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The Lived Experience of Glue Ear:  
Voices of mothers and young people

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

2014

Carmel Irene Capewell

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## Contents

### Chapter 1

#### Introduction to the thesis

1.1 Introduction	1
1.2 Researching the lived experience of Glue Ear: motivations for the study	2
1.3 The purpose of the study: Aims and objectives	5
1.4 Structure of the thesis	7

### Chapter 2

#### Literature Review

2.1 Introduction	9
2.1.1 Purpose	9
2.1.2 Search of the key terms	9
2.1.3 Construction of Glue Ear	11
2.1.4 Qualitative Studies of Glue Ear and Parents	11
2.1.5 Teachers' knowledge of Glue Ear	12
2.1.6 Prevalence of Glue Ear in infancy and early years of education	13
2.1.7 Assessing the impact of Glue Ear	14
2.1.7.1 Contradictory Research Results	15
2.1.7.2 Issues in the data collection methods	18
2.1.8 Key developmental and educational themes identified in the literature	19
2.1.8.1 Behaviour and Social Skills and links to behaviourally-based conditions	20
2.1.8.2 Language and speech development and Glue Ear	26
2.1.8.3 Reading Performance and Glue Ear	30
2.1.9 Conclusions - Temporary, Trivial and Medical	34
2.1.10 Summary of the findings from the literature and implications for future research	34
2.1.10.1 Implications for future research	35

### Chapter 3

#### Research Methodology 1: Putting participants' words at the centre of the research

3.1 Introduction	37
3.2 Methodological Aims	38

3.3 The benefits of a qualitative approach	39
3.4 A Phenomenological Approach	41
3.4.1 Husserl’s contribution to Phenomenology	43
3.4.2 Heidegger’s contribution to Phenomenology	45
3.4.3 Merleau-Ponty’s Contribution to Phenomenology	47
3.4.4 Selecting the appropriate phenomenological approach	49
3.5 Interpretative Phenomenological Analysis (IPA)	50
3.5.1 Assessing the semi-structured interview as a method for data gathering	51
3.6 Exploring the use of Visual images	53
3.6.1 Data Gathering using Freire and Photovoice to supplement IPA	54
3.7 The rationale for combining Photovoice and IPA	57
3.8 Data Analysis using IPA	59
3.9 Summary	60

## Chapter 4

### Research Methodology 2: Design and Implementation

4.1 Introduction	62
4.2 Participant recruitment	62
4.2.1 Sample Size and criteria	62
4.2.2 Recruitment strategies	64
4.2.3 Gaining participant agreement	66
4.2.4 Health Care and Educational Professionals	69
4.3 Design development and modifications	70
4.4 Participant-Researcher Interaction	77
4.5 Development of the photomontage method in this research	86
4.6 Ethical issues	89
4.6.1 Informed Consent	89
4.6.2 Anonymity and Confidentiality	91
4.6.3 Right to Withdraw	93
4.6.4 Respect for participants	94
4.6.5 Potential copyright infringement	95
4.7 Review	95
4.7.1 Limitations	95
4.7.2 Strengths	97

4.7.3 Summary	98
Chapter 5	
Research Methodology 3: Data Analysis	
5.1 Introduction	99
5.2 Transcription	100
5.3 A Structured approach to data analysis	102
5.3.1 Preparing to analyse the data	102
5.3.2 Initial Analysis	103
5.3.3 Data Interpretation	106
5.3.4 Generating themes	107
5.3.5 Linking the analysis to previous research	111
5.3.6 Rigour of the analysis	114
5.3.7 Summary	116
Chapter 6	
Mothers' stories: Living with a child with long-term Glue Ear: I keep on Knocking but there's no one there	
6.1 Introduction	117
6.2 Discussion of the Super-Ordinate Themes	121
6.2.1 Knowing Experts or Knowledgeable Mothers	124
6.2.1.1 To ease mother's anxieties	126
6.2.1.2 Roundabouts and repetition	132
6.2.1.3 Diminished and dismissed	137
6.2.2 Motherhood, but not as I imagined it	148
6.2.2.1 He sat on my lap	149
6.2.2.2 Lonely and alone in my own family	153
6.2.3 It's not a proper special need	156
6.3 Conclusions	156
Chapter 7	
Living with long-term Glue Ear: Listening to what the young people have to say	
7.1 Introduction	159
7.1.1 Parents as Gatekeepers	161
7.2 Discussion of the Super-Ordinate Themes	163
7.2.1 'Never Mind'	164

7.2.1.1 ‘The Stress’	165
7.2.1.2 ‘The Gap’	172
7.2.1.3 The Fear	178
7.2.2 Stuck	181
7.2.2.1 Sidelined: Discussions between Healthcare Professionals and Mothers	182
7.2.2.2 ‘In between’: Stuck in limbo	188
7.3 Conclusions	191
Chapter 8	
Comparison of Mothers, Young People and Professional Views: 360°	
8.1 Introduction	194
8.2 The value of taking a 360° Perspective	196
8.3 A common condition but limited knowledge	197
8.4 Medical professionals have knowledge, but no time to explain it	221
8.5 Adults and Young People have different voices	231
8.6 Conclusions	238
Chapter 9	
Answering the research questions: Conclusions and Further Research	
9.1 Introduction	243
9.2 Review of research questions	244
9.2.1 Research question 1	244
9.2.2 Research question 2	254
9.2.3 Research question 3	262
9.3 Conclusions	268
9.3.1 Limitations	268
9.3.2 Strengths	269
9.3.3 Recommendations for further research	270
9.3.4 Recommendations for practice	273
9.3.5 The contribution of this thesis to knowledge	274
9.3.6 Summary of the research	277

## Chapter 10

### My road to a PhD: Thoughts, Reflections and Learning

10.1 Introduction	279
10.2 My aspirations to start a PhD	281
10.3 From Quantitative to Qualitative Researcher	284
10.4 Reflection	288
10.5 Reflexivity	294
10.6 Academic writing	296
10.7 Conclusions	299

References	302
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### Appendices

Appendix 1 - Summary findings of previous research	348
Appendix 2 - Sample reflective logs	356
Appendix 3 - Parent recruitment poster and leaflet of my details	357
Appendix 4 - Interview schedule – semi structured interview	358
Appendix 5 - Young person invitation letter	359
Appendix 6 - IPA London Group – suggested themes	360
Appendix 7 - An investigation into the social and educational effects of glue ear	362
Appendix 8 – Participation record	363
Appendix 9 – University of Northampton conference presentation	368
Appendix 10 – Student’s progress summary	369
Appendix 11 – Critical Appraisal Skills Programme	370
Appendix 12 – Comments on Glue Session for Early Childhood Studies session	374

### List of Figures and Tables

#### Figures

Figure 4.1 Short extract from Russell’s and Stewie’s discussions	73
Figure 4.2 Boy on the edge of the playground (Reconstructed)	87
Figure 4.3 Screaming Woman (Reconstructed)	88
Figure 5.1 Jane’s Photomontage (Reconstructed)	101
Figure 5.2 Caz’s image Daisy in ear muffs (Reconstructed)	101
Figure 5.3 Jane’s image Strict school teacher (Reconstructed)	107
Figure 5.4 Daisy’s image Never Mind	110

Figure 5.5 Stewie’s image Stressed (Reconstructed)	110
Figure 5.6 Jane’s/Wendy’s image Boy on the edge of the playground (Reconstructed)	112
Figure 6.1 Wendy’s image Badge of Expert Patients	125
Figure 6.2 Wendy’s image The Angry Consultant	127
Figure 6.3 Marian’s image Conflicting road signs	128
Figure 6.4 Miranda’s image Young girl in pain	130
Figure 6.5 Kate’s image Young girl in pain	130
Figure 6.6 Wendy’s image Amoxicillin	133
Figure 6.7 Miranda’s image Bottle of penicillin	134
Figure 6.8 Kate’s image Wobbly clock	134
Figure 6.9 Wendy’s image A bucket	135
Figure 6.10 Marion’s image Dark tunnel	139
Figure 6.11 Kate’s image Young girl waiting (Reconstructed)	140
Figure 6.12 Jane’s image Strict school teacher (Reconstructed)	144
Figure 6.13 Wendy’s image Young boy on Mother’s lap (Reconstructed)	150
Figure 6.14 Jane’s image Toddler music group (Reconstructed)	151
Figure 6.15 Marion’s image Swirl of emotions	154
Figure 6.16 Lois’s image Crying woman (Reconstructed)	155
Figure 7.1 Daisy’s image ‘Never Mind’	164
Figure 7.2 Stewie’s image Stressed (Reconstructed)	166
Figure 7.3 Daisy’s image Shouting person	167
Figure 7.4 Hogan (2014) Tri-Level Reaction and Fusion Model	170
Figure 7.5 Stewie’s image ‘Angry’ (Reconstructed)	172
Figure 8.1 Otto’s image Girl at School (Reconstructed)	198
Figure 8.2 Jane’s image Boy on the edge of the playground (Reconstructed)	199
Figure 8.3 Wendy’s image Needle	227
Figure 8.4 Wendy’s image Boy with an inhalation mask	227
Figure 8.5 Wendy’s image Boy with a bloodshot eye (Reconstructed)	227
Figure 8.6 Otto’s image Young person preparing for surgery	228
Figure 8.7 Otto’s image Permanently damaged middle ear	236
Figure 9.1 Wendy’s image of Young boy on mother’s Lap (Reconstructed)	259
Figure 9.2 Jane’s image Toddler music group (Reconstructed)	259
Figure 10.1 Personal and academic skill development Entry from 2 May 2011 Log	291

Tables	
Table 2.1 Age and percentages of children with Glue Ear	14
Table 4.1 Conversion of contact to fully progressing to participation	67
Table 4.2 Participants: Description and relationship	68
Table 4.3 Lois describing Stewie's behaviour with analysis commentary	81
Table 4.4 Images and commentary from my personal montage and reflection	85
Table 5.1 Levels of analysis key for colours and fonts in transcripts	103
Table 5.2 Analysis of Jane's words to identify theme of 'Judgement'	104
Table 6.1 Mothers' Themes	122
Table 7.1 Young People's Themes	163

## **Abstract**

This qualitative research enabled the participants (three young people, aged nine to fourteen years, and seven mothers) to explain their experience of living with long-term Glue Ear. As far as I could ascertain this is the first research in which young people and their mothers have led the researcher in exploring their experience. This innovative research illustrates the effects of the condition at home and school. It provides insight into participants' views of interactions with healthcare and educational professionals.

Photovoice is usually used with groups, but in this research it was successfully adapted to enable individual participants to reflect on their experience. The data was analysed using Interpretative Phenomenological Analysis (IPA) to keep the focus on each participant's words. Innovatively combining these two methodologies provided depth to both the data gathering and the data analysis. Five healthcare and educational professionals were interviewed to understand their perspective.

The contribution of this research is that the methodology enabled young people and their mothers to reflect on their experience and lead the researcher in understanding the impact Glue Ear had on their day-to-day life. It highlighted the need for educational professionals to receive more formal training about Glue Ear's potential educational and social impacts and to potentially adapt their teaching and learning practices to better support affected students. Young people and their parents demonstrated that they have valuable information to contribute to decisions about their healthcare and education requirements and would welcome the opportunity to work collaboratively with such professionals.

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## **Publications arising from this thesis**

### **Journal Articles**

Capewell, C. (2014) Hear today but may not tomorrow – the implications of Glue Ear –research findings. *The British Psychological Society, DECPDebate*, 150, 27-31.

Capewell, C. (2014) Temporary but not trivial: Language and reading skills in children with ongoing glue ear. *Assessment and Development Matters*, 6(2), 24-27.

Capewell, C. (2014) The Hearing Environment. *Support for Learning*, 29(2), 102-116.

Capewell, C. (2014) From Ears to Experience: Insights into Living with Long-Term Glue Ear. *CORERJ*, 1(1), 40-58.

Capewell, C. and Ralph, S. (2014) Living with Glue Ear: Researching the educational needs: Listening to the voices of a mother and child. (In review).

### **Book Chapters**

Ralph, S. and Capewell, C. (2014) A real voice in research for disabled people and their families. In Naukowa, R., Bragieli, J., Gornicka, B. (eds.) *Parenting in the context of disability and neglect*. Poland: Uniwersytet Opolski, pp. 47-61.

### **Conference proceedings**

Inter University Symposium (2014) The Insider Perspective of the researcher (with Patricia McCarthy) *Journal 1*, 75-84.

*Papers from the School of Education Research Conference Saturday 1 December (2012)*  
University of Birmingham - Listen to what the children have to say, 62-68.

## **Chapter 1**

### **Introduction to the thesis**

#### 1.1 Introduction

Glue Ear is a common condition impacting upon most young children, and their families, to varying degrees. There has, however, been limited research in which participants freely express their experience of living with the long-term condition. The voice of the young person is notably absent in previous research. This thesis explores the development of a methodology that enabled the voices of a small sample of young people and their mothers to be in the centre of the research. Data gathering took place between May 2012 and November 2013 in a number of English counties. This research adapted and combined the methodologies of Photovoice and Interpretative Phenomenological Analysis (IPA).

From a search of the literature, I believe that this is the first time that young people (aged 9-14 years) have directly explored their experience of living with this chronic condition. Additionally, this is the first qualitative study which has taken place outside the clinical/medical context. Although the intent was to recruit parents and siblings, in the event it was only mothers who volunteered. The data gathering was participant-led. Participants created a photomontage to visually represent their experience of living with ongoing Glue Ear. They met with me to discuss their photomontages in a participant-led discussion. They decided the order in which they explained their interpretation of the images. I did not see their photomontages until we met. To supplement the views of the young people and mothers, as well as gain insight into their knowledge and understanding of Glue Ear, a small group of professionals representative of those with whom the young people interacted were interviewed using a combination of participant-led discussion and semi-structured interviews.

The IPA methodology provided an in-depth analysis and interpretation of common themes which summarised the participants' lived experience of the specific phenomenon of Glue Ear with the focus of participants' experience. The young people involved demonstrated that they were able to clearly articulate and analyse their experience thus providing insight into how the condition impacted their daily life. This demonstrated that young people are competent to explore the impact that the condition has on them. Additionally, the themes which were derived from the separate analysis of the mothers' exploration of their photo-montages indicated that Glue Ear was not a temporary and trivial condition for these young people and their mothers. It had implications for the mental health of both groups, for the academic performance and social skills of the young people and the way in which the young people and their mothers are informed about and involved in decisions about treatment options.

The Department of Health (2003) promotes the active involvement of young people in decisions about their treatment by providing them with appropriate information. Although the young people in this study were willing to participate and be part of the decision-making about their treatment, they did not feel that they were given that opportunity by the adults around them.

## 1.2 Researching the lived experience of Glue Ear: motivations for the study

We live in a hearing society. In the first five years of life the foundations of learning speech, language and social interaction are laid down. However, for some children this is disrupted by a common childhood disease, Glue Ear<sup>1</sup> or Otitis Media. It results in temporary deafness, with up to 90% of children having at least one episode by the age of 2 years of age (Bluestone and Klein, 2007). Hearing impairment resulting from the condition can last for a period of 6-10 weeks at a time. It is usually accompanied by ear infections causing pain and fever leading to both the child

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<sup>1</sup> Although healthcare professionals refer to the condition as Otitis Media, Glue Ear is the term used throughout this thesis as that is the description used by young people and their parents. As their voice is central to the research, their language was given priority.

and their parents having disrupted sleep and consequent irritability. Although it has a reputation for being common, and therefore trivial, about 30% of children will spend a third of the time up to the age of 9 years of age with some degree of hearing loss (Wilson, 2009). Despite its implications for potentially disrupting learning and social skills there has been little research conducted in the field of education.

It is a continuum condition with some children having one or two episodes while others continue to have repeated ear infections into adulthood resulting in damage to the structure of the ear and sometimes permanent hearing loss. If it persists for more than three months, the child usually has surgery to insert grommets (small plastic tubes which ventilate the ear drum and enable the build up of fluid, which accompanies the condition, to drain so that the middle ear can dry out).

Information given to parents about the operation concentrates on the procedure and the likely outcomes of it (Campbell and Lennox, 2010). It is not always explained clearly that this is a temporary fix, with the grommets falling out within 6-9 months of the operation. This is because by that time the condition should have spontaneously resolved with the child having no more episodes. There is no cure and there is uncertainty as to what causes it. Additionally, there is no clear way to identify which children will have recurring episodes until they do so. There has been limited investigation into those with the long-term condition, and most research findings do not take account of the continuum nature of the condition.

This medical approach of focusing on the physical illness and treatment (Boudreau *et al.*, 2007) means that the parents of children with the recurring condition are left expecting it to resolve and no longer be part of their lives. In the meantime, they have 6-monthly visits to Ear Nose and Throat (ENT) consultants and hearing tests. Although Department of Health publications (2004, 2003) emphasise policies whereby patients are provided with information thus encouraging them to take an active role in decision-making, the reality is that NHS ENT clinics are busy places with a focus on meeting appointment time targets, leaving little time for discussion. There may

be a philosophy to involve young people in their treatment (Department of Health, 2004) and give them appropriate information, but they tend to be passive information-givers, with discussions more likely to be between parent and physician (Gabe *et al.*, 2004).

Because Glue Ear is predominantly described in medical terms, teachers may either feel that it does not have educational implications or that they are not equipped to deal with it (Nabors *et al.*, 2008). Although the condition is very prevalent in children under 7 years of age, it is not covered in initial teacher training (ITT) or in programmes of continuing professional development (CPD). This can lead to situations whereby any behavioural issues the child has because of ongoing pain from ear aches or frustration from an inability to hear are perceived by teachers as residing in the child or the result of poor parenting skills.

Parents also have this medical view of the condition. They are encouraged to consider it as temporary and, once resolved, having no long-term implications for their child's learning as they will be able to catch-up with their peers. The information that they receive about it is primarily based on the physiology of the ear. Because it is seen as a temporary condition there are no widespread support groups for either parents or young people which can lead to feelings of isolation in both parents and young people.

The focus of most research into the condition is based on medical treatments and comparisons of the impact of the timing of a child's grommet surgery. There are very few qualitative studies and those that exist (Asmussen *et al.*, 1999; Wuest and Stern, 1990) are potentially dated, based in the North American health service context and concerned with parental coping mechanisms when a child has an ear infection rather than gaining an understanding of the educational, social or behavioural implications from the young person's perspective. From my review of the literature, I was unable to find any research in which parents and young people provide their views of what it is like to live with the condition long-term.

My interest in this condition originated from personal experience as I am the mother of two children with ongoing Glue Ear. They are now in their twenties, continue to have recurring episodes of Glue Ear and accompanying hearing loss. This first began in my son from when he was under 6 months of age and in my daughter when she was around 12 months old. My son has permanent deafness in one ear due to the condition. The information we received about it from the medical profession focused on the physiology of the ear. There was a lack of discussion about its implications for those young people with the ongoing condition and very little identification that it may impact social skills or behaviour.

It is from the perspective that there appeared to be a lack of qualitative research in this area, that the experience of young people and their parents was missing from the literature and a personal desire to understand any social or behavioural implications of the long-term condition that the research for this thesis developed. I was aware of my personal interest and experience so I wanted to find a methodology that placed the participants in this research at the centre of the data gathering process.

### 1.3 The purpose of the study: Aims and objectives

The overall aims of this doctoral research were to gain insight into the experiences of living long term with Glue Ear as a young person, as the parent of such a child and to develop a methodology which put the participants' words at the centre of the research process. This study is timely and relevant because government policies in both education and healthcare are promoting the active involvement of young people in decision-making about matters that concern them (Department of Health, 2003: DfE, 2003) and the joint publication by the Departments of Education and Health (2014) regarding the new code of practice for special educational needs and disabilities (SEND). The government has reviewed the provision for students with special educational needs and disability (Department for Education, 2011) placing

greater focus on working across healthcare and educational settings to enable more holistic provision. Additionally, concerns have been raised in recent years about the over-medicalisation of childhood (Timimi, 2002), particularly regarding young people being labelled as Attention Deficit Hyperactivity Disorder (ADHD). This is an imprecise term with diagnosis based on behavioural descriptions rather than having a physiological underpinning. While I have been undertaking my research there has been increasing questioning of the use of blanket terms, such as Dyslexia (Elliott and Grigorenko, 2014) with which there is a recognised overlap with Glue Ear (Peer, 2005).

The experience of individuals provides a valuable insight into the impact that a condition such as Glue Ear has on daily life. The voices of young people, in particular, have been missing from the literature. Parents had been consulted in previous research but usually to respond to questionnaires rather than being asked about the personal implications of being the parent of child with the long-term condition. There has been very limited research into the continuum nature of Glue Ear, particularly for those with permanent damage to the structure of the ear.

The objectives of this research are to:

- identify a research methodology to enable parents and young people to reflect on their experience of having long-term Glue Ear
- put the participants' voices at the centre of the research
- gain insight into the impact of long-term Glue Ear
  - on the young person
  - on their parents
- identify what support would encourage parents and young people to have a more participatory role with educational and healthcare professionals
- raise the level of awareness in educational and healthcare professionals of the impact that the condition has on the lives of young people and parents.

The Research Questions are:

- What is it like to live with ongoing Glue Ear as a young person?
- What is it like to be the parent of a child with ongoing Glue Ear?
- What is an effective methodology to ensure that the voices of young people and their parent are at the centre of the research process?

#### 1.4 Structure of the thesis

This thesis consists of ten chapters. Chapter Two is a critical review of the literature, particularly the potential impact the condition may have on language development, behaviour and social skills. It also identifies an apparent overlap between Glue Ear and the behaviours associated with Dyslexia, Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (ASD). An understanding of the literature helped to clarify the research questions. Three methodological chapters follow as background and data to assess the achievement of the third research question. The ontological and epistemological underpinning for this research is explained in Chapter Three. Chapter Four examines methodological issues from the design and implementation phases in this research. Chapter Five details the data analysis process. The lived experiences of the mothers (Chapters Six) and young people (Chapter Seven) are summarised through the themes resulting from an IPA analysis. Chapter Eight compares and contrasts the perspective of the different participant groups in this research: the mothers, the young people and the small sample of relevant professionals. This is to provide a wider view of the knowledge, understanding and impression that each group considers the condition has on young people. Chapter Nine is the Discussion Chapter. Each research question is evaluated as to whether this research potentially increases understanding of how long-term Glue Ear can affect young people and their mothers. It includes an assessment of whether the research methodology encouraged the participants to express their experiences. The chapter concludes with a summary of the strengths and limitations of this research and suggestions for further investigation. Chapter Ten

reviews my experience and learning during my PhD journey as I move towards achieving a career in research. The references used in the research and the appendices, providing relevant background details, are at the end of this thesis.

## Chapter 2

### Literature Review

#### 2.1 Introduction

##### 2.1.1 Purpose

This literature review critically assesses the extent that previous research has incorporated the lived experience and how those findings suggest the condition is likely to affect young people's social skills, language development and academic performance. Most of the previous research into Glue Ear has taken a medical perspective, the intent of which appeared to be to understand its causes, assess whether it impacts learning and to improve the success of treatment options. In this literature review, I specifically focused on the questions:

- For those young people with the condition, what evidence exists as to how it influences educational, social and behavioural outcomes?
- What knowledge do educational professionals have of it?
- What is known of its consequences for the parents of young people with the ongoing condition?
- What methodologies have been used to gather the data?

##### 2.1.2 Search of the key terms

A systematic literature review was undertaken. A key-word search based on 'otitis media' and 'glue ear' was conducted through Metalib, using the data-bases of CINAL, EBSCO, Web of Science, ZETOC and Swetswise to identify existing research into the condition. The initial search date was from 1970 to 2011, which has been revisited and updated to 2014 as this research has continued. English was set as the publication language. Articles and books from

around the world were identified. Using the search term 'otitis media' resulted in 29,649 items. Although it is common in children with congenital conditions, such as Down's Syndrome or Cleft Palate (Zeisel and Roberts, 2003) only references for children without such conditions were included in the literature search and review. This was to avoid factors which may affect development or language skills but were not related to Glue Ear. A search of EBSCO combining 'otitis media' and 'school' resulted in 3,033 results. The abstracts were read to eliminate those with terms related to the medical treatment: 'classification', 'complications', 'diagnosis', 'history', 'antibiotics' and 'surgery'. Refining the search criteria to 'children' reduced the number of articles to 32, of which 7 were related to performance in school, language development or parent-doctor interaction in the treatment of a young person with it. The percentage of research papers directly related to children in a school situation was less than 1%. A further search of 'otitis media' and 'teachers' returned 57 results. The key words were scanned for the terms 'teacher', 'staff development', 'educational strategies' or 'school'. This left 23 results which directly related to children's behaviour or performance in schools. Even with quite specific 'school-related' criteria in this latter search, only 40% of the articles related specifically to the education of children. From a review of 'school-associated' articles, 'medical schools' was the focus of many papers. As a result of this review, I concluded that there has been very limited research into its impact in the home and/or school environment, as the focus has been on its medical implications, leading to it being constructed as a physiological condition.

Most researchers into the condition have a healthcare background, such as General Practitioner, (Arquedas *et al.*, 2010), Ear, Nose and Throat (ENT) consultants, (Brouwer *et al.*, 2007) audiologists (Gravel, 2003) or speech and language therapists (Roberts *et al.*, 2004a).

Participants for studies have primarily been recruited from hospital/clinical settings. This may, in part, explain the primarily physiological construction of the condition, focused on the ears.

### 2.1.3 Construction of Glue Ear

The first references to Glue Ear are in Egyptian times which created awareness that it was not only painful but also life threatening. This situation remains today in less economically developed countries (Acuin, 2004). This has led to it being constructed within a medical context as an illness to be treated. Although it occurs in all populations, some groups have higher incident rates, such as Indigenous Australians (O'Connor *et al.*, 2009) and Native North American populations (Bowd, 2005). Issues around diagnosis, (Carlson and Carlson, 2003), causes (Damoiseaux *et al.*, 2006), adherence to treatment guidelines (Daniel *et al.*, 2013), the effectiveness of surgery (LaVonne, 1986) and use of antibiotics (Venekamp *et al.*, 2013) were identified by reading the abstracts. The aim was to assess whether their focus was how the condition impacts young people and their parents or if their content had a medical focus. Research about parents' concerns of the efficacy of antibiotic treatments and damage to the immune response (Varrasso *et al.*, 2006, Jonsson and Haraldsson, 2002) were included as they related to parent-doctor joint decision-making.

### 2.1.4 Qualitative Studies of Glue Ear and Parents

There have been relatively few studies into the condition using qualitative methods, and none which included the active involvement of young people. The focus was on parental responses to the condition rather than those of young people. Wuest and Stern (1990) used a grounded theory approach to investigate how parents of children with ongoing Glue Ear developed coping strategies when communicating with medical professionals about their child. Asmussen *et al.* (1999) investigated the impact of the condition on family life and parental coping strategies when the child had ear infections. Their research suggests that parents find dealing with a child with the acute condition very difficult. As the research was conducted in North America the cost implications of the medical care was a main issue for parents, which has less applicability to the

UK due to the NHS not charging at point of use. Both Wuest and Stern (1990) and Asmussen *et al.* (1999) highlighted the frustration that parents felt when dealing with healthcare professionals. The research identified that parents felt they would benefit from more formal support, but this finding does not appear to have been implemented. In the UK there are still no organised support groups available to parents or young people with the condition. This may be because it is constructed as a temporary issue which, for most young people, will resolve without ongoing impact (Bluestone and Klein, 2007).

#### 2.1.5 Teachers' knowledge of Glue Ear

Although there is some research involving teachers, they are generally information givers, responding to questionnaires (Higson and Haggard, 2005), or being observed by researchers (Vernon-Feagans and Manlove, 2005) rather than taking a leading role investigating its impact in the classroom environment. Teachers were recruited to a research programme aimed at reducing ear infections in young children by Danhauer *et al.* (2011). The teachers indicated that they had no training in ear infections, although they believed that these could impact negatively on a child's life. After a short time they found barriers preventing them from participating further. Despite this lack of knowledge or involvement on the part of teachers in research into the condition, leaflets provided to parents suggest that their child should talk to their teachers about when they can't hear (East Cheshire NHS Trust, 2012). However, the child may not have the confidence or understanding to specify how he/she could be best supported.

Higson and Haggard (2005) compared and contrasted how different groups (teachers, parents and ENT surgeons) involved with children with Glue Ear perceived the condition. In their review of the literature, they highlighted that teachers have little knowledge about it with their main source of information about the condition derived from responding to individual children and/or through parents providing some insight into its potential impact on their child. Parents

themselves may lack broader knowledge of the developmental and educational impact of the condition, yet the suggestion seems to be that they are the ones to whom teachers will look to for guidance. Teachers appear to have very limited understanding of the condition or how to support a child with it, but school is where children spend the greater part of their waking day (Feakes, 1996). It could be that teachers see it as a medical problem and their lack of training leads them to overlook its educational and developmental consequences. The high rate of incidence of the condition among children below 7 years of age would suggest that training early years' educational professionals is a priority.

#### 2.1.6 Prevalence of Glue Ear in infancy and the early years of education

Maw (1995) provided a summary of studies showing prevalence rates (Table 2.1), suggesting that there is a higher incidence in younger children (Suarez Nieto *et al.*, 1983) with a peak at age 2 years. Brooks (1976) found another peak at 5 years but suggested that this could be because of the confounding factor of poor housing conditions in his participants. Bluestone and Klein (2007) suggest that increased incidence at 5-6 years of age could be the result of children starting school when they are exposed to more children and their immune systems are challenged. This could lead to more respiratory infections which are linked to Glue Ear. The level of conflict in results is demonstrated in a comparison of research by Silva *et al.* (1982) who found an increased incidence in 5 year olds. However, Chalmers *et al.* (1989), using the same data, did not. Greater incidence in winter indicates a seasonal variation (Zielhuis *et al.*, 1990). Being in a nursery environment may also be linked to higher incidence (Birch and Elbrond, 1986; Rovers *et al.*, 1999). This high incidence rate occurs at the stage of development when children are starting to talk, interact with others and learning to read and write. However their teachers appear to have limited understanding of the condition or strategies for helping children to overcome any potential barriers to learning and social development.

**Table 2.1 Age and percentages of children with Glue Ear**

<b>Study (Year) (Country)</b>	<b>Age range</b>	<b>Prevalence %</b>
Brooks (1976) (UK)	5-7	50
Lous and Fiellau-Nikolajsen (1981) (Denmark)	2-4	30
	7	26
Birch and Elbrond (1986) (Denmark)	Day-care	70
	Home-care	40
	Both locations	15
Silva <i>et al.</i> (1982) (New Zealand)	5	17
Suarez Nieto <i>et al.</i> (1983) (Spain)	2	39
Chalmers <i>et al.</i> (1989) (New Zealand)	5	10.5
Zielhuis <i>et al.</i> (1990) (Netherlands)	winter	39
	summer	24

### 2.1.7 Assessing the impact of Glue Ear

Research into the potential impact of the condition on children has been published across the world. Findings have been reported from the UK (Maw, 1995), USA, (Bluestone, 2003), Canada, (Dube *et al.*, 2011), New Zealand, (Silva and Stanton, 1996), Australia, (Lowell and Devlin, 1998), Israel, (Golz *et al.*, 2006), Iran, (Bidadi *et al.*, 2008), Turkey (Habesoglu *et al.*, 2011), Italy (Bellussi *et al.*, 2005) and the Netherlands (Timmerman *et al.*, 1999). However, there is a lack of clear consensus among researchers about the potential consequences of the condition. A further complicating factor in assessing the impact of this condition is that there are some children who appear asymptomatic but may still have hearing difficulties. This could result in behavioural and/or developmental results being attributed to other conditions (Marchant *et al.*, 1984).

### 2.1.7.1 Contradictory Research Results

While one set of researchers (Luotonen *et al.*, 1998) may find a statistically significant link between the frequency of episodes before the age of 3 years and later school performance, another group (Roberts *et al.*, 1989) may not. The continuum nature of the condition whereby some children have one or two episodes beginning at a wide age range (typically 2-7 years), others may have episodes from as early as 3 months continuing on into adulthood. This is not widely recognised within the research. If a child has ongoing episodes for a long period of time, then they are likely to have continuing hearing loss. If a child only has one or two episodes then there may well be no adverse effects. Not all studies use 'hearing loss' as the independent variable (Hogan *et al.*, 1997) so some studies may include children whose hearing is within normal thresholds thus potentially confounding the results.

Methodological shortcomings have been identified in meta-analysis/systematic reviews (Gunasekera *et al.* 2009; Roberts *et al.*, 2004a; Rosenfeld, 2003; Casby, 2001; Wallace and Hooper, 1997) as a potential explanation for the contradictory findings. A recurring methodological issue focussing a lot of debate has been about the use of retrospective data rather than prospective designs (Paradise *et al.*, 2000). Retrospective data is liable to be subject to problems of participants' memory, potentially using their present knowledge to influence their recall of past events. This led to the identification of the need to undertake carefully controlled long-term, prospective randomised controlled trials (Feldman *et al.*, 1999; Maw, 1995; Teele *et al.*, 1990). These have primarily been comparing developmental and educational outcomes between children with and without Glue Ear and/or early or late surgery to put in ventilation tubes (grommets) to equalise the air pressure on either side of the ear drum. Even using this highly regarded approach the results are inconclusive.

Population studies, with specific information about large numbers of children over a long period of time, provide an alternative approach to investigating the condition. Examples of this method are the Dunedin Multidisciplinary Health and Development Study, New Zealand, (Chalmers *et al.*, 1989) and the Avon Longitudinal Study of Parents and Children (ALSPAC) in the UK (Wilson, 2009). The studies investigated potential educational implications but the results report global trends with little information about the needs of an individual child or the impact on parents.

There has been much research into whether or not there are any long-term developmental implications associated with delaying putting grommets into children with Glue Ear (Paradise *et al.*, 2007). After a prospective study of 11 years, Feldman and Paradise (2009:44) asserted that their findings, ‘constituted strong evidence that persistent early-life MEE did not cause later developmental disorders or compromise the rate of development in these otherwise normal children’. However of the 206 children who were originally allocated to the ‘early surgery’ group, only 79% had grommets inserted within the planned 180 day goal. However 21% of children who did not meet the time requirement for insertion of grommets remained as part of the data analysis. Of the 196 children who were allocated to ‘late surgery’ (scheduled to have grommet surgery 6 months from the time of joining the trial), 11% had surgery within the 180 day period set for the ‘early surgery’ group. Again their data remained in the ‘late surgery’ group data (Paradise *et al.*, 2001). The data collection did not therefore comply with the original criteria set for each group in this randomised clinical trial. Furthermore, as children were selected on the basis of having had persistent Glue Ear from 2 months to 3 years, any child who had grommets prior to their third birthday would have been excluded from participating. I would suggest that the children with early surgery, who are at extreme end of the continuum in their experience of the condition, are most likely to be at risk of developmental consequences. Thus the findings do not reflect the full spectrum of those with the condition.

The position paper prepared by ENT UK (2009) makes the point that such ‘switching’ between groups is not always taken into account, but that it is likely to skew the statistical results if children who actually have surgery continue to be reported as part of the ‘no surgery’ group. This situation is more common than is highlighted in results. Hall *et al.* (2009) used ALSPAC data with a subset of children identified as having ongoing Glue Ear and associated developmental problems (Childhood Otitis Media with Effusion Trial – COMET). They originally used a randomised clinical trial in which 182 children were assigned either to ‘early surgery’ or ‘watchful waiting’ groups. However, by the 18 month follow-up point 85% of all participants had actually had grommets inserted as a result of concerns about development or parental pressure. This calls into question the reliability of the results of previous research.

Rather than a large-scale prospective study Winskel (2006) conducted a matched-pairs design based on 43 children, aged 6-8 years, with a repeated history of the condition. ‘Repeated history’ was defined as those children who had four or more episodes and/or who had grommet surgery before the age of 3 years. A comparison group of children from the same school and class were identified as being free from the condition. There are a number of advantages in this study over the ones previously described: the children had a more extreme history of Glue Ear from an early age; the matched-pairs design meant that there could be a direct comparison between children in the same class, from a similar background and experience. The language measures used were more specific, examining phonology and morphology, which have been identified as being important to the development of reading skills (Petinou *et al.*, 2001). Other studies (Paradise *et al.*, 2001; Silva *et al.*, 1982) used more global language development measures, such as receptive and expressive language, which may not be sufficiently sensitive to identify the exact impact of the condition. Winskel’s (2006) study does have issues around generalising the findings to other groups as all the participants were white; their parents had high levels of education and were in professional jobs. However, the key findings are that in those children with early onset and prolonged experience of the condition, their language skills and reading abilities were

statistically significantly poorer than those in the comparison group. This research does take into account the continuum nature of Glue Ear, including children with the most severe form of the condition, who are often overlooked or omitted.

What the results of all of this research do suggest is that this is a condition about which educational professionals working with children under the age of 7 years, in particular, would benefit from having more knowledge and/or training. Widening the dissemination of results beyond those in healthcare and encouraging educational professionals to consider the impact of hearing loss, even if it is intermittent, may benefit many children and help to overcome any early educational disadvantages they may have, before remedial measures are needed.

#### 2.1.7.2 Issues in the data collection methods

A range of methods have been adopted for research into the impact of Glue Ear on young people: psychometrics (Timmerman *et al.*, 2008), observational studies (Freeark *et al.*, 1992) and questionnaires (Higson and Haggard, 2005). Although methods such as structured interviews with parents of young people with the condition, via the telephone (Dube *et al.*, 2011), suggest that participants can contribute their opinions, it is likely that the nature of the questions meant responses were restricted to the agenda of the researcher. This may account for the findings identifying concerns about the use of antibiotics and time spent visiting healthcare professionals. It is as though the researchers, who are mainly healthcare professionals, may not acknowledge the potential expertise parents have about their child, or their situation, resulting in not having the opportunity to identify issues of key importance to them (Kennedy, 2003). Parents and young people have therefore been used as data sources (Dube *et al.*, 2010; Higson and Haggard, 2005) constrained by the questions asked by researchers. The researcher is identifying the scope and design of the study with the parents and young people acting as information givers within the constraints set by the researcher. Most of the research has been conducted remotely such as

through population studies (Wilson, 2009; Chalmers *et al.*, 1989). This leaves a ‘Gap’ in knowledge as to how the young people with the condition, and their parents, experience its day-to-day impact.

#### 2.1.8 Key developmental and educational themes identified in the literature

After reading key words used by the author, titles of articles or book chapters, book summaries and abstracts, three key themes summarise the research in non-medical terms. In this section, the literature identifying links between Glue Ear and other conditions is discussed and related to other commonly identified conditions:

1. Behaviour and social skills and links with Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (ASD)
2. Language and speech development and the overlap with Language processing conditions (Central) Auditory Processing Disorder (CAPD)
3. Reading performance and the relationship to Dyslexia

Each of the themes is evaluated against:

- Data collection methods
- The extent to which the data reflects performance in real life settings
- The role of parent-child interaction
- The potential longer-term impact of the condition on young people.

### 2.1.8.1 Behaviour and Social Skills in Glue Ear and links to behaviourally-based conditions

A chronological framework is used to explore the potential impact identified in the literature on the behaviour and social skills of young people with Glue Ear from birth onwards. It considers the relationship between the primary caregiver and such a child. The intermittent hearing loss associated with the condition and its potential impact on a young child in pre-school and early years at school and home is explored, leading to the condition's potential impact in the teenage years. In all of the studies it is the parent who answers on behalf of their child about such things as their pain levels and behavioural interactions. There seems to be an assumption that the parent has insight into what their child is thinking/feeling but this may not be accurate (Lagattuta *et al.*, 2012). I would suggest that the ongoing hearing loss and recurring pain associated with the condition, with a potential impact on maternal anxiety, may mean that parents are not always best-placed to accurately interpret their child's behaviours or attitudes.

For some children, and their parents, their experience of the condition begins in early infancy, between birth and 6 months of age (Maw, 1995). Some of the studies (Barber *et al.*, 2014; Asmussen *et al.*, 1999) focused on the experiences of children and families when the child was having an acute episode which although short-lived is likely to be very distressing. A baby, in pain with an ear ache, cannot tell the parent what the problem is so they potentially become upset and confused by a child who is obviously distressed but unable to be comforted. If this begins at a very early age, there is some evidence that parent-child attachment may be negatively impacted (McCallum and McKim, 1999) as the parent, typically the mother (Craig, 2006), may have a crying and restless child who is difficult to pacify. This could lead to the mother questioning the effectiveness of her parenting skills. Problems with attachment are more likely if the child has not been diagnosed, perhaps leading to parental feelings of inadequacy and depression (Forgays *et al.*, 1992). The research suggests potential difficulties between mother and child, but there

does not appear to be any support or information for parents in this situation to help them understand that the condition, not them or their child, is the cause of the behaviour.

Lack of sleep for both parent and child is likely to result in irritability (Roberts and Wallace, 1997). This may lead to increased stress levels and frustration within the family situation (Asmussen *et al.*, 1999), potentially resulting in longer term parental anxiety such as questioning the effectiveness of their parenting skills (Dube *et al.*, 2011). Shaikh *et al.* (2010) found that parents of higher socio-economic status (as defined by level of maternal education and health insurance provider) reported higher levels of pain in their child than parents of other socio-economic groups. The reason for this and its impact on the parent-child relationship is not understood. Perhaps more educated mothers may perceive higher levels of maternal stress. This could be interpreted as a problem in the mother rather than investigating the health of the child. This increased maternal anxiety could lead to a problematic development of parent-child bonding.

A child with the chronic form of the condition is likely to have long periods of hearing loss perhaps resulting in less interest or interaction with their parents than unaffected children (Klein, 2000). The parents may come to perceive their child as difficult and so be less responsive (Roberts *et al.*, 1995). This may be exacerbated if children with the chronic condition exhibit problematic behaviours such as being fearful, clingy, fidgety and argumentative (Silva *et al.*, 1982). This could have implications for the parent-child bond if such behavioural aspects of the condition are not explained to parents.

As the child gets older social interactions with their peers and others outside the family become an increasing part of their daily life. However when children have an episode, their hearing is impaired which could make it socially challenging to interact with others (Penn *et al.*, 2004). They are likely to have hearing loss of around 25 decibels making normally spoken sounds such

as 'f', 's' and 'th' hard to distinguish. They may not understand even single syllable words (Gravel and Nozza, 1997). Hearing in a noisy home and classroom environment can result in difficulty understanding what others are saying (Toe, 2009). This could require extra processing time to separate what is being said from the background sounds which can lead to misinterpretation by others regarding the child's behaviours (Capewell, 2014a).

Manlove *et al.*, (2001) suggest that the continued effort of working to hear and understand what is going on may lead to children tuning out as a coping mechanism. This learned behaviour continues even when hearing ability is within normal levels. Others may interpret this as the child ignoring them or not responding to their peers. The result is that some children with the ongoing condition find it easier to withdraw from social interaction (Vernon-Feagans and Manlove, 2005; Pakulski and Kaderavek, 2002).

Speech difficulties develop in some children (Bellussi *et al.*, 2005). As they may not be understood by others (Vernon-Feagans and Manlove, 2005) they could have difficulties in interacting with other children and develop a lack confidence perhaps avoiding speaking for fear of miscomprehension of what they say. Low interaction may result in social isolation. Frohlich *et al.* (2010) highlighted emotional problems and poor peer relationships in children with below average phonological processing skills thus supporting the findings of Bidadi *et al.* (2008).

The effort of trying to understand what is being said may impede the development of theory of mind skills because the child may be slower in developing understanding of social intricacies when interacting with others (Bidadi *et al.*, 2008). For even young children to have successful social interactions, they need to be able to demonstrate 'joint attention' (Bortoli and Brown, 2008) whereby they use both hearing and sight to monitor their environment while paying attention to another person. In practice this may mean that a child is engaging with another child on a shared activity, while simultaneously responding to sounds and sights around him/her. The

ability to switch attention quickly between visual and auditory information may be difficult for children with hearing impairment. It is not uncommon for children with Glue Ear to be more affected in one ear than the other so demonstrating different behaviour depending upon where they are situated in relation to others.

Munroe (2010) identified that in cases where a child with the condition has one ear with better hearing than the other, the plasticity of the brain changes resulting in the less efficient ear becoming a 'lazy ear' with the brain not attending to the information received through it. This can mean that no input is interpreted by the brain from that ear. In the classroom and at home this can result in the child being labelled as inattentive, off task or rude by being unresponsive. The child's behaviour is likely to be seen as the problem rather than as a consequence of the condition.

Children with the chronic condition have been described as demonstrating problematic behaviours, for example being fearful, overly dependent or hot-tempered (Silva *et al.*, 1982). Haggard *et al.*, (1994) reported that parents of affected children described them as having frequent displays of frustration and bad temper, speculating that it results from impaired hearing. Similarly, Bess *et al.* (1998) identified that children with minimal hearing loss are likely to be more tired and lower in energy than other children leading to lower self-confidence and smaller friendship groups than their normal hearing peers. Such behaviours may result in poor integration with their peers. Problematic behaviours may be more likely in younger children who perhaps do not have the language skills to explain their difficulties or not have developed effective strategies for managing their emotions. They may therefore be regarded as somewhat socially immature for their age. Bennett *et al.* (2001) suggest that problematic social skills continue into teenage years, including behaviours such as being anti-social, neurotic and hyperactive.

Glue Ear has been identified primarily as a temporary medical condition with most research focused on understanding what is happening with the physiology of the ear. Its implications in emotional outcomes have generally been overlooked. I would suggest that more consideration needs to be given to the possible consequences of social withdrawal, lack of concentration and immature social skills as attributable to it. In some instances such behaviours may have been attributed to other labels. Cacace and McFarland (2006) make the point that some children with a history of chronic Glue Ear exhibit the same behaviours as those with ADHD, such as difficulty identifying the location of a sound source, having to have things repeated and problems remembering spoken information. Glue Ear may be associated only with recurring ear infections rather than having a wider impact. However, there seems to be some similarity in behaviours between the two conditions, such as lack of concentration, hyperactivity, impulsiveness and being easily distracted. In a comparison of children referred to a centre for behavioural difficulties, Adelman *et al.* (1990) found that those with a diagnosis of ADHD were more likely to have a history of repeated ear infections than a comparison group of children with learning difficulties. This makes the connection between the two conditions but leaves unanswered the relationship between cause and effect and the extent of the overlap.

Silva *et al.* (1982) highlighted that mothers have rated their children as more distractible, disobedient or difficult when they have temporary hearing loss. The intermittent nature of the hearing loss could lead parents to conclude that the child is at fault. Sometimes this leads to a search for an explanation of the behaviours associated with Glue Ear being overlooked, or not considered, as the cause because of its perception as trivial. Potentially this could lead to misdiagnoses with one of the various attention deficit disorders (Capewell, 2014b). ADHD is assessed through behaviours rather than on a bio-physical model so it could be worthwhile checking if a child has a history of ear infections and hearing loss as an alternative explanation of cause.

Autistic spectrum disorder (ASD) is another condition which has seen an increase in frequency over the last few decades. However there is a lack of clarity about the diagnosis for those children whose behaviours are perhaps better described as being ‘reminiscent of autism’ (Frith, 2014: 744). There may well be an overlap between poor social skills perceived in children with early chronic Glue Ear and ASD. Tajima-Pozo *et al.* (2010) described how after surgery for Glue Ear a five-year-old child previously diagnosed as ASD, showed substantial change in his behaviour. His speech improved, he had fewer sleeping problems, his temper-tantrums diminished and he was more willing to interact with others. This case study approach suggests that paying attention to an individual could provide more insight into that person’s behaviours as well as widen understanding of potential impacts for labelling children.

A hypersensitivity to noise is often seen as symptomatic of increased sensory perception in children with ASD (Preece and Jordan, 2007). Baguley (2003:582) defines hyperacusis as: ‘an extreme sensitivity to everyday noises (washing machine, lawnmower) which are perceived as being so loud that they cause distress’. Hyperacusis and tinnitus were found by Coelho *et al.* (2007) in 37% of children, aged 5-12 years, who had hearing loss associated with Glue Ear, supporting earlier research findings by Mills and Cherry (1984). Children with intermittent loss may find that when their hearing returns to normal levels they have increased sensitivity so show avoidance behaviours and distress when confronted by everyday objects such as vacuum cleaners. To better understand such potential impact Sun *et al.* (2011) undertook an animal study in which they simulated the physiological changes associated with Glue Ear. They found that there were changes in the brain development of the animals such as exhibiting frenzied activity in response to noise and trying to escape it. Children with the ongoing condition may respond to loud noises with distress and hide under tables as a way of blocking out the sound (Capewell, 2014b). Without wider knowledge of this research, it is reasonable for behaviours to be attributed to causes other than Glue Ear.

I am not making the suggestion that ADHD and ASD are not an appropriate diagnosis for many children (and adults). However, the research explored suggests that there may be an overlap or even alternative explanations in some instances which are better identified as a consequence of Glue Ear. Particularly in educational contexts, where the research about this condition is not well known, it may be beneficial to focus on gaining a history of ear infections as a first step.

#### 2.1.8.2 Language and speech development and Glue Ear

Leviton and Bellinger (1986) suggest that for children with no other long-term health or developmental problems, two main hypotheses continue to provide the basis for investigating language acquisition and development in children with Glue Ear. The first identifies a 'critical period', during the first three years of life, when speech and language is developing at its fastest, requiring more or less steady input if language is to be learned (Menyuk, 1986). This coincides with the time when children are most at risk of the condition along with its highest rate of incidence. The second hypothesis suggests that it is the combination of hearing loss with the number of episodes (Roberts and Wallace, 1997) which leads to children falling behind their peers. The children believed to be most at risk are those with the high numbers of episodes as they are assumed to have greatest hearing loss (Teele *et al.*, 1984).

Casby (2001) in his meta-analysis of research into speech and language development in children with the condition highlighted that studies document the number and duration of episodes but lack data about the level of hearing loss. Because studies used different global measures of language comparisons between the findings about skills proved difficult. In their meta-analysis, Roberts *et al.* (2004a) concluded that there are no clear findings regarding the condition and language development.

Rather than comparing the results of studies, I reviewed studies investigating specific language skills development in those children with the condition from an early age. I wondered if there were factors which complicate language development in children with the condition before 6 months of age. McCallum and McKim (1999) considered the quality and type of interaction between the caregiver and the child. Before a child starts to crawl or walk interaction is most frequently face-to-face. It could be that those children with the early chronic form seem less responsive to caregivers, perhaps by babbling less. Thus they are not encouraging caregivers to vocalise to them, reducing their experience of language.

Rvachew *et al.* (1996:250) investigated canonical babbling which they defined as ‘a consonant and a vowel-like utterance produced with normal resonance and phonation’, for example ‘gu’. They suggest that this is the precursor to the development of phonological skills required for understanding language. They found that children with early onset (birth to 6 months) showed a consistently lower rate of canonical babbling than their unaffected peers, therefore potentially lacking the foundations for later language development.

Interactions between parents and children with/without the condition were investigated by Yont *et al.* (2001). They found that children of 12 months with the chronic condition were less likely to use accompanying gestures to help parents understand their meaning. This may lead to fewer opportunities to develop language skills through attending and mimicking what their caregivers say. In a further study, Yont *et al.* (2003) found that parents of children with the recurring condition were more likely to direct attention of their 12 month old child to specific objects or actions. Wallace *et al.* (1996) observed that type of interaction resulted in the caregiver not asking questions of the child or offering information, perhaps leading to poorer language skills. These children may not develop complex expressive language skills as they experience less variety in the language structures they experience. Mean length utterances (MLU), a common technique for assessing children’s language skills, counts the average number of syllables a child

uses in spontaneous conversation. Zumach *et al.* (2010) found that those children with high numbers of episodes in their early life were likely to make statistically significant shorter MLUs than their non-affected peers. The findings from the research reviewed here counter the idea that there are no long lasting effects on language development in these children, particularly for those with very early onset of the condition.

Although it is characterised as temporary, Harrison (2006) found evidence that if a child has repeated episodes at an early age there may be permanent (Central) Auditory Processing, (C)AP, changes in the brain. Following verbal instructions delivered in quick succession may be difficult as the child may require additional processing time (Roberts *et al.*, 2004b). This may lead to poor verbal memory with some of the information lost or misinterpreted. Following language with complex syntactical structures may lead to misunderstanding perhaps resulting in the child doing the wrong thing and appearing to be disorganised (Walinder *et al.*, 2007).

The potentially longer-term impact on the (C)AP due to peripheral hearing loss in the middle ear from repeated ear infections has been identified but may not be widely known (Pillsbury *et al.*, 1991; Gunnarson and Finitzo, 1991). These changes in the brain, which remain after surgery for those children with the ongoing condition, undermines the temporary label often attached to it. As the child gets older, the complexity and dependence on language in school increases so the condition could impact the young person's academic success. Children with the ongoing condition may benefit from changes in the classroom to better support their ability to hear as well as implementing strategies to improve their listening skills (Edwards, 1991). For this to happen, educational professionals need to know about these potential outcomes and understand what appropriate actions to take which suggests that there may well be a need for training about the condition in initial teacher training and CPD.

The research in this section suggests that for some children changes in the brain occur because of early experience of the condition. With the advent of increasingly more sophisticated non-invasive techniques for assessing brain function more detail about the longer term impact of the condition may be identified in the future. The changes in brain plasticity could mean that children with ongoing intermittent hearing loss perhaps process language differently to their normal hearing peers, maybe because they do not consistently receive the same words in the same way. Holm and Kunze (1969) used a matched-pairs design comparing children with the chronic condition with their unaffected peers and found that affected children had significantly poorer auditory processing skills both in receiving auditory information and verbally responding to it. Additionally, Katz and Tillery (2004) found that children with the long-term condition had difficulty in blending phonemes, thus potentially making it difficult for them to understand language.

Borges *et al.* (2013) found that children who had the chronic condition and did not receive grommets until after the age of 6 years continued to have difficulties processing language. The brains of these children interpreted speech and phonemes differently to normal hearing children. Part of the explanation for this might be that they are less competent at distinguishing sounds in noisy environments, being hampered in their ability to filter out background noise (Hogan and Moore, 2003). It seems that the children most impacted are those with the highest number of episodes and consequent hearing loss. These children may not hear voice sounds in the same way as others because of the combination of hearing loss and background noise interference. This could result in not being clear about the meaning of words resulting in poor comprehension of what is said to them. This perhaps also results in poorer articulation with the result that they are not understood by others (Hasenstab, 1987), so less inclined to speak thus reducing their opportunities to develop their language skills.

Assessing global language skills rather than investigating the impact of the condition on particular aspects of language learning, such as use of language (Zumach *et al.*, 2010) or types of interaction with others when first learning language (Yont *et al.*, 2001), have made comparisons between research findings difficult. However, it does appear that children with a history of chronic Glue Ear perform at the level of much younger children when using phonological skills and they have difficulty retaining a list of words and understanding sentences with a complex structure (Nittrouer and Burton, 2005). It seems likely that children with the long-term condition, particularly those who have had repeated episodes, are more susceptible to developing language acquisition and processing disorders. As there seems to be a complex interaction within the brain and experience it may be that further investigations need to focus on specific language skills to gain greater insight into how the condition impacts speech and comprehension.

#### 2.1.8.3 Reading Performance and Glue Ear

To progress in schools, children need to be able to: read to gain information; write down their ideas and give responses to show understanding and knowledge; and communicate verbally to clarify information and extend their thinking. With each school year there is increasing emphasis on the need for proficiency in these skills and to use and understand more complex language. Teachers have an expectation that students in their class will be able to read, write and comprehend at age appropriate levels. One potential impact of Glue Ear is that the intermittent hearing loss may impact students' ability to perform at the same level as their peers.

The Greater Boston Otitis Media Study Group is one of the prospective longitudinal studies used to assess the impact of Glue Ear on school performance. Teele *et al.* (1990) found a relationship between the number of episodes before the age of 3 years and school performance in reading, maths and IQ scores when tested at age 7 years. Those with continuing episodes up to age 7 years were most affected. They took the continuum nature of Glue Ear into account with

participants grouped according to age of onset and severity of episodes. No differentiation was made as to whether or not the children had grommets. Differences in socio-economic status were based on maternal education and parental profession. All of these factors help to give more reliability to the study, as potential confounding variables were taken into account. Developing the condition after the age of 3 years did not appear to impact performance at age 7 years. This potential educational disadvantage seems to apply in non-English speaking countries with similar findings in Saudi Arabia (Azab and Rhman, 2014) and Finland (Luotonen *et al.*, 1998).

This difference in frequency and age of onset of the condition was explored in more detail by Golz *et al.* (2006) who followed up children with the chronic condition, comparing them to non-affected children in a carefully controlled matched-pair study. In comparison to the controls, children with the ongoing condition up to an average age of 11 years, made more statistically significant reading mistakes. Although all students showed improvement in their reading, the chronic children were poorer readers. Teachers and parents need to be aware of these potential educational implications perhaps placing less emphasis on a child making age appropriate progress. The greater proficiency in reading skills, required in later school years, particularly in extracting and interpreting information, could mean that young people with the chronic condition may not achieve their full academic potential. Such students may benefit from greater teacher awareness of their condition (Capewell, 2014c). Bennett *et al.* (2001) identified that teenagers with an early history of it had a two-year difference between their chronological and reading age. As most studies do not continue beyond 11 years, these figures may be under-reported.

Winkel (2006) examined the impact of an early history of the condition on phonological, semantic and narrative skills to assess the impact on reading performance in school-aged children. She suggests that poor phonological development and word decoding, where the sounds (phonemes) are matched to the written representation (grapheme), lead to these children having difficulties when learning to read. Her use of specific language measures may account for

the difference in results when compared to those of longitudinal studies (Feldman and Paradise, 2009; Maw, 1995) where their findings indicate that children would catch up with their unaffected peers. If children have difficulty in matching sounds with words accurately, then vocabulary development may be hampered. Perhaps children with the ongoing condition may not hear words in the same way every time the word is said which could result in taking longer to learn new words. They also appear to have difficulty decoding words. Roth *et al.* (2002) identified that vocabulary is important in children's reading comprehension abilities at age 6 years, so children with the ongoing condition are likely to be at a disadvantage when learning to read as they may have a smaller bank of language.

Durand *et al.* (2013) used some of the same data from the Pittsburgh study (Feldman and Paradise, 2009). Previously the data had been analysed using global reading measures. But they found that those children who had difficulty decoding words at 3 years of age continued to have poorer reading abilities at the age of 11 years. Research by Kindig and Richards (2000) found that students aged 8-10 years who had four or more episodes prior to the age of 3 years performed significantly worse than their unaffected peers on a range of reading tests. These results could indicate that those young people who have early onset of the condition and continue to have episodes into adolescence may be most at risk of educational disadvantage compared to their unaffected peers. If knowledge of this research is not known by parents and educational professionals, children may not be sufficiently supported so that they may become frustrated because they have not achieved the same skills as their peers, perhaps leading to negative emotional outcomes or disengagement with school.

Some of the conflicting results in previous longitudinal studies may be clarified when the number of episodes a child has is taken into account. Additionally, it seems that the subtlety of how the condition impacts on reading is better understood when specific skills are explored rather than using global reading tests. Although young people with chronic Glue Ear appear to

demonstrate progress, it seems that the condition may impede them in attaining their full potential which could mean that they lag behind their peers.

Poor reading, spelling and writing skills are often associated with Dyslexia. It is said to occur when 'accurate and fluent word reading and/or spelling develops very incompletely or with great difficulty. This focuses on literacy learning at the 'word level' and implies that the problem is severe and persistent despite appropriate learning opportunities' (Reason and Wood, 2005:8). It is an imprecise term which results in confusion among educators as to its causes, consequences and actions (Elliott and Grigorenko, 2014; Kerr, 2001). There appear to be a number of overlaps between Dyslexia and Glue Ear. Peer (2009) indicated that about 70% of children have both conditions. It may be that the ongoing literacy difficulties experienced by some children are better explained by Glue Ear rather than labelling them as 'dyslexic'.

O'Brien *et al.*, (2012) identified a sub-type of Dyslexia linked to phonological deficits, which is the specific modality difficulty of children with Glue Ear. As Winskel (2006) suggested, the acquisition of phonics in children with the ongoing condition is slower thus hampering them when decoding the written word. This can result in slower progress in achieving proficient reading skills (Golz *et al.*, 2006). Problems of holding and processing information in memory are related to difficulties in working memory associated with the phonological loop (Schuchardt *et al.*, 2013). Such difficulties have been described earlier and it seems likely that such processing problems are attributable to Glue Ear.

Previous sections have identified the research linking the condition with literacy difficulties. It may be an effective starting point to begin assessment for Dyslexia by investigating if the young person has had a history of recurring ear infections and if so, how many and at what age they began. I think it is reasonable to suggest that for some young people the basis of their difficulties comes from Glue Ear instead of Dyslexia. Perhaps some of the difficulty in attributing academic

difficulties to Glue Ear results from its construction as primarily a medical condition, with no long-term effects.

#### 2.1.9 Conclusions - Temporary, Trivial and Medical

For the majority of young people and their families, Glue Ear is a temporary experience which has resolved by about the age of 9 years. It is therefore not surprising that the bulk of the research has focused on children up to this age. This temporary construction leads to a belief that any impact will be short-lived and that children will catch up (Teele *et al.*, 1990). Recent studies into its impact on brain development (Borges *et al.*, 2013; Sun *et al.*, 2011) suggest that there may well be longer term changes that need to be taken into account, particularly for those young people who have recurring episodes of Glue Ear before the age of 3 years.

Glue Ear is perceived as a trivial condition because it is no longer life threatening for most populations in the more economically developed parts of the world (Acuin, 2004). Generally research has been undertaken from a medical perspective investigating the causes (Bluestone and Klein, 2007), the effectiveness of available treatment options (Maw, 1995) and prevalence (Arquedas *et al.*, 2010). The additional burden on learning, particularly for indigenous populations (O'Connor *et al.*, 2009; Bowd, 2005) and its possible impact on attachment (McCallum and McKim, 1999), parental stress (Barber *et al.*, 2014) and early models of social interaction (Vernon-Feagans and Manlove, 2005) could have potentially more serious and long-term implications.

#### 2.1.10 Summary of the findings from the literature and implications for future research

The following points have emerged from the literature review:

- The majority of the research has been quantitative

- Researchers are predominantly healthcare professionals
- There has been little direct involvement by parents expressing their own views
- No action has been taken in providing parental support
- Young people have not had an active role in the research
- Information has been obtained predominantly through parental proxies
- The voice of participants is missing from the research
- Glue Ear has been contextualised as primarily a medical condition with limited insight into its:
  - continuum nature
  - impact on daily life
  - educational consequences
- Educational professionals appear to have limited understanding and training in it
- There are overlaps between it and other conditions but it is not perceived to be the cause of behavioural and educational difficulties.

#### 2.1.10.1 Implications for future research

Very little is known about the daily life of those young people, and their families, who develop Glue Ear at an early age and for whom it continues into adolescence. There has been limited research regarding its psycho-social affects. There are suggestions in the literature that mothers of those children with chronic early onset of it may be more anxious, but this has not been explored in depth. Perhaps some young people are diagnosed as having other more high profile conditions because of the medical construction of Glue Ear. Teele *et al.* (1990:692) suggest that

‘... the differences, or sequelae, will probably be subtle or unnoticed for any single child.

The child may not reach his or her potential capabilities but may not appear impaired.

On average, affected children do not appear to function as well as they might.’

