., 2007; Damoiseaux, Rovers, Van Balen, Hoes & de Melker, 2006). Audiologists and speech and language therapists have concentrated on the identification of the impact of hearing loss, comparing children with 'normal' hearing and children with a history of Glue Ear using tests of language skills (Winskel, 2006; Roberts et al., 2004). There has been little investigation into what it is like for a young person to live with the condition, the impact it has on the lives of parents (Asmussen, Olson & Sullivan, 1999), and very limited research into educational professionals' understanding of how the condition affects academic and social interactions (Higson & Haggard, 2005; Haggard, Smith & Nicholls, 2003).

Quantitative methods, longitudinal studies, either prospective or retrospective, or randomised clinical trials, have been primarily used for clinical investigations (Gunasekera et al., 2009). In quantitative longitudinal studies, the data comes in the form of population statistics, thus, individuals are categorised into data clusters: gender, ethnicity, socio-economic background, age of first incidence of Glue Ear and type of treatment given. The relationship between the researchers and participants is remote and they never meet. In randomised clinical trials, limited and controlled interaction between the researcher and participants is seen as best practice. Those collecting data know little about the purpose of the study or the details of the participant's condition (blind studies). In some cases the research findings have been reported as 'ears' or 'children's ears' (Carlson & Carlson, 2003), a particularly objectifying representation emphasising the separation between the person, the condition and its impact.

The findings from such research focus primarily on the condition and functioning of the ears, rather than its impact on the whole person. It does not take into account the continuum nature of the condition or the individual experience of each child. The richness of the individual's personal circumstances is eliminated. No insight is gained into how individuals respond to the experience of long-term Glue Ear. Encouraging the active involvement and contribution of participants about their experiences, description and perceptions of how it affects them, puts them in the centre of the research process as reflexive people rather than just 'ears.'

2. Theoretical perspective

In most studies, researchers take a post-positivist (Feldman & Paradise, 2009; (Gunasekera, et al., 2009) approach to understand the impact of Glue Ear. They develop hypotheses, which are tested as a way of developing generalisations and identifying cause-effect explanations. In most of the studies cited, the aim is to clarify what impact the condition has on the ears leading to an understanding about what is the best course of action from a medical perspective. The researcher objectively interprets the facts to extend knowledge (Guba & Lincoln, 1994). The research into the condition has not produced replicable results but rather contradictions between the findings of different studies (Paradise et al., 2003; Hogan, Stratford & Moore, 1997). This has led to questions about flaws in methodology (Gunasekera et al., 2009). The results usually concentrate on physiology, than the impact on the young person.

An alternative paradigm is to investigate the experience of the individual as he/she constructs an understanding to make sense of a specific phenomenon. In the case of Glue Ear this explores how to deal with the intermittent hearing loss, the pain of ear aches, trying to find a cure and reflecting on how the condition impacts on daily life. In previous research, the absence of participants' own accounts has led to a lack of richness and depth. Husserl, a German philosopher and one of the founders of phenomenology, proposed the idea of going 'back to the thing itself' (Kockelmans, 1967). This approach shifts the focus from the 'ears' to the 'experience' of how the condition impacts the person in the context of his/her daily life. The focus is on the young person with Glue Ear and other family members, notably mothers, who are likely to be the prime caregiver (Craig, 2005). The aim is to understand how each person constructs and understands their experience (Guba & Lincoln, 1994). This is an ideographic approach which values and recognises that individual experience provides insight and illumination into how young people live with intermittent hearing loss.

Therefore, a phenomenological approach was selected as it focuses on lived experience. Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) puts the participant's experience at the centre of the research process. The interpretation is based on the concept of the double hermeneutic. The researcher encourages participants to reflect and make sense of their experience. Together, the researcher and the participant, discuss and interpret the participant's words to develop further understanding of his/her experience. In IPA participant's words are at the centre of the analysis. This methodology identifies that marginalised voices are important and need to be heard.

Prior to this research, there have been limited studies using open-ended questions with adults, and no studies in which young people have been asked directly about their lived experience of Glue Ear. IPA acknowledges the participant as the expert in his/her own experiences. Each participant is initially treated as a case study to gain an in-depth insight into his/her individual situation with themes identified. The case studies are then combined to look for similar and dissimilar themes. The research employs the double hermeneutic to both support the individual participants in understanding their experience as well as the researcher interpreting the descriptions of a small group of similar participants. Homogeneity of samples, with participants sharing similar characteristics, adds depth to the analysis as it looks for common patterns across participants, yet acknowledges individual responses (Smith et al., 2009).

