CONSTRUCTING SPACES OF AUTHENTIC ENGAGEMENT THROUGH EMBODIED PRACTICE: AN EXPLORATION OF DEAF PEOPLES’ AND NURSES’ EXPERIENCES OF INTERACTING

MEGAN ELEANOR DICKSON

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Dedication

For Eli, Esther, Anna, Florence & Rachel who always remind me to make time to play

Abstract

Background: British Sign Language (BSL) is the visual-spatial language of deaf people in Scotland. For deaf, BSL users all contact with the NHS takes place in a hearing led context where spoken English is the primary mode of communication. Healthcare can therefore be challenging for deaf people to access and engage in. The implicit assumptions of the biomedical perspective, that views deafness as an illness to be 'cured', often underpin and shape healthcare practices. In this context, there is a lack of acknowledgement of deaf peoples' linguistic and cultural status. There has been recognition in healthcare literature that access to healthcare is problematic for deaf people. However, the majority of this literature is informed by the biomedical perspective, privileging positivist approaches to treating deaf people. This has resulted in knowledge that does acknowledge the social world in which deaf peoples' experiences of healthcare take place. Conceptualising healthcare as a form of social relationship, this research explored nurses' and deaf peoples' experiences of interacting with one another.

Approach and methods: This research is situated in the critical creative paradigm and underpinned by Gadamer's hermeneutics and Merleau-Ponty's philosophy of embodiment. The hermeneutic perspective enabled exploration of participants' relational and contextual experiences of interacting, and creative methods enabled access to the participants' and researcher's embodied knowledge of these experiences. Semi-structured interviews with deaf, BSL users and nurses who had provided care for a deaf person were undertaken over a period of 10 months. A focus group of BSL/English interpreters was also carried out.

Findings: The findings revealed that nurses often articulated and embodied predominantly biomedical understandings of what it means to be deaf. Approaching care from this perspective, nurses often struggled to acknowledge or respond to deaf peoples' visual-spatial ways of being and knowing. Healthcare environments were therefore frequently experienced by deaf people as hearing spaces in which they were systematically disempowered due to the oppression of their visual-spatial nature and language. This created divisive boundaries between deaf people and nurses that limited the potential for an effective nursing relationship to develop. Nurses who displayed qualities of openness and curiosity developed alternative ways of thinking about deafness. These had the potential to transform their approaches to practice that enabled collaborative relationships to develop.

Conclusions and implications: This research has demonstrated that healthcare spaces are relational and therefore constructed by the social actions of the people in them. For nurses to construct spaces that are respectful of and embodied deaf culture, the significance of the whole body in developing relational practice must be recognised. Such understanding and knowledge could enable nurses to approach practice with an awareness of how both their own and deaf peoples' embodied experiences can inform care. This necessitates reflexivity in which nurses recognise and question the assumptions that underpin their practice. Recognising the significance of deaf peoples' visual-spatial experience and embodied understanding of the world has the potential to contribute to emancipatory and empowering approaches to caring for deaf people.

Keywords: deaf, British Sign Language, embodiment, embodied practice, creative hermeneutics

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To those individuals at Deaf Action and my colleagues in the Hearing Sciences Division. Thank you for your guidance and challenging me as I navigated new terrain. I hope that we can continue to share and examine our perspectives together. To my wonderful colleagues in Nursing, Occupational Therapy and Arts Therapies at QMU, your friendship and laughter at the coffee table has sustained me.

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Chapter 1: Introduction & background

Introduction

My journey in constructing this thesis began in 2013 when I experienced a profoundly "disorientating dilemma" (Mezirow 1991, p.102) in which my values, beliefs and assumptions related to my own and others' experience of deafness were thrown into question. I experienced this dilemma during my undergraduate studies when the familiar biomedical perspective, that had been a key element of my initial education as a nurse, was confronted by a different perspective. Up until that point, I had never questioned the meaning of deafness and after engaging with a different perspective to that of the biomedical construction, I experienced a state of disequilibrium as my understanding of my identity, my body and my profession, that were unconsciously held, no longer seemed sufficient. As a nurse and hearing aid wearer, this thesis is both personally and professionally motivated by a passion to see different people, communities and disciplines engage meaningfully. When I started my doctoral studentship in 2016, I set out to understand how deaf people and hearing people can create meaning and shared understanding in the space between different communities, ideologies, language practices and political aspirations. My aim was not to "settle" various debates. Instead, I wanted to explore and critique them to gain a better understanding of the challenges and possibilities in relationships. In this chapter, I set the scene for the thesis to position myself in relation to it: firstly, providing context to the study and secondly reflecting on my personal experience of hearing loss and professional experience of nursing. This identifies my motivation for the current research in greater depth.

Background

The Scottish Government (2017, p.4) has committed to making "Scotland the best place in the world to live, work and visit for people whose first or preferred language is British Sign Language (BSL)". BSL is the indigenous language of deaf people in Scotland. Produced by the body and perceived visually, BSL is a vibrant visual-spatial language (Brien 1992). The number of people in Scotland who use BSL as their first or preferred language is estimated to between 5,000 and 6,000 (Scottish Council on Deafness 2018). Contrary to common belief, BSL is not a signed equivalent of English but is a language in its own right, with linguistic structures that are as sophisticated as natural spoken languages (Sutton-Spence and Woll 1998). Additionally, sign languages differ from spoken language in their mode of delivery. While spoken languages are auditory-oral, sign languages are visual-spatial (Glickman and Hall

2018). For many deaf people, interactions with hearing people, who do not sign, necessitate the use of a BSL/English interpreter (Bontempo 2015). Deaf people are in the unique position in which use of interpreters is often a lifelong experience (Napier et al. 2010). Therefore, access to interpreting services is essential for empowering deaf people to live autonomously. However, due to dominant language ideologies and constructions of deafness, the need for a BSL/English interpreter often goes unrecognised. Healthcare has been highlighted by deaf communities as the most problematic service with which to access and engage (SignHealth 2014; Kuenburgh et al. 2016). I believe this is due to dominant constructions of health and prevailing attitudes about what it means to be deaf, which are informed by the biomedical perspective.

The meaning of health has evolved over time. In keeping with the biomedical perspective, early definitions of health focused on the body's ability to function. Health was therefore, viewed as a state of normal function that could be disrupted by disease from time to time. In 1978, Engel emphasised the limitations of the traditional biomedical perspective, arguing that it did not acknowledge or value the social, psychological and behavioural dimensions of health and illness. As a result, biomedically informed definitions failed to account for the person with the condition or their experience and attitude towards it. Whilst Engel (1978) argued that the psychosocial model could complement the biomedical model, and despite the subsequent expansion of the concept of health, the view of health as 'normality' has persisted over time, with medical professionals often focusing on efficiency of bodily systems and absence of disease (Nettleton 2013). Baxter (2018) argued that notions of normality are historically specific, culturally defined and dependent on contemporary knowledge, meaning that professional practices are not of themselves reflective of the biomedical perspective. Rather, it is the implicit assumptions, associated attitudes, and their social consequences that reflect the perspective (Young and Temple 2014). For Foucault (1973), who was influenced by relational conceptualisations of power, these attitudes manifest in day-to-day clinical practices and contribute to the social constructions and production of 'biomedical discourse[1]'.

In a broad societal context, deafness is often understood from the dominant ideology of the biomedical perspective (Kuenburg et al. 2016). Biomedical measures and discourses define deafness as a loss of hearing that is quantified in decibels and

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[1] A discourse being the means through which we have come to know, understand and respond to aspects of our lives.

managed through use of a hearing aid (Kramer and Brown 2019). Many people who lose their hearing later in life report that ‘hearing loss’ is an appropriate description of their experience as they feel their sense of ‘normal’ (hearing) self has been disrupted (Temple and Young 2014). However, deaf scholars (Kusters et al. 2017) argue that the biomedical discourse has dominated and controlled the construction of knowledge about deafness, even in societal cultures beyond healthcare, defining *all* people who are deaf as deviant and impaired. This culture has been challenged by deaf communities who do not define deafness as a loss or deviance from the ‘norm’, but as a positive experience incorporating a thriving cultural-linguistic identity (Ladd 2003). The tension between these two constructions of deafness and the relationship between the people who express them has been widely documented. However, there is a dearth of research that explores how such constructions manifest socially in the healthcare setting.

For deaf people, contact with the National Health Service (NHS) takes place in a hearing led context where spoken English is the primary mode of communication. This can be a challenging place for BSL users to navigate if they are unable to express themselves in their first language (Emond et al. 2015a). Deaf people rarely meet healthcare professionals who share their language or who have appropriate awareness of alternative constructions of deafness to that of the biomedical perspective (Glickman 2013). Often viewed as a disability group rather than a linguistic minority, deaf peoples’ right to access healthcare in BSL often goes unrecognised (De Meulder 2015). As a result, communication exchanged between healthcare professionals and deaf people is often compromised (SignHealth 2014). In addition to deaf peoples’ experiences of communication in a hearing context, nurses also report challenges that have the potential to compromise in the provision of care (Humphries 2017). The implications of these shared challenges are vast. However, the primary implication is numerous, potentially conflicting perspectives. In response to deaf communities’ campaign for access to public services in BSL, the Scottish Government passed the BSL (Scotland) Act 2015 in October 2015.

The BSL (Scotland) Act 2015 promoted the use of BSL in Scotland, requiring public bodies, including the NHS to develop BSL plans that outline how they will promote and raise awareness of the language. In healthcare, the main aim set out by the BSL National Plan (Scottish Government 2017, p.29) stated that BSL users “…will have access to the information and services they need to live active, healthy lives, and to make informed choices at every stage of their lives”. While Scotland has made positive progress in legally recognising BSL as one of the natural languages of the country, provisions for recognition of a language does not always translate into policies and resources (Napier and Leeson 2016). Consultation events held with deaf communities in Scotland have shown that deaf people are consistently being failed by ‘the system’ (McLean 2015).

With health and wellbeing highlighted as areas of priority for deaf communities in Scotland (Scottish Government 2015), it is timely and crucial that understanding of deaf peoples’ experiences of healthcare practice is developed. This understanding can help us identify the knowledge and actions that are needed to develop culture and improve practices for care, thereby achieving the strategic objectives of the BSL (Scotland) Act 2015.

Situating myself

My interest in nursing care for the deaf community has grown out of my personal background and through my work as a nurse. To set the context for my thesis, this section illuminates the personal and professional experiences that have guided me to this point. My experiences are included to enable the reader to gain a sense of my values, who I am and how these experiences influenced my perception of the wider world and myself. It is from this position that I embody a certain way of understanding how the theoretical perspective of this thesis (the ontology) is informed. Such ontological awareness therefore forms the underpinning of research and how my position in the world will influence my practice as a nurse and researcher (Crotty 1998).

Born in Northern Ireland, I grew up in the countryside. The patchwork fields of the Emerald Isle were my adventurous playground. My father and grandfather instilled in me a deep love for the earth. They taught me how to make jam from the berries that lined the hedgerows, build nesting boxes for birds and grow vegetables from seeds. In summer, our gardens were an explosion of colour. I explored barefoot, collected tadpoles, watched them hatch from eggs and transform into frogs. In winter, we fed the birds lard and seeds to help them survive the cold weather and admired the frost covered spider webs. As I develop a greater awareness of my values and beliefs through these experiences, I see how my relationship with nature taught me the embodied nature of knowing. This is evident in the ecological approach to understanding that I have adopted in which human systems are deeply and tacitly connected to the natural world surrounding them. Such understanding has become a significant element of my practice as a nurse, researcher and educator and is central to this thesis.

For the early part of my childhood, the countryside sheltered me from the political context of Northern Ireland. I remained blissfully unaware of any conflict in Northern Ireland until my first day of high school when I was asked if I was ‘Catholic’ or ‘Protestant’. Over time, I became aware of what it meant to find myself on the opposite side of an invisible dividing line in my hometown. This ‘Us’ v ‘Them’ mentality, although not actively supported by the majority, was maintained by how our lives were structured to avoid the collision of two cultural narratives. Despite the Good Friday Agreement formally ending the period in Northern Ireland known as “The Troubles” in 1998, peace often felt uncertain. Riot vans and helicopters policing public disorder in the streets were not unusual sights. The sporadic episodes of violence often made me question the nature and purpose of the peace lines in Northern Ireland that act as barriers to separate neighborhoods. Did these borders facilitate peace or sustain the *them and us* narrative? Upon reflection, I recognise that the history of The Troubles resides in communities that have multiple stories and truths. Such truths reflect the paradoxes and contradictions that emerge when people interpret the same event from different viewpoints. This understanding is not confined to the Northern Irish context, but to all contexts that involve human interaction. I now believe that conflict is sustained and remains resistant to resolution and transformation through harsh barriers. While it often did not feel safe to explore the borderlands in Northern Ireland, through my involvement in small cross-community projects, I began to see that boundaries have the potential to be fertile places with the potential for different sorts of relationships. This taught me the importance of relational ways of being and has shaped my practice.

At the age of fifteen, my hearing deteriorated dramatically. Doctors diagnosed an autoimmune disorder. Unable to isolate a time when I had been ill, my parents and I were left confused by this diagnosis. After numerous tests and visits to audiology, a doctor informed me that there was no cure, and I was fitted with bilateral hearing aids. Although I was unable to tolerate the uncomfortable hearing aids for longer than one hour, I would notice the birds singing or my cat purring when I had them in. The initial feeling of joy that these sounds prompted was quickly replaced by the realisation that without hearing aids, I had not been picking up these sounds. I was embarrassed and the words of the audiologist repeated over in my head ‘your hearing is as bad as an old persons’. I believe that the sense of lacking something seeped into my consciousness and influenced my outlook on life. My experience of care in the audiology department was heavily influenced by the biomedical model of service delivery and I became familiar with terms such as ‘hearing impaired’, ‘loss’ and ‘disabled’ that were used to define my condition. The language and attitudes of audiologists therefore played a central role in shaping and maintaining my understanding of deafness.

Over time, I developed tactics to hide my hearing loss and pass as ‘normal’[2] but was often exhausted from processing and constructing meaning out of half-heard words and sentences. During this time, my parents gently encouraged me to sign up to an introductory sign language course. To my surprise, my BSL tutor on this course was deaf and spoken English was forbidden from the classroom. My tutor communicated vibrantly in BSL, enabling me to develop basic BSL skills and a growing awareness of deaf peoples’ sense of pride in their language and community. This pride was a stark contrast to my personal perspective of being hard of hearing. I was intrigued by the tutor’s embodied ways of thinking about, knowing and understanding the world that differed dramatically from my own. These differing assumptions and values evident in my teacher’s expression of her language and culture felt separate to my experience of deafness in the biomedical culture. After one year, the BSL course was cancelled due to lack of interest and so my exposure to BSL was paused. However, it was from my interaction with my deaf tutor that I began to question and deconstruct assumptions inherent in the biomedical construction of deafness.

When it was my time to leave school, I chose to pursue an undergraduate degree in nursing. Through her stories of nursing, my Mum taught me that health and illness were not restricted to physical wellbeing, but included psychological, social as well as spiritual elements of being human. Through her relational practice[3], I often witnessed my Mum caring for people (friends, family, and patients) and navigating conversations that would help others make sense of their experiences. The art of helping another person to navigate life challenges and answer existential questions emphasised to me the interwoven nature of health and spirituality. Going to university was not only my time to ‘fly the nest’ but to escape Northern Ireland’s political landscape. Drawn to Scotland because of its picturesque countryside, I began my nursing undergraduate degree at Queen Margaret University (QMU).

During one of my clinical placements as a student nurse I witnessed a deaf woman arrive for an outpatient appointment. At the reception desk, the woman gestured for a

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[2] The concept of ‘passing for normal’ was developed by Goffman (1963, p.87) who identified covering and passing as strategies used by people to minimise their experiences of stigma.

[3] Relational practice recognises the significance of relationship as the foundation for caring (Hartrick 1997).

pen and paper from the receptionist. I watched as the receptionist and woman communicated through written English. Uncomfortable at the thought of having to communicate treatment plans and medical information through written communication, I wondered how I could care for this woman. Although I did not have direct input into this woman's care, my curiosity led me to search for information about how people who are deaf experience nursing care. My search for literature regarding BSL user's experience of healthcare led me to ample material related to age related hearing loss. This held parallels with my experience as a teenager searching for support. Primarily portrayed as elderly, frail and vulnerable, the literature was failing to illustrate the diverse experiences of people who live with deafness. My quest for information broadened and gained depth as I chose to focus my undergraduate dissertation on deaf patient's experiences of communicating with nurses in Scotland. An iteration of this literature review has been published in a peer reviewed journal (Dickson and Magowan 2014) (see Appendix 1). This search for understanding led me to further explore and critique different discourses of what it means to be deaf and ultimately led to a personal “disorientating dilemma” (Mezirow 1991, p.102), mentioned earlier in this chapter. This reading triggered a critical internal dialogue that led me to question my experience and understanding of my own hearing loss in relation to my identity and sense of self.

After graduating, I worked as a research associate for six months in the Division of Nursing at QMU. During this time, I wrote a rapid literature review and key findings for the development of a model for effective listening and learning with older people (McCormack et al. 2015). In this project, I worked alongside experienced practice developers who valued and intentionally pursued relational ways of being with transformative and emancipatory intent. This differed from my practice as a student nurse in which I had often experienced routine approaches to care that shaped the social practices in healthcare contexts. This was the first time I had questioned my experience of practice in relation to theories of person-centredness. After spending 18 months working in clinical practice, curiosity steered me back to QMU as I sought to further explore the relationship between deaf communities, healthcare and my own profession. Being embedded in the Centre for Person-Centred Practice Research has created the space and support for me to develop my understanding and practice of person-centred theory. During my time undertaking this thesis, I have continued as a BSL student and have successfully completed my level two BSL qualification with the Scottish Qualifications Authority. My interaction with deaf people, both in my BSL lessons and in my research, have challenged me to think differently about and with my body. This has not only helped me to continue to write my story of hearing loss with a greater sense of purpose and peace but has taught me to be more attentive to the way in which we can express ourselves in subtle ways in clinical and research practice.

In summary, this section has provided a personal backdrop to the thesis, and my own personal story of living with a hearing loss. It justifies my interest in this topic but also sets the scene for different lines of discourse that will be critically explored throughout this thesis. My positionality is dynamic, with notions of insider/outsider often overlapping and intersecting. These ideas of positionality will continue to be explored throughout this thesis. This thesis critically presents my exploration of the relationships and conversations between people who are hearing and who are deaf. I am curious about who 'we'[4] are and what 'we' can create if we learn to shift our perception of the borders between each other.

Chapter summary and thesis structure

In this chapter I have introduced two overarching constructions of deafness that present conflicting understandings of what it means to be deaf. I have shown that the dominant construction of deafness stems from the biomedical perspective and fails to acknowledge deaf peoples' linguistic status. This has implications for deaf peoples' access to healthcare services in BSL and raises questions about how conflicting constructions of deafness manifest in the healthcare setting. I have presented my own positioning in relation to the study, sharing my personal experience of being a hearing aid wearer and my professional experiences as a nurse.

The thesis is presented in nine chapters, each of which contains a series of sections. Its structure aims to stay close to the research process as it unfolded and evolved over time.

In *Chapter Two*, I critically discuss the social constructions of 'deafness' and 'being deaf' from a social science stance. By challenging dominant constructions and ideologies, I highlight the impact these can have on the everyday lives of deaf people. Lastly, I critically review how these constructions have influenced the development of policies that influence deaf peoples' lives in Scotland.

In *Chapter Three*, I identify the question that underpinned the literature review, explaining the strategies for searching and reviewing relevant literature. Using the

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[4] The term 'we' is used in recognition of the interconnections that I believe can exist.

theoretical concepts explored in *Chapter Two* to inform my critique, I critically explore the empirical research related to deaf peoples' experiences of healthcare. Through identification of the research landscape and gaps, this review concludes by identifying potential research directions and lays out the research objectives.

The focus of *Chapter Four* is to outline the philosophical underpinnings of the study. Through an exploration of personhood, my own values and beliefs, and a range of different philosophical perspectives that inform my thinking, I position myself both ontologically and epistemologically in the study. The underpinnings combine assumptions from the interpretive and critical paradigm and are strongly influenced by Merleau-Ponty's (2012) concept of embodiment.

In *Chapter Five*, I provide an account of the methodology adopted in the research. Situating the study in a paradigm of critical creativity (McCormack and Titchen 2006), I draw from my philosophical principles to design a methodological framework located in hermeneutics (Gadamer 2013) that serve to guide my research. Through the development of methodological principles, I clarify the overall purpose as well as the more detailed focus of the study. By setting out the chosen methodology, I show why these are best suited to help me answer my research questions.

The aim of *Chapter Six* is to describe the methods employed in the context of the chosen research paradigm. I provide an overview of the recruitment process and introduce the research participants. I show how the epistemological stance and ontological position through which the data are examined impacts on the decisions made in the research design. Giving attention to the ethical considerations that were relevant to the research process, I also provide a reflection on the various dilemmas relevant to the process of undertaking this particular study.

In *Chapter Seven,* I present the findings of the thesis in which four themes and 11 sub-themes are described. The themes that were drawn out of the data are presented to portray the story that unfolded during data collection and analysis.

In *Chapter Eight*, I provide a discussion based on findings and outcomes. I begin this chapter by highlighting new knowledge that has been produced from the data and the themes identified. I then outline the implications of that new knowledge by theorising the data. This is achieved by connecting this inductively derived knowledge with existing evidence, concepts and theories and challenging existing dominant understandings, practice and ways of being that this research exposed.

Recommendations that I have drawn from the research will be outlined and the existing and potential implications of the study for nursing practice, education and future research will be highlighted.

As the concluding chapter, in *Chapter Nine* I provide a conclusion to the study by highlighting the strengths and limitations of the research. I conclude this thesis with a critical reflexive analysis of the experience of doing research and what it means for the future, including my intentions to build on this work, disseminate it and celebrate it.

A note on my writing voice

To connect to the stance taken to the research, I intentionally use a more personal yet academic writing voice. By writing in the first person and reflecting openly about my own experiences of being hard of hearing, I aim to provide an authentic account of the research process. To illustrate the development of my thinking over time, I narrate the story of my research.

Chapter 2: Evolving conceptualisations of deafness

Introduction

In *Chapter One*, I presented the various questions that arose from my own personal and professional experiences. I introduced two overarching perspectives of deafness (cultural and biomedical) and indicated that a tension exists between the two because of the attitudes, beliefs and knowledge about deaf people and communities that each produces. Taking a social science stance, the purpose of this chapter is to critically discuss the social constructions and contexts in which understandings of 'deafness' and 'being deaf' have developed over time. I will explore how these constructions have shaped the language status of BSL in Scotland and subsequently on policy that affects deaf peoples' lives. This is crucial to this thesis because the challenges experienced by minority groups in healthcare are often manifestations of the wider social issues that have relevance to their lives (Dreachslin et al. 2012). The overarching purpose of this chapter is therefore to inform the world I have stepped into, but previously only understood from my personal perspective as a nurse and from my personal experience of being hard of hearing.