It seemed that it would be illuminating to investigate the condition at the level of the individual child to gain insight into its ‘subtle’ potential consequences. A methodology in which young people and their parents were at the centre of the data gathering was needed. This could provide information to fill in some of the gaps in knowledge identified above. It would enable young people and their parents to actively reflect upon and express how the condition impacted them emotionally and cover all aspects of their lives.

## Chapter 3

### Research Methodology 1: Putting participants' words at the centre of the research

#### 3.1 Introduction

The aim of this research was to gain insight into how young people and their parents perceived long-term Glue Ear impacted all aspects of their lives, including their interactions with healthcare and educational professionals. I therefore wanted to develop a methodology that encouraged collaboration between the participants and myself, as the researcher. The aim was to have participants' words at the centre of the research. I was keen for young people to personally express their views rather than have their parents respond on their behalf. This chapter summarises the theoretical underpinning for selecting a qualitative approach along with the rationale for using the methodologies of IPA and Photovoice. It explores how combining and adapting these two qualitative methodologies, at different stages in the research process, provided participant-led data gathering along with an in-depth analysis and interpretation of their words.

As identified in the literature review chapter, researchers have sought parental views. However, these were perhaps constrained by the researcher's agenda through the use of semi-structured interviews (Dube *et al.*, 2011) or questionnaires allowing for only a few open responses (Barber *et al.*, 2014). There has been limited previous qualitative research (Asmussen *et al.*, 1999; Wuest and Stern, 1990), which is nearly two decades old, so may not be reflective of current society or clinical practice. Rather than consulting young people directly, parental proxies have been used to access understanding of the condition's impact on them (Bennett *et al.*, 2001) and their interactions in the classroom (Stenton, 2003). However, the young people were not active participants in research about their medical treatment or academic performance.

### 3.2 Methodological Aims

The aim of my research methodology was to:

- Place participants, both young people and their parents, at the centre of the data gathering
- Use methodologies suitable for both young people and their parents
- Incorporate data based on opinions, feelings and experiences
- Collect data in a structured and coherent manner
- Demonstrate transparency at all stages of the research process.

The success criteria for the methodology were that it encouraged participants to:

- Explore their understanding of the condition
- Identify specific situations related to their experience of it
- Reflect on the impact it had on them
- Explain its emotional consequences
- Provide professionals with information about how the condition impacts their life.

A key goal in the development of my approach was to encourage and support participants to reflect, analyse and document their daily experience of living with the condition (Capewell, 2014d). As the voice of young people was absent from research in this condition, I wanted to promote ways of encouraging them to express themselves freely (Coppock, 2011; Druckett *et al.*, 2010). This issue is discussed in more detail later in this chapter, particularly how young people tend to perceive adults as having power over them and that adult views are more important than their own.

This chapter provides a sequential explanation about my philosophical development in the methodological choices I made for this research. I examine the:

- Benefits of adopting a qualitative approach
- Selection of a phenomenological approach (Silverman, 2010)
- Explanation of Interpretative Phenomenological Analysis (Smith *et al.*, 2009)
- Exploration of visual images and selection of Photovoice (Wang and Burris, 1997)
- Rationale for combining Photovoice and IPA
- Justification for applying IPA to the analysis of data.

### 3.3 The benefits of a qualitative approach

By employing a qualitative approach ‘the researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting’ (Cresswell, 2008:15). Previous quantitative research into Glue Ear may have led to evidence-based medicine (Rosenfeld, 2003) helping to identify the best treatment option to minimise long-term consequences of the condition, but it has not provided insight into understanding what it is like to live with it. This research is focused on the individuality of each participant, encouraging them to express their experience in their own words about their daily life, keeping their words at the centre of a qualitative methodology. The aim was to provide a more effective mechanism for understanding each participant as an individual, rather than analysing numbers to provide overall trends about groups of participants, as is generally found in quantitative research.

With a qualitative methodology, the researcher still adheres to the rigours of a scientific and systematic approach (Silverman, 2010). The qualitative researcher gains insight into the participants’ perspective through the application of analytical methods. Guba and Lincoln (1994) suggest that exploring participants’ lived experience is likely to provide greater understanding of

the impact of the findings suggested by previous quantitative research. This supports the point previously cited by Teele *et al.* (1990), at the conclusion of Chapter Two, regarding the subtle differences that Glue Ear has on individuals. This research could illuminate the diverse outcomes for individual children in speech development (Zumach *et al.*, 2010), parent-child interactions (McCallum and McKim, 1999) and parental stress levels (Forgays *et al.*, 1992).

Miles (2011), in her research in Zambia and Tanzania into teachers' confidence in teaching students with special needs, found that using photographs with young people provided them with the opportunity to raise and discuss issues which might otherwise not have been explored. I believed that visual images could encourage young people with long-term Glue Ear to provide their perspective, and that of their parents, about situations raised in the literature. An example of this was the identification that young children with the condition tend to withdraw from noisy situations (Vernon-Feagans and Manlove, 2005). I reasoned that through adopting the methodologies used in this research then the young people could discuss the reason that they may withdraw; the mother might reflect on her response to such behaviour including the responses of educational professionals.

The participants in this research are similar to those described by Kaplan *et al.* (2011:195) who 'would traditionally be the subject of others' research ...' so data needed to be gathered through a method that encouraged them to 'address and share important aspects of their life'. In much of the previous research into Glue Ear participants have had a passive role, so I wanted to adopt a methodology that clearly demonstrated to them that, as the researcher, I valued their contribution, would listen to them (Pearson and Ralph, 2007) and saw them as the experts in their experience of Glue Ear.

### 3.4 A Phenomenological Approach

Phenomenology is the study of experience. This research is related to the phenomenon of Glue Ear and each participant's understanding of it. This experience has not previously been investigated in depth. A phenomenological approach encourages people to explore their experience and understanding of the particular object of the research. Phenomenology has moved from a philosophical position of trying to understand how life's experiences shape a person, to investigating what can be learned about the experiences of individuals with regard to a specific situation. Moustakas (1994:14) defined it as: 'The understanding of meaningful concrete relations implicit in the original description of experience in the context of a particular situation' (original author's emphasis). An interpretative phenomenological methodology was used in this research to enable participants to have greater power and control in identifying, discussing and prioritising issues they considered as key in their experiences of the condition. Van Manen (1990) identifies that phenomenological research always begins with the participants describing their lived experience before encouraging them to reflect on those experiences as well as their personal response to them. Participants are encouraged to reach an understanding, or hermeneutic, of how they construct or interpret the way they have been affected by a particular aspect of their life (Holstein and Gubrium, 2005).

In IPA research, the hermeneutic concept is developed so that the researcher also forms her own interpretation of the participant's situation and shares it with them. At the simplest level Smith *et al.* (2009:21) defines hermeneutics as 'the theory of interpretation'. Smith (2004) identifies how the researcher uses the double hermeneutic technique to support participants in reinterpreting the meaning they place on a situation. Through reflection and review, the participant and the researcher, together, synthesise their thoughts while exploring a phenomenon. Participants in this research explored their experience of the condition's impact on their life and I tried to understand the meaning they attributed to their situation. I used techniques such as reflecting back to them

the specific words or phrases they used, exploring their reasons for choosing them and asking them their definitions of particular words or phrases. This provided greater clarity about their situation as they also reinterpreted their understanding of what particular experiences meant to them. Additional probing was sometimes required to gain more insight into why they had chosen a specific example or how they had developed their interpretation. Through both of us, participant and researcher, reflecting and sharing our thoughts, deeper insight was gained into the meaning attributed to their experience. A double hermeneutic is achieved when both researcher and participant share their understandings of a situation to construct new meaning.

The researcher's observations come from paying close attention to the participants' words, then sharing those words and observations with them. In other methodologies this reflective practice does not occur because only the researcher constructs the interpretation, potentially not sharing it with participants. Although this is not always followed in phenomenological studies, I considered that offering the interpretation to participants in this study was a way of demonstrating to them that they were central to the process.

Smith *et al.* (2009) suggest that it is through investigating the lived experience of individuals that generalised statements about the particular phenomenon can be identified. Initially the words of an individual are analysed as he/she makes sense of a specific experience. The researcher encourages participants to use their own words to describe events and emotional responses and works with them to reflect and reconstruct their understanding of that situation. Giving a central place to the understanding of people living with Glue Ear was the focus of this research. A methodology was required which placed emphasis on encouraging and supporting participants, and the researcher, to work collaboratively to gain greater insight into participants' interpretation and reflection on their experience.

### 3.4.1 Husserl's contribution to Phenomenology

Much of the research into Glue Ear has focused on its potential physiological impact, rather than insight into how the young person or their parent experiences it. For example Vernon-Feagans *et al.* (2007) identified that a 25Db hearing loss is common for young people with the condition resulting in sounds becoming muffled. This lack of speech clarity can lead to an incomplete understanding of what is said. If this happens frequently, as is likely with young people with the long-term condition, it may result in changes in how the brain processes auditory information (Borges *et al.*, 2013). Such explanations may provide understanding of the body's physiological response, but does not provide insight into the emotional impact. I wanted a methodology that supported the young person with the condition to explore the psychological impact of intermittent hearing loss, and for their parents to reflect on their concerns about having a child with hearing loss. Phenomenology is based on a philosophy set out by Husserl (Kockelmans, 1967). He was originally a mathematician who turned to philosophy as he was dissatisfied with empirical science's lack of investigation into the conscious awareness of participants.

Husserl wanted to understand the 'essence' of an experience (Kockelmans, 1967), which he believed could be achieved through two processes: eidetic reduction and phenomenological reduction. In Husserl's original philosophy they were the same and not seen as research approaches. However, as the philosophy of phenomenology developed into a psychological methodology, differences have developed. The goal of eidetic reduction is to review the phenomenon through the perspectives of different participants to identify the common properties of the experience. The aim is to achieve a better understanding of what is the essence (common features/aspects) of the phenomenon. In my research, participants' experience of Glue Ear has differed. For example, for parents the age at which their child was diagnosed and how that diagnosis was made, the length of time which they had it, their current age, and the present status

of their child's ears. By distilling these experiences, the essence of the condition can be identified.

Phenomenological reduction is based on reflection and review. Participants explore their personal response to a particular aspect of the phenomenon across a range of situations. The participants, individually and collectively, illustrate how they each construct their situation and respond to similar experiences. As the psychological methodology of phenomenology developed, researchers began to compile the individual participant's essence into thematic conclusions applicable to a group of participants. In my research an example of this was demonstrated in interactions between parents and professionals. Parental concerns when their child is very young may be different when their child is older (Brewer *et al.*, 2007). Hewitt-Taylor (2004) suggests that parents' previous experience of professionals influences future interactions. It is through the analysis and dissection of the words, body language and other linguistic devices, for example, tone, tempo and syntax, that the essential aspects of an individual's experience are condensed into a set of themes. The phenomenological reduction results from initially treating each participant's experience as a case study to identify recurring themes across a range of situations. This is developed further through exploring commonalities between the participants' descriptions and testing these against any differences individual participants identify. Through comparing and contrasting their experiences of the phenomenon its essential aspects can be defined.

Husserl (Kockelmans, 1967) considered 'bracketing' to be an important process in phenomenology, developing the concept from mathematics whereby different parts of an equation are separated out to be dealt with independently. He related the importance of separating off what was known from scientific (quantitative) investigations so that they did not direct the findings of a phenomenological investigation. By summarising the findings of previous research (Appendix 1), I became consciously aware of what I had learned from the literature

review and to try to avoid referring to it when initially speaking with participants so that I did not shape their ideas about what I wanted to learn from them. Whether or not it is really possible to ‘bracket’ information off is problematic (Becker, 1992). However bringing to consciousness what I had learned from previous research at least made me aware of the need to let participants lead me in understanding their situation and what was important to them. The alternative would be only to explore their experience in the light of findings from previous research.

The process of bracketing raised my awareness of how knowledge and experience could influence participants’ responses. Benner (1994) suggests keeping written reflective logs throughout the research process as a way of recording assumptions of what participants might identify as important issues in their experience and construction of the condition (Becker, 1992). The act of writing added depth to my reflection and provided the opportunity to review how I changed my assumptions about participants. Appendix 2 identifies a sample of the reflective logs I have written when interacting with participants. As I am the mother of two young adults with long-term Glue Ear, this reflective process helped me to identify how my personal experiences are echoed by comments made by some of the participants. It raised my awareness of the importance of not overlaying my experiences onto those of the participants. This is discussed more in Chapter Four, Section 4.3.

### 3.4.2 Heidegger’s contribution to Phenomenology

Heidegger (1996:121) developed the idea of ‘Dasein’. He defined this as ‘whom the person regards him/herself to be and how each of us responds and changes in relation to situations and interactions with others’. ‘Dasein’ translates as ‘being there’ so is based on the idea that through, self-reflection and conscious awareness, individuals come to an increased understanding of how different experiences change them over time. As a result of experience and increased confidence in their own expertise, Wuest and Stern (1990) concluded that parents of

children with Glue Ear changed the way in which they responded to health care professionals. They proposed that initially parents may relinquish control to the experts assuming that from their training they know the best course of action and will cure their child's Glue Ear. But as parents' personal experience develops and their child continues to experience the condition, then they take greater control of their child's care, putting more trust in their own judgement. They start to develop a belief that they are the experts in the management of their child's experience of the condition. Similarly, young people may also start to make predictions about what will happen in the progression of the condition and want more information and involvement.

For Heidegger (1988), an important element of hermeneutics, with its central concept being interpretation, was the idea of 'logos'. This is not merely the sounds or words used, but the deeper meanings underpinning what the participant is trying to express. Interpretation takes place on many levels '...persons are fundamentally self-interpreting beings for whom things have significance, understanding human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied' (Leonard, 1994:55). The manifest or literal meaning is the surface level interpretation. The latent or implied meaning relates to a more complex level involving interpretation and thinking. Heidegger (1988) identified that the interpretation and review of meanings at different levels could be seen as the Hermeneutic Circle. One layer of understanding leads to re-examining what participants said and how they said it to gain greater insight into their meaning. Becker (1992) identified that in-depth analysis of transcripts is essential for effective phenomenological studies. Involving the participant in the researcher's interpretation and sharing that understanding is part of the process of gaining greater insight into the participant's perception (Fjelland and Gjengedal, 1994). Openly discussing my assumptions and interpretations with participants in this research was important for demonstrating belief in their expertise of the condition and for gaining new insights into how it can impact the lives of those involved. Including within the methodology opportunities for participants to reflect throughout the research was important as

this could enable them to re-interpret their experiences and increase their understanding of how the condition impacted them.

### 3.4.3 Merleau-Ponty's Contribution to Phenomenology

Merleau-Ponty (1962) took the idea of embodiment, as explored by other phenomenologists, in a different direction. He considered that only the individual could access their own emotions and that each person interprets the world based on a personal perspective. This is shaped by their experiences and their emotional responses to them. This is termed 'embodiment' whereby a person's physical being and previous emotional experiences shape how they interpret events and respond to situations. The physical body of a person shapes the way in which they experience and interpret the world. This idea of uniqueness means that although people may share common experiences, each person will interpret it differently. Exploring those different interpretations can lead to a more complete understanding of the phenomenon.

In this research, participants were encouraged to explore their reactions to specific situations. For example a mother of a child with Glue Ear might focus on specific episodes which had happened, along with the emotions evoked in her by those circumstances. This was situated within the context of her life experiences and personality, so could include her knowledge of the condition; how she related to the professionals who treated, educated or interacted with her child; her views of what a mother should be and how she came to those views; along with other factors which may have impacted her response, such as cultural background, educational level or age. Similarly, the young people experienced Glue Ear in a way that was unique to each of them. In a phenomenological study, the participant takes an active role and is encouraged to reflect upon their own experiences and explore their perceptions of others (Merleau-Ponty, 1962).

The researcher listens not only to what is said, but also analyses the language and non-verbal communication used to describe it. All the time the researcher is thinking about what the participant's response is suggesting and how they are experiencing it (Gee, 2011). Throughout this research, I consciously kept my interpretations grounded in the participants' words and the way in which they expressed themselves when exploring their chosen images. This research methodology developed by learning from each participant how they interpreted their circumstances and asking them what was important for them to help me to understand their experience of the condition. Throughout the research, I kept uppermost in my mind that the participants, no matter what their age, were the experts in their experience. Although I shared my interpretation of what they said, I wanted them to take the lead in the topics discussed and to have editorial rights over the interpretation. Previous research has not consciously included incorporating reflection time for participants. I wanted them to have the opportunity to think about the important issues for them so I could gain insight into their individual constructions of what it is like to live with long-term Glue Ear.

The methods in this research contrast with previous studies as to how Glue Ear impacts children's development and behaviour. A number of researchers (Timmerman *et al.*, 2008; Higson and Haggard, 2005; Stenton, 2003) have constructed questionnaires based on theoretical models about the possible developmental implications of the condition. Their motivation for such research tended to be to gather data upon which to make evidence-based decisions for surgical intervention. The researchers pre-set the questions and used Likert scales as their response mechanism. The lack of open-ended questions thus excluded participants spontaneously relating personal experiences or identifying issues of importance to them. The agenda of the researcher may unintentionally have shaped the findings, as participants could only answer what they were asked (Timmerman *et al.*, 2008).

#### 3.4.4 Selecting the appropriate phenomenological approach

From reviewing the literature, I believe that this is the first research investigating Glue Ear where the individual voice of each participant was at the core of the research. Therefore, the data gathering method needed to enable participants to express themselves. ‘Voice’ is defined here as ‘people whose stories are not often documented, publicised, listened to and afforded significance’ (Goodley *et al.*, 2004:87). This research aimed to ‘afford significance’ to the views and experiences of people living with the condition on a day-to-day basis rather than being marginalised and having their experience constructed by others (Yost and Chmielewski 2013). My goal was for participants in this research to feel that I was listening to them. Phenomenology is concerned with understanding individual experience, so was the appropriate methodology for this research.

In this section I provide a brief summary of my rationale for selecting IPA from the range of phenomenological approaches. Van Manen (1990) used hermeneutic phenomenology to gather data to provide an understanding of the experience of fatherhood. However, his focus was on the situation rather than an analysis of the experience itself. This research focused on the experience rather than the situation therefore, hermeneutic phenomenology seemed inappropriate. Giorgi’s (1997) descriptive phenomenology tends to combine the voices of the participants. Although individuals express their experience, the single voice is not central to developing understanding of the experience. Willig (2007) identified that this can lead to the individual richness of each person being lost. I wanted to maintain the focus on the individual voice. Such personal accounts have previously been neglected in developing an understanding of Glue Ear.

There were two groups in this research: young people with the long-term condition and their parents. I identified that investigating the perspectives of both groups would provide a fuller picture of how individuals experienced it. While the young people can identify situations and

feelings when they can not hear, parents can supplement the impact of the condition through their observations of the response of others when their child does not hear or respond. IPA was adopted because it was the phenomenological approach which emphasised the importance of the individual voice.

### 3.5 Interpretative Phenomenological Analysis (IPA)

Smith *et al.* (2009:187) identified that effective IPA research results from, ‘an intense interpretative engagement with personal verbal material obtained from the participant’. This quote highlights three key elements relevant to the methodological selection for the data gathering phase in this research. Participants needed to be ‘engaged’ so that they made active contributions. The data was ‘verbal’ with participants using their voice to express both what they experienced and their feelings. Data was ‘from the participant’ rather than following the researcher’s agenda.

IPA researchers use an interrogative process so that each participant makes sense of and interprets their experience (the double hermeneutic). It initially uses a case study approach for each participant before combining experiences thematically. The individual participant’s voice remains central throughout the process. IPA has a ‘focus on personal meaning and sense-making in a particular context, for people who share a particular experience’ (Smith *et al.*, 2009:45). The personal circumstance of the participant sets the context for how each of them reacts individually, but the focus remains on their experience. Participants’ meaning making in this research was in the context of how they interpreted a condition which is regarded as non-life threatening, common, trivial and temporary.

### 3.5.1 Assessing the semi-structured interview as a method for data gathering

Semi-structured interviews are the most common method for collecting data from participants in IPA studies, which leads to it almost being used by default. In this section I challenge whether it is the most appropriate tool if participants are to lead the data gathering process and freely express their views in depth. The subtle and various ways in which the researcher could potentially and/or unconsciously influence the participants are discussed.

The purpose of the data gathering phase in IPA research is to elicit participants' understanding of their experience. However, if a semi-structured interview is used then it is the researcher who constructs an interview schedule in advance 'because the process of developing a schedule requires us to think explicitly about what we expect the interview to cover' (Smith *et al.*, 2009:58). The preparation of schedules prior to meeting participants can lead to researchers bringing their own ideas and beliefs to the interview thus possibly influencing its direction. This is because participants have little or no input (Smith *et al.*, 2009) nor can they reflect on the interview questions beforehand (Dearnley 2005; Kvale 1983). In this research, participants were encouraged to consciously reflect on the specific topic of Glue Ear to express their perspective, through the process of talking and thinking about particular episodes related to their experiences. However the data may have lacked the depth central to the IPA methodology if participants had not had time to reflect and bring out their most salient examples. This could impact the quality of the data if the participants had not had the opportunity to sufficiently engage with the content prior to the interview.

The traditional semi-structured interview puts the researcher at the centre of the data gathering process rather than encouraging the participants to freely explore how they constructed their experience by identifying issues of importance to them. This could particularly be the case with young people who often find that they are following an adult's agenda and expected to be

compliant in meeting such requests (Lowe, 2012; Alderson, 2008). Sending the interview schedule in advance to participants could provide them with the opportunity to reflect and identify relevant experiences or examples they may wish to discuss. However, the researcher has pre-prepared the topics so the participants may focus only on those rather than aspects of importance to them.

The participant's contribution is likely to be influenced by the way they are recruited and how the interview is conducted. By their interactive nature, interviews often have a conversational feel (Nunkoosing, 2005) which can inadvertently result in leading questions (Foddy, 1994). Potter and Hepburn (2005) suggest that this interactive nature may lead to the researcher unconsciously influencing participants. This could happen if the researcher gives the participants positive encouragement when they answer questions in one way and not another (Turner, 2010). The ways an interviewer can potentially shape participants' responses is discussed in detail in Opendakker (2006). In some cases the participant has been persuaded to take part by other people so may therefore not fully engage during an interview. This is more likely to occur with young people (Christensen, 2004; Valentine, 1999). There is some evidence to indicate that participants are reluctant to discuss sensitive areas (Potter, 2010) which could have happened in this research as emotive experiences were discussed.

I wanted a data gathering process suitable for young people and their parents whereby they reflected on their experience of the condition and led the researcher through the discussion. The data needed to be verbal to meet the IPA criteria for analysis, but the interview did not seem to be the most effective method to achieve the aims of this research. Visual methods have been used with adults (Knoblauch *et al.*, 2008) and young people, including those with disabilities (Thomson, 2008; Ralph and Prevett, 2014) and seemed to offer participants greater control in generating data.

### 3.6 Exploring the use of Visual images

Visual methods potentially offered participants both the opportunity to reflect on experiences associated with Glue Ear as well as the power over what was, and was not disclosed as they could edit out any material they did not want to share (Brown *et al.*, 2010). There are a range of visual methodologies that have been used in research, such as video diaries (Noyes, 2004), still photographs (Carrington *et al.*, 2007) and photo elicitation (Miles and Kaplan, 2005).

Video diaries seemed to provide the participant with control over what they produced and initially appeared to offer the time for reflection that was missing in semi-structured interviews. However, Gibson (2005) highlighted that participants interpret what they think the researcher wants sometimes based on the recruitment context or what they are told. This can occur even when they are given very little direction by the researcher. Perhaps participants perceive the researcher as in control which can lead to a video being a choreographed presentation rather than a diary illustrating their experience. They may construct a self-representation that they perceive as being acceptable to others. Gibson (2005), in her study using video diaries, found that more personal details came from supplementary interviews.

An additional issue of using video is that IPA-based research requires close and detailed analysis of the data. This raised the practical issue that the potential volume of material produced for transcription may have been too much. It could have led to an unreasonable demand on participants' time if they were to share their interpretation of what they produced with the researcher. The use of video diaries seemed to sit more closely with ethnographic studies where there is less sharing and interaction between researcher and participant, and less depth of analysis of the participant's words (Pink, 2001).

Shinebourne and Smith (2011) successfully combined paintings produced by participants with the IPA methodology. However, the paintings were produced at different points in the participants' experience of recovering from addiction as part of voluntary attendance at painting classes. One set of paintings was produced early in the recovery experience reflecting the feelings and thoughts at that point. The participants then compared those painting with ones painted more recently, at a time much later in their recovery process. This provided the opportunity to compare and contrast feelings and events over a period of time. However, the experience of Glue Ear did not seem to reflect the same situation as that in Shinebourne and Smith's (2011) study. It would also require that participants felt confident in constructing paintings which is not always the case.

Fischman (2001) suggests that photographs can be effectively used in educational research, particularly to encourage participants to explain what an image means and the importance of it. He stresses that visual images should contribute something to the data collection and that a photo can be used as a springboard to gaining understanding of the wider context in which it was taken as well as the impact it has on the people connected with it. This suggests that photographs could encourage participants to reflect and concentrate on what is important to them. Participants in this research used images to explore situations/events as well as their feelings thus, covering the breadth and depth of their long term experience of Glue Ear. Using visual images provided plenty of opportunities for them to reflect independently on their experiences without being directed by the researcher's agenda.

### 3.6.1 Data Gathering using Freire and Photovoice to supplement IPA

Applying Freirian principles whereby participants are encouraged to see themselves as experts and to lead the researcher in data gathering seemed appropriate to this research. Although I retained control of the research process and made methodological decisions, I wanted to

encourage participants to express their views about their experience of the condition freely, rather than filter them through what they believed I, as the researcher, required.

Freire (1996) was interested in the idea that some people are kept in subjugation as a result of a lack of knowledge and understanding about the wider picture of their situation, which he termed being 'oppressed'. In my research, the parents and young people could be deemed to be marginalised voices. Parents have not previously been asked to identify the issues they saw as priorities, and young people have not been asked for their views about their experience of the condition. The focus of this research was the participants' experience of the condition and the impact they felt it had on their lives. This included their interaction with educational and health care experts. For example, the medical perspective that Glue Ear is a short term condition generally remedied by surgery with no further impact, does not incorporate participants' experience of intermittent deafness or the potential repercussions on social skills and academic performance. If participants were to truly explore and disclose their experience of the condition, I needed to find a way to convince them that I believed they had greater expertise than me. This resonates with the idea that Freire promulgated that the teacher becomes the learner and the learner becomes the teacher (Freire, 1996). Participants needed to be encouraged to see that the expertise resided in them rather than myself as the researcher.

Moss *et al.* (2007) based their work on Freirian philosophy and suggest that when young people are encouraged to explore their experience they provide more complete explanations than when asked direct questions. Photographs provide a means for participants to articulate their views and can be used as a basis for identifying aspects of their lives which are important to the individual rather than those suggested by the researcher (Kaplan *et al.*, 2007). Using Freirian principles requires the researcher to listen with an open mind, which accords with IPA as researchers are encouraged to bring to consciousness assumptions and personal experiences

which they need to set aside when interacting with participants (Smith *et al.*, 2009). My personal exploration of this is discussed in Section 4.3 in Chapter Four.

Caroline Wang was strongly influenced by Freire in the development of the Photovoice methodology (Wang and Burris, 1997). Rather than providing participants with drawings as Freire (1996) did, Wang *et al.* (2004) encouraged participants to take their own photographs to depict their lives and to consciously consider the way in which their situation impacts their emotions. Most Photovoice work is with people in disadvantaged communities (Wang *et al.*, 1998). Wang states that, 'The Photovoice concept is designed to enable people to produce and discuss photographs as a means of catalyzing personal and community change' (Wang, 2003:181). Wang *et al.* (2004) suggests that it is through the use of visual images that the experiences and perceptions of participants are communicated more clearly to others and that the individuals concerned are more able to reflect critically on their situation. It has been used successfully with young people and adults (Streng *et al.*, 2004). This is supported by research in the educational context (Carrington *et al.*, 2007; Miles and Kaplan, 2005). In my research the goal was to encourage participants to create visual images as the basis for a verbal description of the recurring themes typifying situations and emotions in their experience of Glue Ear.

The philosophy of Photovoice is to empower participants to communicate their specific situation. Through creating photographs, and describing them in their own words, the participants shape the message that they wish to communicate potentially empowering them more so than would happen by talking to a researcher in an interview. Because Photovoice puts the choice of photographs and messages in the hands of the participants, they have greater potential to highlight their priorities. The focus of photographs as a discussion point between the researcher and the participant has shown that perhaps more sensitive aspects are discussed than may otherwise have been the case (Drew *et al.*, 2010) and that individuals can explore their own self images (Pearson and Ralph, 2007) and assumptions (Kaplan *et al.*, 2011). Photovoice can be said

to be phenomenological as it is focused on the participants' experience and encourages reflection on that experience.

In this research young people and their family members were asked to create a photomontage as the means of articulating their experience of the condition. The details of the process are discussed in Section 4.2 in Chapter Four. This approach is in keeping with the philosophy of participants controlling what is shared.

### 3.7 The rationale for combining Photovoice and IPA

To my knowledge, the two methodologies of Photovoice and IPA have not been combined to allow the strengths of each to increase the rigour of the research process. Photovoice provided a mechanism for participants to reflect on their situation and take control of the direction and content of issues to be addressed in the data gathering phase, whereas IPA was used to deepen the data analysis and explore the participants' perspective thus gaining new insights and understanding into their experience of a specific phenomenon. In this research, the images and the words combined to explore events, feelings and perceptions of the experience of long-term Glue Ear which provided insight into how the findings from the quantitative research manifested themselves at an individual level. In this research the images and dialogue gathered through Photovoice were integral to the IPA analysis stage. This contrasts with previous IPA studies (Shinebourne and Smith, 2011) in which the images were used to stimulate discussion between the researcher and the participant.

IPA was developed to analyse the experience of an individual's response to a particular phenomenon (Smith *et al.*, 2009). The researcher plays an active role in the interpretation of the participant's words (Brocki and Wearden, 2006), particularly during the analysis of the data.

However, I propose that the participant's experience could be filtered by the researcher if there is

a pre-prepared interview schedule. In this research the researcher-led semi-structured interview was replaced by the development of a participant-led discussion (Capewell, 2014d), a one-to-one discussion in which participants explored their interpretation of the individual images comprising their photomontages. They controlled the agenda by selecting the order in which the images were explored, how they were linked and each one's relative importance in their experience of the condition. I saw their images for the first time at the meeting arranged to discuss them. This lack of pre-knowledge of the images meant that I could not begin to make interpretations or assumptions about the participants' experience. When sensitive issues were raised the shared focus of both participant and researcher was on the images so eye contact could be comfortably avoided. There was role reversal from the usual interview situation as it was the participant who selected the images, had reflected on them in advance and understood their significance. As the researcher I listened and responded to the information provided by the participants. I propose that this approach communicated to the participants that they were in control and proved suitable for both young people and their mothers.

Photovoice is descriptive in its analysis with the mnemonic SHOWeD providing five basic questions to facilitate each participant to voice their comments on their photographs (Wang, 2003). The questions are: 'S': What do you See here? 'H': What's really *Happening* here? 'HOW': How does this relate to *Our* lives? 'E': Why does this problem, concern, or strength *Exist*? 'D' leads to action: What can we *Do* about it? (Wang and Pies 2004:98). However, the analysis in Photovoice is achieved through critical group discussion (Wang *et al.*, 2004), whereby each participant builds on the ideas and comments of others in the group to achieve more insight into their own experience. The photographs provide a visualisation of what is important to the participants. In discussion with others, they clarify and explore their situation, potentially highlighting injustices (Streng *et al.*, 2004). As the philosophy behind Photovoice is taking action, there is a focus on making changes to improve participants' current situation of trying to influence policy makers. The focus is on the collective voice rather than exploring an

individual's response to their situation. This would have meant that the centrality of the individual voice in IPA could potentially have been lost if the analysis process of Photovoice was used.

Baker and Wang (2006) explored older people's individual experience of back pain, but concluded that the methodology lacked depth in the analysis of the dialogue when working one-to-one with participants. In Photovoice the group facilitation process increases awareness in participants of their specific situation. Through sharing interpretations of photographs, group members deepen their understanding of the current situation (Miles, 2011). Specific support groups for parents and young people with Glue Ear do not exist so this necessitated that data gathering in my research was with individuals. I concluded that using Photovoice for data gathering and IPA for data analysis would result in a more effective method. IPA is designed for use with individuals (Smith *et al.*, 2009) with the focus of the analysis on the participant's dialogue, so was therefore appropriate for the data analysis phase in this research. The analysis applies a more structured framework for examining each participant's data in detail than is available through Photovoice (Gee, 2011).

### 3.8 Data Analysis using IPA

Brocki and Wearden (2006) identify that the analysis process in IPA requires the researcher to elicit a deeper meaning than the participants initially have; not from a theoretical model, but by using the researcher's own understanding of the situation. Going back to the material a number of times and looking at it in depth from the perspectives of description of situations, the language used and the concepts identified, enables the researcher and the participant to gain greater insight into latent, or underlying, meaning of the words (Ayers and Forshaw, 2010). Most importantly for this research was the maintenance of the participant's voice at the centre of the data analysis. More detail about how IPA was used in the data analysis is contained in Chapter 5.

### 3.9 Summary

Much of the previous research into Glue Ear has focused on understanding the physiology of the condition and how it potentially impacts language development and the auditory processing system. In quantitative methodologies participants are treated as objects to be measured, subjects in randomised clinical trials with mathematical tests of statistical significance applied to research results (Fjelland and Gjengedal, 1994). I proposed an alternative approach in which participants took a more active role and were at the centre of the data gathering process. Directly involving young people, to verbalise the impact of the condition on all aspects of their day-to-day lives and educational experience, is a neglected area of knowledge which I wanted to address in this research. Therefore, developing a methodology in which young people, in particular, felt confident to express their views was important. I believe that combining Photovoice and IPA strengthened the research process. The issues discussed in this chapter are summarised as follows:

- Using IPA in gathering data may inadvertently cause the researcher to establish the parameters of what is covered so perhaps not accessing the participants' view of their experience of the phenomenon of Glue Ear
- Photovoice encourages participants to reflect on the issues of importance to them and provides them with the time to establish what they wish to discuss with the researcher
- The development of the participant-led discussion in this research, meant that participants led exploration of their images and controlled:
  - how they interpreted the task
  - what they produced
  - the order in which the images were discussed
  - interpreting the meaning of the images
- The Photovoice methodology can lack depth of analysis when used with individuals

- IPA's strength in the analysis phase comes from its structured approach and detailed scrutiny of the participant's dialogue and delivery so that the participant and researcher reflect upon and deepen the interpretation of participants' experience.

The next chapter explores how the chosen methodologies were applied in this research.

## **Chapter 4**

### **Research Methodology 2: Design and Implementation**

#### **4.1 Introduction**

In this chapter I analyse and evaluate the practicalities associated with implementing this research. The following issues are examined:

1. Locating and recruiting participants who proved difficult to identify
2. Modifications to the design and adaptations in the methodologies
3. Participant-Researcher interaction
4. Addressing ethical issues, paying particular attention to those concerned with recruiting and working with young people.

The theoretical underpinning in this research was based on putting the participants' voices at the centre of the data gathering. I acknowledged from the outset that the methods would develop as the research proceeded. My experience echoes that of Miles and Kaplan (2005), whereby the use of images developed and clarified during the research process. This meant learning from the first participants, in particular, and throughout the data gathering process to make changes identified through reflecting on my own practice (Yost and Chmielewski, 2013) and participants' responses. All participants' data was included in the analysis and discussion to demonstrate respect for their participation and to value their contribution.

#### **4.2 Participant recruitment**

##### **4.2.1 Sample Size and criteria**

I initially planned to recruit five parent-and child dyads as the centre of the research. The intention was that others, such as the non-participating parent and any siblings, would be invited to become involved as they could bring different perspectives and experiences of living with

Glue Ear. As not every dyad would have other family members who would want to participate, I anticipated a sample size of about 20 participants.

The selection criteria were that the young person would:

- Be aged between 10-16 years old
- Have been diagnosed with Glue Ear under 5 years of age
- Had at least one set of grommets
- Continue to have episodes of Glue Ear
- Not have any other developmental condition, such as Down's Syndrome.

The age range of 10-16 years was selected as these young people would potentially be able to reflect on and articulate their experiences/emotions more coherently than younger children. Formal diagnosis and having had at least one set of grommets were important as this would ensure that the young people and their parents would have interacted with the healthcare system, experienced recurring ear infections and have knowledge of the implications of hearing impairment through repeated episodes of Glue Ear. The continuance of the condition would provide participants with a breadth of experience on which to reflect and compare over time. Parents, too, would have long-term experience of living with a child with the ongoing condition and be able to provide an overview of the important considerations at different ages for themselves and their children. Excluding other developmental conditions was an attempt to focus on the impact of Glue Ear.

Haggard *et al.* (2003) suggested the value of directly consulting adolescents about their experience of the condition rather than using only parental views (Bennett *et al.*, 2001; Asmussen, 1999). Through observational studies, Vernon-Feagans and Manlove (2005) explored how the condition impacted younger children, although the children's understanding of the condition was not elicited. This research aimed to explore the value of including young people's

own accounts of their experience rather than having them filtered through others (Druckett *et al.*, 2010).

#### 4.2.2 Recruitment strategies

I recognised from the outset that participant recruitment would be difficult. There is no clear place, other than clinical settings, through which participants can be contacted. Unlike other conditions there are no support groups for those with Glue Ear. I wanted to keep recruitment as contextually free as possible to avoid participants making assumptions about the focus that I had as a researcher (Miles *et al.*, 2012).

Most of the previous research into this condition has tended to be primarily in the healthcare/ clinical settings and linked to medical issues. The findings suggest that participants focus on context as a way of shaping their responses. When parents were recruited via clinical situations (Asmussen *et al.*, 1999), where their child was being treated surgically for the condition, they responded by identifying issues such as pain management and practicalities such as taking time off work to look after a sick child. I realised that I would need to brief participants carefully to ensure they were clear about the purpose of this research and to encourage them to identify issues and experiences from a variety of settings. Unless there is a direct medical link to the research, it can prove difficult to recruit through hospital clinics, as patients' focus is on their appointment (Baker and Wang, 2006). As my interest was the impact of Glue Ear on day-to-day life I wanted participants to take a very broad view of their experience of it. I therefore made the conscious decision not to recruit through the National Health Service (NHS).

Making contact with young people with the condition proved to be problematic. Their active assent to the research was important if their views were to be accessed but informed consent was initially required from their parents (Masson, 2004). I considered that schools might be a

potential source of participants. Although aware of the issues identified above regarding how the recruitment context may influence participants' responses, I decided that even if this were to happen, there has been limited research involving young people's experience of the impact of Glue Ear in the school context so a novel perspective would be provided in contrast to previous research even if that became the main focus of their responses. I used formal channels of contacts through The University of Northampton School of Education by sending out a mail shot. In addition I contacted local schools by phone, letter and email then followed up with further phone calls. Either there was no response or the School Secretary proved a formidable gatekeeper (Sixsmith *et al.*, 2003).

I tried to identify participants through the Special Education Needs Co-ordinators (SENCOs) online forum, but was told that no records were kept for children who have Glue Ear. This included those with ongoing hospital outpatient appointments. The comments suggested that it was seen as a medical and not an educational condition. Despite the prevalence of it in the early years of school, parents were not asked about conductive hearing loss on school enrolment. It seemed that it was only recognised in school records if the child wore a hearing aid or had speech and language therapy through the school.

I used third party introductions such as notices in libraries, community centres or associated groups such as National Deaf Children's Association (NDCS), Sure Start Groups and Brownie and Cub groups. This posed an additional difficulty as I did not meet the parents directly and meant negotiating access through gatekeepers. However, most organisations were prepared to display posters (Appendix 3 – Parent recruitment poster) explaining my research and contact details. I attempted to make direct face-to-face contact with parents to improve recruitment. I was given permission to talk about my research to parents of younger children who attended a pre-reading group session at a library. There were positive comments and questions from the parents which indicated they had experience of Glue Ear. However, no one followed up by

contacting me to take part. To avoid embarrassment in front of others, all those who attended were given an A4 copy of the poster with my details (Appendix 3). I also put up a poster on the library information board.

As a strategy to gain direct contact with parents of children with Glue Ear, I logged into internet forums and discussion groups on the topic. I recognised potential ethical issues connected with privacy, confidentiality and anonymity of the forum users. Therefore, from my entrance into the groups I stated that I was a researcher doing a PhD on living with long-term Glue Ear.

Anonymity of forum members is protected through the use of pseudonyms. In membership groups such as Mumsnet, Netmums and the NDCS, I contacted the web administrator prior to joining or signing in, for permission to access the site. To substantiate my credentials as a bona fide researcher, I set up a link on the university's website. This allowed potential participants independent access to my research as well as a means of contacting me. I posted on the noticeboards for internet chat groups relevant to Glue Ear where they were available. Friends and work colleagues were enlisted to see if their contacts with schools, friends, colleagues and family could help with recruitment. The most effective strategies were through the internet and friends and work colleagues recommending someone. No participants participated from educational or third party sources.

#### 4.2.3 Gaining participant agreement

Table 4.1 summarises the conversion of the thirty one potential participants (including young people) who showed initial interest through to those who participated fully in the research. The reasons for participant drop out were not investigated as from the outset I had emphasised their right to withdraw at any point without having to provide an explanation. I decided that asking for their reasons for discontinuing participation would have been inappropriate. Of the sixteen families visited to discuss the project in more detail, most stopped responding to attempts to

contact them or said that they were too busy to participate at the time. Of the ten participants who produced photomontages and discussed them, three were young people. The participants were from a variety of places in England. Although the original recruitment criterion was for parents, only mothers took part in the research. When meeting with families I had spoken directly with some of the fathers and siblings who were invited to take part but, despite initial interest, none of them did.

**Table 4.1 Conversion of contact to fully progressing to participation**

<b>Method of contact</b>	<b>Stage 1 Phone chat</b>	<b>Stage 2 Visit</b>	<b>Stage 3 Participation</b>	<b>No Consent Discussion</b>
Schools/Libraries	0	0	0	0
Internet	11	6	4	2 <sup>1</sup>
Work contacts	12	5	5	2 <sup>1</sup>
Colleagues' contacts	8	5	1	0
<b>Total</b>	<b>31</b>	<b>16</b>	<b>10</b>	<b>4</b>

<sup>1</sup>I spoke in detail to these people but did not get informed consent to record as they did not meet the original recruitment criteria.

In the early stages of recruitment I held in-depth discussions with people who did not meet the selection criteria: three were mothers whose children were younger than the specified recruitment age; and an adult who continued to have Glue Ear. The condition seemed to arouse different issues for parents based on their child's age. In future I would widen the recruitment age criteria. In hindsight, it would have been better to have involved these people as they would have added a different perspective of living long term with the condition. Their data was not included as I had not obtained informed consent for their participation nor had I made digital recordings of their comments.

**Table 4.2 Participants: Description and relationship**

<b>Young person</b>	<b>Age in Years</b>	<b>Mother</b>	<b>Participated</b>
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

Based on learning as the data gathering phase continued, I did recruit four mothers who volunteered to be part of the research but did not wish their child to be included. They contributed their experiences about being the mother of a child with long-term Glue Ear so added further data to the research. Table 4.2 provides full details of the participants who took part in all stages of the research process. Pseudonyms are used to protect their identity. Full details of their participation and analysis of their data are examined in Chapters Six and Seven.

A rationale for small sample sizes in IPA is to allow for detailed and subtle analysis of each participant's data (Collins and Nicolson, 2002). A homogenous sample is identified by Smith *et al.* (2009:50) as a positive feature in IPA research as it provides the researcher with the opportunity to 'examine in detail psychological variability within the group, by analysing the patterns of convergence and divergence which arise.' The similarities among the mothers in this research were that they were all white British, aged between 35-45 years, educated to tertiary level, worked in professional roles and with the exception of one woman (Miranda), lived with their child's father. All of their children met the selection criteria as they were diagnosed at a very early age. The children ranged in age from 7-18 years at the time of the research, with most continuing to experience Glue Ear. The differences were in where they lived in England and the number of their siblings.

It may be that participants are reticent to come forward for qualitative research because they are being asked to disclose information of a personal nature and to reflect on their feelings.

Difficulty in recruiting participants is not unique to my research (Sixsmith *et al.*, 2003; Glucksmann, 1995). I might have been more successful if I had tried more avenues of meeting participants face to face as a way of establishing rapport prior to recruitment. Having some sort of personal contact (work colleagues or friend recommendations) may give the researcher more credibility. An alternative recruitment strategy might have been contacting the officials of Parents' and Friends' Associations as a way of accessing parents as this may have led to greater opportunities for developing a snowball technique.

#### 4.2.4 Health Care and Educational Professionals

In the planning stage I had considered recruiting the professionals with whom the families interacted in managing their Glue Ear. However, I recognised potential issues of confidentiality therefore that area of recruitment was not pursued. Later I decided to include representatives of the professional groups mentioned by participants to gain insight into their understanding, knowledge and perceptions of the condition. The issues of access remained but professional contacts proved productive. I interviewed 5 professionals:

- An ENT surgeon
- An educational psychologist
- An audiologist
- A primary school teacher
- A secondary school teacher.

The ENT surgeon and secondary teacher prepared photomontages which they explained in a participant-led discussion. An interview schedule (Appendix 4), using broadly the same questions with each participant, was used to conduct semi-structured interviews. The professionals' responses are explored in Chapter Eight. It may be worthwhile doing further

research into professionals' understanding of the condition to gain insight how it has come to be constructed as trivial, temporary, medical and without long-term implications for education or psycho-social development. Additionally, it could be beneficial to investigate the knowledge, skills and training professionals see themselves requiring if they are to provide information and support to parents and young people with the ongoing condition.

#### 4.3 Design development and modifications

The research methodologies, Photovoice and IPA, have a philosophical foundation of exploring individual participant's experience, putting their voice at the centre of the research, encouraging the self-reflective tendencies of people and recognising participants as experts in their situation.

Therefore, the design of this research required methods that:

- Enabled participants to take the lead in identifying topics important to them
- Encouraged reflection about how they experienced Glue Ear
- Were suitable for young people and their parents
- Produced data suitable for IPA analysis.

Photovoice encourages participants to reflect on their situation and, through the creation of images, enables them to articulate the impact of their experience (Liebenberg, 2009). The images provide the photograph element (photo) with participants' voice coming from discussion of them. Photovoice has been successful in encouraging young people and people with disabilities to share their experiences in education (Jefferies and Hyde, 2009; Boxall and Ralph, 2009; Kaplan *et al.*, 2007) and living with ongoing health conditions (Rich *et al.*, 2000). Traditionally in Photovoice projects participants are given disposable cameras which they return to the researchers for developing (Wang *et al.*, 2004). They were not used in this research because the families had at least one digital camera in their household or a camera integrated into their phone. Digital cameras give participants greater control over the photographs as there is no need for the film to be returned to the researcher for developing. Participants can delete images as they

wish before the researcher can view them. A digital camera was available for participants to borrow.

Participants produced their data by creating a photomontage of images. Although they were asked to create a series of photographs, the participants in this research chose to download images from the internet which depicted their overall experience of living with the long-term condition. Participants were encouraged to identify experiences related to feelings, situations or places. At the initial meeting, before actually creating the images, we discussed the sorts of things they might include. We agreed that at a follow-up meeting, they would explain to me what the images meant to them. I came to call the second meeting a participant-led discussion as the participants, rather than the researcher, set the topics for discussion and the order in which the images were explored. Drew *et al.* (2010) indicated that young people's participation in qualitative research is enhanced by some structure for a task. Russell, the first young person participant, explained to me that he wasn't sure what was required of him. Consequently I asked other young people to think about good and bad experiences and their feelings about the condition.

Russell and his mother, Jane, were the first participants. Russell selected his pseudonym based on his dog's breed. They were given a selection of media (video camera, digital camera, voice recorder). This was to provide them with a choice over the way data was produced so they could select a medium with which they were most comfortable (Cotton *et al.*, 2010; Jefferies and Hyde, 2009). However, too many options of equipment proved to be confusing. Jane commented that she was not sure if she needed to use all of them. From this experience, I learned it was better to limit the range of media offered and to follow more closely the Photovoice process.

Christensen (2004) emphasised that young people need to be convinced that the adult is really interested in their point of view, by perhaps following the young person's agenda rather than pushing their own, with rapport building being crucial for disclosure. In the first meeting, I included the young person in the discussion about the research and what they needed to do. I related their role in the data gathering as similar to how other people help them complete a school project. I wanted them to see themselves as an expert.

Russell and Jane both elected to use the video recorder and made diary entries of on average 25 seconds in length. Their focus for the most part was on recent events, and included a visit to the swimming pool and to the ENT consultant. The video entries did not appear to encourage reflection over the longer term so were not producing the type of data relevant to either a Photovoice or IPA study. Russell also used the digital voice recorder. Unlike Jane, he did not produce a photomontage. Neither Jane nor Russell used the stills camera. The technology itself became the focus of Russell's attention. He explained that he had spent most of the time practising with the video filming his dog or objects.

Young people as research participants can sometimes become uncomfortable with seeing/hearing themselves (Lawthom *et al.*, 2012) in recordings. When playing back the video, Russell became uncomfortable and said his voice sounded 'silly'. To reassure him, I recorded my voice and after we had listened to me he agreed that it didn't matter how we sounded but what we said was the important thing. Listening and responding to his point of view demonstrated that things that mattered to him were important to me. I would suggest that this helps to build trust and confidence in the young person as to the sincerity of the adult researcher (Christensen, 2004).

As I did not feel confident enough with the technology, the structure of the discussion with Russell became playing each recording then stopping after each and asking him about it. This became quite stilted and resulted in a question/answer format. This did not encourage Russell to

explore how he experienced Glue Ear. We just went from one recording to the next without any real review of the issues raised. The stop/start format also impeded the rapport between Russell and me. When reflecting on this process I recognised that I needed to be more confident in dealing with the technology to avoid interrupting the flow of what participants were expressing. Furthermore, I recognised that too much choice of technology became a distraction. From that point on participants were asked to construct still images.

The benefit of making the adaptation to the data gathering process is illustrated in Figure 4.1, in which two short extracts from the transcripts of Russell and another young participant, Stewie. He produced a photomontage. Both Russell and Stewie were about 10 years of age and shared similar backgrounds: both lived with their parents, attended similar types of schools, resided in the commuter belt of large cities and had very similar experience of Glue Ear. The extracts focus on how they perceived the condition impacted them.

#### **Figure 4.1 Short extract from Russell's and Stewie's discussions**

##### **Russell – Talking about his experiences and explaining the content of his video diary**

##### **Russell describing his ears – video clip (37 seconds)**

My ears have been aching and errere a bit leaky as well and errrr why does **everything** have to happen? Seriously.... it's annoying, yow.... well leaky and discharge and well not discharging but a bit errrrer ..... bit annoying really as though yep. Not that great (*each word emphasised separately*).

##### **Discussion with C: Carmel (researcher) and R: Russell (participant)**

C: What are you talking about?

R: My ears.

C: So have they been leaking recently?

R: (Nodded) Well not exactly but a bit.

C: A bit.

R: (Nodded)

C: When was the last time they leaked?

R: Few weeks ago probably. They've been a bit achy today.

C: When they are achy how does that make you feel?

R: Bit annoyed.

C: In what way?

R: Just annoyed.

C: Annoyed with what?

R: That they're aching. Basically stinging.

**Stewie – Talking about adaptations that the teacher makes, based on discussing his 'angry' picture: C: Carmel (researcher) and S: Stewie (participant)**

**S:** That one, erm yeah it's angry because if I get pains in my ears erm also erm like when the teachers are not helping me and erm it's just when I really can't hear much and when it's not just easy to understand.

**C:** So can you think of what would make it, what makes it easier to understand?

**S:** Erm what makes it easy to understand

**C:** Mmmh like times when it's easy to understand?

**S:** When it's easy to understand ....Probably when I'm closer to the desk because like when the teacher lets me come closer to the desk with like some other people but other teachers don't let you, but that helps when they let you come closer when they're talking.

**C:** When you say, 'Closer to the desk.' Does that mean when the chair is in front of the desk, or/

**S:** No you're at your desk around the thing, you take your chair and put it at the desk.

**C:** Oh so you are at the teacher's desk.

**S:** Yeah so some people do that and 'cos there are a few people who have like what I have, but not as bad as me.

Stewie's image 'Angry'



In the excerpt with Russell I began by asking him what the extract was about but I mainly repeated what he had said on the visual recording. I asked a series of questions to try to get him to explore what he had said. He either answered with very short answers or nodded. In contrast, Stewie began by explaining what the 'angry' image meant to him and opened up a number of different situations. He focused on the emotion of anger which he related to his condition. I asked questions based on what he said. Stewie provided detail and cut me off to explain what he meant, perhaps suggesting that he was confident. The interchange between Stewie and me is more conversational than the stilted series of questions and short answers with Russell. The two short extracts covered similar content but I suggest that the quality of the data was much better through the use of images which Stewie had selected.

I would suggest that creating the images gave Stewie time to reflect about how the condition impacted him whereas Russell's video diary recorded recent experiences. A main reason for

using visual methods was to encourage participants to reflect. Whereas Russell focused on the present, Stewie explored a pattern of behaviour and interaction between himself and the teacher over time. Stewie seemed more reflective when explaining his situation perhaps because he had made a conscious choice about the images he selected. Russell responded to my questions but had not time to think about whether this situation was part of a pattern. Before and after the discussion they chatted quite freely so the method is likely to account for most of the differences between their descriptions and levels of reflection. When researching with young people, there needs to be creativity in the way in which they are encouraged to participate (Bird *et al.*, 2013) and relate to the researcher to maximise their interaction and contribution of their views and feelings (Lewis and Lindsay, 2000). Creating a photomontage seemed to increase the young person's confidence.

Jane, Russell's mother, produced some short video entries and a photomontage with an accompanying mind map to explain it. She was happy to discuss the photomontage and referred to her mind map from time to time. However, she did not wish to review or discuss either the mind map or her video diary entries in any detail. If I had explored the video diaries without involving Jane, there would have been a lack of the double hermeneutic as she would not have contributed her interpretation of the events she described (Smith *et al.*, 2009). Without the reflection and discussion element, it seemed that I would be interpreting the content rather than the participant. This is contrary to the principles of both IPA and Photovoice. The focus of the analysis of Jane's data was primarily from her photomontage in which she explored her experiences of her son's condition and the impact it had on her (Ralph and Capewell, 2014). As we discussed her images there was a deepening of her understanding and interpretation of them (double hermeneutic). She led the discussion and was in control of what was said, which is in keeping with Photovoice whereby the images provide the participant with the means to voice their understanding of their situation. The reflective and interactive nature of the discussion provided the depth of dialogue suitable for IPA analysis.

The individual nature of the participant-led discussion enabled each participant to provide detailed explanations of their images. However as the group element from the Photovoice method was missing, as the researcher, I needed to fulfil that role by questioning and encouraging reflection and reinterpretation to gain the rich and detailed data (Gee, 2011) IPA required. As Boxall and Ralph (2009:47) highlight, 'In Photovoice, learning occurs in dialogue; it is important therefore that research participants, not researchers or professionals, decide which photographs are selected'. In this research the photomontage was constructed independently of the researcher so the participants were therefore firmly in control of the image selection process. Because participants chose to use images downloaded from the internet they were able to consider in detail what the images meant prior to discussion with me. In this research the learning for both participants and myself developed through the interaction in the participant-led discussion, with plenty of opportunity to clarify the meaning the images held for the participant and to increase my comprehension of their significance. The techniques of probing and reflecting were used to deepen the participant's understanding of their experience of Glue Ear.

When participants have been provided with a disposable camera of 36 shots (Drew *et al.*, 2010; Booth and Booth, 2003), they have often found it difficult to finish the roll of film. In this research, participants were not asked to create a specific number of images. This encouraged them to make their own choices, rather than being directed by the researcher. Requiring a specific number of images might have led to participants feeling that they had failed the task which may have led them to withdraw.

Reflecting on the method it seemed better to provide more structure and follow more closely the Photovoice method. After my experience with Russell and Jane, participants were asked to create a photomontage which summed up their wider experience of Glue Ear. The data collection process consisted of two meetings, after initial telephone and email contact. The purpose of the

initial meeting was to explain the research and the method and ask them to complete the informed consent forms. When discussing the research aim, participants spontaneously described events related to how the condition had impacted them. For example, young people and parents identified repeated visits to the doctor or operations as something associated with the condition. I suggested that they might like to take a photograph of a hospital sign and make some notes about what the image meant. Learning from Jane's reluctance to use her mindmap when describing her photomontage and being mindful that young people may see writing things down as a homework task, I was keen to stress that it would be useful if they thought about the meaning of the images that they would create then explain them in detail when I returned. This was an adaptation of the Photovoice methodology in which participants usually provide a caption for their photographs (Wang and Pies, 2004).

#### 4.4 Participant-Researcher Interaction

This section explores the interaction between participants and myself, as the researcher. I wished to avoid influencing participants, as I wanted to bring to consciousness that I:

- am the mother of two young adults who continue to have Glue Ear
- needed to avoid letting my personal agenda shape what was said
- recognise the importance of maintaining reflective practices to identify personal preconceptions (Smith *et al.*, 2009) throughout the data gathering and analysis stages
- indicate clearly to participants, of all ages, that their experience and perceptions were important and they were the focus of the data gathering process.

In human interactions people actively construct and interpret the relationship between themselves and others. Miles *et al.* (2012) explained how participants can assume from the researcher's background or association with organisations, the purpose of the research and the specific interests of the researcher leading them to construct the information they provide in the

context of their interpretations. I have attempted to position myself as independent of an organisation or group or even a job role to minimise participants providing information based in only one context (Walsham, 2006). From my first contact with the participants, I emphasised that I was interested in their experiences. I disclosed to participants that I was the mother of two young adults with continuing Glue Ear. I wanted to be transparent about my own background and the rationale for my interest in their experiences and feelings (Etherington, 2004) to encourage them to explore a range of situations in which the condition impacted upon their lives. I wished to avoid the situation identified by Gibson (2005) whereby participant's assumptions about the researcher's interest impacted the quality of information disclosed.

Although I have set the research question and have greater control over the research process, I have tried to demonstrate to participants that I regard them as the experts in their own lives. The power relationship in qualitative methods remains with the researcher because: 'Those researched are regarded ... as the passive givers of information, with the researcher acting as a sponge soaking up the details provided' (Maynard, 1995: 15). The use of the photomontage was a deliberate attempt to break down the data gathering process from being researcher-led to the participants being active constructors rather than 'passive givers'. I did not wish to use my personal experience as the agenda for what participants discussed (Corbin Dwyer and Buckle, 2009).

As a researcher, I am an insider in the experience as to some extent I am exploring issues where my own experience may overlap with those of the participants. This position has advantages (Berger, 2013) and can help to build rapport. Having first-hand knowledge of the situation provides shared language and familiarity with the contexts of the condition (Gemignani 2011; Kacen and Chaitin 2006). For example, I shared knowledge and understanding of 'grommets' and 't-tubes' so participants did not bother explaining such specialist terminology. Corbin Dwyer and Buckle (2009) suggest that participants may be more open with researchers with prior

experience. In this researcher they were inclined to use the phrase *you know* to acknowledge our common background. However, I found that a disadvantage of this personal experience is that sometimes I recalled painful personal memories. Using reflective logs and consciously recognising my experiences proved to be effective ways of dealing with the emotions aroused (Kennedy *et al.*, 2014).

Smith *et al.* (2009: 25) emphasise that although researchers always bring their own background, these 'fore-understandings' need to be explored throughout the research process if the participant's perspective is to be the focus of the data gathering, analysis and interpretation. Throughout my research, I used reflective practice to review my own thoughts and actions when interacting with participants. Berger (2013) makes the point that researchers, particularly those with experience of the phenomenon being investigated, need to explore the role of self within the research process so that they bring to consciousness their own prejudices, experiences and knowledge from the planning of the research project, while gathering data and when analysing it. This ensures that there is a constant self-monitoring regarding how these personal aspects impact upon the relationship with participants and the interpretation of the data. Smith *et al.* (2009) develop Heidegger's idea of 'fore-understanding' and recognise that it is important that researchers recognise that setting aside their personal knowledge, assumptions and pre-conceptions is only partially possible, as some things will remain hidden from themselves. As information is brought to consciousness throughout the research process it highlights the need for the researcher to continually record and reflect.

An example of this self-monitoring happened when I reviewed my interchange with Jane, the first participant. I had not disclosed anything about our shared experiences while she described her photomontage as I believed it better to keep a professional distance between us by being a detached observer (Sprague and Hayes, 2000; Ladner, 1987). I did not respond to her emotional disclosure when she explained an incident in which she had felt judged by the SENCO

(Explained in more detail in Table 5.2) about her parenting skills because Russell didn't join in with other children. In the recording I made in the car immediately after leaving her, my emotions are evident: *What she was saying about tiger mum and it's all those levels of frustration so for me it's just this same situation yet again. That the child is not really considered. Frustration, all the time fighting. Frustration. It did bring back echoes for me. My emotional response – the repetition of frustration; that there are levels of frustration; and that we shared similar experiences. I was neither detached nor an observer as I acknowledged the echoes of my own experience in hers, but I hadn't shared this with Jane. At the time I had felt that I did not want to influence how she was interpreting her experience.*

However, on reflection I decided that by assuming the detached observer role, I was creating a power differential (Finlay, 2012) so not treating Jane as an equal in the data gathering process. As part of a thank-you email to Jane a few weeks later, I included the following comment: *As you know I have a son with Glue Ear, and when you were describing Russell's 'quirky' social skills I saw my own son very much. Jane seemed to appreciate my response in her response email: Thank you for your note and kind words, Carmel. I think our boys are both a bit special.* In a short space of time, I resolved that disclosing similar personal experiences would not reduce the rigour of my research (Malacrida, 2007).

When reviewing the transcripts for the IPA analysis, I added a reflection stage to assess the way in which I interacted with participants. By reviewing what the participant said and my response, I wanted to identify whether I was influencing the data gathered (Etherington, 2004). Sometimes my personal experience interrupted what the participant was exploring. The red/bold writing in Table 4.3 signifies where I allowed my own discomfort at the conversation to shut down a line of discussion. The purpose of the other colours/fonts in the analysis is explored in Chapter Five. When Lois explained Stewie's behaviour as *awkward* I became aware that I had potentially closed her down through describing his behaviour as having *ants in his pants*. In hindsight I

realised it could have been more productive to have reflected back her words, *storm off*, *shout* or *be awkward* to gain more understanding of the impact this had on her, her husband and the atmosphere in their home.