Freire (1996) explored the way in which some groups may feel that their view is of less value than those asking for it. To overcome this, he asked participants to describe what they saw in line drawings which he provided. The aim was to encourage reflection and demonstrate that they had insightful comments to make. Wang developed Freire's philosophy of empowering participants into the Photovoice methodology (Wang, Morrel-Samuels, Hutchinson, Bell & Pestronk, 2004). Participants create their own photographs that identify issues of key importance to their experience. The participants lead the researcher to understand their priorities. This accords with Freire's (1996, p. 61) philosophy of the teacher becoming the learner, and the learner becoming the teacher.

The theoretical underpinning for my research can be summarised in four points. There is no one reality which can be identified through only investigating the physiology of the ears. People construct their own reality through their experiences and the insights that develop through reflecting upon those experiences. Glue Ear can impact participants' lives in different, but equally valid ways, resulting in diverse perceptions. Setting the context of research in the lived experience can thus be seen as of complementary value to hypothesis testing. This paper considers only a small part of my wider doctoral research. It looks at the process that I used to answer the research question: What is the experience of being the parent of a child with ongoing Glue Ear?

3. Methodological Design

In IPA, the preferred method for gathering phenomenological data is through semi-structured interviews (Smith, Flowers & Larkin, 2009). This usually means that the researcher constructs an interview schedule (Kvale, 1983) which participants do not usually see in advance and which may not align with their view of the key issues in experiencing Glue Ear. This approach does not encourage participants to reflect in advance. This could mean that participants may answer interview questions in a limited and/or superficial manner. Although the interview schedule may not be followed exactly, the researcher has set the agenda so is in control of the topics to be covered,

Although researchers seek to establish rapport with participants, there is an issue of power differentials. The researcher may ask questions that participants could feel obliged to respond. Participants may use strategies for avoiding questions, such as appearing tired, or not directly answering what is asked, or responding in a socially desirable way (Anyan, 2013). However, the researcher is directing the process by setting the topics for discussion, rather than encouraging participants to identify issues, which they see as central to their experience.

Photovoice techniques (Wang & Burris, 1997) provide a participant-focused data collection method in contrast to interviews. Participants identify issues, which are of importance to them, then take photographs or create images to represent them. Photovoice is usually used with community groups to focus on improving their situation (Wang et al., 2004). The photographs are used as a stimulus for group discussion. Each participant takes photographs on their own, then selects those which they wish to share. In a group each participant explains the meaning the photograph has for him/her. Other participants contribute their ideas, and interpretations are facilitated by the researcher. This process develops a depth of understanding in relation to the personal memories or experiences. The outcome is formulated as a 'consensus caption' for each photograph (Wang et al., 2004).

Baker and Wang (2006) used Photovoice to explore the lived experience of chronic pain. They identified that there was a lack of depth in the explanation and interpretation of the photographs because the group discussion element was missing. In the study described in this paper, a participant-led discussion was developed, whereby the participant explained and discussed the meaning of each image she used. The researcher asked questions for clarification or probed for further detail.

Photovoice provides participants with a way to identify their key issues. IPA is used for data analysis as it explores and interprets participant's words in depth. The final stage in the methodology is to relate the findings from previous research (the 'ears') to the experiences described by participants in this study. This demonstrates how ideographic findings can identify potential situations in which nomothetic findings can apply.

4. Sample

Participant recruitment was difficult as lack of support groups meant that parents of children with long term Glue Ear were not easily located. A conscious decision was made to avoid recruiting through specific settings such as hospital clinics or schools as the research aim was to gather data about the day-to-day experience of the impact of the condition. Previous research has raised the issue that some participants assume that the researcher is only interested in the issues relating to the recruitment context (Gibson, 2005). In total, ten participants were recruited from on-line Glue Ear chat forums and through colleagues. Although parents were invited to participate, it was only mothers who agreed to take part. IPA practice advocates homogeneous small sample sizes to encourage extremely detailed analysis of individual cases (Smith et al., 2009).

Table 1

Participants' Description and Relationship

Young person	Age in Years	Mother	Participated
Russell	9	Jane	Both
Stewie	10	Lois	Both
Daisy	14	Caz	Both
Helen	18	Miranda	Mother only
Peter	14	Wendy	Mother only
Poppy	7	Marian	Mother only
Pippa	18	Kate	Mother only

Note. Participants selected their own pseudonyms to protect their identity.