Purpose and method

It is my belief that deaf peoples' ontologies (ways of being) and epistemologies (ways of knowing) offer a useful perspective from which to understand deaf peoples' experiences of health and healthcare. As such, a focus on the 'person' is central to this chapter. By challenging dominant constructions and ideologies, I will discuss how these constructions may influence the development of healthcare practices and policies. Additionally, I decided to recognise the differing perspectives that need to inform the research approaches and methods of this study if social change is to occur (Jacobs et al. 2017). Lastly, this chapter of my work has enabled me to adopt a new perspective (instrument for synthesis) in the critique of available empirical research discussed in *Chapter Three*. Therefore, this chapter provides a framework and the theoretical foundations that underpin subsequent chapters.

This chapter is scholar-managed as opposed to mechanically produced, allowing for interpretation, reflection and critique across multiple epistemologies. This has enabled me to include valuable content that would have been omitted by employing a stricter methodology. I was not attempting to undertake a systematic review of this theoretical literature, so whilst I have identified and read a large amount, this section is systematic in terms of transparency and appropriateness of method (Greenhalgh et al. 2018).

Challenges of the literature and my stance

Emphasizing a limitation of this chapter, it must be acknowledged that there is likely to be a body of deaf literature[5] (signed, visual) that has not been addressed in the writing of this review. Harmon (2007) and Murray (2017), both deaf academics, highlight that the ongoing tension between written and signed languages[6] has resulted in numerous deaf academics taking a resistance perspective and avoiding writing in English. This resistance is based on the belief that writing in English displaces deaf peoples' cultural identity, which is grounded in a visual-spatial language. At present, my BSL skills are not refined enough to comprehend and critically review signed literature. However, I believe there is a need for a dialogue to be opened between the hearing academic community and the deaf academic community for shared learning, research and practice development to take place. There is currently an increasing awareness of this need among both deaf and hearing academics in Deaf Studies[7]. As a result, several academic blogs (Acadeafic 2019) have implemented a bilingual policy that insists on blog versions in both English and a sign language, which I believe is a positive contribution towards knowledge exchange and collaboration, and I have incorporated these information sources into this review. Additionally, I hope to contribute to such literature by disseminating the findings of this research in both BSL and English[8].

Social constructions of deafness and being deaf

In this section, I introduce and critique three main perspectives associated with what it is to be deaf and the language usage associated with them. These are often referred to as the biomedical, disability and sociocultural "models of deafness"[9] by academics. Lane (1992), a deaf academic, argues that these models are not just ways of describing variations between deaf people who speak and those who use sign language, but that they highlight the socially constructed nature of different understandings of what it is to be deaf. Many authors (Young and Temple 2014; Napier and Leeson 2016) have suggested that attempts to distinguish between various models of deafness can be unhelpful as it is an overly simplistic understanding

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[5] Baynton (2006) highlights that the notion of deaf literature is an oxymoron as the term literature derives from the Latin *litere* or letter suggesting written form.

[6] This tension stems from the misunderstanding that written English is a variation of sign language. However, sign languages do not have a written form. This tension will be explored in more depth later in this chapter.

[7] The field of Deaf Studies will be explored in more depth later in this chapter.

[8] My plan for dissemination of this research will be explored in *Chapter Nine*.

[9] Temple and Young (2014) argue that the term "models of deafness" is problematic in itself as the term "deafness" relates to a biophysical condition, therefore excluding linguistic and cultural perspectives.

of deafness and has the potential to create binary systems that exclude individuals or groups of people who are deaf. However, deconstructing these models can help us to question our own and others understanding of what it means to be deaf. Importantly, exploring these models forces a consideration of the assumptions that healthcare professionals and researchers, such as me, might bring into their practice about what it is to be deaf. This is fundamental to the thesis because such beliefs about deafness will influence how relationships take shape in research and healthcare.

Biomedical model

From a biomedical perspective, being deaf or deafness is constructed as a measurable physical disability (Kramer and Brown 2019). Providing a definition of deafness, Leigh and Andrews (2017) explain that if a person cannot hear, it means that the ear, auditory nerve, or brain is not deciphering and interpreting sounds. This definition stems from the epistemological assumption that knowledge is observable and measurable, and that health is determined by the absence of biological abnormality (Yuill et al. 2010). From this perspective, the ‘norm’ is defined as full hearing, in terms of quality and of range. Therefore, the biomedical model is defined not just by an interest in the physiology of hearing but rather on deafness as an impairment and deviation from the norm (Lane 1992). From this perspective, emphasis is placed on diagnosis, and treatment with a goal of curing or overcoming deafness. Audiology is the discipline that focuses on the study of normal hearing and hearing disorders (Kramer and Brown 2019). An audiologist is a qualified healthcare professional whose role includes identifying, assessing, treating and preventing hearing and balance disorders. A description of how hearing loss is diagnosed and what can be done to improve function can be found in Appendix 2. Young and Temple (2014) claim that for many professionals, parents of deaf children and adults deafened later in life, it is self-evident that deafness is a product of loss of function. Therefore, for many people, understanding deafness from a biomedical perspective is a coherent proposition that does not require examination or questioning (Baynton 2006). This construction is therefore the dominant understanding of deafness in wider society that situates *hearingness* as the ‘norm’.

The language of the biomedical approach to deafness, predominant in medicine and allied health professions such as audiologists, produces terminology such as ‘hearing impaired’, ‘partial hearing’ and ‘hard of hearing’. The construction of deafness as a loss of hearing produces and maintains understandings of deafness that Temple and Young (2014) claim are accepted as reflection of reality. By using the term “deafness”, the attribute is objectified in such a way that it can be spoken about as something that happens to people, rather than being part of the person (Temple and Young 2014). Therefore, it becomes possible to write about the impact of deafness, to measure and categorise audiological ranges and to seek to understand causes of deafness. Following a renewed focus on deaf epistemologies and ontologies, defined by Kusters et al. (2017, p.9) as a “sensory turn”, deaf academics such as Friedner (2012) have emphasised the biological state of being deaf as central to understanding deaf peoples’ lives. However, for those who view their deafness from a cultural and linguistic perspective, the problem is that the biomedical model discourse defines their body as deviant and impaired (Campbell 2009).

The term *loss* (as in hearing loss) expresses the grief a person, born hearing, might experience if their hearing deteriorated in later life. Identified in the literature, the stages of grief experienced when hearing function deteriorates often reflect the same stages as those facing serious illness – denial, anger, bargaining, depression, acceptance (Tate Maltby 2019). Furthermore, this loss is understood to influence relationships, confidence, sense of identity and sense of safety (Goffman 1963; Hogan et al. 2011; Barker et al. 2017), reducing a person’s overall quality of life (Nordvik et al. 2018). For those who lose their hearing later in life (including me), deafness does indeed happen *to* them; hearing loss is an apt description, and the sense of normal (hearing) self has been forever changed (Young and Temple 2014). However, the experience of a person who develops progressive hearing loss in later life is not easily compared to someone who is prelingually[10] deaf and has used a sign language to communicate from an early age.

With a focus on the management and treatment of deafness, individuals are often provided with a hearing aid to compensate for audiological deterioration. Other medical interventions aimed at managing deafness include speech and language therapy, surgeries and other hearing technologies such as brain stem implants (Kramer and Brown 2019). These interventions are part of the idea that deafness requires a solution. All such devices and interventions can and do enhance the ability to hear in some form. Temple and Young (2014) emphasise that from the biomedical perspective, failure to restore or improve hearing and speech through such medical interventions are unethical, in the same way as failure to treat or cure an illness would be viewed as unethical. However, viewing such medical interventions as solutions to

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[10] The term prelingually deaf is used to describe people who have lost their hearing before they have acquired a language. Preston (1994) highlights that this term assumes that acquisition of language means acquiring a spoken language. This reflects the rigidity of norms.

deafness fails to acknowledge their limitations (Leigh and Andrew 2017). In *Chapter One*, as I highlighted from my own experience of getting hearing aids, auditory aids can enhance a person's ability to hear noises, but their auditory world remains significantly different and less well-defined than the auditory world of those with full hearing. Therefore, these 'solutions' to deafness, fail to take into account how a person's sense of the world or ontology is different to that of a hearing person (Diprose 2019). Medical interventions in the healthcare setting, such as fitting hearing aids, are not what define a biomedical model of deafness but the unrealistic and unhelpful goal of 'cure'. The implicit assumptions of the biomedical perspective, associated attitudes and their social consequences privilege one way of being over another and actively seek to impose a preference (hearing) and oppresses another (being deaf) (Temple and Young 2014). Foucault (1973) claimed that such attitudes could manifest in day-to-day clinical practices and contribute to the social constructions and production of 'biomedical discourse' and the 'clinical gaze' in wider society.

Hearing screening has emerged as an important aspect of new-born care, so deafness is often identified and diagnosed early (NHS 2020). With 90-95% of deaf children being born to hearing parents (Kyle and Woll 1985)[11], who often have no knowledge of the needs of a deaf child, support and advice is sought from healthcare professionals. These professionals play a crucial part in steering early intervention and decisions regarding language, communication and education. Leigh and Andrews (2017) maintain that the majority of healthcare professionals, such as audiologists, do not interact frequently with deaf people and therefore have limited professional awareness about alternative perspectives to that of the biomedical model. Subsequently, limited information is given to hearing parents related to sign languages and deaf communities. Rather, advice is dominated by the biomedical perspective which focuses on rectifying hearing loss and encouraging spoken language development (Sager 2019). Such recommendations are based on a combination of misperceptions about sign languages, hearing peoples' fears about the difficulty of learning a sign language and lack of resources to support sign language development (Humphries et al. 2017). While the misperceptions about sign languages will be explored later in this chapter, it is important to note that healthcare professional's advice and attitudes result in the physiology of deafness becoming the central established *issue* of deaf peoples' lives from an early age. While many healthcare professionals may be ignorant of alternative perspectives of deafness,

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[11] Precise statistics concerning the deaf population as a whole are challenging to obtain. However, Brien (1992) highlights that the above estimates are widely accepted.

Temple and Young (2014) argue that whether conscious opposition to or unconscious bias lies at the heart of the biomedical model perspective are irrelevant because the consequences for deaf people are the same; systematic rejection of sign languages and alternative ways of being deaf. Such perspectives have the potential to significantly impact on deaf children's attitudes towards, values and beliefs regarding deafness, language ideologies[12] and their own personhood.

Disability model

In the late 20th century, activists in the disability rights movement challenged the 'common sense' understanding of disability which led to Oliver (1983) forming 'the social model of disability'. This social movement had a significant impact on the lives of deaf people (Burch and Kafer 2010).

The social model of disability has worked to change society's perceptions of disability arising from the consequences of an individual's impairment, defined in terms of the body and its functioning. It is distinguished from the biomedical model through differing definitions of disability. While the biomedical model defines disability in terms of individual deficit, the social model defines disability as a social creation and more specifically, as a relationship between people with impairments and a disabling society (Shakespeare 2017). Therefore, rather than the problem of disability lying with the person with disabilities, the social model argues that the problem is in the way that normalcy is constructed (Davis 2017). By highlighting that the challenges faced by disabled people are the result of social oppression and exclusion, rather than their individual deficits, the aim of the social model is to accept impairment and to remove disability (Shakespeare 2017). According to this view, the social and material conditions need to change rather than the person with disabilities.

Thomas (2007) argues that the strengths of the social model of disability include its clear agenda for social change and the sense of collective identity that disabled people have built as a result. Additionally, in the UK the social model has had a key role in shaping policies. Subsequently it has legally secured the right to full access to services for people with disabilities (Disability Discrimination Act 1995; Equality Act 2010). While many deaf people in the UK have supported the social model of disability and in fact benefited from its legislative consequences, there remains a concern amongst deaf communities that by accepting impairment and disability discourse,

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[12] Language ideologies are thoughts and beliefs about languages and the people who use them (Kusters et al. 2020).

their language and culture remain invisible (Lane et al. 1996; Young and Temple 2014). This issue stems from deaf people having dual-category status (De Meulder 2017a) or being defined as 'intersectional', which reflects a belief that deaf people have dynamic, overlapping and converging identities that shape their experiences (Cooper 2016). The two identities relevant to this discussion are deaf peoples' ascribed status as both a linguistic minority and a disability group.

Whilst holding dual-category status and being defined as intersectional may not appear problematic in theory, De Meulder and Murray (2017) argue that the policies that have governed deaf peoples' lives traditionally place more emphasis on defining deaf people as disabled. Therefore, while the social model of disability discourse does not itself deny a cultural or linguistic understanding of being deaf, Temple and Young (2014) argue that to accept an understanding of inequality from a social model of disability perspective is to privilege one kind of explanation of inequality (the disability rights discourse) over another (that of language rights). This has resulted in sign languages being neglected in minority language policies and spoken minority languages (Lawson et al. 2019). The impact of being neglected in such policies is that deaf people are continuing to be defined as disabled and their linguistic needs overlooked. Therefore, for many academics and activists who are deaf, these two models of deafness are not compatible because the social model of disability obstructs their struggle for linguistic rights (Ladd 2003; De Meulder 2017a). This will be explored in relation to disability legislation in Scotland later in this chapter.

Another major critique of the social model of disability is its disembodied notion of disability. The foundational argument of the social model of disability is that it opposes the notion that 'disability' is all about the body and its impairments (Thomas 2007). Therefore, the social model of disability tends to deny a person's experience of the physical body, insisting that physical differences and restrictions are socially created (Morris 1991). However, Bahan (2014) considers the sensory orientation of deaf people as central to understanding deaf ontologies. This will be explored further in this chapter and in *Chapter Four*.

Sociocultural model

In contrast to the perspective that deafness is a physical disability, many sign language users experience being deaf as a social relation[13] and a common thread

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[13] Bayton (2006) argued that being deaf shapes how a person relates to others because of the visual-spatial nature of sign language.

that connects BSL users (Baynton 2006). This is a sociocultural model of deafness that embraces deaf communities as linguistic minorities who share a common experience of life. Unlike the pathological understandings associated with deficiency and loss, the sociocultural model places emphasis on the uniqueness of a deaf person's experience of the world (deaf ontology) (Edwards and Harold 2014).

Deaf academics, Padden and Humphries (2005) argue that deaf peoples' common experience of the world manifests itself in the notion of 'deaf culture'. One of the earliest definitions of deaf culture states that:

> "Members of Deaf culture behave as Deaf people do, use the language of Deaf people, and share the beliefs of Deaf people toward themselves and other people who are not Deaf" (Padden 1980, p.92-93).

This definition has since been critiqued as limiting, with deaf culture understood to be an umbrella term for sign language use, collectivity and identity, deaf values, deaf behaviour, deaf art and aesthetics (Padden and Humphries 2005). Whilst distinctions between terms used to describe deafness have been found to be largely unhelpful, the concept of deaf culture has been instrumental in fostering deaf peoples' felt "sense of difference" (Ginsburg & Rapp 2013, p.59). Therefore, Attfield (2013) emphasises that the deaf sociocultural model has provided many people in deaf communities with a collective[14] sense of belonging and identity.

Deaf peoples' acceptance of their deafness, sense of identity and approach to communication can be heavily influenced by the deficiency and 'loss' evident in the biomedical construction narrated about deaf peoples' lives in wider society (Sager 2019). Rather than remedy their deafness through speech therapies, surgeries and hearing technology, deaf culture celebrates people for who they are and what they can do. This sense of pride in being deaf is a characteristic of deaf culture (Ladd 2003). Many deaf people describe experiencing a sense of coming home as they are embraced for who they are in deaf spaces (Leigh 2009; Holcomb 2013). However, as most deaf people have hearing parents with no early exposure to the deaf community, the journey to becoming part of this culture can be challenging (Ladd 2003). Deaf communities often offer strategies for managing participation in a world where people are predominantly hearing. Core elements of deaf culture (such as values) that are

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[14] It is widely documented by deaf academics (Ladd 2003; Bauman and Murray 2013; De Meulder 2017b) that deaf people hold collectivist values that aim to embrace all deaf people who use a sign language.

embraced by the deaf community include full access to communication, information sharing, healthy identity formation and self-determination (Ladd 2003).

Taking into consideration the many ways in which a person can be deaf, Turner (1994) has questioned whether there is a singular deaf culture. Because many deaf people integrate into the deaf community later in life, deaf people are heterogeneous and culturally diverse. Even though they contain shared traits, members are also members of the non-deaf cultures of their family and communities. Therefore, Humphries (2008) argues that less time should be spent by academics discussing culture and more time studying discourses of culture. However, academics appear to be at odds about how to apply this approach to research (Friedner and Kusters 2020). For instance, Friedner and Kusters (2020) believe that similarities between deaf persons should be the focus of research. Yet Padden and Humpries (2005) suggest that the separation between deaf and hearing people should be celebrated, arguing that these differences provide a basis from which to discuss deaf ways of being. This disagreement indicates different discourses regarding deaf culture, signifying the existence of perspectives of deaf cultures in the academic community.

Bahan (1994) has previously pointed out that deaf culture is an academic term that is not widely used by deaf people arguing that, in deaf communities, the signed concepts DEAF-WORLD[15] and DEAF-WAY are more commonly used to express the experience of being deaf. Although the term deaf culture has seen increasing use in deaf communities because of Bahan's claim (Murray 2017), there continues to be varying opinions on the value of the concept. However, overall, there is recognition that the concept can be valuable for both academics and deaf people. For example, Murray (2017) highlighted the value for academics, in using the concept to remain closely connected to the experiences of the people they seek to empower. Ladd (2003) also believes that the distinction is a necessary form of strategic essentialism[16]. Nevertheless, whilst the deaf sociocultural model has clearly facilitated political activism by providing a framework for empowerment (Mole 2018), the dichotomy of opinion in the academic community also provides justification to move beyond trying

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[15] Although there is no written form of sign language, glossing is a method for describing the meaning of a sign. Glossing involves using English words, written in capitals. Many signs cannot be glossed using a single English word, because as with other languages, there is no exact English translation (Sutton-Spence & Woll 1998).

[16] Spivak (1996) developed the notion of strategic essentialism to describe the political use of what is considered to be an essence or fixed identity, while accepting that there are in principle no essential identities.

to ‘prove’ the existence of concepts towards exploration of deaf ontologies and epistemologies (Humphries 2008).

In distinguishing between and critiquing three main constructions of deafness, it is evident that there are points of intersection (Young and Temple 2014). For example, the disability and sociocultural model are both driven by social change. Therefore, these differing perspectives can be understood as in dialogue with one another rather than distinctions. While the constructions explored so far clarify different constructions of deafness, they are somewhat constraining due to lack of exploration of the diverse ways in which a person can be deaf. Seeking a more emancipatory approach, the Deaf Studies paradigm addresses this limitation.

Deaf Studies paradigm

The term Deaf Studies was coined in 1984 at the University of Bristol after the establishment of the Centre for Deaf Studies (Marschark and Humphries 2010). Therefore, it can be viewed as an academic field (Kusters et al. 2017). The foundations of Deaf Studies originally focused on exploring the language, culture and lives of deaf sign language users from a sociocultural rather than biomedical model perspective. However, seeking to move beyond the reactive nature of the sociocultural model to focus on the positive experiences as well as oppression and inequalities, Deaf Studies academics have developed an increasing awareness of the diversity of what it means to be deaf. Davis (2002) claimed that this moved Deaf Studies beyond the first wave of identity politics to explore a range of deaf ontologies. This construction of deafness moves beyond the social justice agenda of the sociocultural model to an increasingly emancipatory and empowering perspective (Kusters et al. 2017).

The Deaf Studies paradigm was developed with an emancipatory intent to free deaf people from the constraints of dominant biomedical and disability models of practice and understanding, and to respond to deaf communities’ needs through collaborative working between hearing and deaf people (Murray 2017). Deaf academics, Kusters et al. (2017), have defined Deaf Studies as a multidisciplinary field which remains dedicated to exploring and celebrating deaf culture and critiquing ideologies that have developed around dominant constructions of deafness. Deaf Studies emerged after

Stokoe[17] (1960), an American linguist and professor at Gallaudet University[18], highlighted that sign languages have similar characteristics to spoken languages and are therefore authentic languages. This perspective created impetus for deaf communities to challenge dominant constructions of deafness and ultimately led to deaf people viewing themselves as a cultural and linguistic community (Ladd 2003).

Following Stokoe's research, deaf communities were significantly influenced by the spirit of the civil rights movement of the 1960's and 1970's (Jankowski 1997) and began to develop a socio-political voice. This political concern may have emerged from parallels that were drawn between the deaf community and other oppressed groups such as First Nations and African peoples (Lane 1992; Ladd 2003). Deaf Studies was established during this time, to develop new frameworks of understanding for the meaning of deafness. Humphries (2008, p.35) called the early work in Deaf Studies "talking culture"; a determined effort to present an alternative view of deafness to wider society that steered away from the biomedical model.

Dirksen et al. (2016) argued that the cultural exploration and critique of power structure in Deaf Studies has served as a powerful drive for emancipation and empowerment for the deaf community. This approach to knowledge generation has been vital in drawing attention to how deafness has been, and is still being conceptualised, and is viewed as a political effort to impact policy that influences the lives of deaf people (Kusters et al. 2017). Such explorations and critiques of power structures are evident in worldwide campaigns for the recognition of sign languages. Deaf Studies discourse is increasingly identifying deaf, sign language users as linguistic minorities (Batterbury et al. 2007; Napier & Leeson 2016) and ethnic minorities (Lane et al. 2011; Ladd & Lane 2013) as possessing their own social, cultural and linguistic practices (Holcomb 2013; Friedner & Kusters 2015).

Sanchez (2017) believes that the Deaf Studies paradigm has been slow to influence healthcare disciplines and societal norms as the majority of work has only been of significance to those situated inside it. This issue may have restricted the impact of Deaf Studies to deaf people themselves and hearing people who use sign language. However, Kusters et al. (2017) highlight that the contribution of academic work from Deaf Studies is slowly becoming more visible in other fields and is beginning to have

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[17] Stokoe was himself hearing.

[18] Gallaudet University is the world's only university designed to be barrier-free for deaf and hard of hearing students. It has led in education of deaf and hearing people and deaf rights worldwide (Gallaudet University 2020).

an impact on other disciplines. For example, researchers in the field of architecture are utilising deaf peoples' visual nature and experience to inform and influence mainstream architectural practices with the intention of making design more universal (Edwards and Harold 2014). Despite the slow pace of impact, the concepts that have emerged from Deaf Studies provide more inclusive, collectively orientated and useful ways of understanding and situating deafness as a valued and defining experience that can be used to support deaf people. In the next section, I will examine theories that have developed in Deaf Studies that situate my own view of how deafness and deaf people can be understood.