**Table 4.3 Lois describing Stewie’s behaviour with analysis commentary**

Transcript	Initial analysis
<p><b>C:</b> But when, from what you’re saying is it that when his hearing’s bad that he becomes this kind of ... ants in his pants person?</p> <p><b>L:</b> Yeah, yeah he can be yeah. He can’t sit and watch a TV programme, he can’t sit and erm have a conversation, can’t erm, he might storm off about things, he might shout, might be awkward, Yeah?</p> <p><b>C:</b> Mmmhh. What about rough and tumble play, has he ever been involved in, did he like that as a kid, or younger one?</p>	<p><b>I should have stopped after ‘becomes this kind of..’ as giving the description leads Lois to a description.</b></p> <p><i>Again the use of ‘yeah’ in a confirmatory way. Repetition of ‘can’t sit’ and ‘erm’ Lois is struggling to explain what it is like when Stewie’s hearing is bad.</i></p> <p>Lois describes how Stewie becomes difficult. She describes a very angry person.</p> <p><i>Lois uses negative verbs ‘storm off’, ‘shout’, ‘be awkward’. She uses ‘yeah’ for support. Downplays Stewie’s behaviour</i></p> <p><u>Lois starts to describe how difficult Stewie can be to live with.</u></p> <p><b>Should have asked her to describe ‘awkward’ and give examples of the behaviour. I need to listen more and not follow my own line of thought or avoid probing because I want to lower my own discomfort. I totally change the subject.</b></p>

*Green/italics = analysis of the language* Blue/plain text = description of a situation  
 Brown/underlined = concepts, ideas portrayed **Red/Bold = reflection and improvements on the way I am questioning/interacting with the participant**

Table 4.3 explores my reflection on the discussion with Lois. To some extent my personal experience of similar situations and feelings of impotence and lack of ability to find a solution, caused me to cut the discussion short and change the subject (Bishop and Shepherd, 2011). The question remains whether I did this for Lois or myself. Perhaps a less involved researcher would have explored these situations in more detail to gain greater insight. There is a tension between avoiding causing distress and letting Lois choose what she did or did not wish to discuss. It would have been better practice for me to have asked questions in both the examples cited in Table 4.3 then check whether she wished to continue. I would have demonstrated respect for her

if I had followed her lead. Instead I believe that I disempowered her and made assumptions about her emotional state based on my own feelings.

In the log I wrote after doing the analysis I realised that there were two things that I needed to do: the first was to go back to Lois and ask her more about Stewie's awkward behaviour and how this impacted their home life. She had previously agreed that I could contact her to clarify aspects in the transcription. The second thing was that, after the first analysis, I realised that participants might raise some things that I might find upsetting as they echoed my own experience and that I would need to find ways of reducing any possible emotional impact on myself (Kennedy *et al.*, 2014).

Feminist methodologies have influenced my perception of participants (Sprague, 2005; Stanley, 1990), as I believed that they were the experts in their lives and what they knew was of value to understanding the lived experience of Glue Ear. This was not to suggest that they knew everything, but rather that they had a particular insight which had not previously been explored in detail. This was particularly the case for the young people whom had not before been asked for their views about living with the condition. The process of reflection involved in creating a photomontage encouraged them to consciously think about how the condition had impacted them. Through exploring their images in the participant-led discussion they provided in-depth insight into this.

For the most part the voices of parents, and especially young people with the condition, have been marginalised. There has been a tendency to research 'on' rather than 'with' (Boxall and Ralph, 2009; Sprague and Hayes, 2000; Ladner, 1987). The researcher has controlled the content and context. I acknowledge that participants in this research were not involved in the development of the research, but the aim of using the photomontage approach was for them to identify their issues for discussion, without recourse to any pre-prepared interview schedule on

my part. The focus was on reducing the power differentials between researcher and participant whereby participants were at the centre of producing data with a focus on their lived experience (Miles, 2011; Sprague, 2005; Harding, 1987). The importance of exploring my own prejudices, principles and experiences to develop a reciprocal relationship with participants through reflexive practice (Etherington, 2004) led me to contact participants and explain that I thought that I had missed something and asked for further help and for them to comment upon their case study.

I tried to identify ways in which the power dynamics between researcher-participant could be further reduced (Finlay and Gough, 2003). Arranging meetings at a time and place convenient to participants, not setting a specific format or number of images for the photomontage, accepting participants' interpretation of what constituted an 'image' and participants selecting the sequence in which the photomontage was explored are small aspects of the research process but hopefully ones that shifted control to them. Data production was in the participants' hands as they decided what they disclosed about their lived experience.

Young people are used to adult's agendas dominating what is said (Lowe, 2012) and perhaps are used to following the lead of the researcher (Christensen, 2004). This became apparent at the first meeting with participants as often the young person did not pay very much attention to the conversation. I made efforts to talk directly to them and asked about their experience of Glue Ear. I checked that they were willing to take part and that they understood that their views were of equal importance to those of their parents. When discussing their photomontage I tried to set the young person at ease. For example Stewie commented that he had only four images so I assured him that there was not a set number required. Daisy swore when discussing her images but I did not comment as I wanted her to understand that although I was an adult I did not have any authority over her language.

Prior to recruiting any participants, I decided to construct my own photomontage and a dialogue to accompany it (Table 4.4). The rationale for this was threefold. Firstly, I wanted to test out/pilot the method to see how time-consuming it was and whether it was an achievable task. I wanted to be aware of some of the potential questions participants might ask about completing the task. Secondly, part of the IPA methodology includes a commitment to consciously bring one's own perceptions and assumptions to the forefront, what Smith *et al.* (2009: 25) regard as one's own 'fore-understandings'. Thirdly, as an insider researcher, I wanted to explore my personal situation in advance to be aware of the feelings that discussing similar experiences may bring out. I recognised that I needed to separate these from the research process to avoid a situation of feeling overwhelmed by emotions when with a participant (Dickson-Swift *et al.*, 2008). I also wanted to protect myself from feeling upset (Etherington, 2004) so identifying potential issues which might arise, in advance meant I was more prepared that I might find some of the participants' experiences similar to my own.

A dilemma I faced in sharing my own photomontage concerned the protection of the anonymity and privacy of my own family. The issues were twofold. Firstly my children had not agreed to participate in the research and if I used personal photographs and images then their identity would be exposed. These are now published on-line and if I included the whole photomontage then potentially I would lose control over who would see them and how they could be used (Boxall and Ralph, 2009). Secondly, my personal reflections were very private and I only wanted to partially disclose the information they contained so there were issues around my own confidentiality (Dickson-Swift *et al.*, 2008). When completing my photomontage, I downloaded some images from the internet as well as using personal photographs. The compromise position I have adopted has been to include a section of my photomontage (Table 4.4). This illustrates the process I went through and identifies some of the ways in which Glue Ear has impacted on my experience of being a mother.

**Table 4.4 Images and commentary from my personal montage and reflection**

Image	Commentary
	<p>There is a big ear in the middle of the page which symbolises how much the condition has dominated our lives; the picture has arms and legs to suggest that Glue Ear almost had a personality of its own.</p>
	<p>The stairway to nowhere on the opposite side of the page suggests that whichever direction I look there was no real way forward or 'up'. Although there appeared to be two options, in fact both go nowhere</p>
	<p>The phone is how many times I made calls and tried to find out about support but it was almost as though there was no one to call or, when I did speak to someone, it wasn't their job. I felt that the phone just rang without being answered.</p>
	<p>The closed door with the word 'closed' on it and the person outside again suggests that there was no where to go where I would receive help. The word 'closed' emphasised the lack of access to help. What came to mind was that none of the agencies seemed interested in a child with the condition. It also brought to mind my recent search when looking for participants and that the website for the hearing support group in the local council mentions that this isn't the site for glue ear.</p>
	<p>The big 'prohibited' symbol on the right hand side of the page symbolised what little help there is and almost that officialdom doesn't want to know. It emphasised that 'this' was no place for parents or children with Glue Ear.</p>

The layout in my photomontage led to a narrative, as shown in the 'Commentary' column. Table 4.4 identifies some of the key aspects which I found in reflecting on my personal experience of Glue Ear. In my photomontage the placement of the images created a structure of the importance they represented in my experience of the condition. The image of the ear was in the centre of the page and was anthropomorphised, with arms and legs to identify its personality. It was big as it dominated, so putting it into the centre of the picture emphasising what an overriding element it was. However, it did not have any facial features so there was no way to interact with it; it could hear but not speak. This echoed my experience of feeling that I never had any feedback. This juxtaposed with the situation of my children, who were often able to speak, but not hear clearly. I recalled a strong sense of isolation when they were younger, which was represented through use

of the prohibited sign, the phone that never seemed to be answered and the closed door. The door was not only shut but had the word 'closed' written on it to underline there was no help. The stairway led nowhere, but it appeared to have two options at the top, although neither went anywhere. The idea of having a choice was an illusion. I have revisited my photomontage a number of times during the course of this research and found that each time it produced another layer to my reflection. For example, on the second time I reviewed the image of the Ear, I realised that it only took information in but never gave anything back, so although it dominated my family life, it left us all voiceless. I also recalled that my sense of isolation came from initially knowing other mothers whose children had Glue Ear, but in their child the condition resolved so it was as though my children and I were left behind while others resumed a normal life.

I had self-censored my photomontage, whereby I recalled instances and experiences which I did not include. It was likely that participants did the same as a way of protecting themselves, their child and their impression with the researcher (Leary and Allen, 2011). It is acknowledged in qualitative research that participants are actively constructing what they disclose (Silverman, 2010). Respecting their right to do so is an important consideration in ethical research. However, despite such issues I concluded that as this is the first research in which participants have led the topics discussed, it has provided insight which would potentially not have been disclosed. The issues identified by the participants provided an awareness of how the long-term condition impacted their day-to-day life.

#### 4.5 Development of the photomontage method in this research

Producing a photomontage was developed as a method for data gathering in this research (Capewell, 2014d). All participants chose to access images from the internet, which is an adaptation to the Photovoice methodology as participants usually take their own photographs. In

future research I would encourage participants to access their images through the internet as it seemed to encourage reflection and increases protection of identity. Although not explored in detail as part of this research, most of the mothers spontaneously explained how they chose a time to produce their photomontage and sat at the computer. A common comment was made that they searched through a number of images related to a phrase that they had identified. For example, three of the mothers selected the same image of a young boy standing apart from others (Figure 4.2). They explained that they had rejected a number of images before choosing this specific one and that they had refined the phraseology to identify the image.

**Figure 4.2 Boy on the edge of the playground (Reconstructed)**



When I constructed my own photomontage, I realised that downloading images from the internet meant that I spent more time thinking about what I wanted to express rather than working out how I could create a photograph of the idea I wished to portray. The internet provides a wide range of images to choose from, including cartoons, drawings and photographs. This enabled me to display quite subtle nuances within the images I selected. Developing the search terms to produce the image I wanted helped to develop my understanding of the concepts I wished to express, which encouraged reflection. This suggests that rather than participants being constrained by what they could photograph the images accurately portrayed what they wanted to express.

The mothers and young people used images which depicted their emotional responses to living with the ongoing condition. For example two of the mothers used images of a woman screaming

(Figure 4.3) to depict how overwhelmed they felt. This provided insight not only into the external pressures of repeated visits to hospital clinics and doctor's surgeries and coping in schools, but insight into their feelings. Their issues are explored in Chapter Six for the mothers and Chapter Seven for the young people. It seems that the photomontage technique enabled the participants to explore their responses to the condition in great detail.

**Figure 4.3 Screaming woman (Reconstructed)**



After creating my own photomontage, I realised that it would have been useful to talk through the images with someone and have them question and follow up what I said as a way of developing further my understanding of my experience of the condition. This suggested that the role for the researcher is to facilitate the participant thus gaining greater insight into the meaning of the images and help with the interpretative element of IPA. In Photovoice, the researcher encourages the participants to explain the meaning of their images as a way of developing their voice (Wang *et al.*, 2004). The shared meaning constructed through discussing the images deepens their understanding of their meaning as they interact with others who share similar experiences. It aligns with the way the researcher in IPA supports and encourages the participants to extend their interpretation of their situation through the concept of the double hermeneutic (Smith *et al.*, 2009). In IPA the researcher takes an active part in meaning making

with participants, similar to the role of the other group members in Photovoice, who add their interpretations of the images (Wang, 2003).

The creation and review of images worked equally well with adults and young people. It would be worthwhile to research the way in which participants created their photomontage to gain some understanding of how they selected the images and their rationale for doing so. It would be useful to explore whether the creation of photomontages promoted reflection and if it provided participants with a way of identifying the issues important to them when exploring their experience of a particular phenomenon. Undertaking further research by applying the construction of photomontages to young people's experience of chronic illnesses could help them gain insight into how they perceive their condition affects them.

#### 4.6 Ethical issues

##### 4.6.1 Informed Consent

This research received ethical approval by The University of Northampton's Research Degrees Committee and complied with the ethical guidelines of BERA (2011), the British Psychological Society (2010) and Photovoice (2009). Involving young people in research raises major ethical concerns (Boxall and Ralph, 2009). David *et al.* (2001) suggest that additional strategies need to be employed to ensure that young people fully understand and give their informed consent and that it should be an ongoing rather than a one off procedure. The strategies used in this research were designed to engage young people in discussions about the task, seek their examples about their experience of Glue Ear and to ask them whether they would like to participate.

In the past it has been sufficient to ask parents/carers for permission but since the advent of the UN Convention on the Rights of the Child (Sinclair Taylor, 2000; UNICEF, 1989), researchers

are more aware of the importance of the need to gain young people's active assent (Miles, 2011). BERA's (2011) guidelines in particular raise the issue that children have the right to understand what they are agreeing to do. A goal of this research was to provide young people with the opportunity to explore how Glue Ear impacted their daily life. I wanted to create an environment in which they recognised that they could choose if they wished to be involved, to freely express their views and that what they said would make a valuable contribution to the research. Ralph and Prett (2014) identify that it is important for young and/or disabled people to have a clear understanding of the research in which they are involved, so I made extra efforts to achieve this. In this research as I particularly wanted the young people to understand the research and be willing to participate. I always explained the research process in detail to the young person and checked their understanding by asking for examples of what I meant. As parents retain the legal right to provide consent for their child's participation in research (Alderson, 2008), they were always present in the initial meeting with the young people.

In the initial telephone or email contact with parents, I gained their permission to write separately to their child (Appendix 5 – Young person invitation letter). The letters to young people were piloted by asking two young people, outside of the study, but of similar ages, to read the letter and explain the contents back to me so that I could be sure that the language and tone were appropriate. After this feedback, the font size was enlarged to 14 point, sentences were shortened and technical language was changed. For example, 'research' became 'university project' and simple rather than complex sentences were used. Prior to the first meeting all participants were sent informed consent forms to read through. They were signed at the start of my first visit. The mothers signed the informed consent for themselves and their child to take part in the research. Young people signed a separate form of their own.

Valentine (1999) points out that sometimes parents agree on behalf of their child and that young people have strategies to minimise their involvement in research to which they have not fully

consented. They can use tactics such as not answering questions or giving one word answers. I have endeavoured to ensure the young people's active agreement. The task of young people creating images of their own demonstrated that they understood the research task and chose to be involved. Taking the lead in the participant-led discussion which followed the creation of the photomontage by explaining the meaning of the images demonstrated their active engagement in the research.

Dissemination of research is an area which is often overlooked when gaining informed consent. This needs particular consideration in image-based research, such as Photovoice, which could include photographs of participants (Photovoice, 2009). Young people may not understand that their images could be presented at academic conferences and printed in journals (Davies and Wilson, 2006). I included an explanation of these situations to participants when gaining their informed consent informing them that some images might appear on the internet.

#### 4.6.2 Anonymity and Confidentiality

In Photovoice research the creation of images by participants adds a further layer of complexity to issues around anonymity. I followed the ethical guidelines for Photovoice (2009) by alerting participants to protect their own identities by not photographing themselves, friends or local landmarks and checking that any personal information would not be revealed in the backgrounds of photographs (Clark *et al.*, 2010). I explained that they needed to ask permission of others before photographing them. If they wished to appear in the photographs, they needed to be aware that their anonymity could no longer be assured (Lawthom *et al.*, 2012). All participants were asked to choose a pseudonym to protect their identity. I provided one to those who did not wish to select their own.

In the data collection phase for the first mother-son dyad, Jane and Russell, they produced video diaries which were to camera. This meant that there was a chance of their anonymity being breached if I used that data in presentations, even if they gave permission to do so. This highlighted an issue of whether young people would fully understand the way the material could be shown and used at academic conferences. I was concerned that this could be potentially exploitative. Davies and Wilson (2006) asked young people with learning difficulties to make video diaries which identified them, showed their homes and disclosed their feelings about making the transition from school to adult life. This was produced as a video used for training purposes and available on the internet for payment of a small fee. The authors do not fully disclose if the young people really understood the extent to which the material that they produced would be used and whether they were aware they would be identifiable. Lawthom *et al.* (2012) suggest that although young people may agree to have the material shared at one point, they may change their mind at a later date perhaps being embarrassed by images of their younger selves. In this research the issue was resolved as the videos are kept in encrypted software and the recordings will be erased upon completion of my doctorate. They have not been used in any form of dissemination.

Aldridge *et al.* (2010) discussed the importance of maintaining confidentiality within data storage, particularly for qualitative data. For my research all data, including recordings and transcriptions, is stored using participants' pseudonyms. Only the transcriptions have been used in data analysis, writing up and dissemination. All data in software form is kept on password protected storage devices and paper copies are kept in locked drawers. Any reference to geographical location, such as the names of schools, hospitals or sports clubs, was removed from the transcriptions. Only the informed consent forms have participants' real names. These are kept in a locked filing cabinet and I hold the only key. The University of Northampton's procedures for retaining this information are followed. All files are stored under participants' pseudonyms and I refer to them using only those names.

To protect the confidentiality of what was said by parents and young people I requested permission from parents and young people to discuss their photomontages separately with only the parent or young person in the room. It is important to realise that neither parents nor the young person may wish to share their emotions and experiences with each other (Mauthner, 1997). Gardner and Randall (2012) highlighted that the presence of a parent can alter how the young person participates or even may answer questions for the young person. Individual conversations with the young person helped to minimise such a situation.

Issues of child protection were relevant to this research. I had the appropriate clearance for talking to young people on their own (CRB check relevant at the time of data gathering) and showed this to parents at our first meeting, having previously offered to send a copy by email or post if they had wanted it prior to our first meeting. Additionally, a potential situation could occur whereby a young person might disclose something that meant they were at risk of harm. Although the situation did not occur, I was familiar with safeguarding procedures prior to commencing participant recruitment. I knew that if such a situation occurred I would have explained to the young person that either they would need to talk to a parent, teacher or another adult or if they did not do that then I would have to talk about it with their parent or another responsible adult.

#### 4.6.3 Right to Withdraw

There are times when researchers put their need to complete research over following their own ethical statements. Booth and Booth (2003) used data from participants who had withdrawn from the research even though they had stated that their data would be destroyed after their departure. Participants' right to withdraw must be unconditional. Throughout this research I stressed that participants could withdraw at any point in the process. They were assured that they did not have to answer any question they did not wish to. In this research one young person who had

initially agreed to participate as part of a mother-child dyad withdrew. The mother was keen for her child to be a participant. The young person and I had agreed to meet in a public café with the mother's permission but the meeting was cancelled. Further attempts to reschedule the meeting received no response. I maintained confidentiality by not disclosing to the mother the young person's withdrawal and made no further contact.

After initial contact with participants, if they did not respond after four times, either by email or telephone, I stopped trying to reach them. For example, one family who I visited had agreed to a follow-up meeting two weeks later at which we would discuss their photomontages. Just before the meeting, I received a text message to say that they would be unable to meet due to a family bereavement. I acknowledged the text and sent a message three weeks later, which received no response. I followed this up with a phone call which was answered but the participant said she was busy. I agreed to phone back. This was followed up a few weeks later with an email to which there was no response then a phone call which went to voicemail. I accepted that for whatever reason the family no longer wished to participate. This situation occurred with six other participants. Although it is frustrating as a researcher not to know the reason for non-participation, I felt it was important to respect their lack of contact rather than pursue it further, particularly in a situation where there was a potentially sick child.

#### 4.6.4 Respect for participants

Originally I had thought that there maybe up to four visits over a six week period with each participant. However, it soon became apparent that this would place too great a time requirement upon them. The structure was altered so that there were two face-to-face meetings, supplemented by email or telephone contact. I offered to send a copy of the case study interpretation of their photomontage to all participants for their review and comments, but only one person accepted the offer.

#### 4.6.5 Potential copyright infringement

Participants in this research downloaded images from the internet, which could have led to copyright infringements. The Chair of the University's Research Ethics Committee advised me that there are no copyright issues when the images were used in the discussions between the participants and me. However, if any image was used publicly, such as in a journal article, then I would need permission from the copyright holder.

Obtaining copyright permission proved to be potentially both costly and time-consuming.

Finding the images on the internet and its owner took a lot of time as I did not know the phrase which had been used to generate the image. Additionally the search results are always changing. I did identify some of the images and investigated the costs for using them but a pay per use fee proved to be very expensive. Images in which people appeared were the most problematic.

Therefore, with the permission of the participants, I reconstructed most of the images so that I hold the copyright. The people in the reconstructed photographs have agreed that they are acting a role and I have kept them informed where and when their photographs have been used. I will continue to seek their ongoing permission to use their photographs.

#### 4.7 Review

##### 4.7.1 Limitations

The major limitation of this research is the small number of participants. The methods of recruitment did not elicit the planned number of participants, and gaining direct access to potential participants was extremely difficult. However, those who did participate demonstrated a willingness to be involved and to share their experiences in some depth. Smith *et al.* (2009) argue that IPA studies benefit from an in-depth focus on a few participants to allow for greater

exploration of the data than would be practical if more participants were involved. The prime concern is the quality of the data. I would argue that the development of the photomontage method for data gathering provides insight into the phenomenon. Participants reflected on their experience of Glue Ear and gave detailed responses about their key issues.

Adult-young person discussions do not always support young people in fully exploring their experiences (Drew *et al.*, 2010). Coppock (2011) advises asking young people about which methods they would prefer to use so that they have greater control over the research process. Kuchah and Pinter (2012) suggest that when young people work in groups their shared understanding and interaction during discussion encourages the emergence of issues which are important to them. In future research, if groups of young people could be recruited, I would like to involve them earlier in the research design. Following the Photovoice method (Wang *et al.*, 2004) more closely would enable the young people to discuss their photomontages with each other.

I was sometimes overly concerned about whether the recording device was working which meant that I sometimes interrupted the flow of what participants were saying. This happened with Stewie, a young person, when he was disclosing what caused him to get 'annoyed'. By fidgeting with the recorder, I broke his train of thought and cut him off mid-sentence. This led to a lost opportunity and potentially signalled that I was not interested in what he was saying. I learned to increase my confidence with technology by practicing with it and checking beforehand that everything is functioning as well as using a second recording device.

#### 4.7.2 Strengths

Participants successfully used the photomontage method. During the initial meeting with them, as they talked about their experiences of Glue Ear, they clarified their understanding of the task of creating a photomontage. This provided them with a clear understanding of the task using content they had generated. The photomontage provided a flexible format which accommodated participants' choice, from one page with the images laid out in a particular order, two pages with different themes – 'practical' and 'emotional' through to PowerPoint presentations covering the main aspects they wanted to highlight. The method did result in reflection as participants had thought about a range of experiences before meeting with me and could provide detailed and specific examples from a range of contexts.

Having the photomontage as the basis of the discussion gave the participants control. As I did not see their images in advance of the second meeting, there was a role reversal from the usual interview format whereby the researcher knows the questions in advance. I describe this as a participant-led discussion because although I still followed up things about which I was uncertain or needed to clarify for further detail, the participant led the agenda and direction of the discussion.

Participants of all ages were willing and able to explore and explain their experiences. In reviewing the transcripts, participants were talking about 90% of the time. There were instances of the young people finishing my sentences and cutting across me which perhaps suggests that they felt confident and were not conscious of the adult-young person power dynamic.

### 4.7.3 Summary

The focus of this chapter was the design, methodological and ethical issues relevant to data gathering phase. It provides information about the rigour of the data gathering and background to help in the assessment of my third research question: What is an effective methodology to ensure that the voices of young people and their parents are at the centre of the research process? I explored how the research moved from a theoretical understanding of what I was trying to achieve to developing and changing the design as I worked with each participant. Personal reflection was central to reviewing and developing the design to enable refinement of the research methods. I identified that a balance was needed between giving participants choice and overwhelming them with options. Throughout this research I have kept reflective logs which are explored in more detail in Chapter Ten. Examples of reflection in this chapter include reviewing the way I have/have not asked participants questions, considering my own experience of Glue Ear and identifying how I could have improved participant recruitment. This practice continues in the next chapter which explores the development and implementation of the data analysis.

## Chapter 5

### Research Methodology 3: Data Analysis

#### 5.1 Introduction

This chapter provides an in-depth review of the data analysis process used in this research. As Smith *et al.* (2009: 79) explain, IPA analysis is the detailed exploration of the meaning that participants put on a situation and the way in which the researcher interprets what is said. To provide transparency as to how the themes in this research were developed, excerpts from the participants' transcriptions and short examples of the analysis process are provided of the:

- Stages in reviewing the transcriptions
- Structured approach used to analyse the transcriptions
- Way in which participants' words formed the basis for identifying themes
- Application of previous quantitative research findings to the participant's experience of Glue Ear
- Methods used to demonstrate rigour in the analysis.

An exploration of how the implications of the themes and findings relate to wider psychological theory (Brocki and Wearden, 2005) is explored in Chapters Six and Seven. To avoid copyright infringement, I have reconstructed those images in this chapter to which that situation could apply. To provide transparency and an audit trail (Pringle *et al.*, 2011) of the stages in the data analysis process, examples are provided from different participants' transcriptions and their related photomontages. Smith *et al.* (2009) believe that IPA analysis is grounded in the participants' words therefore direct quotes are used to explain each stage in the process of this research. Each participant's transcription and photomontage was developed into a detailed case study before comparisons and contrasts were made between them. I have not made a separate interpretation of the participants' images as the Photovoice methodology is clear that it is the

participants who put meaning on them. Their interpretation of the photograph's meaning resulted from reflection and discussion of them.

## 5.2 Transcription

To gain familiarity with the participants' words, before beginning analysis, Smith *et al.* (2009) recommends researchers read and reread the transcripts. As part of gaining such insight, I produced my own transcriptions including the words and details of speech patterns. After the meeting with a participant, I set aside time to listen to the audio recording without transcribing it. As the images formed an integral part of the analysis, they are referenced along with the transcription. While I listened to the recording, I had the photomontage in front of me so that I could follow what was said in the context of the images. I made notes and reflected upon my initial impressions of the participant's descriptions as part of the ongoing fore-understanding process thus separating my own interpretations from the participants' words (Smith and Osborn, 2004).

In my reflective log of my first impressions from listening to the first mother participant, Jane, I noted that I was struck by the strong initial sense of her experience being highly medicalised through her repeated reference to doctors, audiology and hospital visits. The top half of her photomontage was dominated by images of hospital and doctors' signs along with pictures of bottles of antibiotics overlaying each other (Figure 5.1). As the participant-led discussion proceeded, she began to focus on the 'nightmare' quality of how she was trying to negotiate the difficulties that Russell, her son, was experiencing with his current class teacher (Ralph and Capewell, 2014). The accompanying image of an old fashioned school master with gown and cane was slightly obscured by other images and in black and white, contrasting with the colour in the other pictures (Figure 5.1).

**Figure 5.1 Jane’s Photomontage (Reconstructed)**



Within the transcription, I included the length of any pauses, interruptions, laughter or other non-word information. This enabled me to identify how the pauses contributed to the meaning of what was being said. The benefit of such detail is illustrated in an example of the transcription of another mother, Caz. This section demonstrates how her emotions changed as she talked about her picture of Daisy, her daughter, in ear muffs (Figure 5.2). She had explained that the ear muffs represented the way in which Daisy’s experience is ‘muffled’ as the clarity of sound is deadened due to Glue Ear. The image (Figure 5.2) and the extract from the transcription show how the participant-led discussion of the photomontage provided insight into Caz’s experience.

**Figure 5.2 Caz’s image Daisy in ear muffs (Reconstructed)**



Initially Caz spoke fluently, with few fillers or pauses: *And when she moved schools it was a problem, because it's a big school and they're supposed to go from one area to another and if she's not heard what they've said and when she moved schools she was quite shy so she didn't like to ask erm and so she*, (Caz, 1: 23-25). But as she explored how Daisy was potentially feeling and impacted by the condition, her speech slowed down and she repeated phrases *when she moved school* and used fillers, such as *erm* with pauses: *and so she..... it must have been upsetting for her, but she, or ummm she thinks that people weren't told what they were meant to do, and they had, but she just hadn't heard*, (Caz, 1: 26-28). This detailed review of Caz's dialogue provides an emotionally-charged reflection of her understanding of Daisy's early experience of secondary school which is the aim of an IPA study.

### 5.3 A Structured approach to data analysis

Smith (2004) suggests that a structured approach for examining the data is not always regarded as necessary. However, I considered that as I was new to IPA using a framework (Gee, 2011) would enable me to develop my understanding of the methodology. It also provided more rigour as the steps in the analysis process are open to scrutiny (Pringle *et al.*, 2011). I integrated the participant's photomontage into the usual IPA analysis process as I looked at the specific images relevant to the participant's dialogue.

#### 5.3.1 Preparing to analyse the data

I adopted the use of colours and fonts to identify the different levels of analysis (Table 5.1). Different colours and font styles were used to distinguish the specific type of analysis. When the text is in black and white print, the font styles provide clarity of which style relates to which level of analysis. As previously explained (Chapter 4, Table 4.3) I added the **bold** font (**red**) to enable me to reflect on my actions during the participant-led discussion. Table 5.2 provides an

illustrated example of applying the font/colour to the different types of analysis when reviewing a participant’s transcript.

**Table 5.1 Levels of analysis key for colours and fonts in transcripts**

<b>Colour</b>	<b>Font</b>	<b>Analysis</b>
Blue	plain text	description of situation
Green	<i>italics</i>	<i>analysis of the language</i>
Brown	<u>underline</u>	<u>concepts, ideas portrayed</u>
Red	<b>bold</b>	<b>review of own style</b>

### 5.3.2 Initial Analysis

Gee (2011) recommends putting the transcript into a table then annotating the different levels of analysis, using three columns. The middle column contains the participant’s words (the transcription), the right hand column summarises descriptions, language and concepts, while the left-hand column shows the development of themes. Smith *et al.* (2009) recommend looking at the transcription sequentially. This involves the following process:

1. In the right-hand column identify each situation in the transcription then summarise it in descriptive terms, without making any interpretation of the meaning (Blue/plain text)
2. In the same column, review the way in which the participant uses language making notes of what is said as well as how (*Green/italics*)
3. Still in the right-hand column, each situation is reviewed through the language to identify concepts that might be suggested (Brown/underline).
4. The left-hand column is used to identify themes from the overall transcription, which are likely to develop through a number of iterations.

This process is followed for each participant with the aim of producing an overall summary of common themes from all participants. In this research there were two groups of participants, mothers and young people so each group were dealt with separately before relating the findings between each of the groups.

**Table 5.2 Analysis of Jane’s words to identify theme of ‘Judgement’**

<b>Jane Review of Photo Montage - Stage 2 – Initial Notetaking</b>		
<b>Emergent Themes</b>	<b>Original Transcript</b>	<b>Exploratory Comments</b>
<p>Bad parent <i>Judgemental nature of professionals</i></p> <p><i>Fear of judgement by professionals</i> <i>Fault of parent</i></p> <p><i>Stigmatised as a ‘bad mother’</i></p> <p>Non-expert parent vs expert professional</p>	<p>J: It’s the comments that <i>SENCOs make about parents</i> and parenting skills. Because R was <i>quite withdrawn, not withdrawn</i>, but <i>didn’t want to socialise particularly before we</i> went through the Ed Psych reviews and all the rest of it. The SENCO said, because I know the SENCO, she said to me, ‘<i>It’s a good job</i> that we know you and your older son, otherwise I <i>would have thought</i> that there was a <i>problem at home with you.</i>’ I think she meant it as a compliment?</p> <p>C: <b>What kind of problem?</b></p> <p>J: <i>I don’t know, I don’t know she didn’t she didn’t</i> but <i>she’d decided</i> that R’s <i>rather</i> strange behaviour. Because it was a <i>bit strange</i>, he’d just opt out of things. <i>They’d</i> want him to sit on the carpet and things and he’d say, ‘It’s OK, I’m fine doing this.’ Wasn’t rude (high voice) didn’t want to join in maybe. She thought that it was <i>something to do with parenting, I don’t know</i>, but <i>she’d made a judgement</i>. She said, ‘Because we know you and his brother then we know he got school fine, there’s <i>clearly not a problem at home.</i>’ But <i>she’d decided</i> that .... So I think <i>they decide. She’d made a judgement, she’d decided.</i></p>	<p>J describes her interaction with the SENCO when concern about his social interaction skills were assessed by an educational psychologist. <u>Are SENCOs and others aware of the judgements and the potential implications? Could it be that making judgements leads to over complicating the situation? Lack of professionals understanding? The SENCO’s judgement is the problem is with the child and potential a ‘parenting’ issue than it being a possible consequence of glue ear: ‘made a judgement’</u></p> <p><u>Lack of consultation with Jane beforehand. Insinuation that there is a problem with Jane’s parenting skills, but she is not given the right of reply.</u></p>

*Green/italics = analysis of the language* Blue/plain text = description of a situation  
Brown/underline = concepts, ideas portrayed

The first participant analysed in IPA research is usually developed as a case study to generate the initial themes (Yost and Chmielewski, 2013). Table 5.2 shows a worked example of the analysis of a section of the first participant, Jane’s transcription. The plain font (blue) summarised the situation being described, in this case an assessment by an educational psychologist resulting

from the SENCO's concern about the way Russell, her son, interacted socially with other children. The italics font (green) was used primarily within the transcription to highlight the way Jane used language and syntactical devices to explore her reaction and understanding of the situation. These were sometimes supplemented with interpretative comments in the right hand column also in italics (green). When Jane was unsure or confused she tended to repeat things, such as *quite withdrawn*, where she used the adjective *quite* to clarify the extent to which Russell was *withdrawn*. She repeated *I don't know* which seemed to indicate her confusion about the reasons the SENCO wanted Russell assessed. She used the 3<sup>rd</sup> person anonymous *they* to indicate that she felt that a *judgement* had been made regarding her parenting skills. During this section Jane disclosed more information about her feelings. This detailed analysis of the individual participant's words is a central tenet of the IPA methodology.

As IPA is interpretative, the underline font (brown) comments (Table 5.2) identified my initial understanding of Jane's perspective of how she was impacted by having a child with long-term Glue Ear. The initial theme of *judgement* developed from her use of the phrase, so grounding my interpretation in her words. She felt that she was seen as lacking in good parenting skills, resulting in part, from not being involved in the decision to consult an educational psychologist. IPA intensely scrutinises each word, looking for patterns both within each transcription and between those of all participants. It is this close examination which results in understanding the subtlety of meaning in the layers of what participants are both saying and leaving unsaid. It was through reviewing, comparing and contrasting sections within each participant's transcription and then between the participants that I eventually derived the mothers' themes, Chapter 6, Table 6.1.

I used the left hand column to identify themes after the elements of the right hand column had been reviewed (Gee, 2011). The first time I went through the transcription I used plain black font then black italic font to summarise and review the themes at a second point in time.

In my assessment of my behaviour in this section (bold font/red) I identified that I reflected back to Jane her word, *problem* to gain further insight into her interpretation. This was an example of the double hermeneutic whereby through my question she expanded her reflection on how she interpreted the SENCO's behaviour about Russell's behaviour in the school environment. I remained silent while Jane talked to avoid interrupting her thoughts.

### 5.3.3 Data Interpretation

Once the annotations on the transcription were completed I considered Jane's use of language in more detail. The use of the verb *make* suggested that Jane saw the SENCO actively constructing a view about *parents* in general and not just her. She then explored her understanding of Russell's behaviour – initially using the noun *withdrawn* but then clarifying by negating, *not*, to conclude that actually Russell was making an active choice to not participate; *he didn't want to*. Jane explored how the SENCO's comments made her feel judged, *a problem at home with you*. Clearly the use of the 2<sup>nd</sup> person singular, *you* put the emphasis on Jane. The SENCO qualified her judgement *It's a good job* and *we know you and your older son* so the problem must have been in Russell. I interpreted what she said underline (brown), through asking myself a series of questions about what this incident implied, not just about what had happened to Jane but more widely about the SENCO's behaviour and how this could potentially impact the educational experience for young people with long-term Glue Ear.

Table 5.2 demonstrates the depth of the analysis of each participant's discussion. Specific words are examined then related to the whole sentence along with the way it was said (tone, tempo, emphasis). Each sentence is related more widely to the individual participant's whole transcription. There was a revisiting of analysis between the various aspects of the hermeneutic circle. The idea is to explore the data at various levels in a variety of ways to gain insight into the way the participant constructs meaning from this experience (Kockelmans, 1967). There is no

intention to explain what has happened; the focus is on examining the participant's response. The emergent themes are explored through psychological theory. In this case around how professionals *judge* those using their services or models of what are the behaviours of a *good mother*. This is explored in more detail in Chapter Six.

This section of the participant-led discussion was generated from the image of the old-fashioned strict school teacher (Figure 5.3). The photograph evolved into experiences about school and from the particular situation about Russell's difficulties with his current teacher (Ralph and Capewell, 2014). Jane made comparisons with other teachers where the relationship was more positive and Russell had felt more supported. She also talked about her relationship with the Head Teacher eventually leading her to explore the situation with the SENCO. Throughout her participant-led discussion Jane controlled what was said about the images to cover a range of situations.

**Figure 5.3 Jane's image Strict school teacher (Reconstructed)**



#### 5.3.4 Generating themes

The purpose of the final stage in the analysis, as suggested by Cronin-Davis *et al.* (2009), is to generate themes, which can then be linked to existing literature or theories to inform understanding of the lived experience of the condition. In this research, these themes provided

insight into how the findings of previous quantitative studies apply to the participants as well as how psychological theory develops the understanding of the psycho-social impact of the condition on mothers and young people.

This process is additive and cyclical starting with reviewing the concepts generated as the data was analysed and noted in the right-hand column, as seen in Table 5.2 in underline (brown) text. Smith *et al.* (2009) call these ‘emergent themes’ as they become known from detailed examination of the participant’s words. Using the data from Table 5.2 as an example, Jane explained that the SENCO had made a *judgement* and subsequently the idea developed that she felt Judged. This is noted in the left column in Table 5.2. Wherever possible the participant’s words are used to identify themes (Reid *et al.*, 2005) from the text as a way of ensuring that they come from the participants, rather than being based on the researcher’s interpretation (Pringle *et al.*, 2011). Such a process underlines the central role that the participants’ interpretation of events has in IPA and helps to demonstrate transparency in how the themes are selected. Using the participants’ words to identify a theme acknowledged my epistemological view that participants were actively making sense of their situation and that through following their lead greater insight can be gained about their experience (Smith *et al.*, 2009).

In this example, as more participants’ words were analysed and comparisons made between them, then the name of the theme changed to reflect more clearly the essence of their experience and interpretation. The theme Judgement changed to Non-expert parent vs expert professional, then finally developed into Knowing Experts or Knowledgeable Mothers to become a super-ordinate theme with further sub-themes identifying the separate aspects of it (Table 6.1). An explanation of the meaning that participants placed on this super-ordinate and sub-themes, the interpretative phase of IPA, is provided in Chapter Six.

For the purposes of rigour in explaining how each theme was developed a worked example is provided of the process by which the young people's emergent theme of Frustration/Anger was developed into the super-ordinate theme, Never Mind, and the sub-theme, The Stress. The young people provide an illustrative example as their small sample size, of three participants, means their data is more manageable to explore. This process is based on understanding how the participants express their individual experiences so that the impact of the phenomena of Glue Ear can be better understood (Brocki and Wearden, 2006). It is through this shared exploration (Cronin-Davis *et al.*, 2009) of the characteristics that participants attributed to their anger/frustration when interacting with others and reflecting on the meaning of the associated feelings, that as a researcher, I was able to interpret their experience. Smith *et al.* (2009) describe this as the double hermeneutic whereby as the participants explore the nature of their feelings, and the situations in which it develops, through the use of questions of clarification, as the researcher, I further interpret the meaning of their subjective world. In this research, the images produced by participants added another dimension as their selection had provided participants with opportunities to reflect on the aspects which they felt were central to their experience of the condition. Encouraging reflection by participants is an important tenet of IPA (Reid *et al.*, 2005).

Once all of the participants' data was analysed, I transferred their comments to an excel spreadsheet using the page and line number to reference specific quotes. These were then grouped into clusters of similar verbatim comments made by each participant. As Brocki and Wearden (2006) explain this is an iterative process in which the participants had reflected on their experiences as they discussed their images with me. Each participant's comments were read a number of times before a title for the theme emerged. The young people explained shared feelings of Frustration/Anger. The title of the super-ordinate theme developed from Daisy's image, Never Mind (Figure 5.4) with the sub-theme derived from Stewie's image of Stressed (Figure 5.5).

Figure 5.4 Daisy's image Never Mind      Figure 5.5 Stewie's image Stressed (Reconstructed)



The three young people described this feeling in varying detail. Russell explained the problems his ears caused him, both the practicalities of keeping them clean and not fully knowing what was going on around him: *My ears have been gunky recently. And you have to keep having to clear out my ears and it's horrible. Baby wipes and they get soggy so it's not that nice or ... And my hearing hasn't been great, so just, just not that great really and I hate having **bad** ears,* (Russell, Ear Ache 3-6). Stewie named his feelings as *stress* resulting from not fully understanding what he was meant to do in the school context and how, in order to function, he had to do extra and different things from his classmates: *when I can't hear all of the time and like erm I have to get things repeated at times and like erm, I always have to go up closer to the desk as I just can't hear, and sometimes like er ... I just can't hear at times, so like, yeah, so I just get stressed about that.* (Stewie, 2: 13-16). Whereas for Daisy, it was the way in which her hearing interfered with her ability to communicate with her friends and caused her to wonder if they were not talking loudly enough for her to hear on purpose, as a way of excluding her: *I'm like paranoid about what they're saying and that I can never really hear people, I can hear all right but it's a bit.... a bit annoying 'cos a lot of my friends are a bit loud when they want to be and then half the time they're really quiet* (Daisy, 1:10-13).

The young people explained their feelings in response to situations which caused them anxiety and stress, but they down played it, as was suggested in Russell's use of the phrase *not that*

*great*. There was an element of him understating the emotional impact rather than focusing on the unpleasantness, even though he had described how *horrible* it was which he juxtaposed with the phrase *it's not that nice*. Similarly, Stewie mitigated his description of becoming stressed with the modifier *just*. Daisy minimised the impact of not being able to hear and worrying about her friends' motives by moderating how she felt by saying *it's a bit annoying* in contrast to her description of being *paranoid*. It was almost as though these are self-protective devices that are summed up in the *Never Mind* interpretation of the experiences being something they will not worry about or that they try to shrug off. The psycho-social implications of this super-ordinate theme are discussed in more detail in Chapter Seven.

### 5.3.5 Linking the analysis to previous research

Brocki and Wearden (2006) suggest that IPA's contribution can be found in helping to understand that physical illnesses impact the whole person and that the perceptions of the person with the condition provide a more holistic picture of the affect it has in the context of their life world. I would argue that in this research there was value in including the mothers' perceptions as they played a pivotal role in the young person's life and were the main channel of communication between educational and healthcare professionals. A benefit of adopting an ideographic approach, such as IPA, as suggested by Pringle *et al.* (2011) is that the findings of the previous quantitative research can be applied to the participants' descriptions of their experiences.

This section explores the links between the experience of the participants in this study (mothers and young people) with findings from some of the previous quantitative research. This follows the spirit of Husserl (Kockelmans, 1967) who suggests that the lived experience of individuals of a particular phenomenon provides greater insight into what it is like to be inside the condition. Heidegger's concept of Dasein (Chapter Three, Section 3.4.2) is relevant in this section. For the

young people and their mothers in this research, the quantitative findings provided context to their experience so differentiating their personal response from consequences of the condition.

During the analysis I identified anything in the participants' transcriptions which related to previous related research. This was to provide insight into how the findings of such research applied to the experience of those with the long-term condition. A few examples are provided here to illustrate the overlap between the mothers' descriptions of their child and the literature supporting their comments. Jane, Lois and Wendy described how their sons withdrew from social contact. Jane and Wendy used the same downloaded image from the internet of a young boy on the sidelines (Figure 5.6 Boy on the edge of the playground). Lois explained Stewie's behaviour in the nursery environment, with her comments echoed by the other mothers: *They used to say, "he ignores us", "he doesn't take any notice when we say it's circle time" or "He sits under the table,"* (Lois, 1: 17-18). This behaviour was described in the literature where it is noted that it is not unusual for young children with Glue Ear to withdraw from groups (Vernon-Feagans and Manlove, 1996) as they are likely to find listening in noise difficult (Toe 2009; Gravel and Wallace, 1992) or that perhaps the hearing loss meant that they do not actually hear what they are being asked to do (Hogan *et al.*, 1997).

**Figure 5.6 Jane's/Wendy's image Boy on the edge of the playground (Reconstructed)**



The problematic way in which children with the long-term condition interacted with their peers was not confined to boys, as Marian explained when Poppy was playing with other children in her own home: *M: She'll spectate. C: What does that.. what does she do? M: She'll watch, so if*

*uhmm they're, erm if they're playing... so for example, she might have 3 or 4 friends round and if erm uhm... one of them...if one of them... erm she'll tend to be the one who **won't** suggest the games. Or they'll start playing a game and she won't want to play it but she won't say anything, so she'll just drift off, she erm she won't say anything...* (Marian, 6: 10-16). The complexity of the impact of Glue Ear was evidenced in this quote by Marian. Duncan (1999) identified no significant differences in the conversational skills of children with mild hearing loss when compared to their age-matched peers, which is supported by Poppy's development of friendship skills. However, Bess *et al.* (1998) found that children with mild sensorineural hearing loss (MSL), with a functional loss similar to that of Glue Ear, demonstrated statistically significant less competence in their self-esteem skills. It could be that Poppy, and the other children in this research, found it more difficult to negotiate the complexities of social interaction when playing with others (Bortoli and Brown, 2008).

Some issues are less well reported in the literature so are not highlighted in the information that parents are given. Wendy and Marian both identified that their children often vomited and that this became part of their routine: *And.. and the thing was it was such a normal process for me, because everywhere we went he was sick, I cleared it up ... or he went somewhere else and he was sick and they cleared it up and I got an earful about it.... Ahmm ... it was very normal for me* (Wendy, 1: 45-48). With a very similar description, Marian explained: *she was throwing up a lot through exercise. Erm just because of all the congestion. From an early age she was throwing up with congestion. .... Erm the school actually. I had to go up to the school and tell them not to send her home after the 3<sup>rd</sup> time* (Marian, 10: 15-18). The literature is not clear on the links between persistent vomiting in some children as a part of ongoing Glue Ear in early childhood. Feinmesser *et al.* (1993) recommend grommet surgery as a way of stopping it whereas Weick and Kane (2003) suggest that it is a side-effect of the antibiotics while Venekamp *et al.* (2013) suggest antibiotics should be used to prevent it. Wendy came to see it as part of who Peter was whereas Marian provided her own explanation of it being the result of a

build-up of mucous. In quantitative methods of data collection, the voice and the experience of individuals are not reported so parents and young people with the condition are left confused as to what is and is not part of the condition.

The findings of much of the research into Glue Ear have not shown statistically significant results. I would suggest that applying the results from the clinical literature to individual experience is likely to increase understanding of the complexities of this condition. This research provides illustrative examples of the subtle differences, at the individual level, as suggested by Teele *et al.* (1990) and highlighted in the conclusions in Chapter Two.

#### 5.3.6 Rigour of the analysis

The four criteria used to demonstrate rigour in the analysis of the data in this research are based on the model of trustworthiness put forward by Lincoln and Guba (1985) as developed by Thomas and Magilvy (2011:152). The four elements are: credibility, transferability, dependability and confirmability.

‘Credibility’ requires that the conclusions reached are identified as accurate. In this research this is demonstrated through referring the conclusions and case histories back to the participants and the review of the themes identified by the IPA Group in London (Appendix 6). Biggerstaff and Thompson (2008) identify that IPA is concerned with understanding the meaning that participants put on their experience. Researchers need to demonstrate that their conclusions reflect participants’ understanding of their situation and that the conclusions and interpretation is based on a thorough analysis of the data. In this research, participants were offered the opportunity to read, edit and comment on their case study as being in accord with how they interpreted their experience (Smith *et al.*, 2009). Rather than take up additional time, participants and I communicated through a series of email conversations (Meho, 2006). As contact was

already established with participants there was more chance of a quick response. In some cases I had already asked for additional support and clarification through this means so participants felt that they had the authority to correct any comments as well as give an update on their current situation, if that had changed or they wished to do so. Either participants did not make any alterations or did not respond to the offer to comment.

The other way of checking whether the super-ordinate and sub-themes I identified were creditable was by consulting with the IPA London group. The members are all active researchers using the IPA methodology. Twenty attendees were given different short excerpts with the related image and worked in pairs to suggest a theme for the dialogue (Appendix 6). There was general consensus with the themes I had identified. For example I had named a sub-ordinate theme 'Repeated experiences' which was supported by group members labelling the excerpts as 'repetitive, roundabout that she can't get off' and 'going round in circles'

'Transferability' as described by Thomas and Magilvy (2011) is something that has been attempted in this research through comparing and contrasting the way in which the mothers and young people expressed their views on similar situations, which is developed in Chapter Eight. However, before the requirements of these criteria are established, further research with a different group of participants would be required.

'Dependability' in the Thomas and Magilvy (2011) model is mirrored in the concept described by Yardley (2000:222) who uses the terms 'Transparency and coherence'. 'Transparency' relates to the detail provided about the way in which the data was collected (see Chapter Four) and analysed. In this chapter, I have specified the processes used and provided examples of how the analysis was completed. The layout of this chapter has followed a logical order in which the data was analysed to provide coherence, with each step supported by examples and explanations to enable the reader to gain insight into the stages of the analysis. This provides a type of audit trail

which can be followed and checked by other researchers. My supervisors undertook sample analyses to assess whether I was analysing and interpreting the data in accordance with IPA principles. Applying the framework suggested by Gee (2011) and considering the points identified in critical reviews of the methodology (Pringle *et al.*, 2011; Brocki and Wearden, 2006; Reid *et al.*, 2005) with regard to my research were other steps I applied in trying to achieve transparency.

The concept of 'confirmability' is based on the notion that the researcher demonstrates self-criticism and makes explicit their underlying assumptions throughout the process through reflexivity (Etherington, 2004). Excerpts from my reflective logs clarified my own thoughts throughout the research process. The practice of Fore-understanding and undertaking and sharing my own photomontage (Chapter 4) are part of this process. I would include the action of reviewing the transcriptions to assess whether the style and type of questioning I adopted are examples of self-criticism. Chapter Ten demonstrates my personal reflections and reflexive actions as I carried out the research.

### 5.3.7 Summary

This chapter has illustrated the process through which the data was analysed using the IPA methodology alongside the visual images provided by participants in their photomontages. Throughout the chapter there are examples of how and why the data was analysed, along with justifications for all the steps in the process. Making the links between an individual's experience of Glue Ear and previous research gave insight into how the findings can be applied to individual participant's lived experience. In the following chapters the psychological impact of the condition on mothers and the young people is explored.

## Chapter 6

### **Mothers' stories: Living with a child with long-term Glue Ear: I keep on knocking but there's no one there**

#### 6.1 Introduction

The mothers in this research found themselves in an ambiguous position. They had a child with Glue Ear. This condition is constructed as temporary, medical and with no long-term health or educational consequences. Their children, however, had repeated ear infections from a young age with at least two operations under a general anaesthetic. There was no improvement in their children's hearing levels. They perceived their children as demonstrating problematic behaviours. Their experiences were not a reflection of the general description of the condition, but they continued to hold that majority perspective. Both their concerns for their child and their personal anxiety levels increased while they waited for the condition to resolve.

The title of this chapter 'I keep on knocking but there's no one there', is a metaphor which highlights some of the situations they identified. The 1<sup>st</sup> person singular pronoun, 'I', represents the loneliness which they expressed and how they felt isolated from others, including their family and friends. There was a strong element of repetition in the situations they faced and their efforts to try to improve their child's experience – at school, with healthcare professions and in social situations – hence the use of the phrase 'keep on'. This also included the element of their determination to persist. The verb 'knocking' related to the idea that the mothers were trying to gain access/attention of someone who could help. There was also a hint of an idea of something outside the norm that they were dealing with, as in an unexplained sound. The 'but' represented their feelings of constant disappointment of a condition which they were told was temporary, yet kept recurring as a negative aspect of their life. The mothers expressed how there was 'no one' who could really help them. This also highlighted the impact of lack of support groups for this

condition; they had to be self-reliant and develop their own resources. The idea of being in the wrong place was reflected in the ‘there’, almost as though they should have been somewhere else but could not find the right route.

Because the condition resolves itself for about 80% of children by the age of 9 years (Bluestone, 2003), it is unsurprising that the mothers in this study had an expectation that their child would grow out of it. Feldman and Paradise (2009) suggest that it has no long-term consequences and it is not constructed as serious or life-threatening. Berland (2009) makes the point that when something is described as an ‘illness’ this implies that you will recover from it. Interpreting the condition in these ways was appropriate for this research as both the young people and their parents believed that there would be a point, for them too, when they would be Glue Ear free.

The mothers in this research were caught in a situation whereby the condition was perceived as temporary, but that was not their experience. This tended to lead them to reject any idea that their child had a chronic childhood illness, with potentially more than just healthcare implications. However, for the mothers and young people in this research, the way the condition manifested itself, did meet the four criteria identified by Mokkink *et al.* (2008:1444) of a chronic illness:

- (1) Occurring in children aged 0 to 18 years;
- (2) Having a diagnosis based on medical scientific knowledge which can be established using instruments according to professional standards;
- (3) Not (yet) curable;
- (4) Present for longer than three months or very probably will last longer than three months, or having occurred three times or more during the past year and likely to reoccur.

When this definition is applied to Glue Ear it becomes apparent that the condition, in some children does meet the criteria for a chronic illness, and certainly applied to those in this research:

1. It occurs in the 0-18 years' age group, with the highest incidence in children under 7 years of age, but can begin as early as 3 months and continue beyond the age of 18 years. The young people in this research were in that age range.
2. Diagnosis is made by examining the ear to identify the presence of specific characteristics, such as an outwardly bulging ear drum, red/inflamed ear drum and observation of fluid in the middle ear cavity. ENT consultants have general agreement about the characteristics of the condition (Bluestone, 2003). All of the young people in this research continued to regularly visit an ENT consultant. Those children, whose mothers took part in the research, did have a formal diagnosis and had repeated ear infections.
3. Although grommets are used to ventilate the ear drum, they are not a cure. Investigations still continue as to the cause so a cure can be identified but at present one does not exist. All the young people in this study had at least two sets of grommets.
4. The younger a child has his/her first experience of the condition, then the more likely that it will continue (Winskel, 2006). Although in some cases the condition does clear spontaneously, the current NICE guidelines for *Surgical management of otitis media with effusion in children* (2008) suggest a period of active observation whereby the status of the child's ear drums are monitored. The expectation is therefore that it is likely to continue for a minimum of three months. As it is a continuum condition, it is difficult to identify when it is 'acute', causing pain and distress while it occurs, but having the expectation that it will resolve, rather than 'chronic' with the realisation that it will continue for years. All of the young people had had a continuous period of the condition for longer than five years which started from under three years of age.

Despite not generally being interpreted as a chronic illness, all of the mothers in this research (see Chapter 4, Section 4.1 for details of the participating mothers) had a child who met the criteria identified by Mokkink *et al.* (2008). However, neither they, nor the healthcare professionals with whom they interacted, interpreted the child's condition as a chronic illness. As a consequence educational professionals did not perceive it as a serious or ongoing condition. The result for the mothers in this research was a lack of role clarity about how they potentially perceived themselves. They did not differentiate their child from others in his/her peer group, but their child was different due to reoccurring infections, ongoing hearing loss and regular hospital visits. But their child's condition was not like asthma or diabetes, conditions which require monitoring and specific medication. As their child's hearing loss was intermittent and temporary the mothers did not identify their child as having a disability. They were therefore left in a situation of being the mother of a child who was not quite like others, but with neither a 'real' medical condition nor a disability. For example, Caz, one of the mothers, was surprised when the consultant suggested that her daughter, Daisy, could have hearing aids as she had previously told her daughter: *Oh no, you won't be that bad* (Caz, 4: 30). Similarly another mother, Wendy, believed that her son, Peter's hearing loss was mild compared to *the mum whose child has proper hearing issues such as wearing hearing aids* (Wendy's emphasis, 19: 37). It seemed that some sort of aid was required before a condition could be deemed serious. The intermittent nature of the hearing loss led mothers, young people and professionals not to interpret the young people as having a form of deafness.

As educational professionals perceive the condition in medical terms, any educational support is generally not deemed necessary. Specific action in the classroom was not forthcoming because, as one of the mothers, Jane, identified it was *not a confirmed special need* (Jane, 4: 49).

Educational Psychologists may note that a child had a history of Glue Ear but not always link it to impacting academic performance or behavioural issues. This could then lead to potential

repercussions of the condition being attributed to other causes. For example, of the young people in this research, Russell had been identified as dyslexic and Daisy's poor concentration and distractibility labelled as ADHD. Tajima-Pozo *et al.* (2010) reported on the case of a five year old boy who was believed to be on the autistic spectrum. However his behavioural issues were no longer evident after he had a grommet operation to relieve the symptoms of his Glue Ear.

The original design for this research included the involvement of both parents and siblings, but it was only mothers who took part in creating photomontages and discussing them. It is acknowledged in the literature (Preece 2014; Cridland *et al.*, 2013; Johnson and Simpson, 2013) that this is often the case with research into children with ongoing health or developmental conditions. Throughout the rest of this chapter I use the personal pronoun 'she' to acknowledge this, rather than give the impression that the mothers' comments apply equally to both parents. Having only mothers in this study provided the opportunity to explore the similarities and differences in their reactions to having a child with this chronic condition as well as the impact it had upon their estimation of their mothering skills and their psychological well-being.

## 6.2 Discussion of the Super-Ordinate Themes

My search of the literature did not identify any previous research which provided details of mothers' experience of having a child with the ongoing condition or its potential impact on their emotions. How the mothers individually interpreted the condition and their personal responses to supporting their child, provided insight into the complexity of the condition and much wider implications than have generally been acknowledged. I have used previous research findings into the condition and psychological theory to develop the mothers' interpretations of their situations and experiences.

As shown in Table 6.1, Mothers' Themes, the IPA analysis resulted in three super-ordinate themes, with either two or three sub-themes. These were developed from the mothers' exploration of their experiences in the participant-led discussion and further analysis and interpretation of their words. The themes summarised the mothers' understanding of their experience of the condition and how it impacted their child, and subsequently them. The emphasis was on their interpretations of their experience and the emotional consequences that having a child with the long-term condition had on them. The names of the themes tended to be developed from words which the mothers used as they explored their lived experience of the condition and came to examine the essence of the phenomenon of Glue Ear.

**Table 6.1 Mothers' Themes**

<b>1. Knowing Experts or Knowledgeable Mothers</b>		
1.1. To ease mother's anxieties	1.2. Roundabouts and repetition	1.3. Diminished and dismissed
<b>2. Motherhood, but not as I imagined it</b>		
2.1. He sat on my lap		2.2. Lonely and alone in my family
<b>3. It's not a proper special need</b>		
3.1. Temporary and medical		3.2. It must be something else

The first super-ordinate theme, 'Knowing Expert or Knowledgeable Mother' was the strongest theme and is examined in most detail. It considers the interaction between mothers and healthcare and educational professionals as the mothers tried to interpret and manage their child's condition. Two of the mothers, Wendy and Kate, specifically talked about their expertise in their child. Jane, Lois and Miranda highlighted that they had concerns about their child's condition which were not taken seriously by healthcare professionals. Marian and Kate faced dilemmas about the way healthcare professionals did not always seem to have the level of

expertise which the mothers assumed. Kate and Caz were nurses, but their formal qualifications were not always taken into account.

The second super-ordinate theme, 'Motherhood, but not as I imagined it', explores the emotional impact for the mothers of living with a child who had the longer-term, chronic form of the condition rather than the more usual temporary childhood illness. The sub-theme, 'He sat on my lap', reflects on the impact that the young people's behaviour had on the way in which the mothers assessed their skills as a mother. The second sub-theme, 'Lonely and alone in my family', explores feelings of loneliness and isolation that resulted, for some of the mothers, of having a child with the long-term form of the condition.

The third theme, 'It's not a proper special need', highlights the way in which the condition is constructed within the medical context as common and temporary. Because it is explained in physiological terms, teachers do not perceive it as within their expertise. Equally the mothers did not always attribute their child's problematic behaviours to the condition.

Part of the difficulty for the mothers in this research was that there were no support groups for either parents or young people with Glue Ear. The outcome was that the mothers developed their own strategies, such as relying on their own resources, questioning the interpretation of what healthcare professionals told them or participated in internet chat forums on the subject.

However, there remained a feeling that they neither had any real answers nor a clear source of reliable information. Because the condition was positioned as a common childhood ailment, the mothers did not discuss seeking out other mothers in a similar position. This generally led to feelings of isolation and anxiety, which could perhaps be lessened by receiving more information about the condition's behavioural and academic implications as well as the opportunity to discuss in detail, with a qualified professional, alternative treatment options to grommet surgery.

### 6.2.1 Knowing Experts or Knowledgeable Mothers

The main element of this super-ordinate theme is the mothers' exploration of their interaction with healthcare and educational professionals. The mothers identified how they negotiated the power differentials, real and perceived, between themselves and these professionals. Initially the mothers had faith in such professionals and wanted to follow their lead, but as their experience and confidence in their own knowledge increased, they began to perceive themselves as the expert in their own child. Wuest and Stern's (1990) research found that as the parents' experience of their children's recurring ear infections increased, they recognised the symptoms of Glue Ear in their child and developed strategies which worked for them. For the mothers in this research, this often led to a decrease in trust or willingness to unquestioningly follow the professionals' opinions. Despite such feelings, the mothers generally did not openly express their views but continued to comply with the processes and procedures within the educational and healthcare systems. This super-ordinate theme is divided into three sub-themes:

- 'To ease mother's anxieties', which explores the way in which the mothers raised their concerns about their child's hearing. This was often interpreted by the healthcare professionals as a 'problem' within the mother.
- 'Roundabouts and repetitions' considers the nature of ongoing visits to doctors' surgeries and hospital clinics where the mothers identified that they were part of a 'system' into which they had little input.
- 'Diminished and dismissed' focuses on the mothers' desire to work in partnership, but this was not always received positively by professionals. This was despite the messages from government initiatives by the Department for Education (2003) and the Department of Health (2003), which focus on educational and healthcare professionals involving, supporting and listening to parents.

Wendy's image from her photomontage, Badge of Expert Patients (Figure 6.1), summed up the ambiguity that the mothers felt. As she explained: *I now consider myself an expert patient, I'm not an expert by any stretch but I certainly, I consider myself ... I know exactly where I'm coming from. I know enough about ears* (Wendy, 15: 2-6). She expressed how she understood how the condition manifested itself in her son and that she probably had greater insight into the day-to-day impact of the condition than most doctors. Kate identified similar feelings. They demonstrated frustration at the professionals' lack of acknowledgement of their expertise. However, Wendy identified limitations in her expertise, *I'm not an expert by any stretch* but, she also knew *exactly where I'm coming from*. This apparent contradiction is explored in more detail in the explanation of the sub-themes.

**Figure 6.1 Wendy's image Badge of Expert Patients**



This theme developed from the way the mothers discussed how they interacted with the healthcare and educational professionals, including their efforts to develop good relationships with them. The behaviour and attitudes of the healthcare and educational professionals towards the mothers impacted how the latter negotiated those relationships when trying to achieve the best outcome for their child.