Table 1 identifies the relationship between the participants. In total there were seven mothers, three of whom had a son/daughter who also participated. The mothers were aged between 35-45 years; 6 were living with the child's father; all were in professional roles (f/t and p/t); all had higher education qualifications. They live in England and all are white. The ages of the non-participating young people, at time of the data gathering, ranged from 7-18 years, four of whom were female and three males.

The young people who participated were two boys (9-10 years) and one girl (14 years). One of the boys had a brother, seven years older and the other two participants were the only child. They all attended state schools and were treated within the NHS. They all had Glue Ear from under the age of 3 years and had undergone at least two grommet operations (where small ventilation tubes are inserted into the ear drum under general anaesthetic to relieve the pressure and drain the fluid from the middle ear).

5. Method

Prior to the commencement of data gathering full ethical approval for the project was received from The University of Northampton Ethics' Committee. Whenever further adaptations or modifications to the method were needed, supplementary ethical approval was gained prior to implementation of the changes. The ethical guidelines of the British Psychological Society (BPS; 2009) and British Educational Research Association (BERA; 2011) were followed.

This section looks at the specific method of data gathering related to the mothers as there were modifications made for the young people. Information relating to the young people is outside the scope of this paper. During an initial meeting with the participants, at a place and time of their choosing, informed consent was explained and gained. Participants had previously been provided with information and encouraged to discuss it with a person of their choice whom they trusted and felt would advise them well. In this first meeting, the mothers spontaneously shared examples, situations or concerns of how their experience of being the mother of a child with on-going Glue Ear had impacted them. These examples were used to help to clarify what was required in producing a photomontage typifying the impact of Glue Ear on them. For example, one participant identified repeated visits to hospitals so it was suggested that a photograph of a hospital or a hospital sign could be used as a stimulus for further reflection and discussion. Participants were advised to protect their identity by not taking photographs of locations which could be identified, or including the names of places. They were also asked to obtain permission from people before they took their photograph. The ethical principles of Photovoice were followed in the briefing (Photovoice, 2009).

The task was explained in terms of taking photographs/creating images, which represented their own feelings, experiences or descriptions of living with a child with long-term Glue Ear. They were asked to create a photomontage of different images, but the number of photographs/images was not specified. When a young person and his/her parent were both participants, they were asked to create their photomontages separately. At this meeting, a time, date and place for a second meeting was agreed at which the photomontages would be discussed.

At the second meeting, the researcher saw the photomontages for the first time. Agreement was sought for the discussion to be digitally recorded. Participants were asked to choose a pseudonym to protect their anonymity. They were asked with which picture they wished to start and explained what it meant to them and why it had been selected. The researcher asked questions for clarification or to gain greater detail. This participant-led discussion provided details about each of the images.

A small sample of Jane's data provides an illustration of the methodology at the data gathering and data analysis stages.

Figure 1. Jane's Photomontage

Jane's Photomontage provided an example of a photomontage. The guidance given to participants was to take photographs and initially they were provided with the loan of a digital camera, however, all participants downloaded images from the internet. The reason for this was not explored with them. However, to paraphrase participants, they selected a time to do the task, sat down at their computer and searched for images on the Google search engine. They explained that they may have a search term, such as 'boy alone' for which they had an image in their mind and sought out something that approximated what they visualised.

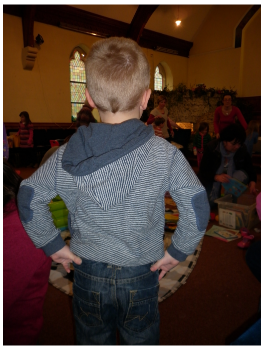

Figure 2. Russell 'on his own.'

The image in Figure 2 (reconstructed) was used independently by three different mothers as an image representative of their son's behaviour. Participants came from different parts of England and did not know each other, so it was likely that the image represented a common experience rather than a coincidence. Data was gathered over an 18 month period and a search by the researcher showed that the image was not the first one corresponding to the search term 'boy on his own.' It was likely that the mothers had to reject other images before this one was selected.