It is crucial to this thesis to explore and critique common concepts of Deaf Studies to understand how they are drawn from, and relate to, existing healthcare theory. There has been much debate about the key concepts in Deaf Studies. For instance, Dirksen et al. (2016) have highlighted the foundational theoretical concepts as culture, audism, Deafhood, sensory orientation, Deaf Gain, intersectionality and Deaf Theory. Whereas, Kusters et al. (2017) have noted deaf culture and deaf communities as the core underpinning concepts. Although Deaf Studies, as a field, is often broadly defined as including any knowledge related to deaf people (O'Brien 2017), I focus on specific strands in the field that explore deaf peoples' ontologies and epistemologies in this review. It is critical to engage with such literature to gain insight into deaf peoples' understanding of self and create knowledge that is more collaborative and acceptable to both deaf and hearing people.

d/Deaf distinction

The distinction between deaf people who use sign languages and those who identify based on their hearing loss was created to descript medically orientated discourses concerning deafness (Napier and Leeson 2016). Woodward (1975) used the term "deaf" to represent non-signing deaf people, and "Deaf" (capital D) for signing people who consider themselves members of a cultural community. The use of capital 'D' has become widespread in Deaf Studies, sign linguistics and sign language interpreting literature since Woodward distinguished between the terms in 1975 (Woodward 1975). However, the distinction between "deaf" and "Deaf" is far from clear-cut, as Lane (2005) acknowledges, stating there is a grey area between the two; for example, some hard of hearing people are active in deaf communities while others are not. Additionally, the complexities of sign language transmission, progression in medical interventions and changes in educational policy (explored below) results in many deaf people integrating into a sign language community as late learners of BSL (Dirksen et al. 2016; De Meulder et al. 2019b). Therefore, whilst such a distinction may be easy to represent in principle, many grapple with the complexities of applying this distinction to diverse people and societies who share a wide variety of experiences of being deaf (Woodward and Horejes 2016).

More recently, Woodward and Horejes (2016) highlighted that academics have misunderstood and mis-cited Woodward's work as he did not present the d/Deaf distinction as a taxonomy, but purely to provide academic distinction in his own work. They argued that this misunderstanding of the d/Deaf distinction resulted in the uncritical application of the term as a convenient way to categorise audiological and sociocultural aspects of deafness. This categorisation has resulted in unintended connections with the biomedical model of deafness. Woodward has since clarified his belief that a person can be both deaf and Deaf at the same time (Woodward and Horejes 2016) and has outlined the significance of the sociocultural experience of being deaf as a way of understanding deaf experience.

Despite Woodward placing emphasis on the sociocultural experience of being deaf, Kusters et al. (2017) maintained that use of d/Deaf distinction has remained problematic because many continue to apply it to differentiate not only between signing deaf people (Deaf) and non-signing deaf people (deaf), but also between worldviews and identities. This has resulted in a debate about who belongs in deaf communities and situates some people on the margins. Such a rigid taxonomy has been described as:

> "…dangerous, colonizing and ethnocentric, and one that perpetuates a superfluous debate that lacks constructive dialogue about the meaning of being deaf/Deaf" (Woodward and Horejes 2016, p.286).

Hoffmeister (2007) believed that the debate about the d/Deaf distinction reflects a perception of identity as isolated and static and one that is lacking consideration for race, class, gender, ethnicity, disability, sexual orientation or other elements that may contribute to a person's sense of self. This has created tensions for deaf people who identify with both constructions of deafness and thereby affects social inclusion and exclusion (Napier & Leeson 2016). This discussion is significant as it recognises the diverse experiences that deaf people have of being deaf and raises questions about deaf peoples'' experiences of the perceived divide between deaf and hearing worlds.

A range of additional terms have been developed to distinguish the audiological elements of deafness (measurable hearing levels) from those of socialisation, acculturation and identity (deaf as a sociocultural reference) reflecting the ongoing tensions between the models. Academics have used deaf and hearing to denote specifically audiological traits, Deaf and Hearing[19] to denote (or emphasise) identity or sociocultural issues, and d/Deaf and h/Hearing to denote and highlight the often inherently mixed nature of audiological and sociocultural conditions. Even when these distinctions are directly cited, usage can be inconsistent (Senghas and Monaghan 2002). Furthermore, concerns regarding deafness, whether sociocultural or biomedical, are not limited to binary distinctions. Roots (1999) argues that to standardise deaf identity risks validating and excluding practices where an elite form of deaf culture is projected and legitimised. The results of this standarisation are that some people will be discriminated against as not deaf enough to be “Deaf” (Ladd 2005). This has led to a debate as to how differentiations are made between the many ways in which it is possible to be d/Deaf or whether differentiations should be made (Kusters et al. 2017).

Several researchers are moving away from the practice of using the terms Deaf vs. deaf as they believe the d/Deaf dichotomy is in fact an oversimplification of an increasingly complex set of identities and language preferences (Napier & Leeson 2016; De Meulder 2017a). More recently the use of the ‘D’ has been openly debated due to the ever-evolving nature of deaf communities (Napier and Leeson 2016; Kusters et al. 2017; Napier et al. 2019). Individuals may be profoundly deaf; they may choose to wear hearing aids or a cochlear implant; they may be able to speak and make use of some residual hearing; but ultimately, they prefer to communicate via a sign language and identify as a deaf person. Suggestions have been made that deaf people should be referred to as “sign language users” (Bahan 1997), “sign language persons” (Jokinen 2001), “sign language peoples’” (Batterbury 2012; Batterbury et al. 2007), “people of the eye” (Lane et al. 2011; McKee 2001) and “a visual variety of the human race” (Bahan 2008). However, as O’Brien and Kusters (2017) have emphasised these terms also pose problems and taxonomies, as not all deaf people are visually oriented to an equal or similar extent, or in the same ways.

It has therefore become clear that the current widespread use of capital ‘D’ cannot serve as a shorthand summary of the experiences of deaf, sign language users (Thoutenhoofd 1998), that deaf identity is fluid, situated and contextual (Chapman and Dammeyer 2017), and that the boundaries between d/Deaf need to be treated with caution as these borders are often blurred (Woodward and Horejes 2016). This

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[19] Complementing Deaf/deaf distinctions, equivalent Hearing/hearing distinctions have also been developed. “Hearing” referring to hearing-identified society and culture (and by extension mainstream society and culture), and “hearing” is used to denote only audiological ability.

has implications for this thesis, as it is evident that a ‘one size fits all’ approach cannot be taken to either caring for deaf people or enabling them to take part in research.

Audism and hearing privilege

Audism is a term coined by deaf academic, Tom Humphries (1977, p.2), defined as the “notion that one is superior based on one’s ability to hear or behave in the manner of one who hears”. Comparable to the notion of racism, Humphries (2008) developed the term to express the ways in which individuals hold beliefs and exhibit behaviours that express prejudices towards deaf people. Humphries was interested in how prejudice affects deaf peoples’ lives, and how deaf people may inherit and internalise prejudices. Humphries (1977, p.12) argued that audism is embedded in societies internationally stating that being hearing does not automatically make a person an *audist* but that our society and its’ views on deafness make audism “almost a certainty”. Humphries (2008) maintained that, as a result, deaf people unconsciously internalise audism and disempower themselves by actively participating in the oppression of other deaf people. This relates to Freire’s (2017) understanding that those who are disadvantaged internalise the consciousness of dominant groups in society. A common example of audism cited by Leigh et al. (2018) occurs when a deaf person and hearing person experience challenges communicating with one another. In this situation, the communication challenge is often framed because of a deaf person’s inability to use spoken English, rather than a recognition that there is no common language for communication to take place.

Lane (1999), a hearing academic, applied the notion of audism to systemic practices that discriminate against deaf people, arguing that it is institutional audism that locates the problem of deafness in deaf peoples’ pathophysiology and communicative ability, rather than in hearing peoples’ perspective or worldview. Critiquing educational and medical organisations’ claims of helping or caring for deaf people, Lane (1999) highlighted that they often assume authority over deaf peoples’ lives, making decisions for them without considering their beliefs. This authoritative audist practice can be linked to Foucault’s (1973) concept of power and the idea that people can exercise power unknowingly. Bauman (2004, p.240) referred to this powering using the term “hearing privilege”. Although Bauman did not suggest what impact this has upon interactions between deaf people and hearing people in healthcare settings, it is evident that a biomedical model perspective may cultivate and maintain such discriminatory practices by viewing deafness as a condition to be cured or overcome.

Bauman (2004) argues that hearing privilege is evident across disciplines, institutions and cultures and that it manifests, and is sustained through the mundane and systemic privileging of hearing ability. He claimed it arises when “hearing people view their social, cultural, and economic experiences as a norm that all deaf people should experience” (Napier & Leeson 2016, p.11). In contrast to disability studies, Bauman (2004) assigned the origins of audism and hearing privilege to the longstanding notion that to be human is to be able to speak. This suggests that the ability to acquire a spoken language is an essential attribute of personhood; a notion I will challenge in *Chapter Four*. Exploring this hearing privilege further, Bauman considered Derrida’s (1990) critique of phonocentrism; the privileging of spoken voice that is often equated with authoritative power. Derrida (1990) challenged the notion that voice is equated with language, and although he did not engage in discussions related to constructions of deafness or sign languages, he raised questions about different ways of being and expressing self, which have been valuable in the field of Deaf Studies.

The concept of phonocentrism has highlighed the central focus that spoken languages have taken in the study of linguistics and enabled a critique of the enduring claim that “sound is an internal, intrinsic element to language” (Bauman 2004, p.243). Such a belief excludes sign languages and other forms of written language. This application of phonocentrism to the analysis of audism essentially questions the values, beliefs or unconscious ‘norms’ underlying societal systems and behaviours. However, Myers and Fernandes’ (2010) caution against this interpretation of audism and phonocentrism, believing that it continues to polarise hearing and deaf people, spoken languages and sign languages with no thought to how shared meaning can be created.

As with various concepts in Deaf Studies, these are arguments against the use of potentially provocative beliefs underpinning the concepts of audism and hearing privilege. However, these concepts highlight important ideas about oppression that function in wider society and emphasise how deaf peoples’ health and wellbeing may be affected by being deaf in such societies. Gertz and Bauman (2016) have argued that if audism and hearing privilege are internalised and unexamined by deaf people, they may believe the only way to flourish is to become like a hearing person. Therefore, audist beliefs have the potential to affect deaf peoples’ sense of self, produce unhealthy relationships between hearing and deaf people and ultimately prevent a sense of well-being. This has implications for the relationships between deaf people, healthcare professionals and researchers.

Deaf Identity

MacIntyre (1992) observes that the culture in which a person exists shapes their identity and being. Given that deaf culture has undergone significant shifts because of the emergence of Deaf Studies, it follows that perceptions of 'deaf identity' have changed significantly (Napier and Leeson 2016). The process of deaf identity formation is complex as it is influenced by countless factors, including wider society's attitudes towards deafness and BSL, the family environment they grow up in, educational experiences and the time at which they are introduced to the deaf community (Leigh and O'Brien 2020).

For deaf people, identity formation has an added element of complexity that stems from the conflicting and coercive explanations of what it means to be deaf (Preston 1994). The previous explorations of Deaf Studies concepts in this chapter provide some insight into the challenges deaf people may face in the development of a positive identity. For instance, audism may result in a person believing that they need to become like a hearing, speaking person. Thus, the dominant biomedical construction of deafness continues to influence deaf peoples' sense of self and identity through their interactions with hearing people who are unaware of alternative perspectives. The concepts of 'Deafhood' (Ladd 2003) and 'Deaf Gain' (Bauman and Murray 2013) reflect the approaches intended to address societal, institutional and cultural challenges related to deaf peoples' identity development. The adoption of Deafhood as a buzzword in deaf communities indicates its acceptance as an approach that does indeed address such issues (Kusters and Meulder 2013).

Deafhood

The term 'Deafhood' was coined by Ladd (2003) and represents "the struggle of each Deaf child, Deaf family, and Deaf adult to explain to themselves and each other their own existence in the world" (Ladd 2003, p.3). Therefore, a central theme of Ladd's theory is the power struggle between deaf and hearing people. Whilst the term is often used to disrupt medically orientated discourses concerning deafness, Kusters and De Meulder (2013) emphasise that Ladd explains the concept in several different ways and that there is no concrete definition of Deafhood. Ladd (2003; 2005) claimed that Deafhood offers an understanding of deafness constructed out of deaf peoples' own ontologies that emphasises the possibilities, rather than the deficits, related to being deaf. Ladd describes the struggles of deaf people to explain their existence and to understand their deafness as a process, reflecting Carl Rogers' (1980) notion of becoming. Rogers (1980) argued that our personhood is not fixed but develops through time. Therefore, rather than being defined by permanent traits, characteristics and behaviours, Rogers argued that personhood was a process of becoming. Such a perspective emphasises the potential for growth.

Ladd (2010, cited in Kusters and De Meulder 2013, p.430) has also framed Deafhood as a concept used as a “deconstructive tool for more efficient analysis of oppression”. This framing of the concept refers to the internalised oppression that can occur as a result of educational approaches and language ideologies that deny deaf people their language and culture. Ladd (2010, cited in Kusters and De Meulder 2013, p.430) believed that these oppressions lead to destructive patterns of thinking that are deeply rooted in deaf cultures. These destructive patterns include deaf peoples’ lack of awareness of the positive meanings of being deaf, lack of acceptance of sign languages as genuine languages and a general attitude of dislike towards hearing people. This explanation of the concept indicates that it was not simply developed as a positive way of framing deaf ontologies but also as a consciousness raising strategy that enabled deaf people to examine their sense of self (Kusters and De Meulder 2013).

Kusters and De Meulder (2013) have argued that a strength of the concept Deafhood is its abstract and ambiguous nature, which enables deaf people to explore notions of “Deaf selves” (Ladd 2008, p.43). Although they acknowledge the essentialist core of the concept, they argue that Ladd intended to encourage openness to diverse ways of being deaf. This openness was believed to avoid the exclusion often associated with the d/Deaf distinction. Deafhood can therefore be viewed as a liberating, empowering philosophy and counter narrative to hegemonic structures and discourses that enable deaf people to create their own ontologies and becoming (Leigh and O’Brien 2020).

The emergence of concepts such as Deafhood (Ladd 2003), Deafnicity (Eckert 2005) Deaf ethnicity (Lane 2005) and DEAF-SAME[20] (Friedner & Kusters 2015) reflect significant attempts by deaf communities to redefine their identities to escape the reductionist lens of definitions imposed[21] by the majority hearing group and to fight against oppression (Ladd and Lane 2013). However, these concepts are often

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[20] DEAF-SAME is a sign gloss.

[21] Deaf peoples’ struggle for self-determination has parallels with other minority languages such as Welsh and Gaelic, and with indigenous groups such as the Māori (Smiler and McKee 2007). Relevant parallels can also be made with language minorities, ethnic minorities, gender groups, women and disabled people (Ladd 2003).

adopted and used to reflect a state of permanence rather than a becoming and growth (McIlroy and Storbeck 2011). If uncritically adopted as ideologies with strict boundaries, rather than as helpful framing concepts, they may fail to acknowledge that while many deaf people have similar experiences, differences and diversity exist in and across deaf communities.

In recognition of the danger of recreating boundaries around identities through use of terms like Deafhood to define the deaf self and experience, the terms “hybridity” (Breivik 2005, p.202), ‘‘inbetweenity’’ and living ‘‘between spaces’’ (Brueggemann 2009, p.24) have been used to encourage the consideration of the diversity of identity arising from heterogeneous experiences. These terms frame identity as a quest for belonging instead of a narrow quest for self-definition. Napier and Leeson (2016) suggest that these terms indicate the place or significance of relationships between the use of sign language and the wider ‘hearing world’, with the connection between people being the space of identity development. Thus, Deafhood recognises that intersectional layers, such as language, culture, disability, society, and politics, contribute to the unique identity of each deaf person (Young and Temple 2014), as does the deep connection felt between deaf people around the world that stems from the experience of being deaf (Friedner & Kusters 2015).

Deaf Gain

The term Deaf Gain was created by Bauman and Murray (2009) to challenge the dominant notion of deafness as a loss, by directing attention to the linguistic, social, cultural and biological benefits of deafness. In a

> “… reframing of ‘deaf’ as a form of sensory and cognitive diversity that has the potential to contribute to the greater good of humanity.” (Bauman and Murray 2009, p.3)

Deaf Gain questioned what can be gained from an understanding of deaf ontologies and epistemologies. Bauman and Murray (2014) have advanced the notion of Deaf Gain, suggesting that it poses two main questions; how can deaf people learn to notice and uphold their gain? And how can hearing people come to appreciate Deaf Gain? These questions relate to how deaf peoples’ unique perspectives and knowledge can be valued.

The concept of Deaf Gain was intended to counterbalance cultural issues that diminish the experience of being deaf and to challenge common perceptions of deafness. However, Sanchez (2017) argued that the concept may, like other concepts associated with deaf culture, also create a problematic binary division between gain and loss. Sanchez (2017) suggested that it may do so by indicating that biological deafness, and the social realities surrounding it are primarily positive and beneficial to an individual, thus failing to acknowledge the challenging reality of many deaf peoples' experiences. Friedner (2015) furthers this argument, stating that an uncritical focus on Deaf Gain could disregard deaf peoples' experiences of education, employment and daily interaction with hearing people in which they are often disenfranchised. Despite the potential implications of this concept, it could be significant in challenging dominant understandings of deafness and present an opportunity for a positive transition in focus from notions of positive and negative experience to range and variety in experiences. Such opportunities enable deafness to be framed differently and avoid a dominant discourse that claims one truth and type of experience.

While most of the concepts generated from Deaf Studies were originally created to defend the position of deaf sign language users and their linguistic and cultural identity (Bauman and Murray 2014), Kusters et al. (2017) argue that care must be taken not to use them as frozen ways of thinking in analysing deaf peoples' lives.

Summary and implications for this research

In the first section of this chapter, I introduced and critiqued the main constructions of what it is to be deaf and the language usage associated with them. Many of these concepts can be viewed as essentialist and have the potential to exclude, exert power over people and oppress. However, others have often provided a foundation for deaf people to explore their own identities positively and highlight deaf peoples' struggle for social justice. The differentiation between different constructions of deafness is in one sense helpful in clearly distinguishing between those who associate themselves with deaf communities and those who do not. However, there are evidently points of intersection between the biomedical, disability and sociocultural models of deafness. Therefore, these differing constructions can be viewed as being in dialogue with one another, rather than as having clear distinctions. This dialogue manifests in discussions about deaf ontologies. Such discussions have been mostly restricted to the field of Deaf Studies in which academics have committed to understanding deaf peoples' ontologies and epistemologies.

The literature indicates that the biomedical model remains a powerful paradigm in wider society and healthcare. However, the defining feature of the biomedical model, deaf as *loss* of hearing, does not account for or reflect deaf peoples' diverse experiences. It is evident that an uncritical application of or acceptance of any construction as ‘more valid’ has the potential to shape and define deaf peoples’ relationship with hearing people. From a social science perspective, the language we use creates meaning in what it communicates about our perspectives and values. Therefore, it becomes clear that the language researchers use is significant as it can indicate deliberate choices and perspectives. Considering the different ways it is possible to experience being deaf, I will work with different terminology and notions of what it means to be deaf in this thesis to explore if and how these come into conversation in healthcare contexts and relationships. I recognised this as an important element of my critical reading for this chapter and something that informed my critique of the empirical research in *Chapter Three*.

Scottish policy context

Introduction

From a political perspective, developing and planning services to meet deaf peoples’ needs is challenging due to the lack of demographic information available (Reynolds 2007). As noted in *Chapter One*, the exact number of people in Scotland who use BSL as their first or preferred language is unknown (British Deaf Association 2019). Ladd (2003) noted that ascertaining the exact number of people who belong to the deaf community has proved challenging because of the confusion between biomedical and sociocultural perspectives and misunderstandings of sign languages that result in deaf people being ‘invisible’ or not accounted for in national statistics. However, there are estimated to be between 5,000 and 6,000 people in Scotland who are deaf and for whom BSL is their first and preferred language (Scottish Council on Deafness 2018).

As critically discussed earlier in this chapter, one of the most significant influences of the biomedical construction of deafness, is that deaf people are viewed as disabled rather than as a cultural-linguistic minority. As a result, policies that have governed deaf peoples’ lives have traditionally defined deaf people as disabled. The implicit assumptions in this disability framework have resulted in inadequate adjustments that misunderstand deaf peoples’ language and their needs. Additionally, this disability framework has resulted in BSL being neglected in minority language policies. In this section, I will critically discuss how the disability framework has shaped the language status of BSL, the policies that have governed deaf peoples’ lives and the subsequent impact these have on the provision of access to public services in BSL. In examining historical and current attitudes and policies related to BSL in Scotland, it is necessary to look at the relationship between language policy and ideology. Therefore, I will now discuss language ideologies in Scotland, their impact on deaf peoples' language fluency and their influence on policy. I will discuss how language policies can be viewed as ideological constructs that reflect and (re)produce the distribution of power in society.

Language status, acquisition and fluency

Language ideologies are thoughts and beliefs about languages and the people who use them. Therefore, attitudes about what language is (and is not), how and where languages are used, their value and their origins are expressed in language ideologies (Kusters et al. 2020). Despite sign languages being acknowledged as bona fide languages by linguists, there continues to be widespread ignorance about sign language in wider society. Generally held misconceptions about sign languages include the ideas that sign languages lack grammatical structure, are merely gesture, are universal, portray the objective in mime, and cannot be used to express abstract ideas (Burns et al. 2001). As a result, spoken and written language are viewed as having higher status and being of more value. This ideology continues to maintain the low status of sign languages and results in the oppression of those using sign languages. The low status of sign languages continues to have an enduring influence on deaf peoples' opportunities to acquire a fluent language, be educated in their first language and gain access to information and services in sign language (Kusters et al. 2020).

For much of history, the use of sign language by deaf people has been actively discouraged by the wider hearing community (Facchini 1985; Brien 1992; Ladd 2003). This is a result of the English speaking majority often believing that sign language is a barrier to the acquisition of a written/spoken language, which is believed to have a higher status. Howes and Classen (2014) believe that this theory has developed as a result of the ability to hear and speak being historically viewed as prime indicators of the ability to reason. Therefore, educational and healthcare establishments believe that deaf people should learn English (spoken and written) to fully integrate into wider society. This ideology which privileges spoken and written language over signed ones, often denying the validity of sign languages, is known as oralism (Gertz and Boudreault 2016).