### 6.2.1.1 To ease mother's anxieties

In the first sub-theme, 'To ease mother's anxieties', Jane described her general practitioner's (GP) response to her concerns about Russell's hearing difficulties: *So in the end I sat and wept in the doctor's surgery. I said, 'For God's sake, I keep telling you he can not hear.'* She put her head on one side and went, *'If it would ease your anxiety, Mother, we'll refer you.'* (Jane, 6: 7-9). The use of the 2<sup>nd</sup> person singular pronouns, *your* and *you*, kept the focus on the mother. It summarised the way in which the healthcare professionals, in particular, interpreted the mothers' concern about their child as being a problem within them. They were seen as lacking the expertise appropriate to identify the right course of action for their child. Describing Jane as 'mother' could be interpreted as quite patronising, as she was seen as a role rather than an individual. Although the Department of Health (2003) encourages mothers to think that they have an active role to play in promoting and maintaining their child's health and well being, the power differentials are such that the mothers had to convince these gatekeepers to take action.

In this sub-theme the mothers recognised their own expertise in their child based on their instincts and experience (Capewell, 2014e). However, the healthcare professionals seemed assured of their own expertise so did not listen to the mothers. The problem for the mothers was twofold. On the one hand, they had to persuade the professionals that they were not being over-emotional (Bellussi *et al.*, 2005), and on the other they needed to negotiate a situation in which the healthcare professional was the gatekeeper to appropriate diagnosis and treatment (Hewitt-Taylor, 2004). This led to interactions with healthcare professionals sometimes being described in catastrophic terms: *Diagnosis was a nightmare. They didn't believe me. The health visitors just didn't believe me. I kept saying, 'He can't hear, he can't hear, he can't hear, he can't hear.'* They kept saying, *'You're comparing him to your eldest child and he was very developed.'* And I was thinking, *'I'm not.'* Honestly he really, really can't hear and then he failed his hearing test at 6 months (Jane, 6: 2-6). She used the anonymous 3<sup>rd</sup> person *they* to indicate that there was

more than one person who *didn't believe* her. She repeated *can't hear* four times to stress the quality of a nightmare such as when you can not get your voice heard. Marchbank (2011) recognised that healthcare professionals need to take mothers' concerns more seriously, particularly about a child's hearing and speech and language development. Jane's description had the nightmare quality in which somebody speaks but they have no voice. She felt that she was unheard and that her account of the situation was dismissed.

Wendy also related how she felt voiceless during repeated visits to her GP with her son, Peter, who was constantly being sick. She believed that there was something wrong as he had already failed his toddler hearing check at 16 months: *From a very young age I thought there was problems. He was constantly being sick, when I went and urm.. to my GP, he'd say, you know, 'Oh he'll grow out of it.' You know, 'All kids go through this.' You know. 'You're being... overemotional about this.' You know. 'Don't over-react about it.'* (Wendy, 2:5-8). The GP determined that the problem was with Wendy, she was *being... overemotional* and told *'Don't over-react about it'*. Her concerns went unheard and although, she had expertise in her child, the greater professional expertise of the GP prevailed, *'Oh he'll grow out of it.'* *'All kids go through this'*. As Peter was her first child she perceived that she lacked expertise in children overall, whereas her GP had greater knowledge about *All kids*.

### **Figure 6.2 Wendy's image The Angry Consultant**

**Redacted image copyright issue**

Wendy's persistence eventually led to an appointment with a paediatric ENT consultant (Figure 6.2. The Angry Consultant). She explained that the consultant was angry, not with her, but the GP: *He took one look at Peter's ears, and he actually said, he actually swore and he said, 'Why the f.. haven't I seen this child before?' and I said, 'Well actually I've been pushing, pushing and pushing to get him here and no one's taken me seriously.'* (Wendy, 3: 5-9). The GP had acted as a gatekeeper thereby preventing access to the consultant who believed that Peter should have been referred earlier. Wendy repeated *pushing* three times emphasising her repeated efforts to access the consultant. In the hierarchy of experts, Wendy felt that she was vindicated in her knowledge of Peter as the consultant had ratified her expert position, over the GP's diagnosis.

Another first time mum, Marian, discussed how she was unsure whether to follow her concerns. She used her image of the conflicting road signs (Figure 6.3.) to indicate her confusion: *Erm she, you know she starts getting coughs, she starts getting colds, but of course, you know you're told that's normal 'all babies and young children have 8 colds a year' and blah di blah, so you just go on and you go to the doctors and the GP and whatever and they're all very lovely, but you know you just deal with that issue at the time...* (Marion, 3: 18-21). Despite her GP's reassurance *that's normal*, to suggest that her experience was no different to others, and his use of the statistic: *'all babies and young children have 8 colds a year'*, Marion was unsure. She lacked personal knowledge of an alternative course of action, but she felt a lack of her regard for her expertise in her daughter.

**Figure 6.3 Marian's image Conflicting road signs**



Marian's trust in experts was further undermined as she continued her reflection of the conflicting and confusing road signs (Figure 6.3.). Glue Ear was one of the many diagnoses she received connected to Poppy's recurring chest infections and rhinitis. There was a lack of clarity about her daughter's diagnosis: *So this idea of these arrows so this umh so actually this picture's quite good because it's not suggesting any particular arrow is wrong or right, but there is that big question mark and that is us, that is my husband and I emerging from this going, 'This isn't making any sense.'* (Marion, 4: 26-29). Marian related that this confused cycle of not really understanding her daughter's illness continued for four to five years. There was a strong sense of ambiguity about her situation, *it's not suggesting any particular arrow is wrong or right*, but there was not a clear road to follow. The experts may not have listened to her, but the situation was further compounded as Poppy saw different consultants for her Glue Ear than for her respiratory health problems. From Marian's viewpoint the experts were not listening to her, but nor did they communicate with each other. For her the *big question mark* represented *my husband and I* recognising the confusion among the experts. They realised that the situation *isn't making any sense* to anyone and that there was not a specific expert on whom they could rely.

Similarly, Miranda experienced the conflicted nature of interacting with experts when she explored the meaning of her image of a young girl in pain (Figure 6.4.), who represented her daughter, Helen. In a previous encounter with her GP she had been labelled as a: *whittling parent* (Miranda, 1: 39) when she had pushed for support over a problem with her older son. However, she developed skills in working around the GPs to ensure that she gained appropriate treatment: *So I now know which doctor to pick, when I want medicine I go to that one, and when I just want a sympathetic ear I go to that one.* (Miranda, 1: 41, 2: 1-2). Miranda aligned herself with the Health Visitor who documented Helen's recurring ear infections: *it is noted in her red book by the Health Visitor* (Miranda, 1: 8). Her account of the situation through the eyes of a mother was supported by the authorised evidence written by an expert in the appropriate document, the *red*

book. Although Miranda might not have had her voice heard, she showed her competence in managing the situation.

**Figure 6.4 Miranda's image**    **Young girl in pain**



**Figure 6.5 Kate's image**



In a very similar image to that of Miranda, (Figure 6.5), of a young girl in pain, Kate, another mother, explained how her professional expertise as a children's nurse was not recognised by her GP. She detailed her daughter, Pippa's, recurring ear infections: *a cartoon character of a little girl who's got curly hair, with a sore ear and her face is very painful. And that's it, that's the nub of it. What I've got is a child, a daughter who is in pain and I can't do anything about that, I can't help. I can give her calpol and that helps but it doesn't take the pain away. It doesn't resolve the problem.* (Kate, 1: 4-8). Even though Kate had expertise in dealing with sick children, she was unable to provide an effective treatment for her *daughter who is in pain and I can't do anything*. She could not act, as she was reliant on the GP to write a prescription for an antibiotic to treat the infection. Her professional voice was diminished and silenced as her GP placed Kate in the inexperienced mother role. She had to follow the same procedure as everyone else: *I have to wait for doctor's appointments, in the doctor's waiting room, and doctor's appointments when I know what's wrong with my child, I know what I need for my child, I know what can make her better, but I have to go through a gatekeeper to get something called antibiotics which are something which are very innocuous. And it's very frustrating for me because the ability to help my child has been taken out of my hands, even though I know exactly the right things to do for her...* (Kate, 1:10-16). Despite her professional identity, she was silenced because *the ability to help my child has been taken out of my hands*. Ryan and

Runswick-Cole (2008) identified that mothers of disabled children often develop skills in supporting their child and negotiating with professionals in their child's best interests. These skills are different to the skills of other mothers but are not always respected or acknowledged by professionals.

The mothers in this research explored how the healthcare professions told them that what was happening with their child was *normal* even though they did not feel it was. Gunnarsson *et al.* (2013) explain interactions with healthcare professionals which were as equally problematic as for the mothers in this research. There was a similar narration about how the mothers tried to act as responsible parents by taking action, but felt disempowered by those experts with whom they came in contact. The mothers in this research felt justified in taking action, thereby exercising agency, when they achieved a diagnosis. For example, Wendy felt vindicated in her efforts by the response of the ENT consultant, as did Jane when the audiologist confirmed that Russell *can't hear*. The mothers felt their expertise in their own child was validated when other healthcare professions confirmed their assessments. They could then represent themselves as good mothers, thus refuting the *over-anxious* label which they had contested, and confirming their belief as having expertise in their child's health.

The initial lack of acknowledgment of their expertise in their children led the mothers' perception that not only did the healthcare professionals not listen to them but also reduced feelings of positive interactions. Finset (2012: 362) highlighted that when healthcare professionals respond actively to affective cues then patients feel a greater sense of agency, less emotional distress, more compliance with treatment and greater satisfaction with the consultation than when such hints are not picked up. The importance of acknowledging patients' expertise in their own health, or in this research their child's situation, was identified by Jagosh *et al.* (2011) as leading to better diagnosis, enhanced doctor-patient relationships and increased confidence in

their ability to cope with the health concern. The intention of the mothers in this research was to try to improve their child's health status; they became frustrated when that aim was thwarted.

Because of the chronic nature of the illness in their children, the mothers recounted the same experiences many times over a number of years, with repeated operations, under a general anaesthetic, to insert grommets and concern about the potential impact of antibiotics on their children's immune system. This provided them with expertise and knowledge about their child's response to the condition and how to provide optimum care for their child. However, the healthcare professionals with whom they interacted did not seem to either recognise or acknowledge this. The mothers had to reinforce their own expertise. Their situation was potentially exacerbated by not being in contact with others in similar circumstances with whom they could have shared their experience and expertise. The mothers in this research had children with the ongoing or chronic form of Glue Ear, but there did not appear to be any difference in the way in which the healthcare professionals interacted with them compared to those mothers whose children had the more usual temporary form. The longer the condition remains and the more episodes a child has then the more likelihood there will be long-term damage to the structure of the ear and permanent hearing loss in some cases (Bluestone and Klein, 2007) but the mothers in this research did not appear to have been given that information.

#### 6.2.1.2 Roundabouts and repetition

All of the mothers talked about the experience of repeated visits to the GP because of their children's recurring ear infections. For the most part, when they talked about repetitive experiences, it was in connection with healthcare professionals, which could be a result of the way in which the condition is constructed as primarily a medical condition. A familiar experience for the mothers in this research was regular attendance at the local doctor's surgery to get a prescription for antibiotics and attending hospital clinics every 6 months from early in their

child's life. For the mothers, the medical construction of the Glue Ear was reinforced as they kept going round a familiar cycle. They came to recognise the signs of ear infections, such as their child pulling their ears, tiredness and irritability (Goldberg and McCormack Richburg, 2004). This then began the recurring roundabout of a visit to the GP, a prescription for antibiotics and a child in pain until the ear infection cleared, probably followed by a period of 8-10 weeks of hearing loss (Gunasekera *et al.*, 2009). Interspersed within this were visits to the ENT clinic where their child had a hearing test and a short visit with the consultant. Meanwhile there was an expectation that because the condition was labelled as *temporary* it would resolve and their child would be left with no long-term repercussions.

The mothers' comments were almost interchangeable on some aspects of the condition and none more so than when they described the repeated prescriptions for antibiotics. Wendy, Jane and Miranda included images of bottles of antibiotics in their photomontages. Wendy explained the repetition of this experience, when exploring Figure 6.6, a picture of a bottle of amoxicillin: *But the amoxicillin, I mean God, he must have... literally he must have had hundreds of bottles of it, he was literally on it... I mean at one point after between his sets of grommets I think he was on amoxicillin every day for 18 months* (Wendy, 13: 13-15).

#### **Figure 6.6 Wendy's image Amoxicillin**



She confirmed her expertise in identifying the specific antibiotic, *amoxicillin*, which Peter was prescribed, rather than using a more generic term. She emphasised the frequency of Peter having to have antibiotics, probably three times a day, *every day for 18 months*. There was not only the

repetition of ensuring that Peter had the *amoxicillin* but that this would be for recurring ear infections, until he had a second operation to insert *grommets*. Wendy's explanation of her situation suggested a period of years when Peter was a young child, with repeated interactions with healthcare professionals who used medical terminology. Although she did not frame it as such, her experience met the criteria of a chronic illness (Mokkink *et al.*, 2008).

**Figure 6.7 Miranda's image Bottle of penicillin**



Miranda's repeated experience of the frequency of infections and prescriptions for antibiotics was clarified through the image of a bottle of penicillin (Figure 6.7): *I can't tell you how many times she had it, but it is noted in her red book by the Health Visitor so she must have been fairly young when she started getting it... so then we had the er various different forms of penicillin – banana, strawberry and all the rest of it.* (Miranda, 1: 7-10). The recurring experience of innumerable ear infections became blurred with such repetition that Miranda was unable to recall exactly *how many times* it happened. The only variety to the repetitive nature of the ear infections related to the *various different forms of penicillin – banana, strawberry.*

**Figure 6.8 Kate's image Wobbly clock**



The way in which the experiences were repeated so often that they become blurred and indistinguishable led to time being interpreted differently to its normal passage. Kate highlighted this cyclical nature of the mothers' experience of Glue Ear when exploring her image (Figure 6.8): *So this is a wobbly clock rather than a straightforward clock, because when she's in pain you need instant help to sort it out but you're always waiting there's nothing I can do about straightening the clock out, I can't.* (Kate, 1: 28-31). Every time Pippa had an ear infection, Kate wanted *instant help* but instead she appeared to see herself in an endless, repeated cycle of *waiting*, she was further exasperated because *there's nothing I can do*, so she was impotent to help her daughter. From previous experience she knew what she needed, but time slowed as she waited. Her knowledge and expertise about what Pippa required were useless because she could not resolve the situation without the assistance of the doctors. As a children's nurse, Kate understood the condition to be temporary. In the meantime she was caught in an alternative timeframe governed by repeated visits to her doctor. She was *waiting* on many levels: in the sense of physically sitting in the doctor's waiting room, for appointment letters to come through the letterbox and also for the condition in her daughter to resolve. The lack of progress over time was compounded as Pippa, who was 18 years old at the time of the research, still had recurring bouts of Glue Ear along with permanent damage to her ear drum and middle ear bones. Kate's frustration was summed up in the focus of her inability to act through her use of the 1<sup>st</sup> person singular pronoun *I*. She was stuck in a dimension of time but felt that she had no chance of success in *straightening the clock out, I can't*. Although she had knowledge, all she could do was sit and wait and worry because she had no control.

**Figure 6.9 Wendy's image A bucket**



Wendy had repeated experiences and lack of control, but was somewhat different to the other mothers. Peter was constantly sick. She used the image of a bucket, Figure 6.9, to explain the extent to which this experience dominated both Peter's early years and her perception of motherhood: *And.. and the thing was it was such a normal process for me, because everywhere we went he was sick, I cleared it up ... or he went somewhere else and he was sick and they cleared it up and I got an earful about it.... Ahmm ... it was very normal for me, and it wasn't until my daughter came along that I realised that it wasn't normal, this isn't what normal parents deal with.* (Wendy, 1: 45-49). Wendy highlighted that she had accepted Peter's sickness as being *normal for me*. She repeated *normal* but the meaning of the word changed for her. Initially it was *normal* in terms of being part of her everyday experience. However she came to realise that actually most mothers did not experience this as part of their routine so it was actually abnormal and it highlighted to her that such an experience set her apart, thus having a different maternal experience. She stressed the repetitive nature of the experience as it happened *everywhere*.

The mothers in this research were stuck in a repetitive cycle. Time was measured by Kate's wobbly clock so that there was a lack of clarity about its passing because one experience became blurred and overlaid by another. While they needed instant help to relieve their child's pain, they had to wait. Their children had recurring ear infections and the mothers adopted medical terminology and understanding such as which was the appropriate antibiotic for their child. Even though they developed their expertise, their knowledge did not provide them with answers. As suggested by Marian through her use of confusing road signs, it is as though they were stuck on a roundabout without a clear idea of the appropriate road to take. The mothers were in a time warp: waiting at the GP's surgery for antibiotics, in the ENT clinics for regular check ups, the outcome of which remained the same. Most of all they waited for their child's condition to fulfil the description of it being temporary which would spontaneously resolve leaving no long-lasting effects.

Despite the repeated ear infections and accompanying hearing loss, the mothers' construction of Glue Ear as a temporary condition was not addressed. Each recurring ear infection was perceived as a short-term set back. Neither the mothers nor the healthcare professionals repositioned the young people as having a chronic condition. They talked of hearing difficulties but not in terms of it being a 'disability' or 'impairment'. A consistency in the literature, across time, appears to be a desire by mothers to avoid such labels (Landsman, 2005; Voysey, 1975). It seemed more palatable to ignore the passing of time along with the repeated experiences rather than potentially reconstruct their child as having a longer-term impairment. As the professionals did not alter the way in which they talked about treatment options or discussed how long the young person would have the condition, they seemed to reinforce the mothers' perceptions.

#### 6.2.1.3 Diminished and dismissed

Increasingly in the last decade, government policies (DfE 2003) have promoted involving young people and their parents in partnership working arrangements with educational and healthcare professionals to achieve the best outcome for the child. The joint publication by the Department for Education and Skills and the Department of Health of the *National Service Framework for Children, Young People and Maternity Services: Core Standards* (2004: 9) highlights the goal of giving more information, choice and power to parents and young people over the 'support and treatment they receive, and involving them in planning their care and services'. This approach is reinforced in the Department for Education *Home-School Agreements: Guidance for local authorities and governing bodies* (2013) which suggests developing a common ethos with schools and parents sharing information so that the student achieves his/her full potential. The mothers in this research were well-educated and in professional roles so they were likely to have accessed such information and be willing to work with other professionals to achieve the best outcome for their child.

Whereas the mothers acknowledged respect for the professionals' expertise, they also wanted recognition of their proficiency in understanding their child's condition and to work in a collegiate way. However, as was identified in this sub-theme, the emotional outcome for the mothers was that they often felt personally diminished when the professionals retreated to exerting power or following procedures, with the information and expertise of the mothers being regarded as perhaps of less value. Additionally, the mothers explained that in some interactions, the professionals used dismissive body language tactics such as turning away from them.

Initially the mothers were prepared to acquiesce to the doctor's expertise. However, as Marian described, knowledge of her own child caused her to question the doctors' self-professed expertise: *And was told..... 'No we're **very** confident with our diagnosis.' ..... Because the logic wasn't stacking up for me in my layman's terms. And you come away and you think, well they're doctors so must be right (spoken quietly). But then that questioning in my mind, because hang on the logic isn't making sense to me.* (Marian, 2: 16-20). When Marian questioned the doctors' assessment of the situation, she was rapidly dismissed. As she stressed, they were *very confident*. She was not provided with the opportunity to discuss her concerns or the rationale for her judgement. Even though the questions remained in her head, she didn't challenge them further but described how she felt diminished because *they're doctors so must be right*. She accepted their message of superior knowledge, even though she did not appear to fully believe it because *the logic isn't making sense*. She was left feeling confused and questioned herself as to what she understood about her daughter's condition. Emotionally she seemed to be rebuffed by the authoritative account of the doctors.

Despite governmental policies the reality, from Marian's perspective, was different. The healthcare professionals had greater expertise. She then had to manage the tension between answering her own concerns while acknowledging that she did not have medical training, *in my layman's terms*, and balancing the need to ensure that Poppy's health did not suffer. Such

situations diminished her ability and efforts to work in partnership with the professionals. Gunnarsson *et al.* (2013) make the point that when mothers consult healthcare professionals, they want to trust what they are saying, however they also want recognition of their maternal concerns and wish their views to be taken into account. Marian and her husband were in the position of wanting to trust the doctors, but also feeling that they had valuable information to contribute.

Marian's bewilderment was summed up in her Figure 6.10, Dark Tunnel. She indicated how she was torn between her own concerns and the conflicting advice she was given by doctors. She explored her feelings of confusion as she interpreted her image of being in a dark tunnel: *you may not ask questions quick enough, you may not always have a reference point to go to, so in that sense either a lack of information or me not knowing what to push for, erm.... so just trudging on really, this idea of trudging on... in a line, but in the dark, alone. Because actually there's lots of things you're not aware of .....* (Marion, 1:37-41).

**Figure 6.10 Marion's image Dark tunnel**



Marion appeared to be emotionally weighed down by her concerns. The verb *trudging* indicated a slow, laborious pace. She emphasised her sense of confusion, *in the dark, alone*, to mean that she could not see things clearly because of the darkness which led her to have a sense of isolation. She was *alone*. She appeared to feel both overwhelmed, and to some extent trapped. As she explained: *about being in the dark, being in a tunnel that didn't seem to have a light at the*

*end of it* (Marion, 1:19-20). The tunnel was not only dark, but lacked a *light at the end*. This was indicative of feelings of hopelessness; that she lacked direction or a clear endpoint to aim for. Having no *reference point to go to* emphasised the loneliness that the mothers in this research felt. They had no access to the resources of a support group or network of other mothers from whom they could ask for help or draw support.

Similarly, Kate used the image of a young girl waiting (Figure 6.11) to suggest that she felt reduced in stature: *So what I have is a lot of waiting. Waiting on my own and feeling like a child waiting on my own. Because although I'm the adult in this relationship and I have a child, I can't do anything. I have to wait* (Kate, 1.8-10). The use of the analogy of *feeling like a child* emphasised Kate's sense of impotence. Despite her knowledge, both professionally and personally, it was as though that had been dismissed and she had to follow the doctor's procedures, just like others who did not share her qualifications. The image of the child indicated her reduced status with adults in control.

**Figure 6.11 Kate's image Young girl waiting (Reconstructed)**



She reconstructed and reviewed her experience and feelings as she talked with me: *they still didn't listen to me. But you know I was the Expert, and there isn't a picture of an expert I should have that because I am an Expert ABOUT MY CHILD, not necessarily about Glue Ear or anything, but about MY child* (Kate, 2: 10-13). She emphasised her specific area of expertise in

knowing her child, by stressing the 1<sup>st</sup> person possessive pronoun, *MY* twice within the same sentence and using the 1<sup>st</sup> person pronoun *I* to demonstrate ownership of her knowledge and expertise. However, she identified that, the anonymous 3<sup>rd</sup> person plural, *they*, dismissed her. *They still didn't listen to me* with the emphasis on *still* emphasising the continuing situation.

The mothers in this research seem to want additional powers in the treatment of their child Gunnarsson *et al.* (2013). This accords with increasing moves to encourage greater patient participation in decision-making (Finset, 2012). However, Hewitt-Taylor (2004) makes the point that often healthcare professionals see themselves as the experts in specific conditions and it is they who have traditionally made decisions about whether or not to share this information. Without the co-operation of healthcare professionals in sharing decision-making, nothing is likely to change.

Jane described a brief interchange with an ENT consultant, in which he appeared to be listening to her preferences: *He said, 'Well we have some ongoing problems, so I think it's some more grommets.'* *And I went, 'Not keen because they keep going and he's had T-tubes as well and he's pushed those out, so....'* *He said, 'the other option's a hearing aid, so we'll go for that. That sounds like a better option for you, so go get in the queue.'* *And we'd gone.* (Jane, 5: 18-21).

Although there was not a great deal of discussion between Jane and the consultant, he did accept her wishes regarding Russell's treatment. However he remained in control. The interchange lasted for about two minutes in Jane's view, thus emphasising her perception of how brief the consultation had been through her description, *And we'd gone.* Jane's impression was of not being in control. She did not leave the room, it was almost as though the room had left her. The consultant did not appear to want to extend the discussion or ask if Jane, or Russell, had any questions about the option of a hearing aid. She had been processed so the consultant could move on to the next patient.

Kenney *et al.* (2010) highlighted that in many cases medical professionals have a different understanding of their communication style to that of their patients. Although he used the 1<sup>st</sup> person plural *we* to identify the problem, his use of the first person singular *I* indicated he had made the decision. Jane was dismissed and told to *go get in the queue*. The omission of any pronoun made it sound like a command. There was no discussion about the benefits of the alternative treatment option or what it would entail. While the consultant may have described himself as responding to the patient's needs, Jane perceived that she was not involved in the decision but given an instruction. Russell and she were not treated as individuals but as though they were one of many interchangeable mother-child pairs with Glue Ear. Jane and Russell were dismissed from his view and no account seemed to have been taken of any emotional needs they may have had.

From her experience of watching Stewie have repeated audiology tests, Lois had developed elements of expertise to be able to identify when something was different: *We'd been through to audiology first, and audiology had done the hearing test, and I've seen that many now that I know when something was wrong, so I knew that something was wrong on this test so we went through to the other side and the consultant said, 'What do you want?' So I just said, 'Is there anything wrong with his ears?' 'No, nothing at all.' .... OK, so ..... I was getting upset by that point 'cos I thought, 'I'm not stupid.'I've seen that many now that I know when something was wrong*. However, the consultant dismissed her concerns so she became upset. Potentially she felt diminished but affirmed her self-image but only through thinking: *I'm not stupid*.

Lois did not feel her emotions were acknowledged and, for her, the consultant's dismissive attitude was demonstrated when: *He wouldn't speak to me anymore this consultant, and he gave me this prescription and basically turned his back and started going on the computer.* (Lois, 3: 3-5). For Lois, the consultant terminated the visit when he *started going on the computer*.

Although she had further questions he had already moved on. There are strong parallels between Lois's and Jane's experience, but with different consultants in separate locations. It was as though the mothers were being processed, similar to products in a factory production line. Whereas the Department of Health (2004) expresses policies about individual patient needs being at the core of the NHS and listening to mothers and young people, this practice was not experienced by the mothers in this research. There was no mention that the young people were involved in the consultation. The description did not reflect the model suggested by Howells and Lopez (2008) of a slower pace to the consultation to better accommodate the needs of young people. This is particularly relevant when the young person has a hearing impairment so likely to need more time to process information.

The mothers in this research recognised the potential impact on communication of the busy hospital environment. Kenny *et al.* (2010) highlighted that professionals may not be aware of how the way they speak and behave is interpreted by patients. Professionals need to engender trust and confidence in parents that their child is getting the best support, but they may not always acknowledge parental expertise in their child. Boudreau *et al.* (2007) explore the impact on patient relationships when healthcare professionals base their interaction on a model of diagnosis and treatment. The mothers in this research wanted recognition that they had developed their expertise through experiencing the extreme form of the condition in their child (Capewell, 2014e). This led to them feeling that they were devalued by the attitude of the healthcare professionals.

A similar situation occurred when the mothers tried to talk to teachers to minimise any difficulties that their children may experience in the classroom. This was not always successful (Ralph and Capewell, 2014). At the start of the year, Jane had followed her usual practice of visiting the teacher to tell him about Russell's hearing problems. However, she felt rebuffed: *I always go and see the class teacher the first week that they're back because it's a new teacher*

*and there's never any handover. So I say let me talk to you about Russell's ears* (Jane, 1: 27-29). Her practice accords with the advice in the Department for Education *Home-School Agreements: Guidance for local authorities and governing bodies* (2013) that parents should share relevant information with teachers about issues which might impact on their child's learning or development. Jane was aware that Russell's school did not always pass on information about his hearing difficulties to his new teacher, *there's never any handover*. However, from her perspective, this teacher was not receptive to her attempts at collaboration: *But he said, 'No, No, No, I know all about glue ear.'* (Jane, 1: 31-32). Jane interpreted his repetition of *No*, as being dismissed in her attempts to work together with him.

**Figure 6.12 Jane's image Strict school teacher (Reconstructed)**



Jane became very frustrated in her thwarted attempts to develop a partnership approach. As the school year continued the relationship with Russell's teacher proved to be very problematic. This was illustrated both by the image she chose for the teacher, Figure 6.12, Strict school teacher, and how she explained their relationship by May: *but he's been keeping him in because he takes so long to do the work, longer to do the work, and it will take him longer to do the tasks. He was doing that before Easter – at break time and play time and then we got the report in 'So yeah, I'll give him more time, he should have more time.'* *But he's still keeping him at lunchtime to do it. Well that feels like a punishment, there should be, they should find some other way of.... Grr eeh. Yeah he's just a PILLOCK.* (Jane, 1: 44-49). Jane was clearly frustrated. Russell had recently been identified as being Dyslexic, which had been done through the school. He had

always been slower than his classmates to complete tasks, which is a feature of young people with long-term Glue Ear (Schuchardt *et al.*, 2013). Jane felt dismissed by the teacher who was clearly not following through on what they had agreed. Russell's needs were not being taken into account, despite Jane's best efforts.

Caz's experiences followed the same pattern in her interaction with Daisy's secondary school. She had informed them of Daisy's needs and did not want to be critical of the school, but, the teachers were not taking action: *school are all right I mean .... They didn't insist on things, like her.... She needs to sit at the front and she needs to sit in the middle, for both conditions really, so there's no sort of sound coming in and there's no sideways distractions coming in and she can hear what's being said and that there's no other noises in between her and the teacher. And that wasn't happening. Daisy says that's not necessary 'cos she'd rather sit at the back but it wasn't happening. But they are good and if I just put in, just point out to them that that's what she needs to do then they're fine. It would have helped if one person had made sure that all teachers were aware* (Caz, 3: 12-21). Caz had informed the school of the optimum place for Daisy to sit, but *they didn't insist on things*. Caz was a nurse and had a good understanding of how Daisy's hearing was impacted, and that she needed *no sideways distractions coming in and she can hear what's being said and that there's no other noises in between her and the teacher*. Although Caz did not state it directly, there was a suggestion that she had pointed out Daisy's needs more than once, *if I just put in, just point out to them*. However it seemed that there was a lack of consistency in following up on the information that she had provided. Mukherjee *et al.* (2002) identified that parents are often the communication channel across the boundaries of NHS, school and home. Caz's medical background meant that she was better placed than most parents to fulfil this role, but she appeared unable to achieve the optimum support for Daisy.

Some children with Glue Ear can vomit without having a gastric infection (Venekamp *et al.*, 2013; Weick and Kane, 2003). Marian described negotiating around school policies: *And the*

*school to be fair used to send her home and I had to go up and explain that if she was ... actually had no symptoms before or any sickness and no symptoms after of any sickness then she wasn't ill.* (Marian, 12: 25-27). Other mothers were not always so successful in communicating the side-effects of the condition. Both Miranda and Wendy explained that they were less successful in attempting to persuade their children's schools that the sickness was part of the condition. They were dismissed as the school policy had to prevail and they would comply even though it may not be appropriate.

Even though parents may want to work in partnership and share their experiences, some schools were not always willing to take advice from parents. As Lois related: *I keep saying to her, 'Do you want me to send information in about glue ear and tinnitus again?' 'Cos I keep giving it to her all the time but she says, 'No I've still got it.'* (Lois, 3: 15-17). This was not a one-off attempt as Lois *keeps saying* that she had knowledge and information which she was willing to share. The Head Teacher's response of *No I've still got it*, left Lois feeling diminished as there was a suggestion that it perhaps had not been read. Lois might be an expert in Stewie's condition but the Head Teacher was in control of the school.

Crozier (2000) explores how misunderstandings can develop between parents wanting to provide information about their children which teachers can sometime see as an attempt to gain additional resources for their child. There is also an issue of power in that parents can be perceived as encroaching into the educational professional's area of expertise. Cole (2007) suggests that generally educational professionals do not see parents as partners, despite what policy documents might promote. Instead, the power relationship is such that when parents fulfil the role and function that educationalists wish them to, then they are 'supporters' and when they do not they are 'problems' (Cole, 2007: 166). The mothers in this research preferred to be perceived as 'supporters' but still wanted to ensure their child received appropriate support. Just

as they did with the healthcare professionals, the mothers had to balance achieving support and understanding of their children's condition against alienating the teachers.

As the condition is primarily perceived in medical terms and labelled as temporary, common and without long-term consequences, the mothers in this research had children who were therefore not regarded as having a special need. This sometimes resulted in the mother being perceived as the problem or the young person was misdiagnosed with other conditions such as ADHD (Capewell 2014b). Despite the prevalence of support groups and availability of counselling, Glue Ear remains outside such assistance which could lead people to think that the condition is probably quite trivial.

Because the hearing loss associated with the condition is intermittent, in the school environment, there could be a misconception that there is not a problem with hearing but behaviour. Teachers could potentially consider that the mother is being over-anxious, fussing or not encouraging appropriate social skills in their child. Jackson (2013) suggests that the complexity of living with a chronic condition is not always understood by teachers so there is often a lack of communication between teacher, parent and student about the requirements for a specific child.

When interacting with teachers, the mothers in this research seemed to be aware of not appearing to want all the resources focused on their child to the detriment of other children and to promote good parent-teacher relationships (Landeros, 2011). However, they did want teachers to demonstrate awareness of the implications of the condition for their child and to make minor adjustments in the classroom for them. They highlighted the need for co-ordinated communication between teachers within the school.

Despite the messages about working in partnership with both healthcare and educational professionals through patient participation initiatives and home-school agreements, the

experience of the mothers in this research suggest that power was retained by the professionals. This led to frustration and anxiety in the mothers as to how to best support their child, with accompanying feelings of being dismissed and diminished. Ryan and Runswick-Cole (2008) explore how mothers of children with disabilities have to negotiate and advocate on behalf of their child, which potentially comes at an emotional cost to the mothers. This position seemed to be reflected by the mothers in this research. They appeared to perceive themselves as having a child with a temporary problem with their hearing, which, when it was present, required adjustments. The professionals with whom they interacted did not appear to always value the knowledge and expertise they had in their own child. They also lacked any ongoing formal support or information about how to manage the condition in the long term.

#### 6.2.2 Motherhood, but not as I imagined it

For the mothers in this research their experience is in contrast with the images of motherhood as portrayed in baby books (Hays, 1996; Marshall, 1991). Those manuals set the expectation of having a perfect baby with motherhood constructed as providing joy and fulfilment for women. There is very little information for expectant mothers to suggest that anything can go wrong, with an emphasis on allaying any fears (Landsman, 2005). The temporary and medical labels which are central features to the construction of Glue Ear added further complexity for the mothers in this research. For all intents and purposes they had a 'normal' child who happened to have a common but ongoing ear condition. The healthcare professionals with whom they interacted did not differentiate the way in which they treated their child to any other child with the condition. For the mothers in this research their experience of Glue Ear was years, not months. I am not aware of any other research in which mothers have explored the long-term emotional impact of having a child with the ongoing condition has on them or how they interpreted their mothering skills.

### 6.2.2.1 He sat on my lap

Bach (2014) highlighted that middle-class mothers are expected to produce children with good social skills. If they do not then they are unsuccessful or poor mothers as judged by themselves and others around them. With the exception of Caz and Kate, the mothers in this research explored the ways in which, from an early age, they tried to socialise their children and provided them with opportunities to mix with other children. Their children, however, did not appear to respond as expected.

Wendy's exploration of her image of a young boy on his mother's lap (Figure 6.13) resonated with comments of other mothers: *Whenever, whenever we went to a party, he was always on my lap. Whenever we went to Tumble Tots or anything, those socialisation kind of things... he was always on my lap, he didn't want to engage, he didn't want to take part.... He wanted to be there. I'd say, 'Do you want to go?' He'd say, 'Yes.'* *But when we got there, he'd sit on my lap* (Wendy, 1: 23-27). She emphasised that Peter *was always on my lap*. She appeared to have concerns about his lack of engagement, which she could consider may reflect on her effectiveness as a parent. However, Bortoli and Brown (2008) indicated that children develop the ability to interact with one child while monitoring the activity of other children around them. Peter's hearing loss may have caused him difficulty in developing such skills, so perhaps finding it easier to look on at other children. Silva *et al.* (1982) found that children with recurring Glue Ear are more likely to be clingy and fearful than those children without the condition. Peter appeared to follow that pattern. If such information is not available to mothers, then they can interpret their child's behaviour as either a failing within themselves or their child.

**Figure 6.13 Wendy's image Young boy on Mother's lap (Reconstructed)**



Wendy's frustration was evident: *I'm a very social person I've always felt that social activities were very... umm very important for them. They were heavily socialised, so I could have just sat at home with a bucket of toys, instead I was out every day at another playgroup, another pre-school event, another Tumble Tots, another whatever.* (Wendy, 2: 27-30). She was trying to fulfil the cultural mores of being a 'good' mother, as she highlighted her belief that *social activities were very... umm very important* and that to accomplish this she made sure that her children were *heavily socialised*. To achieve the appropriate level of socialisation she went out *every day* to a variety of activities.

Hayes (1996:54) conducted a sociological analysis of best selling childrearing manuals, from which she distilled the features that mothers need to demonstrate: 'childcare is primarily the responsibility of the individual mother; appropriate development is achieved through child-centred methods which are expert-guided, emotionally absorbing, labour intensive and financially expensive.' Wendy was striving to meet these requirements of the good mother by ensuring that her children were well socialised. There was an element that she was putting her children's needs before her own as she used the conditional tense *could have* to suggest that there were alternatives to her attendance at a variety of groups, which may well have proved financially costly. In another section of her participant-led discussion, she referred to Peter's frequent sickness. As he was regularly sent home from pre-schools, she was required to look after him. This took precedence over her own emotional needs: *any notion I had of wanting*

*to go back to work or into education ... had to constantly get canned because I knew... that we wouldn't go a week without him being off school for one or two days.* (Wendy, 3: 38-41).

Although child-rearing is supposed to be self-fulfilling in itself and mothers should put their child's needs before their own, the emotional cost of mothers is often not understood. Wendy's disappointment perhaps came from her plan of Peter going to pre-school while she returned to study or work *constantly got canned* because they did not *go a week without him being off school for one or two days*.

**Figure 6.14 Jane's image Toddler music group (Reconstructed)**



Jane (Figure 6.14) related a similar situation with Russell whose behaviour did not result in Jane's feelings being 'emotionally absorbing' (Hayes, 1996:54). In contrast she explained: *Poor soul I used to drag him along to all these groups like Jo Jingles and group singing, mother and toddler and like he used to spend the whole time with his hands over his ears* (Jane, 3:18-19). Jane's commitment to socialising Russell meant that she would *drag him along*. Again the literature potentially provides an explanation for why he would *spend the whole time with his hands over his ears*. Sensitivity to noise, hyperacusis, has been linked to a history of Glue Ear (Coelho and Sanchez, 2004) and its effects on the brain have been demonstrated in research on animals (Sun *et al.*, 2011). It could be that the noise made by the other children and the musical instruments could have been overwhelming for Russell. The responses of the mothers in this research indicated that they were unaware of this common response to noise for children with a history of Glue Ear. As the healthcare professionals' focus is on the medical aspects of the

condition it is unlikely they would share such behavioural characteristics, even if they knew them. The lack of support groups for Glue Ear left these mothers isolated from others in a similar situation to theirs. Therefore, this could result in them feeling that either that they were doing something 'wrong' or that there was a problem in their child.

Other mothers had comparable situations regarding socialising their child. Lois explored how Stewie had difficulties when playing with other boys, particularly when rough and tumble play was involved. She had a dilemma as to whether or not to disclose Stewie's hearing problems: *I don't sort of shout it from the roof tops*; and Miriam explained how Helen *doesn't understand the politics of girls* so found it easier to be friends with boys. They did not appear to have resolved whether their child's social skills difficulties were a result of their actions or something within their child. Kate was the exception as she did not explore Pippa's social skills. Pippa had two siblings which may account for the differences or it could be that Kate chose not to disclose any differences as she kept her focus on the medical treatment and was keen to identify Glue Ear as a mild condition, in keeping with its medical construction.

Lupton's (2011) study of 60 mothers in Sydney, Australia, identified the mothers' beliefs in the importance of child development for both their child and themselves. She highlighted that this can become a very competitive situation, leading them to make social comparisons between their own child and those of others. The mothers from more socially advantaged backgrounds, in particular, were keen for their children to reach developmental milestones at the appropriate age, or even better, younger. It was likely that Wendy was aware that Peter's disinclination to join in with the other children would not go unnoticed by the other mothers in her circle. She mentioned in the discussion that she remained in regular contact with a number of the mothers with whom she had attended National Childbirth Trust classes until Peter was in school. Ridgeway's (2006) Status Construction Theory explores how different social groups, in this situation mothers, place themselves in a hierarchy according to their achievements in relation to others. It could be that

those mothers, such as Wendy, whose children do not accomplish the group norms of developmental milestones are placed in a lesser position in relation to others, as the construction would be that they are less successful mothers.

Ryan and Runswick-Cole (2008) propose that mothers of children with disabilities negotiate their self-perceptions in a situation in which, although they are not disabled, by virtue of association with their child's condition, they are perceived as having a disability. Mothers of children with ongoing Glue Ear face a situation whereby their children are neither disabled nor non-disabled. The construction of their child's condition as temporary and intermittent meant that the mother's identity lacked clarity. They may not have wanted to draw attention to their child's 'difference' because of a belief that the condition would resolve but simultaneously they were aware of the difficulties that their child had in negotiating a world in which they had a degree of hearing impairment.

#### 6.2.2.2 Lonely and alone in my own family

The mothers in this study referred to their emotional well-being which is not well documented in the literature about the condition. They discussed their feelings of loneliness and a sense of isolation as they tried to negotiate the burden of having a child with long-term Glue Ear. Their children were often in pain because of recurring ear infections and showed frustration at not being able to hear clearly or always interact appropriately with other children. None of the mothers in this research said that they knew anyone else whose child had the same condition to whom they could turn to for support. Perhaps because the condition is constructed as non-life-threatening and common, they hesitated to express their worries but this resulted in feelings of loneliness and emotional upset.

**Figure 6.15 Marion's image Swirl of emotions**



Marion used an image of a swirl of emotions (Figure 6.15) to depict her conflicting feelings. She felt under pressure to appear positive and not express any negative thoughts: *in my head it was quite a lonely time. Because although I have a husband and I have family, but whether ... I felt.... In my emotion I felt quite ... at times I felt, you know, is it **my** fault, at times I couldn't really express that, partly because it isn't really positive or helpful.* (Marion, 1: 32-35). She reflected the turmoil in the image, as her loneliness was *in my head*. She struggled to express her emotion, repeating *... I felt...* three times and pausing. This was in contrast to her otherwise fluent style of delivery. Other people were physically around her *I have a husband and I have family*, but there were some thoughts she felt unable to share. She wondered *is it **my** fault*, emphasising ***my***. This suggested the 'mother-guilt' of feeling responsible for perhaps not having done the right thing during pregnancy or perhaps in Poppy's early months (Landsman, 2005). She emphasised keeping her fears to herself as they weren't *really positive or helpful*. Perhaps not being able to express her concerns, left her feeling isolated.

Marion's emotions dominated her, as she represented in the image: *this emotion, this whirlwind of emotion, this maelstrom ... this was to signify that it was very emotional, very erratic. This is to signify that it was very erratic, quite chaotic at times, in terms of my emotions* (Marion, 1:45-47). She did not appear to be in control of her feelings. They were a *whirlwind* and a *maelstrom*. The visual image and the words Marion used are suggestive of an emotional hurricane, very

*erratic, quite chaotic*. She was dealing with a lack of clarity or understanding both about Poppy's condition and how she was experiencing it emotionally.

**Figure 6.16 Lois's image Crying woman (Reconstructed)**



Lois reiterated this sense of being overwhelmed by her feelings when she explained the meaning of Figure 6.16, Crying woman. The emotional impact, of not being able to improve things for her son and not fully understanding his condition, resulted in distress and confusion in Lois: *There's nothing I can do about it. So I just sit and cry some nights*. (Lois, 6: 41-42). She underlined her sense of helplessness as there was *nothing* that she could do. In the same way as Marion, Lois felt she was alone. There did not appear to be anyone in whom she could confide and share her concerns. She was most upset when Stewie became *fed up with it so much and he'll say, 'Chop me ears off', he says that sometimes, erm it, it's sad that really isn't it... really sad, suppose that that's the thing for me... that sometimes .... he seems quite sad ..... and that really upsets me*. (Lois, 12: 16-19). Because Stewie *seems quite sad* and Lois was powerless to improve his situation, it resulted in her feeling distressed and impotent. The mothers in this study have children who have a chronic illness which is not described as such. Because Glue Ear is seen as temporary, emotionally the mothers lacked clarity about their role and other people did not perhaps perceive them as needing any additional support to other mothers with children of a similar age.

Hullman *et al.* (2010) suggest that parents of children with diseases such as asthma and diabetes have higher rates of stress than those of children with cancer. They speculated that this may be

due to the chronic and unpredictable nature of the conditions. This situation could equally apply to mothers of young people with ongoing Glue Ear who have the added difficulty that the condition is not perceived as serious. Currently, available information for parents of young people with the condition is primarily medical with the emotional needs of parents seemingly overlooked. Lederberg and Golbach (2002) reported that the emotional well-being and self-esteem of mothers of children with hearing impairment is to some extent dependent upon their perceived level of social support. It seems that mothers of children with chronic Glue Ear could well benefit from access to others in a similar situation and for more account to be taken of their emotional well-being and need for greater social support.

### 6.2.3 It's not a proper special need

This theme is explored in Chapter Eight as it is constructed within the context of how educational professionals interpret the condition.

## 6.3 Conclusions

Understanding the impact Glue Ear has in day-to-day life is generally lacking in previous research. The mothers in this research explained the impact the condition had on them. Creating a photomontage, based on Photovoice principles, provided them with time to reflect. In IPA the analysis is interpretative on the part of the researcher so I have considered some of the emotional turmoil which the mothers described in relation to how the mothers in this research could construct themselves as mothers.

Despite all the rhetoric about parents working collaboratively with healthcare and educational professionals, the mothers in this research seemed to believe that, for the most part, their views and expertise were sub-ordinate to those of the professionals. They emphasised their expertise in

how the condition manifested itself in their child. However, they appeared to be constrained by their recognition that healthcare professionals, in particular, controlled access to resources required by their child to alleviate pain and reduce the likelihood of ongoing hearing loss. Healthcare and educational contexts had processes and procedures which tended to restrict the mothers' ability to act. The cultural context for these mothers was that if they directly challenged the expertise of the professionals with whom they interacted then they could be seen as a 'bad' parent who lacked 'support' for the professionals.

Glue Ear is perceived as being a common, temporary, medical condition which is not life-threatening. For the mothers in this research, the difficulty was that their child effectively had a chronic condition which, for most of them, appeared to have long-term consequences. The professionals did not treat their child any differently to those children with the less complicated form of the condition. For these mothers Glue Ear was not a trivial condition. No one talked of it in terms of being a chronic illness even though the way it manifested itself in the young people in this study met the criteria (Mokkink *et al.*, 2008). The impact for these mothers of such contextualisation resulted in feelings of confusion regarding their place in the hierarchy of motherhood. Their children were not 'normal' because they had ongoing health problems which required regular medical intervention. However, the messages they received were that the condition would resolve itself and there would be no long-term health or educational consequences. Perhaps interpreting the condition as finite in their child, meant that they did not construct themselves as having children with a disability or impairment. They did not describe their children as 'deaf'.

The condition was described using medical terminology which left the mothers confused about any problematic behaviours displayed by their children. They interpreted these as residing within the individual child. The mothers in this study were well-educated, middle-class, white British women who appeared to attribute a key part of their identity to their role as a mother.

Subscribing to this view had responsibilities such as ensuring that their child demonstrated good social skills and was a productive member of society. Such a view of motherhood was also competitive including making comparisons between their child's behaviour with that of other children. The result of such comparisons provided the mothers with a position in their social circle hierarchy. There was a sub-text that if their child did not demonstrate appropriate levels of social competence then the problem resided in them, as the mother.

The mothers in this research shared the emotional impact that being the parent of a child with the long-term form of the condition had on them. Most of them expressed a strong sense of isolation. There are no support groups for people affected by the condition. They are separated from other mothers whose child has chronic Glue Ear with whom they could perhaps share concerns and glean information. The official channels do not help them make sense of the condition. Glue Ear has a Cinderella status. Although it may be the root cause of problems for young people, it is neither discussed nor constructed as a special need. In some cases this has resulted in the mothers either looking for a label to enable their children's additional needs to be supported or not voicing their concerns that their child may have a condition such as autism. The implications of these findings are explored and discussed in more detail in Chapter Nine. How the young people interpreted their experience of living with long-term Glue Ear is explored in the next chapter.

## Chapter 7

### Living with long-term Glue Ear: Listening to what the young people have to say

#### 7.1 Introduction

One of my research questions was: What is it like to live with ongoing Glue Ear as a young person? This chapter explores the perspective offered by the young people in this research. An analysis of the words from the participant-led discussions of Daisy, Russell and Stewie, the young people who participated in this research, highlighted some of the issues which were important to them. Previous research has omitted the voices of young people. Listening to their perspective can help to expand knowledge about how ongoing Glue Ear effects young people's social interactions, education and medical wellbeing as well as its potential emotional impact. Daisy, Russell and Stewie's comments provide valuable insight, from their point of view, into potential improvements to educational and healthcare practices and how, in future, young people with the long-term condition could be better supported.

The context for this research is based on the principles of consulting young people about their health care and educational requirements as enshrined in the United Nations Convention of the Rights of the Child (1989), Section 12. This provides the right for the child to express his/her views about matters relevant to him/her. The issue is not about whether young people should be included in research, but how this can be done effectively.

In the healthcare situation, the policy regarding consultation of young people is clearly stated in the Department of Health (2003, p. 9): 'They should be encouraged to be active partners in decisions about their health and care and, where possible, be able to exercise choice.' The aspiration appears to be that young people will be consulted and informed about the specifics of their treatment and be given options. However this seems to rarely happen in practice. Alderson (2007) identifies that the legal position regarding healthcare treatment in the UK, and in other

countries in the world, includes the concept of the ‘competent child’ (DfE 2003). The philosophy is that children should be provided with appropriate information about their treatment and involved in decision-making. The young people in this research appeared to have had a passive role in establishing their needs, despite their obvious capacity to effectively contribute. Daisy, Stewie and Russell had opinions about their healthcare but appeared to have been omitted from the consultation process by both healthcare professionals and their mothers.

There has been increasing recognition since the implementation of the UN Convention on the Rights of the Child (1989) that young people should be involved in the decision-making about the support they need in schools (Shevlin and Rose, 2008); but this may not always happen. In the educational context McPhillips *et al.* (2012) demonstrate that young people have the competence and confidence to reflect on their own needs and identify appropriate support to enhance their learning. Young people with Glue Ear may not have had their views listened to in the educational context as the condition is not constructed as a special need. However, the literature and the comments from their mothers and the young people in this study suggest that adaptations and adjustments in the classroom would be of benefit to them. Those young people who have repeated ear infections and accompanying hearing loss associated with the condition are most at risk of developing language processing difficulties, such as slower processing speed related to difficulties with working memory capacity and the ability to understand complex sentences (Capewell, 2014c). This may mean that they may require some minor adjustments in the classroom environment if they are to achieve their full potential (Capewell, 2014a). The results of this research clearly demonstrated that young people have insightful comments to make, if professionals provide them with the opportunity to express their views and make the time to listen to them.

Even though young people may be willing to participate in consultation with professionals and researchers, they may not either have the opportunities or encouragement to do so. The issues

around this are briefly explored in this chapter, particularly when parents act as gatekeepers. They may consider that participation would not be in the best interests of their child and that their innocence needs protecting (Lowe, 2012).

### 7.1.1 Parents as Gatekeepers

In this research, access to the young people was through their parents. When talking about the research with the mothers, I explained that I would like to involve their son/daughter. In four cases the parents agreed that this would be acceptable, however, one felt that her child may feel uncomfortable talking to me. In another instance the young person agreed to take part, but then did not produce a photomontage or respond to further communications. Three of the mothers said that they would ask their child about being involved, but despite reminders, this did not happen. Those mothers chose to meet me at a neutral location away from their home. In future research I would be more aware of this issue and try to develop strategies for overcoming parents' potential barriers to permitting their children to participate.

Murray (2011) in her critical review of gaining access to young children explained that adults have control over whether or not their children can become involved, with the final decision remaining in parental hands. Research evidence suggests (Savage and McCarron 2009; Rodriguez *et al.*, 2006) that some parents are likely to not even discuss the research with their child, preferring to make the decision for them. For some parents this view is likely to have resulted from a desire to protect their child from a potentially upsetting experience (Lowe, 2012). Some of the parents in this research perceived their experience of parenting a child with long-term Glue Ear as upsetting so may have projected those feelings onto their child thus wishing to avoid their child feeling upset.

Prout (2005) identified that the slow rate of physical development of children and dependency on their parents is sometimes equated with an equal lack of emotional and psychological maturity. This approach sees children as 'human becomings' and not capable of making their own decisions or providing insight into their experience. The mothers in this study could have adopted this view as their children had a physical condition which required them to provide more support than mothers of similarly aged children. The recurring ear infections and hospital visits may have led the mothers to see their children as more vulnerable so needing extra protection.

However, in some cases dealing with an ongoing health condition can lead to an increase in maturity and insight into a child's circumstances (Alderson 2007). She further explains that for those parents of children with ongoing health issues, the parent does not want to relinquish control over the decision-making process to the child. It could be that the mothers in this research felt that it was their responsibility to make decisions for their children, such as whether the child should have grommet surgery or a hearing aid. Both those decisions may lead to the child being upset and it could be that avoiding involvement in this research was an extension of that thinking.

Savage and McCarron (2009) suggest that making direct contact face-to-face with young people may be the most effective way to recruit participants, however there remains the legal position whereby parents must be the first point of contact. While the need to protect young people must remain a key concern, their rights to express their views and be involved also needs consideration (Murray, 2011). In this research the young people provided valuable insight as to what it is like to live with long-term Glue Ear. This suggests that continued efforts need to be made to involve more young people as well as recognise their need for protection, including acknowledgement of the parents' legal responsibilities.

## 7.2 Discussion of the Super-Ordinate Themes

To my knowledge, this research is the first in which young people with long term experience of the condition have themselves described their emotional responses, rather than their answers being filtered by a parent, or limited to topics chosen by researchers. Previous research has mostly focused on improvements to young people's ability to hear more effectively after grommet surgery, measured through questionnaires completed by parental proxies (Dube *et al.*, 2011; Timmerman *et al.*, 2007). Those results are based on the perceptions and interpretations of adults, usually mothers. This research provided young people with the opportunity to explore and express their feelings about the impact the condition had on them from day-to-day. They highlighted the actions that they, and others, could take to minimise the affects of the condition. Additionally they identified situations when they would have benefited from others having greater understanding of the condition and they way in which it impacted them. Two super-ordinate themes, 'Never Mind' and 'Stuck', were identified as summarising their issues.

**Table 7.1 Young People's Themes**

<b>1. 'Never Mind'</b>		
1.1. 'The Stress'	1.2. 'The Gap'	1.3. 'The Fear'
<b>2. Stuck</b>		
2.1. Sidelined	2.2. In between	

Table 7.1, Young People's Themes, provides an overview of the two super-ordinate themes and their accompanying sub-themes identified from the analysis. The first super-ordinate theme concerned emotional issues, regarding how the three young people tried to make sense of their own emotions in response to both the situations they faced and their treatment by others; adults and young people. The 'Never Mind' label for the first super-ordinate theme came from an image produced by Daisy (Figure 7.1). The second super-ordinate theme, 'Stuck', summarised the young people's situation whereby they are constrained by the ongoing nature of a condition

which is usually regarded as temporary combined with the way in which adults do not always make efforts to include them.

**Figure 7.1 Daisy's image 'Never Mind'**



### 7.2.1 'Never Mind'

This super-ordinate theme was developed from the way in which the young people attempted to minimise their emotional response, of feeling dismissed by others, resulting from their inability to hear. It has three sub-themes. An overview is provided here followed by a more detailed exploration later in the chapter:

- 'The Stress; of living in a confusing world where sound is either muffled or overwhelming; with the need to have things repeated, which does not always happen
- 'The Gap' between what they can decipher is going on around them and their decision whether or not to disclose their hearing loss
- 'The Fear' of operations along with the lack of consultation of their wishes by the adults, leaving them feeling passive and objectified.

Daisy used the image and phrase 'Never Mind' (Figure 7.1) to indicate that she felt an outsider in a lot of conversations with others, leading her to wonder whether she was being deliberately excluded: *it says, 'Never Mind', 'cos people like say something to me, I don't hear them and go, 'What' and they say it again, and I say, 'What?' and they're like, 'Never mind, It's OK, never*

*mind' and they're just kind of .... 'Forget about it', but I'm like paranoid about what they're saying* (Daisy, 1: 7-10). It is unclear whether Daisy was talking about her friends as she used the collective noun, *people*. She emphasised that she needed things repeated a number of times and that sometimes others did not always do so. There was a suggestion that she felt dismissed when they used the phrase *Never mind*. Potentially this situation could be avoided if her classmates had a greater awareness of Glue Ear and its consequences.

The phrase 'Never Mind' suggested that the thing was not worth worrying about, that it was not important or that no extra consideration was required of the issue. In this case, the impression was that there was little consideration by others of the individual upset felt by Daisy, Russell and Stewie in the situations they described. To some extent this was compounded by the construction of Glue Ear as a trivial condition. Overall there did not seem to be any provision made in the classroom to enhance their hearing, or even an acknowledgement that anything was required. Generally the young people avoided bringing attention to themselves, but tried to integrate with their classmates. The conflict between what they could hear, why they needed to have things repeated and the construction of the condition led to emotional repercussions for them.

#### 7.2.1.1 'The Stress'

The focus of this sub-theme was the emotional impact on the young people of never fully following what was being said by others. It developed from Stewie's 'Stressed' image (Figure 7.2). Daisy and Russell both shared the emotion of frustration. Balen *et al.* (2006) propose that young people are those best placed to explore and provide insight into their social worlds. The three young people in this research articulated their emotions and the situations in which they had difficulty.

**Figure 7.2 Stewie's image Stressed (Reconstructed)**



Stewie labelled his image of a boy sitting with his computer as ‘Stressed’ (Figure 7.2). As he explained: *There are things I get stressed about, like annoyed about, stressed about like when I can't hear all of the time and like erm I have to get things repeated at times and like erm, I always have to go up closer to the desk as I just can't hear, and sometimes like er ... I just can't hear at times, so like, yeah, so I just get stressed about that.* (Stewie, 2: 11-15). He recognised that his need to have things repeated caused him *stress*. However this was only *at times* so underlining the intermittent nature of his hearing loss. By repeating *stressed* three times, he highlighted the extent of his emotional upset. He wanted to hear and understand but he *can't* thus being disabled in his efforts to interact with others. He seemed to be controlled by his ears with them compelling him to behave in a way not necessarily of his choice, as suggested by the imperatives: *I have to*, and *I always have*. Perhaps part of his *stress* results from feeling a lack of control.

Lowe (2012) identifies the concept of the ‘unauthorised child’ whereby children see themselves as subordinate to the control of adults. This resonated with Stewie's explanation of having to do things. In addition to being subject to the requirements of the adults in the classroom, as are all children, his ears imposed extra requirements upon him because they were unable to process sound effectively. According to Olli *et al.* (2012) the child in the classroom has limited latitude

to achieve a sense of agency by deciding on a course of action and taking the consequences for the decision. However, without a sense of agency and control over one's own life, a child could feel that they are not valued. Stewie, and the others, needed to feel that they were part of the school community, even if their needs were different to most of their peers. Equally, if they were to co-operate with healthcare professionals, it was important that they felt that their opinions were listened to and valued by adults.

**Figure 7.3 Daisy's image Shouting person**



Daisy used an image of a shouting person (Figure 7.3) to discuss what triggered her anger: *I get really angry .... and upset .....like I want to..... punch something.... Because it's really annoying because I can't hear what people say sometimes, I miss out and then ..... people are like, 'I said that to you.' And I'm, 'Did you?' and then they yell at me and then 'Oh you've got bad hearing haven't you?'* (Daisy, 4:32-26). For Daisy, there was a two-way interaction; she became angry, to the extent that she wanted to ..... *punch something* but equally other people were frustrated so that *they yell at me*. There was a hint that she saw her friends as mocking her when they yelled: *'Oh you've got bad hearing haven't you?'* She wanted them to speak loudly enough for her to hear them, but did not want them to *yell*. Using *Oh* implied that others were almost belittling her as it is an expression that can mean either surprise or dismissal. She recognised that in part her anger was because she *missed out*. Saying *sometimes* demonstrated the intermittent nature of her hearing impairment and was similar to Stewie's description. Maybe she felt angry because her

hearing loss did not elicit a positive response from her peers. As with Stewie, Daisy's ears appeared to dictate what she could and could not do.

The physical repercussions of the condition were demonstrated by Russell. His ear drum had burst just prior to his participation in this research. The fluid from the middle ear then discharged from his ear canal: *My ears have been gunky recently. And you have to keep having to clear out your ears and it's horrible. Baby wipes and they get soggy so it's not that nice or ... And my hearing hasn't been great, so just, just not that great really and I hate having **bad** ears*, (Russell, Gunky ears: 3-6). Russell's ears, too, seemed to control him. He used the continuous imperative *keep having to* thus emphasising his lack of choice. He talked about his actions using the 2<sup>nd</sup> person singular *you*, rather than referring to himself using the 1<sup>st</sup> person, *I*, potentially distancing himself from the need to clean his ears. Describing the *soggy baby wipes* highlighted the unpleasant nature of the discharge. Although he did not mention the response of his classmates to his ear cleaning, they would be unlikely to show sympathy for him. He seemed to share Daisy and Stewie's feelings of stress when he emphasised that: *I hate having **bad** ears*. Russell had no choice but to clean his ears thus he was set apart from others.

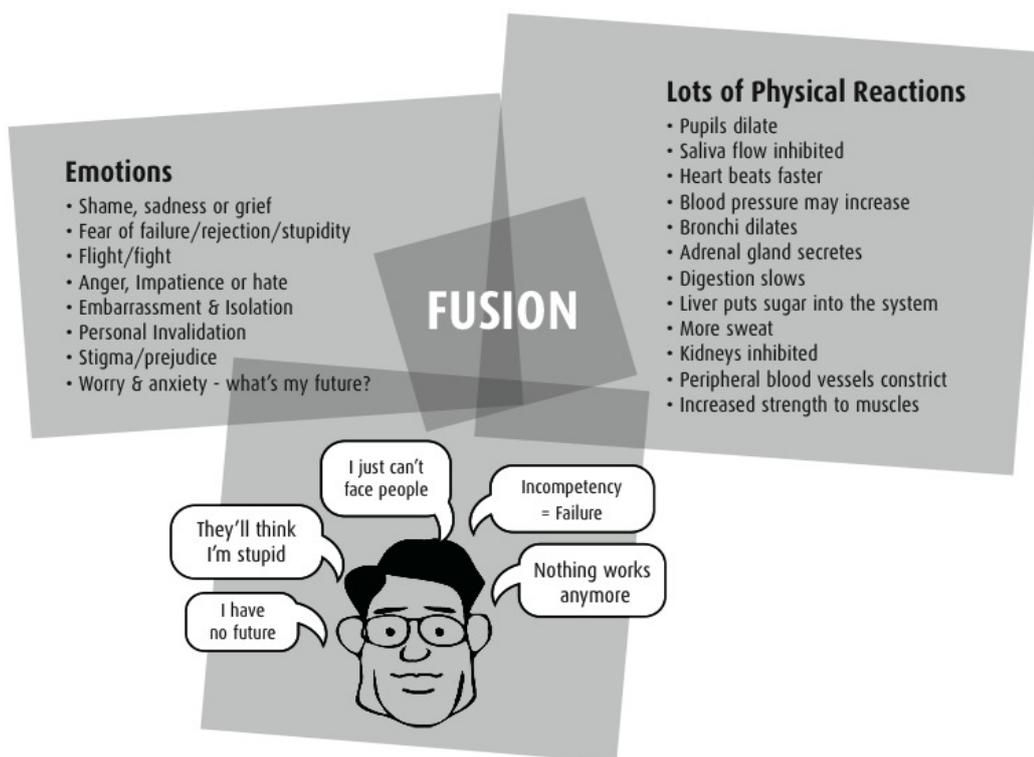
The difficulties in the school environment for Daisy, Stewie and Russell are threefold. Firstly, as Miles (2011:1097) highlights: 'Most children who experience difficulties in school cannot easily be identified as 'different' from their peers because their learning difficulties are not necessarily visible.' This is especially the case with hearing loss. Secondly, Angelides and Aravi (2006-2007) explain that even when young people in mainstream schools need support this is not always forthcoming either by the teachers or other students. Thirdly, Glue Ear is not regarded as a special need in most schools.