Participants were very articulate when describing the images, often providing specific examples of situations linked to the pictures: this may be because they had the opportunity to reflect on their experiences and feelings and were in control of the direction and content of the discussion. Jane's dialogue (Table 2) linked the image of Russell to her observations about his behaviour. She described how she had seen him as 'alone' over a period of time and explored her understanding of his behaviour.

Table 2
Jane's Dialogue Describing Russell 'On His Own'

Emergent Themes	Original Transcript	Exploratory Comments
Separate and different to other children Conflict with school staff Guilt for mother as her child is not 'normal'	Jane: Yeah *that's him. That's him on his own*. Yes. Yeah *on his own*. Researcher: Is that what he's like in the playground? Jane: Yeah a little bit, he'll attach himself to somebody. Usually an adult. It's *not* that he's miserable, *no*, just *separated*, on the sidelines. But *not unhappy* about it. This was the battle I always had with him lower down. But I'd say, well actually *he's quite happy…..* being separated. But you keep saying, "Yes but he MUST join in too." "Yeah but he's *not* stroppy about it." He'd say, "Yeah I'm all right." "Come and play Russell." "*No* I'm OK."	**Describing Russell in the playground or when around other children** *Repetition of 'that's him'; 'on his own' – emphasis* *Use of negatives 'not', 'un', 'no' to indicate Russell is all right with the situation* Idea of Russell being 'separated' and 'sidelined' Conflict between Russell's behaviour and adult requirements 'MUST join in'

Note: In the column headed 'Exploratory Comments' the bold font indicates a description of a situation, italic font is used for comments on the language (Italics are also used to identify in the 'Original Transcript' column), underlined font identifies emerging concepts of what the participant might mean.

6. Data Analysis

IPA provided a structured framework for analysing each participant's transcript (Gee, 2011). The researcher may reread and review each transcript several times, with each reading having a different focus. The initial readings were for sense and familiarisation with the participant's speech pattern and were followed by: (1) summarising each situation the participant described; (2) analysing the language at word, phrase, sentence and pragmatic levels and (3) the identification of initial concepts/themes. The researcher aimed to understand the participant's interpretation of events and, to some extent, was constrained by the participant, needing to justify an interpretation in the light of the participant's words. A case study was created for each participant identifying perhaps three or four themes. Because of space limitations, Table 2 provides a small sample of transcript and analysis stages.

In the planning stages for this research, the images were envisaged as being used as a starting point for discussion. In IPA, participant's words are the foundation for the detailed analysis. However, the image and the words became intertwined so that both form an integral part of the analysis. Analysing the words without reference to the image attached would be likely to detract from understanding the participant's experience.

In the image in Figure 2, Russell was standing apart from the other children. He was standing upright and did not appear to be upset. The way he had his hands on his hips suggested an interested spectator. This impression was reflected in Jane's description of the image. In Table 2 Jane described Russell as 'separate' from other children. She used negative moderators to accentuate that Russell was 'fine' with being separate - *not;* repetition of *separated.* Jane identified that Russell was comfortable *on th*e *sidelines*. He was more likely to *attach himself* to an adult. Jane saw herself in a *battle* with staff as they insisted that *he MUST (Jane's emphasis) join in too*. The theme which emerged from this section was Russell being 'separate' from other children. There was an underlying tension that Jane felt herself being judged by the staff with whom she had to *battle*, perhaps feeling guilty that she had not socialised Russell appropriately. This small section of transcript was compared to other parts of the transcripts to eventually develop overarching themes which typified Jane's experience.

One theme which developed from the comments of Jane and the other mothers was that Glue Ear is not constructed as a special need. This resulted in misunderstandings as described by Jane in her interactions with Russell's teachers. Because the condition is constructed as physiological, affecting the ears, it is not generally regarded by educational professionals as impacting behaviour. Therefore any behaviour which teachers regard as outside the norm is deemed to be within the child rather than a consequence of the condition. This lack of knowledge could be minimised by comparing the behaviours described by the mothers to the existing literature and communicating this to educationalists.

Such a level of analysis compared the general findings from the quantitative literature with the experiences described by the mothers. One finding suggested that children with Glue Ear may find it difficult to identify the speaker when in large groups decreasing their understanding of speech in noise resulting in the sounds heard by the child becoming a mix and jumble. Vernon-Feagans and Manlove (1996) carried out an observational study of young children in a day-care setting. They found that the children who had chronic Glue Ear were more likely to play by themselves and less likely to initiate interaction with other children, in comparison to other children who did not have Glue Ear. According to this finding, Russell may stay on the sidelines because he found it difficult to differentiate speech in the noisy playground environment.