Currently, oralism continues to be encouraged in medical and educational fields. Therefore, sign languages continue to be oppressed, despite spoken languages not being optimally accessible for deaf people (Kusters et al. 2017). For deaf people who cannot access spoken language, being raised without early and consistent access to sign language often prevents development of any fundamental language abilities (Glickman 2013). As highlighted earlier in this chapter, 90-95% of deaf children are born to hearing parents who have no knowledge of a sign language (Kyle and Woll 1985). Growing up in a home in which the spoken and written language is more predominantly used unquestionably affects language acquisition. Those born to deaf parents are exposed to a fluid model of BSL, while those born to hearing parents may only begin to learn BSL when they start school or are introduced to the deaf community. The different paths to competence in sign language results in wide variations in language fluency and use (De Meulder et al. 2019c) with deaf children of deaf parents frequently having higher levels of overall language fluency and educational achievement than the deaf children of hearing parents (Marschark and Spencer 2010). This is a result of them developing a degree of bilingualism, in BSL and English (spoken and/or written) that puts them at an advantage (Young et al. 2019).

Despite a vast amount of corrective work carried out in the late 20th century to establish that sign languages are natural languages, sign language dysfluency remains. Glickman and Hall (2018) argue that language deprivation is a social problem. The effect of suppressing the language and culture of deaf people has left signing communities in the UK with a legacy from which they are now only slowly recovering (Kusters et al. 2017). This legacy includes high degrees of illiteracy, low self-esteem, low educational achievements, and devaluation of language. Therefore, just like any other minority language, the status of sign languages is the result of social, political and historical processes linked to wider unequal power relations (May 2012).

Disability and equality legislation relating to BSL

Equality and disability policies were viewed as adequate protection for deaf peoples' language rights in Scotland until 2015. As the rights of access to BSL/English interpreters were based on the grounds of disability rather the cultural linguistic status of deaf people prior to 2015 (Haualand and Holmström 2019), services built upon these policies were not adequate to address cultural linguistic needs or ensure deaf peoples' access to appropriate services. Although the disability framework has since been acknowledged by the Scottish Government (Macpherson 2015) as inadequate for ensuring access to services in BSL, the underlying assumptions inherent in the disability framework remain visible through implicit assumptions that guide behaviour (Argyris and Schön 1996).

In March 2003, the UK Government officially recognised BSL as being a distinct minority language and it was formally recognised as such by the Scottish Government in March 2011 (Office for Disability Issues 2010). However, in contrast to the recognition of most spoken languages, the recognition of sign languages has not always led to the language's inclusion in language legislation as the ideals defined in policy are often not lived out in a real-life context (De Meulder et al. 2019a). In the UK, recognition took the form of 'recognition' funding, provided to third sector organisations (Lawson et al. 2019). Lawson et al. (2019) state that this was a small amount of funding provided to charities that had relatively little impact on the experiences of deaf communities and did not provide deaf people with legal protection that would promote and facilitate access to education, information and other services in BSL. Consequently, the rights of users of BSL remained protected under equality, as well as disability legislation. De Meulder (2015) has labelled such recognition as 'implicit' recognition that acknowledges the use of sign language via measures addressing disability access but does not recognise BSL in dedicated language laws. In Scotland, there are two laws that are relevant to deaf peoples' access to healthcare services, the Disability Discrimination Act 1995 and the Equality Act 2010.

The Disability Discrimination Act 1995 introduced the concept of 'reasonable adjustment' that requires service providers to take steps to remove barriers to accessing services. Although it is seen as good practice to include service users with disabilities in the process of considering what reasonable adjustments are appropriate, the responsibility remains with the service provider to determine what is a reasonable adjustment (Lacey and Gildea 2011). Under this Act in Scotland, the government argued that reasonable adjustment to secure access to public services for deaf people included providing a BSL/English interpreter, in addition to printed and online information in plain English, subtitling or signed videos (Perez et al. 2006). Similar to the disability act, under the Equality Act 2010, the NHS must not allow a disabled person to be discriminated against by any of their service providers. NHS organisations are obligated to make reasonable adjustments (auxiliary aid or service) to ensure that any information that they provide is in accessible format for their service users. This act was developed to prevent a person with a disability from being put at a substantial disadvantage compared to non-disabled people. Both of these acts have the potential to secure the linguistic rights of deaf people, provided that service providers understand what reasonable adjustments to make to meet an individual's language needs. However, taking into account the differing conceptualisations of deafness and lack of understanding about BSL as a bona fide language, questions are raised as to what assumptions would underpin a service provider's understanding and choice of 'reasonable' adjustments for a deaf person.

Considering the cost of booking a BSL/English interpreter and/or producing a signed video, Turner (2009) argues that public services in Scotland frequently opt for written English as a reasonable adjustment. However, sign languages have no written form. The decision to opt for written English therefore indicates numerous assumptions made about BSL, including the belief that its use is the linguistic preference of deaf people, rather than the only language that is fully accessible to many. Batterbury (2012) argues that such policies deliver unsatisfactory outcomes that do not solve linguistic exclusion but continue to misunderstand the significance of sign language in deaf peoples' lives. According to Turner (2009) such exclusionary behaviour has become unquestionable as it is normalised by the majority and embedded in institutionally audist routines. These assumptions indicate that the laws previously believed to support deaf people were not effective in securing deaf peoples' linguistic right. This reiterates Young and Temples (2014) argument that to accept inequality from a social model of disability perspective is to privilege one explanation of inequality (disability rights discourse), over another, that of language rights. Additionally, De Meulder (2017a) argued that protecting BSL under a disability framework has perpetuated a historical view of sign language as a problem perspective (Ruiz 1984). Consequently, while the aforementioned legislation was intended to support and protect deaf peoples' linguistic rights, policies that place emphasis on defining deaf people as disabled fail to secure such rights and subsequently fail to provide full access to services. Recent legislative advances in Scotland may go some way towards addressing these gaps in UK policy.

Language legislation

Although it has become clear that sign languages are fully-fledged languages, they have traditionally been neglected by minority language policies (De Meulder et al. 2019a). This is reflected in the wording used in worldwide language policies that focus on securing rights for regional and minority languages '*spoken'* in each territory (Batterbury 2012). Therefore, as a concept, the centrality of 'recognition' is rooted in language ideologies, emphasizing the normativity of the spoken mode (Hill 2013; De Meulder et al. 2019a). As a result, spoken languages such as Welsh and Gaelic have increasingly gained support, but the UK's sign languages have yet to receive similar acknowledgement (Lawson et al. 2019).

Gaining legislation that recognises sign languages as legitimate languages has been on the agenda of numerous deaf communities around the world as far back as the 1980's (De Meulder et al. 2019a). However, during the 1990's it became a widespread political priority that indicated a turn from disability to linguistic human rights discourse (Murray 2015a). In the UK, campaigns for recognition were initially driven by charities such as the British Deaf Association (BDA) and National Union of the Deaf (Ladd 2003). However, in the late 1990's ownership of the BSL campaign was claimed by the Federation of Deaf People (FDP) (British Deaf Association 2015). The FDP organised a series of marches in London during 1999, 2000 and 2001 (Stiles 2013), stating a collective purpose:

> "We demand that the British Government fully and unconditionally accept BSL as a bona fide language, native to this land, with full access through it for all who wish to use it" (FDP 1999, cited in Lawson et al. 2019, p.69).

Despite deaf communities' campaigning, their ideals and demands for recognition have been challenged by powerful, well-established organisations in recent times. In 2012, the Proposed Sign Language Scotland Bill (Griffin 2012a) which promoted the need for legislation encouraging the use of BSL in Scotland, proposed that public recognition could be gained through awareness raising. The Bill demanded that public services, such as the NHS, would publish BSL plans to improve services for deaf people and train staff who are likely to interact with, and support BSL users. NHS Education for Scotland (NES 2012) responded to this expectation, stating that there was no need for such a bill because they believed the Equality Act 2010 provided an adequate incentive for the production of accessible information and services for deaf people (Griffin 2012b). However, the Scottish Council on Deafness (SCoD 2013) responded with similar arguments to that explored earlier in this chapter, highlighting that deaf BSL users are only covered by the Equality Act 2010, granting them access to services and information in their first language, if they consider themselves to be disabled. They argued that this interpretation of legislation did not enhance linguistic equality but fostered discrimination.

The challenges that deaf campaigners and communities have faced at a political level are apparent in the response to the aforementioned legislative developments. For instance, Ladd (2003) noted that many deaf people feel that policy makers have failed to listen to their concerns and acknowledge the status of sign languages as true languages. Additionally, these challenges raise questions for me as to the appropriateness of hearing policy makers' response to the needs of sign language users, without engaging with deaf people about their experiences. Thus, it seems to me that the policy implemented to protect deaf peoples' rights has been developed without meaningful participation or understanding of deaf communities or their needs. The disabled status ascribed to deaf people through this legislation reinforces the dominance of biomedical discourse and misunderstanding of BSL and does not secure linguistic access. Without guaranteed access to services in BSL, deaf people remain disadvantaged.

Despite the ongoing opposition to framing deaf peoples' right from a linguistic rather than a disability perspective, deaf people in Scotland have made significant developments in their influence over legislation. The proposal of the Sign Language Scotland Bill (Griffin 2012a), made by the SCoD, was underpinned by the argument that BSL users were expected to respond to disability discrimination legislation (Equality Act 2010) in English in order to secure access to services in their own language. The aim of the Bill was to develop legislation that would enable BSL users to claim language rights. As a result, the British Sign Language (Scotland) Act 2015 was proposed and passed by the Scottish Parliament. Scotland therefore became the first country in the UK to acknowledge BSL on the same footing as English and Gaelic.

The Act put a duty on Scottish Ministers to promote the use and understanding of BSL by preparing and publishing national BSL plans for services. In response to their duty, Scottish ministers supported establishment of a BSL National Advisory Group (NAG). This group worked in partnership with BSL users in Scotland to develop the first National Plan (Scottish Government 2017). The plan, created in consultation with representatives of the community, aimed to reflect the views and needs of the BSL community in Scotland. Since publication of the plan in 2017[22], service providers, including NHS Boards and universities, have been developing local BSL plans, that reflect the priorities set out in the National Plan. These developments represent a significant positive step towards securing deaf peoples' right to access services in sign language. However, as with the development of the Gaelic Language (Scotland) Act 2005 and the Welsh Language Act 1993, there are often challenges to implementing the ideals of a formulated language policy into practice (Mac Síthigh 2018). A number of issues emerged during the development of the National Plan (De Meulder 2015), including: imbalanced representation in strategic development; and lack of responsibility and accountability processes in the plan and lack of detail regarding implementation of the plan.

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[22] The national plan was published in BSL and English to ensure BSL users had access.

Throughout the consultation period and development of the BSL National Plan, De Meulder (2015, p.446) highlighted a “representative imbalance” with the majority of consultations involving a large number of people who represent users of BSL alongside people who use BSL, rather than deaf people themselves. Questions regarding representation emerged when an absence of deaf community participation was recognised. As legislation to protect and encourage the use of sign language has previously been shaped by disability discourse and inadequate engagement with BSL signers themselves (De Meulder 2015), such development processes can result in social control and non-participation in which the hearing majority make decisions for deaf people (Bereford & Croft 1993). Reagan (2008) argues that while language planning can act as a tool for empowerment and liberation, it can similarly be used as a means of oppression and domination. Therefore, sign language planning continues to be perceived as a problematic concept, driven by hearing people who have the potential to control deaf people and their language use (Napier et al. 2015).

Similarly, De Meulder (2015) claimed that the BSL Act’s biggest weakness is that it demonstrates a lack of duty to deliver full access to services and education in BSL. For instance, although the Act claims to promote the use of BSL, without guaranteeing deaf people full access to education and services, the challenges that BSL users experience will remain unchanged. Therefore, deaf people are likely to continue to be disadvantaged in comparison to hearing and speaking members of society. This issue is not unique to British strategy. McKee (2011; 2017) has highlighted that while the New Zealand Sign Language (NZSL) Act has also elevated the status of NZSL’s it has done so without allocating resources or planning for the promotion of NZSL. Young et al. (2020) contend that such uncertainty of linguistic access and social participation reinforces structural-level discrimination that prevents deaf people from fully exercising personal agency. Therefore, it is evident that although the BSL (Scotland) Act 2015 is a milestone for sign language rights and policy, it may lead to little action due to the lack of enforceable rights.

Lastly, De Meulder (2015) emphasised that the lack of recognition of BSL users as a culture-linguistic minority in the BSL Act suggests that the attitude is merely symbolic. She suggests that this symbolism has the potential to draw attention to aspirations that do not materialise into action or change. De Meulder and Murray (2017) argued that there are many potential challenges to implementing sign language legislation with the main challenge being a wide disparity between the deaf community’s expectations and the government’s intentions during the drafting of legislation and plans. Furthermore, Lawson et al. (2019) claimed that implementation of the Act will mostly be determined by policy advisers, potentially resulting in the delivery of unsatisfactory outcomes that do not reflect the deaf communities desire for social and linguistic justice. It is evident from the many critiques of the BSL (Scotland) Act 2015 that there remains a gap between what is required to secure BSL linguistic rights and the government’s commitment. Therefore, as De Meulder et al. (2017) emphasised the Scottish government needs to enable deaf people to participate and lead ongoing planning, commit financial resources to the implementation of the act and move beyond mere symbolic recognition to tangible actions that will improve deaf peoples’ access to education and services in BSL. The Scottish government was due to publish a progress report on the BSL (Scotland) Act 2015 in October 2020, with a further set of actions to be delivered by 2023. However, due to the COVID-19 emergency the publication of the progress report has been delayed by a year (Scottish Government 2020).

Interpreter provision in Scotland

For many deaf people, interactions with hearing people, who do not sign, necessitate the use of an interpreter (Bontempo 2015). Deaf people are in the unique position in which use of interpreters is often a lifelong experience (Napier 2020). Widespread failure to provide interpreters in Scotland has been explored by Mapson et al. (2019). In response to the BSL National Plan’s recommendation that more evidence is required to understand how services can be effectively delivered to deaf people, Mapson et al. (2019) carried out a scoping study of BSL interpreting in Scotland using different data sets. A strength of this study is that it included a range of perspectives including BSL users, services providers, third sector organisations, interpreters and interpreting professional bodies. Therefore, it was inclusive of all those involved in the provision and use of interpreters, providing a holistic understanding. Through examining contributions from the BSL community to both the consultation phases of the BSL Bill (later the BSL (Scotland) Act 2015), and the creation of the BSL National Plan 2017-2023, it was reported that the general perception from the deaf community is that there is a shortage of registered interpreters in Scotland. Additionally, online survey responses from 48 public bodies, nine of which were from the health sector (five health boards plus four health and social care partnerships) indicated that interpreter availability is a concern for all public bodies in Scotland. Specific issues relating to the healthcare setting included: demand for interpreters during evenings and weekends; gender matching the interpreter to the BSL user for sensitive appointments; short-notice bookings and the time-consuming process of booking interpreters. Due to the shortage of interpreters, public bodies (including NHS health boards) indicated that bookings need to be made weeks in advance, which is problematic due to the acute nature of many healthcare problems.

Looking more closely at the number of BSL/English interpreters in Scotland, this report stated that in March 2019, there were 109 BSL/English interpreters registered with professional bodies in Scotland. Mapson et al. (2019) noted that this number might be somewhat inaccurate due to the potential for interpreter's dual registration with two registration bodies. In addition to there being an overall shortage of interpreters, findings from this review indicated that newly qualified BSL/English interpreters do not feel adequately prepared for working in healthcare settings due the nuances of working with healthcare terminology. The report anticipated that the use of BSL in Scotland will remain constant but that as a result of increased awareness of rights following the BSL (Scotland) Act 2015, the demand for interpreting services is most likely to increase.

Summary and implications for this research

It is evident from the literature critiqued above that planning services for deaf people remains problematic due to the paucity of statistics related to deaf communities in Scotland. Policies that have governed deaf peoples' lives have traditionally defined deaf people as disabled. The implicit assumptions in the disability framework have resulted in inadequate adjustments that misunderstand deaf peoples' language and their needs. Additionally, this disability framework has resulted in BSL being neglected in minority language policies. While the BSL (Scotland) Act 2015 has contributed to legal recognition of BSL in Scotland, this recognition appears to be symbolic. Legal recognition alone is therefore not sufficient to implement changes that will improve the status and understanding of BSL in Scotland. It is evident that deaf people do not hold positions of leadership from which they can be actively involved and influence political structures and policymaking. Unless the government enables meaningful participation from the deaf community and implements concrete action plans, the BSL (Scotland) Act 2015 will not address issues of discrimination and social exclusion. Subsequently, access to language rights will be applied or ignored at different levels. The BSL (Scotland) Act 2015 is therefore an important symbolic step with much more work to be done to secure linguistic equality and access to services.

Recognising that dominant language ideologies continue to maintain the low status of sign languages in Scotland, I have considered the implications for this research and my own research practices. My main concern was that this research was linguistically accessible for deaf people to comprehend the purpose of the study and to meaningfully participate. These considerations are further addressed in *Chapter Four* and *Five*.

Conclusion

In this chapter, I have discussed differing constructions of deafness. Potential tensions and places of intersection between these constructions were highlighted. Arguably, prioritising one construction of deafness may be somewhat narrow, failing to acknowledge the multiple ways in which a person can be deaf. I therefore do not take the view of one construction of deafness but acknowledge the implications each conceptualisation of deafness may have for understanding the experiences of deaf people and approaching them in both healthcare and research. The biomedical model remains the dominant construction of deafness that manifests in society as a whole and more specifically in healthcare. This construction views hearing as the ‘norm’ and has contributed to certain ‘truths’ and knowledge being prioritised, with deaf peoples’ diverse ontologies and epistemologies often being undervalued. Such has led to language ideologies and power dynamics that may underpin and inform care and research related to deaf people. Additionally, it is evident that in healthcare the prevailing biomedical perspectives play a crucial role in the creation and maintenance of social constructions of deafness.

BSL is the visual–spatial language of deaf people in Scotland. Recognising that deaf peoples’ language is a visual gestural language, access to healthcare services, information and effective relationships with professionals relies on recognition of BSL as a bona fide language. While the BSL (Scotland) Act 2015 has provided legal recognition of BSL in Scotland, I emphasised in this chapter that without implementing action plans the effects of the BSL (Scotland) Act 2015 may be minimal. Therefore, it is unclear what impact the BSL (Scotland) Act 2015 has had on challenging the low status and understanding of BSL in Scotland.

Chapter 3: Literature review

Introduction

In *Chapter Two*, I critically discussed the social constructions and contexts in which ‘deafness’ and ‘being deaf’ have developed over time. By discussing dominant constructions and ideologies, I indicated how these may influence the development of healthcare practices and policies. Believing that differing perspectives have the potential to be complementary but often act as sources of tension and polarity, it is my intention to further bring these perspectives into conversation with one another in this chapter. The purpose of the chapter is to critically review the empirical evidence to answer the research question ‘What are deaf, BSL users’ experiences of healthcare?’.

I will show that the body of research evidence is primarily situated in the biomedical perspective, privileging positivist traditions. From this standpoint, deaf peoples’ experiences of healthcare are often viewed through a biomedical lens with little attention given to the contextual influences and structural disadvantages encountered when accessing healthcare. Using the discussions from *Chapter Two* to critique this biomedical perspective, I will show that deaf peoples’ healthcare experiences need to be understood in the social space and social relationships in which healthcare takes place. From this perspective, nurses are well positioned to influence deaf peoples’ experiences of healthcare. As this literature review is not simply a synthesis of other peoples’ work but also synthesises my own work with the literature (Murray 2017), I will explore what contributions each section makes towards this research. At the end of this chapter, I identify how the literature review informed the development of the research aims and direction of my research.

Unfolding an inclusive stance about knowledge and evidence

This literature review is an updated and much extended version of a previous iteration, published in 2014 (Dickson and Magowan 2014) (see Appendix 1). I conducted the initial review as an undergraduate student through application of a traditional hierarchy of evidence. Therefore, it was constructed from a biomedical base, leaning towards positivism and valuing knowledge generated through scholarship or research alone (Upshur 2001). This resulted in a limited answer to the research question: ‘What are deaf peoples’ experiences of healthcare in Scotland?’ as it perpetuated a “narrowness” of perspective and resulted in incomplete epistemologies with which deaf communities have often been viewed in research (Young and Temple 2014, p.3).

Cody (2006) argues that from a critical social theory perspective, such narrowness can be used as an instrument of oppression by dominant cultures in society if it maintains dominant values and power structures.

From a social science perspective, there is a need to draw from and synthesise a broad body of knowledge derived from various methodological and epistemological traditions (Thomas et al. 2020). This reflects my belief that nursing is both a science and an art. The knowledge base of my practice therefore includes multiple ways of knowing (Carper 1978). From this premise, empirical research is only one source of knowledge that informs clinical decision making and the delivery of healthcare (Upshur and Tracy 2004). While I dispute the positivist belief that empirical evidence should be regarded as the only credible means for generating evidence on which to base knowledge claims, I believe it is important to preserve what is valuable in the concept of evidence informed practice. Avis and Freshwater (2006) argue that what is worth defending in the idea of empiricism is the emphasis it places on critical examination of evidence in the light of theory. Therefore, the critique of the empirical evidence included in this review will be informed by the theoretical concepts explored in *Chapter Two*. From this perspective, I blended a range of knowledge sources and strategies for knowing to produce a meaningful synthesis of evidence relevant to the topic (Greenhalgh 2018).

According to Hart (2018) there are two types of research gaps. The first identifies the gaps in the existing body of knowledge. The second critiques or problematises assumptions that may be unrecognised. Therefore, indicating that knowledge related to the overarching question is inadequate. This can identify methodological or conceptual approaches that have prevented a topic area from progressing. In allowing the theoretical literature explored in *Chapter Two* to inform my critique of the empirical research, I will show that much of the research takes a positivist perspective, that privileged professional knowledge and did not fully inform my research topic. Identifying such a gap creates the foundations in research to develop new transformational knowledge that makes structural and social change possible (Titchen et al. 2017). Creating such knowledge is critical to enacting social justice. Lastly, at the end of this chapter I will identify how the literature review informed the development of the research question and aims.

Search strategy

A comprehensive search for literature was completed by use of electronic databases including the Cumulative Index of Nursing Allied Health Literature (CINAHL), PubMed, MEDLINE, the NHS Knowledge Network and ProQuest. The key words used for the database searches included ‘deaf’ and ‘Sign Language’ or ‘British Sign Language’ and ‘health’ or ‘healthcare’. The terms were used as appropriate for each database and combined using the terms ‘and’, ‘or’ to make the search strategy more specific. In addition to these searches, further literature was identified using a snowball technique. Seminal literature that was predate was included. Literature searches relevant to the thesis were undertaken and updated annually between 2016 and May 2020. It is important to question whether studies from outside the UK are relevant because of differences in political, legal and healthcare structure. However, in the absence of UK based research, literature from further afield was included. The literature search determined that currently there is a small evidence-base in this area.