However, for the three young people in this research, their inability to hear did separate them from their peers. Mitchell and Karchmer (2006), in their demographic study of deaf education in

the USA, found that there was only likely to be one hearing impaired student in mainstream schools. So both teachers and students are probably unfamiliar with the implications of hearing impairment and likely to lack effective strategies for dealing with such students. This could lead to a situation where young people, like Stewie, Daisy and Russell, feel isolated and have to develop their own strategies to manage their hearing difficulties. Not receiving the support they need could increase their stress levels as they may not fully understand their emotions or have the means to master them. Not being able to clearly decipher what people were saying and lacking extra help, resulted in emotional issues related to stress, anger and frustration for the young people in this study. Their teachers' limited awareness of the implications of the condition in the classroom could potentially result in disengagement or even mental health issues for some children with this ongoing condition.

The continued effort of failing to fully understand what is going on around them coupled with their peers' annoyance at having to constantly repeat themselves could lead to difficulties for young people with ongoing Glue Ear. Such a situation led to Daisy feeling rejected by her friends: *I remember there was some invite or something, I can't remember what it was though and they said, 'Oh you've got bad hearing, there's no point in you coming...' I just got turned down ...for it and ..... I was like, ummmh, thanks, yeah I tend to get angry about it.* (Daisy, 4: 37-40). Daisy felt angry, perhaps because her friends were not prepared to make the extra effort required to make sure that she could participate in the activity. The link that her friends made between *bad hearing* and *no point in you coming* suggested that they may not believe that she needed things repeated (Zheng *et al.*, 2003) or that they were not prepared to make the effort required to ensure her inclusion. In either case, Daisy may have developed a negative self-image, potentially reinforced by seeing herself as not good enough for her friends.

**Figure 7.4 Hogan (2014) Tri-Level Reaction and Fusion Model**



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Hogan (2014) summarises the potential outcomes for individuals with hearing loss in a Tri-Level reaction model which he proposes becomes a Fusion of emotions, physical reactions and negative self-talk (Figure 7.4). This model can be applied to the young people in this research, whereby their fight-or-flight response (Jansen *et al.*, 1995) was likely to be frequently activated, negative emotions could occur along with the type of self-talk potentially resulting in low self-esteem. In this section, Daisy, Stewie and Russell have identified experiences arising from their hearing loss which reflected the elements of the model.

Their fight-or-flight response, which Hogan (2014) labelled 'Physical Reactions' in Figure 7.4, was very likely to result from their feelings of anger and upset. Russell emphasised that he hated having *bad ears*; Stewie focused on the *stress* he frequently felt in the classroom environment and Daisy explained how she became very angry and wanted to *punch something*. These negative emotions potentially raised blood pressure, increased heart rate and resulted in adrenalin

being released into their blood stream. If repeated often enough it could lead to long-term health issues.

In terms of Hogan's Emotional domain (Figure 7.4), the young people expressed negative feelings. Daisy felt rejected when she perceived that her friends had *put her down* with the accompanying emotion of anger. Stewie repeated how he felt *stressed* and potentially embarrassed at *having to go close to the teacher's table*. Russell was likely to have experienced some stigma because of having to clean out his *gunky* ears resulting in *soggy baby wipes*. Peer friendships and support are particularly important during adolescence as young people develop their sense of personal identity. Garcia (2010) suggests that there is limited understanding of how adolescents manage situations which they find stressful or what longer-term impact this has on them. The young people expressed emotions that belie the description of Glue Ear as being trivial and without long-term implications. This may be because there has been limited research into the psycho-social implications of the condition for young people and they have not previously been directly consulted.

The third element of Hogan's model (2014) (Figure 7.4) explores the impact of negative self-talk. Being the only person in the class with hearing loss could perhaps lead to feelings of isolation (Mitchell and Karchmer, 2006). It is likely that having to have things repeated could result in being labelled as 'stupid' by classmates and consequently sidelined by them. Brunberg *et al.* (2008) identified that young people with mild-moderate hearing loss or unilateral hearing loss reported that they were depressed and were bullied by their fellow students. The young people in this research did not discuss bullying issues, but they did identify themselves as feeling apart from their classmates. This could lead to feelings of inadequacy maybe leading to negative self-talk about not fitting in with others as could well develop from Daisy's feeling of rejection by her friends.

### 7.2.1.2 'The Gap'

There are two aspects to this sub-theme. The first relates to Russell and Stewie not disclosing their hearing difficulties to their classmates. The second element was the response of their teachers who either did not know or did not take into account potential difficulties linked to the hearing loss associated with the long-term condition. Daisy was in secondary school so had a number of teachers. Without effective communication with all of her teachers then her inability to hear clearly could have been identified as a behavioural problem within her. These situations were likely to result in a 'Gap' between what the young people in this research could decipher going on around them and their ability to perform on an equal footing with their peers.

**Figure 7.5 Stewie's image 'Angry' (Reconstructed)**



When explaining his Angry image (Figure 7.5), Stewie recounted how he became upset in school: *I was like doing this comprehension and I couldn't hear some of the answers* (Stewie, 2: 23-24). Because he was unable to keep up with the teacher and check whether his answers were right or wrong, he felt angry, perhaps blaming his ears for his difficulties. Nittrouer and Burton (2005) suggest that repeated episodes of Glue Ear from an early age lead to young people having difficulty processing information at the same rate as their normal-hearing peers. Stewie's teacher did not seem to be aware of what was happening to him but he did not appear to have said anything, perhaps adopting the 'Never Mind' approach of remaining silent. Though internalising his feelings, it was likely that his blood pressure elevated and his heart rate increased. Stewie's

image depicted high levels of rage and was perhaps chosen to demonstrate the physical and emotional impact of his anger on him.

Guardino and Antia (2012) explain that for children with a mild degree of hearing loss, the background noise in classrooms results in them being difficult listening environments. This is likely to apply to the young people in this research. Stewie was probably trying to concentrate on the teacher's voice and his classmates may have been paying attention. However, in the normal classroom environment there are high levels of ambient noise resulting from students moving their chairs, rustling papers or talking quietly to each other (Capewell, 2014a). It was likely that blocking out such noises would be difficult for Stewie (Manlove *et al.*, 2001) so distracting him and causing him difficulty in following what the teacher was saying. Such conditions could lead to a 'gap' in what the young people in this research could understand in the busy classroom environment and also how they behave. They related becoming upset and frustrated because they could not follow what was happening, but their teachers probably did not understand the cause of such emotions as they were unlikely to understand the impact of the background noise.

Russell had not fully disclosed to his classmates the extent of his hearing problems: *Well the other kids at school don't know how bad it is. (Whispering) I told it to one person and then they spread it to the whole school. (He started to move around the table, still whispering).* (Russell, Gunky ears: 3-7). His use of *spread* and *to the whole school*, said in a whisper and his body language of beginning to move around indicated that he was uncomfortable talking about letting other people know that he had hearing difficulties. It seemed that his disclosure to one person had not been kept confidential, perhaps resulting in him feeling that his trust had been misplaced. He ended his discussion with me at this point. Potentially he did not want to stigmatise himself as being different as maybe he was concerned about the impact of his disclosure on his interactions with his classmates. However, by not telling others of his hearing difficulties, he may have disabled himself. If others did not understand that he could not always hear then they

were not given the opportunity to help him. From Russell's perspective it could be that he did not want to highlight any weakness as it could have left him more vulnerable to bullying (Brunnberg *et al.*, 2008).

Stewie's teacher knew about his hearing loss and checked with him about what support he needed. He appreciated the effort she made: *she like always asks if I'm all right, she like asks if I'm OK and she's like a real help to me.* (Stewie, 2:28-29). This quote came in the context of when he was explaining the difference between what actions he perceived as attributable to *good and bad teachers*. Stewie believed that a key characteristic of a *good teacher*, was that she checked his needs and demonstrated her understanding of his situation, thus closing the 'gap', but not requiring Stewie speak up for himself. Russell appeared to be uncomfortable in acknowledging his hearing loss, so he may not have had the confidence to explain to his teacher what help he needed or the teacher may not have been receptive to his efforts of asking for support. It may be that Russell and Stewie either did not want to adopt the role of being their own self-advocate by identifying their needs then asking their teachers for specific help or lacked understanding as to what impeded their hearing in a classroom (Toe, 2009).

Goodley (2000) explored the meaning of 'self-advocacy' which can cover a range of actions at the individual and the collective level. An example of the latter was Stewie's explanation of how he worked with his teacher to ensure that when his hearing was not at its optimum level she could support him. In contrast some of his other teachers expected him to perform at the individual level and specify himself what help he needed and the actions required from teachers for him to perform at his best. Goodley (2000) noted that high levels of self-confidence are required if an individual is to take the initiative about what is helpful for them. Teachers are in charge in schools and students are expected to conform to classroom expectations of behaviour so may lack the confidence to state their needs. Lowe (2012) observed that even very young children know that the teacher has control and children are expected to follow the adult rules. As

Hogan's (2014) Tri-level Reaction and Fusion model (Figure 7.4) suggests, young people with hearing loss may have developed a negative self-image so may not wish to highlight any difficulties or differences they have and could lack self-confidence. It would appear to be better if teachers were more vigilant about an individual student's needs and be prepared to initiate conversations as to how they could be best supported.

Although Daisy's classmates were aware of her *bad hearing* she did not appear to have discussed it with her teachers. She related an incident in the classroom: *the teacher came up to me and was talking to me and trying to help me .... And then I ..... turned around and said like 'Thank you' and I did my work and whatever and he was still stood there staring at me and he mouthed it and I couldn't understand any of what ..... and I'd said thank you, and he was like, And he gave me a detention and I'm like, I can't hear you.....* (Daisy, 5: 6-11). Rather than saying to the teacher that she could not hear, Daisy followed the social conventions of the classroom and the behaviours of a good student, by saying *thank you* to the teacher when she thought he had finished talking. From her perspective *he mouthed it and I couldn't understand any of what .....*, indicated her inability to hear him. However, the teacher misinterpreted her behaviour: *'It is so rude to ignore me.'* The resulting misinterpretation was that Daisy had a detention accompanied by feelings of injustice whereas the teacher probably labelled her as *rude*. The 'gap' was between what Daisy was prepared to disclose and what the teacher should know, but led to a poor teacher-pupil relationships.

Daisy did not appear to want to be different to her classmates: *They don't treat you specially... My mum and dad are always like, 'Sit at the front of the classroom.'* *But I don't really want to, because most of the time the teacher writes down on the board, and they think like I'm missing out a lot, but I'm actually not, it's just that erm I'm not that smart, and a lot of time I just don't really understand stuff. My parents think it's to do with my hearing, but I don't really think it is....* (Daisy, 1: 44-49). Daisy seemed to believe that teachers were used to pupils with poor

hearing, although this is unlikely to be the case (Mitchell and Karchmer, 2006). As Miles (2011) indicated hearing loss is invisible which is compounded for Glue Ear as it is not seen as a special need therefore the teachers *don't treat you specially*. Daisy attributed her poor academic performance to shortcomings within herself: *I'm not that smart, and a lot of time I just don't really understand stuff*. It seemed that Daisy was participating in the negative self-talk identified by Hogan (2014).

However, it is the responsibility of the school and teachers to ensure that the 'gap' which Daisy experienced was closed (Murray, 2006) rather than requiring her to identify and specify what actions they needed to take. Daisy was 14 years of age at the time of the research so acceptance by her peer group and being like them was important (Garcia, 2010). She appeared to attribute her poor school performance as something lacking in herself rather than being potentially a failure by her teachers to support her.

Russell appeared to experience school in a similar way to Daisy. There had been a change in classroom practice because: *School's now sort of helping now they **know** funnily enough that my hearing's dropped, because 'cos I'm getting a hearing aid so it's actually quite good... because now they've moved me in different spaces so that I have my good ear facing the teacher and things... so in the input I can actually **hear** what's happening instead of missing out things....* (Russell, School: 1-5). Russell's new seat in the classroom meant that he could be part of the lesson as he *can actually **hear** what's happening instead of missing out things...* He demonstrated that he knew that he had previously been *missing out things*, which was likely to have led to feelings of isolation, activated his stress response and potentially self-talk about being personally inadequate (Hogan, 2014). It seemed that there were limits to the improvement as they were *sort of helping*. The school seemed to be responding because Russell was *getting a hearing aid* which signified a sensory loss.

Part of the difficulty for young people with ongoing Glue Ear in the school context is that the condition is often seen as trivial and temporary. It is expected to spontaneously resolve for most children by seven to nine years of age (Bluestone and Klein, 2007). The implications for Stewie, Russell and Daisy, and young people like them, were that their teachers did not expect them to have any associated difficulties thus did not routinely make adjustments for them. This resulted in a 'gap' between what they needed and the support provided. In addition to impeding their academic performance, the lack of understanding was likely to impact the young people's psycho-emotional wellbeing through potentially viewing themselves in a negative way. The frequent triggering of their fight or flight response could develop into long-term health implications unless effective coping strategies are developed (Compas *et al.*, 2001).

Thomas (2004) discusses how a biologically-based impairment, in this case hearing loss, results in disability when a person's activities result from socially imposed restrictions. In the classroom situation, the young people in this study were less able to perform at their optimum level because small adjustments, which would have enabled them to interact with their peers and to follow what the teacher was saying, were not routinely made. Although they had agency to act, young people are inhibited by classroom behavioural norms and the power differential between students and teachers (Lowe, 2012). Stewie's teacher demonstrated that she understood his condition and involved him in the decision-making about what adjustments would be helpful. Russell's school took action on being told he needed a hearing aid thus recognising his hearing impairment. The less informal interaction between parents and teachers in secondary school resulted in Daisy needing to speak to her teachers. It could be argued that she was old enough to be her own self advocate, however she seemed to lack the confidence and appeared not to want to draw attention to herself.

Georgeson *et al.* (2014) suggest that young people with disabilities benefit when their teachers consult them about how to best support their learning. Their self-advocacy skills are developed

as they communicate their needs and ways to support them. However, educational professionals need to become adept at listening and responding positively to their students. Learning such skills from an early age is likely to increase a young person's confidence and therefore help them achieve their full potential. The comments by the young people in this research suggest that although they may know what help they need, they are not always encouraged to express it.

#### 7.2.1.3 'The Fear'

The young people in this research identified grommet surgery as stressful and caused them mental anxiety. The hospital systems took precedence over any consultation with them. 'The Fear' is examined by Daisy and Stewie about their response to having a general anaesthetic. Much of the experience for those with ongoing Glue Ear relates to regular hospital visits and operations. Daisy, Stewie and Russell knew what to expect when they had surgery as they have all had at least two operations.

Stewie's anxiety was evident when he explained his perceptions of going into the operating room: *they stick like these needles in my hand. It's horrible so like I've still got the marks for them and I have to do it like while I'm playing the game and it really hurts and they put me to sleep and then I come back and I've got a sore throat and everything and then I have to have them removed and they really hurt and it's horrible* (Stewie, 4: 6-10). Stewie fluently detailed each step, almost as though he was separated from the experience. However, he focused on the resulting pain, *really hurts* which he repeated and *sore throat*. He used the 3<sup>rd</sup> person pronoun *they* suggestive that the process was impersonal. The verb *stick* objectified his body, but he still felt pain. Although he was aware that they were no longer physically present, *the marks* remained as longer term emotional scars in his memory; those made by the needles and the people who put them in. He used to *have to do it* and *I have to have them removed* with the imperative form *have* indicated compulsion and a lack of choice on his part. Perhaps the medical

team were trying to distract him by *playing the game* as they put the needle into his hand. But his previous experience of the pain caused him anxiety and knowledge that it would hurt. Stewie seemed to feel the procedure was impersonal, as no one appeared to talk to him or comforted him. He was left with a fear of operations and needles.

Similarly, Daisy recalled her previous grommet operations: *I had a really bad experience with one when I was really younger and they jabbed me in the wrong place in the back of my hand and it was really really horrible and even though I don't remember the pain, just the thought of it makes me cringe* (Daisy, 9:22-24). Daisy used *jabbed* an emotive and somewhat violent description. She emphasised that the needles were *really, really horrible*, an almost identical description to Stewie. Daisy believed that the needle had been inserted *in the wrong place in the back of my hand* suggesting that the process had not been explained in a way that she understood, as the back of her hand would be the appropriate place. She too had an ongoing fear of needles in any situation. These two young people had never met and lived in different parts of England, but their experiences and language were very similar, as was the impact of having injections.

There are written policies in hospitals about consulting with young people and giving them choices about their treatment (Department of Health, 2004, 2003). Williams and Noyes (2009) make the point that although parents generally have the legal responsibility for giving permission for treatment, there are some decisions that children are regarded as being competent to make and should be provided with the opportunity to do so. The way in which an anaesthetic is administered is specifically cited in their work. Despite Williams and Noyes' (2009) comments about consultation, the young people in this research did not believe that they were given a choice about the way the anaesthesia was administered. The adult notion of consultation is in evidence in the National Deaf Children's Society book, 'Harvey gets grommets' (2012), written to explain to young people the reasons for their grommet surgery. With regard to surgery, it only

says that Harvey will be put to sleep, with little explanation of the procedure. In contrast, Dooley (1996), in his children's story, identified the importance of young people being given a choice in their treatment, therefore less likely to be upset in the long-term. Coyne (2006) makes the point that when young people are consulted and involved in what is happening then they are less distressed by even painful procedures. If policies are to be changed then there needs to be greater awareness among healthcare professionals of how young people feel as well as genuinely giving them the opportunity to express a choice. This is probably more important for those young people with the ongoing condition who have had more than one set of grommets as they know what will happen with potentially additional upset for them. Their fears could be prevented by talking to them. As inserting grommets is the most common reason for surgery in young people (Zumach *et al.*, 2010) it may mean that healthcare professionals see it as a straightforward procedure and routine operation. It may be that the impact on individual young people (and their parents) is not in the forefront of their thinking. Although there may be large numbers of operations, as the comments by these young people indicated, the individual impact may be much greater.

There has been increasing awareness of the need to involve young people in their treatment (Gabe *et al.*, 2004) but this has not necessarily been translated into practice. There was a strong sense that Daisy and Stewie felt that they had no choice in what happened to them and that they must comply with the adults' instructions. If policy and practice are to align then issues need to be considered from the young people's point of view. They needed to be asked what their experience of treatment had been and consulted about what information they wanted or needed. It could be that having a single point of contact from whom the young person could seek information and share their point of view would make the experience of operations far less distressing. The young people did not describe any attempt to argue so appear to have complied with the procedures, even though their feelings about needles being *horrible* and frightening

were clear from what they said. It was as though their bodies were the focus of the healthcare professionals rather than consideration being given to them as people.

Martenson and Fagerskiold (2007: 43) make the point that 'Health professionals should focus on the child/young person as an individual and design information specifically for them'. This may not be easy within the constraints of the NHS, but is necessary if young people's stress and fear are to be reduced. If young people are not given the opportunity to openly express how they feel about the hospital procedures then they are not being treated as an individual. The young people in this research may not have said anything at the time of surgery, but their 'Fear' associated with it was clear. Their description of being compelled to do things with no recall of the hospital staff's names suggested that they felt that there was a 'Never Mind' attitude towards them with the NHS process taking precedence over their individuality.

### 7.2.2 Stuck

The name of the second super-ordinate theme 'Stuck' is suggestive of the way in which the young people saw themselves as being unable to move forward and that they have had choices taken away from them. The title came from the interpretation that they were caught in situations over which they had no control and seemed to have to comply with the wishes of the adults around them. They seemed to believe that they had little choice in the options available to them. They experienced very little in the way of meaningful consultation. They perhaps felt removed from 'normal' children but did not describe themselves as having either an illness, or a disability. One reason that Daisy complied with actions with which she did not want was that she did not want to go deaf. The young people tended to describe themselves as having *bad ears* rather than referring to their hearing difficulties.

This super-ordinate theme, 'Stuck', highlights the young people's situation whereby they are constrained by the condition and the responses of others. It has two sub-themes, which are summarised as:

- 'Sidelined' identifies the way in which they perceived healthcare professionals as communicating primarily with their mothers. They suggested that they had limited information about their condition or involvement in its treatment, positioning themselves as onlookers
- 'In-between' describes the limbo situation in which they have continued hearing difficulties and pain, but are told that they have a condition which is usually regarded as temporary with no long-term effects. They were therefore 'in between', their hearing was impaired so they were not like their peers and the condition had not resolved.

#### 7.2.2.1 Sidelined: Discussions between Healthcare Professionals and Mothers

Just as the young people did not appear to be involved in making decisions about their operations or routinely asked about what support would benefit them in an educational context, the same pattern appeared in their interaction with healthcare professionals at their routine hospital visits. They did not perceive themselves as involved in discussions about how they experienced the condition or how it impacted their day-to-day life (Capewell, 2014e). They did not appear to be provided with accessible information which would enable them to contribute to consultations about what options were available to help them improve their situation. The young people in this research appeared to be on the 'sidelines' of conversations about them. The pattern seemed to be that the ENT consultant gathered information from others, such as audiologists and parents, to make decisions about the best course of action. This follows the traditional paternalistic approach (Williams and Noyes, 2009) which is increasingly under pressure to change to a more collaborative patient-centred style including the young person taking an active role.

Daisy explained a typical visit for one of her regular check-ups: *Well I'll get there and sit in the waiting room and they'll call me in. Sit me down, check my ears ..... and most of the time, it's 'There's minor infection, bit of air trapped behind the ear drum..... ermm ..... slight infection, perforation ..... might need an operation, come back in 6 months time.'* Much the same thing every time. (Daisy, 3: 42-45). Daisy used imperative verb commands, *sit, call, check* to itemise the procedure she followed. She used the passive voice which emphasised her lack of agency in even small things in her interaction with the ENT consultant: *Sit me down*. Daisy's definition of *a bit of air trapped behind the ear drum* suggested that she did not really have a clear understanding of her condition. Daisy appeared to be almost observing herself. She did not demonstrate any emotions giving the impression of her body being processed. In a similar way, Stewie related the audiology tests, required before seeing the consultant: *When I normally go well I usually have to have a hearing test but I don't really need it because I've done about 900 of them* (Stewie, 4: 30-31). Stewie's use of the imperative *have to* contrasted with his view that he didn't *really need it*. Just as with Daisy, Stewie was in a repeated situation which he seemed not to fully understand. They seemed to regard the repeated experience of hospital visits as *Much the same thing every time* (Daisy) and as just part of their lives, *normally, usually* (Stewie). Again, Stewie seemed emotionally remote during the hospital visits where his ears were the focus of attention. This was in the context of a condition which is generally regarded as temporary.

However for Russell, Stewie and Daisy, their experience meets the definition of having a chronic condition. Kennedy (2012: 864) identified the criteria as:

- a medical condition
- lasting longer than 3 months
- the child, and family, undergoing repeated involvement with the healthcare system.

The criteria are met through their regular and ongoing visits to hospital over the years and along with their repeated operations. I would suggest that in this context, their input about the

condition and how it impacts them provides healthcare professionals with opportunities to gain valuable insights into it. Garth and Aroni (2003) suggest that young people provide a different perspective on their condition than that of parents and that active involvement and understanding of one's health condition promotes better psychological health. Given the concerns raised earlier about the potential psychological repercussions of young people with ongoing Glue Ear, their involvement in medical consultations should be promoted on those grounds alone.

Gabe *et al.* (2004) recommend that for successful partnerships between physicians and patients, especially when young people are involved, there needs to be:

- effective communication, using appropriate language
- the doctor needs to listen and involve the young person so that their view is understood
- a balance between acknowledging the parent's role in the decision-making but also seeing the child as competent to make decisions.

This model is based on the premise that young people are competent and capable of analysing and evaluating their experience to offer meaningful insights to others. Examples from the young people's transcriptions in this research illustrate why such an approach would be beneficial if applied in the healthcare context for young people such as Daisy, Stewie and Russell.

The first point is to provide accessible and relevant information as the basis of effective communication. This was not reflected by the young people in this research. Daisy explored her understanding of her condition: *I just get told that I've got bad hearing. They all talk in all big medical terms. I've got bad hearing..... I know I've got perforations in both of them..... but.....* (Daisy, 3:26-30). The language of the doctors *big medical terms* indicated that she did not feel involved, understand the language used or helped to understand her condition. While she *just get told, they all talk*, which suggested that Daisy did not see herself as part of the conversation, but rather on the sidelines. Her experience led her to construct an interpretation of

her condition. It consisted of *bad hearing* which led to *perforations in both* of her ears. The *big medical terms* were not part of her construction and further removed her from participating.

Daisy thought that the doctors made efforts to communicate with her, explaining that they: *Talk to both of us because .... They talk to me and try to make it as easy ... for me to understand, but .... They more talk to my mum when it comes to bigger terms ....* (Daisy, 4: 7-8). Although they try their efforts did not appear to include clarifying the terms used or checking her understanding. Daisy seemed to regard her mother as understanding more *They more talk* to her. As Caz, her mother, was a nurse it maybe that she shared a common language with the doctors and did not think to check whether Daisy understood. There may have been an assumption on the part of the adults that sometime in the past Daisy had received an explanation or that she would ask if she required information. Alternatively they could have been acting from the deficit model of childhood (Uprichard, 2008) whereby she was initially regarded as too young to understand without revising their assumptions as she had grown older. As Glue Ear is usually temporary the need to update information for those young people in whom the condition continues, could be overlooked.

Co-operation from patients, particularly young people, can be achieved by listening to their point of view so that greater insight into their experiences and emotional responses about what has happened in the past can be achieved. Russell clearly articulated his emotional response to his experience of failed operations: *they always said to me, 'Oh get grommets' and they have **never** worked, **never** in my life and they just come out with me so it's **no good** really so yeah, not that great* (Russell, Ear Ache: 12-14). However, it seemed unlikely that the adults around him were aware of his disappointment that grommet surgery had ***never** worked*. He may have benefited from other options being explored much earlier. The consultant's voice dominated Russell's account: *they always said* with *always* suggesting a lack of exploration of alternatives to surgery. The use of the 3<sup>rd</sup> person plural, *they*, which he repeated three times indicated that there was a

lack of personal connection between Russell and the healthcare professionals. He emphasised the futility of going through an operation as he stressed *never* and that they *come out with me*.

Perhaps the use of the first person pronoun suggested that he believed that it was in some way his fault that the grommets came out perhaps suggesting that he had a negative self-image (Hogan, 2014). He seemed upset that he continued to have ear aches and hearing difficulties but there was not any recognition of his feelings. Daisy and Stewie had similar experiences with grommets not improving their hearing and reflected Russell's negative view that nothing would improve their hearing (Capewell, 2014e). They were potentially on the 'Side-lines' in the sense that other children had grommets and their condition improved whereas they were 'Stuck' in an ongoing cycle of hospital visits.

Parental decision-making seemed to have prevailed as Russell was to get a hearing aid.

However, he did not have appropriate information or understanding of the rationale behind the decision: *I'm getting a hearing aid, so that should help, but... you never know really.... So yeah.... So at some point I'm getting one, but I'm not exactly sure what.... Still annoying ....*

(Russell, Ear Ache: 7-9). Everything seemed a bit uncertain to him, *it should help* but he was not clear about its impact. Perhaps his previous unsuccessful grommet surgery was shaping his uncertainty *but... you never know really....* that hearing aids would lead to any improvement in his hearing. He was 'Stuck' in a queue *Having to wait for everything* waiting for a change in his circumstances which perhaps made him feel different from his peers.

He did not appear to have been included in the decision-making process about getting a hearing aid and he seemed to have limited information about how this would happen. He demonstrated resourcefulness by talking to the only person he knew who had a hearing aid: *there's one teacher who has a hearing aid at school, has a hearing aid, well a caretaker and he's always saying that usually get a mould done, then wait about 2 weeks then get it.* (Russell, Hearing aid commentary: 11-13). It could be that he wondered whether having the mould done would require another

operation, as that had been his previous experience with grommet surgery. No one seemed to have explained things in a meaningful way to him or to have asked him if he had any questions. He appeared to have been ‘Sidelined’ as a person. As his ears were examined by the consultant, they were more involved in the decision than him.

Parental rights appear to have dominated whether Daisy would have a hearing aid. Her mother appeared to be the one who made the decision: *my mum, she’s played it out, she doesn’t want a hearing aid, so I’m definitely not having a hearing aid* (Daisy: 7:8-9). The adverb *definitely* indicated that there would be no more discussion about hearing aids. Daisy’s phrasing indicated that Caz did not want a hearing aid, therefore Daisy would not have one. This implied that Daisy was not part of the decision-making, as the agreement was between the doctor and Caz. Despite Daisy being much older than the children in Lowe’s (2012) study, she was treated as an ‘unauthorised child’ who was not entitled to have an opinion or to voice it. Although Alderson (2007) identified that by the age of 12 years, young people would be seen as competent to be part of the decision-making process this did not happen with Daisy. Caz’s wishes took precedence.

Greater insight could be gained about the condition if the young person’s competence was recognised and they were asked about their experiences. There is recognition that some young people with chronic Glue Ear will have tinnitus (Gordts and Decreton 2007; Mills and Cherry 1984). For Stewie, tinnitus was another barrier preventing him from functioning like his classmates. He analysed the impact of it: *it’s like painful and stuff and all the noise and stuff, all I know is that it’s painful. It annoys me.* (Stewie, 5:19-20). He kept returning to the pain it caused him, with the *noise* being a major factor in his distress. It was as though he could not escape from it: *it’s like buzzing in my right and like a screech in my left. Like yrrrr like that. Noises are what’s like really really bugging me they won’t stop.* (Stewie, 5: 34-36). The use of the 3<sup>rd</sup> person *it* implied that the tinnitus was not part of him, but a separate unwelcome, constant companion blighting his life. Stewie provided a detail account about how his tinnitus manifested

itself. However, his doctors did not appear to ask him about this aspect of his condition thus not recognising how Stewie's insight into his experience could provide them with greater knowledge.

Applying the framework suggested by Gabe *et al.* (2004) would enable young people to deepen healthcare professionals understanding of chronic conditions such as ongoing Glue Ear.

Listening to young people's experiences could also provide insight into the emotional impact that the condition has, thus developing an appreciation that it is not purely physiological but impacted the whole person. If the rights of the child as embodied in the United Nations declaration (1989) are to be enacted, then young people need to be given appropriate information about their condition and opportunities to participate in decision-making regarding their treatment and care. This research, albeit on a small scale, has demonstrated that when asked, young people are competent and confident in articulating the consequences of their experience of long-term Glue Ear.

#### 7.2.2.2 'In between': Stuck in limbo

Although 80% of young people under the age of nine years will have at least one episode of Glue Ear (Bluestone and Klein, 2007), for the vast majority this will be only one or two incidents. It is therefore easy to understand why the condition is described as temporary and trivial, with no long-term effects. However, this was not the situation for Daisy, Russell and Stewie or their parents. From an early age, they experienced repeated ear infections, accompanied by pain, with unsuccessful operations aimed at relieving the symptoms. Being in the minority could have resulted in them understanding the condition from a majority perspective. This meant that they waited for the time when it would no longer be part of their lives. As it is constructed as something temporary this may explain why there are no support groups for the condition.

This is likely to have a psychological impact on their parents and the young people themselves. While others grow out of it, these young people continue to have pain and discomfort, particularly when it is accompanied by tinnitus. For young people, such as those involved in this research, the early onset and continuing recurrence of the condition, was likely to cause educational and psychological implications (Teele *et al.*, 1990). From these young people there was the opportunity to understand the long-term implications of the condition in more detail and, from this research, gain a greater understanding of the psycho-social implications as the young people were expressing their views. This sub-theme explored the way in which these young people live with a condition which everyone around them defined as finite. This resulted in them feeling that they did not have a disability, as that was something that lasts for life; they do not have a special need, as the educational professionals with whom they came in contact did not interpret the condition in that way; and the healthcare professionals assured them that this was not a chronic illness but only a temporary condition, which would resolve itself.

The young people reported that they felt ongoing pain, which has not been widely reported in the literature. Russell's ears had caused him pain during the time he was involved in the research. He explained the impact and how it felt: *My ears have been **aching** today, for some odd reason and they're just a bit annoying really .... not great, thing, aching for a long time like, about 2 minutes that's quite a long for me so that's not great*, (Russell, Ear ache: 1-3). He seemed to underplay the impact of the pain, *not great*. It may be that low grade pain was something that he experienced quite regularly and was therefore part of his life. He described his ears using the 3<sup>rd</sup> person *they* which suggested them being apart from him. Just as with Stewie, Russell too had an unwelcome companion who accompanied him and over which he had no control. It could be that the ongoing pain was more of an issue to them than the adults around them were aware. The comments from the young people in this research would suggest a need to approach them in a way that acknowledged their experience as different from that of most young people with the condition.

Stewie's exploration of the impact of repeated hospital visits provided insight that no differentiation was made by healthcare professionals regarding the continuum nature of the condition. His refusal to willingly comply with the hospital process of having a hearing test needed to include his context: *because I've done about 900 of them and I refused to go* (Stewie, 4: 27). Without acknowledging his long-term experience of the condition, he could have been labelled as 'difficult'. For Stewie the compulsion to have a hearing test as unnecessary, *I don't need it because I've done about 900 of them*. From his experience yet another hearing test would result in yet another failure which could impact negatively on his self-image. He knew what previous results have been and could only expect the same again. No one provided an explanation for why he needed to be placed in a position of failure again.

Daisy described a number of hospital visits, but reduced them to *pretty much the same old thing* (Daisy, 4: 4), with the visits *every couple of months* (Daisy, 3: 38). She seemed to have felt that she received a repeated message and that there was a futility about the visits: *it's kind of a waste of time to sit in the same room ..... for what an hour, an hour and a half to hear the same thing that I hear every time.... It's just a waste isn't it? An hour, an hour and a half of my life that I'm never going to get back, because I know exactly what they're going to say .....* (Daisy, 8: 39-42). Her repetition of, *same room, same thing, every time*, emphasised that she felt as though she was reliving the same experience with no benefit to her. There was no acknowledgement of the potential negative impact on her self esteem resulting from the lack of improvement in her hearing. She was processed rather than acknowledged as a young person facing a difficult situation. Potentially she experienced more disappointment and felt that she was the cause of the failure of the operations.

The Department of Health's National Service Framework for Children (2004) identified as a core principle that healthcare professionals need to seek to understand the young person's perspective.

They need not only to ask for their opinion, but to demonstrate that it makes a valuable contribution in their treatment. However from what the young people have said in this research, their ears made their contribution to the consultation. There appears to be a need to develop materials that are accessible to young people, thus avoiding the use of *big words*' and *medical terms* which Daisy described (Martenson and Fagerskiold, 2007). Russell appeared to want more information about hearing aids such as how they worked and how they would be fitted. Having to rely on his own resources to gain information could have led him to misinterpret what would happen, potentially causing him unnecessary upset. Stewie and Daisy identified that they were unclear why they needed to have repeated visits and tests. There was a sense that things were being 'done to them' with the expectation that they would comply without complaint, but without being offered explanations of the reasons. It was likely that the clinic situations in which they were being seen were busy with little time for explanations (Gabe *et al.*, 2004). There was an element in all of them of having lost hope that things would improve and that they had resigned themselves to having operations which they did not believe would *work*.

### 7.3 Conclusions

One of the key messages of the National Service Framework for Children, Young People and Maternity Services (2004: 9) is: 'Give children, young people and their parents increased information, power and choice over the support and treatment they receive, and involve them in planning their care and services'. This aspiration did not appear to be a reality for Russell, Stewie and Daisy. Russell identified that he wished that he had been given information about the options of hearing aids and grommet surgery earlier. Daisy acknowledged that her mother's decision would prevail and she did not appear to be consulted by the healthcare professionals.

Gabe *et al.* (2004) explored the context in which consultations take place within the National Health Service (NHS) where the physical environment is very utilitarian in terms of the building, furniture and lacking child-friendliness. This is likely to be the case for many children with Glue Ear as they are usually seen in a general ENT clinic rather than a paediatric setting. Although the UN Convention of the Rights of the Child (1989), article 12 identifies the rights of children/young people to be consulted and encouraged to give their views, there is a restriction in terms of chronological and developmental competence, which presumably is a decision that adults would make. There is the additional pressure to adhere to the time constraints allocated for each consultation. However, if young people with the chronic condition are to learn to participate more fully in their treatment then these issues need to be addressed and effective ways of communicating with them developed. The young people in this research had valuable insights into what it is like to live long term with Glue Ear. If they were listened to more closely, it could provide ENT consultants with more detailed information as to how it manifests itself in the extreme form, perhaps suggesting avenues for further research into better and more effective treatment.

The young people commented in solution-orientated ways as to how they could be better supported in the classroom environment. For example Stewie identified actions that his *good* teacher took which supported him in achieving his full potential. Russell identified that by moving him to a position where he could hear meant that he was less likely to miss out on what was going on around him. In contrast Daisy seemed to have to rely on her own resources to identify what was important but did not appear to be performing very well academically. She then attributed this to herself rather than her learning environment. Some research has indicated (Byrnes and Richards, 2011; Lewis *et al.*, 2007) that involving and encouraging young people to identify how they can be better supported leads to improved educational outcomes than relying only on suggestions by teachers or parents.

Russell, Stewie and Daisy raised issues around the need for better communication between themselves, their parents and healthcare and educational professionals as a way of understanding the issues which they faced. Prior to this research, young people have not provided their perceptions as to the potential impact on the emotional repercussions of this condition. It may be that Daisy and Stewie not wanting to comply with audiology tests may have been an emotional response to their feelings of continual failure of the treatments that they have received. They clearly expressed how distressing they found the experience of operations. In the school environment, they could find interactions with their peers problematic and their learning needs seemed to be generally overlooked by teachers. The issues which they raised around their frequent experience of pain and discomfort have not previously been identified in the literature. If young people are encouraged to identify issues which are important to them, then adults are likely to gain greater insight into the lived experience of the condition, rather than making assumptions about what it is like for young people. The next chapter explores how young people, mothers and a small group of professionals interpreted the experience of ongoing Glue Ear.

## Chapter 8

### Comparison of Mothers, Young People and Professionals Views: 360°

#### 8.1 Introduction

This research was set in the context of national and international policies which suggest that young people and their parents should be central to making choices in their treatment (Department of Health, 2004) and have a greater say than previously may have been the case in their education and healthcare (UNICEF, 1989). The passing of the Children and Families Act 2014 and the publication of the new guidelines for special needs provision (Department for Education and Department of Health, 2014) has widened the definition of special needs so that ‘long-term’ refers to a condition lasting more than a year and includes sensory impairments. It reinforces the message that young people and their parents should take an active role in decision-making. The prime focus of this research was to gain insight into how a small sample of young people with ongoing Glue Ear, and their mothers, experienced and perceived the impact the condition had on them. Therefore the voices of professionals, with whom mothers and young people interacted about the condition, were not included in the original design.

However, from the analysis of the mothers’ experiences (Chapter 6), it appeared that they did not always perceive the professionals with whom they interacted as supportive or that they acknowledged the mother’s expertise about her child and way Glue Ear impacted him/her. Similarly, the young people (Chapter 7) indicated that the professionals did not always include them in discussions about their condition or in the choices and decisions made about how to best support them. It seemed reasonable therefore to access some of those professionals in order to understand their perspective and knowledge of the condition and the role that they thought that mothers and young people had in dealing with the long-term condition.

A range of views from different perspectives is not usually included in Glue Ear research. I believe that adding the views from a small sample of professionals to those of the mothers and young people provides a broader perspective (360°) than is present in the wider literature. The professionals represented in this chapter are: an ENT consultant (Otto), an Audiologist (Annie), a Reception/Year 1 Teacher (Rachel), a secondary teacher (Terry) and an Educational Psychologist (Brian). All names are pseudonyms and their use emphasises that these are individual voices and not representatives of their professions. The professionals came from locations across England so their knowledge is likely to be more reflective of general levels of understanding of the condition rather than linked to a specific place. Not all professionals who interact with the young people with the condition and their mothers are represented because such an inclusive list is outside the scope of this research. Within this chapter, the views of the professionals are compared and contrasted with those of each other and with the mothers and young people who participated in this research.

Increasingly there is acknowledgement of the importance of consulting young people (Fleming, 2013; Alderson, 2008), rather than relying on the views of parental proxies. However in most research the young people are not directly consulted so there is no information about their perceptions as to how the condition affects them. In this research, young people used their own voice to explain their experiences. Examples of the same situation discussed by a mother and her child are used to illustrate how a more complete view can be gained by including the views of young people directly rather than adults filtering their perceptions.

## 8.2 The value of taking a 360° Perspective

The 360° Feedback system is based on the involvement of a wide range of roles so that there can be increased understanding of different perspectives and enhanced learning to effect change (Tee and Ahmed, 2013). If young people are to obtain a more central role in contributing to their healthcare and educational experience of the condition, then ways need to be found to include them and to understand the valuable contribution they have to make. Coyne (2008), from a healthcare perspective, and Shevlin and Rose (2008), from the educational context, identify that although children often want to participate they are not always encouraged to do so. In this chapter I argue that including their views potentially leads to more effective practice, in both healthcare and educational settings, and increased understanding for professionals of what it is like to live with long-term Glue Ear.

The balance of power will remain with professionals, unless all parties have access to and can understand available information as well as having the opportunity to contribute their views. These existing differences in knowledge about Glue Ear were demonstrated in research by Higson and Haggard (2005). They used a multiple-choice questionnaire to review the way in which teachers, parents and ENT surgeons viewed and understood the condition. They found that teachers had a very low level of knowledge about how they could improve the listening environment for young people with the condition. Their findings identified that parents were considered the main communication channel between medical and educational professionals but may lack the confidence and knowledge to fully undertake such a role. ENT consultants had the most knowledge about the condition but had little time in the clinical setting to explore with parents the behavioural implications of the condition and the treatment options available for Glue Ear. The research questionnaire (Higson and Haggard, 2005) did not include all relevant issues. For example there were few questions about social skills. There was no opportunity provided, in that research, for the young people to express their views.

The findings from Higson and Haggard's (2005) research provide a framework for analysing the findings from the qualitative, semi-structured interviews with professionals in this research. This chapter applies the data gathered in my research to compare and contrast the different perspectives of the various groups involved in supporting those with the condition. The aim is to illustrate how the perspective of individuals having various roles impacts the young person with the ongoing condition and to identify where there is a need for further research or changes in practice to achieve better support for those young people.

### 8.3 A common condition but limited knowledge

Higson and Haggard (2005) highlighted that ENT consultants have the most knowledge about the condition. Otto, the ENT consultant in this research, constructed a photomontage in the form of a PowerPoint presentation using a series of images. He explored his understanding of the condition through this. In addition to his clinical knowledge, he identified a number of implications for potential behavioural issues in the classroom. His photo of a girl at school (Figure 8.1) provided the stimulus for the following comments. I have related these to the existing literature (shown in brackets): *If they don't hear effectively they can go into their own little world (Manlove et al.,2001). If they don't hear or they don't know what's going on (Klein, 2000), they don't hear what's going on (Bess et al.,1998), they don't interact with their friends (Pakulski and Kaderavek, 2002) and their family (Yont et al., 2001). They don't pay attention at school (Hogan and Moore, 2003). In younger children it affects their speech (Bellussi et al., 2005) because they don't hear properly and their speech doesn't develop in older children and then when they're at school they don't hear properly (Munroe, 2010). Then they're at school and they're day dreaming, in their own little world.* (Otto, 1: 11-17). Otto's understanding of the condition reflects findings from the literature about its potential behavioural impact in classroom performance.

**Figure 8.1 Otto's image Girl at School (Reconstructed)**



Jane, Caz, Wendy, Lois and Marian, mothers in this study, all identified that their child had developed a tendency to day dream. They variously described this as *off with the fairies* (Lois), *in her own bubble world* (Marian) and *away on her own* (Caz). The link between the behaviour and the condition was not always made by the mothers who tended to view it as something about their child. They did not perceive it as a coping strategy to provide respite from the high level of concentration needed to process what was being said or to filter out sounds to which they did not wish to attend.

Otto's knowledge appeared to be much greater than that of the educational professionals with whom parents are likely to look to for understanding the problematic behaviours he explained. Brian, the educational psychologist in this research, acknowledged his limited understanding of the condition: *Just through what I've picked up over the years, I haven't read any articles on it. I've come across a few children who people have said that they have Glue Ear, or had it in the past* (Brian, 1: 15-17). However, he was in the role from which schools might expect support for a child who was not paying attention or with poor social interaction skills. As Jane, Russell's mother, related (in Chapter 5, Table 5.2) the SENCO had been concerned about Russell's tendency to withdraw from others, so had asked an educational psychologist for an assessment. The educational psychologist decided that Russell had *quirky social skills*. However, this vague description could lead some parents to make their own diagnosis and labelling their child with other conditions which may share similar observable behaviours. But Brian explained that he

would not necessarily challenge the parent's assessment: *if parents are convinced that he has ASD, it's very foolish of me to tell them that he hasn't.* (Brian, 3: 1-2). Although he may not wish to argue with parents, it could be suggested that if he had appropriate knowledge about Glue Ear, then he might be in a position to reassure them that intermittent hearing loss could lead to social withdrawal in young people, such as Russell, who have the condition long-term or in those who have moderate hearing loss.

The mothers in this study expressed concern about their children's behaviour and in some cases looked for explanations excluding Glue Ear. This may have been because, based on the information that they had been provided, they tended to construct the condition in medical terms, therefore not including any potential behavioural implications. However, there was a strong overlap between the mothers' explanation of their child's social interactions and the list of likely behaviours, based on reading the literature, provided by Otto.

**Figure 8.2 Jane's image Boy on the edge of the playground (Reconstructed)**



Most of the mothers raised the issue of the way their child appeared to be a bystander in their interactions with others, particularly in unstructured group situations. When exploring the image of the boy standing on the edge of the playground (Figure 8.2), Jane stated: *basically he isn't really bothered about other people. He doesn't do groups of any kind.* (Jane, 2: 19-20). She noted that although Russell had friends, he preferred to be on his own. Wendy described similar behaviours in her son, Peter: *he had friends but he never wanted to engage with them. Even from*

a very young age (Wendy, 1: 13-14). Marian explored how her daughter, Poppy, was a *spectator*. *She'll watch, so if uhmm they're, erm if they're playing... so for example, she might have 3 or 4 friends round and if erm uhm... one of them...if one of them... erm she'll tend to be the one who won't suggest the games. Or they'll start playing a game and she won't want to play it but she won't say anything, so she'll just drift off* (Marian, her emphasis, 6: 12-15). In an almost identical home situation, Miranda explained how Helen, her daughter: *sometimes when she had friends home, she'd play with them for a little while, then she'd want them to go home because she didn't want to play with them anymore. She likes her own space and her own company.* (Miranda, 8: 31-33). For Caz, her 14 year old daughter, Daisy's, behaviour continued to the time of the research: *she doesn't do eye contact, that well, doesn't engage with people, unless she chooses to and then she can be absolutely fine.* (Caz, 5: 1, 6: 2). Caz identified Daisy as socially competent, *absolutely fine*, however in the same way as the other mothers related, the key was that their child did not really appear to want to engage in social interactions.

The mothers' accounts of their children's social skills showed striking similarities in their preference for being on their own and tolerating other people for a limited amount of time. Lois explored such a pattern in her son, Stewie. The exception was in his relationship with his friend, J: *He's two years older. But he has a speech impairment as well so that .... Kind of.....they, they used to be great for each other you know that he'd understand that J had a stammer so he'd wait and ... he'd say, 'People don't wait and listen to him.' And stuff like that and J would know that Stewie couldn't always hear things so it was great really .... erm yeah.* (Lois, 9: 35-39). Lois explained that the two boys seemed to understand what the other one needed so their friendship was perhaps built on mutual respect. From the way the mothers described their children's behaviour, it suggested that the young people had difficulties with social interaction so it was perhaps easier to withdraw.

Similarly, Daisy, Stewie and Russell highlighted that they recognised for themselves that their relationships with others had an element of distrust (Chapter 7). Daisy had friends who knew about her hearing problems but she felt that they did not always make sufficient effort to accommodate her needs or take the time to include her. Russell perhaps did not wish to make himself different and therefore potentially vulnerable, by confiding about his hearing difficulties. Stewie, in contrast, had a close friend who was a great support to him. Whether these potentially distant relationships were a result of choice or circumstance was not explored. However, this may well be an area for further research to develop a greater understanding, from the young people's perspective, how their hearing difficulties impacted their social relationships.

Angelides and Aravi (2006) explored the experiences of students with hearing difficulties when attending specialist and mainstream schools in Cyprus. They found that the hearing-impaired students tended not to mix in socially with other students in mainstream schools. The students explained that they felt that others did not understand their needs or the ways they had difficulty communicating with them. However, it seems that when someone understands the specific needs and makes adjustments, as Stewie and J did for each other, then the social interaction is much smoother, potentially leading to better skills development. If teachers do not have knowledge of the potential impact of Glue Ear on social skills then they could perceive the situation as something within the child, the home environment or due to another cause.

This lack of awareness of the behavioural implications of the condition among teachers became apparent when I met Rachel, a Reception/Year 1 teacher. Although initially she did not believe that she had very much knowledge of the condition, she was able to use her experience to identify some common characteristics that children with Glue Ear appeared to have: *I think that it makes them very distracted. So they find it really difficult to tune in and I think that it's really difficult that when they come in, it's really easy to think that they're just young and easily distractible, whereas that's not what it really is. Whereas sometimes we pick up a problem when*

*they don't seem to make much progress in phonics, when they seem to have difficulty tuning into the sounds. So we sometimes pick it up that way, but we've had children where the problem has been picked up by the school nurse and they've made really good progress in phonics* (Rachel, 1: 13-23). Otto, the ENT consultant identified, that young people with the condition *day dreaming, in their own little world*. Rachel reflected this behaviour as not *tuning in*, perhaps attributing it to something within the child rather than a result of the condition, perhaps because she lacked knowledge about it. Her main focus was on their academic performance, where behaviours such as being *easily distractible* resulted in the child not *making much progress in phonics*.

Rachel explained that for those children who made *good progress in phonics*, it was the school nurse who tended to identify a hearing problem as part of the health checks with the Reception children. Annie, the audiologist, explained that often this focus on the performance of the 'average' child can impede an individual child reaching his/her full potential: *we are only assessing verbal language, I don't care if you think they are age appropriate, if they are in the top 10<sup>th</sup> percentile, then they should be 3 years ahead* (Annie, 4: 10-12). The importance of considering what constitutes *appropriate progress* needs to be related to the individual child rather than accepting performance against the norms of age group average. If teachers had broad knowledge of the potential impacts of Glue Ear in behavioural and functional hearing implications then it is likely that they would be able to better support each such student to achieve his/her full potential. Early years' practitioners in particular, who potentially see many children affected by the condition, are likely to benefit from increasing their knowledge about the broader aspects of the condition. There is a strong case to be made for sharing the research findings from the healthcare field (speech and language therapists, ENT consultants and audiologists) with educational professionals. The latter are in the position of seeing the day-to-day impact of the condition and, with knowledge of it, could perhaps improve young people's performance by making minor adjustments in the classroom.

Higson and Haggard (2005) in their comparison of the understanding of the impact of Glue Ear found that generally teachers were more concerned with language skills than parents or ENT consultants. Rachel demonstrated such bias when recounting her experience of a girl who was in Year 3, when we spoke. She had a history of Glue Ear, but the staff did not link that to her behavioural issues: *she had had 2 sets of grommets and her speech was quite difficult when she came to us. She's improved now, but we thought that that was probably linked to her hearing issues.* (Rachel, 3: 39-41). Rachel made the expected association between poor speech and hearing loss. However, she was reticent to connect the girl's behaviour when she joined the school to the condition: *She was a nightmare, an absolute nightmare. She was incredibly aggressive, she'd try to get out the building, we don't think it was just related to Glue Ear, she was the middle one of 5 children so we thought there was a lot of middle-child syndrome* (Rachel, 3:46-48). Interpreting the girl's behaviour through knowledge of the condition may have provided a different explanation. Not being able to hear or make herself understood could lead to the girl feeling frustration with this potentially developing into aggression (Bidadi *et al.*, 2008). Sensitivity to noise and not being able to block out sounds is common in children with Glue Ear (Sun *et al.*, 2011). Possibly the girl found the noise of other children and the reverberation of sound upon her entrance into the school building of a morning overwhelming thus leading to her wanting to escape by getting out of the building (Toe, 2009). However, in this case the staff considered that her behaviour was more likely to be related to issues within the family, *middle-child syndrome*. Despite two years of speech and language therapy leading to improved speech and potentially the girl's Glue Ear resolving, as in the usual progression of the condition, Rachel continued to attribute the change in her behaviour solely to the school's efforts: *we've worked really hard with the family* (Rachel, 4: 11). This pattern was reminiscent of Jane's situation (Chapter 5, Section 5.3.2 Initial Analysis) when the SENCO suggested that Russell's behaviour pattern might be linked to poor parenting skills.

Perhaps further research could investigate if there is a widespread tendency by teachers to assign student's problematic behaviours to issues in the home rather than check in the first instance if the child has a history of an illness which needs to be taken into account. In the last few years, quite rightly, there has been greater emphasis on child protection issues so this may have raised teachers' awareness of that as the source of behavioural problems. The comments by mothers and young people in this research suggested that there may be a case to be made for increasing teachers' knowledge of medical conditions, such as Glue Ear, as a way of reducing the likelihood of behavioural difficulties developing.

Rachel explained that there was no formal system for collecting and sharing health information about for example, children's Glue Ear status. This led to the school relying upon parents, usually the mother, to inform the class teacher. She discussed a student whom she described as *flitty* through her Reception year at school, who had: *moved out of my class now, but I still have her for phonics and I've now heard on the grapevine that they're checking to see if it's something else.*

*C: Did she get referred to ENT?*

*R: I don't honestly know. I think she has been referred because she's been for a hospital visit, 'cos I'm not her teacher anymore, but I'm sure the other teacher said that she'd been to a hospital visit and they were investigating to see if it's more than just Glue Ear. (Rachel, 2:26-43).* Rachel demonstrated her perception that the condition is not serious: *if it's more than just Glue Ear.* The use of *just* suggests that the condition itself can not cause problems. Additionally, Rachel currently received her information through *the grapevine*. One drawback of such an informal situation is that the relevant staff may not receive appropriate information which could help them in supporting the child to reach his/her full potential or be able to take account of specific support which may be needed. There is also an ethical issue of respecting the privacy of the child and family to prevent such information becoming part of staffroom gossip. If there were a formal system for recording information and passing it along to all of the relevant staff

then the child's needs could be clearly understood and lessons planned appropriately. The information could be treated with due respect for confidentiality.

Although the Reception children have a routine health check, this is carried out by the school nurse and so is separate to what teachers may see as their remit in supporting a child academically or needing to have any knowledge of common medical conditions that they may have. Unless there was a problem with phonics, Rachel explained that it was seen as the role of the school nurse to pick up any hearing problems. Although Glue Ear is common up to the age of 7 years of age, Rachel explained that her knowledge about the condition had come through experience, in a similar way to how Brian, the educational psychologist, had described. She did not appear to actively seek out relevant research or information about the condition. She had received no formal training in it as either part of her initial teacher training or in-service provision. Rachel had recently taken on the role of SENCO, so her lack of understanding of the condition could potentially impact the whole school. This suggests that there is a need to provide all teachers with easily accessible information on this condition along with its behavioural implications and strategies to be used in the classroom to minimise its potential impact.

Terry, the secondary school teacher, had received some training in his initial teacher training about visual and hearing impairments because one of the other students organised it as she was going to be teaching in a school for students with visual impairment. This was not part of the usual initial teacher training undergraduate course, but resulted from the personal interest and initiative of one of the students. As Glue Ear is a condition that continues on for some young people into secondary school, as demonstrated by Daisy in this research, there is a need for training teachers in all stages of education about its possible repercussions. They need to know not only about the condition but also how to best support the individual student.

The lack of formal systems whereby a teacher is informed of any additional needs that a student may have was also absent in Terry's school: *there is no [system], the information is out there*

*and the assumption is that people go and find out* (Terry, 2: 4-6). As he went on to explain, a further difficulty was that individual teachers have to be proactive and access information: *through the SENCO you can get information, but if it hasn't been picked up or if the previous school hasn't sent the information in good time, you would struggle with that as well. So we had an issue with a primary school that did not send their folders in good time, so what that meant was that it was people were working on instinct or calling the parents* (Terry, 2: 12-16). As Glue Ear is not regarded as something of high priority then the information might take longer to be passed on. Terry explained that in the secondary environment students often move between schools, some students come from overseas and so the information may either not be passed on or not available. The situation of teachers not being given information was reflected in what Jane, Lois and Caz had to say (Chapter 6). An alternative to a formal system through the SENCO might be for the teacher to take the initiative and ask a student who was struggling if they had any difficulties which may impact their work.

The lack of readily available information can lead to situations in which the student is aware of his/her condition, but the teacher does not know leading to a mismatch in interpretation and expectation. Daisy demonstrated such an interaction with her teacher (Chapter 7) who was trying to help her but gave her a detention as he interpreted her behaviour as rude as he did not know of her hearing loss. Terry had experienced a similar situation with one of his current students. He used the third person, plural, when referring to the student: *They could hear from one ear but had problems and I didn't realise that and I'd set them a task in which they had to look across the wall, and they kept trying to turn their chair in a place that could get them within my voice projection or within a place that they could hear what I was saying. And I kept thinking, you know, can you sit properly, can you face the front.* (Terry, 1: 41-45). The student tried to improve his chances of participating in the lesson by turning his chair around; however, Terry assumed he was distracted in some way because he was not *facing the front*. It could be argued that secondary school students potentially have the maturity to explain their hearing difficulties

to the teacher and ask for adjustments. Daisy explained (Chapter 7) that although her parents wanted her to take such action, she did not want to. The difficulties encountered by parents and young people in explaining to teachers the hearing implications associated with Glue Ear were explored in Chapters 6 and 7.

Terry discussed his understanding of how a student may not wish to bring attention to himself, but still need extra support. Terry explored the situation of a student who was no longer in his class but he had found out, through staffroom conversations, that the student had been in hospital for treatment for Glue Ear. *He was in a sort of bottom group, but he was quite bright, seemed like a nice lad I should say but he had behavioural issues and now in retrospect maybe he wasn't accessing everything that was going on in the lesson maybe he wasn't hearing everything. But in secondary school there is stigmatisation and kids will hide their problems and not come forth and say, 'I'm having trouble hearing, can I come and sit at the front?'* (Terry, 2: 35-40). Terry assessed the student as in a *sort of bottom group* yet he was *quite bright, seemed like a nice lad*, however *he had behavioural issues*. In retrospect Terry considered that perhaps this was because *he wasn't accessing everything that was going on in the lesson maybe he wasn't hearing everything*. Terry lacked formal training in how best to support students with health problems which could impact their performance and behaviour. His lack of knowledge about Glue Ear could be part of the reason, with his colleagues likely to be in the same situation, why the boy's aggressive behaviour had escalated over time.

This situation was similar to the way in which Rachel described her young pupil. It seemed that perhaps teachers interpreted behavioural issues as a problem within the student rather than thinking about what it must be like not to be able to hear everything that was going on so perhaps having problems with processing all the available information. Such difficulties are likely to impact not only academic performance, but also potentially lead to frustration and poor peer relationships (Bennett *et al.*, 2001). It was unclear whether Terry thought he should have been

told about the student's condition, the student should have told him or he should have noticed it. The words of Annie, the audiologist, are reflected in this situation whereby the student was making progress, but perhaps not at the same rate as would happen if everyone knew about his condition and adopted appropriate strategies to support him.

Behavioural issues due to the frustration of *maybe he wasn't accessing everything that was going on in the lesson maybe he wasn't hearing everything* (Terry, 2: 36) were expressed by participants in this research. Stewie (Chapter 7) explained how his *stress* appeared when he could not follow his teacher's explanation of answers to a comprehension exercise. Jane, Russell's mother, highlighted that Russell's teacher's style of giving instructions caused Russell confusion and disengagement: *So he gives all these instructions and Russell doesn't know what he's doing plus the fact that he's dyslexic, so his processing is slightly slow anyway so he doesn't stand a chance, so then he gets cross, and he'll just go, 'What's the point?' (J put imaginary pencil down and sat back)* (Jane, 2: 33-35). This type of situation could be overcome if all parties shared information about the condition to provide students with a better opportunity to achieve their potential and stay engaged with school.

There are a number of issues which would benefit further exploration of this situation in future research. As the condition is often associated with fluctuating hearing loss, it poses additional difficulties in explaining that sometimes there is no need for any adjustments to be made, while at other times there will be. Zheng *et al.* (2003) suggest that teachers and peers do not understand how different environments can alter whether someone with hearing difficulties can hear and often underestimate the need to make allowances for them. In this research, neither the mothers nor the young people with the condition described themselves as 'deaf' and there was an expectation that the condition would resolve so there would not be a long-term problem. They are therefore in a situation of potentially not wanting to draw attention to themselves or being regarded as overly demanding. Developing the skills of self-advocacy takes confidence and

support (Goodley, 2000) which suggests that perhaps teachers need to provide the environment in which this is encouraged. However, teachers too need self-confidence to encourage self-advocacy skills in their students. If they do not have the appropriate training in developing strategies which encourage young people to express themselves or a good understanding of the condition then this is unlikely to happen.