Children with hearing impairment, including long-term Glue Ear, may find it difficult to maintain a conversational thread with the many switches of topic, which they may not follow (Duncan, 1999). Russell may have found that an adult was likely to speak more clearly so he could follow what was being said. Russell's teachers recognised the importance of social skills, but perhaps did not enable him to participate. Withdrawing from situations in which there are many people talking may be a coping mechanism for children with the condition, as they might not be able to differentiate who says what or to screen out background noise (Whitlock & Dodd, 2006). It may be that even when hearing does improve, the child may continue to withdraw as a learned behaviour. Similar findings have been found by other researchers (Bortoli & Brown, 2008; Peer, 2005; Hall, Grose & Drake, 1997) when investigating the impact on listening skills of children with chronic Glue Ear or children with hearing loss.

Neither Jane nor the teachers identified that Russell's behaviour could be attributed to his Glue Ear, which suggested that there was limited knowledge of the behavioural aspects of the condition. In other parts of the transcript, Jane gave detailed descriptions of the medical aspects of the condition, which supported that the knowledge about Glue Ear was positioned in the medical rather than educational context.

Most of the quantitative research had been conducted in controlled conditions, with the focus on ear function. Asking Jane about her observations of Russell's behaviour places him in the real world, attaching the 'ears' to a person gave some understanding of Russell's experience. Combining the ideographic experience with the findings of nomothetic research helped to give more depth to understanding how individuals 'experience' Glue Ear.

7. Ethical Considerations

In early Photovoice projects the participants were provided with disposable cameras which they returned to the researcher for developing. An ethical issue can arise if the researcher looks at the photographs before returning them to the participant. In such a situation the researcher may give precedence to their own priorities such as meeting research outcomes and funders' requirements (Booth & Booth, 2003). This potentially compromises the participant's right to withdraw and control of what is shared with the researcher. The use of digital cameras gives participants greater control as the researcher only sees the photographs which the participant chooses to show as images can be reviewed and deleted in advance by the participant. Asking participants to construct their own photomontage avoids the researcher potentially using images which the participant does not want to share.

Accepting the way participants interpret the task to produce the images/photographs in a layout of their choice and not being directive demonstrates that they have control. However, the use of internet images raised the issue of copyright. To overcome this, permission was obtained from participants for the images and photomontages to be reconstructed by the researcher using her own photographs. An advantage for participants of downloading images from the internet was that it ensured their anonymity. Once the analysis was completed it was sent to the participant for comment and any amendments they may have wished to make.

In the original design, it was planned to made observations of the young people in their classroom to gather data of the young person's behaviour. However, on reflection, this activity did not happen as it may have breached the confidentiality of the participants, who may have felt that their comments could be relayed to educational staff, in spite of whatever assurances given that this would not happen.

8. Findings

8.1 Strengths

This research actively encouraged participants to describe their experiences in their own words and images, after a period of reflection. It also provided insights which are unlikely to have come from the researcher setting the agenda for an interview. Additionally, participants had the option to identify issues of importance to them. They were encouraged to review the analysis, to make comments and edit. Issues were covered over a wide time period rather than focusing on current concerns.

Using an ideographic approach gives greater depth and insight into individual experiences which is not possible in large-scale quantitative projects. Glue Ear is a continuum condition so the participants in this study were drawn from those with the more chronic form with the expectation that those with the most experience could explore a range of ways in which the condition had impacted their lives.

Researching the mothers' perceptions of the impact Glue Ear had on their child's daily life identified specific issues regarding education and psycho-social skills where there has been little research. Moreover, relating specific issues from experience to the wider literature can provide parents with information that they can share with teachers about how the condition impacts the way a child interacts with his/her peers, particularly for those children with chronic condition.

8.2 Limitations

This was a small scale study which meant that the findings are more illuminative than generalisable. This was particularly so as the mothers who participated are well-educated and articulate so their experiences may not be typical of mothers who do not share the same socio-economic background. However, their experiences were problematic when interacting with educational professionals, such as the way in which teachers in this example suggested that Russell 'MUST' join in rather than exploring reasons for his behaviour.

Participants self-selected and were recruited primarily from internet web discussion groups. This could mean that their experiences and issues may not be typical of the wider population. They may have had unresolved problems which they wanted to discuss so were more willing to take part in the research.