Search and review process

During the search process, abstracts or whole texts were scrutinized for relevance to the thesis and the review question: ‘What are deaf, BSL user’s experiences of healthcare?’. It is important to emphasise the complexity of finding and critically analysing relevant empirical research when understandings of deafness as a concept are poorly and inconsistently defined. Although I have argued, in *Chapter Two*, that distinctions between different ways in which a person can be deaf are often not clear-cut, research studies that grouped English speaking, hard of hearing people and deaf, sign language users together were excluded. The rationale being that although some of the needs of these two groups will overlap, the focus of this study is on sign language users. Researchers that recruit deaf and hard of hearing participants collectively often employ methods that render participation inaccessible to sign language users (Rogers et al. 2018). Therefore, the findings of such studies do not consider deaf sign language users’ experiences and perspectives.

I identified relevant literature and critically evaluated it using a simple appraisal tool that I adapted from the Scottish Intercollegiate Guidelines Network’s (SIGN 2016) checklist for critical appraisal (see Appendix 3). This enabled the assessment of literature sources in terms of the aim and nature of literature, the research process and outcomes, the methodological quality of the literature and key findings. Finally, I developed an evidence table in which I collated summaries from each piece of evidence (see Appendix 4). The sample of literature was drawn from a broad period (1999-2019). The initial searches yielded over 1000 references and after scrutinizing abstracts for relevance to the research question, a final total of 17 empirical literature sources were included in this section relating to deaf peoples’ experiences of healthcare.

Access

Access to healthcare services

In the empirical research, several studies indicated that public services are challenging for deaf people to access due to practical difficulties related to the nature of service provision. To assess the extent of access to public services by deaf BSL users in Scotland, Kyle et al. (2005) carried out a mixed methods study in which individual semi-structured interviews and focus group discussions were carried out with 80 deaf people across Scotland. There were no instances of direct access to public services in BSL. Participants therefore reported frustration when in contact with hearing services and considered contact with the NHS the most problematic. Frustration stemmed from access and navigation of services relying on use of spoken and written English. Specific examples of the challenges faced by deaf people included booking an appointment, receiving information about an appointment, checking-in for an appointment and being informed that it is time for the appointment, all of which rely on having an understanding of written and spoken English and/or having the ability to hear spoken word. Without an accessible way of contacting services via a video relay service (VRS)[23], deaf people have to rely on family members or others to make appointments. This has implications for deaf peoples' sense of autonomy and confidentiality. As emphasised in *Chapter Two*, lack of access to services in BSL perpetuates deaf peoples' dependence on others and sustains the view that deaf people require support to function in everyday life (Leigh and Andrews 2017).

Reporting on more specific issues related to access to NHS services, Reeves et al. (2003) carried out a mixed methods study to evaluate access for deaf people to primary and Accident and Emergency (A&E) services in the Northwest of England. Indicating that deaf peoples' access to services begin the moment they wish to contact a health service, Reeves et al. (2003) reported that out of the 22 A&E departments that were included in the study, two units possessed a textphone[24] that would allow a deaf person to communicate with the department by text, but neither was in operation.

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[23] VRS allows hearing and deaf people to communicate via the telephone through a BSL/English interpreter (contactScotland-BSL 2019).

[24] A textphone allows a person to communicate by text via a telephone line. Messages are typed, by the deaf person, onto a keyboard and responses are displayed on a screen. This allows two-way communication. A textphone can be used to make and receive calls from a telephone user, via a service called 'text relay'. The text relay assistant will speak a text message out to the hearing person and text their response back to the deaf person (Action on Hearing Loss 2018).

Similarly, Steinberg et al. (2006) who carried out a mixed methods study that aimed to better understand the healthcare experiences of deaf American Sign Language (ASL) users reported that difficulty contacting specific services, caused by reliance on telephone-based communication, resulted in them going directly to the emergency department with healthcare concerns. Acknowledging that health behaviours that result in inappropriate A&E attendances are multifaceted, Ismail et al. (2013) argue that absent, inadequate or inaccessible primary care resources are the main determinants. While inappropriate attendance at emergency departments is problematic for healthcare systems, the 'inappropriate attendance' label can be challenged by the need to consider perceptions and understanding of health and the healthcare system that leads to such behaviour (Breen et al. 2013).

It must also be noted that adjustments such as textphones do not provide full access to all members of the deaf community, as use of a textphone relies on written English. Therefore, although this is an adjustment considered 'reasonable' by the service provider it does not necessarily provide access for all deaf people. This highlights the inadequacies of the Disability Discrimination Act 1995, explored in *Chapter Two*, in which notions of access are determined and defined by the hearing majority. None of the units in the study by Reeves et al. (2003) had a visual patient call system, meaning that all relied on deaf people responding to a verbal call. Managers of many of the A&E departments noted that deaf people would be personally approached when it was their turn to be seen by a healthcare professional. However, upon assessment by the researcher only six (27%) of the receptionists claimed to use this procedure to inform deaf people that a healthcare professional was ready to see them. This is backed up by anecdotal evidence that deaf people experience anxiety in waiting rooms due to fear of not hearing or accurately lip-reading their name being called (Fellinger et al. 2012; Glickman 2013). These studies draw attention to the way access to healthcare is shaped by power imbalances.

Exploring deaf New Zealand Sign Language (NZSL) users' access to healthcare, Witko et al. (2017) carried out focus groups (n=32) and individual semi-structured (n=9) interviews with deaf people and their families. Additionally, they conducted semi-structured interviews (n=2) and focus groups (n=57) with healthcare professionals. Similar to studies carried out by Kyle et al. (2005) and Reeves et al. (2003), the main findings of this study indicated that deaf people often faced sensory barriers to accessing and navigating the healthcare system. Participants emphasised that methods of booking appointments, accessing healthcare buildings and responding to healthcare professionals in waiting rooms relied on the ability to speak and hear. Despite informing reception staff that they need to be alerted to their appointment via a shoulder tap, these accommodations were often not provided. Therefore, participants expressed having to intensely observe healthcare professionals in waiting rooms to discern when their name is being called and reported that as a result, they frequently miss appointments. One of the strengths of this study is that a deaf steering group co-designed the research and validated the findings. Such participatory approaches are more likely to produce culturally sensitive research methods that enable deaf people to meaningfully take part (Liamputtong 2010).

Exploring deaf peoples' access to dementia services, Ferguson-Coleman et al. (2014) carried out three deaf-led focus groups with 26 deaf people. In this study, primary care services and organisations that represent the voices of people with dementia, were not perceived as being beneficial to deaf people due to inaccessibility of the services. Given the deaf communities strong and valued traditions of collective responsibility[25] participants in this study believed that the 'deaf-led' third sector organisations that actively work with deaf communities, should take responsibility for delivering services and support to deaf people with dementia. Such organisations were perceived to understand deaf peoples' linguistic needs and cultural differences. In the UK, third sector organisations that are deaf led often co-produce their services with deaf communities and as a result, may have the understanding required to respond to deaf peoples' needs (Scottish Third Sector Research Forum 2016). In contrast, mainstream third sector organisations were viewed as inaccessible by the deaf people in this study. This is an issue because such third sector organisations are understood to contribute heavily to health and social care services delivery in Scotland (Scottish Government 2011). This issue challenges the assumptions, positionality and culture of healthcare professionals that create or perpetuate poor access to healthcare.

The findings of these studies (Reeves et al. 2003; Kyle et al. 2005; Ferguson-Coleman et al. 2014; Witko et al. 2017) align with the themes arising from consultation events during the development of the BSL National Plan, which McLean (2015) summarises as a systemic failure to provide access to public services for deaf people. While these studies raise an awareness of the broad challenge faced by deaf people when accessing healthcare services, without attending to the social, political and historical influences, explored in *Chapter Two*, the challenges faced by deaf people may be conceptualised from a biomedical perspective (Horrill et al. 2018). Such an approach

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[25] Community values of collectivism, information sharing and reciprocity in deaf communities are well documented (Murray 2017).

equates access with the physical accessibility of services. While this remains important, as deaf people require BSL to access healthcare services, it may limit an understanding of accessibility for deaf people. From a social science perspective, meaning is constructed through social interaction (Crotty 1998). Therefore, the social world (context and relations) in which care of deaf people takes place is key. Without knowledge and understanding of such relationships in the context of healthcare, questions are raised as to how healthcare practitioners can employ methods to improve the accessibility of healthcare practice and research for deaf people. Temple and Young (2014) argued that much of the research related to deaf communities maintains a focus on deaf peoples' need for access to services yet does not elaborate on deaf peoples' social relationships with services providers at the point of care. Such an approach may address the power dynamics that contribute to poor access.

Summary and implications for this research

It is evident that challenges to accessing services begin the moment a deaf person wishes to make initial contact with a service with access relying heavily on written and spoken English. As most NHS services are designed from a dominant hearing perspective, in which hearing and spoken English are primary means of communicating, deaf people may experience a wider structural oppression in the NHS. Deaf peoples' access to services relies heavily on the practical need to gain access in BSL. While the practical challenges of not having access to healthcare services in BSL are significant, the literature explored in *Chapter Two* emphasises the social element of access. From this perspective, the contextual factors located in social relationships are key to understanding and improving access.

Access to effective communication with healthcare professionals

As shown in *Chapter Two*, BSL is the first language of deaf people in Scotland and therefore, the most effective means for deaf people to both perceive others and express themselves when communicating. Anecdotal evidence suggests that low fund of information (Pollard 2002)[26], lack of healthcare terminology in BSL (Napier et al. 2015) and language dysfluency (Glickman and Hall 2018) all have the potential to significantly affect deaf peoples' communication with healthcare professionals. Although deaf people may creatively utilise a wide range of ways to communicate with hearing people including writing down words and gesturing (Kusters et al. 2017), such strategies may be effective for simple transactions but are insufficient for more

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[26] Fund of information refers to the accumulated knowledge individuals have from picking up facts through casual conversation and access to media (Pollard 2002).

complex conversations such as communicating healthcare information (Young et al. 2019).

Many of the studies included in the literature review reported communication difficulties that deaf people experience in both primary and secondary care. To explore the healthcare experiences of deaf people in the USA, Steinberg et al. (2006) conducted a qualitative descriptive study, recruiting 91 deaf adults from local deaf communities across three cities. Four semi-structured focus groups were conducted. The participants consistently expressed communication difficulties with a recurrent theme of fear of the consequences of miscommunicating. Positive experiences were characterised by the presence of a medically experienced qualified ASL interpreter, health care professionals with ASL skills, and doctors who made an effort to improve communication. Similarly, Parise (1999) conducted semi-structured individual and focus group interviews with 10 deaf participants in Quebec with the aim of exploring their healthcare experiences. Participants expressed feeling alienated, rejected and powerless when in contact with healthcare professionals due to the ineffective methods employed to facilitate communication. Themes of disempowerment and fear of the consequences of miscommunication were also evident in the study by Witko et al. (2017) in which participants expressed not fully understanding healthcare information without the presence of a professional interpreter.

Seeking to explore deaf peoples' experiences of communicating with nurses in the USA, Gilchrist (2000) carried out a hermeneutic phenomenological study informed by Van Manen's (1990) philosophy. This study recruited 11 deaf adults aged between 26 and 76 and consisted of individual, open-ended semi-structured interviews. Nurses were often viewed as too busy to spend time communicating and clarifying information about participant's health and care plans. In contrast, some nurses went out of their way to spend time helping deaf participants to understand this information. Despite the majority of participants expressing the need for a qualified ASL interpreter to fully access information, nurses often utilised written English to communicate. Most participants expressed that nurses did not offer or present options for communicating but that this decision was made on their behalf. Written and spoken English were viewed by participants as having the potential to effectively communicate information if they had a good understanding of English and nurses dedicated time to communicating the information in plain English.

It is evident from these studies (Parise 1999; Gilchrist 2000; Steinberg et al. 2006; Witko et al. 2017) that ineffective communication methods are often employed by healthcare professionals in the healthcare setting. Steinberg et al. (2006), Reeves et al. (2003), Parise (1999), Gilchrist (2000) and Witko et al. (2017) all reported common alternatives to the use of qualified interpreters including lip-reading and written communication. Although oral skills (speech and lip-reading) can assist some deaf people in understanding English, in practice they are challenging to acquire and cannot be viewed as effective. Additionally, linguistic studies have demonstrated that only 30-45% of the English language is discernible through lip-reading, while contextualisation and guessing determine the remainder (Lieu et al. 2007). The challenges of using oral skills were reflected in Parise's (1999) study. Participants reported that lip-reading and writing to communicate health issues were laborious, overwhelming and emotionally draining methods, with the provision of a qualified interpreter identified as creating a sense of ease around healthcare experiences. In addition to the studies critiqued above, both the study by Kyle et al. (2005) and anecdotal evidence (BDA 2016) reported that deaf people are frequently expected to try to speak, lip-read and/or read and write in English when in contact with hearing people, with no option but to "grin and bear" (Kyle et al. 2005, p.22) these inappropriate forms of communication. Additionally, participants in the Witko et al. (2017) study reported not having the confidence or being too unwell to advocate for full communication.

Research conducted by Ipsos MORI, on behalf of SignHealth (2013), reported similar findings in the UK. An online survey that aimed to understand deaf peoples' access to public services in the UK was completed by 533 deaf people. Comparing participant's current and preferred means of communicating, half of the respondents (51%) responded that they currently communicated with healthcare professionals using BSL and an interpreter, although 86% would prefer to communicate in this way. Almost half of the deaf participants (46%) reported that they currently communicated with healthcare professionals via written English, while 23% reported that they used spoken English and lip-reading. None of the respondents who reported using written and spoken English preferred to communicate in this way. These studies indicate that despite the majority of deaf people requiring access to healthcare information in their first language, the decision often remains out of their control. A limitation of these studies is that healthcare professional's reasons for not booking an interpreter were not explored. However, a number of participants in the Ferguson-Coleman et al. study (2014) noted healthcare professional's attitudes towards BSL and the number of false beliefs about sign languages as potential reasons. Similarly, the findings of the Witko et al. (2017) study suggested that healthcare professionals are often unaware of the risks of not using professional sign language interpreters. This may indicate that while healthcare professionals may not intend to cause distress or harm through ineffective communication, many are ignorant to deaf peoples' communication needs.

In the study by Ferguson–Coleman et al. (2014), participants noted that communication in primary care settings was experienced as more positive for participants due to NHS staff members being familiar with individuals and therefore more likely to have an in-depth understanding of their language needs. This finding is backed up by anecdotal evidence collated from consultation events with deaf communities across Scotland (BDA 2016). From these consultation events, the BDA (2016) have reported that a BSL/English interpreter is more likely to be booked if a General Practitioner (GP) is familiar with the deaf person. However, this was not always the case with a small number of participants expressing continuous communication misunderstandings between them and their GP. Such misunderstandings arose either because no interpreter was available, or the GP did not see the necessity of an interpreter. Additionally, the findings of Reeves et al. (2003) indicated that deaf people are significantly less likely to hold positive views of their GP than that of the general population.

The potential consequences of miscommunication between healthcare professionals and deaf people were highlighted in a number of studies. The deaf people who took part in the research by Witko et al. (2017) and Gilchrist (2000) reported receiving healthcare treatment and undergoing procedures with little understanding about what was going on. One participant in the Gilchrist (2000) study stated that they had undergone surgery without knowing what surgical procedure they were having. For a number of participants in the study by Ferguson-Coleman et al. (2014) miscommunication led to misdiagnosis, while participants in the Witko et al. (2017) study reported discontinuing treatment when they did not understand the need for it. Participants in both Reeves et al. (2003) and Witko et al. (2017) studies expressed concerns about medication education and instructions. For one participant in Witko et al. (2017), misunderstanding instructions from her GP had resulted in her discontinuing blood pressure medication and potentially contributed to her having a stroke. Such findings raise significant ethical concerns related to informed consent and patient safety. The implications of ineffective communication are therefore vast with serious consequences for deaf individual's physical and emotional wellbeing.

The findings of many of the studies explored in this section equate full access to communication and participation in healthcare with linguistic access. While linguistic access to healthcare is evidently a primary concern for deaf people, several researchers in the field of Deaf Studies (De Meulder and Haualand 2019; Young et al. 2020) asserted that BSL should not be viewed as a quick fix for access and participation. They argue that by conceptualising the issues of access as simply linguistic, the diverse and complex language practices of deaf people are ignored. Therefore, taking into consideration the communicative skills and needs of deaf people that go beyond the need for access to information in BSL, healthcare professionals require a more nuanced understanding of deaf peoples' cultural and linguistic needs. The importance of more nuanced understanding of access to healthcare was highlighted in Gilchrist's (2000) research. The findings emphasised the significance of visual information to accessing information and navigating the healthcare system, with participants highlighting the key role the sense of sight plays in their everyday lives. From coding and labelling the data, Gilchrist (2000) constructed four major themes including Portraits of Deafness, Seeing the Words, Seeing Ourselves and Seeing Nurses. In these themes, participants expressed a need to see not only ASL but also gesture, facial expression and body language to make sense of their interactions and healthcare experiences. Therefore, while access to sign language may be required for deaf people to access information related to their health, Gilchrist (2000) suggests that there are communicative acts beyond language that are significant in deaf peoples' experiences of healthcare. Such communicative acts require more attention and research.

Summary and implications for the thesis

Communication difficulties were a common theme identified across several research studies that covered a range of settings and contexts. In healthcare interactions, healthcare professionals often equated effective communication with written and spoken English, with few recognising that these methods are not substitutes for a sign language. The mode of communication appeared to be often determined by the healthcare professional. The implications of these shortcomings for the deaf community are that it will be challenging to gain knowledge and understanding of their own health and actively participate in decisions regarding their health and care. Such ineffective communication methods have the potential to result in misdiagnosis and mistreatment while causing the deaf person emotional strain. Therefore, by using inappropriate methods of communication, healthcare professionals are engaging in unconscious discriminatory practices. Lastly, the importance of visual navigation of the healthcare experience was emphasised by Gilchrist (2000), suggesting that deaf peoples' communication needs extend beyond access to information in BSL.

Access to interpreters

Many of the studies (Parise 1999; Gilchrist 2000; Reeves et al. 2003; Steinberg et al. 2006; Witko et al. 2017) discussed in this literature review conclude that the deaf participants most valued being able to communicate with healthcare professionals in their first language. As a result, the deaf people who took part in the study conducted by Kyle et al. (2005) indicated that provision of a sign language interpreter was their main priority. For many participants in the Gilchrist (2000) and Witko et al. (2017) studies, having the autonomy to choose when to have an interpreter and when not to have one was important, suggesting that deaf people may make contextual language choices. However, as highlighted earlier many studies reported lack of choice and inconsistent interpreter provision (Steinberg et al. 2006; Witko et al. 2017). Challenges to having a sign language interpreter present in healthcare interactions were evident. These challenges included failure to provide an interpreter, shortage of qualified interpreters and use of ad hoc interpreters such as family members. Additionally, there are range of considerations beyond the most basic need for deaf people to have access to information in their own language. Each of these will now be explored.

In the study by Reeves et al. (2003) 54% of participants expressed a preference for communication support via a qualified interpreter, However, in contrast 16% had never considered using an interpreter or did not know how to book one. Similarly, the UK study by SignHealth (2013) reported that 86% of participants reported the desire to communicate via a qualified BSL/English interpreter, with 51% reporting that this was the communication method implemented in practice. A limitation of both Reeves et al. (2003) and SignHealth (2013) is that they did not explore participant’s reasons for not considering or having an interpreter present. However, Steinberg et al. (2006) stated that many of the participants who felt negatively about their healthcare experience in their study had limited knowledge of their legal rights and/or complaints procedures in the healthcare system. Similarly, in the UK, anecdotal evidence gathered by the BDA (2012b) indicates a paucity of knowledge among the deaf community concerning legislation and how it can be enforced. Furthermore, Leigh and Andrews (2017) argued that the ongoing reluctance of hearing service providers to accommodate the linguistic needs of deaf people, in all areas of life, has contributed to low expectations and feelings of powerlessness, in which deaf people may accept the position of being a passive recipient of care.

Recognising that qualified interpreters are in short supply, deaf participants in the study by Gilchrist (2000) reported that healthcare professionals often view them as troublesome for requesting an ASL interpreter. However, participants highlighted that an interpreter was necessary for both themselves and healthcare professionals to effectively communicate with one another. These findings highlight the tendency of healthcare professionals to see necessity, ownership and relevance of the interpreter ‘for’ the deaf person rather than for all. Despite viewing the interpreter as ‘for’ the deaf person, the decision of whether or not an interpreter is ‘needed’ was reported as often being made by healthcare professionals. This is an example of healthcare professionals problematising sign language or its users, which Haualand and Holmström (2019) claim contributes to and maintains the low status of a language via language shaming. Therefore, healthcare professional’s attitudes and practice have the potential to sustain the low language status of BSL.

Two of the studies (Reeves et al. 2003; Witko 2017) included in this review explored the processes in use for obtaining a BSL/English interpreter. From the 22 A&E departments that were included in the study carried out by Reeves et al. (2003), 68% of healthcare respondents indicated that their unit had a system in place for obtaining BSL/English interpreters, although many did not have experience of arranging bookings for BSL/English interpreters. Following semi-structured interviews with A&E staff, Reeves et al. (2003) suggested that there was a lack of understanding about how to book an interpreter amongst staff. This finding emphasises that while NHS boards might have interpreting policies, their effectiveness relied on staff’s knowledge of the need for an interpreter and how to implement these policies in practice. The healthcare professionals who took part in the study by Witko et al. (2017) reported various processes for obtaining NZSL interpreters. Due to problems with interpreter availability some participants reported bypassing formal interpreter booking agencies to directly book freelance interpreters. In these instances, the healthcare professionals felt they had more control over the booking process. Participants indicated that when appointments were arranged in advance, this provided time to arrange an interpreter. However, unplanned or urgent appointments presented challenges to booking interpreters and often proceeded without one. Financial constraints and unclear lines of authority to book interpreters were also emphasised as preventing healthcare professionals from booking interpreters. The findings of these studies suggest that healthcare professionals reasons for not booking interpreters may be multifaceted.

Steinberg et al. (2006), SignHealth (2013), Witko (2017) and Reeves et al. (2003) all reported ad hoc interpreters, including family members and staff members, being used to interpret healthcare encounters. An ad hoc interpreter or lay interpreter is defined as an untrained person who is called upon to interpret, such as a family member, a bilingual staff member or a self-declared bilingual who volunteers to interpret in the healthcare setting (Mikkelson and Jourdenais 2015). In Reeves et al. (2003) 31% of deaf people who participated preferred a family member or friend to interpret ad hoc, while six departments (27%) made use of a hospital staff member with sign language skills to interpret. In contrast, SignHealth (2013) reported 17% of participants used friends and family as ad hoc interpreters, with 3% communicating this as a preference. It is unknown what sign language qualifications, if any, family members and friends who act as ad hoc interpreters had in many of these studies. However, three of the staff in the Reeves et al. (2003) study were qualified to BSL level two, while one other was working towards level two. Although this may appear more desirable than using family members to interpret, the BDA (2012b) emphasised that to competently interpret between BSL and English, a person should hold a National Vocational Qualification (NVQ) level six in BSL/English interpreting and be registered with a professional body. Therefore, the qualifications held by the staff in this study were sufficient to engage a deaf person in a basic conversation but insufficient for interpreting purposes in a healthcare context.