When discussions do not take place and teachers are not equipped with the skills to take the initiative in encouraging students and parents to explain the impact of ongoing frustration and under-achievement, the student's behaviour may deteriorate. Terry discussed such a situation with one of his students whose behaviour was such that he was accompanied full time by a teaching assistant. However, Glue Ear may not be identified as the underlying reason for the behaviour, perhaps because it is perceived as a medical condition. Despite his awareness of the hearing implications, Terry did not appear to have made the link between the condition, potential frustration and behavioural issues: *I'm not aware of whether someone with specifically Glue Ear would have a learning support but in this case he has other things, like behavioural issues, I'm not sure if there is a link between the behavioural issues and the hearing issues, but they've been listed as having behavioural issues. BESD obviously they've got that as well.*

*C: So what sort of behavioural issues?*

*T: It's more of struggling and linked to interaction and if something is not going quite right, or they feel like they haven't been treated fairly or something has changed, then they may just be very aggressive in some cases, or put other kids in danger so it's just making sure that they have someone to calm them down should that happen.* (Terry, 3: 22-30). Although Terry seemed aware that someone may become frustrated if they can not hear, in the case of this student he was *not sure if there is a link between the behavioural issues and the hearing issues.* It seemed that he regarded the behavioural issues as being caused by BESD (Behavioural, Emotional and Social Difficulties). Silva *et al.* (1982) identified that children with the long-term condition can become aggressive and Bennett *et al.* (2001) highlighted that aggressive, anti-social and neurotic

behaviour can continue into teenage years. The student appeared to have difficulty in social interactions perhaps because he could not follow the conversation and missed information so he interpreted this as not having *been treated fairly*. There was a similarity in this description with the way in which Daisy felt that her friends sometimes did not make allowance for her hearing difficulties and she wondered if they were mocking her by not speaking loudly enough for her to follow the conversation or talked over each other so that she could not follow the thread of what was being said.

I explored with Terry whether he had spoken to the boy to find out more about his condition:

*No, well because again it's quite a sensitive issue, because you know his condition, you try and accommodate it you try to be as normal as any student with any learning or any if they are struggling it's better to be as normal as possible whether they can't hear or they have a speech difficulty or any other defect, so I try and not to address issues and try and treat them as normal as possible.* (Terry, 4: 13-15). Shevlin and Rose (2008) summarise the legislation which emphasises how students should be active participants in identifying how they can best be helped to access the curriculum. They underline that if students are to make a positive contribution to society then they need to learn how to develop those skills. In this section, Terry emphasised that he considered *it's better to be as normal as possible*, and that *I try and not to address issues and try and treat them as normal as possible. I try not to talk*. Terry did not address the issue directly with the student as he thought that *it's quite a sensitive issue*. He stated that he chose *not specifically to talk to the young person*. Marshall *et al.* (2002) identified that sometimes it is the teacher's personal discomfort about discussing disabilities rather than the student's willingness to talk about their condition as to what help would benefit him/her.

As Shevlin and Rose (2008) point out, there is a mismatch between legislation and classroom practice in directly consulting students about their needs. Daisy (Chapter 7) explained that she was open with her classmates about her hearing loss, but her teacher did not appear to know

about it or encourage her to identify what would help her. By not talking to the young person directly teachers are potentially missing out on ways to keep students engaged in school thus potentially improving their educational performance and reducing their stress levels. As Stewie related (Chapter 7) when his 'good' teacher asked him what support he needed he was much calmer and able to perform more effectively in the classroom which was, for him, a very confusing environment. Although Terry's intention was potentially not to draw attention to his student's special needs, by not taking them into account, he was disabling him (Murray, 2006).

Rachel, Terry, and potentially many more of their colleagues, need training in understanding that the condition has wider implications than just affecting phonic development and may lead to a young person developing behavioural issues if they are not appropriately supported. It would seem worthwhile to help teachers in developing strategies and frameworks to encourage their students to explain how the condition impacts on their participation in the classroom. The intention would be for the teacher and student to collaborate to identify the optimum ways for the student to engage with the learning. It may be that teachers need support in exploring their personal responses to interacting with students with special needs (Marshall *et al.*, 2002).

A similar lack of consultation with parents also seemed to be occurring. When discussing the student with Glue Ear and behavioural issues, Terry clarified that he would approach other adults: *maybe speaking with his form tutor or maybe with other stakeholders, yes or parents at parents' evening,*

*C: So have you seen his parents at all?*

*T: I think that we have... I did see them last year, but it was a sort of brief sort of we never really got to discuss anything with the condition it was more about how he was getting on.* (Terry, 4: 17-19). Rather than consulting the boy's parents and asking for their suggestions as to how their son could be best supported the conversation was *more about how he was getting on*. It seemed that he therefore missed another opportunity to improve the boy's participation in school.

The reticence of teachers to acknowledge parental expertise in their children was highlighted by the mothers in this research. Teachers often dismissed them when they offered additional information, such as happened to Lois and Jane (Chapter 6). Miranda identified a situation when she went into school to talk about the wider implications of her daughter, Helen's hearing loss: *I went in and said to the teacher that I was worried about her self esteem and I can remember the response even to this day. 'Self-esteem isn't something that's affected by what we do, it's what they're born with.'* Do you know what, at that I thought, you know what, this isn't the right place for her. (Miranda, 8: 6-9). Miranda chose to move her daughter, but not all parents have the opportunity to do so. Cervetti *et al.* (2014) highlighted that when parents and teachers work together then the student has a more positive outcome.

Rachel and Terry both identified that they had limited knowledge or training in Glue Ear so their understanding of the wider implications of the condition would be likely to be limited. It does appear that part of the problem was that they did not believe that their students' problematic behaviour was linked to Glue Ear and it seemed that it was not perceived as a special need. Teachers regularly receive training in child protection issues. It may be that, as the numbers of children for whom adjustments need to be made increases in mainstream schools, then regular reminders about the responsibility of teachers to consult with both young people and their parents about the specific support they need would be beneficial. It may also mean that teachers' confidence in discussing such needs would increase as it becomes incorporated into their practice. Consultation with young people and parents is a requirement of the *Special educational needs and disability code of practice* (2014). If discussing specific needs with individual students becomes part of the school's measurement culture, then it is likely to lead to an increase in the prioritisation for such training.

Brian, the educational psychologist, recruited as part of the professional group had a background as a teacher and had worked as an educational psychologist since the early 1990s. As stated

earlier, Brian had not been trained to understand the condition. His assessment was that *it is diagnosed by medics and you need equipment and you need expertise in hearing in order to identify it* (Brian, 1: 26-27). The medicalisation of the condition may lead to focusing on its physiological aspects rather than educational and behavioural implications. It seemed therefore that educational professionals are likely not to develop their understanding of this condition because they primarily perceive it in medical terms.

Brian speculated that *a child can have difficulties with language development as a result of it just not hearing what's going on.* (Brian, 1: 22-23). His explanation of the condition focused on language difficulties. He identified that if a child had a history of colds, he would include in a report that Glue Ear could be investigated. Similarly, when I asked what knowledge of the condition did he think there was in schools he explained: *I'd say there is very little in fact. They might complain that the child is not responding or doesn't have a good level of language, but I'm not sure that the teacher would come up with the idea that the child might have Glue Ear.* (Brian, 2: 14-18). He seemed to associate the condition primarily with cognitive issues. This suggests that there is a need for training and increased understanding of the condition among a breadth of educational professionals.

Because it does not have a high profile among educational professionals, or the public at large, and the behavioural and social aspects of the condition are not widely understood, this may lead to its repercussions in young people being misattributed. Brian's assessment was that school staff and parents are quite likely to label a child with behavioural issues as being on the autistic spectrum or showing the characteristics of ADHD because information about those conditions is frequently in the press or on television. He explained that such conditions are: *socially constructed, and two professionals, even two psychologists could see the same child and come up with different conclusions. We have to be very cautious in how we approach matters, and very sensitive ones, and if parents are convinced that he has ASD, it's very foolish of me to tell them*

*that he hasn't.* (Brian, 1 :49-50, 2: 1-2). It seemed that the lack of agreement among professionals undermined Brian's ability to dispute parental assumptions. The parental opinion in this case took precedence over the professional view. A further complication that he highlighted was that because of budget cuts and changes in government policy: *people have become more careful about their area of expertise and far less joined up thinking than there used to be because people are fearful of their jobs. Also hostility of encroaching on others' expertise.* (3: 10-12). From Brian's review of the situation, it seemed that issues between professionals in lack of consistency in diagnosis and territoriality, when working in multi-agency teams, diminished the value of their professional expertise and opinion. Although policies emphasise listening to parents' views about their children, it is important to set this within the context of professional knowledge to either investigate the condition further or use the parent's specific knowledge of their child. It seemed that Brian sometimes acquiesced to parental opinion, which may not be backed by a professional diagnosis and potentially not in the young person's best interest.

Many of the mothers and the young people in this research discussed their interaction with audiologists who conduct the hearing tests as part of the regular hospital check-up process. Otto identified that the results of the audiogram are one of the key elements in his decision-making as to whether he would put a young person forward for surgery. Annie was recruited to explore the view of Glue Ear from an audiologist's perspective. As well as her professional experience in that role, her current position was in a university where she educated and supervised both trainee audiologists and teachers of the deaf.

Annie identified that pragmatic language skills were important not only for children's understanding of language but also for their social integration. She highlighted the potential problems: *If you are the person who doesn't quite get it or has to constantly look at your neighbour or has to constantly say, 'Can you repeat that?' 'What?' What does that do to you as*

*a person when you constantly have to have things repeated and constantly trying to understand things* (Annie, 1: 48-50, 2: 1). She emphasised the repetitive nature of this situation by repeating *constantly*. Annie could empathise that it would be highly likely that this could lead to young people with the condition developing low self-esteem or being rejected by their peers. The need for repetition and the impact it had on an individual's stress level was recognised by Stewie (Chapter 7) as leading to him feeling fed up and increasing his stress levels. Similarly, in Daisy (Chapter 7) it aroused feelings of exclusion and extreme anger.

Annie put into context the potential issues associated with constructing Glue Ear as a temporary condition resulting in mild hearing loss. Firstly, because it was not well understood in educational contexts then the hearing loss is attributed to a shortcoming within the child: *if you are a quiet child, or the naughty child or the child that we don't think is very bright, then it's all put down to that. And so what we do is there are intrinsic features of children and there are extrinsic features of children and what we do is we manipulate the extrinsic features to disable the children.* (Annie, 2: 2-6). Rachel demonstrated this when she described one of her female students as *a nightmare* and *aggressive*. Applying Annie's concepts of *intrinsic features*, hearing loss and personality, were reinterpreted as the *extrinsic feature* of poor behaviour resulting from *family issues* (Rachel). Jane experienced this situation (in Chapter 5) when the SENCO interpreted Russell's tendency to withdraw as potentially symptomatic of Jane having poor parenting skills. Russell's hearing loss and coping strategy of social withdrawal needed to be interpreted in the environmental context of a very noisy classroom in which he could not block out the sounds to which he did not wish to attend. Terry interpreted his student's aggressive behaviour as a factor of his behavioural difficulties rather than reinterpreting it as frustration at not being sure what was going on in the classroom or being able to interact effectively with his peers, which had led to aggressive behaviour. In all these situations, if the condition was better understood by educational professionals then the environmental factors disabling the child could be changed for more positive outcomes (Goodley, 2011).

Annie clearly understood the condition and where it was located in terms of funding, which related to Brian's assessment. Some parents identified their child as having a condition with a high profile which was likely to attract greater support for their child with the diagnosis being hard to dispute as the behavioural attributes can result in differences of opinion in professionals (Bruchmuller *et al.*, 2012). Because the wider behavioural implications of Glue Ear are not widely known among professionals or parents, a repeated history of it was not considered important but *goes in the report* (Brian, 1: 30). This was compounded because of funding cuts, leading to limited availability from specialist support teachers: *Teachers of deaf will pick up children with conductive hearing loss in some areas and talk to the parents, give support in schools. But as services contract and are cut then they will be the first to go.* (Annie, 4: 5-8). Annie identified that not only are there inconsistencies across the UK as to whether young people with conductive hearing loss (Glue Ear) are supported in schools but, as Brian also noted, funding cuts mean that services are being contracted. This suggests that it is unlikely that support for the condition will increase in the near future. If young people with the condition are to achieve their full potential, then there needs to be greater understanding of the wider implications of it among class teachers. This again supports the need for the development of appropriate training material.

Annie highlighted the continuum nature of the condition: *It is recognised that it has an effect, but it's episodic and for one child it will resolve by the age of 2, for another at the age of 6 and for some children it won't resolve. It's very hard to make any overall statements about it,* (Annie, 6: 1-4). She explained the way in which it could impact individuals differently and how the description could trivialise its impact: *People say, 'Well they've only got Glue Ear and it's a mild loss.' And what they forget is that mild is referring to a number, but not to an individual. So mild may be massive in terms of effect.* (Annie, 2:46-48). Annie's use of *only* as an adjective to describe the condition explained how it was dismissed. However, as previously demonstrated (Chapter 2) by Winkler (2006) even in those children in whom the condition resolved by 7 years

of age, if they have had repeated episodes from an early age, their reading skills remain significantly less developed than those of their unaffected peers.

Annie explained that describing hearing loss in terms of decibels may not fully explain how the condition impacted each person with the same decibel loss resulting in different perceptions as to what they could hear. This is in part explained by the continuum nature of the condition and also variations in a child's environment (physical, social, family and economic conditions) potentially resulting in a variety of outcomes. The results of this mild hearing loss can be: *subtle, the effects are in some ways more pervasive because you don't see it. They don't have a hearing aid to even indicate a hearing loss.* (Annie, 3: 1-2). Hearing impairment is by its nature invisible. For Glue Ear the intermittent nature of this loss means that most children are not offered the option of a hearing aid so there is no visible presence to their hearing loss and there are times when they can hear at the same level as their peers.

The educational professionals, Brian, Rachel and Terry, who participated in this research explained that they had no formal training in Glue Ear and had limited understanding of its impact on educational performance, primarily identifying its impact in terms of not developing phonetic skills at the same rate as other children and having difficulty hearing in class. The ENT consultant, Otto, had wider knowledge about the behavioural aspects of the condition, but these were not communicated to parents. Annie, the audiologist, demonstrated a clear understanding of the physiological implications of the condition as well as the behavioural and social implications. However most audiologists play a subsidiary role in interacting with parents and young people with the results of audiograms either being presented in specialised technical terms or communicated by the ENT consultant.

In the educational context, Glue Ear seemed to be viewed as a temporary and trivial condition. Teachers would perhaps benefit from taking a pro-active approach by asking about hearing

difficulties and discussing the implications of these with parents and young people to identify ways in which the student can be best supported. If the policy of involving young people in discussing what adjustments they need is to become integrated into classroom practice then it needs to become part of the procedures by which teachers are measured, in the same way as teachers' contribution to students' exam performance is monitored. As the young people in this research indicated, they may not have the confidence to be their own self-advocate and look to the adult to take the initiative in talking about their needs.

The mothers in this research identified that they were quite isolated from other mothers who had a child with Glue Ear. This suggests that they would benefit from the opportunity to participate in a support group for this condition to gain information about the condition's potential behavioural and social consequences and strategies for dealing with them. Glue Ear is far more than fluid rather than air being present in the middle ear and that is a message that needs to be spread far more widely among educational professionals and parents. This is an area where shared knowledge and working in partnership is likely to support the child in achieving his/her full potential.

The educational professionals identified Glue Ear as a medical condition. Brian explained the process for dealing with the condition in his local area as: *go through the school doctor and then the doctor would route on. We do actually in fact here have a hearing impaired team but they don't do the early assessments, they have to go to hospital to be assessed.* (Brian, 2: 21-23). *The school doctor and the hospital* are identified as the way for diagnosis with the *hearing impaired team* not being involved in *early assessments*. This positions the condition within the medical rather than educational field.

Similarly Rachel explained how one mother who was concerned about her daughter's hearing early in the school year: *She went to the doctor, she went to the health visitor and they said the*

*school nurse will be coming in. So I actually went to the school nurse and said, 'This mum's really quite concerned. We would really like to have her tested.'* But then it dragged on, presumably because there was some hold up, somebody was off sick, so it did take quite a few months. The school nurse was quite late coming in last year. (Rachel, 2:1-5). Rachel's description of the mother trying to get help for her child is similar to the experience of some of the mothers in this research (Chapter 6). For the child described by Rachel the situation continued for approximately eighteen months, which could potentially have impacted her academic progress. However, the expertise in this condition is perceived as residing in the healthcare system and until the child is assessed in that context, schools seem reluctant to act.

In contrast to the passive role which educational professionals see themselves as having, Otto, the ENT consultant, considered they have an essential part to play in diagnosis. He explained: *I think that teachers do have a very important role to play because they will be able to pick up which children are having a problem hearing, which children are paying attention, which children are day dreaming and they'll be able to pick up which children don't hear.* (Otto, 5: 23-26). From Otto's perspective teachers are best placed to identify the relevant behaviours in the classroom thus recognising those young people most likely to benefit from referral. As Annie, the audiologist, observed, behaviour in the young person's hearing environment is a better indication of the impact of hearing loss than the decibel range indicated by an audiogram. However, until teachers are aware and have confidence in undertaking this role, it is unlikely that they will become more proactive.

Otto also pointed out that post-diagnosis, the teacher needed to be taking the initiative: *it's sitting the child in such a way that the teacher can talk to the child's good ear and I think it's crucial that teachers know about hearing loss so that they can actively manage the child and do active rehabilitation kinds of thing.* (Otto, 5: 45-47). He emphasised that *it's crucial* that teachers understand both the impact of hearing loss and the strategies they can adopt to support their

students: *a teacher who taps them on the shoulder and checks that they are paying attention* (Otto, 5: 49-50). However, from what the educational professionals in this research said, they appeared to lack understanding of the implications of the condition in the classroom or what they can do to support their students.

Rather than a subsidiary role, Otto explained that *in some circumstances where the child has a teacher who is interested in hearing loss and who is interested in support then the child can avoid having grommets because the mild hearing impairment can be overcome by the teacher working with the child in a slightly different way* (Otto, 6: 5-9). At the present time, however, teachers do not appear to be aware of the central part they have to play or the amount of difference they could make for a young person with the condition. Stewie (Chapter 7) explained how the support from his *good teacher* enabled him to participate more fully and achieve *A grades on his report card*, which resulted in Lois, his mother, feeling proud.

It seems that there is a very strong case to be made for including knowledge of the condition as well as strategies for how young people can be supported in initial teacher training and as part of continuing professional development (CPD) activities for early years' practitioners, teaching assistants, teachers and educational psychologists. This would help to reposition the condition as being relevant in the educational context and develop a much greater understanding of its implications for young people's learning, social skills and behaviour. Rather than a peripheral exercise, I would suggest that all educational professionals need ongoing access to relevant material about Glue Ear and their role in minimising its impact. It could be of value to investigate the development of online training materials as a cost-effective and practical means of providing relevant training and development.

#### 8.4 Medical professionals have knowledge, but no time to explain it

The medical construction of the condition was demonstrated by the mothers in this research (Chapter 6) who described it in such terms but appeared to have less understanding of its implications for social and behavioural outcomes. They had experience of regular hospital visits and the young people in this research had at least two grommet operations. This next section explores the experience of interactions between professionals, mothers and young people within the healthcare context.

The lack of involvement of young people in their treatment and how mothers and young people can have different views was illustrated by Caz and Daisy. Although Caz was aware that Daisy was amenable to the idea of hearing aids: *And then we walked into the doctor and he said, 'Well you know, you could always have hearing aids.'* And I thought, *'Ohh, well.'* *'Cos it hadn't even occurred to me that she'd be bad enough. But Daisy was all for it,* (Caz, 4: 30-33). Caz appeared to have not considered Daisy's hearing loss sufficiently *bad enough* for hearing aids. Although she acknowledged Daisy's response, *was all for it* Caz was less enthusiastic. Hearing aids were offered again on a subsequent visit, but Caz explained: *But it wouldn't really help her as it would just make all noises louder and that would just distract her.* (Caz, 4: 33-36). It seemed that Caz based her decision on her beliefs. Even though Daisy: *was quite acceptable to wearing hearing aids.* (Caz, 4: 36-37), and despite policies about young people being active participants in decisions about their treatment, in this research, mothers' preferences seemed to prevail.

Daisy's understanding of what a hearing aid does seemed a bit confused: *'Cos I don't want a hearing aid because part of that dims your hearing, if you have a hearing aid it works for you but then, you apparently have to decide ... .. Umhh..... yeah it works for you but then your hearing gets so used to it that when you take it out your hearing is like..... what. So it just messes up your hearing, so I don't really want a hearing aid.....* (Daisy, 7: 2-6). Daisy highlighted a

number of times throughout the participant-led discussion that retaining her current level of hearing was very important to her.

Annie, the audiologist, discussed hearing aids as a treatment for Glue Ear: *if you simply make it louder, appropriately and you guard against over-amplification then what you could do is to take a child from hearing (mumble) to hearing normally and they would have normal speech perception.* (Annie, 2: 33-36). Even though they may be helpful, there was an issue with *over-amplification*. Although an alternative existed: *it's quite unusual for a child with Glue Ear to have a radio hearing aid, because people say, 'Well they've only got Glue Ear and it's a mild loss.'* (Annie, 2: 44-46). Annie's description of *only got* trivialised the condition. The result being that although the technology was available, it probably would not be offered due to the condition's portrayal.

Gabe *et al.* (2004) suggested that there are likely to be different coalitions in a triadic discussion when young people are encouraged to participate in deciding their treatment options, particularly where parents retain the right to consent to treatment. However, it seemed that the necessary time for these relationships was not provided. For young people with ongoing Glue Ear it could be argued that the mother and young person already have experience of the condition and are more aware of the impact that it has than others with the less mild form. However their specific needs appeared to be overlooked and there seemed to be little differentiation in the treatment of those with the most extreme form of the condition. Otto, the ENT consultant, potentially provided an insight into the lack of information provision and discussion on the part of the ENT consultants: *I suspect that to a large extent the parents already have chosen their preferred option then I've got no problem with that because to some extent there are three reasonable options and if they have chosen one of those options then to some extent I'm happy to go along with that if they have chosen a reasonable option.* (Otto, 4: 20-24). The *three reasonable options* are to wait and do nothing; put in a set of grommets; or have a hearing aid.

However there are two issues worth considering. Firstly, it was not clear where and how Otto expected the parents to have gained appropriate and sufficient information on which, along with the young people, they could base their decision. Secondly, the consultant may well retain control rather than develop collaborative discussions to actively seek the young person's view. Otto recognised that: *parents are very much influenced by the setting and what the person tells them. I am an ENT surgeon so I'm going to tell them about surgery, so if I was a hearing aid dispenser then I'd talk to them about hearing aids.* (Otto, 3: 48-50). The mothers in this research shared Otto's view that they tended to be guided by the advice of the ENT consultant. As Kate, one of the mothers, suggested when discussing her image in Figure 6.11 of a young girl waiting, the experts tend to control the resources and the mothers and young people can feel compelled to comply.

Annie, the audiologist, appeared to support the mothers' views as to whom had the decision-making power: *it might be incredibly clearly apparent in an ENT's mind, and the service providers and the hierarchies of power. You know the surgeon is at the top of course* (Annie, 2: 21-23). In her point of view the ENT consultant really made the choice: *So there is an issue with Glue Ear, how do you treat it? You can watch and wait, you can have hearing aids, you can antibiotics, you can have grommets, but actually in all the outcomes are more or less the same. So where you live will depend upon what you get. If you are in nominally Xshire, then the ENT consultants will say, 'There's no point in having all these surgeries, there's not point in having anaesthetics that compromises the health of the child give them a hearing aid and they will use it when they've got Glue Ear.'* (Annie, 2: 11-17). Equally, as she identified, *you might be in another area where they say, 'Oh grommets for everyone.'* So you have the patchwork of what's going, because the evidence base doesn't tell us what to do. (Annie, 2: 19-22). Annie and Otto agreed on the possible treatment options. Despite the NICE guidelines (2008) identifying the conditions required for surgery, they agreed that there was no uniform practice across England. Their shared perception seemed to be that parents tended to be reliant on the ENT consultant's

knowledge and his/her preference about the best course of action. This left parents and young people with the illusion of choice but actually they have limited information on which to make an informed decision. This is compounded as the material that they can readily access is written from a medical perspective with a concentration on grommet surgery, or descriptions of the impact on the middle ear.

Otto explained that although Glue Ear may be a very common condition, not all ENT consultants considered it important: *there are people who are interested in head and neck cancer and they're interested in that and whether the person will live or die and if they see a child with Glue Ear they're not going to be interested in that* (Otto, 9: 30-32). Such disinterest on the part of the consultant in the condition might explain why some of the mothers felt that there was not a lot of discussion. Additionally this could perhaps mean that not all consultants have the most up-to-date information about its social and educational implications. They may perceive the condition would resolve by the time the young person was 7 years of age, so potentially not understanding its continuum nature. The mothers and young people in this research experienced the condition in its extreme form.

Kate highlighted the treatment implications for a young person which can result when the ENT consultant has limited information about the condition. She had been attending a clinic in a large town with her daughter, Pippa, until she was offered an appointment at a closer hospital. She had not considered that there would be any difference in the level of care that Pippa would receive. However, as she related: *What they didn't tell us was that the person we were seeing was a throat specialist not an ear specialist, this went on for about 3 or 4 years* (Kate, 4: 3-5). It was only after she changed an appointment and returned to the main hospital that she understood the effects of not seeing a specialist with an interest in Glue Ear: *And we went to the town and had a completely different experience and the person said, 'What have you been doing about all this?' And I was unaware of the hole getting larger and I said, 'Well nobody's said anything because*

*they've looked at Pippa's ears and said that it's all fine.' They said, 'Who have you been seeing?' and we gave them the name and they went... 'they don't really know about ears'...*

(Kate, 4: 10-15). Although Kate had trusted in the system and believed that her daughter was getting specialist treatment, by default she found this was not the case.

Perhaps because Pippa did not have a life threatening condition or one in which the consultant had a specific interest, clinically there was very little that could be done about the hole in Pippa's ear drum, so it was monitored and documented. Potentially the labels of 'temporary' and 'common' meant that the condition was taken less seriously, even if Pippa had permanent hearing loss, maybe the consultant's perspective was that her life was not in danger. Although Kate was a children's nurse and had medical training, she had not understood that different ENT consultants had different interests. In their grounded theory study, Wuest and Stern (1990) found that mothers of children with ongoing Glue Ear initially wanted to trust the knowledge of medical professionals. A breakdown in belief in the medical professional's skill, can lead mothers to both identify actions which return their sense of agency for protecting their child (Gunnarsson et al, 2013) but also safeguard their own image of being a 'good' mother. Kate took action to find another professional whom she regarded as having appropriate knowledge and turned to her for support in Pippa's care.

As Otto explained, ENT Consultants are in a vulnerable position. They lack understanding about what causes Glue Ear and are unable to specify which child will have long-term damage as a result of it (Bluestone and Klein, 2007). In the clinical context, patients are unlikely to want to hear their healthcare professional, whom they are likely to look for answers, say that he/she does not know what caused it; when an individual child would grow out of it; or if it would result in long-term and permanent hearing loss. Otto emphasised that the grommets are not a cure, but their function is to relieve pain by reducing the associated ear infections until the condition resolves. However, his explanation to parents was deliberately vague: *in my practice I would*

*specifically say that there are some children who will have to have grommets again, which is a roundabout way of saying that grommets won't cure it. But then again I won't say to them that it won't cure Glue Ear because there are some children who won't have to have grommets again.* (Otto, 3: 26-29). Although he was not being clear in saying that he could not predict the outcome of surgery in a particular child, he faced the dilemma of not wanting to reduce parents' faith in his expertise.

Although ENT consultants may have the most knowledge about the potential implications of Glue Ear (Higson and Haggard, 2005), they lack the time in the clinical setting to discuss and explain these to parents and young people. Otto explained that the condition is multi-faceted and in the context of the busy clinical setting there was not time to fully discuss with parents and young people its complexity or to encourage and respond to questions. However, the Department of Health (2004) highlights that young people should take an active role in decisions about their treatment. If they are to do this then they need information which is understandable and appropriate for them. Martenson and Fagerskiold (2007) found in their study of the interaction between parents, young people and healthcare professionals in an outpatient clinic that nurses played a key role in supporting young people to understand their condition better and to answer their questions. With the current economic restrictions and the way in which ENT clinics are organised with a mix of different ages of patients, the resources are unlikely to be available for such support. However, well set up support groups for young people and their parents, could provide an alternative means through which such issues could be explored in a more appropriate setting. This may apply equally to those who experience the condition as temporary through to those with the recurring condition experienced by young people into adulthood.

Another area in the treatment of Glue Ear where the voices of young people appear to be marginalised is in their preparation for grommet surgery. From the perspective of the young people and the mothers in this research the procedures of the hospital seemed to dominate over

active consultation and choice. The most stressful part of the whole situation for the young people and their mothers was the administration of the anaesthetic by injection. Stewie and Daisy detailed their fear of the needle associated with having an anaesthetic and their resultant high level of anxiety (Chapter 7). In this section the focus is from the perspective of some of the mothers in this research, supplemented by Otto's viewpoint.

Wendy related her memory of her son, Peter's, response to the administration of the anaesthetic for his first grommet surgery. She used three images to explore her reactions: Figure 8.4 a picture of a large needle, Figure 8.5 of a boy using an inhalation mask and Figure 8.6 of a boy with a blood shot eye. The number of images she used was perhaps an indication of the extent that the experience impacted her emotionally. She felt that she was neither prepared for what to expect nor given sufficient information to minimise Peter responding negatively.

#### Wendy's images:

**Figure 8.3  
Needle**



**Figure 8.4  
Boy with an  
inhalation mask**

Redacted Image

**Figure 8.5 Boy with a  
bloodshot eye  
(Reconstructed)**



She explained that initially the anaesthetist had attempted to put a cannula into Peter's hand but he had not co-operated. The *anaesthetist said, 'Right we're not going to go down the injection route, we're going to have to gas him.'*... *So we were in the pre-med room, whatever it is. So.. so they put the gas mask on him and he was he was hysterical, hysterical, absolutely hysterical. But they said, 'Look this is going to be uncomfortable for you, but the only way we're going to get this boy knocked out is to mask him.'* (Wendy, 4: 28-33). In this situation, Wendy was a bystander to what was happening to her son. From her account, the anaesthetist was in control and his

focus appeared to be on his task rather than considering Wendy's potential response to how his language objectified Peter *have to gas him, this boy knocked out and mask him*. It seemed that no one was responding to Peter as a person *this boy* and no one appeared to talk to him to try to calm him down. Wendy's repetition of *hysterical* indicated how she perceived his level of distress, but she remained on the outside of caring for her son. The anaesthetist demonstrated some understanding of Wendy's potential response, *uncomfortable for you*, but this seemed to underplay her likely feelings. Wendy's lack of familiarity with the environment was captured in how she labelled the room *pre-med room, whatever it is*. Her experience seemed similar to how the Daisy and Stewie (Chapter 7) explained the procedure. Both Daisy and Stewie emphasised that they were not given a choice as to how the anaesthetic was administered. It seemed that in all cases the children's bodies were processed, with the healthcare professionals in control but no account being taken of their emotions.

Otto used Figure 8.6, Preparing for an operation, to acknowledge that children could find surgery frightening. Although the young person in his picture was being given the initial anaesthetic by the mother, and there was a sibling present, this did not represent Stewie's experience. He had to *choose my Mum or my Dad to come, then I have to go into this room* (Stewie, 4: 4-6). His language, repetition of *have to*, indicated that Stewie's felt compelled to comply.

**Figure 8.6 Otto's image Young person preparing for surgery**

**Redacted image copyright issue**

Otto recognised that perhaps healthcare professionals do not consciously involve the young person or their family in selecting the method for the anaesthetic: *for some children they end up*

*coming back time and time again and that is also important as if they have a bad experience the first time, or maybe the second time then they remember the needle from before and get anxious.* (Otto, 1: 31-34). Otto recognised that the needle would cause *anxiety* in most children. Stewie and Daisy found the situation very distressing, maybe more so as they are in the group of children who have had recurring operations. However, the hospital procedure appeared to take priority over offering the young person a choice. Wendy's description of Peter's response highlighted that the whole situation was emotionally fraught for both mother and child. Although it seems that there was clarity on the part of all concerned as to what would be a less stressful way to deal with the situation, there appeared to be a lack of impetus for change.

Aguilera *et al.* (2003) found that in the USA the inhalation method is preferred as it is perceived to be less distressing for young people. However, in the UK inserting a cannula is the more likely method. In a comparison study of administering the anaesthetic by needle or through a mask, Aguilera *et al.* (2003), in their UK research, found that there was less anxiety in young people who used the mask than in those young people who had a needle. Perhaps more research is needed on the practices and choice offered to young people and their parents as is suggested by the Department of Health (2004) whereby young people would take a more active role in making decisions such as the administration of anaesthetic. If a Glue Ear support group existed for both parents and young people, then it might be the appropriate channel through which this issue could be discussed so that hospital procedures could be reviewed. A support group could perhaps enable young people to develop appropriate material for explaining all of the aspects of grommet surgery and enabling them to play a fully informed part in their treatment.

ENT consultants have more knowledge than either parents or teachers that Glue Ear has more than health implications for those young people who have repeated episodes (Higson and Haggard, 2005). Annie demonstrated that other healthcare professionals, such as audiologists, share this understanding of the potential impact of the condition. However, there seemed to be a

gap between what the healthcare professionals know and what they disseminate. Although there are policy documents (Department of Health, 2004; Department of Health, 2003) about the importance of young people and their families being involved in decision-making and having the information necessary to make informed consent, this does not seem to have translated into practice.

In the busy hospital environment, from what participants in this research have said, the healthcare professionals seemed more intent on meeting consultation timescale targets and patient throughput figures. Perhaps because involvement of young people in their treatment is not measured, then there is no incentive to explain the different treatment options or to develop strategies for involving young people in discussions. The culture of the ENT consultant making the decision as to which treatment option the young person will follow seems to continue to prevail currently.

In Otto's view, and he was supported by Annie, there were four agreed ways of treating the condition: do nothing and wait to see if the condition resolves itself; take antibiotics for the recurring ear infections; have grommet surgery, despite a lack of clarity as to which patients are most likely to benefit; or have a hearing aid. Caz and Jane were the only two mothers who appeared to have been offered this last option. However, they were not provided with detailed information about how they would work and what the benefits and drawbacks might be. Because the hearing loss associated with Glue Ear was perceived as mild Annie explained that the hearing aid device most likely to be helpful would not usually be prescribed. This reinforces the message that it is perceived as a trivial condition.

The perceptions of participants in this research suggested that the power for decision-making is controlled by the ENT consultants. Although the mothers and young people may want more relevant information and opportunities to participate in decision-making they do not currently

appear to have a way of expressing their wishes. This could lead healthcare professionals, in particular, to believe that no one is asking for it. Although grommet surgery is the most likely reason for an operation in children there are no Glue Ear support groups, perhaps because the repeated message is that it is a temporary condition. This means that there is no channel through which young people with Glue Ear, and their parents, can express their collective voices or share their thoughts, experiences, fears or information. There is no easily definable place from which to seek information and most of the available literature for parents and young people has a medical focus. The lack of opportunity to meet others with children who have the same diagnosis means that each young person and their parents have to rely on their own resources. It could be that because the condition is perceived as common and temporary then this leads people to think that they do not need to explore it further as it will soon resolve. This mindset seems to remain even in those mothers for whom the condition has been part of their lives for years. The young people lack the opportunity to learn about their condition or be able to consider their options as most of the time they do not appear to be involved in the medical consultation.

### 8.5 Adults and Young People have different voices

Research into Glue Ear across the years has tended to use parental proxies as the main source of information (Barber *et al.*, 2014; Shaikh *et al.*, 2010; Asmussen *et al.*, 1999). The studies have focused on either when the child has an ear infection or the impact of grommet surgery.

However, recent studies using questionnaires have identified that, particularly with regard to social and emotional aspects of a young person's life, then parents may not reflect the views of the young person (Matsumoto *et al.*, 2011; Jokovic *et al.*, 2003). Doctors and fathers seem to show less agreement between young people and their mothers however the differences are greatest when rating emotional upset and pain, with young people rating this higher than their parents (Morrow *et al.*, 2012). The following section explores the value of encouraging young people to express issues which are of importance to them.

In this research, young people were asked directly to explore their experience of Glue Ear, as were their mothers. This led to situations in which the mother identified one view of a situation whereas their child had a different perspective. A case study approach was used by Capewell and Ralph (2014) to illustrate the importance of asking young people for their views of what support is helpful in the school setting. They suggest that although mothers may have a good relationship with their child, the young person may be best placed to articulate their specific requirements. Additionally contrasting opinions between the parent and child suggested that optimal actions may not occur if the mother's voice took precedence over the young person's view.

In this section some examples which occurred spontaneously during the course of this research are provided to illustrate the benefits of asking young people directly for their views. In some of the examples, the views of a professional are included as they made comments on the same issue. Although the professional may understand the condition from a theoretical perspective it is the lived experience of the mothers and young people that contributes depth to that knowledge.

For Russell it seemed that aching ears was something familiar and in the background: *My ears have been **aching** today, for some odd reason and they're just a bit annoying really .... not great, think, aching for a long time like, about 2 minutes that's quite a long for me so that's not great* (Russell, Ear Ache:1-3, his emphasis). He timed the aching which was for *about 2 minutes* and had emphasised his discomfort **aching**. This was a situation which he brought up and focused on as a key aspect for him. It could be that Russell had learned to live with low level pain rather than it not being a more or less ongoing part of his experience. The implications for him in a school environment are that this would be likely to reduce his ability to concentrate and perhaps resulting in irritability.

Pain associated with long-term Glue Ear appears to be under-reported in the literature. Otto explained that: *Lots of children under 2 get lots of ear infections, but once they're beyond 2 then they tend not to get ear infections and it is the hearing that is a problem. Some children tend to get eustachian tube dysfunction so they will say that they get popping if they swallow or if they're flying they'll get painful and popping.* (Otto, 8: 33-34). In part his lack of awareness about pain might be because, as he explained, ear infections tend to be dealt with by general practitioners or walk-in clinics as they require immediate attention. Thus he missed the acute experience of the condition as his appointments are scheduled well in advance. His assumption therefore was that once the children are *beyond 2 then they tend not to get ear infections*. This did not align with the views of the mothers or the young people in this study, but did demonstrate the compartmentalised thinking inherent in the way professionals deal and understand the condition.

Jane, Russell's mother, seemed aware of his level of discomfort: *He gets uumm .... Yeah they get, they pop and then they bang and then he's wincy wincy.* (Jane, 7: 25-26). Jane's description seemed to demonstrate the pattern related to Otto's description of: *eustachian tube dysfunction*. Jane described Russell as *quite roughy toughy with his ear infections. Really doesn't.... If it perforates and he's at school then obviously he's off that day and then back again.* (Jane, 7: 17-19). In her interpretation, Russell seemed to cope with the pain and not take very much time off school. Perhaps he had learned to integrate pain as part of his daily life, therefore not complaining about it. Potentially as no one asked about ear ache, and he was unlikely to have contributed information about his experience when visiting the consultant, then the adults around him did not fully appreciate some aspects of the condition.

Stewie explained that he had tinnitus. He explored in some detail what this was like. He found it: *like .... like ... not the best because it's like painful and stuff and all the noise and stuff, all I know is that it's painful. It annoys me.* (Stewie, 5: 19-20). He repeated *painful* and identified that

the *all the noise annoys me*. He went on to discuss the *and stuff* which he had repeated. *It makes like a loud buzzing noise or like an nnnnn and you have to bang your ears to stop it*. (Stewie, 5: 22-23). The only way he could find to stop it was to *bang your ears*. He clarified the *loud buzzing noise or like an nnnnn* by individualising the different sounds between his right and left ears: *it's like buzzing in my right and like a screech in my left*. (Stewie, 5: 34). The noises caused him distress: *Like yrrrr like that. Noises are what's like really really bugging me they won't stop* (Stewie, 5: 36). He emphasised how upsetting he found them and their unremitting nature. His experience suggested that his tinnitus to some extent dominated his life and controlled him.

Lois, Stewie's mother, was aware of the distress that the tinnitus caused him: *he gets fed up with it so much and he'll say, 'Chop me ears off', he says that sometimes*, (Lois, 12: 16-17). Her own emotions were impacted as she felt helpless to improve his situation and impotent in her role of protecting her son. Lois explained that she did not feel that there was much help for Stewie with his tinnitus: *the last consultant said he didn't know anything about tinnitus.... You know it's just not discussed..... But you know I believe that it's not often diagnosed in children, so .... Maybe that's the issue, they don't know what to say. ...* (Lois, 13: 7-10). Lois's sense of helplessness to support Stewie was greater because even the doctors did not seem to know much about childhood tinnitus. Although it may be *not often diagnosed in children* for Stewie and Lois it was something that dominated their lives. In this situation their views were very close and Lois had a depth of insight into Stewie's situation.

In contrast to the distress that Stewie felt about his tinnitus and the anxiety that this led to for Lois, Otto considered that tinnitus was not an issue for children: *if you ask them if they have a ringing or a buzzing then they'll have it but it does come as part and parcel of not being able to hear properly. If you can not hear for any reason then you do tend to get tinnitus, and lots of children with Glue Ear do have tinnitus but they don't complain and it doesn't bother them. It is rare for a child to come in and say that the ringing and the buzzing bother me*. (Otto, 8: 20-24).

Otto showed awareness of the physical manifestation of the tinnitus and described it in similar terms to those used by Stewie, *ringing or a buzzing*. Otto linked hearing impairment and tinnitus, *If you can not hear for any reason then you do tend to get tinnitus*. However, he dismissed it as something minor, *they don't complain and it doesn't bother them*. Otto supported this conclusion through quite a simplistic view of childhood, *They're active during the day and they're running about and they go home and they fall into bed and they go to sleep*. (Otto, 8: 25-26). However the emotional upset it caused Stewie, and Lois, emphasised the importance of providing young people with the opportunity to express their experience if healthcare professionals are to gain greater understanding of the lived experience of the condition, particularly from a young person's point of view.

The tripartite nature of young people with health issues is acknowledged in Department of Health (2003, p. 12). This situation can become more problematic if the parent and the young person do not agree on the best course of action. Some young people with ongoing Glue Ear can require complicated surgery. Increasingly there is acknowledgement that the young person may be competent to express an opinion, but the parent retains legal permission for surgery until the young person is aged 18 years. Therefore, the views of both parent and young person need to be respected. In this research such a situation had developed between Caz and her daughter, Daisy. Ongoing Glue Ear had resulted in permanent and serious damage to Daisy's hearing. This did not really seem to be acknowledged by either of them, perhaps because it had not been clearly explained. Daisy had already had one operation to repair the hole in her right ear drum, and Caz wanted her to have the left ear drum repaired. This was complicated surgery requiring reconstruction of the ear bones and a skin graft to repair the ear drum.

Using Figure 8.7, Damaged Middle Ear, Otto summarised the medical situation: *...with repeated glue and from repeated surgery then there can be long term problems to the middle ear and a perforated ear drum and you permanently lose hearing so it becomes something that doesn't*

*resolve at 10 or 11 years and that then causes permanent hearing impairment and that then becomes something a huge part of the workload from our point of view and whether its repairing the ear drum or whether it becomes trying to reconstruct the ear and it becomes much more complicated surgery and not like grommets which is simple surgery, it becomes much longer surgery up to several hours and then it has several risks such as facial nerve palsy or losing hearing completely, problems with tinnitus and problems with balance. (Otto, 6: 19-26).*

**Figure 8.7 Otto's image Permanently damaged middle ear**



Daisy explained that her first such operation to repair her ear drum had not worked: *I remember the last operation, the big one I had .... Ummh after I had it, they were like, 'Her hearing should improve, her hearing should have improved by now, you should have noticed a difference.' .....* *But it didn't and when I went back a few weeks later, a couple of months later, they said, 'How's your hearing, it should be perfect by now.' .....* *But it's not ..... It's just as bad, probably even worse..... and then they put things in my ear and I pushed them away and said, 'I'm not sitting here and I'm fed up with you playing around in my ears and stuff. Just leave me alone.'* (Daisy, 7: 28-35). The operation had left Daisy with additional hearing loss. She had suffered the disappointment of yet another failed operation. Daisy may have felt judged through the repeated use of *should* by the doctors. It seemed that she blamed herself for the lack of improvement in her hearing. From her explanation of what the doctors said, using the 3<sup>rd</sup> person singular, *it*, referring to her hearing loss and her ears, it was as though there was not any apparent recognition

of the emotional consequences for her, of her disappointment at having increased hearing loss.

From her perspective, the doctors were talking about her, not to her.

As highlighted in Chapter 7, Daisy had a poor self-image. This interaction with the doctors seemed to provide her with the potential for more negative self-talk and to blame herself for things not turning out as expected (Hogan, 2014). She identified that there were repeated visits, *a few weeks later, a couple of months later*. The doctors appeared to be focused on her ear *they put things in my ear*, thus she was disembodied as her ear was the centre of attention with little recognition of her as a person. The use of the third person pronoun *her* implied that Daisy was not being spoken to directly. She repeated throughout her participant-led discussion that she was afraid that if she agreed to another operation she would lose the level of hearing that she currently had. If young people, like Daisy, are sidelined from full participation then they may well withdraw co-operation and internalise concerns. At fourteen years of age, she met the Department of Health criteria of ‘competence’ but the healthcare professionals and her mother did not acknowledge her right to consultation or involvement.

Caz wanted Daisy to have the operation to repair her other ear drum and believed that the best way of achieving this would be by persuading her that, after the operation, she would be able to swim freely: *she’s like a fish, she could swim all day, all night and never come out the water, but obviously with perforated ear drums you can’t do that, but erm we are going to use that to push her to have the other ear drum repaired. Because if that’s repaired and we look after it then she’ll be able to swim without having these horrible ear plugs in that don’t really work.* (Caz, 5: 14-19). Although Caz understood Daisy’s love of swimming, she has failed to address Daisy’s greater concern of additional hearing loss. Caz focused on the practicalities and cosmetic issues of not having to wear *these horrible ear plugs*. She had already convinced Daisy that hearing aids were not going to help her hearing and part of that might have been linked to the *ugliness* of

the hearing aids. However, Caz did not seem to be aware of Daisy's emotional turmoil or feelings of failure regarding unsuccessful operations to improve her hearing.

Including young people's voices provided direct insight into having Glue Ear long-term and how they felt about the condition. Their views differed to those of the adults around them.

Encouraging them to reflect on their experiences provided greater understanding of both the complexities of the long-term condition and the emotional implications for the young people.

Russell had potentially integrated low-grade, background pain as part of his experience rather than seeing it as a feature of the condition. Stewie highlighted that perhaps tinnitus in young people can be as debilitating as in adults and cause equally as much distress. Perhaps the reason that pain and tinnitus are not spontaneously reported by young people is that the professionals do not provide them with the opportunity to raise such issues. Daisy had lived with the condition longest and displayed emotional distress. It seemed that healthcare professionals do not consider potential mental health issues that may develop in those young people with the long-term condition as a result of frustration, disappointment, physical pain and lack of acknowledgement of the way Glue Ear impacts their daily life.

## 8.6 Conclusions

By comparing and contrasting the comments of the young people, parents and professionals, a key issue which emerged from this research is that most professionals lack understanding of the lived experience of the impact of the hearing loss caused by Glue Ear and its potential emotional consequences for young people. This research illustrated the valuable contribution that young people have to play. In the Department for Education and Department of Health (2014, p. 20), Clause 1.6 highlights that 'Children have a right to receive and impart information, to express an opinion and to have that opinion taken into account in any matters affecting them from the early years.' It is becoming increasingly relevant that research includes young people speaking for

themselves rather than through an adult proxy. Additionally, ways need to be found to encourage their views in educational and healthcare contexts. The young people in this research demonstrated their capacity to express their views, which were often different to the adults' interpretation of the situation.

As suggested by the mothers and young people, there is limited knowledge of how Glue Ear can impact behaviour and its emotional impact even when it is a short term condition. Rachel, the Reception/Year 1 teacher, appeared to be reticent to assign behavioural attributes to the condition, particular those of frustration and stress at not being able to hear others or make oneself understood. However, Daisy, Stewie and Russell explained that these are key elements to their experience and that they want understanding and acknowledgement from their teachers. Although Terry did not appear to perceive that the boy in his class may have social and behavioural difficulties linked to Glue Ear, Daisy articulated some of the distress she felt in interactions with both teachers and her classmates reflecting the desire to *punch something*. Terry indicated that his student was perceived as a potential danger to others when *things didn't go his way with his classmates*. The teachers seemed more willing to locate the basis of aggressive behaviours in the family or the student, rather than asking the young person what was making them angry and listening to their point of view.

Teachers would benefit from training in strategies for discussing the problems that healthcare or learning difficulties cause young people and working with them to minimise those impacts. Some teachers may need extra support in initiating conversations about what could be regarded as sensitive subjects. As Annie, the audiologist, highlighted, even if a student appeared to be making age appropriate progress, he/she may not actually be achieving his/her full potential. I recommend including understanding of the condition both within initial training for educational professionals and in CPD activities so that they have a wider understanding of its potential behavioural, social and learning implications in both the short and longer term.

In this research the pathway for decisions about treatment options were made by the healthcare professionals. It seemed that hospital procedures and usual practice was maintained in such things as the administration of anaesthetic with little apparent consultation of either the young person or their mother. Healthcare professionals, such as Otto and Annie, appeared to have a good understanding of the wider consequences of the condition. However, there is little time to provide information in busy clinic conditions where the focus is on meeting targeted consultation times. However, to become effective in decision-making, both young people and their parents need access to reliable, relevant information presented in an accessible format. This needs to be more broadly-based than the medical implications. The availability of such information would provide parents and young people with the potential to make informed choices. Resources need to be developed so that young people and their parents have the opportunity to discuss and ask questions if they are to fully understand the various options available to them.

Information based on well-constructed research does exist. However, the findings are not always on websites available to the general public. Either access requires affiliation with an academic institution or the language may be aimed at a specific professional audience, assuming a technical vocabulary. On-line provision with open access of reputable sourced material written for a general audience is a high priority and needs to be the focus of research in the near future.

Perhaps one of the reasons that the voices of young people are not heard in healthcare consultations or that parents are not seen as equal partners is the lack of any type of support group. There is a lack of opportunity for both parents and young people to share their experiences of the condition and to identify that many of the issues that they face are common to others thus part of the condition, rather than attributable to the quirks of individual personalities. One role a support group could provide is time for young people to raise questions, be given adequate time to process the information and to develop strategies to have the confidence to

explain their experience. They could benefit from highlighting how the condition impacts on more than their ears. Young people's voice needs to be in the forefront, with all professionals willing to listen with an open mind rather than make assumptions about how young people think and feel.

Whether it is about treatment options, including how an anaesthetic is to be administered, or the likely success rate of a surgical procedure, young people need to be included in the discussion. Alternatives to surgery need to be presented in a comprehensible way so that both parents and young people can understand the implications. At the present time it seems that the healthcare professional makes the decision and imparts it to the parent, with the young person on the sidelines. When there is a selection of options these are often pre-selected by the healthcare professional so choices are limited. Although paediatric nurses have played a role in imparting information in other contexts, this may not be either financially or practical viable with regard to Glue Ear.

The lack of support also applies in educational contexts. To develop the confidence young people need to express their opinions or experiences they need support in developing self-advocacy skills. Additionally educational professionals need help in understanding that if young people are expressing their specific needs then adult power is not being usurped. It may be that practical activities based on understanding how the young person with Glue Ear experiences the classroom environments need to be developed. For example a whole class activity which explores the different barriers resulting from hearing loss and the support required to improve learning opportunities could be gathered as a way of widening the understanding of all parties as to what it is like to have the condition.

Policies are in place giving rights to young people to provide their opinions. They are willing and able to express their views. Their perspective is not always the same as the adults around them

who may falsely attribute feelings or cognitive abilities which do not reflect their situation or abilities. However, what is currently lacking is for young people to have access to information which increases their understanding of their situation so that they are able to make knowledge-based decisions. They also lack an appropriate forum in which they can compare and contrast their views with young people in a similar situation to theirs. Excluding voices of young people in healthcare and educational contexts means that part of the 'story' is missing.

## Chapter 9

### Answering the research questions: Conclusions and Further Research

#### 9.1 Introduction

The purpose of this chapter is to evaluate the extent to which the research questions have been answered and the contribution that the findings have made to understanding the experience of mothers and young people living long-term with Glue Ear. The research findings are drawn together to develop some conclusions about each of the research questions. I identify the strengths and limitations of this research and suggest avenues for further research.

The research questions for this study were deliberately broad as the purpose was to gain insight into what the participants, mothers and young people, regarded as important in living with the condition. Mothers (Chapter 6) and young people (Chapter 7) explored their experiences, which were then compared and contrasted, with the views of a small group of professionals with whom they typically interacted (Chapter 8). Although not in the original design, accessing the views of this small group of professionals was included to provide an understanding of the knowledge and perception of some of those specialists whom parents and young people with Glue Ear typically encounter.

A review of the literature indicated that there were questionnaire responses from some healthcare and educational professionals about their understanding of the condition (Higson and Haggard, 2005) but no qualitative investigations. I could not therefore access their views from that data, so asked for their opinions and perceptions of the condition. The intention of this research was to identify actions which could be either implemented or researched to advance awareness of the social and behavioural implications of Glue Ear. I considered that seeking the views of all parties, mothers, young people and professionals, was likely to lead to a broader understanding

of their current experiences. This is based on the assumption that incorporating more views could lead to an appreciation of the different issues that various groups may have.

The outcomes from this research are intended to illustrate the experience of those with the ongoing form of the condition. Most previous research into Glue Ear has not taken into account the continuum nature of the condition nor the particular impact that it has for those young people, and their families, in whom it does not resolve as expected by the ages of seven-nine years. Some of the wider effects of this long-term situation for both the young people and their mothers are discussed in this chapter. The findings of this research may assist the professionals who deal with these young people, and their mothers, to potentially identify how their practice could take greater account of how the recurring condition is more complex than is generally assumed.

This chapter explores the contribution that this research has made to increased understanding of how mothers' and young people's views can be elicited. The importance of accessing those views is reviewed. This chapter concludes with the identification of potential areas for future research. The difficulties encountered during this research were identified when discussing the data analysis aspects of the research methodology in Chapter 4, so are not included here.

## 9.2 Review of research questions

### 9.2.1 Research question 1: What is it like to live with ongoing Glue Ear as a young person?

What has been absent from the literature is an exploration of how the young people with ongoing Glue Ear understand its impact on them. Chapter 7 provides details of the analysis of what the young people, in this research, had to say. Two main themes were identified: 'Never mind' and 'Stuck'. The former revealed psycho-social issues related to negative emotions, such as stress and frustration, a sense of isolation from their peers and fear connected to their surgical

treatment. This is not in the literature. I would speculate that this is potentially because young people have not been seen as capable of contributing, so their voices were best filtered through adults answering for them (Haggard *et al.*, 2003).

The second theme, 'Stuck', focused on the lack of communication about the condition between young people and healthcare professionals. The young people tended to be in the role of providing information about their ears as their bodies were processed. Explaining the impact of the condition in terms of 'ears' (Carlson and Carlson, 2003) may be accurate, but it potentially reinforces the way in which healthcare professionals objectify young people. The focus becomes the illness and its physiology. Such an approach does not support healthcare professionals in moving towards considering the socio-psychological impact on the person (Boudreau *et al.*, 2007). Daisy, Stewie and Russell did not perceive that anyone took the time to find out about their needs or to always explain their condition in a way which was comprehensible to them.

The context in which the young people in this research viewed their condition is of relevance to understanding some of their comments and behaviours. The three of them described themselves as having *bad hearing*, but did not perceive themselves as deaf. Daisy's reluctance to have an operation to repair her perforated ear drum was because she did not want to further decrease her ability to hear. However, Stewie was aware that his hearing fluctuated as sometime he did not need additional help from his teachers. Russell had been told that he was to get a hearing aid but had little information about the detail of what this entailed.

In Chapter 7 the main theme of 'Never mind' identified by Stewie, Daisy and Russell highlighted the psycho-social implications of living with the condition long-term. 'Stress' was something that they expressed as being a main feature in their lives. This has potential long-term implications for their physical and mental health (Hogan, 2014). It seems that they would benefit from being supported to help find strategies to effectively manage their feelings and the

situations that result in their stress response being activated. One common trigger that the young people identified was not being able to fully follow what was being said in the school situation. For example, Daisy explained that she sometimes felt *paranoid* that perhaps her friends deliberately did not speak loudly enough for her to hear as a way of excluding her. Russell became uncomfortable and started to move around when talking about telling other people about his ear problems.

The situations that the young people described were a direct result of their ongoing Glue Ear. As the condition is experienced as temporary for most children, the needs of young people like those in this research, who have the long-term condition, appear to have been over-looked. However, it may also be the case that even those children in whom it resolves may have difficulties when they have hearing loss. In Chapter 8, Rachel, the Reception/Year 1 teacher in this research, identified the aggressive and frustrated behaviour of one of her pupils. The girl had had two sets of grommets and initial speech difficulties related to the condition. Although I did not speak directly to the child, her behaviour appeared to reflect the feelings and behaviours expressed by the young people in this research.

The general lack of understanding of the condition by teachers compounds the difficulties that the young people identified. Daisy felt that her teacher had treated her unfairly when she had not been able to hear what he had said. She had tried to pretend she had followed his comments, but her behaviour had been misinterpreted. Similarly Russell explained that things were better for him as the teacher had moved him so that he could hear what was being said in the classroom, *now that he knows I'm getting a hearing aid*. The symbol of the hearing aid may have indicated to the teacher that Russell's hearing problem was serious. Stewie highlighted that when his teacher checked with him whether he could hear, and made adjustments for him, such as moving him to her desk, then he felt that he could participate equally with his classmates.

A difficulty that some students may have is whether teachers consider Glue Ear to cause problems for pupils. If they do not see it as having implications for learning then they may not take action. As was identified in Chapter 8, there is a lack of awareness among educational professionals of the impact the condition can have. Mukherjee *et al.* (2002) highlight that teachers generally do not feel that they have adequate training to deal with students' medical conditions. Training about the condition is not included in initial teacher training, despite its prevalence in children under the age of seven years. Specifically, in the case of Glue Ear, Danhauer *et al.* (2011) suggest that even though teachers may understand the implications of repeated ear infections, when asked to make special adjustments for the pupils, the requirements of classroom processes soon led to them being discontinued.

The young people explained that they did not always disclose their hearing problems to either their classmates or their teachers. Russell had confided in one of his classmates about his Glue Ear, who had then *spread it across the school*. He appeared to not generally disclose his hearing difficulties. Perhaps concerns about being stigmatised as different (Erlich, 2012), leads young people not to discuss their hearing loss. By not disclosing his hearing difficulties, Russell may have felt some shame about his hearing loss; he explained how he had to constantly clean out his ears as they were *leaking*. As Mitchell and Karchmer (2006) highlight students with hearing difficulties tend to find that they are the only such person in the school, so they do not have other children to whom they can look for support. For young people with Glue Ear this is further compounded as the condition is not regarded as causing difficulties. Hogan *et al.* (2011: 378) in their research into the emotional and behavioural outcomes of children with hearing problems, specifically excluded children with Glue Ear because 'the conditions are quite different and have differing clinical implications for care'. There appears to be a general lack of account taken that Glue Ear is a continuum condition and for those young people with the ongoing condition, the lack of differentiation of their condition, results in a potential dismissal of their needs. I would argue that the lack of acknowledgement of the permanent level of hearing loss by young people,

such as those in this research, puts an additional burden on their emotional health. This could be avoided if there were a different interpretation of the way the condition manifests itself in them.

Although Daisy's friends knew that she had a hearing problem, she did not appear to reveal it to her teachers or follow her parents' advice that she ask to sit at the front of the class so she could be closer to the teacher and potentially know what was going on. As part of Daisy's explanation as to why she did not communicate her hearing difficulties to teachers or ask for support, she said that her poor academic performance was because she was *not very clever*. (See p.175 for a fuller discussion of this situation). It seemed that she considered that she was the problem.

Hogan (2014) identified that poor self-image can be an issue for those with hearing difficulties. If her teachers had made adjustments to minimise the impact of her hearing difficulties, for her then it may have meant she could have followed what was happening in the classroom more easily. Daisy demonstrated feelings of mistrust of others, as she explained that she sometimes felt others were deliberately excluding her. This could potentially lead to feelings of isolation and in the long-term behavioural or mental health issues. As she did not know anyone with the same condition, she had no one with whom to share similar experiences. This could lead her to conclude that the difficulties she had were from something within her.

This situation can be compounded for young people such as Russell and Daisy if their teachers do not regard their condition as causing any problems. Terry, the secondary teacher, identified that he taught a student with Glue Ear. He explained that rather than initiate a conversation about the student's needs, he would wait for the student to discuss the situation. Terry's belief was that the student probably would not want to talk about it. However, Stewie highlighted that he appreciated it when his teacher took action to support him and asked him if he needed help. Equally he identified that he had a friend who supported him and told the teacher when Stewie's ears were hurting him. Classrooms are usually controlled by teachers(Lowe, 2012), so young

people with the long-term condition, who may already feel isolated or not wish to draw attention to themselves, perhaps feel that they lack the agency to be their own self-advocates.

Rather than expecting a young person to ask for things that could help them to achieve their potential, adults need to support them and provide strategies to develop their ability to express their difficulties. Kumpulainen *et al.* (2014) suggested that promoting children's positive psychosocial well-being is important if they are to avoid feeling isolated and marginalised. They made the link between poor self-image and low academic success. They argue that if a child develops a sense that their actions can lead to positive outcomes for them then they are likely to become more confident as well as develop greater resilience if things do not go well for them. Teachers are highlighted as having an important part to play in encouraging a sense of agency in young people.

However, as Goodley (2000) pointed out self-advocacy requires self-confidence if someone is to identify their needs and be assertive in having them met. As Stewie highlighted, he preferred his teacher to initiate the discussion about his needs then he could contribute. Although Jane, Russell's mother, had spoken to his school teacher a number of times, she had not achieved the adjustments from which she believed Russell would benefit. Russell was therefore unlikely to believe that he could achieve more than his mother. As identified earlier, he was ambivalent about disclosing his hearing difficulties to others so would be unlikely to ask his teacher for additional support. As Shevlin and Rose (2008) explain there may be policies about including young people in decision-making about their needs but teachers are not always pro-active in making it happen.

A further potential barrier to the students with long-term Glue Ear achieving appropriate support is that their condition is not seen as a special need. It is primarily contextualised as a temporary medical condition. Teachers often regard medical conditions as outside their area of expertise

(Mukherjee *et al.*, 2002). Terry, the secondary teacher, suggested a further difficulty is that the condition is invisible so teachers could not be expected to be able to tell whether or not someone can hear. Russell indicated that a hearing aid symbolised that action was required on the part of the teacher as it represented an inability to hear at the level of his peers.

Of the three young people in this study, Stewie appeared to be supported most effectively. He liked his teacher and she worked in partnership with him to achieve optimal outcomes. However, he had another teacher two days a week to whom he referred as his *bad teacher*. She did not make adjustments for him which resulted in him feeling frustrated. Jane, Russell's mother, explained that at one point Russell had a supportive teacher. When she knew she was not going to be in class, Jane said that she always reminded Russell to ask for additional help. However, without the self-confidence to ask and the belief that there would be a positive outcome, young people are unlikely to act.

As discussed in the Literature Review (Chapter 2), the research evidence exists that reading and language can be impacted by Glue Ear, particularly for those children who have repeated episodes before three years of age. However, this does not seem to be widely known among educators. For the young people in this study, the lack of clarity about their condition or understanding of its potential impact on behaviour and social skills left them quite isolated. They did not appear to feel that they were encouraged to express their needs. This suggests that there is a strong case for educating the educational professionals about the need for a system incorporating students' views as to how they can be appropriately supported if the potential difficulties that can result from the condition are to be avoided.

From the exploration of their experiences related to the theme 'Stuck', the young people in this research appeared to portray themselves as ears, with limited acknowledgment of the body to which they were attached. I have interpreted the comments of the young people in this research

in the context of the policy statements contained in the Department of Health (2003) which indicates that young people should be provided with clear and comprehensible information about their condition. They should be consulted about their wishes and be able to participate in treatment options and decisions. The message contained in the framework is that the young people should be treated as people and take an active role in what is happening to them.