Conclusion

Although Glue Ear is widespread in children in the early years of their education, educational professionals seem to have limited knowledge about the condition and potentially perceive it as a 'temporary' condition with no long term implications. Previous longitudinal randomised controlled clinical trials (Paradise et al., 2007) have not explored the impact of the long term condition at the level of the individual. There has been a tendency to separate the 'ears' and the condition from the whole child. There has been little appreciation of the impact of it on the day-to-day experience of those children with the more chronic form of the condition.

Making use of images available on the internet enabled the participants to explore abstract concepts, rather than being constrained by what they could photograph. This could have meant that they spent more time reflecting on what they wished to explore and discuss and less on how to portray it. I had initially thought that asking participants to create their own photographs would provide them with the opportunity to set their own agenda for the discussion. I have learned that it is very important in participatory research not to be too prescriptive in what you ask participants to do but encourage them to interpret the task in a way which is meaningful to them. Throughout the meetings with participants I had said that they were the expert in their situation, therefore accepting the participants' interpretation of the task demonstrated that as the researcher, they would lead me. During the discussion, the images provided a shared focus for both the researcher and the participant thus reducing the need for eye contact which may have helped disclosure around potentially sensitive issues.

The methodology used in this research aimed at encouraging participants to take a more central role in identifying what they considered were their issues. Rather than the researcher constructing an interview schedule giving a basic structure for the topics discussed, participants were encouraged to reflect on their perceptions and to identify what they wished to highlight. The mothers were asked to think about their feelings in relation to how Glue Ear impacted on their role as a mother; a perspective which is not often found in the literature.

References

Anyan, F. (2013). The influence of power shifts in data collection and analysis stages: A focus on qualitative research interview. *Qualitative Report, 18,* 1-9.

Asmussen, L., Olson, L. & Sullivan, S. (1999). 'You have to live it to understand it…' Family experiences with chronic otitis media in children. *Ambulatory Child Health, 5*(4), 303-312.

Baker, T. & Wang, C. (2006). Photovoice: Use of a participatory action research method to explore the chronic pain experience in older adults. *Qualitative Health Research, 16*(10), 1405-1413.

Bannon, M. (1995). Teachers' awareness and role in childhood chronic illness. In Spencer, N. (Ed.) *Progress in community child health* (Vol. 1) (pp. 125-140). Edinburgh: Churchill Livingstone.

Bluestone, C., Gates, G., Klein, J., Lim, D., Mogi, G., Ogra, P., Paparella, M., Paradise, J. & Tos, M. (2002). Definitions, terminology, classification of otitis media. *Annals of Otology, Rhinology & Laryngology, 111,* 8-18.

Booth, T. & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society, 18*(4), 431-442.

Bortoli, A. & Brown, P. (2008). The social attention skills of pre-school children with an intellectual disability and children with a hearing loss. *Australian Journal of Early Childhood, 33*(4), 25-33.

British Educational Research Association. (2011). *Ethical guidelines for educational research*. London: BERA.

British Psychological Society. (2009). *Code of ethics and conduct*. Leicester: BPS.

Carlson, L. & Carlson, R. (2003). Diagnosis. In Rosenfeld, R. & Bluestone, C. (Eds.), *Evidence-based otitis media* (2nd ed.) (pp. 136-146). Hamilton, Canada: B. C. Decker.

Craig, L. (2005). Father care means Father share?: A comparison of how mothers and fathers in intact families spend time with children. *Gender & Society, 20, 2*59-281.

Damoiseaux, R., Rovers, M., Van Balen, F., Hoes, A. & De Melker, R. (2006). Long-term prognosis of acute otitis media in infancy: Determinants of recurrent acute otitis media and persistent middle ear effusion. *Family Practitioner, 23,* 40-45.

Duncan, J. (1999). Conversational Skills of children with hearing loss and children with normal hearing in an integrated setting. *Volta Review*, *101*(4) 193-211.

Feldman, H. & Paradise, J. (2009). OME and child development: rethinking management of otitis media with effusion. *Contemporary Pediatrics, 26,* 40-47.

Freire, P. (1996). *Pedagogy of the oppressed.* (M.B. Ramos, Trans.) London: Continuum. (Original work published 1970).

Gee, P. (2011). 'Approach and sensibility': A personal reflection of analysis and writing using interpretative phenomenological analysis. *Qualitative Methods in Psychology Bulletin,11,* 8-22.