A limitation of Reeves et al. (2003) and SignHealth (2013) is that researchers did not explore deaf peoples' reasons for preferring family members or friends to interpret for them. However, the findings of Witko et al. (2017) reported that members of the older generation expressed being unaccustomed to using qualified interpreters and therefore felt more comfortable communicating through someone familiar. Cokely (2005) maintained that deaf people may prefer 'evolved' ad hoc interpreters who have grown up in the deaf community, inherited BSL and deaf culture from family and friends, over 'schooled' interpreters who have gained a professional qualification but may not have a high degree of fluency and cultural knowledge. This re-emphasises the need for an ongoing collaboration between the interpreting profession and deaf people to develop effective practices. Additionally, it reiterates the importance of autonomy and choice in making language decisions. Although an ad hoc interpreter may have a high degree of cultural knowledge, Parekh and Childs (2016) argue that without a comprehensive understanding of medical terminology, they could potentially cause harm by increasing risk of misinterpretation and subsequent poor assessment, misdiagnosis and delayed or incorrect treatment. Therefore, the choice of interpreter can have significant ethical implications (Drugan 2017).

It is evident from the literature that access to qualified interpreters is a pressing concern for deaf people in accessing healthcare. However, Deaf Studies academics (De Meulder and Haualand 2019; Young et al. 2020) argue that because this is a deaf person's most basic consideration, other issues related to accessing interpreters are often overlooked. Examples of such concerns are whether the interpreter is known and/or trusted, qualified to an appropriate level and if it is appropriate for them to be interpreting for a specific healthcare encounter. For example, it may be inappropriate for a male interpreter to translate for a female deaf person getting an intimate gynaecological examination. Therefore, increased access to interpreters is often uncritically proposed as the solution to a lack of access to healthcare for deaf people.

While I believe that an increase in BSL/English interpreters is essential for improved access to healthcare, to conceptualise the issue as one of straightforward linguistic access is to overlook the interactive nature of the interpreting process. Viewing the interpretive act in this way requires consideration of the relationships in the triad[27]. For example, De Meulder and Haualand (2019) highlighted the importance of healthcare professional's knowledge and awareness about interpreters and interpreting processes (including its capabilities and constraints) and knowledge about deaf people and sign languages as fundamental for effective interpreting to take place. This has also been emphasised in the Public Health Scotland (2020) competency framework for interpreting, in which a key practice for NHS staff is to understand the role of the interpreter, the complexity of the interpreting process and the kind of challenges interpreters may face when interpreting in the medical setting. Therefore, this suggests that access to interpreters for deaf people needs to be considered alongside the knowledge and understanding that healthcare professionals need to contribute towards an effective interpreted interaction.

Summary and implications for the thesis

This section has highlighted that having a qualified interpreter in healthcare situations is important for most BSL users as this provides access to information in their first language. The consequences of not having an interpreter can be vast. While the majority of deaf people in the studies reviewed would prefer to have an interpreter present, having the choice to make autonomous decisions about effective communication was important. Making such a decision depended on the context and nature of the interaction. Interpreters were understood by deaf participants as being necessary for both participants to communicate effectively. However, many deaf people experienced their language being problematised and therefore felt that asking for an interpreter was burdensome for healthcare professionals. Lastly, beyond the

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[27] Metzger (1999) proposes a triadic view of the interpreted interaction where all are actively engaged in the communicative event. This notion will be explored further in *Chapter Five*.

most basic need for access to information via an interpreter, it is evident that healthcare professionals need to develop a greater awareness of the interpreting process and BSL. This is crucial to ensure full understanding of health information for deaf people. The need for an awareness of the interpreting process is also crucial to the development of this research and will be explored further in *Chapter Six*.

Mode of access to healthcare information and education

From the review thus far, evidence suggests that deaf people are often expected to communicate with healthcare professionals via written and spoken English. A number of studies have highlighted the ineffectiveness of these methods for communicating healthcare information to deaf people. Additionally, a number of potential reasons for these methods continuously being employed by healthcare professionals have been highlighted. Recognising deaf peoples' visual-gestural language, these findings raise questions as to how deaf people obtain health information and knowledge. This section will further explore the empirical research that explores deaf peoples' understanding and knowledge of health. Much of this research remains focused on assessing deaf peoples' health literacy, knowledge and adherence to health promotion.

McKee et al. (2015) carried out a cross sectional study to assess the prevalence of inadequate health literacy among deaf ASL users (n=166) in comparison to hearing English speakers (n=239). In this study a health literacy instrument, health survey and heart disease fact questionnaire were translated and adapted into ASL. By producing a health literacy instrument, McKee et al. (2015) argued that low health literacy could be identified and gaps in knowledge addressed. The results of this study indicated that deaf participants were more likely to have lower health literacy scores ($p<0.01$), less knowledge of heart disease ($p<0.001$) and a higher correlation between health knowledge and health literacy scores ($p<0.001$) than hearing participants. McKee et al. (2015) stated that the health literacy instrument used in this study measured aspects of numeracy, document literacy, and reading literacy. Therefore, this study focused primarily on functional health literacy, an individual's ability to read and understand health information (Okan et al. 2019). While measuring functional health literacy may provide useful information related to the accessibility of written healthcare information for deaf people, McKee et al. (2015) framed the problem of poor literacy as deaf peoples' (in)ability to read and comprehend English. As explored in *Chapter Two*, the reason that functional literacy levels in the deaf community are low is multifaceted. However, by choosing to assess deaf peoples' access to healthcare information by measuring their functional literacy abilities, dominant language ideologies explored in *Chapter Two* are maintained with the significance of sign language to deaf peoples' understanding being ignored.

Looking to assess the impact of health promotion and Cardiovascular Disease (CVD) risk assessment on coronary heart disease risk estimates in the deaf community, Patel et al. (2011) carried out a pilot study as part of a community CVD risk assessment programme. The programme known as 'Healthy Hearts', was launched in the West Midlands, UK and focused on community screening among ethnic minorities. Data were collected during 10 health-screening events that included assessments of blood pressure, weight, lipidaemia, fasting glucose levels and smoking habits. Patel et al. (2011) stated that the design and delivery of the assessments and health promotion in their study was tailored to community needs. However, the research team gave no further information about how this was achieved aside from "community involvement" and "the use of an interpreter" (p.2). Twenty participants who were identified as high risk through a CVD assessment took part in a health promotion activity in which a cardiovascular specialist communicated the significance of their risk and provided risk reduction advice. Additionally, participants were provided with dietary and lifestyle advice from a nutritionist. Six months after the health assessment and health promotion, participants took part in a comparative health assessment. From the sample of 20 participants, none achieved a reduction of risk of CVD. In their discussion, Patel et al. (2011, p.4) stated that the ability to carry out their health promotion with the deaf community was "very difficult" due to the deaf peoples' limited level of English vocabulary. Additionally, they stated that "sign language appears to be underdeveloped" (p.4), reporting that there was no BSL sign for cholesterol. Unfortunately, no attempt was made in the reporting or discussion of this study to uncover the reasons why deaf peoples' understanding of healthcare terminology may be lacking.

When adapting healthcare instruments for deaf people, Glickman and Hall (2018) emphasise that there are fundamental linguistic adaptations that need taken into account, with careful attention being paid to the difference between spoken language modes (auditory-oral) and sign languages (visual-spatial). Therefore, to ensure that English language-based materials are avoided, deaf peoples' visual orientation needs to be prioritised in adapting materials and assessments (Anderson and Wolf Craig 2018). This presents a major limitation of the studies carried out by McKee et al. (2015) and Patel et al. (2011) as the complexities of translating instruments designed for hearing and speaking English users into sign language were not addressed. Both studies by McKee et al. (2011) and Patel et al. (2015) are examples of language as a problem (Ruiz 1984) view of sign language that was explored earlier in *Chapter Two*. This attitude places higher status on spoken languages and creates an expectation that the deaf community should learn to read and write English if they are to understand healthcare information. Additionally, it does not acknowledge the visual-gestural nature of sign language that may be key to understanding how deaf people can be enabled and empowered to access healthcare information.

McKee et al. (2011) carried out a qualitative study that aimed to explore deaf peoples' understanding of cardiovascular health, preventive behaviours and health information sources. Four focus groups of deaf participants (n=22) were conducted by deaf researchers fluent in ASL. Cardiovascular health knowledge varied widely among participants. While general knowledge strengths included common heart disease symptoms, the dangers of smoking and the basic benefits of exercise, there were several areas of knowledge inconsistency and misinformation. These included the dangers of illegal drugs, heart and brain anatomy and knowledge of medication. Communication and language barriers posed a major challenge to accessing health information among participants, including information received from healthcare professionals and access to information out with the healthcare environment. Interpreters and ASL-fluent medical professionals provided valuable access to health information and support. ASL accessible workshops were suggested as effective methods of disseminating healthcare, cardiovascular and general healthcare information. Subtitled TV was also identified a source of knowledge. However, as with previous studies (Gilchrist 2000; Kyle et al. 2005; Witko et al. 2017) many participants found it challenging to understanding complex medical terminology used when English was the method of communication.

Similarly, Pinilla et al. (2019) conducted a qualitative study with a social constructivist approach with the aim of exploring deaf sign language user's perceptions of non-communicable disease and diabetes prevention in Germany. Semi-structured interviews with two people with and 13 people without a history of diabetes were conducted to explore their perspectives. The findings of this study indicated that while diabetes knowledge depended on individual experience, participants often misunderstood diabetes as a primarily acute condition. Additionally, most participants were not aware that diabetes could potentially be prevented through lifestyle choices. The signs used for concepts related to diabetes were highlighted as an indicator of level of knowledge and health literacy amongst deaf people. Health information related to diabetes and general health was predominantly sourced from the internet by participants. Such information was often provided in written and spoken German, with participants expressing the need for information to be available in sign language. Lastly, due to persisting communication barriers with health professionals and the nuances of communicating healthcare information in sign language, this study indicated that an understanding of how sign language differs from English is necessary to provide deaf sign language users with adequate access to any healthcare information. While this study was carried out in Germany, it reiterates the need to develop health education interventions that take into consideration the linguistic complexity of adapting healthcare information into a visual mode.

There are numerous researchers who have employed methodologies and methods that acknowledge sign languages as authentic, visual languages, and the language diversity in deaf communities. In the USA, Jensen et al. (2013) and Sacks et al. (2012) have carried out evaluative studies aimed at developing healthcare educational videos that are linguistically and culturally appropriate for deaf communities. Jensen et al. (2013) carried out an evaluative study in which they developed and measured the effectiveness of an ovarian cancer education video in ASL. The educational video was developed and reviewed collaboratively between medical experts, ASL linguistics and deaf community members to ensure cultural alignment and linguistic accuracy. This involved a multistage process in which medical experts wrote the video script, this was reviewed by ASL linguists, third sector and deaf community members, it was forward and back translated, signed and recorded by native ASL users and then viewed by members of the deaf community who had not previously seen the video. Recognising the potential language dysfluency and lack of healthcare terminology amongst deaf communities, challenges to creating the educational video were highlighted. For example, in translating the video script the word “tissue” presented challenges because it only has a single meaning in ASL – a paper handkerchief. However, the research team addressed such challenges by utlitising graphics and providing a detailed explanation. Deaf (n=55) and hearing (n=52) women’s general, ovarian and total cancer knowledge were assessed before and after the video using a cancer knowledge survey that had previously been pilot tested with both deaf and hearing women. This study tested four hypotheses; 1. Deaf women will have significantly lower baseline general, ovarian and total cancer knowledge scores than hearing women 2. Both deaf and hearing women’s knowledge will increase from pre- to post-intervention 3. Knowledge increases will be equivalent for deaf and hearing women and 4. Deaf women’s post-intervention scores would equal or exceed hearing women’s baseline scores. The findings of this study supported all four hypotheses. However, while deaf women’s general, ovarian and total cancer knowledge scores increased, closing a baseline gap, hearing women’s post-video knowledge had improved to the extent that a new knowledge gap developed. This raises questions related to the complexity of closing the knowledge gap between deaf and hearing peoples' healthcare knowledge and emphasises the need for more research that takes into consideration the wider contextual and social influences of deaf peoples' healthcare understanding and knowledge.

In a corresponding study, Sacks et al. (2013) carried out an evaluation of a testicular cancer educational video using equivalent methods and hypotheses. The results supported three out of four hypotheses, with knowledge increase being greater in hearing men compared to deaf men. A major limitation of both these studies is that a high percentage of participants had reported previous involvement in cancer related education programmes and therefore may have had access to cancer information in ASL in comparison to the average deaf person. However, the findings emphasise that for deaf people to effectively access healthcare information and promotion it needs to be delivered in sign language with visual enhancements. Additionally, in developing and delivering healthcare information the potential language variation, limited healthcare terminology in sign language and the low fund of information that deaf people may hold need to be taken into consideration. Rather than these challenges resulting in deaf people and their language being problematised, these two studies focused on how to enable deaf people to obtain, process and use healthcare information. The findings of these studies suggest that by embracing iconicity and utilising visuals to enhance understanding, there is increased potential for deaf people to understand healthcare information.

Although there are no research studies that explore the full range of health terminology in BSL, anecdotal evidence suggests that, like most other sign languages, a fully developed vocabulary for health terms has not yet been developed (Johnston 2003; Napier et al. 2015). Several authors (Napier et al. 2015; Sterckeman and Dagron 2017) have argued that although there is a limited vocabulary of healthcare terms in sign language, it is possible to communicate everything about health without a standardised bank of terms by taking advantage of one of its fundamental characteristics: iconicity. Brien (1992) describes iconicity as involving a perceivable link between meaning (what is communicated) and form (the way it is communicated). Therefore, in sign language the shape and form of some signs closely resemble what they represent. By visually describing body functions and expressing medical concepts and creatively using iconicity to its full potential, the functioning of the body can be explained in a way that is understood by sign language users. Therefore, it is recognised that interpreters often create vocabulary, in negotiation with the deaf person they are working with, to cover gaps in terminology in specific contexts[28] (Napier et al. 2011; Napier et al. 2015).

The above studies indicate that a more nuanced understanding of how deaf people can be empowered to understand and use healthcare information is needed. Such an approach needs to take into consideration the visual nature of how deaf people construct knowledge, the language diversity in deaf communities and the strengths of BSL, such as iconicity, that may have the potential to empower deaf people to actively participate in decisions about their health and care.

Summary and implications for this research

The studies critiqued in this subsection indicate a lower level of baseline knowledge of certain health conditions in the deaf community in comparison to the general population. Despite the limitations of the studies, there is a wealth of anecdotal evidence (Harmer 1999; Lezzoni et al. 2004; Scheier 2009; BDA 2012a; Barber 2013) supporting findings that deaf peoples' understanding of health-related information is limited. Considering the language dysfluency and lack of access to healthcare in BSL explored earlier in this chapter, this is not a surprise. However, recognising deaf peoples' orientation (visual) and mode of communication (visual-spatial sign language) questions arise as to how healthcare knowledge can be acquired and made meaningful to deaf people. Therefore, rather than measuring knowledge and understanding, future research should ask questions about how deaf people construct their knowledge and understanding. This places a shared responsibility on those on the receiving end of health communication and those responsible for communicating health information. I therefore argue that lack of access to healthcare information is a social practice that relies on shared understanding and effective communication between healthcare professionals and deaf people. More research is needed to develop a deeper understanding of how deaf people can be provided with healthcare information and education using techniques that are enabling and empowering.

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[28] The general language ideology in deaf communities is that deaf people have a level of ownership of sign language and the creation of new signs (Ladd et al. 2003). Therefore, Napier et al. (2015) have highlighted that being sensitive to this ideology, interpreters are likely to distance themselves from the idea that they have input into the way sign language terminology develops and changes over time.

Attitudes, knowledge and awareness amongst healthcare professionals

To provide healthcare that is responsive to diverse populations and cultural needs, Jongen et al. (2018) argued that cultural competence is essential. Research suggests that when healthcare providers lack cultural competence, minority groups, such as deaf communities, are adversely affected (Alizadeh and Chavan 2015). While there is no widely agreed definition of cultural competence, it is thought to include the attitudes and practices of healthcare professionals, services and whole systems (Jongen et al. 2018). Many of the studies (Parise 1999; Gilchrist 2000; Reeves et al. 2003; Steinberg et al. 2006; Witko et al. 2017) discussed in this literature review conclude that the deaf participants most value being able to communicate in their preferred language with someone who is aware of the cultural differences that exist between those who are deaf and those who hear. Knowledge and awareness of BSL and deaf culture are often defined as ‘Deaf Awareness’. While there is no agreed definition of deaf awareness, there are numerous formal and informal deaf awareness training courses that range in their content, delivery and length. The aim of deaf awareness training is to raise awareness and understanding of sign language and alternative perspectives to that of the biomedical model, with the intent of enabling organisations and business to become more accessible for deaf people (Signature 2018). As indicated by the research critiqued above, healthcare professional’s perceptions and knowledge of deafness and sign language heavily influence the decisions made when caring for a deaf person. These can often result in inadequate methods of communication that negatively influence a deaf person’s healthcare experience. Additionally, participants in a number of studies (Parise 1999; Gilchrist 2000; Witko et al. 2017) expressed feeling devalued by comments or behaviours that reflect the biomedical model of deafness. A number of empirical research studies have been carried out to understand the impact that increased knowledge and understanding of deaf peoples’ language and culture could have on healthcare professional’s attitudes and knowledge of deafness.

In a study carried out in the UK, Cooper et al. (2003) examined mental healthcare professionals’ attitudes towards deaf people in relation to their previous contact with deaf people and their knowledge of deafness. To measure participants (n=121) previous contact with deaf people and attitude towards deafness, a questionnaire that had been developed and previously tested by the researchers, was completed by a range of mental healthcare professionals. The questionnaire consisted of a measure designed to assess the amount of contact participants had experienced with people who are deaf, a 22-item attitude measure and 10 multiple choice questions that aimed to assess participants knowledge of deafness. The results of the study indicated no significant relationship between participants' attitude and knowledge scores (*p=0.119*). The researchers claimed that no significant correlation was found between professionals' attitude scores and total amount of contact with deaf people with a lower 'status'. However, a correlation was found between participants' attitude scores and their contact with deaf people of an equal or higher 'status' (*rho=0.25*). A limitation of this study is that the researchers did not provide a definition of 'status'. Additionally, the significance of this correlation is ambiguous as no *p* value is provided. Lastly, participants who had deaf awareness training had a more positive attitude (*p<0.05*) towards deaf people than those who did not.

Hoang et al. (2011) and Gilmore (2019) both carried out research to assess the impact that educational training programmes have on medical students' attitudes towards and knowledge of deafness. Hoang et al. (2011) carried out a comparative study at the University of California, that aimed to test the hypothesis that medical students would demonstrate greater knowledge of deaf culture and deaf patients after completing a Deaf Community Training (DCT) programme. The two-year DCT programme included self-directed reading of literature related to deaf culture, an ASL class and a residential ASL/Deaf culture immersion programme at Gallaudet University during which they engaged with deaf community members and taught health promotion workshops to deaf people. Knowledge of deaf culture and deaf patients was assessed using a survey that comprised of six multiple choice and 28 true-false questions. Participants included university faculty (n=130), DCT medical students (n=22), and non-DCT medical students (n=211). The findings from this study supported the hypothesis that DCT medical students had a significantly higher (*p<0.01*) overall knowledge scores than faculty and non-DCT medical students.

Similarly, Gilmore (2019) carried out a mixed methods study in the UK to evaluate the impact of deaf awareness training on attitudes towards and knowledge of deafness and explored whether such attitudes and knowledge persisted over time. The deaf awareness course ran over 12 weeks and consisted of 17 BSL classes, two taught deaf awareness sessions and one session to develop an online BSL medical dictionary for students. Each of these was developed collaboratively between Action on Hearing Loss staff and medical educators. Using the questionnaire developed by Cooper et al. (2004) participants' (n=29) attitudes were assessed before and after the course, then compared with a control group (n=33). Previous medical students who had completed the course (n=70) also took part. Findings from this study indicated that students who completed the course had significantly higher knowledge scores ($p=0.03$) and more positive attitudes ($p<0.001$) than those in the control group. Additionally, there was no significant difference in either knowledge or attitudes scores in those who had just completed the course and those who had completed it in the past, indicating that knowledge and positive attitudes persisted over time.

The findings of these studies indicate that increased awareness and knowledge of sign language and deaf culture can positively influence healthcare professionals' attitudes towards deafness. Therefore, interventions to increase healthcare professionals' knowledge and understanding of BSL and deaf culture have the potential to influence cultural competence. One of the limitations of the above studies is that while they objectively quantify participants' attitudes and knowledge, these measures do not explore how the attitudes or knowledge translate into practice. Therefore, how this knowledge manifests in the social and interpersonal relationships between deaf people and hearing healthcare professionals remains unknown. Furthermore, Jongen et al. (2018) argued that improving the outcomes of minority groups requires structural changes at organisational level that reinforce and sustain behaviour changes in healthcare professionals. Therefore, a multi-level approach is needed that addresses the attitudes and practices of healthcare professionals, individual services and whole systems. Lastly, these studies focused primarily on doctors and medical students with little attention paid to nursing staff. With nurses making up the majority of the workforce and often providing 24-hour care to patients, it is evident that their attitudes and its influence on their practice will contribute significantly towards deaf peoples' experiences of healthcare.

Summary and implications for this research

To provide healthcare that is responsive to deaf peoples' needs, knowledge and awareness of deaf peoples' language and culture are needed. This section critiqued the small volume of literature that explores the relationship between knowledge of and attitudes towards deaf people and how these might be improved through educational programmes. Two of the studies indicated that educational programmes have the potential to improve healthcare professionals' attitudes and knowledge of deaf people. However, it is unclear how such knowledge translates into practice. Therefore, more research is needed to explore the impact that education about deaf people and BSL can have on healthcare professionals' approach to caring for deaf people. While a number of studies (Hoang et al. 2011; Gilmore et al. 2019) examine the doctor-patient dynamic, there appears to be a dearth of literature concerning deaf people in relation to nursing practice.

Conclusion and implications for this research

This literature review was driven by the question ‘What are deaf peoples’ experiences of healthcare’. In answering this question, I have used the social context (*Chapter Two*) to inform my critique of the empirical research (*Chapter Three*). At this point, I believe it is useful to acknowledge the ways in which the two chapters inter-relate, confront and complement one another.