However, this is not how the young people described their interactions with healthcare professionals. It was as though their ears were the focus of attention and they were not involved as people. Their experience of having the condition long-term did not appear to be taken into account and their descriptions indicated that they had followed the same process approximately every six months with clinic appointments being interspersed with grommet surgery. The young people understood what was happening to their bodies, but they appeared to consider that there was a lack of acknowledgement by others of them as people.

Stewie's account of having an anaesthetic (Chapter 7, Section 7.2.1.3) illustrated the way in which his body became an object to those around him. His description of the situation omitted any dialogue, but focused on actions: *they stick*. Although he demonstrated how he perceived it, *horrible, really hurts* and *sore throat*, it was as though he was the only one aware of these things. Although Otto, the ENT consultant, acknowledged in Chapter 8, that some children will feel *anxious*, he did not take the young person's perspective but put himself as outside that part of the process. This seemed to reflect the situation that Daisy and Stewie were relating; that they found having anaesthetics distressing, but no one acknowledged it or consulted them about how the circumstances could be improved to reduce their anxiety. Russell had an opinion and wanted to make his voice heard. Effectively his mother did not want him to have further surgery, the consultant made a decision and Russell was left with no information as to what was involved. The young people wanted to be given sufficient information and then allowed to be part of the decision-making process.

Sahlsten *et al.* (2008) highlight how the language of participation lacks clarity. The terms ‘consumer’ and ‘user’ are used interchangeably by healthcare professionals but their meanings are very different. Although the language of policies is about options, which is reflected in the idea of a ‘consumer’ which has choice implicit within the meaning; ‘user’ more closely aligns with the experience of the young people in this research whereby they were recipients of the services of the NHS. The latter term reflects the passive role that Stewie, Daisy and Russell explained. There was certainly no evidence that they were involved in collaboration with the healthcare professionals, which implied an element of choice with alternatives and joint decision-making. Additionally, the young people explained that their mothers had not included them in the decision-making process. This potentially reflects Prout’s (2005, p. 37) position that the modern concept of an ‘ideal’ childhood is based on viewing young people as either not having opinions or that their mothers are more capable of speaking on their behalf.

Even in the regular checkups, the young people pointed out that things were done to them but they did not seem to be given an explanation or asked for permission. Daisy and Stewie both explained that there had been times when they refused to co-operate. Daisy emphasised the way in which she felt that she was being processed and not treated as an individual when she emphasised, *he’s not me and he doesn’t really know what it is like to be me and he was like just making a guess about what he can see. And them constantly reminding me about it.* (Daisy, 4: 46-49). She highlighted that the consultant was making decisions about her based on looking at her ears. The emotional upset resulting from problems with her ears was not acknowledged. She had previously explained that the consultant used *big medical words* which meant that she did not understand what he was saying. Equally, she had knowledge which the consultant was not asking of her or taking into account. This was reflected in how she was not allowed to escape from the burden of her ears in her day-to-day life.

Although young people might be generally perceived by both the professionals with whom they interact and their mothers as naïve and in need of protection (Prout, 2005), Daisy, Stewie and Russell demonstrated sophistication in their thinking. The healthcare professionals were following their usual interpretation of the condition by dealing with it as part of the functioning hearing system. Hence the consultant looked in Daisy's ears to decide how it was impacting her. However, as Bullington (2009, p. 102) discusses this does not take into account the 'lived in body' that Daisy inhabited. This was the body which caused her to have experiences that were different to her peer group. She knew that she was not able to fully participate in conversations with her friends; she was excluded from some activities with them as they did not want to make the effort to repeat or explain things so that she understood. Because of their long-term experience of the condition, and potentially their understanding of intermittent hearing loss, whereby they knew what it was like to hear as others do, the young people in this research perceived their condition as more than just related to their hearing status. They interacted with the world differently because of the way in which their ears did or did not function.

They were placed in a position of being treated like other young people with Glue Ear, but their experience was substantially different. For them, the condition had not resolved and it had a long-term impact. For Stewie it was the ongoing impact of dealing with tinnitus which was with him every day and from which he tried to escape. For Russell, it was dealing with his *gunky ears* and the unpleasant bodily function of having to clean them out as well as having to get rid of the baby wipes which he used. For Daisy, it was the fear that she would lose what hearing she had left and being in dispute with her parents about having an operation that she did not want. They experienced the condition differently to those who had it on a temporary basis, but there was no acknowledgement of this by the professionals around them, or by their parents.

Although there were only three young people who participated in this research and the findings may not be generalisable to all young people with ongoing Glue Ear, I would suggest that the

findings do provide an insight into the condition not previously explored. Educational professionals need to be aware that it impacts the young people's psycho-social development and the way in which they develop friendship and their sense of self-esteem. It is far more than a simple medical condition and does need to be repositioned as a special need for some young people, particularly those with the long-term condition. Healthcare professionals need to consider the impact on the whole person and not see it as a short-term condition connected only to the ears.

#### 9.2.2 Research question 2: What is it like to be the mother of a child with ongoing Glue Ear?

The themes from the analysis of the mothers' participant-led discussion were explored in Chapter 6. The purpose of this section is to review whether Research question 2: What is it like to be the mother of a child with ongoing Glue Ear? was answered. By using wider psychological theory about the constructions of motherhood, I explore the way in which the mothers of children with ongoing Glue Ear evaluated their mothering skills when comparing themselves to mothers whose children either did or did not have health/disability issues. I considered their construction of their mothering skills in terms of their psycho-social health.

The mothers in this study were all white, British, middle-class, well-educated, professional women in full or part-time work. It could be argued that they are not representative of all mothers of children with chronic Glue Ear. However, I would suggest that if these women faced some of the issues they did, then the implications for those mothers who do not have the same privileged backgrounds as them, or whose first language is not English, are likely to encounter even more difficulties.

One of the themes that developed from this research was 'Motherhood but not as I expected it'. This theme explored the way that very early in their child's life they were negotiating an

unexpected situation which they were told by healthcare professionals was 'normal'. For example, Marion highlighted that she was told *all babies get at least 8 coughs and colds in their first year*, but she soon experienced repeated situations in which her daughter, Poppy, was hospitalised for respiratory infections and pneumonia; Wendy faced situations in which her son, Peter, was repeatedly sick during his first five years, but was reassured by her GP that he *will grow out of it by the time he's five*; Jane kept going back to her GP saying, *He can't hear, he can't hear*; and Lois was confronted every evening upon her son, Stewie's, return from pre-school with *a pile of behaviour sheets saying that he's aggressive, he ignores us*. Although they negotiated these obstacles, they were repeatedly reassured that their child's behaviour was within the 'normal' range and they must deal with it.

In her exploration of the development of modern motherhood, Hayes (1996) identifies that mothers are expected to be guided by experts, both during their pregnancy and as their child develops. This deferral to experts was evident in the mothers' comments in this research. Despite any misgivings they might have felt, they explained how they made repeated visits to healthcare professionals and felt rebuffed in their own mother instincts. Although these mothers expressed feelings of loneliness, anxiety and distress (Chapter 6) these emotions were not sanctioned by the healthcare professionals with whom they interacted.

Any feelings that they had that their child was difficult or the experience of dealing with a child who was constantly sick and being a burden was kept to themselves. The cultural messages they received were that motherhood fulfilled their roles as women and this included ensuring that the child should be the centre of their universe (Lupton, 2011). They were trying to be a 'good mother' who kept her child safe and did not complain. The messages that the mothers in this research received from the healthcare professionals was that their baby's behaviour was perfectly normal and that the problem was them and their anxiety.

A complication for the mothers in this research was that Glue Ear is positioned as a temporary condition, with an expectation that it spontaneously resolves in children. The usual expectation is that this happens by seven to nine years of age. It was therefore not something that they would need to adjust to either in their own position as a mother, or in the way they viewed their child. Although there may be some maternal guilt about being responsible for causing it as Marion expressed, most of the mothers knew that it was very common with approximately 80% of all children having at least one episode of the condition before the age of nine years of age. They inhabited a place in which they were dealing with a child with a medical condition, which may require operations and regular hospital visits, but this was only temporary so their mindset could become one of optimism and looking forward to the future. The regularity of ear infections and clinic visits meant that the repetition led to a blurring of visits and time, as there was nothing really distinct about the situation. As Kate identified in Chapter 6, they lived with a *wobbly clock* which meant time was experienced differently for them than for other mothers.

Landsman (2005, p. 125) identifies in some conditions, and I would suggest Glue Ear is among them, the child is positioned in a 'rehabilitation variant' of disability. This construction differs from the more usual medical model of disability which has two positions in that the child is either disabled or not. Landsman (2005) suggests an alternative view whereby the child will be given appropriate treatment and rehabilitated therefore no longer have the condition and soon catch up with his/her peers without any long-lasting effects. For the mothers in this research, their child required only a minor and routine operation, thousands of which are carried out across the world every day in every year. As Otto, the ENT consultant explained the surgery, *lasts no more than 10 minutes*. There was the caveat that some children would need another set of grommets, but this was not often explained or emphasised. In the medical model of disability the expertise to treat the child remains the remit of the medical professional. The mothers had to listen to the expert, follow his advice and the problem would be resolved.

There was therefore, no need for the mothers in this research to position themselves as having a child with a disability. The message that mothers of children with Glue Ear received is that although the child has a hearing impairment it is both mild and temporary so there will be no long-term reduction in their hearing abilities nor will they be regarded as deaf. Their hearing loss is such that they will not require an external sign such as a hearing aid as Caz, Wendy and Lois from this study explained to their children, *you won't be as bad as that*. The repeated message about Glue Ear is that it is trivial and in the same category as the common cold.

The mothers in this study were in the opposite position to that described by Landsman (2005), in which mothers have to reposition their future so that it is dominated by having a child with a permanent disability. Those mothers have to negotiate treatment and support options to achieve the best outcome for their child and to overcome the unfair barriers put in their child's way by an unjust society. Neither are they in the position suggested by Ryan and Runswick-Cole (2008) in which the mothers of disabled children have to negotiate a world in which their child has a disability and the mother does not, but there still remains an element whereby she is stigmatised. Nor do they view themselves as being the parent of a child with a chronic illness who often has difficulties in interacting socially with their peers (Martinez *et al.*, 2011) and requires daily medication that needs to be managed. This is despite (as was identified in Chapter 6) Glue Ear meeting the criteria for being defined as a chronic illness. Unlike the situation for the majority of mothers of children with Glue Ear, the position the mothers in this research found themselves in was more closely aligned to those mothers of children with disabilities.

This mismatch between the way in which the healthcare professionals position the condition and the issues raised by the mothers in this research was illustrated through their concerns about their children's behaviours. As explored in Chapter 8, with the exception of Kate, all the mothers expressed concern about their child's social skills. This led to feelings of uncertainty in most of the mothers. All of the mothers in this research had children who had long-term hearing loss, but

that did not seem to have been taken into account in their discussions with healthcare professionals. Rather than acknowledging that potentially the hearing impairment and the associated pain of recurring ear infections may lead to problematic social skills, the mothers looked for other explanations. Miranda and Jane explained that their children had been identified as being dyslexic and Caz explained that Daisy had a diagnosis of ADHD. Lois identified a number of repetitive behaviours in Stewie and that he had previously been considered as on the autistic spectrum. The mothers in this research were left with an experience of uncertainty and confusion. Their children were not disabled but did have hearing impairment which was not labelled as such. The mothers considered that their children demonstrated behaviours which potentially made them different from their peers, yet they remained unexplained and perhaps could be seen as a 'quirk' of personality.

The mothers in this study placed a high value on socialising their children leading to perhaps questioning their skills of being good mothers when they perceived their efforts as being unsuccessful. This focus on social skills development is reflected in the literature. Phoenix and Woollett (1991) identified that middle class mothers are seen as the key transmitters of the social culture and take this role very seriously. The qualities that constitute being a good mother in terms of developing social skills in their child appear to have remained constant in Western European societies for some time (Lupton, 2011; Johnston and Swanson, 2003; Hayes, 1996; Kaplan, 1992). The mothers were trying to develop behaviours that were deemed valuable in their society, including: encouraging independence and self motivation, expressing their emotions in a positive manner (avoiding temper tantrums), honesty and good relationships with others (Bach, 2014, p. 225).

Lupton (2011) highlighted that the mothers in her study were very competitive when assessing their own and each other's children in reaching key developmental milestones and demonstrating desirable social behaviours. Status Construction Theory (Ridgeway, 2006) provides a framework

for exploring the emotional well-being of the mothers in this research based on their children's behaviour. Each mother's perception of her skill as a good mother is dependent on being ranked above or below other group members. The mothers in this study were well-educated, white and middle-class which placed them within a particular social strata. They were likely to see themselves as more privileged and powerful than others such as young, single mothers living on benefits. However, within their own social strata a hierarchy develops related to their performance in achieving group norms. In this case their effectiveness in reaching 'good mother' status was based on the extent to which their children demonstrated appropriate behaviours.

Despite their best efforts, some of the mothers in this research felt that their child was not demonstrating those values. For example, Wendy expressed disappointment when Peter remained on her knee (Figure 9.1) when they attended social gatherings and children's parties. He was not showing the appropriate level of independence.

**Figure 9.1 Wendy's image Young boy on mother's Lap (Reconstructed)**



**Figure 9.2 Jane's image Toddler music group (Reconstructed)**



Similarly Jane expressed determination in her efforts to encourage Russell to join in at mother and toddler groups (Figure 9.2) despite him screaming every time they went. He could be perceived by others as having a temper tantrum thus not controlling his emotions in a positive manner. If Status Construction Theory (Ridgeway, 2006) were applied to these situations Wendy and Jane could believe that their position in the social hierarchy would fall. This was because those mothers whose children do exhibit appropriate social behaviours are able to judge Wendy

and Jane based on Peter and Russell's lack of skills. Not only are they likely to know others are judging them, but Wendy and Jane are likely to deem themselves as not demonstrating good mother skills. If they accepted the medical summary that their child only had Glue Ear then they would be likely to take personal responsibility by labelling themselves as 'bad mothers' perhaps then feeling guilty and anxious (Dudley-Marling, 2001)

It would be likely that even if they regarded their child as disabled, then that would lower their position in the social strata. Landsman (2005) suggests that a mother who has a disabled child is perceived as having done something wrong during her pregnancy so disability has a stigma attached to it. Thus a mother in this category has less social capital so is lower in the hierarchy. Ryan and Runswick-Cole (2008) explore the dilemma that some mothers have between obtaining a diagnosis of their child's condition as opposed to the degree to which their child's disability is evident to others. On the one hand a diagnosis provides a label which can be used when communicating with others about their child's condition, thus potentially reducing personal blame and moving the behaviours away from the specific child to the characteristics of the condition. However, this potentially moves the mother out of the category of a 'normal' mother.

Lois explained how she negotiated such a situation when Stewie's hearing impairment meant that he sometimes didn't concentrate or listen to his coach or other team members when playing football. When another child's father commented on this, making a judgemental statement about his behaviour, she had to decide whether to provide a reason which could then have made Stewie seem different in some way, or keep quiet. Having to make such decisions caused additional emotional upset to the mothers in this research. The invisible nature of Glue Ear means that there is no outward sign that indicates their status to others.

Because Glue Ear is regarded as both temporary and not leading to long-term implications, the mothers had a further conflict in the extent to which they regarded themselves as the parent of a disabled child. Landsman (2005) explores this conflict within mothers as to whether or not to accept the diagnosis of their child as having a disability. For the mothers in my research, the positioning of the condition can mean that they may have felt fraudulent if they did position themselves as having a child with a disability. There was an expectation that the condition would resolve and not recur. Additionally the hearing impairment was intermittent with the children having times when they could hear clearly thus not needing any adjustment by others. These dilemmas had implications for the mental well-being of the mothers in this research. As they did not know other mothers with a child who had a similar experience of the condition, they were isolated from others with whom they could potentially have discussed their experiences to reach a shared understanding of their situation.

Ridgeway (2006) identifies that Status Construction Theory enables people to position themselves in relation to others. To some extent this moves the focus away from the individual being assessed by others, perhaps reducing personal guilt and self-blame. Thus with greater knowledge of the potential impact of Glue Ear on their child's social and behavioural skills, the mothers could have readjusted their view from seeing themselves as failing to socialise their child to one of challenging the dominant view of the condition.

Ryan and Runswick-Cole (2009, p. 204) explain how mothers develop their skills in restructuring the way in which healthcare and educational professionals perceive their child's condition. Jane and Kate positioned themselves as a tiger and a polar bear in terms of protecting their children from negative impacts, which provided them with a sense of agency and being able to take action. On the other hand, Lois felt overwhelmed, uncertain and alone resulting in her spending nights crying out of frustration, fear and concern for Stewie.

I would argue that the findings from this research have provided greater insight into the way in which the mothers of children with long term Glue Ear experience motherhood and their personal efficacy than was previously known. The mothers in this research provided examples from a range of situations in which their child's condition impacted them. They identified the issues that they have encountered while trying to create collaborative relationships with educational and healthcare professionals (Chapter 6). It appeared that the mothers were not provided with appropriate information or understanding regarding their child's condition so they were not best placed to make informed choices about available options. As they lacked sufficient information on the likely impact of the condition in the school environment they could not be an effective channel of communication between healthcare and educational professionals. The psycho-social impact of the child's condition on mothers has not been previously identified.

### 9.2.3 Research question 3: What is an effective methodology to ensure that the voices of young people and their parents are at the centre of the research process?

Integral to this research was identifying and assessing the effectiveness of a research method through which the experiences of mothers and young people with long-term Glue Ear could be explored and interpreted based on them establishing the topics in a participant-led discussion. This section reviews the strengths, weaknesses and areas for further investigation of using such a methodology. Providing the means through which young people and parents can express their views is of relevance in light of current policies (Department of Education and Department for Health, 2014; Department of Health, 2003; DfE, 2003) which are seeking for young people and their parents to take a more active involvement in their education and healthcare.

An explanation of how and why the research methodology used in this research was developed is provided in Chapters 3, 4 and 5. The purpose of this section is to assess whether the research methodology developed enabled young people with ongoing Glue Ear, and their mothers, to

explore issues that were important to them rather than being directed by myself, as researcher. Many of the comments I make in this section are speculative as to participants' motives for undertaking a task in a particular way. It could be beneficial to undertake research into the motivations of participants to evaluate whether my comments reflect their perspective.

Included in this assessment is whether using the adapted Photovoice methodology produced data that identified participants' issues and if it stimulated dialogue which answered Research Questions 1 and 2. Also examined is if an IPA analysis is grounded in what the participants regarded as important and whether the interpretation stayed close to their meaning and provided greater insight into the impact of Glue Ear on participants' psycho-social well-being. A review of whether the interpretation of the participants' words was reflective of their meaning is contained in Chapter Five.

My personal experience, as the mother of two children who have ongoing Glue Ear, provided the impetus for the development of the methodology. I wanted to try to minimise my influence on the issues that the participants identified or the way in which they discussed them. Early on in the data gathering process I tried to remain 'objective' and keep myself 'detached' from what participants were saying so that the results would have greater validity as they would be value-free (Maynard, 1995). However, I realised that being a 'value-free' researcher is not possible. I had chosen the topic, set the research questions and identified the parameters of the research. I wondered if my experiences of Glue Ear would be similar to those of the mothers and their children in this research.

Prior to starting participant recruitment, I decided that I would share with participants our similar experience of Glue Ear. I decided that I wanted them to put my interest in that context rather than have them assume another reason for why I was undertaking the research. I was aware that they

could be more likely to discuss their experiences as there may well be an assumption on their part that I would have shared similar situations (Berger, 2013).

As the recruitment phrase developed, I became more aware that I shared many similar characteristics with the participants, in terms of gender, ethnicity, class and educational status. This was both a benefit, in that I could easily relate to the way they explained their reactions to the way in which professionals treated them, but I had to be very careful not to project my own experiences onto them in the way in which I interpreted what they told me. While reviewing a participant's transcript with one of my supervisors, she made the comment that she didn't think I 'liked' the participant. As we discussed this I realised that I had judged the participant about the way in which she had dealt with the dismissive attitude of the ENT consultant. I had interpreted her behaviour in terms of what I had done in similar circumstances. I went back to the transcript and reviewed my interpretation, checking that I focused on her words and the way in which she related the event. Just because she had not done what I would have done, did not make my way of doing things better. I think that without having taken the time to understand reflexive practice then the quality of my analysis could have been compromised. IPA requires the researcher to base their interpretation in the participant's words and meanings rather than the researcher making judgements.

The participants' photomontages developed through their interpretation of the task. I did not indicate a specific format, but had asked them to create a 'photomontage', nor had I set a requirement for the number of images that they should produce. In the latter stages I asked for permission to record the first meeting as a way of checking what I said during the briefing. These recordings were not transcribed or used in the data analysis. I did this as I was surprised that all participants used images from the internet to create their photomontages and wondered if it was something I was saying in the briefing. I used the word 'image' but as an alternative to 'photograph' and 'picture'. It could be that the participants decided to use the internet as a source

of their images because they often used it as a source of information or in their professional lives.

At the start of the participant-led discussion, some of the mothers identified that they chose a time to sit down and create their photomontages. From a shared culture perspective, I believe that as most of the women were in professional jobs, producing PowerPoint presentations was very familiar for them. I am speculating that this was a familiar activity and that was why it was chosen. An early concern was whether creating images would be too time-consuming. This could have been the case if personal photographs were taken. It may be that looking on the internet for specific images which represented a particular phrase that they wanted to portray was a more effective way of doing the task for them. It was likely to be quicker than working out how to portray an image and did not require good photographic skills. Using the internet meant that the task could be completed at any time of day. Some of the women talked about sitting down in the evening so doing the task, using the internet, could have meant that it could be combined with other responsibilities.

Using images from the internet provided the opportunity to add another layer of anonymity for participants (Capewell, 2014d). In some cases the participants were being critical of educational and healthcare professionals with whom they came in contact. It may be that using images meant that the individuals could not be identified so their comments could be more candid. Of the seven mothers only one professional was named. Wendy, one of the mothers, used the ENT consultant's name in the context of having had a positive experience as he identified Peter's Glue Ear. After the operation Peter's sickness reduced substantially and she referred to the consultant as her *angel*, because he gave her the normality that she had craved.

Although I had constructed my own photomontage, I had not really thought about what others would include in theirs. Both the young people and the mothers included images which related to

their emotional well-being, either positively or negatively. Although during the construction of my own photomontage (discussed in Chapter 5), my memories triggered many emotional responses I had not assumed that others would do the same. I would suggest that this shows that the methodology helped participants to reflect about what was significant in their experiences of the condition and to identify issues that they wished to disclose.

Participation by young people can be problematic as to whether they are doing so because they want to or whether they have been ‘coerced’ by adults (Valentine, 1999). In this research, all participants were asked to create their photomontage separately. They then talked through the meaning of the images with me. I would suggest that the creation of photomontages provided evidence that the young people were consenting to participate in the research. If they did not create a photomontage then their involvement in the research would have stopped – I did not prepare a back-up interview schedule just in case that situation arose. Although there were only three young people who took part, and only two produced photomontages, the method did lead them to be very reflective in what the images meant. Russell was given a choice of options and did not produce a photomontage. This is discussed in Chapter 5. It would be worthwhile to use the method again with a group of young people to discuss their experiences as a way of verifying the research method.

In summary, I would suggest that the methodology worked effectively in gaining insight into participants’ experience of living long-term with Glue Ear. Creating their own images meant that they set the agenda for the participant-led discussion. Rather than in a semi-structured interview in which the researcher sets the agenda, in this research participants had time to reflect not only on what they wished to share, but also to identify relevant examples to clarify their intended meaning for the images.

IPA is a methodology which has been used extensively in health research in particular to gain insight into what it is like to live long-term with a particular condition (Shinebourne and Smith, 2011; Glasscoe and Smith, 2011; Brewer *et al.*, 2007). Using IPA as the means of analysing the data provided detailed insight into the participants' interpretation of their experience. Applying psychological theory to their explanation of their experiences added another layer to the interpretation of their meaning. Interpretation on different levels is a key element of IPA. Baker and Wang (2006) explained that in their use of Photovoice with individuals there was a lack of depth to the analysis. The detailed examination of the participants' words was explored in the Data Analysis section (Chapter 5). I believe that applying IPA during the analysis phase, as in this research, provides the interpretative element of participants' images which develops in Photovoice through group discussion as to the meaning of the photographs.

I was aware at the outset that asking participants to create photomontages as the main method for data gathering was a risk. If they had not done the task, it would have been unlikely that I could have then asked them if they would participate in an interview. It would have been more likely that they would have not returned my phone calls or emails. As participants were extremely difficult to identify and recruit this could have meant that I would not have had any data to analyse.

However, the participants did produce photomontages. The issues that they raised, particularly to do with the emotional responses to living with Glue Ear is not something I believe I would have included in an interview schedule, particularly not with young people as I would have been concerned about potential ethical issues. Participants were able to provide detailed examples to explain some of the situations they identified in general terms. This is probably because they had time to reflect on what they believed to be important issues for them in their experience and then had to find an image which reflected this. I think that if participants have reflection time then it avoids what I term as the 'crossing the car park moment'. That is the situation when someone

has been at an interview then leaves the room and later identifies what they consider to be a better answer and more representative of their experience.

Asking young people to create a photomontage and then being led by them as to which order they wanted to discuss the images helped to break down some of the adult-young person power differentials. They had chosen the images and could not only tell me about something that I had not seen until they showed it to me, but were also controlling the order and content of the discussion.

### 9.3 Conclusions

#### 9.3.1 Limitations

The following were identified as limitations of this research. They have been discussed in more detail in various chapters of the thesis so are summarised here to identify points for further consideration when designing future research.

- The very small sample of young people may mean that the issues identified in this research are specific to those individuals
- The young people were ‘volunteered’ by their parents, which limited those involved. The parents acted as gatekeepers so there could be something different about this group of young people, and their parents
- In the early meetings with participants I found that I was being overly cautious and not probing in detail when the issue raised was something about which I was uncomfortable
- I did not involve the young people, in particular, as to what would be an acceptable method for them through which to collect the data. I have since found by attendance at the Young People’s Consultative Group (YPAG) at Nottingham Hospital that young

people can provide imaginative and engaging tasks which might be a more attractive task than one designed by an adult

- In the original design parents and siblings were part of the recruitment strategy. Although I have acknowledged this by referring to ‘mothers’ throughout all phases in the research, greater depth could have been achieved by having other family members involved
- The qualitative literature is dated and related to the North American context so may not be relevant to UK experience
- The participants were a homogenous group of white, middle-class, educated participants so their experience may not be the same as that of other groups
- I was in control of the research process and there may be more effective ways of answering the research questions or deciding if those questions are of importance to participants. In future research, I would like to provide participants with a more active role in controlling all aspects of the research process from the outset.

### 9.3.2 Strengths

This research does have a number of strengths, particularly in terms of exploring the development of participant involvement and innovation in the methodology:

- Young people were involved in this research and expressed their views without having them filtered through a researcher-constructed interview schedule
- Participants set the agenda for the data gathering and were in control of the location and place for the discussion. They had greater control than in interview situations. They spontaneously identified the issues rather than being asked about them directly
- Although this research has only used a small number of participants they did not know each other and came from different parts of England so their experiences may be more typical than if they were all recruited from one location

- Involving a small sample of professionals did provide insight into how the professionals perceived their knowledge and understanding of Glue Ear. The views of those professionals in this research did reflect what participants had related were their experiences of interacting with them
- The difficulties that the mothers in this research related provide insight into the difficulties of parents and professionals establishing collaborative partnerships. This is particularly important in the context of current government policies of increasing the active role of young people and parents in decision-making.

### 9.3.3 Recommendations for further research

- Young People's Advisory Group (YPAG)

Evidence from this research suggests that young people need to be given the opportunity and means to participate in their treatment. Perhaps meeting others with the condition would help them to reduce their sense of isolation whereby they are 'different' to their peers. It could be valuable to set up a YPAG type group to inform practice and provide young people with a forum to express their opinions. This could perhaps form the basis of developing a skills package for self-advocacy skills to enable them to have their voice heard.

There is currently little information that is provided in a format that is easily-accessible for young people about the condition. It may be useful investigating what information young people would find useful to have about the condition, health-related, treatment options and educational-related. This would include identifying the media most appropriate for the material and how it can be accessed.

- Developing materials for Healthcare and Educational Professionals

The experiences of the participants in this research suggest that the condition is more complex than healthcare and educational professionals may believe. Although the healthcare professionals seemed to have a good understanding of previous research into the condition, responding to the young people and their mothers' emotions did not appear to be a priority. Educational professionals appear to lack information as to how the condition could impact on students' academic performance and emotional well-being, so are likely to benefit from easily accessible materials to increase their knowledge.

Currently young people have very limited opportunities to provide information to healthcare and educational professionals about how the condition impacts them. Healthcare professionals rely upon parental proxies to assess a young person's progress in school. It may be worthwhile developing a tool through which young people can communicate with both groups of professionals about how their hearing loss impacts them in lessons and the school environment. It could include issues such as the impact of tinnitus, pain, frequency and extent of hearing loss and optimum and disabling hearing environments.

- Parental Support Groups

In the current climate of support groups, it is surprising that no such group exists for parents/carers of young people with the condition. It is likely that parents of children who have the condition in its different forms and at different ages may have different needs. It would be worthwhile investigating what those needs are and the most effective way of meeting them. The findings from this research and my discussions with other parents informally suggest that there is a need for emotional support for mothers of young people with Glue Ear. Their concerns may be

different at different ages but seem to apply in all situations where their child has recurring ear infections.

If parents are to fully participate in the decision-making process then they need more information than is currently available. This seems particularly to be the case for understanding the range of treatment options available and the positive features and drawbacks of each. This relates to the behavioural and educational implications of the condition as well as the treatment options.

- Development of the methodology

This methodology appeared to encourage the participation of young people in identifying issues of importance to them. It may be worthwhile applying it to a wider range of participants with Glue Ear to see if similar issues arise. Equally it may be useful to apply it to young people with other chronic conditions to see if it helps promote their insight into the way the condition impacts their lives and how they could take greater control in dealing with the condition and developing positive mental health.

Equally its use could be explored with adults who have other health conditions as a way of encouraging them to explore their experiences and identify what support would be useful to them.

The methodology could return to its group use in the more traditional Photovoice approach to develop shared understanding of health conditions and reducing a personal sense of isolation. I would recommend continuing to combine Photovoice with IPA but perhaps involving the participants far more, than was the case in this research, in analysing and interpreting the data.

#### 9.3.4 Recommendations for practice

The young people and their parents in this research identified that they would like to have more information about Glue Ear and their treatment options. Russell explained in Chapter Six that he would have liked to have had a choice between grommets and a hearing aid. Daisy appeared uncertain as to how a hearing aid would benefit her and had been disappointed with the results of the operation to repair her ear drum. Stewie had very little respite from the tinnitus which accompanied his Glue Ear. Although the mothers in this research had a good understanding of how the condition impacted their child, their expertise was not always recognised. The healthcare professionals appeared to have a good understanding of the implications of the condition but did not always have the time to fully explain them.

Within the healthcare context it seems that it would be beneficial to provide leaflets in language and formats accessible to both parents and young people. These could cover a range of aspects from the potential behavioural implications of the condition through to different treatment options and the benefits and drawbacks of each. It may be of value to train all healthcare professionals involved in treating a young person with Glue Ear in appropriate ways to interact with them. This could include how they give information, the importance of giving the young person time to process what is being said and ways to encourage them to ask questions and participate in decision-making. It seems that parental expertise in the condition in their child could be acknowledged more widely. It may mean that changes in the way in which effectiveness of treatment is measured such as a greater focus on patient satisfaction and less on complying with consultation visit length.

Similarly, educational professionals would benefit from being provided with information about the possible repercussions of Glue Ear in the classroom and the types of actions that individual teachers can take to improve the situation for such students. Encouraging young people with the

condition to explain what actions they find helpful and working in partnership with parents could provide educational professionals with greater insight about the condition. Teachers would benefit from thinking about some of the possible sources of distraction for students with hearing loss and what individual action they could take to minimise the impact of these. For example, checking that chairs have rubber tips on the end of the legs to reduce scraping, considering the number of hard surfaces within the room which cause the sound to deteriorate and remembering to stand in a position in which students can see their mouth (Capewell, 2014a). Educational professionals would benefit from gaining a better understanding of the potential behavioural issues that can arise from ongoing Glue Ear such as the frustration of not always being able to hear clearly and the implications of this for young people when interacting with their peers. This would help to position Glue Ear as more than a common, temporary, medical condition.

#### 9.3.5. The contribution of this thesis to knowledge

One of the aims of this research was to raise educational professionals' awareness of the implications of Glue Ear in the classroom and on the possible impact on the social skills of students with this condition. To achieve this, I have participated in a range of conferences and written articles for practitioner and academic journals. Initially I published in student conference proceedings and have progressed to highly regarded peer reviewed journals, having recently had a paper accepted by JORSEN. I have presented at national and international conferences to a range of audiences (psychologists, teachers, educational academics and healthcare specialists). Appendix Eight provides details as does the section on Publications arising from this thesis. In this section, I summarise some of the comments and feedback I have received which has helped to raise greater awareness in professionals about the implications of Glue Ear which is often perceived as a trivial condition.

After my presentation at the BPS Division of Child and Educational Psychologists' Conference in January, 2014, one of the Educational Psychologists present said to me that he would in future consider that Glue Ear may be the cause of problematic behaviour such as students being disorganised or inattentive. He explained that previously he may have noted a history of the condition, but not considered its consequences. Another delegate identified that although she would expect inattention in students identified as ADHD, it may mean that the temporary hearing loss for those young people who also have Glue Ear may compound the difficulties and warrant consideration. As a result of the conference, I was asked to write an article for the Educational Psychologists' practitioner journal (Capewell, 2014b) in which I identify potential implications for attachment and parent-child interaction based on research by speech and language therapists and audiologists. I was approached by the editor of another practitioner journal, Assessment and Development Matters, to write an article. To avoid duplication I highlighted the implications of repeated episodes of Glue Ear on language and reading development (Capewell, 2014c).

Attendance at the Cambridge University School of Education Post-Graduate Student Conference in 2013 provided me with the opportunity to write a peer-reviewed article (Capewell, 2014d) in which I explained my research methodology and raised the profile of the impact that Glue Ear can have in the classroom. One of the reviewers commented that this was 'an under-researched area in the context of education and made a valuable contribution to raising awareness of its potential impact on teaching and learning'. Similarly, my presentation at the Diversity in Organisations, Communities and Nations Conference in Vienna, 2014 provided me with the opportunity to meet educational professionals from Canada and Australia who discussed how Glue Ear can be overlooked as potentially causing difficulties in reading and social skills for some students. This led to writing an article (Capewell and Ralph, 2014) for their peer reviewed journal, The International Journal of Diverse Identities. This has been accepted and is at the typesetting stage. The article uses the case study of Lois and Stewie, with information taken

from Chapters Six and Seven of this thesis. It highlights the importance of teachers talking to young people with the condition, directly about how to improve their opportunities to participate in school by making minor adjustments.

I have been a guest lecturer for students within The University of Northampton and Bishop Grosseteste, Lincoln undertaking courses related to psychology, special educational needs and early years studies. Students have commented that it has raised the importance of knowing about the condition, particularly for those involved with children under the age of seven years. Through their own participation in simulation activities, they recognised that the condition can impact on learning and development as well as have potential behavioural implications (Appendix 12). A presentation at a conference in Poland on the theme of parenting children with special educational needs and disabilities led to the inclusion of a chapter in a book (Ralph and Capewell, 2014). The subject of the chapter used the case study information from Jane, Chapter Six of the thesis, regarding her difficulties in communicating with Russell's teacher. The aim was to highlight the benefits of teachers and parents working in partnership to help students with special needs which may otherwise go unrecognised. Glue Ear is a condition which is often overlooked.

In June 2014, I presented at the bi-annual conference of European Pediatric Otorhinolaryngology Congress (Capewell, 2014e) in which I explained the perceptions of mothers and young people regarding how Glue Ear has social and emotional consequences. One of the delegates who spoke to me discussed the need for more active listening by ENT consultants to how young people experience the condition. This conference led to an invitation to submit an article for a peer reviewed ENT journal and an invitation to speak to parents of girls with Turner Syndrome at their annual conference. A high percentage of girls with Turner Syndrome also have Glue Ear and parents welcomed the opportunity to understand the potential impact it has on learning and behaviour.

I have been awarded a small research grant to develop a process for ways in which young children (aged between two to seven years) can communicate to their parents and educators about environments in which they find it easy and difficult to hear. This is an extension of the findings from this thesis that consulting young people can be beneficial in understanding their needs. As part of a participant recruitment strategy I publicised the research on the SENCO on-line forum and at a recent seminar to teachers and early years practitioners. This resulted in a number of SENCOs showing interest in knowing more about the impact of Glue Ear. This has been a change from when I started my research in 2011 when SENCOs did not see the condition as part of their concern as it was perceived as being a medical condition so outside of their remit.

To develop the methodology of combining Photovoice and IPA, I have been successful in bidding with a colleague from the School of Health at the university to explore the experience of women with a recent diagnosis of breast cancer. The aim is to gain insight into the emotional impact on them of such a diagnosis then develop this into teaching materials for healthcare professionals.

### 9.3.6 Summary of the Research

The lived experience of Glue Ear has not previously been explored in the literature. There has been no previous research into this condition in which participants and researchers have the same level of opportunity to establish what is to be discussed. Young people's voices have been absent from previous research into the condition. Perhaps because participants with Glue Ear are difficult to locate, previous research has been primarily in the clinical or healthcare context, which may have shaped participants' understanding of the researcher's interest.

This research highlighted the emotional impact of the condition on both young people and their mothers. It seems that far from being a medical condition with no long term impacts, there is a need for young people to be better supported by their teachers if they are to achieve their individual full potential. It is not enough to perceive them as performing around the class average. The emotional turmoil expressed by the young people, and the mothers, in this research has been largely overlooked by healthcare and educational professionals interacting with those experiencing long-term Glue Ear. There appears to be a need for greater support and more accessible information about the condition. I believe that Daisy, Stewie and Russell have demonstrated that young people have a valuable contribution to make to research.

## Chapter 10

### My road to a PhD: Thoughts, Reflections and Learning

#### 10.1 Introduction

When applying for my PhD I thought it would be like my masters only ‘bigger’ and ‘harder’, but I’m not sure that I fully understood what I meant by those terms. I had wanted to do a PhD for a number of years and include a brief summary of how I eventually applied to The University of Northampton in November, 2010. Throughout the week long induction programme I attended in February, 2011, there were recurring comments that a PhD was a ‘journey’. At the time I did not understand what that meant. However, I have gained greater clarity as I have progressed on my own voyage. For me this has been the trip of a lifetime and I am glad that I have kept a ‘diary’ in various forms documenting the changes that have taken place in me as well as providing me with examples of how my skills have changed and developed.

I could not cover every aspect of the journey in this chapter, but have focused on what I consider the main changes that have occurred in me. These include the development in my thinking and practical skills. Perhaps the biggest change for me has been unlearning and changing the way in which I understand the world in terms of my ontological and epistemological positions; I now align myself closely with a social constructionist perspective whereas I definitely started out with a post-positivist perspective. Reflection and reflexive practice have been key aspects in my development. I have had to unlearn my previous writing style. This has been personally very difficult as writing was something I thought I was good at. What I now realise is that I was good at writing within a commercial context, and need to maintain that skill. Academic writing requires more precision and if I am to be successful in an academic setting I need to adopt that style and learn new skills.

As with all journeys, the people I have encountered along the way have added to my experience and given me new insights into myself and my work as a researcher. Many of the contacts that I have made at academic or professional conferences have influenced my thinking and have been incorporated with my research as I have been able to quote from their presentations and published research. Other people have introduced me to writers, theorists or models which have again influenced my thinking.

A key realisation for me is that a lot of this journey has been about developing my philosophical understanding, hence the 'P' in PhD. At the start I knew what a 'fact' was and who had 'knowledge'; it is probably more accurate to say that I thought I did. I have gained much greater insight into the concept of 'researcher bias' along with the subtle ways in which the researcher can influence the relationship with participants to shape their responses. The more I have read has led me to realise the less I know. Although the logical part of me acknowledges that there is simply too much published to allow me to read everything that I might find useful, insightful or helpful, the learner inside urges me to keep on trying.

At the interview for my PhD, I was asked various questions by the interview panel which made me pause. For example, my interviewers wanted to know what part I saw young people and their parents playing in the research process; what age of children with the condition would I involve; and what sort of information would I be looking to use. I did not have answers to those questions, nor thankfully was I expected to. However, my mind was introduced to more possibilities than I had previously considered. At that point, my belief was that I would need to undertake a quantitative study to ensure that I kept my personal experience out of the research therefore not influencing the results. Although blissfully unaware at the time, my PhD journey had begun.

## 10.2 My aspirations to start a PhD

I had been determined not to start my PhD until I could devote what I saw as adequate time. I suppose like many people it remained on my wish list for a number of years. I have always enjoyed learning and increasing my academic performance. Across the years there have been various topics that have gone through my mind. In my early investigations as to how I would achieve a PhD, I initially believed that I would need a master's degree in a relevant subject.

At that time I wanted to do a psychology-based research project. Therefore, I began by converting my B.A., in English Literature and Modern European History, into B.Sc in Psychology through a conversion course at the Open University. This was followed by an MSc in Occupational Psychology. My vague idea was that I would undertake a PhD investigating the psychological impact of survivor syndrome in UK companies. This was in the context of massive redundancies during the late 1990s when a number of large organisations in the UK had reduced their workforce by significant numbers. I wanted to investigate the impact of remaining employed in an organisation in which many colleagues, doing a similar role to the 'survivor', were made redundant. At the time I was working within BT's management training college prior to leaving and starting my own consultancy company. It seemed that in many large organisations, such as BT, there was a reduction in productivity, an aversion to risk-taking and an over-reliance on procedures in problem-solving and decision-making in those who remained in the organisation. Although I was enthusiastic to start and passionate about the topic, my family and work circumstances at the time were not conducive to the level of commitment I felt were required for a PhD.

In the intervening period between then and beginning my PhD at The University of Northampton in 2011, I became more and more interested in the impact that long-term Glue Ear has on children's psycho-social development. This interest developed from seeing the condition in my

nieces and nephews and then in my own children, both of whom have had the condition from when they were babies and continue to have recurring episodes to the present time. Although it is the most common reason for children seeing their general practitioner and having surgery in developed countries, there has been little investigation into its implications in the educational field, and even less regarding how it potentially impacts social development and self-esteem.

I had some reservations about my ability to undertake a PhD and considered a number of alternatives. My son prompted me into action when he asked if I was ever going to get on and do the PhD I had talked about all his life. After a telephone conversation with Richard Rose, I applied to The University of Northampton in November 2010. I attended an interview in December 2010 and was given an offer to undertake a self-funded PhD. I was allocated two supervisors, one from the School of Health and the other from the School of Education. I had some reservations about this choice as I had read enough to see that for the greater part Glue Ear was perceived as a common, temporary, trivial medical condition which affected most children to varying degrees. However, I was not interested in its medical construction or origins, but rather how it impacted on the lives of young people with the condition and repercussions on family life. As I felt lucky to have been given an offer, I kept silent and considered that ‘they’ probably knew better than me. However, I did feel that I wanted to use the training and development I had gained from my psychology degrees. It was a situation of feeling happy but apprehensive.

On the five day induction programme in February 2011, all students were asked to make a short presentation about their ideas for their research project. My PowerPoint for that presentation is in Appendix 7, *An investigation into the social and educational effects of Glue Ear*. My previous research experience was quantitative therefore my first thoughts were to undertake an investigative study using psychometric and sociometric profiling comparing the friendship groups of children with and without a history of Glue Ear. My main reservation at the time was

whether there I would reach statistically significant results, which led me to question whether it would actually make a contribution to knowledge as required for the award of a PhD. However, I considered that as there was a huge gap in knowledge in the psycho-social impact of the condition, even no clear results would make a contribution. From my reading of previous research into the condition, a lack of clear cut results was a common occurrence; therefore the results could still add to knowledge.

During the induction programme all the students were asked to identify a skill or quality that we could offer to our peers. I thought that my ability to be enthusiastic would be useful as I am interested in everything so willing to listen and discuss any topic. Equally I am always interested in moving forward with a project which I decided would be useful when someone felt their work was not progressing. Some people thought I was joking; I was not. I hope that I have supported others by being enthusiastic. This trait has certainly kept me focused on achieving my submission date. Thinking, reflecting, being open to new ideas and learning are key skills in achieving a PhD. However, probably the most important skill is to action plan how the next step is going to be accomplished. I believe the most important personal quality is self-discipline. I think I have demonstrated my commitment to my goal during the last 3 ½ years.

I have been goal orientated but not single minded. The result has been that I have taken the opportunities available to explore what I did not know and to gain insight into how academia operates. This has resulted in becoming involved in a wide range of learning activities. These have included attendance at training courses, within and external to the university. My Participation Record, Appendix 8, documents the range of workshops, courses and seminars that I have attended as well as the conferences, involvement in committees, publications and research activities with which I have engaged. It was through listening to the advice and information from these events, that I have developed my skills and knowledge. I believe this has improved my research. For example, at the outset I was fairly sure that a quantitative project would be the

best way forward. However, attendance at a seminar on qualitative methods resulted in a complete change of mind about the research question I wanted to answer as well as the most effective way to accomplish it.

### 10.3 From Quantitative to Qualitative Researcher

The thing that has remained constant throughout my PhD journey is the topic area, Glue Ear, with a specific focus on its impact on psycho-social development. In May 2012, I made a presentation at The University of Northampton School of Education Research Students' Conference, Appendix 9. This summarised how my thinking had changed between February 2011 and May 2012 and what I had learned in the first year of my PhD about my research question. Early on my enthusiasm for getting on with things was in evidence and I was keen to start writing out my proposal. My supervisor at the time, Sarah Neill, kept urging me to think about my ontological and epistemological positions. Although I felt frustrated by this delay, I kept to the spirit of being open-minded, and attended a seminar on qualitative methods.

During that seminar, run by Jane Callaghan, I had a revelation that I had been blindly following a post-positivist tradition looking for the 'facts' about psycho-social development. This was a major change in my thinking and it is not an exaggeration to say that I felt like the rug had been pulled from underneath me; it was a complete paradigm shift. I realised that actually what I wanted to know about was the experience of living with long-term Glue Ear from the point of view of a young person and their parents. I acknowledged that I had previously not given any credence to the insight that individuals can provide about their own lives through consciously reflecting on their experience. I recognised that if they would share their thoughts with me, as the researcher, it would provide much greater insight into the impact of the condition on individuals than yet another quantitative study using multivariate analysis to assess how different factors worked in combination. What had been worrying me from my first presentation on the induction

programme was the issue of what if my results did not have statistical significance and the lack of replication of results in the many studies. Focusing on social skills had not previously been investigated, particularly in the school context.

As I sat there I recalled an experience the previous year when my son and I had attended an exhibition at the Wellcome Collection. It was called 'Bones' and consisted of skeletons and bones which had been unearthed during excavations for new buildings in London. It provided fascinating evidence of the sorts of diseases that the people of the time had suffered. Some of the skeletons had been exhumed from deconsecrated churchyards. I was mesmerised but noticed my son was uncomfortable. I asked what was troubling him and he replied, 'You are **such** a scientist.' It was not a compliment. He explained that those people had been buried in what they regarded as hallowed ground and had a set of beliefs that stated that on Judgement Day they would rise and live again. He also made the point that some of the skeletons were named individuals which meant that potentially their heirs could unexpectedly come across them if they visited the exhibition. I had been looking at the bones, he had been thinking about the people.

Sitting in that room listening to what Jane had to say, I realised I was doing the 'scientist thing' again. I was really struck that up until that point I had considered that the researcher was in a superior role and that I would be observing naïve participants. As a researcher I would be apart from the participants. I felt ashamed of my superior stance. I have always viewed myself as someone who respects others and believe that people should have equality of opportunity. I realised that my own children often provide me with insight into their lives and that there was a high likelihood that other young people could do the same. I was well aware of my 'mother' role in understanding the condition, but I had been prepared to silence the views of others. I had been trying to keep my experiences separate from my research but in doing so I was taking the life out of any findings.

I felt sick and excited at the same time as this would be learning a whole new way of carrying out research and require a major change in my philosophical thinking about what constitutes research. But I suddenly had clarity that the questions I wanted to know the answers to were: *What is the lived experience of young people with long term Glue Ear?* I accompanied this with wanting to understand the impact the condition has on other family members, but in the end the practicalities of recruitment, focused it on a second question of: *What is the lived experience of being the mother of a child with long-term Glue Ear?*

The research questions took some time to formulate after quite a lot of reading, thinking and reiterations. From my initial interview, I remembered those questions about what role parents and young people would play in the research. I had not understood them then, but was starting to realise how important those questions were. My reading of the literature identified that there had been little exploration of how children experience Glue Ear so this seemed to be a key area for investigation. As far as I could find there was recognition that their opinions mattered, but it was either too hard to research or no one would fund it. This seemed like an ideal area to explore, and certainly seemed like the 'gap' which would give me the opportunity to 'make a contribution to knowledge'. It felt like a challenge, and I have always been willing to try to do different things. I was funding myself so this looked like an opportunity.

I felt that I was starting to understand the metaphor of a journey because a lot of the experience is connected to the people whom you meet along the way. With a PhD this is not only the physical people who have influenced me but also the writers of texts, philosophies and ideas. Lincoln and Guba (1994) explore the differences between the various paradigms and after a lot of concentration, I developed awareness that I wanted participants to be at the centre of my research and that I wanted to work from a constructivist perspective. Silverman (2010) provided me with a clear framework to help me to identify the most appropriate methodology.

As I explored previous research into Glue Ear (Zumach *et al.*, 2010; Winskel, 2006; Vernon-Feagans *et al.*, 2003; Maw, 1995; Klein *et al.*, 1992) I understood that the participants had been passive, with data collected through conditions manipulated by the researcher. There was a distancing between the participants and the researcher, whereas I believed that the participants really had valuable insights to share about their experience. I could still see the value of quantitative research but it was not what I wanted to do.

I became more interested in the way in which people are likely to change and develop as a result of experience through reflection and sense-making to actively construct their interpretation of their situation, with their concerns and issues changing over time (Cohen *et al.*, 2007). I explored the idea of the voice of the participant (Guba and Lincoln, 1994) and how I was interested in the idea of co-constructing my understanding of what it is like to live with Glue Ear, or be a parent of a child with the condition. My quantitative paradigm shift from post-positivist to social constructionist has increased my skill set as a researcher, but also enabled me to identify the value of considering the findings of quantitative studies in terms of the ideographic experience thus adding depth and increased understanding of the condition in naturally occurring situations.

The particular experience of individuals, from their personal worlds, meant that the focus of my research study took a phenomenological stance (Moustakas, 1994). This led to a constructivist perspective in which I came to understand that the reality of one person may be very different to someone else in a similar situation, but it is formed relative to their own experiences, mindset and general stance of interpreting the world (Guba and Lincoln, 2005). The value of finding out about the way in which people come to interpret their experience provides a more holistic picture than is achieved when everyone's results are combined as in quantitative research. I wanted to find a way of valuing the individual voice. After a great deal of reading about phenomenology I decided that IPA (Smith *et al.*, 2009) would provide me with the structure with which I would

feel comfortable in my shift from quantitative to qualitative researcher. It would enable me to apply psychological theory (something I wanted to do) and keep the words of individual participant's at the centre of the whole process.

As I explored in the presentation given at the research students conference in 2012 (Appendix 9), IPA appeared to offer me a way of focusing on each participant's words. However, I was uncomfortable with the semi-structured interview as the method for data gathering as the researcher seemed to be taking a controlling position which could lead me to diminishing the role of the participants. I was concerned that my 'scientist thing' would lead me to become too reliant on the findings from the previous research. I would prepare an interview schedule which may mean that the participants may not highlight issues of importance to them.

I stated to explore visual methods then someone mentioned that it would be worthwhile having a conversation with Sue Ralph, a visiting professor who had a particular interest in participant voice and using photographs for participants to explore their situations. This led to another step change in my thinking. She introduced me to the work of Paulo Freire (1996) then Caroline Wang and Mary Ann Burris (1997). Freire's ideas about recognising the value of individuals resonated with me and I adapted his phrase to become 'the researcher becomes the participant and the participant, the researcher'. I liked the way Wang encouraged participants to create their own photographs and images. This seemed to provide a way of putting participants at the centre of data generation and hopefully alert me if my 'scientist thing' tried to take control.

#### 10.4 Reflection

From the outset my supervisors have encouraged me to adopt a model of reflection with which I feel comfortable and emphasised the value of maintaining a written 'diary' throughout my PhD journey. In addition to reflecting on my own practice, Silverman (2010) identified the need for qualitative researchers in particular to review their own position in relation to their research.

IPA, my chosen research methodology, underlined the importance of researchers considering their own position with regard to the topic they are investigating. In this section I identify the various ways in which I have used reflection throughout my PhD journey and the benefits this brought to me.

I adopted the Gibbs (1988) reflection model as the basis for how my research practice could be improved. I find it straightforward and have used it for a number of years. The six stage process of: description, emotions, evaluation, analysis, conclusion and action planning slows down the review process. This model has made me think about different aspects in detail then to draw conclusions and plan for further improvements, thus trying to prevent making the same mistakes.

I provide an example of how I applied Gibbs' model to review an exchange that I had with a mother during the participant recruitment phase. This was important learning for me as I allowed my 'scientist thing' to take over and recognised that I had perhaps been too inflexible in applying participant recruitment criteria. I took every opportunity I could to recruit participants by meeting people face-to-face as this helped us to establish personal contact. I was aware that I was asking them to talk about potentially emotional issues so felt that meeting them might help to establish rapport. I was invited to attend a local branch of the National Deaf Children's Society (NDCS) group. They do not regard Glue Ear as a central part of their role because it is not regarded as a permanent hearing loss. However, the organisation recognises that some of the issues that parents of children with the condition overlap with those of their members, such as dealing with a child who can not always hear but has to live in a hearing world. As part of their invitation to attend the event, the organiser had allowed me to include information about my research and said that I would be present at the event. During the event a mother approached me to say that she would be interested in participating in my research project. Her daughter was outside of the age range that I was recruiting so I explained that I would be happy to talk to her,

but that they didn't meet the criteria for participation – I did phrase it more sensitively. She spoke at length about her situation. The 'scientist thing' had taken over.

My feelings were mixed as I was having difficulty recruiting, and what she told me really provided good insight into how it can affect children, as well as the emotional impact on mothers. I felt very sorry for her as she described herself as very isolated and was desperate for the school to be supportive, which they weren't. In the evaluation phase of Gibbs' model, I realised that she had some excellent things to share, but I had excluded her from the research. Furthermore I could not use her data as I had not gained informed consent and it would be unethical to do so. Additionally I had not recorded what she said so the data would not be suitable for IPA analysis and I hadn't asked her to create a photomontage. In analysing what had happened, I identified that I had been too rigid in applying my recruitment criteria and that there could be a good case to be made for adjusting the participant selection criteria so that parents could participate even if the child did not. My 'scientist thing' had dominated me and I was not recognising the value of the individual voice. From what she said, it was apparent that parents of younger children might face different, but equally relevant issues which would add to knowledge and understanding about the condition. My conclusion was that, in future, I would include anyone who wanted to participate no matter what their child's age. The action was that I did contact her as I had agreed to send her some information and asked her if she would like to participate. She didn't reply. This situation led to the inclusion of mothers on their own rather than in the dyad (mother-child) that I had originally planned.

From my first supervision, I was encouraged to find a format for a reflective writing log that I could use throughout my PhD. Appendix 10, Student's Progress Summary, provides the structure that I used, which resulted from a Google search. My PhD has been plagued by problems with my paperwork. There were some issues about missing signatures on my PhD offer which meant that after an initial meeting in early March, my supervisors would not meet with me these were

resolved. It also meant that I did not have access to the library facilities. Therefore, my second supervision meeting did not take place until mid May. Figure 10.1 contains an excerpt from my progress summary written on 2nd May 200, which I completed as preparation for the supervisory meeting. I have focused on the section, 'personal actions and academic skill development'. The format of recording progress helped me to keep motivated, as I identified my progress and clarified future actions. Looking at this log now reminds me of the obstacles that I have overcome.

**Figure 10.1 Personal and academic skill development Entry from 2 May 2011 Log**

Research skills – working through the Cohen, Manion and Morrison Research methods book.  
Attended 2 day course on How to be an effective researcher.  
Completed 1<sup>st</sup> critique.  
Slowly making progress with Refworks and Metalib.  
Have used reflective techniques.  
Attending Quantitative workshop on 5<sup>th</sup> May.

I realised that even though the system was slowing me down I could rely on my own resources. On the Induction programme I had met other people from the School of Education and they have provided an extremely strong support network. From them I learned that they had been advised to read particular key texts about research skills, such as Cohen *et al.* (2007). As I didn't have library, I bought the book and began reading to maximise holiday time away from my full-time job.

I believe that completing my research study has only been part of my PhD journey. Equally important have been participating in a range of events and meeting and maintaining contact with people. Meeting and staying in contact with people has provided me with a support network which has been extremely beneficial to successfully completing a PhD. For example, rarely is everyone in the same emotional state at the same time, so sometimes I have listened to problems and made positive comments or suggestions and at other times others have done the same for me. I have found that the PhD journey is something that only those who have or are experiencing can

really understand. My husband and children have been incredibly supportive but sometimes I have needed to talk things through with my peers. Although I am quite action-orientated by nature, there have been situations that have needed reflection and probing from someone not emotionally close to me to enable me to understand the politics of the situation.

Part of the entry in Figure 10.1 stated 'Completed 1<sup>st</sup> critique'. This refers to 'The Critical Appraisal Skills Programme' (CASP) (Appendix 11) consisting of a set of questions used to evaluate qualitative research. When starting my PhD, I recognised that, as I had been away from formal study for some time I would need to renew my skills. One of these would be to successfully critically evaluate research. The detailed questions in the CASP helped me to focus on the key aspects of the research. Using this tool helped me to realise that it is not enough to know what is written about my topic but to evaluate its usefulness in terms of rigour of the methodology, whether the aims were met, if the methodology selected was appropriate to the aims and highlighted the importance of considering whether it was ethically-conducted research. Not only did taking this approach help me in assessing the research of others, but made me realise that others would be asking those same questions about my work. I therefore needed to make sure that I clearly communicated what I had done in those specified areas.

The path of my PhD journey has not always been smooth. I have had to develop resilience to keep going. Adopting reflective practice has helped with practical frustrations such as those concerned with participant recruitment. Through discussions with others, I have found this is a recurring difficulty for many involved in researching with people. Writing down those frustrations has helped me to keep things in perspective as is illustrated in the following example taken from my reflective log written in September 2012: *There were times in the recruitment process when I felt utter despair that I would ever actually get to talk to anyone. I completely empathise with Glucksman (1995:161) 'I am also now convinced that if I had stood in Salford precinct or Boston market wearing a sandwich board saying who I wanted to contact I would*

*have found as many, or more, suitable interviewees as through the more conventional and laborious methods.’ This is certainly a strategy I could adopt in future. It may be that people are reticent to put themselves forward. Alternatively, it could be that difficulty in recruiting is glossed over in most research reports or even that recruiting for qualitative projects in which participants are asked to disclose information about themselves is more difficult.’* Although I was perturbed at the time, reading accounts of the difficulties of others, talking to my colleagues and just thinking about the reasons perhaps why participants were not coming forward developed my ability to keep going. It also meant that looking back on the logs when I have analysed all the data from participants and have had to edit down their comments, made me feel grateful that I have too much data. This backward/forward reflection kept things in perspective. I am highly likely to face the same situation in future, so it is good to have a record.

A particularly difficult situation that I faced during my PhD journey was the need to change supervisors. I undertook my PhD on a part-time basis which meant that I have needed to juggle my work commitments around those of studying. Non-academic term time is when I have focused my efforts on my PhD. This proved very problematic in terms of one of my supervisors who only worked school term time. This was compounded as the other supervisor whom I was originally allocated felt that the demands on her non-PhD role meant that she did not have the time to spend with me. Using Gibbs’ model (1988) meant that I could write down what the issues of this situation were for me, identify the potential perspective of my supervisors and prepare for a discussion in which we could rationally discuss the situation to find a productive way forward. I think that being a mature student helped in these circumstances as I am used to being self-reliant and have the experience to identify when a situation requires action. I had been aware from early on that I saw my work in Education and Psychology and the situation enabled me to make that move. The result was that after the Registration process was completed, I changed my supervisory team by approaching two supervisors who have good knowledge of the methodologies I wanted to use and less formal time constraints. Getting the paperwork sorted out

for the change was less smooth, but my tendency to pursue things proved useful. It also taught me the importance of understanding and monitoring the administrative procedures from the outset.

Reflection has been important if my research practice is to improve by considering what has happened and hopefully how it can be improved (Gibbs, 1988). However, it usually takes a retrospective view as the focus is on what has happened and how to improve things in the future. In qualitative research, in particular, there is also a need to develop skills concerned with reflexivity.

### 10.5 Reflexivity

Finlay and Gough (2003, p. ix) explain that ‘reflection can be defined as “thinking about something” after the event’ whereas ‘reflexivity’ is described as undertaking a ‘thoughtful, self-aware analysis of the intersubjective dynamics between researcher and the researched’.

Undertaking reflexivity has been important in this research because of my personal experience of the topic and my desire to separate my situation from that of the participants. I have learned that I need to be ‘self-aware’ by bringing to consciousness my cultural assumptions (including social class, education and personality) then consider how this was likely to impact upon the participant. I came to recognise that we all bring biases to the research process and these could affect the way in which I interacted with participants. A big learning point for me was the way that reflexivity required a conscious decision as to how, as the researcher, I position myself with the participants.

The easy part for me was in deciding that I would disclose that I am the mother of two children who continue to have Glue Ear into their twenties. However, initially I did not disclose to a participant when they related a situation that I had faced or did not share any of the findings from

the literature. This was my 'scientist thing' in operation. My post-positivist stance, with the requirement that I remain detached from the participants, not disclose information about myself and try not to influence their reactions, has remained a voice in my head. The volume level of that voice changed at different points. I have had to silence it when exploring the participant's reality so that I was able to sometimes share similar experiences between us. Sometimes this was so that I could gain greater insight into how the condition impacted both mothers and young people. At other times it was to acknowledge that it may be the condition which was causing the behaviour and not something 'wrong' with the child or the mother.

In the early meetings with potential participants my post-positivist voice dominated my thinking as it warned that I must not 'contaminate' participant's descriptions and issues or blur the line between researcher and participant. However, reflexivity led me to reconsider my position. Part of my reason for adopting the Photovoice methodology was awareness of the power differential between the researcher and the participant in semi/unstructured interviews. I also considered that the participants in this research were marginalised voices as they had never been encouraged to express their point of view on their experiences. Previous researchers had shaped participant's responses through the questions they had asked. The question I realised I needed to consider was that by not sharing and disclosing knowledge then wasn't I exerting a position of power over participants? Pondering this issued resulted in changing my practice so that when a particular issue arose for a participant and, it seemed to cause them difficulty, I asked if they wanted to know what previous research findings had suggested. Rather than interrupting the flow of the participant-led discussion, we tended to talk about such things after the images had been discussed. It also meant that if participants had read something or developed their own theory then they were more likely to share this.