Gibson, B. (2005). Co-producing video diaries: The presence of the "absent" researcher. *International Journal of Qualitative Methods, 4*(4), 34-43.

Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In Denzin, N. & Lincoln, Y. (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, California: Sage.

Gunasekera, H., Morris, P., McIntyre, P. & Craig, J. (2009). Management of children with otitis media: A summary of evidence from recent systematic reviews. *Journal of Paediatrics & Child Health, 45*, 554-563.

Haggard, M., Smith, S. & Nicholls, E. (2003). Quality of life and child behaviour. In Rosenfeld, R. & Bluestone, C. (Eds.), *Evidence-based otitis media* (2nd ed.) (pp. 400-428). Hamilton, Canada: B. C. Decker.

Hall, J., Grose, J. & Drake, A. (1997). Effects of otitis media with effusion on auditory processing. In Roberts, J., Wallace, I. & Henderson, F. (Eds.), *Otitis media in young children: Medical, developmental and educational considerations* (pp. 93-108). Baltimore: Paul H. Brookes Publishing.

Higson, J. & Haggard, M. (2005). Parent versus professional views of the developmental impact of a multi-faceted condition at school age: Otitis media with effusion ('glue ear'). *The British Journal of Educational Psychology, 75,* 623-643.

Hogan, S., Stratford, K. & Moore, D. (1997). Duration and recurrence of otitis media with effusion in children from birth to 3 years: A prospective study using monthly otoscopy and tympanometry. *British Medical Journal, 314,* 350-353.

Kockelmans, J. (1967) Husserl's original view on phenomenological psychology. In Kockelmans, J. (Ed.), *Phenomenology: The philosophy of Edmund Husserl and its interpretation* (418-449). New York: Doubleday.

Kvale, S. (1983). The qualitative research interview: A phenomenological and hermeneutical mode of understanding. *Journal of Phenomenological Psychology, 14*(2), 171-196.

Nabors, L., Little, S., Akin-Little, A. & Iobst, E. (2008). Teacher knowledge of and confidence in meeting the needs of children with chronic medical conditions: Pediatric psychology's contribution to education. *Psychology in the Schools, 45,* 217-226.

Paradise, J., Feldman, H., Campbell, T., Dollaghan, C., Rockette, H., Pitcairn, D., … Pelham, W. (2007). Tympanostomy tubes and development outcomes at 9 to 11 years of age. *New England Journal of Medicine, 356*(3), 248-261.

Paradise, J., Dollaghan, C., Campbell, T., Feldman, H., Bernard, B., Colborn, D., … Smith, C. (2003). Otitis media and tympanostomy tube insertion during the first three years of life: Developmental outcomes at the age of four years. *Pediatrics 112*(2), 265-277.

Peer, L. (2005). *Glue ear: An essential guide for teachers, parents and health professionals*. London: David Fulton Publishers Ltd.

Photovoice. (2009). *Statement of ethical practice*. Retrieved from February 25, 2014 from http://www.photovoice.org/images/uploads/pvethicalpractice.pdf

Roberts, J., Hunter, L., Gravel, J., Rosenfeld, R., Berman, S., Haggard, M., … Wallace, I. (2004). Otitis media, hearing loss, and language learning: controversies and current research. *Journal of Developmental And Behavioral Pediatrics, 25*(2), 110-122.

Smith, J., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological research theory, method and research.* London: Sage.

Vernon-Feagans, L. & Manlove, E. (1996). Otitis media and the social behaviour of day-care-attending children. *Child Development*, *67*(4), 1528-1539.

Wang, C., Morrel-Samuels, S., Hutchinson, P., Bell, L. & Pestronk, R. (2004). Flint Photovoice: Community building among youths, adults, and policymakers. *American Journal of Public Health*, *94*(6), 911-913.

Wang, C. & Burris, M. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24,* 369-387.

Whitlock, J. & Dodd, G. (2006). Classroom acoustics-controlling the café effect…is the Lombard Effect the key? *Proceedings of Acoustics 2006: Noise of Progress.* Christchurch, New Zealand.

Wilson, R. (2009). *The impact of glue ear on child development: Examining the* *developmental consequences of recurrent otitis media*. Saarbrucken, Germany: VDM Verlag.

Winskel, H. (2006). The effects of an early history of otitis media on children's language and literacy skill development. *British Journal of Educational Psychology, 76*(4), 727-744.