Due to dominant language ideologies and numerous misunderstandings about sign languages, BSL continues to have a lower language status than spoken English. This has major implications in healthcare as deaf people are often not granted access to services and information in their first language. Additionally, the potential for development of therapeutic relationships is diminished. While there is a lack of empirical research relating to deaf peoples’ experiences of healthcare in general, it is evident from this review that healthcare professionals often fail to recognise deaf peoples’ distinct language preferences and needs presuming they can make meaning out of their healthcare experiences by using spoken and written English. This reflects a systematic prejudice in our society that is linked to notions of audism and phonocentrism. While these outcomes may be unintentional, they are rooted in discriminatory practices and beliefs. This is where deaf peoples’ experiences of healthcare overlap with the main claims of the disability model in that their healthcare disadvantages are socially created and maintained. While such power may be exercised unknowingly, it can disable a deaf person’s authenticity and autonomy. Therefore, deaf people may experience a struggle for equity and social justice.

As a result of social practices in healthcare being heavily influenced by biomedical thinking and dominant language ideologies, potential for errors in diagnosis and lack of compliance with medication and health advice are apparent. Very little general health advice and guidance is available in sign language thus reducing deaf peoples’ ability to take ownership of their healthcare and engage with self-management or preventative self-care. All of the above have the potential to contribute considerably to poorer health outcomes for deaf people in comparison to the general population. Access to BSL/English interpreters is crucial to enabling deaf people to have a positive experience of healthcare. However, as discussed in *Chapter Two* there is anecdotal evidence of widespread failure to provide interpreters in Scotland. While the significance of BSL/English interpreters must be recognised in healthcare settings, it was evident that full access to healthcare should not be simply equate with provision of a BSL/English interpreter. A more nuanced understanding of how deaf people experience the healthcare environment and relationships should inform notions of access.

In common approaches to empirical research, deaf peoples' knowledge and experiences of health and healthcare are often measured according to prescribed norms. For example, lack of medical signs and poor functional literacy were highlighted as problems for deaf communities. From the biomedical perspective, deafness as a characteristic is the reason deaf people face such challenges. Therefore, the problem lies in sign languages and deaf people rather than the social relations and language ideologies evident in these claims. Therefore, it is evident that in empirical research, deaf people are often being measured against hearing norms of spoken/written language and a primarily auditory-oral understanding of the world. Alternatively, by taking into consideration how understanding takes shape visually and through BSL for a deaf person, their experiences of healthcare may be understood differently.

The literature critiqued above emphasises that to create the knowledge base that is needed to inform healthcare for deaf people, a shift in research agendas in needed. Knowledge based only on empirical, objective research findings stripped of context is problematic. While the empirical research critiqued above must not be discarded, evidence regarding contextual influences gained through the theoretical literature adds depth and breadth to existing knowledge and provides insights regarding root causes underlying inequities in healthcare. Such knowledge is key to attending to the social, historical and political contexts of health and are key to disrupting dominant perspectives, such as the biomedical model of deafness.

This literature review attempted to answer the question 'What are deaf peoples' experiences of healthcare?'. It is evident from this literature review that current healthcare practices are not meeting the needs of deaf people. Therefore, this literature review has somewhat answered this question. However, returning to Temple and Young's (2014) argument, that much of the social sciences research continues to maintain a focus on deaf peoples' need for access to services yet does not elaborate on the interactions between service providers and users, I believe it is necessary to explore the social world (context and relations) in which the care of deaf people takes place. While I argue that understanding the challenges deaf people experience when trying to access healthcare services is crucial for service planning, there is a gap in which more in-depth knowledge about the interactions that take place in these services are needed. Such understanding has the potential to inform and implement changes to practice that could improve access to healthcare for deaf people. By situating the potential challenges experienced by deaf people in the social domain, the role nurses play in addressing these experiences becomes clear.

Understanding nursing as a relational practice, in which relationship forms the foundation for caring, I am curious about how the differing perspectives explored throughout this literature review manifest through interpersonal and social interaction. Due to the gap in knowledge regarding the experiences of deaf people interacting with nurses within Scotland, the purpose of the proposed study is exploratory. I propose to address the following questions:

1. What are the experiences of deaf people who have interacted and received care from nurses?
2. What are the experiences of nurses who have interacted and provided care for a deaf person(s)?

The objectives formulated from these questions are as follows:

1. To explore the perceptions that deaf people hold of their interactions with nurses
2. To explore the meanings that interactions with nurses hold for deaf people
3. To explore the perceptions that nurses hold of their interactions with deaf people
4. To explore nurses' values and beliefs about caring for deaf people

While I recognise that the role of the interpreter may appear invisible in the research questions and objectives, they will be written into the story of this research. In the next chapter, I will set out in detail the philosophical perspectives that underpin the research and set the direction for how I will answer the research questions and the type of knowledge that I will generate. These philosophical underpinnings have been informed by the literature.

Chapter 4: Philosophy

Introduction

In *Chapter One*, I told the story of my inspiration for undertaking my research and preparing this thesis. In *Chapter Two* and *Three*, I positioned the study in the literature relating to deaf communities and healthcare research. In this chapter, I will set out my research framework, my philosophical foundations and the principles for my research. I will explore how this research paradigm is reflective of my ontology and enables me to find a theoretical 'home' which provides a focus or perspective from which to answer my research question. This chapter therefore outlines the philosophical underpinnings of the study.

Philosophy is about the study of the fundamental nature of knowledge, reality, and existence, and can be drawn on to understand the essence of experience and being (Heidegger 1996). Philosophical origins underpin and therefore inform how we live (our being) and practice (our doing). This has an impact on how we frame and practice research. The philosophical underpinnings for this study have been developed based on an exploration of personhood, my own values and beliefs, and a range of different philosophical perspectives that I could draw from to inform my thinking. Critical creativity[29] is a paradigmatic synthesis that assumes neither the interpretive paradigm nor critical paradigm alone are sufficient to develop an understanding of ontology (McCormack and Titchen 2006). Therefore, the underpinnings of this study blend assumptions from the interpretive and critical paradigm and are strongly influenced by the philosophical perspectives of Merleau-Ponty (2012) and O'Donohue (2000). The values and beliefs that support the philosophical underpinnings for the thesis have developed over time through my life experiences. By developing coherent philosophical foundations, I articulate the assumptions underpinning my chosen research methodology, design and practice. The intent is to provide ontological and epistemological authenticity[30] (Higgs & Titchen 2007) and to ensure rigour. In doing so, this research is more likely to develop meaningful, new knowledge (McCormack et al. 2017).

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[29] The concept of critical creativity will be explored further in *Chapter Four.*

[30] Authenticity is a Heideggerian concept concerned with focusing on knowing and attending to our everyday ways-of-being in order to see our true self and our unique potential (Heidegger 1996).

In search of my philosophical underpinnings

The research questions for this study have been developed based on a literature review that explored the limited amount of literature related to the healthcare experiences of people who are deaf, both in the UK and further afield. While exploring the literature related to the interaction between healthcare professionals and deaf people, I found that there was ample literature suggesting that communication is poor. Concepts that emerged from my review of literature included oppression and power, reflecting the injustice articulated by deaf people, their families and those who work with them. Initially, these themes drew me towards Paulo Freire's (2017) philosophy of critical pedagogy where the basic premise points to a theory of justice.

Freire (2017) devoted his life to an emancipatory ideal involving a personal commitment to the elimination of suffering and oppression, and the realisation of a more just society. Freire (2017) claimed that people who are oppressed should be given autonomy to decide for themselves what transformation should look like. Believing that people are essentially communicative, Freire (2017) valued purposeful dialogue that enables people who are oppressed to challenge and reform oppressing socio-political structures. Although I can wholeheartedly align with the belief that persons are essentially communicative, my time spent with Freire's (2017) philosophy triggered questions about whether his philosophy limited the potential for meaningful relationship by creating dualistic perspectives of 'us' and 'them'. This 'us against them' mentality often seen in liberation movements can yield questions and answers that fail to reflect our interrelatedness (Buber 2009) as human beings. Therefore, by focusing on the concept of liberation and oppression, I believe questions are asked that are limiting and that do not provide useful, action-orientated answers. The Japanese word 'Mu' is relevant here (Pirsig 1999). Mu means 'no thing' and points outside the process of dualistic discrimination. It states that the context of the question is such that a yes or no answer is inaccurate and should not be given. It says "unask the question". Mu becomes appropriate when the context of the question becomes too small for the truth of the answer. My critique of Freire's arguments guided my search for a philosopher who placed emphasis on *who* we are and *how* we are to be together. Therefore, I searched for a philosophy that would help persons to move towards a human encounter and to generate a fuller, multiple understanding of reality.

It was through the gaps and criticisms of Freire's (2017) philosophy that I became aware of my strong belief that persons are embodied beings. Freire (2017) adopted a Cartesian worldview arguing that dialogue and understanding are primarily cognitive.

From my experience of learning BSL and my practice of yoga and massage therapy, I believe understanding to be more tactile and dynamic. I was intuitively drawn to the work of Merleau-Ponty (2012) who emphasised the grounding of our experience in our bodies, believing our body is the infrastructure through which we experience and act on the world. I believe that these concepts can open up a conversational space about who we are, while embracing the metaphor “dancing with beauty rather than fighting ugliness” (Marshal and Reason 2008, p.4). This would move us into a ‘Mu’ space in which the exploration is focused on mutuality and understanding as opposed to oppression and difference. Pirsig (1999) emphasises that it is *mu* answers that enable growth as our understanding of a concept expands and enlarges.

The nature of being

Ontology is our view of reality and ‘being’ which forms the basis from which researchers begin to imagine or construct a theoretical standpoint (Dewing et al. 2017). Ontological assumptions inform epistemological assumptions which in turn can be seen to inform methodology and the subsequent knowledge developed. Examining human nature and what we believe it means to be a person is part of ontology as it informs our understanding of human motivations for social action (Smith 2003). The focus of inquiry into ‘what is a person’ is age old with a number of diverse viewpoints. Such philosophical standpoints are not static but are constantly evolving and growing as we engage with one another and with the world. For many philosophers this inquiry is a lifelong commitment and never ends. My explorations of what it is to be a person has not resolved all differences in arguments but has in fact resulted, at times, in “deeper levels of confusion” (Smith 2003, p.4). However, it is through the process of trying to understand each other as persons that we conceptualise the world (Scruton 2017). Despite our assumptions regarding personhood often lying hidden, they are powerfully present. Stetsenko (2012) relates this to a deep ocean current that, though invisible, inevitably affects the surface waters and ultimately defines its course. Similarly, our beliefs about personhood shape our worlds. Therefore, it is important to lay down my ontological thinking at this point in the research process. With so many different philosophers to grapple with, I have chosen those that have felt meaningful to me and closely align with my own worldview. Throughout this process, I have continued to return to the research topic and questions ensuring an interplay between my knowledge of the topic, ontology and epistemology. In the next section, I will lay out what this exploration has taught me and articulate how it has enhanced my thinking. Having this philosophical knowledge can enable the development of a rigorous research methodology and research in practice that is driven by values (Dewing et al. 2017).

What is a person?

There are multiple philosophical perspectives that can help answer the question 'what is a person?'. Many variations of these questions help us to cross-examine what we value, believe and think a person to be. The concept of personhood has its roots in Latin philosophy. The Greek *prosopon* means 'visage', 'face' or 'mask' and the Latin, *persona* is thought to come from *per sonare*, the mask through which actors spoke. Cassel (1982) describes the different facets of a person as having a past, having cultural background, roles, relationships with 'others', being political, doing things including action and creation, engaging in regular behaviours, having a physical body, a secret life, an inner world, a perceived future and a transcendent or spiritual dimension. Torchia (2008) takes a different approach suggesting that we must answer the question 'What is a person' in two parts. The central question being *What does it mean to be a person?* And a more basic question *What does it mean to be fully human?* These questions can and have been approached from diverse standpoints including the scientific, religious and philosophical. These standpoints may appear as dichotomies when we look at them academically, with each criticising weakness in the other. However, in our everyday lives the distinctions between these different standpoints are often blurred with each affirming the other. Regardless of perspective, emphasis must be placed on the uniqueness of the human species and the value of the person because through questioning the nature of personhood, we find answers that shape us, our values and the meaning we attach to life. Therefore, I share with you the dialogue that I have engaged in to answer the question 'what is a person?'

The primacy of the mind

Since the time of Aristotle, philosophers have been concerned with setting human beings apart from other animals. As I stated in *Chapter One*, I hold an ecological worldview, believing all organisms are interrelated. Therefore, as Scruton (2017) argues, I believe that we are all animals, with a biology and we are all part of the natural world. Additionally, I believe that all animal species are unique. However, in my research, my concern is not whether non-humans should be considered persons, but that all humans are considered persons with intrinsic worth. I therefore decided that I did not need to consider moral or ethical debates that are associated with discussion about hierarchies of attributes, for example Smith 2003; McCormack and McCance 2010. Alternatively, it was important for me to explore the idea of 'human nature', thinking instead about the ways in which we experience and live in the world.

Defining the nature of human beings is a controversial topic in philosophy. Descartes famously asked the question “But what, then am I?” setting the stage for a philosophical debate that continues to this day. Descartes (1665, p.109) answer to his own question “A thing that thinks. What is that? A thing that doubts, understands, affirms, denies, wills, refuses and which also imagines and senses”. This began the Cartesian dualist argument. Descartes argued the immaterial mind and the material body are separate and that to be human was to have certain ‘states of consciousness’. Mental states and states of the body are therefore ontologically distinct but causally interrelated. The primacy of the mind, based on Cartesian philosophy has underpinned values in the West for many years. This dichotomy of mind/body has focused attention on the cognitive capacities that human beings have and has given little attention to how the body might contribute to experience and meaning. This perspective of human nature therefore argues that ontologically and epistemologically, human beings engage with and understand the world primarily in a cognitive way. This standpoint has endured over time and underpins many of the assumptions that our understanding of human health and wellbeing is based on. This is evident in the separation of hospitals for ‘mental’ health and ‘physical’ health (Sullivan 1986; Stewart 2015; Gendle 2016) and sensory therapies being viewed as ‘complementary’ (Howes and Classen 2014). Torchia (2008) argues that from this view, what is essentially human is restricted to the mind, with personhood also being rooted here.

Based on Heidegger’s (1996) notion of *Dasein* (being), Merleau-Ponty criticised Descartes’ philosophical stance by identifying a failure to account for the grounding of our experience in our bodies. Merleau-Ponty (2012) believed that our body is our infrastructure through which we experience and act on the world (Wilde 1999). What we call ‘mind’ can only exist because we have bodies. His understanding of the body as a subject, rather than object of perceptions, seeks to overcome the limitations of a metaphysical mind/body dualism (Johnson 1999). From this perspective, an understanding of personhood must incorporate awareness of the embodied nature of human beings. In contrasting Descartes and Merleau-Ponty’s philosophies we move from a dualistic claim of disembodied reason (I think, therefore I am) to one where reason is enclosed by embodied form (I can only think because of what I am). My thoughts will be guided by Merleau-Ponty’s (2012) work.

Embodiment

The notion of embodiment is derived from the Heideggerian concept ‘person as embodied’ used in phenomenological philosophy (Heidegger 1996). Heidegger highlighted that when thinking about human beings we must consider their being an existent in a world. In the phenomenological sense, *world* has a different meaning from our common understanding of world as environment or nature. *World* relates to the relationships, practices and language that we have by virtue of being born into a culture (Benner 1994). Heidegger (1996) used the concept of *Dasein*, which translates as ‘Being-there’, and ‘there’ is the world. Heidegger was concerned that philosophy should be capable of telling us the meaning of Being, of where and what *Dasein* is. However, Heidegger’s (1996) philosophy has been critiqued for neglecting the question of the body (Aho 2009). Merleau-Ponty’s work has been the most influential critique of Heidegger’s work. Merleau-Ponty (2012) claimed that Heidegger made little acknowledgement of the “lived body” (Husserl 1952, cited in Moran 2013, p.294) that pre-reflectively negotiates its way through the world. Merleau-Ponty (2012) believed that it is through our bodies that we experience the world. He argued that our bodies are not merely the tangible material that you can see, smell and touch, nor even the internal organs that can be measured, weighed and monitored. He therefore rejected the notion of an objective body and emphasised that we are lived bodies.

As a lived body, embodied nature forms my perception of the world. The body is the general instrument of my comprehension (Merleau-Ponty 2012). However, Merleau-Ponty emphasised that an embodied nature is not the confinement of my perception in a body. Rather, in perceiving, I am intertwined and rooted in the world. Consequently, there is no ontological separation between experiencing “I” and the body as one lives it. Body and world, like past and present are interwoven, and the body is caught up in the “woven fabric” of the world (Merleau-Ponty 1996, p.166). The world both constitutes and is constituted by us. Merleau-Ponty (2012) argued that we see unification with the world in our everyday lives. He used the example of the blind man and his white cane to show the blurring of man and object. For the blind man the cane becomes an extension of his own body that enables orientation to the world. It becomes part of his bodily experiences and abilities. The blind man and his cane become *gestalt*. Gestalt is defined as an organised whole that is perceived as more than the sum of its parts (Oxford Dictionary 2019a). Merleau-Ponty was influenced by gestalt theorists believing that we are in a constant flow of relation to the world that is ever changing. This relation is the “in-between”.

Writing about the primacy of our sensual interplay with and in our world, Merleau-Ponty (2012) examined the paradox of objectivity and subjectivity in a space where we are both seer and seen, viewer and viewed, toucher and touched. From this perspective, meaning is not generated at an interpretive distance or disembodied consciousness but rather created through one's direct bodily engagement with the world, bringing about a personal relation to it (Carman 2008). The body is therefore to be understood as the locus of our being-in-the-world, not merely in space, or in time, but inhabiting space and time. This concept challenges the assumption that personhood is static, emphasizing that we perceive the world in movement as we actively sense it. Therefore, the nature of our being is dynamic, a state in the here and now but also has the potential to change and evolve (Rogers 1980; Maslow 1987; Heron 1992). Personhood is therefore a way of *becoming*, not just a way of *being* (Scruton 2017).

By challenging the notion that personhood is a fixed status or set of criteria emphasis is placed on persons as relational. Merleau-Ponty (2012) characterises a person's relationship with the world as an entirely bodily relation to the environment emphasizing that every perception is communication. This relationship of meaning is co-formed. Abram (1990, p.10) wrote that Merleau-Ponty developed "an awareness of perception as radical participation". From this perspective, perception as a bodily experience is essentially finite and perspectival. My body is "my point of view upon the world" (Merleau-Ponty 1996, p.70), anchored in the structures and the capacities of the body. I can perceive the world, only because I inhabit it and interact with it. Our being-in-the-world is the starting point for all knowledge. Reflective thought therefore, can only develop because of my being-in-the-world and entering into dialogue with it. Our body therefore provides a perceptual 'field' (Husserl 1978) in which our being-in-the-world shapes and structures our experience (Carman 2008).

Without being able to observe or know the world from an interpretive distance, I cannot ever fully grasp the world. All that is visible and the tangible are not, therefore, the world in its wholeness (Merleau-Ponty 2012) but rather a certain field that is limited to what I am sensing in a given moment. Beyond this is a horizon of things, which I do not yet have access to. There is always more to that which appears obvious or in the grasp of my perceived life. Nan Shepherd (2007, p.108) expressed this notion in her celebration of exploring the Scottish Highlands stating, "the thing to be known grows with the knowing". Merleau-Ponty suggests that although the world far exceeds my grasp, I will always find meaning in the world. Smith (2003) reiterates this point emphasizing that we are all meaning making beings whose beliefs about the world are anchored in how we are able to perceive it. Although our perceptions and assumptions about the world cannot be empirically verified, they are real and true to us in that particular moment. Perception then is not where I come to know the world concretely but rather where what I know of the world comes to be questioned and expands. Merleau-Ponty believed that perception never exhausts the world, stating "nothing is more difficult than knowing precisely what we see" (Merleau-Ponty 1962, cited in Carman 2008, p.65). Perception is therefore not an unquestioned belief in an empirical world but rather an attendance to the appearance of the world by the person who is situated in the world temporally and spatially (McLevey 2016). The perspectival character of our opening onto the world is not expressed by Merleau-Ponty as a limitation of our access but rather the very condition of the world's disclosure in its inexhaustibility. This notion connects with the principle of embracing the known and yet to be known of critical creativity that enables human flourishing (McCormack and Titchen 2014).

The Co-Existence of the Senses

For Merleau-Ponty (2012) perceptual meaning is rooted in bodily movement. Therefore, bodily movement is itself laden with meaning and intentionality and that intentionality and meaning lie in movement. Bodily movement is the sensuous rhythm of existence. For Merleau-Ponty (2012) sensations provide an understanding of the perception as a process that unfolds beyond the operations of individual sense structures. Sensations for Merleau-Ponty (2012) are the 'unit of experience'. Opposing the idea that our five senses exist in isolation from one another, Merleau-Ponty believes them to co-exist with one another. Co-existence here refers to the way that the senses engage and act together. It is commonly assumed that each sense has its own sphere. For example, sight is concerned with colour, hearing with sound and taste with flavor. However, neuroscientists now have a more interactive and relational understanding of how the senses function (Howes 2006). Calvert et al. (2004) believe that to fully appreciate the processes underlying our sensory perception, we must understand our sensory pathways. The senses in perceiving objects in the world are not separate but overlap and transgress one another's boundaries. Merleau-Ponty draws from the concept of synesthesia[31], stating that there is "a sense in saying that I see sounds or hear colours" (1996, p.234). Such a thing is possible for Merleau-Ponty because for him the content of perception is 'existential' in a sense that we have still not exhausted (Baldwin 2007). Evelyn Glennie (2003), a deaf percussionist also challenges the conventional understanding of the senses describing her experience of playing music; "I hear through my hands, through my arms, cheekbones, my scalp, my tummy, my chest, my legs and so on". Glennie "listens" to the sound of the instruments by opening up her body and feeling the

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[31] Synaesthesia comes from the Greek *syn*, union and *aesthesis*, sensation. It therefore denotes a union of the senses and refers to the capacity to hear colours, taste shapes or experience other sensory fusions (Cytowic 2002).

vibrations coming through. Her connection to the music does not depend on the ear. She describes our different experiences of music as “our own little sound colors”. “Sound” in this situation can be defined as a vibration through a material medium (Friedner and Helmreich 2012). This raises questions as to how we understand and define the senses and whether we limit their capacity by categorising them neatly. Sound is therefore multimodal and can be experienced by sensory domains beyond the ear (Mills 2015).

Similarly, Merleau-Ponty (2012) believed that we engage in a holistic dialogue with the world through our senses. Therefore, the unity of the senses addresses sensuous relationships that are not confined to the inside of the thematic body. To co-exist is not to exist simply at the same time but to live in contact. Therefore, the senses are not isolated organs but are parts of a more systematic whole that is the existence of the embodied perceiver. We perceive in wholes, not in solitary sensations. The perceiver is situated, perceptually rooted and in touch (literally) with the world. The body therefore has the capacity to relate to things and others outside of itself and is in a constant relationship with the world through senses that move in-between and across the supposed boundary of the inside and the outside of the body. Perception is not something that happens inside of us but that unfolds as we come into contact, perceive and are perceived in relation with the world.