Phenomenologists use the term ‘bracketing’ for the process (Becker 1992) of the researcher keeping a written record of their own thoughts and assumptions about the topic under investigation, responses to what participants say and what the researcher already knows about the subject. This is used as a way of keeping the researcher’s knowledge and experiences separate from the participants. However, Smith *et al.* (2009, p. 35) identify this as ‘the dynamics of preconceptions’, which recognises that researchers have their own assumptions about the topic and need to identify what they know and what they think might happen with interactions with participants. This was an ongoing situation in which, as the researcher, I needed to constantly review. I have found that it was helpful to document my own understanding of my maternal experiences of Glue Ear (which can be found in Chapter 4, Table 4.4).

Through keeping logs and being reflexive about my thoughts and assumptions as I talked to participants and analysing what they said, I have been able to monitor and minimise my influence on participants. As I highlighted in Chapter 4, Table 3, there have been times during data gathering when my personal experience potentially caused me to close someone down. An example of this was when Lois explored how her son, Stewie, could disrupt family life with his outbursts of temper. This led me to include an extra step in the analysis phase in the IPA process. I included a review of my own response to what participants said and became aware of how I might impose my own feelings on them. Being aware of this has helped me to follow the participants’ lead as they made their own decisions about what they disclosed. This has potentially improved the quality of the data. Reflective practices have been a key element to undertaking my PhD.

## 10.6 Academic writing

I have found it hard to come to terms with having to redevelop my writing skills while completing my PhD. This has meant learning to develop a whole new set of skills. I am not

there, but at least I understand to which road signs I need to pay attention. I now realise that academic writing requires not only the skill of putting ideas together, but making sure that those ideas have credibility. This has meant learning how to use appropriate research data bases effectively, to keep good records of the references that I have identified and to use appropriate referencing as required by the publisher, editor or university. Most importantly I have been glad that over the years I have developed skills in being open to feedback and that most people do not want to destroy me, but are genuinely trying to help me improve my skills and performance.

I have certainly learned that if I want to make a statement, then I need to back it up with well-constructed research. In the induction week there was a session on the search system that the library used and another on the referencing software, Metalib and Refworks. I am pleased that I made myself become familiar with them early on. I also took up the opportunity to sit with one of the academic librarians and identify which databases would be most likely to be of value to me. I have kept all my references in Refworks and used its folder system. Whenever I identify a new reference I enter it. I did fall foul of using the bibliography tool as it does not put the information into the text as required. There are other referencing systems, such as Mendely, that I could use but took the decision that I would investigate them after completing my PhD.

Early on in my PhD journey I took time to read about how to do a literature search and write a literature review. I came to appreciate the value of developing good record keeping systems for what I had done. Although it felt tiresome at the time I now realise that it has saved me hours because I do not have to go back and repeat the search. This was a skill I did not previously have. Being painstakingly precise, I believe is very important if my work is to have credibility and rigour. I want a career in research and will not achieve that if I am sloppy or imprecise.

Clarity in communication is required no matter what the purpose of writing. However, a major difference in academic writing is that every word, phrase, clause, sentence can be dissected. In

my previous writing getting the communication out on time was the priority as the message would probably be read for overall meaning. I have had to learn to avoid tortuous sentence structures and imprecise vocabulary. Such language is not acceptable in academic circles, unless perhaps one is a gifted philosopher. Writing, reviewing, rewriting and restructuring are the requirements that I am trying to apply. I have learned to consider the number of ideas within a sentence and whether the message is best communicated through simple, compound or complex sentences. Being aware of the preferences of people who I want to access my writing has been an important learning point. For some people, starting a sentence with a conjunction will result in them focusing on that style issue rather than absorbing the argument I wish to make.

The overall structure and development of my argument is something that I am still developing. There are specific words that have been used in critiquing my work that I have now included into my vocabulary to consider when rereading what I have written. They have become personal shorthand for what I need to do with the text to improve it. By remaining open to feedback and trying to understand what is required of me, I hope that my style more closely approximates the requirements.

Many people have highlighted during my PhD journey that one of the aims is to become an expert in your subject. I now appreciate that this has to include gaining the confidence to 'own' my own work and ideas. In the early stage of the journey, I spent a lot of time critiquing and assessing what others had written. As I proceeded to transfer, I became increasingly aware that it was not enough to state what I had found, evaluate it in the light of the work of others and identify what it was contributing. I had to develop a point of view which I think my work suggests and develop an argument which identifies specific actions as well as persuade others to the same conclusions.

## 10.7 Conclusions

I feel that I have a much better understanding of the concept of the journey of the PhD now than when I started out. It has been very different to any previous academic study. It has certainly not been easy, in terms of overcoming practical obstacles and balancing the demands of study with the other parts of my life. It has been intellectually demanding with regard to the amount of thinking and mental gymnastics required to understand the concepts, theories and philosophies that I have encountered. When I set out on this journey I wanted a challenge and I wanted it to be fun. It has been both.

A key thing that I have learned is the importance of being open to new ways of doing things. This has particularly been the case with adopting a qualitative methodology and questioning the usual methods for conducting the study. I am pleased that I adopted two methodologies and stopped to consider the strengths and weaknesses of each and how they could be modified to produce a means for me to elicit relevant data and to constantly question the way in which I have analysed data. This has taught me to be more flexible rather than rigidly sticking to the original plan. If I could turn the clock back, one thing I would certainly have done was spend more time thinking about who to include in the research, what their perspective could perhaps provide and what would be the drawbacks of including them. I appreciate now that, although parents of younger children may not have the depth of experience of Glue Ear that my original target group do, there are different concerns at different ages. Those adults who spoke to me about their childhood experience of the condition would have added another dimension to the complexities of the condition.

I would say that I have always been a reflective person and have reviewed and learned from what I have done to improve my future practice. Prior to beginning this journey, I would have said that I was aware of the impact of one's own culture, but what reflexivity has taught me is to consider

that in far more detail. Standing back and examining the wider implications of my actions has alerted to me to the consequences of doing one thing, but not considering how that impacts in other ways. This has certainly been the case with regard to the way in which my epistemological stance has changed. I now believe that 'value-free' research does not exist. I think that this is true for all research and certainly needs thinking about.

I have had to re-evaluate and relearn my writing skills. Academic writing is very different to other forms of writing and certainly a long way from the business writing required for much of my career. I am still working to improve this. The need to refer to previous research and to constantly be alert to the need to be evidence-based is something that I think I have improved. The need to review, rewrite and reconsider the language I have used and the way in which I have constructed sentences is something that I will take into the future. Writing articles about my research is improving my skills and will remain an area for development as I try to get published in highly regarded academic journals.

I have had the opportunities to develop my research skills during this journey. Co-authoring three articles was helpful in developing my writing skills, gaining insight into how others write and learning how to collaborate. I recognise the importance of publishing my work and am finding opportunities to do so: this is important both to develop an academic reputation as well as for disseminating my work.

I worked as a volunteer research assistant to a visiting colleague at the university as I realised that I needed to demonstrate recent research activity. I have developed my experience by completing a short paid research project. These activities have enabled me to learn from others so improving my own skills and also to demonstrate that others see that I have value as a researcher.

I have taken every opportunity I could to disseminate my work. As well as presenting at seminars and conferences within the university I have presented at national and international conferences. These have been quite diverse in nature. For example I have made presentations at the Irish Association of Teachers in Special Education (IATSE), the British Psychological Society's Division of Education and Child Psychology (BPSDECP), CAMHS, Conference of the European Paediatric Otorhinolaryngology Surgeons, as well as ECER and British Psychological Society's Qualitative Methods Section Conference. My presentation at BPSDECP led to being asked to write two journal articles.

One of the aims of my research has been to raise awareness of the social, behavioural and educational implications of Glue Ear among healthcare and educational professionals. I believe that this should be part of initial education of these groups so have presented guest lectures to undergraduate courses for Early Years' Practitioners, Children's Nursing, Health and Social Care, Special Needs Practitioners and Psychology students. The comments by one group of students (Appendix 12) suggest that there is not widespread understanding of the condition in the educational context, but that practitioners can see the value of knowledge about it.

My research has highlighted that the educational implications of Glue Ear are under-researched and that it is not covered in teacher training. To make a difference to the young people who have this condition and their parents, my next skill development is to learn to bid successfully for research funding and social enterprise money. Recently I was awarded a small grant to undertake a pilot project to develop an idea that came from my research. I feel as though I am about to set out on a new journey – that of an early career researcher.

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## Appendix 1: Summary findings of previous research

### BEHAVIOUR

Researcher	Date	Issues	Links
Roberts et al	1989	Prospective study looking at cognitive, academic and classroom performance in Year 3 school aged children. Followed up on prospective study. Behaviour ratings in terms of lack of attention focus and dependency showed significant findings. Correlational study – used classroom behaviour inventory, not Rutter. Prospective study – 66 reduced to 41 after 3 years.	North Carolina Mentions Silva
Bennett & Haggard	1999	Investigate associations between history of middle ear disease and psychosocial or cognitive/educational outcomes. Longitudinal birth cohort study – 1970 12,000 children at 5 years and 9,000 at 10 years. Cognitive tests were administered at 5 and 10 years and behavioural problems rated at 10 years by child's teacher. Rutter A scales were used.	UK
Timmerman et al	2000	Preliminary evaluation of a newly developed questionnaire concerning the behaviour of young children with COM and documenting behavioural change after the insertion of t-tubes. 95 parent-child pairs were interviewed using the age-specific questionnaire pre-op and post-op 6 weeks after surgery.	Netherlands
Silva	2001	47 children with bilateral OM were compared with 355 non-OM 5 year old children to determine whether they differed in background characteristics, speech articulation, language or motor development and IQ and behavioural problems. Results – speech articulation ability, verbal comprehension; motor development, IQ and behavioural problems. Specific behavioural issues which resulted in stat sig results were: Observed: Dependency; short attention span; weak goal orientation. Reported: restlessness; fidgety; destructive; not liked by others children; often disobedient.	Dunedin NZ
Timmermann et al	2007	To review questionnaires which have been developed to describe the effects of COM on the daily functioning of children. Identified 15 questionnaires developed for children with COM – 2 evaluated the impact of the insertion of t-tubes. The questionnaires generally covered 6 impact areas (physical symptoms, child development, educational performance, emotional/practical burden and general health status) with physical symptoms most prominent.	Netherlands
Winterbottom, Hind, Smith & Haggard  Relates to Smith & Haggard – Parental involvement	2008	Compares and contrasts parents' and teachers' assessment of children's behaviour. 307 children from non-clinical population aged between 3-7. Psychometric questionnaire looking at factors: aggression; anxiety; context-directed activity; social maturity/communication. Parents and teachers have different views of children's behaviour in terms of appropriateness. Need for greater communication between teachers and parents.	UK
Timmerman, Meesters, Anteunic & Chenault	2007	Psychosocial adaptation in young school children with OM	Netherlands
Bennett, Haggard, Silva, Steward	2001	Behaviour and developmental effects of OME into the teens. Clear focus on the developmental consequences of COM in early childhood and the impact on behaviour – uses the 1970 UK cohort study. Identifies need to explore in more depth long term behavioural implications, suggests that some traits still exist.	UK Refers to Dunedin Uses Rutter scale
Bellussi, Mandala, Passali, Passali, Lauriello, Passali	2005	Correlational study, State-Trait Anxiety role of anxiety of parents and impact on behaviour/social skills. Suggests that parental anxiety has an effect on children. Distraction/need for repetition persists into 5 <sup>th</sup> class.	Italy
Haggard, Birkin, Browning, Gatehouse, Smith	1994	Questionnaire about frequency of COM and behavioural characteristics considered to be linked with OM eg: withdrawn, bad tempered – Given to parents, teachers, various medical groups – Data reported GPs and ENTs frequency/concern scale. Outcome was desire to develop a questionnaire that could be used	UK

## LANGUAGE

Researcher	Date	Issues	Links
Winskel, H	2006	Potential problems of an early history of OM on school-aged children's later language and literacy development. OM Children had lower scores on measures of phonological awareness, rhyme and non-word reading, semantic skills of expressive vocabulary, word definitions and readings.	Padolsky (2008) identifies a type of ADHD + OM which impacts reading age.
Vernon-Feagans, L	2003	How and when OM may impact development: (1) speech processes and phonologic development in early life, (2) receptive and expressive language, especially using language in narratives and to interact with others (pragmatics), (3) attention to language and its implications for schoolage children.	Influenced by Meynuk – Social Constructivist
Casby	2001	Shows that the magnitude of statistical significance of the impact of OM on language is relatively low. However it identifies that there are methodological issues. Focus was on quantitative studies. Lack of knowledge about hearing levels and instruments used to measure language skills.	Meta-analysis
Rovers, M., et al	2000	Randomised control of children with OM who either had ventilation tubes fitted or watchful waiting. Age: 1-2 years. No significant differences found. Researchers suggest that the narrowness of the range of test – normal language only.	
Duncan, J.	1999		
Menyuk, P.*	1987	Delay in specific language aspects: speech sounds that are difficult to process because of their particular acoustic characteristics and difficulty in production of morphological markers that consists of these speech sounds; production of elaborate sentence structures; language perception precedes production and OM may impact upon this; four or more episodes before the age of 7 years, may be a key indicator of language problems. SES may well have an impact. Could be processing difficulties in discrimination and comprehension of language categories.	
Eimas, P.D., Kavanagh J.F.	1986	Conference summary – Identifies link between COM and language difficulties. Belief that intermittent hearing loss might still exert a negative influence on language acquisition. This impact could be mild (15-25 dB) in early childhood, could also impact social and emotional development. Other factors may be influential – sex, IQ, SES, nature of communication between child and parents.	Critical Period Klein – Boston Study Group present Menyuk
Greater Boston Study Group – Teele, D.W., Klein, J.O., Rosner, B.	1984	Prospective study – comparing OM and non-OM from birth to 3 years – standardized tests of speech and language. Significant findings of co-relation. Greater in higher socio-economic groups.	
Holm, V.A., Kunze, L.	1969	16 children aged 5-9 years compared – OM and non-OM – language performance compared ( standardized tests) significant delay in OM group in all language skills requiring the receiving or processing of auditory stimuli or the production of verbal responses.	
Judith S. Gravel+		Assesses the impact of hearing loss on speech and language. Frequently, hearing status has not been evaluated directly with the presence and degree of hearing loss assumed. Conductive hearing loss is frequently considered the mediator of communication and developmental outcomes. Lack of large groups of children with continuous bilateral disease and significant bilateral and unilateral conductive hearing loss have not been examined to determine if there are consequences of persistent impairment. hearing loss. Mediating moderated by extrinsic factors, such as the language environment in the home, maternal responsiveness, the family's SES, and the quality of the day care setting, plus intrinsic variables, such as the child's cognitive capacity and the coexistence of developmental disabilities	Refers to the work of Vernon-Feagans and Roberts
Vernon-Feagans, Vernon & Yont+	2003	Updates research on how OM affects child development, focus on 3 aspects of: (1) speech processes & phonologic development in early	Influenced by

		life, (2) receptive and expressive language, especially using language in narratives and to interact with others (pragmatics), (3) attention to language and its implications for schoolage children.	Meynuk
Roberts, Zeisel, Rosenfeld, Reitz+	2003	Meta-analysis looking at a range of studies assessing hearing loss impact on language skills and development. <b>“cannot substitute for assessing and treating each child on an individual basis.”</b> We found small effects of OM on speech and language development in most children, but existing evidence is not always combinable or generalizable (Table 24-16).Managing young children with histories of OME must consider a particular child’s hearing status, language skills, and development.	
Maw	1995	Prospective study. P.20 Issues for hearing in noisy environments and could lead to inattention. Studies of potentially adverse effects of OME on speech, language and learning development are complex, time consuming and very difficult to control. It may be that there is greater impact if have OM early and low SES. Number of episodes may also be a factor.	Bristol
Gravel and Nozza#	1997	The premise is that listening in competition (noisy environments) may impact children’s academic achievement and/or attention and behaviour.P.64 <b>“...it is more likely that any deleterious outcomes associated with hearing loss and OME will vary from individual to individual, with audiologic and otologic factors interacting in combination with numerous other variables that are unique to each child and his/her circumstances.”</b> See p.82	
Hall, Grose, Drake#	1997	Masking Level Difference (MLD) measures the ability of the auditory system to take advantage of small interaural time and level differences in detecting signals in noisy backgrounds. The available data suggests that children with a history of OME (but normal hearing at the time of testing ) often have reduced MLDs when compared with age matched controls.	
Schwartz, Moody, Petinou#	1997	In order to acquire phonology, a child must be able to perceive, store and analyse the characteristics (eg: consonants, vowels, stress patters, pauses) of the speech and language to which he/she is exposed. Such impairments have a secondary effect on the acquisition of other aspects of language, such as morphology and syntax. Because certain features of morphology (eg inflections such as plural and tense markers, freestanding words such as articles that are unstressed) may be particularly vulnerable to impairment. The central question is what aspects of language are most likely to be affected by transient hearing loss associated with OM.	
Roberts & Wallace#	1997	A child with OME may experience a mild to moderate fluctuating hearing loss and thus receive a partial or inconsistent auditory signal. A mild hearing loss might diminish important auditory signals, making the speech signal more difficult to filter from background noise. As a consequence the child might appear distracted and disorganised. Persistent (prolonged) or frequent (and varied) disruptions in auditory input may impede the discrimination and processing of speech and thus cause the child to encode information incompletely and inaccurately into the database from which language develops. In addition the illness experience itself could cause tiredness, withdrawal, lethargy, distractibility, protest or clinging behaviour as the child seeks familiarity and decreases his/her willingness to explore the surrounding away from a caregiver (Parmelee 1993). <i>This could have implications for social development.</i> P.141!!/153/154/155	

\* Kavanagh, James F (ed) (1987) Otitis Media and Child Development York Press, Parkton, Maryland.

+ Rosenfeld & Bluestone (ed) (2003) Evidence Based OM 2<sup>nd</sup> Edition BC Decker Inc Toronto and London

# Roberts, Wallace and Henderson (ed) 1997 OM in Young Children Paul H Brookes Baltimore

## Cognitive Development

Researcher	Date	Issues	Links
Paradise, J.L. et al Pittsburgh Group	2003	Concluded that OM “is negligibly associated with and probably does not affect development outcomes at age 4”. However, low SES may have an impact; the findings can not be generalised to children with periods of effusion of longer than 90 days bilateral and 135 days unilateral from 2 months to 3 years, who did not respond to antibiotic treatment or to children with moderately severe hearing loss. <i>This would mean that those children with the most severe form of the condition were excluded – the very group who may well be affected in social, language or cognitive terms. Reinforces the idea that medics see the condition as transitory.</i>	
Feldman, H., Gelman, R.	1987*	Theoretical position of cognitive development – function of experience and assumption that absence of experience has deleterious effects.	
Zinkus, P.W.	1987*	Children with auditory processing disorders frequently show difficulties in following sequences of directions, retaining verbal material and short-term memory decay.	
Kagan, J.	1987*	Need to develop different strategies to assess cognitive development which are not based on the idea of general IQ.	
Wallace & Hooper#	1997	Purpose is to synthesise the findings from studies in an attempt to resolve discrepancies by examining methodological factors and the theoretical rationale for the association between OM and cognitive and behavioural outcomes. Many studies have not monitored hearing p.166-19 gives a summary of the studies. Earlier onset of OM seems to have greatest impact – could be that OM impacts specific aspects of cognitive functioning eg: verbal reasoning and attention, and memory. Academic p.173-176. Seems to have most impact on spelling and writing skills. OM and behaviour p.179-181. At age 5 motivation, attention, hyperactivity behaviours (short attention span, weak goal orientation, restlessness, destructiveness, disobedience. <i>Could OM be misdiagnosed as ADHD/Dyslexia.</i> Suggests that OM children may have phonological processing deficits and phonological process training may be of help. Frequent attention checks that OM children have understood the instructions/are on task.	

\* Kavanagh, James F (ed) (1987) Otitis Media and Child Development York Press, Parkton, Maryland.

# Roberts, Wallace and Henderson (ed) 1997 OM in Young Children Paul H Brookes Baltimore

## Academic Performance

Researcher	Date	Issues	Links
Golz et al	2006	If OM does not resolve then it continues to impact reading performance	Golz 2005 Critical period
Golz et al	2005	Suggests that fluctuating hearing loss may cause more problems because of its impact on the development of language.	
Stenton, S.J.	2003	<i>Thesis (Grey Lit) Used a qualitative questionnaire to ask parents about their teenagers social, behavioural and educational performance. A missed opportunity to access teenagers own views on the impact of OM on them.</i>	Could come under social as well
Peters et al	1994	Longitudinal Dutch study looking at reading, writing, spelling of OM children. Conclusion is that it is only reading and spelling which are impacted by OM at an early age, but their findings suggest that OM at age 4+ may have a greater impact. Poor performance by the OM children in word repetition may effect spelling	Support findings of Lous & Fiellau-Nikolajsen 1984 Teele et al 1990
Teele, D.W. et al	1990	Prospective study 207 children with OM – found that time spent with OM during first 3 years of life was significantly associated with lower scores on tests of cognitive ability, speech and language and school performance, mathematics, reading, articulation and morphological markers aged 7 years. <i>Actual measure of hearing loss is not identified, assumed period of time with OM. Implies that under 3 years is a critical factor.</i>	Boston Study Group - Empiricist
Silva et al	1986	Longitudinal study starting at age 3. Tested at 5,7,9,11 with the largest differences at age 5 - lower IQ, poorer speech articulation, verbal comprehension. <i>I have issues about using the Rutter scale for behaviour in terms of sample size and age. There is also an issue around the anxiety aspects which can impact the scores. Smith puts forward a rationale about this to support her development of new measure.</i>	Dunedin Study
Cowley	1996	Longitudinal study from 1981-1991 looking at the incidence of OM in Newcastle (Aus) study to assess the impact of OM on academic performance. 170 children with recurrent and chronic OM given hearing, speech and pre-literacy tests – age range 4yrs 6 months – 6 years. Control group 48. Retested in 1990. Children with OM had a less positive view of themselves or their ability that a control group. The researchers also noted that most early years teachers had little or no knowledge of OM.	Australia Conference Paper
Stanley	1992	Education difficulties occur for a number of reasons: Fluctuating hearing loss undermines students' ability to trust their own abilities. This comes from difficulty because of the way they hear the same input at different times means they find it harder to generalise. Silva 1982 – seen as aggressive and less popular; destructive and lack of popularity may result from frustration. Lack of literature about the educational ramifications of COM Lack of knowledge by primary caregivers; little available to help classroom teachers. Observational case study of 4 children with interviews with parents, teachers, children. Frustration of parents with surgeons who see OM as transitory condition. Teachers are often not aware of the condition, particularly of impact of noisy environment.	Candada MA thesis
Teele, Klein et al	1990	Prospective study to identify the link between IQ, school achievement and speech/language at age 7 years. 194 children followed from birth, able to identify those children who had had OM, included only white, no other condition, English as first language. Included children with tubes. Appeared to be an association between no. of episodes and lowered performance. Some attempt to control for confounding variables. Average IQ 105. Results were that more time spent with OM before age 3 years had lower scores cognitive ability, speech, language and school performance at age 7 year.	Boston Study Critical Period view

## Social Skills/Development

<b>Researcher</b>	<b>Date</b>	<b>Issues</b>	<b>Links</b>
Habesoglu et al	2011	56 participants, age range 9-16 years, 19 males, 37 females, children filled in the questionnaire with support from their parents.	
Bortoli, A & Brown, P.M.	2008	Social attention skills of pre-school children. Videotaped. Children with hearing loss have been found to have fewer interactions with peers and when interactions do occur, they are often shorter in duration and less complex. The Hard of hearing group used visual and parallel play strategies. <i>There may be issues for OM children in terms of turn-taking, sharing, initiating and verbal responses. Attention to the interaction is something else which could be looked at.</i>	
Duncan, J.	1999	Integrated setting for hard of hearing and normal children, matched pairs, quantitative study looking at conversational skills and interaction. Conversational initiation, maintenance, termination, shifting and context. Video-taped in naturalistic and quasi-naturalistic settings. Hard of hearing children were more likely to use physical, non-verbal initiation means, were unaware of initiations from peers: were less likely to maintain the conversation, made fewer contributions, tended to make unrelated comments to the topic at hand: less likely to shift the topic. <i>Type of hearing loss was not specified but there are ideas for aspects which could be considered with OM children.</i>	Conversational Organisational Theory
Kretschmer, R.R. Jr.	1997	The focus in developing communication skills as a way of developing language skills. It looks at the different types discourse. Children with hearing difficulties may benefit from assistance with support in child-to-child interactions. <i>This fits in with the Buddy idea suggested by Stanley, particularly in the playground and in games.</i>	
Vernon-Feagans, L., Manlove, E., Volling, B.L.	1996	Investigates a link between OM and behavioural changes, making them less responsive to changes in the environment, even when well. Findings suggest that they play alone more often, have fewer interactions with peers when in daycare. May contribute to the socially withdrawn child. 36 children, part of an ongoing prospective study, 3 centres, all white children, middle-class, Toddler Behaviour Assessment – 5 temperament dimensions – activity level, anger proneness, interest/persistence, tendency to express pleasure and social fearfulness. Suggests further research into older children's social skills and development.	Penn State Uni Speech/Language Specialist Critical Period

## Parental Experiences of Otitis Media

Researcher	Date	Issues	Links
Wuest & Stern	1990	Grounded Theory study – Learning to manage: 3 aspects: effects of the disease on the child; degree of disruption in family life; relationship with the health care system. 30 participants from 12 families, child under 10 years. Observations and interviews. Learning to manage: from passive to active – leading to ‘becoming an expert’, lack of sleep; conflict of looking after siblings; balancing work requirements; uncertainty about how long the condition will last; worry about the impact of hearing loss and impaired speech development on the child’s ultimate performance in school. Medical professionals keep informing the family that the condition is transitory. Teachers don’t see the problem and often have no knowledge of it. Families constantly looking towards when the problem will end.	Canada Study
Karkanevatos & Lesser	1998	Prospective quantitative questionnaire is used to investigate the parental perceptions on the effectiveness of grommets on general health, language and social skills. Administered pre and post-operatively by parents 150 parents. Only given to parents of 1 <sup>st</sup> insertion grommets. Post-op questionnaire mailed out 12 months later. 113 responses. Factors: Earache, antibiotics, balance, health, hearing, Behaviour and social skills, speech/language.	Liverpool & Southport hospitals Quantitative study
Smith, Haggard, et al	1999	Communication questionnaire using prompts from previous Content Analysis to identify the tactics used by parents when communicating with their children. Aim was to provide parents with tactics for their children as advice in ENT consultations.	Qualitative
Asmussen, L., Sullivan, S	1999	Focus on the Q of L for parents and children. 2 Focus groups of 14 mothers and fathers of children with COM (infant-9 years). Issues raised were the need for family support groups, education materials and better provider-parent communication from health professionals. Issues were lack of information about the illness and future hearing impairment implications. ENT recruitment.	Qualitative
Jonsson H. Haraldsson R.	2002	Semi-structured interviews; 21 parents of pre-school children with newly diagnosed OM, recruited through GPs. Parents’ concerns were about the impact of anti-biotics on the child’s immune system. Parents did not think much about the acute OM.	Qualitative
Feldman et al	2003	Prospective study – potential impact of OM on speech, language, cognition and behaviour 621 children. Parents complete MacArthur Communicative Development Inventories at ages 1,2,3. Negative correlation between language skills and incidence of OM. SES was identified as a confounding variable – correlational study. Could be related to parental communication strategies – parenting strategies (attracting attention; F-F) and the richness of the language environment. The degree of fluctuation in incidence of OM could also be a factor.	Pittsburg Paradise cohort
Higson & Haggard	2005	Comparison of similarities and differences in how the signs, symptoms, development impact of OM are seen by teachers, parents and ENT consultants. 118 teachers, 154 parents, 178 ENT consultants. Questionnaire. Teachers involvement was low. Major differences in priorities and impact: Parents – continued lower hearing problems; Teachers – education, language; Teachers and parents give higher importance to behaviour. Of the categories – ENT consultants rated Balance higher than both groups.	Connections with Paradise
Dube et al	2011	Telephone questionnaire asking about the impact of OM on the impact for the parent/caregiver. 502 people were interviewed. Focus was on the impact on the family – time taken off work, number of visits to doctor/hospital, cost of anti-biotics.	Canada
Winton, Roberts & Zeisel#	1997	Argues for a family-centred approach. Potential impacts: Financial cost (refers to medical insurance); emotional costs (worry and distress over the longer-term implications; fatigue of dealing with an unwell child; impact on work; disruption of family life); impact on behaviour (following instructions, engaging in interactive play; relating positively to peers, siblings).	

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## Quality of Life

Researcher	Date	Issues	Links
Rosenfeld, R et al	1997	Used a Q of L survey – physical suffering; hearing loss; speech impairment; emotional distress; activity limitations; caregiver concerns. 186 children aged 6 months-12 years with COM. Completed by child’s caregiver on entry to ward and 4 weeks later. Focus was on the reliability of the questionnaire.	
Bellusi et al	2005	Correlational study of survey on OM and the State-Trait Anxiety Inventory Test (STAIT). Retrospective questionnaire 252 children (6-11 years) – OM study. STAIT administered to the parents or caregivers of 20 paediatric outpatients 4-12 year). Psycho-social development affected most, especially attention disturbances. Two tests could provide complimentary data to evaluate children with OM. Parents personality may affect the Q of L of children with OM. Children tested in 2 schools. Teachers asked about learning skills, speech impairment and social activity of the children. Parents asked in ENT dept. Correlation between	Italy Critical period Children asked
Vlastos et al	2008	Purpose was to validate a new questionnaire on QofL – caregivers of 45 children 4-14 years) with COM pre-t-tube insertion – COM-5 variation of COM-6 administered 4 times: few weeks, few days pre-op and six months and one year post-op.	Greece
Habesoglu et al	2011	Evaluated use of T-tube insertion on the QofL for COM. Topics: physical symptoms, hearing loss, speech symptoms, social symptoms, and parents’ emotional sumptoms. Questionnaie 56 children – 9-16 years. Patients filled in the questionnaire with their parents (smiley faces and words on likert scale).	Turkey
Dube et al	2010	Telephone interview using a questionnaire. Sleep deprivation Change of daily and social activities, Emotional distress Changing of family plans. Additional 2 domains of impact on siblings. 5 domains about consequences for caregivers. Also overall care giver Qof L. Focus is the questionnaire development. <i>Source of quotable quote on reasons for not using children.</i>	Canada
Boruk et al		Used a proxy of the impact of QofL of Caregiver emotional impact for the child. Prospective study of children aged 6 months to 12 years.	Rosenfeld New York Dube ref
Haggard, Smith and Nicholls+	2003	Looking at a psychometric questionnaire for measuring QofL, compared a range of measures and identifies issues around the definition of the term.	See Smith Thesis
Smith, S	1998	Development of a Psychometric questionnaire to identify the impact of the condition. Used parental proxies, as it was more of a practical than philosophical consideration. Excluded children with COM or those who had had ear drum perforations. Parental and child QofL considered.	

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## Appendix 2: Sample reflective logs

### **Immediate reflections of Russell and Jane conversation 10 May 2012 (Dictated to self on way home in the car)**

R – he didn't describe much but then that was quite interesting because he was describing it from his point of view. I think that it was him saying that the pain, the ear aching that was a constant message, I don't think that is something that I've been particularly aware of, and I think that is what... it's not coming out in the literature, surprise, surprise.

The other thing that is interesting for me is the way he kept referring to the pain. J says he's quite stoical and I think he is but the pain is a major issue for him and he was talking about his ears leaking. Those sorts of things.

What she was saying about tiger mum and it's all those levels of frustration so for me it's just this same situation yet again. That the child is not really considered. Frustration, all the time fighting. Frustration. It did bring back echoes for me. It was interesting when she kept saying about the social skills stuff, and that reminded me of my son and I could see this whole thing of the ears yet again influencing and how he (R) doesn't particularly join in, but he's ok with not joining in and he doesn't have any problems with not joining in. Which is quite interesting.

### **Reflection after listening to tape and going through a structured reflection 12 May 2012**

One thing I need to be aware of is the personal triggers which could come from when the participants (particularly the mothers) are describing situations about their experiences. It was when Julia was talking about dealing with the teachers (Tiger Mum as she called herself) I remembered the feelings I had in similar situations.

### **Researcher vs Parent Reflection - General Talking to People June 2012**

As a **fellow parent** it is difficult not to move to a position of sympathising and sharing stories. At the same time, it is bringing back memories and emotions that I would prefer not to return to. In other ways it is heartening to think that it was not some unusual about my child, but rather a factor of the condition. Part of me would like to say that all will be well, stick in there and keep doing what you're doing and all will be well, my two are happy human beings.

### **Personal response to analysing the transcript January 2013**

This was quite a painful experience. It is easier this time than it was with Jane because I think that I was aware of what happened last time when I felt very upset. This time I was prepared for that and knew that the best way forward was to take a break and do something physical.

## Does your child have glue ear?



This PhD research project on living with Glue Ear aims to carry out an in-depth study of the experience of young people who have had glue ear from a young age, as well as involving their parents.

### Would the study be a good fit for me?

This study might be a good fit for you if you have a child who:

- Had/has a diagnosis of glue ear
- Is aged 2-16 years
- You would be prepared to talk about your experience
- There are no examinations or medical involvement

### Questions? Want to become involved?

Please contact Carmel Capewell

Email: [carmel.capewell@northampton.ac.uk](mailto:carmel.capewell@northampton.ac.uk)

Mobile: 07756 231264

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Sulgrave Room 104  
University of Northampton,  
Boughton Green Road,  
Northampton, NN2 7AL



The Director of Studies for this project is  
Professor Richard Rose 01604 89 2762

## **Appendix 4: Interview schedule – semi structured interview**

### **Interview Schedule for Professionals (without Photomontage)**

**Introduction** of self and purpose of research (PhD; understanding perspective of experience of Glue Ear)

**Purpose of interview:** To gain insight into the perceptions, experience and understanding of 'professional' role; interaction with parents and young people with Glue Ear.

#### **Topics:**

- Description of Glue Ear
- Perception of Glue Ear
- Impact that Glue Ear has on a young person
- Current experience of Glue Ear
- Past experience of Glue Ear
- % frequency of contact with young people with Glue Ear
- Interaction with parents of children with Glue Ear
- Interaction with young people with Glue Ear
- Advice to parents
- Professional role in dealing with Glue Ear
- Extent of interaction with other professionals when dealing with young person with Glue Ear
- 'Treatment' preferences (or if teacher – classroom actions)

#### **Closure**

Anything interviewee would like to add.

Any questions?

Any further advice to me?

Thank for time.

## Appendix 5: Young person invitation letter

Name

Address Details

Date

Dear First Name

### **Investigation into living with Glue Ear**

Thank you for your interest in my university project. I am very keen to find out what you think about having Glue Ear. I want to talk to people who have had glue ear since they were a baby. I see you as the expert in what it is like to live with Glue Ear.

I am writing to let you know what you will be asked to do. You can decide if you want to take part. It is all right if you don't want to.

You will be asked to take photographs and create images that give a picture of what your life is like. You will be asked to think about specific situations that you feel give a good description of what these experiences are like for you. Once you have created your photos I will meet you and you can explain what they mean for you.

Without your help this project could not take place. If you have any further questions before we meet to sign the participant forms or you want any information about our meetings, please do not hesitate to contact me by email:

[carmel.capewell@northampton.ac.uk](mailto:carmel.capewell@northampton.ac.uk) or phone: 07756 231264.

I am looking forward to seeing you and your Mum.

Yours sincerely

Carmel Capewell

## Appendix 6: IPA London Group – suggested themes

### Experience of Glue Ear (1)

#### Jane - mother of Russell aged 9 years

*Going round in circles*

It's repeated, repeated experiences. Cos we're always, we are always back and forward to the hospital either for his ears to be vacuumed out, or for grommets and tubes so that all represents that. So we're always at the doctors for amoxicillin so more than once so that's all the bottles. Because there are a few of those. It just represents it being repeated.

We're always at audiology so that's why there are more of those. More audiology than anything else. More audiology. We've been there every 6 months since he was 6 months. Just represents the experience.

*Very pissed around?  
Nothing is joined up*

We kind of go to 3 different places. We go to Audiology, (C: Where's that?) erm just down the road, in X, we go there every 6 months, and then in between times we go to Y The regional general hospital erm when there's been weekends when he's had massive ear infections, then we've had to go to the regional hospital then we end up getting referred to their system and we see a visiting consultant from Z there, then we've been up to Z separately for his ears to be vacuumed and for his perforations to be checked. It's all a bit, bit, and then there's the GP. Audiology seem to send the copies of the tympanography to the SENCO

*Inconvenience or Not being helped??*



*role of GP? Different to others? Holding things together? Not knowing what to do + where to go. Feeling lost? Confused?*

#### Caz mother of Daisy aged 14 years

we were originally being seen at a big hospital in X, it was a massive hospital and it was very busy and it was a pain in the neck, and then I got her moved to Y and they're much better there, it's nice and small and friendly and they're lovely there and you don't have to wait too long. No, it's actually been ok, ummh there's limited information, the information that I've got like that leaflet it's limited



Beliefs around illness?  
 What is sickness?  
 Physical sickness / feeling sick

**Experience of Glue Ear (3)**

How to define this problem / name it

dizzy like glue ear? like son? on roundabout together?

**Wendy mother of Peter aged 15 years**

Well at that stage it was, just you know, "Oh it's just sticky ear", another round of amoxicillin, here we go again... and it just wavered constantly between him not being on amoxicillin and being on it. And I kept going back to my GP and back to my GP and don't forget every time he's sick in school they won't have him in school for two days.... so then he couldn't go into school and then I had to be at home, and I was at home anyway at that time so it wasn't a problem, but any notion I had of wanting to go back to work or into education ... had to constantly get canned because I knew... that we wouldn't go a week without him being off school for one or two days. Because as soon as he's sick in school they don't want him in, they keep going, "Keep him home." And I'm saying he's not being sick because he has a bug, he's being sick because of his ears....

repeating roundabout she can't get off

C: Yeah  
 W: And they're like, "Fine, but he's sick so he can't come in." ..... So we had that whole roundabout.. and this went on and on and on until eventually he got to aged 5... and I finally said to my GP, "Look this has gone on so long now. This needs to be dealt with." And I'd been asking all the time if she'd refer on because we had private health cover, could she refer on. And she said, "No, no, no." Wouldn't refer. Wouldn't refer. "There's no problem here. You're over-reacting."

other not understanding above



round + round



Order + Control

**Marian, mother of Poppy aged 7 years**

they always saw her as just being ill a lot, they saw us, my wider family saw my mum and my dad .... It all becomes quite practical if they're looking after her, how much medicine do we need to give her, if she needs the inhaler, how do we do that?... Erm.... Of course they were worried about her illness and an underlying cause, but they don't live with us, and we don't see them all that often. When they do it's all part of her's Poppy and here's her bag of medicine. Medicine defined what Poppy could do really. Or in our head it did we tried not to let it happen, but 'Can we let her run around the park?' 'Yeah, yeah!' 'Will she throw up?' 'If she looks like she's going to throw up...' 'cos that was another thing, she was throwing up a lot through exercise. Erm just because of all the congestion. From an early age she was throwing up with congestion. .... Erm the school actually. I had to go up to the school and tell them not to send her home after the 3<sup>rd</sup> time because she wasn't actually having a stomach upset, she was just congested whether it was in here, or in here or in here she had to get rid of it and err..

Relationship - what's real what's not physical vs psychological

Questions how's what? and mum?

is sickness in head? identification

others not understanding - we are also

# Appendix 7: An investigation into the social and educational effects of glue ear

## An investigation into the social and educational effects of glue ear

What is glue ear (otitis media)?



Slide 1

## How does Glue Ear affect children?

In some children, the only sign of glue ear is a change in behaviour. This may include:

- Becoming tired and frustrated
- Preferring to play alone
- Not responding when called
- Falling behind at school
- Behavioural changes can often be mistaken for stubbornness or rudeness. As a result, many children with glue ear are misunderstood or labelled as "difficult."



www.dailymail.com/image/174

Slide 2

### My aim:

To assess the extent to which glue ear impacts social development in boys.

Why "social development"

- The medical treatment is well documented and various strategies are in evidence.
- There is a longitudinal study at the University of Pittsburgh looking at the educational effect of long term glue ear.
- Few investigations and strategies are in place for children with recurring glue ear.
- Children's social and educational development are highest in the 3-8 year old age group.

Slide 3

### Why boys?

- Glue ear appears to be more common in boys than in girls.
- Boys have different play strategies, such as playing in bigger groups and involving physical play activities, such as ball games.
- The consequences could mean that those boys who suffer recurrent bouts of glue ear with associated hearing loss may be more likely to have impaired social development.
- Such boys could be more likely to experience bullying due to their inability to hear and respond – particularly in play situations where loss of directional hearing could have greater impact.
- Restricting the study to boys means reducing one confounding variable of gender.



www.gettyimages.com/stockphoto/746055912/12333img

Slide 4

### What I don't know/haven't decided.

- The actual age group I want to look at.
- The type of glue ear.
- How to eliminate potential confounding variables regarding other factors which could effect social development.
- All the ethical considerations.
- Recruitment of participants.
- Is there actually a question to be answered.
- What is the best methodology – longitudinal, correlation?



Slide 5

## Appendix 8: Participation record

Workshops/Courses attended, with dates	Key learning points; usefulness to project/team/career progression	Relevant skills development;	Contacts, sources for follow-up
21-24 Feb 2011 Induction	Good understanding of the PhD process and support available. Felt that people were approachable and supportive. Notes have been helpful as has the knowledge.	Clarity about PhD requirements. Awareness that it is a process very different to other degrees. Library research tools – metalib, reworks	David Watson Ian Livingstone Meanu, Saneeya, Abide, Jackie, Neil, Benny, Kim, Lucy, Becka
14-15 April 2011 How to be an effective researcher	Pitched at people with less experience.	Waste of time.	Lingling Liu - Birmingham
5 May 2011 Qualitative research: An Introduction	Major paradigm shift when heard about IPA. Focused on the lived experience. Guba & Lincoln. Denzin. Silverman. Jonathan Smith	Understanding of Qualitative paradigm Introduced to IPA and the awareness of focus on the lived experience for the individual	Helen Ure Jane Callaghan
11 June 2011 Saturday School	Library session – Metalib; grey lit.  Getting published	Metalib; <a href="http://www.intute.ac.uk">www.intute.ac.uk</a> ; search suggestions Slicing research; publication in mind	Miggie Pickton
7 Oct. & 24 Nov 2011 Video-making in Collaborative research	Did give alternative methods to photovoice. The idea of visual ethnography, but not right for my project. A lot of information but not structured in the delivery.	University of Wisconsin - alternative to NViVO Issues of ethics, participants in videos, informed consent. Action research – Lewin.	Rob Walker
10-11 November 2011 Masterclass: IPA	Good review of IPA process Confirmed that this is the right methodology for my project Able to check the link between IPA and photovoice	Practical skills development of analyzing data. Reference of Pnina's and the use of art.	Pnina Shinebourne Vibeke Stubbings
10 December 2011 Saturday school session	Writing & structuring thesis	Consider structure early on; UN regs.; read theses; writing always; audit; Thematic approach; learn from 'mistakes' of other theses. Consider examiners.	
9 <sup>th</sup> January 2012	Abstract Training for journal articles, conference presentations and thesis	Word limits; Key words; Sentence structure.	
3-6 July 2012 ESEC	Research presentations	Range of visual methods/Ethical issues	
15 <sup>th</sup> October 2012	Preparing for Transfer	Seminar, chapters, forms, case for transfer	
16 <sup>th</sup> October 2012	Introduction to Qual Paradigms	Good review of qual methods	
21st-23rd November 2012	Photovoice Workshop	Ethics, images, dissemination	
28 <sup>th</sup> November 2012	Social Media Training Session	Dissemination activities: Research Gate	
10 <sup>th</sup> March 2013	Discourse Analysis	Good intro	
29 <sup>th</sup> March 2013	Introduction to research	Bit quick, need to do more	

	bidding	work on this.	
30 <sup>th</sup> May 2013	Intro to IPA	Tried to get group started	
8 <sup>th</sup> July 2013	Loughborough ECER Research Presentation	Dissemination Vs Impact differences	Julia Lindley-Baker
29 <sup>th</sup> October 2013	Preparing for Viva	Planning questions	
16 <sup>th</sup> November 2013	Lindsay Peer Talk	Analysis of data	
10 <sup>th</sup> December 2013	Researching with children conference Nottingham University	YPAG – involve young people in design	Ongoing attendance at the group Kirsty Widdowson YPAG
22 <sup>nd</sup> January 2014	IPA London Group Development of IPA themes	Really helpful feedback	Continued bi-monthly attendance
11 <sup>th</sup> February 2014	7 Secrets of a successful researcher	Well developed seminar, goal setting	
8 <sup>th</sup> March 2014	Future Glue Ear research	YPAG Nottingham Provided ideas for hearing maps	
27 <sup>th</sup> March 2014	Analysing Secondary Data	Good tips for assessing quant. papers	
18 <sup>th</sup> September 2014	Pluralism University of Middlesex		
25 <sup>th</sup> September 2014	NVIVO	Introduction	
10 <sup>th</sup> October 2014	Jorsen Research seminar		
25 <sup>th</sup> November 2014	MHPN CPD Event		

<b>Presentations/Seminars given, with dates</b>	Key learning points; usefulness to project/team/career progression	Relevant skills development;	Contacts, sources for follow-up
School of Education Birmingham 19 <sup>th</sup> November 2011	Poster Presentation: Key note David James, Cardiff – barriers to applying research (low risk culture)	Learned how to make a poster; need handouts. Good awareness for own 'impact'	
University of Northampton School of Social Science – Northampton 9 <sup>th</sup> January 2012	Listening to what the children have to say	Timing, answering questions	Sarah Armstrong-Hallam
University of Northampton – School of Education Research Students' conference 3 <sup>rd</sup> /4 <sup>th</sup> May 2012	Which comes first the research or the research question?		
University of Northampton Graduate School – Poster competition 16 <sup>th</sup> May 2012	Temporary doesn't mean no effects – Living with Otitis Media (Glue Ear)	Be more traditional	
University of Northampton Graduate School Conference 28 <sup>th</sup> June 2012	It's not what you ask, but the way that you ask it. Investigating the lived experience of Otitis Media (Glue Ear)	Language for non-specialist audience Test out AV aspects of presentation	
School of Education Birmingham 1 <sup>st</sup> December 2012	Listen to what the children have to say An investigation into the lived experience of Otitis Media (Glue Ear)		
Transfer Seminar and	The lived experience of Glue		

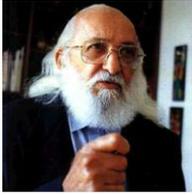
Viva 16 <sup>th</sup> January 2013	Ear		
University of Northampton – School of Education Research Students' conference	Workshop – Visual methods		
Cambridge School of Education Research Students' conference - Cambridge 30 <sup>th</sup> May 2013	From researched on, to researching with: investigating Otitis Media/Glue Ear		Megan Warburg
Trinity College/ University of Northampton Symposium – School of Education Trinity College Dublin 6 June 2013	Contributed to the round table on The researcher as insider		Patricia McCarthy
IATSE Dublin 7 <sup>th</sup> June 2013	Otitis Media/Glue Ear – a common problem		Kate Carr-Fanning
POWS 10 <sup>th</sup> 11 <sup>th</sup> July 2013 Windsor	Mothers and Professionals: A phenomenological study of living with a child with intermittent hearing loss		Edna Kurdi
QMIP 4 <sup>th</sup> -6 <sup>th</sup> September 2013 Huddersfield	Glue that sticks and separates - Symposium	Practice as a group. Present work to professionals	Zoe Boden Nollaig Frost
ECER 10-13 <sup>th</sup> September 2013 Istanbul	Listen to what the children have to say		Vicky Coppock John l'Anson Pam Woollard
Bishop Grosseteste Lincoln - Seminar	Glue Ear in the classroom Trainees in SEN		
Graduate School 20 <sup>th</sup> November 2013	Images of research		
Early Years Seminar 31 <sup>st</sup> October 2013 Jeanne Barczewska	Glue Ear in the early years		
Early Years Seminar 5 <sup>th</sup> December 2013 Helen Trory	Glue Ear in the classroom		
Health & Social Care Students Caroline Chisholm 16 <sup>th</sup> December 2013 Sarah Smith	Seminar – Glue Ear in Young Children		
DECP BPS Oxford 9 <sup>th</sup> -10 <sup>th</sup> January 2014	Intermittent Impact – Summary of the research on educational and developmental implications of Glue Ear/Otitis Media(OM)	Dissemination of impact of Glue Ear. Well received by Ed Psychs.	Charli Franklin (IPA London Group)
Children's Nurses – seminar 13 <sup>th</sup> January 2014 Gail Reoch	Glue Ear and Children's Nurses		
IPA London Group 22 <sup>nd</sup> January 2014	Development of IPA themes	Really helpful feedback	
MPHN 20 <sup>th</sup> February 2014	I keep on knocking but there's no one there – Mother's perspective of living with Glue Ear		Joined committee
Bishop Grosseteste Lincoln – Seminar 7 <sup>th</sup> March 2014	Undergraduate Psychology Students Glue Ear and Brain Plasticity		Olivia Sagen
ESPO 1 <sup>st</sup> -3 <sup>rd</sup> June 2014	The lived experience of Glue Ear – voices of mothers and	European ENT Paediatric consultants –	Arlene Smyth Turner Syndrome

	young people	spreading PPI	
Trinity College/ University of Northampton Symposium 26 <sup>th</sup> June 2014 Northampton	Contributed to Round Table		Renewed contact with Kate Carr-Fanning
University of Northampton – School of Education Research Students’ conference 27-28 June 2014	Workshop – Dissemination and Impact		Nollaig Frost Pam Woollard
CAMHS Northampton 2-4 July 2014	Never Mind, I can’t hear you, the stress of living with Glue Ear: A young person’s perspective		
Diversity in Organizations, Communities & Nations - Vienna 9-11 July 2014	Living with Glue Ear: Researching the educational needs from a mother-child perspective		Anthony Hogan
ECER – Oporto 2-5 September 2014	Paper 1. Glue Ear: Same Situation - different view: A mother and child's interpretation of school adjustments for a young person with chronic Glue Ear Paper 2. With Valentina Grion: The Past, the Present and Future of Educational Research in Europe		Beryl Wintrip
School of Education Research Seminar 6 <sup>th</sup> October 2014	Seminar - The Lived Experience of Chronic Otitis Media (Glue Ear) for young people and their parents		
Turner Syndrome Conference 11 <sup>th</sup> October 2014	Workshop – Glue Ear Awareness for parents		

<b>Other learning activities</b>	Key learning points; usefulness to project/team/career progression	Relevant skills development;	Contacts, sources for follow-up
SCOG committee member 2011-2014	Organising the School of Education Research Students’ conference	Liaising with Key Note speakers; scheduling speakers	
SERT student rep 2012-2013	Understanding the research bidding process		
SEBRDB student rep 2012-2014	Representing student issues on the academic PhD process	Negotiating with Senior academics	
MHPN committee member 2014	Liaising with members in other universities		
PhD Support Meetings July 2011	Support given and received with other students	Support network	
SCRIP July 2012-Present	Psychology research and reading group. Regular attendance.	Developed thinking about philosophical issues; critiquing work	
Psychology Seminars September 2012	Developed knowledge of wider field		
School of Education Research Seminars September 2012	Learning about research in the school	Developed collaborative working, networking	
Book Review	Understanding of academic writing and publishing process Capewell, C. (2012) Book Review: Advances in health psychology critical approaches. Horrocks and Johnson (Eds.), <i>Feminism &amp; Psychology</i> 23, 4, 572-573		Rose Capdevilla
Voluntary Research assistant	Collect UK secondary comprehensive school data: What is a ‘good’ school: A comparative study in 3 countries, France, Italy and UK. Presented at ECER, Porto and		Valentina Grion

	collaborative article planned.	
Research Assistant	Evaluation Project: Effectiveness of Critical Study Skills on-line MOOC.	Ming Nie
Book Review	Capewell, C. (2014) Book Review: Researching with children theory and practice. O'Reilly, M., Ronzoni, P. and Dora, N. <i>Jorsen</i> (In Press)	Pauline Prevett
Journal Article	Capewell, C. and Ralph, S. (Under review) Common Ground Publishing	

# Appendix 9: University of Northampton conference presentation

     <p>Carmel Capewell <a href="mailto:carmel.capewell@northampton.ac.uk">carmel.capewell@northampton.ac.uk</a></p>	   
 <p>Kerlinger (1970) Research is:</p> <ul style="list-style-type: none"> <li>• Systematic and Controlled</li> <li>• Empirical - based on evidence</li> <li>• Self-correcting</li> </ul> 	 
   	   
  	 <h3>References</h3> <p><b>Cohen, L. Manion, L. &amp; Morrison, K.</b> (2007) <i>Research Methods in Education</i> 6th Edition London Routledge</p> <p><b>Freire, P., Macedo, D.M., Bergman-Ramos, M.</b> (2001) <i>Pedagogy of the Oppressed</i> Penguin, London</p> <p><b>Guba, E. G., &amp; Lincoln, Y. S.</b> (1994) Competing paradigms in qualitative research. In N. K. Denzin &amp; Y. S. Lincoln (Eds.), <i>Handbook of qualitative research</i> (pp. 105-117). London: Sage.</p> <p><b>Kerlinger, F.N.</b> (1970) <i>Foundations of Behavioral Research</i> New York Holt, Rinehart &amp; Winston</p> <p><b>Smith, J.A., Flowers, P., Larkin, M.</b> (2009) <i>Interpretative Phenomenological Research Theory, Method and Research</i> Sage, London</p> <p><b>Wang, C. Burris, M.A.</b> (1997) Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment in Health, Education and Behavior vol. 24 no. 3 369-387</p>

## Appendix 10: Student's progress summary

A new summary should be completed before each supervisory meeting, and at regular intervals throughout the period of your research project.

- You should summarise information from your reflective research diary, training records, exchanges with academic colleagues and other relevant sources
- Identify key achievements, skills developments, needs, and impact on Plan of Work for next stage.

Describe your progress over this review period

a) with your research project

Completed further reading, identified University of Nottingham have undertaken research, mainly aimed at parental advice. Critiqued paper connected with it.

b) In you own personal and academic skill development

Research skills – working through the Cohen and Manion Research methods book.  
Attended 2 day course on How to be an effective researcher.  
Completed 1<sup>st</sup> critique.  
Slowly making progress with Refworks and Metalib.  
Have used reflective techniques.  
Attending Quantitative workshop on 5<sup>th</sup> May.

To what extent have you achieved your objectives?

Moving slowly at this point.  
Still need to clarify role of supervisors.  
Recognising that PhD is a process.  
Need to develop 'blog' e-portfolio.

Did you encounter any problems or barriers?

Time is an issue at this time of year.  
Frustration at not being able to get/take books out but now understand the system.  
Realised that I wasn't sure of the plan the supervisors had.

Have you identified any additional needs?

What changes will you make to your skill development plan?

Develop 'academic' language  
How to find out about conferences.

Do you need to modify your Plan of Work for the next stage?

Identify key points here:

Have set new agenda to clarify supervisor roles.  
Want to start putting timescales into moving towards registration.

## Appendix 11: Critical Appraisal Skills Programme

2011. Annals of Otolaryngology Rhinology & Laryngology 120 (5) 326-330  
"Effect of Type 1 Tympanoplasty on the Q. of L. of ch. bren  
Habesoglu, Tulay E.; Habesoglu Mehmet; Duvenci Ildem  
etal.

### Critical Appraisal Skills Programme (CASP)

making sense of evidence

## 10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is *not a definitive guide* and extensive further reading is recommended.

### How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour:** has a thorough and appropriate approach been applied to key research methods in the study?
- **Credibility:** are the findings well presented and meaningful?
- **Relevance:** how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

---

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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## Screening Questions

**1. Was there a clear statement of the aims of the research?**

Yes     No

Consider:

- what the goal of the research was ✓✓ Evaluated the effects of tympanoplasty on the QoL of pediatric patients
- why it is important ✓✓ Little subjective evidence regarding QoL.
- !! - its relevance ✓✓ Need to know patients' subjective experience or the outcomes of <sup>surgery</sup> ~~research~~.

**2. Is a qualitative methodology appropriate?**

p. 326     Yes     No

Consider:

- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

✓✓ "Subjective assessment of postop. symptoms in pediatric patients".

**Is it worth continuing?**

### Detailed questions

*Appropriate research design*

**3. Was the research design appropriate to address the aims of the research?**

Write comments here

Consider:

- if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Validated questionnaire which was modified. Not discussed why but further references given.

*Sampling*

**4. Was the recruitment strategy appropriate to the aims of the research?**

Write comments here

Consider:

- (a) - if the researcher has explained how the participants were selected
- (b) - if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- (c) - if there are any discussions around recruitment (e.g. why some people chose not to take part)

✓✓ Charts of 78 pediatric patients Istanbul com + treated with type 1 tympanoplasty 12/05 - 02/10.

(c) ✓✓ I identified those patients who had other potentially confounding factors were eliminated e.g. "metabolic disease".

✓✓ (a) 56 patients identified

Demographics of participants given  
9-16 yrs No. 14-1.  
19 male 37 female

.....  
Data collection

**5. Were the data collected in a way that addressed the research issue?**

Write comments here

- Consider:
- if the setting for data collection was justified
  - ✓ if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
  - if the researcher has justified the methods chosen
  - if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)
  - if methods were modified during the study. If so, has the researcher explained how and why?
  - if the form of data is clear (e.g. tape recordings, video material, notes etc)
  - if the researcher has discussed saturation of data

Parents with children.  
Questionnaire Validated Q. of L. Com 5.  
Fig. 1. 7 point likert-scale  
Pictorial scale - 10 points  
p. 327 gives details of objective measures

.....  
Reflexivity (research partnership relations/recognition of researcher bias)

!! 6. **Has the relationship between researcher and participants been adequately considered?**

Write comments here

- Consider whether it is clear:
- if the researcher critically examined their own role, potential bias and influence during:
    - formulation of research questions
    - data collection, including sample recruitment and choice of location
  - how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

.....  
Ethical Issues

**7. Have ethical issues been taken into consideration?**

Write comments here

- Consider:
- !! - if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
  - if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
  - if approval has been sought from the ethics committee

"Informed consent was obtained"  
!! No discussion of ethical issues

.....  
Data Analysis

8. Was the data analysis sufficiently rigorous?

Write comments here

Consider:

- if there is an in-depth description of the analysis process ✓✓
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account ✓✓
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation !!

Details of statistical package.  
" B.a. statistician reviewed the results:  
Unrelated T-test parametric  
Related T-test pre/post-op  
Mann Wh. U-test  
Wilcoxon signed test.  
Sig. > 0.05.

Did discuss the validated questionnaire  
reliable instrument.

.....  
Findings

9. Is there a clear statement of findings?

Write comments here

Consider:

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.) ✓✓
- if the findings are discussed in relation to the original research questions ✓✓

Group 1  
56 - 45 children intact tympanic  
Group 2 11 " unsuccessful closure  
Sig.  $p < 0.01$ .

Group 1 | Group 2  
Successful | unsuccessful.  
↳ Physical improvement,  
perhaps due to smaller  
hole

.....  
Value of the research

10. How valuable is the research?

Write comments here

Consider:

- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?) ✓✓
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used !!

✓✓ Recognition and identification  
of subjective measures of QoL.  
✓✓ Effected to have comparisons  
with unsuccessful group.  
Effectiveness of the surgery.

The Group 2 who had unsuccessful  
23/2/12 surgery report less emotional  
distress & Types of ? / How/How  
effect? J

## **Appendix 12: Comments on Glue Ear from the BA (Hons) Early Childhood Studies**

The role of the Senco, Inclusion/SEN, Influence of the Media, Glue Ear have challenged me to become a good practitioner by working and treating everyone equally and have informed me about other diseases or illness that can affect the children or adult alike and how to respect others no matter their disability or person. I would like to know more about glue ear and its implication and the role of the Senco.

Due to the wide range of different topics we have covered, each lecture has been really interesting. They have ranged from Gypsy Travellers to Glue ear has meant that we have gained so much knowledge that can benefit our future practice in so many different ways. The guest speakers that came in were all really enthusiastic and I personally found it extremely beneficial having input from someone with first-hand experience and in some situations still practicing in that particular field.

Glue Ear was something I knew a little bit about due to the fact we had briefly covered it in first year, however I found that the guest speaker made the topic really interesting. I was quite surprised how much I enjoyed that theme as it was never a topic I had looked into.

Over the module, there have been a few areas which have been challenging and have required further reading to aid understanding and reinforcement of knowledge from the sessions in lectures. The first topic would be Otitis Media/ Glue Ear (Capewell, 2013), because it was a new concept that I had not heard of before and was not aware existed, but after the session, I found that it is a common condition in many children. There was also a lecture on glue ear. This was interesting as an activity carried out was to look at teaching strategies and the layout of classrooms. This is something which will be taken into future practice.

The topic of glue ear (Carmel, 2014) was an ear condition I had not heard of before. The activity of sitting back to back with a partner and listening to what your partner is saying with fingers in your ear was an effective way of demonstrating how you would hear if you had glue ear. This experience influenced the suggestions I made when asked how a child with glue ear would cope in different classroom settings. This will influence my future practice because if a child does suffer from glue ear I will know what measures to put in place to enable the child to feel involved in their learning. The measures will include talking facing the child and making sure the child can see the teacher's face if they have to lip read.

As this module is so broad and looks at children in society as a big picture it is inevitable there will be topics that not everyone enjoys. For me Glue ear was one of these. This topic is largely health related and looked into the reasons why children experience glue ear. The health aspect does not interest me and I believe this is why I did not enjoy this topic. However I do now understand how serious glue ear is and the amount of children it affects. The NHS (N.D) suggests that one in five children will experience glue ear in some form. This can be severe or minor. Having this knowledge will help in future practice if a child is not responding when being called this could be one suggestion to their parents to have their ears checked.

I found the topic on glue ear insightful, prior to the lecture I had very little awareness of glue ear, but have learnt how common it is. It is estimated that one in five children aged two will be affected by glue ear, and about eight in ten children will have experienced glue ear before their tenth birthday (NHS, 2013). I learnt of the implications that are caused by glue ear, including tiredness, irritability, and falling behind in class, and an activity where we had to put our fingers in our ears, turn our backs to a partner whilst they talked really put into perspective how difficult it is to hear with glue ear. I was also given time to think of teaching strategies and room layouts that could support a child with glue ear. I am glad to have studied this topic, as previously I did not know how common this condition is, or of its implications. When in practice I will be sure to support those with glue ear, and raise awareness in fellow colleagues.

The impact of 'Glue Ear' on children's learning challenged my thinking after the initial lecture. During my Year 2 placement experience I could put theory into practice and recognise the potential signs of glue ear.

I found the glue ear lecture interesting as I had heard a little about the condition before and I learnt about the symptoms for it and solutions for it. I prepared for this session by looking back at other lecture notes on what Glue Ear. The key themes in the lecture were that it is very common in early childhood and that 'the area of the ear between the ear drum and the cochlea, the middle ear, instead of being filled with air, becomes filled with liquid, which reduces the transmission of sound waves to the auditory nerve.' (Capewell 2013:5) I now understand that many children get the condition by the age of ten and that it is more likely to be diagnosed in boys.