McLevey (2016) suggests that Merleau-Pontys writing about the senses helps us to generate questions about how perceivers literally co-exist with one another. How does space and time impose upon a perceiver in a particular manner of perceiving? In what way might a physical space open up perceptual possibilities for some bodies and close down possibilities for others? Can we pursue spaces that open out ways of being, as opposed to a space which is designed for a single way of being-in-the-world? I will return to these questions in *Chapter Eight*. Rather than reducing perception to a set of operations or functions, Merleau-Ponty’s (2012) philosophy asks questions about the perceiver’s lived-through-word and what navigating that world will look/feel like for each perceiver. It is easy for us to describe things which can be measured and calculated. How we relate to aspects of our world which are sensed and felt is more difficult to describe. Often the nature of our relation to these things changes over time. For example, the atmosphere of a space. Van Manen (2007) suggests that if we were to gain intellectual control over embodied knowledge, we might in fact hinder our ability to do the things we are doing because we are shifting from prereflexive to reflexive mode. However, O’Donohue (2011), emphasises that we can practice the art of attending to the inner rhythm of our lives. Therefore, engaging with and listening to the body, prior to reflection, is the way that we choose our actions in the world and if we were to translate all of our being-in-the-world to language and cognition it would lose the beauty, value and spontaneity.

Habit

As I have explored, Merleau-Ponty (2012) presents a relational ontology, in which being is fundamentally embodied. This has implications for how knowledge is created, acquired and communicated (epistemology). Ultimately, Merleau-Ponty's (2012) epistemology demonstrates that knowledge can manifest itself in and through the body. Polanyi (1969) believed that although tacit knowledge cannot be clearly articulated, we can see it emerging in action when the body knows what to do without deliberation. Others (Titchen and McCormack 2010; Senge et al. 2011) have argued that such knowledge can be captured for a moment in time (contextually) so that we can gain a sense of what is happening 'in real life'. Such understanding may only last for a moment until the next fusion of horizons emerges. Merleau-Ponty (2012) believed that the body creates, maintains and expresses such knowledge through habits. Merleau-Ponty (2012) refers to habit as body memory which is not a recollection or consciousness of the past but a continual reopening of the past as our medium of communication. Because our bodies "remember" more readily than our minds, habit is more than just familiar movement and is not derived from a technique that is rigid and calculated. Rather, it is a flexible and improvised bodily action in which we move intuitively and pre-reflectively (Carman 2008). Gallagher and Zahavi (2008, p.156) characterise habit as being "in rapport with the circumstances that are bodily meaningful". Thus, body memory conveys the familiarity with recurrent typical situations and enables skilled interactions with the environment. However, body memory is more than our body's knack for recalling old, repeated tasks. Where this type of explicit recollection is directed to the past, body memory re-enacts the past through the body's present action.

Crossley (2001, p.123) elaborates on Merleau-Ponty's notion, stating a habit is "an incorporated bodily know-how and practical sense; a perspectival grasp upon the world from the 'point of view' of the body". Similarly, Van Manen (2007, p.20) writes:

> "the act of practice depends on the sense and sensuality of the body, personal presence, relational perceptiveness, tact for knowing what to say and do in contingent situation, thoughtful routines and practices, and other aspects of knowledge that are part pre-reflective, pre-theoretic, pre-linguistic"

Such understanding is not cognitive in the traditional sense, it is sensed rather than thought (Gendlin 1979). These modes of knowing exist essentially in our bodies and relations (Van Manen 1998). Therefore, knowledge manifests itself in action. We can discover what we know in how we act and in what we can do in our relations with others and in our embodied being. Habits are, therefore, practices of the body's knowledge rather than knowledge itself (Hamington 2004). Schön's (1983) notion of artistry is relevant as he believes that we exhibit our knowing in our actions, calling this 'knowing-in-action'. He argues that such habits are not reducible to the exercise of describable, testable or replicable routines. Consequently, there are no universal principles for the art of being and paying attention to your senses. From this perspective, we should not conceive the body as static, with fixed skills and abilities but embrace the body's ability to creativity and intuitively draw from its repertoire of skills and habits (Leder 1990).

Tacit knowledge

Embodied, sensuous perception is a fundamental level of existence that places emphasis on the embodied nature of knowing and meaning making. Polanyi (1969) believes that from an embodiment standpoint all knowledge is either explicitly tacit or rooted in tacit knowledge. The word tacit originates from the Latin *tacitus* meaning to be silent, wordless or noiseless (Zappavigna 2013). After a long analysis of how embodied perception gives us access to the world, Merleau-Ponty (cited in Mazi 2016, p.7) states in Phenomenology of Perception that "what is here required is silence". Building upon this idea in his essays on aesthetics, Merleau-Ponty equates silence with true perception. The silence Merleau-Ponty (2012) refers to is a kind of stillness of dwelling in the body's senses. Therefore, rather than understanding silence in terms of binary opposition to sound, he relates to what Dauenhauer (1980) calls deep silence. This silence requires an openness of encounter with the world. Dauenhauer claims that deep silence is intimately related to tact, and he quotes Gadamer in support of this insight, that "an essential part of tact is in explicitness and inexpressibility" (p.20). Therefore, silence is not a nothingness but a phenomenon in itself (Bindeman 2017), an engagement that the body has with the space it inhabits. This engagement opens access to all the living relationships of experience (Merleau-Ponty 2012). True meaning is found in such engagement, when we pause and inhabit the silence that permeates the world (Mazis 2016). This relates to the principles of critical creativity 'movement in stillness' in which the stillness of reflection creates movement that enables future meaning, understanding and action to occur (McCormack and Titchen 2010). This principle is rooted in claims from ancient traditions across the world that believe reflective spaces and regular silence to quiet the mind, allows understanding and truths to emerge from deeper places within ourselves (Kagge 2017).

Silence is, therefore, how we come to explore our own understanding of the world. "Our view of man will remain superficial so long as we fail to go back to that origin [of silence], so long as we fail to find, beneath the chatter of words, the primordial silence" (Merleau-Ponty 2012, p.214). Subsequently, our knowing is ordinarily tacit, implicit in our patterns of action and in our sense for the things with which we are experiencing. 'Knowledge of' relates to being present in our bodies (Smith 2016). Kagge (2017) believes that we frequently busy ourselves with noise for fear of getting to know others and ourselves better. Similarly, Snowber (2016) argues that we are better at human *doing* than human *being*. O'Donohue (2008) subsequently encourages a mindful mode of stillness, solitude and silence in which we attend to our bodily senses. It is this "art of inwardness" (O'Donohue 2008) that Merleau-Ponty (1964) believes gives us access to our silent, tacit comprehension of the world. Schön (1983) highlights this silent knowing and being as an element of artistry in our navigation of the world. Mazis (2016) emphasises that whether this is a moment of philosophical enquiry or of personal existence, it is a moment easily passed by. Until we embrace silence, we cannot truly encounter our bodies as the pathway to meaning (Mazi 2016).

Spirituality

There is undoubtedly a spiritual element to Merleau-Ponty's writing. Although there is no agreed definition of spirituality, it is often characterised as open-ended and ambiguous in nature (Tsiris 2018). Etymologically, the term spirit comes from the Latin *spiritus* meaning breath (Stevenson 2010, p.1720). Snowber (2016) believed spirituality to be the practice of solitude, which connects to the attentiveness of the body. Therefore, spirituality consists of concerns that belong to the human condition, including; "our relations to others, identity, inquiry into nature, morality and the quest for the truth in knowledge" (Muldoon and Kind 1995, p.333). It is, therefore, ecological and holistic in nature. As I have explored already, Merleau-Ponty (2012) places emphasis on perception as the basis for all knowledge and the body as the basis for all perception. He holds perception as the key to the interplay between us and our relations to others and the world. Merleau-Ponty (2012) describes the nature of being and the origins of knowledge as ambiguous. The world remains inexhaustible. By 'ambiguous' Merleau-Ponty does not intend to convey a sense of vagueness or deception but rather an openness. Our being and becoming involves opening up to the world. In this unfolding, there is always room for multiple interpretations; the world is fundamentally open to us, as we are open to the world.

For Merleau-Ponty (2012), perception is a dialectical relationship between the world and us. It is what makes the world appear to us, and at the same time that which reveals to us that we are in the world:

> “by thus remaking contact with the body and with the world, we shall also rediscover our self, since, perceiving as we do with our body, the body is a natural self and, and as it were, the subject of perception” (Merleau-Ponty 2012, p.239).

Merleau-Ponty thus believes that our perception orientates us and provides us with a sense of belonging or groundedness. This arises in the inseparable relationship between our bodies and the world. O’Donohue (2000) explores this interwoven nature of our experience of self with the world, believing that we find belonging in our engagement with the world. Belonging is not static or fixed to a person or place but is a sense of “the heart and warmth of intimacy” (2000, p.3). O’Donohue (2000) does not characterise this spiritual relation with others and the world as beyond the body but anchors it in bodily experience. “All belonging is an extension of the first and closest belonging of living in your own body. The body is the home which shelters you. All other forms of belonging continue the first belonging” (O’Donohue 2000, p.72). Many new spiritualties, derived from ancient eastern and earth-based traditions, are embracing a renewed respect for the intelligence of embodiment. Yoga, mindfulness and reiki all seek wisdom from what we know through our bodies and grounding ourselves physically, mentally and spiritually. O’Donohue (2000, p.145) borrows the concept of “dwelling” from Heidegger, to express our nature of home and belonging as existential. Belonging is characterised as relational and continually co-created. It has a past, present and future and is understood in the stories we live and share.

Stories

Merleau-Ponty’s philosophy of embodiment emphasises that we can only ever come to understanding others and ourselves by how our bodies respond and react to them. Sensual knowledge and experience of the world come before intellectual and conscious knowledge of the world. We engage through our bodies pre-reflectively and then reflexively. We experience the world directly, and then we experience the world in relation to ourselves. Stories are our reflective expressions situated upon our pre-reflective embodied comprehension of the world (Merleau-Ponty 1964). Storytelling is a means by which we continually gain a sense of understanding oneself in the world (Gadamer 2013). Merleau-Ponty (1964) emphasised that my body is an awareness of the gaze of the other. We fundamentally understand what reality is, who we are, and how we ought to live by locating ourselves in the larger narratives and metanarratives that we hear and tell (Bruner 1990; Ricoeur 1984). Therefore, storytelling provides a way of framing our position, identity and relationships and articulating what it is we perceive (Bruner 1990). Buber (2009) understood story to be a medium in which various existential themes of life – belonging, companionship, sense of home, love could be woven and shared from person to person. Stories (lived and shared) convey both the uniqueness of individual experiencing and the connectedness of all living things (Gunzburg 1997).

Meretoja (2018) emphasises that storytelling is an interpretive practice that does not unveil deep meanings but is an endless activity of (re)orientation, engagement and sense-making. Similarly, Benner (1994, p.116) believes that we engage in "cycles of understanding, interpretation, and critique", viewing all interpretations as complete but never ending. These interpretative practices not only represent the world but take part in performatively shaping it. Exploring storytelling as an activity of organising experiences has a bearing on our sense of who we are (being) and who we could be (becoming) (Meretoja 2018). Ricoeur (1984) also highlighted that no interpretation is exhaustive, and our interpretative relationship to the world involves ongoing engagement.

Shaped by culture

Merleau-Pontys description of the body has a rather mystical essence. He creates a sense of awe at what the body can do, rendering its movement as irreducibly meaningful. This highlights our expressive capacities as emerging in and through relationship. It suggests that our movement and expressions are not fully calculated. However, his writing fails to account for how the body does what it does and how we might be able to expand its capacities and repertoires. This leaves much unexplained. Additionally, Sullivan (2001) criticised Merleau-Ponty for not highlighting that the body both shapes and is shaped by culture and society in complex ways. It is assumed that our common practices are based on shared embodied perceptual capacities (Benner 1985). However, Merleau-Ponty's (2012) understanding of the body's centrality to social life did not touch on how our repertoire of bodily knowledge is culturally tinted. Our understanding of embodiment exists both in (internal) and outside (external) of us. The external understanding of the body that surrounds us is created through culture and society. This is the larger meaning of embodiment. This view of embodiment is lived in the story (master narrative) of society. Therefore, we draw our knowledge of the body from the total sphere of our experiences and social world of relationships. Additionally, the body has long been a metaphor for home, often marking narratives of the self. To have a sense of self is to have a sense of one's location as a person (Harré 1983). Rather than our sense of self being ascribed to us, it is actively negotiated by our histories, cultures and social interactions.

The relationship between body and self, as well as the meaning and definition of the body have changed greatly over the course of history, expressing religious and political beliefs along the way. These beliefs impose themselves on the realities of persons, and project themselves onto what have been thought of as the body politic (Metzger-Traber 2018). Symbolic interactionism[32] explores these concepts from three core principles. The first is that a person acts towards things on the basis of the meaning that the things have for them. Secondly, the meaning of such things arises out of the social interaction that a person has with others. Lastly, these meanings are handled and filtered through an interpretive process (Blumer 1986). Therefore, body, self and social interaction are interrelated. Mead (1934), a symbolic interactionist, believed that we develop our mind and sense of self through the use of language and the playing of roles. Role-playing involves the ability to take on the role of the other, place ourselves in their position in an attempt to comprehend their intentions and actions. By finding meaning in and being aware of peoples' intentions and actions, we determine how we will act with them. Through such awareness, Mead (1934) believed that peoples' actions are altered and that their identities may also be altered as they become different others-to-others.

Similarly, Sabat's (2002) theory maintains that we have different forms of self which emerge through differing contexts and social situations. These include: 1. The self of personal identity, 2. The self of our physical and mental attributes and 3. Social personas that are constructed in different situations. These three selves require acknowledgement and co-operation to maintain some cohesiveness of self (Sabat and Harré 1992). Sabat and Collins (1999) discuss the strength and fragility of each sense of self in terms of the interaction of others causing damage to selfhood. Self-three they argue is constructed, nurtured or changed through interactions with others and is more vulnerable to damage from culture and society than Self one and two. Individuals therefore depend on the affirmation and cooperation of others to co-construct and support a valued social persona.

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[32] Based on the work of Mead and Blumer, symbolic interactionism is concerned with human behaviour, how people perceive others and the nature of peoples' actions in the social world (Blumer 1986; Mead 1934). Central to symbolic interactionism is the belief that what a person says and how they interact, is a consequence of a learned social world, which can be communicated through common systems of symbols such as language and gesture that hold significance and meaning (Blumer 1986).

Loss of self and loss of personhood are concepts not directly linked to a human being's condition but to the behaviours and reactions to being-in-the-world of other persons. Loss of self can occur when people conceptualise or treat us in the way that others us (Goffman 1963). Salzberg (2002) highlights the destructive nature of viewing persons as other creating disconnections between persons. Labels can strongly influence the way a person is experienced and experience themselves. For example, our pre-understanding of terms such as 'dementia', 'autism' or 'deaf' can heavily influence our connection with others and hinder the emergence of connection. Buber (2009), who was heavily influenced by Hasidic Judaism[33] and especially the Hebrew bible, produced a philosophy of dialogue that has the encounter of one person with another as its core feature. Buber (2009) believed that to *be* is to *be in relation with others.* No isolated I exists apart from in relationship to an other. Buber argues that there are fundamentally two potential forms of relation: the 'I-Thou' and the 'I-It'. Buber (2009) labelled an 'I-Thou' way of being which identified the essence of relationship as relating to the uniqueness of the other. Buber (2009) characterised this relationship by mutuality, directness, being present and openness. Therefore, a relation to the other involves approaching and learning from the other, without intending to dominate or project one's own beliefs and values onto the other.

The key to Buber's (2009) concept is not the 'I and Thou' but the hyphenated 'I-Thou'. The significance of the hyphen is what Buber (2009) termed *Dazwischen* 'there in-between'. The fundamental principle in Buber's writing is found in the ontology of 'there in-between' in which the self is located in relationships. Buber (2009) illustrated that through interpersonal and social interaction an individual could be positioned as a lesser person when relating moves from 'I-Thou' to 'I-It'. The relation of a person with objects represents the 'I-It'. In this mode of address, the object is subject to location in time and space and can be ordered and measured. Therefore, when relating to another, 'I-It' implies objectivity and meeting without commitment or engagement. This kind of meeting denies an individual his or her being. When deaf peoples' culture and language are not acknowledged by others, the relationship moves to an 'I-It' position in which the values and beliefs of the individual are not valued in the social interaction.

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[33] Meaning literally the "piety", Hasidism is an Orthodox Judaism that that originated in southeastern Poland. Buber believed that Judaism was a living faith and that Hasidism transformed spiritual knowledge and mysteries into tangible embodied ways of living (Green and Mayse 2019).

Ethics of embodiment

Levinas' (1969) philosophy, like Buber's, privileges relation with other persons as an essential feature of human life and consciousness. Whereas Buber (2009) emphasised the mode in which we address the other, Levinas (1969) concentrated on the ethical importance of the other. Levinas criticised Buber's understanding of radical engagement, arguing that Buber's (2009) philosophy suggests that we can only engage with the other if we surrender difference. This radical otherness was also Levinas' (1969) critique of Merleau-Ponty in which he believed an emphasis on horizons suggested the possibility of someone being absolutely other. Levinas (1969) suggested that by moving from an "I-It" to an "I-Thou" relationship, Buber (2009) suggest a collapse of the other into self. Therefore, to avoid absorbing the other's "difference" into one's "own same", Levinas (1969) emphasised that in relating to the other there is always more than appears to us, always more than we can ever comprehend. While rejecting a view of human relation in which the other is so transcendent that they can never be genuinely understood, Merleau-Ponty, similarly describes a chiasmic intertwining in which the other is always intertwined with self without being reduced to each other. Therefore, the other retains difference but has the capacity to relate. Both Buber's (2009) and Merleau-Ponty's (2012) work are dialogic philosophies that emphasise being's praxis[34] with the world. Levinas (1969) however, believed that Buber's (2009) philosophy lacked a responsibility to the other. This ethical responsibility and relation, for Levinas, cannot be reduced to an act of self-affirmation or to one of selflessness, but instead emerges in the welcome of the other. According to Levinas' ethics, there is no home without hospitality, no identity prior to alterity, no self before other. Therefore, he calls for a radical ethics of being-for-the-other. Although Merleau-Ponty does not explicitly lay down his ethics, I believe his philosophical explorations grapple with the web of relationships through which we stand to one another as expressive and responsible agents. Therefore, I argue that Merleau-Ponty's writing had an ethical current underpinning many of his central concepts that points towards relational ethics. Levinas (1969) believed that this moral obligation first takes hold of us through our bodies.

Conclusion and implications for this research

The philosophical underpinnings of this study are drawn from Merleau-Ponty's (2012) understanding of our embodied nature. I believe the essence of personhood to be dialogical (Buber 2009, Merleau-Ponty 2012), embodied (Merleu-Ponty 2012), ethical

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[34] Mindful doing with moral intent (Titchen and Hardy 2009).

(Levinas 1969) and spiritual (O'Donohue 2000). Ultimately, we perceive and come to know the world through our bodies. Merleau-Ponty (2012) emphasises that the body and mind are elements of one organic process. Each aspect of a person is grounded in engagement with the context. However, we often live assuming and acting according to a set of dichotomies that distinguish mind from body, reason from emotions and thought from feeling. These notions are so embedded in the Western world that they are almost viewed as an unquestionable fact of human nature. There are many manifestations of this dualism in our everyday lives. This focus on the external, rather than the internal body is what leads us to unconsciously pay less attention to the sensing body. This mind/body split is often evident in healthcare settings, where focus is often placed on measuring, calculating and diagnosing the body. By speaking of an individual separated and disconnected from their body, we overlook the human body as mediating all experiences of the world.

Merleau-Ponty's (2012) philosophy has implications for this study as it raises questions about how our being (ontology) and knowing (epistemology) are shaped by our sensory perceptions. Deaf peoples' primary sensory orientations have been well documented as visual and spatial (Kusters et al. 2017). Although I have highlighted, in *Chapter Two*, that not all deaf people are visual to the same extent, it is evident that visual-spatial sensory orientation forms the basis of an individual's perception. Recognising the different nature of deaf and hearing peoples' ontologies and epistemologies, raises questions about how nurses and deaf people can create shared meaning that upholds these and relate to the uniqueness of the other.

If personhood is constructed and maintained in the social environment all persons are involved in a creative process of cultivating and renovating both the self and reality/realities collectively. This embraces the ontological assumption of multiple truths or multiple realities i.e., that each person has an understanding of reality from an individual perspective (Erlingsson and Brysiewiez 2013). The strengths of qualitative research lie in its attempt to carry out dialogue between different ways of being, to appreciate the fluidity and multilayered complexity of human realities. Rather than seeking to gain awareness from a dichotomous perspective the goal is to arrive at an account – a kind of "translation at the crossroads" that would make it possible to link, but not reduce, one perspective to another (Wertsch 1997, p.7). Buber (2009) believed that we expand our understanding of one another by being attentive to the personhood of others and self. This emphasises that taking time (reflection in silence) to translate and share actually engages praxis (intention and moral actions) so that a person can 'cross the road' in an intentional way.

Chapter 5: Methodology

Introduction

Having explored and defined the philosophical underpinnings of this study in *Chapter Four*, I then developed them into a compatible methodology for use in my research. This chapter provides an account of the methodological principles adopted in the research. Methodology is the overarching approach to research and encompasses both philosophy and research methods (McGregor 2018). I have chosen to split my explanation of the methodology and methods of this research into two chapters; *Chapter Five* (methodology), in which I will discuss how I have applied my philosophical perspectives into a research methodology and *Chapter Six* (methods), in which I will provide a description of each stage of the research. By laying out my methodology and methods in two chapters, I will demonstrate how my ontological and epistemological positioning transfers into the methodology of the study and then how methodology guides the methods. Because philosophy and research methods are intertwined (Higgs and Titchen 2007), it is crucial to be clear about decisions regarding methodology and how these helped me to decide upon the most appropriate research methods to use. By making explicit the research decisions I have taken, I aim to ensure the rigour and validity of my work (Dewing et al. 2017). From my exploration of current empirical literature in *Chapter Three*, it is apparent that no previous research study has addressed the questions and objectives that have developed in my research study. Although this thesis does not start from a blank canvas, it does seek to explore a subject about which little is known. In order to achieve this, the research study takes an exploratory stance.

Exploratory Research

In this research, I initially sought to explore nursing and deaf peoples' perceptions of being together and engaging in relationship. By employing principles from Merleau-Ponty (2012) and Gadamer's (2013) philosophies, I believe we can gain new insight into meeting in the spaces in-between. Exploratory research aims to seek new insights and ask questions that will lay the groundwork for future research. It is often employed to find out what is happening in little understood situations (Robson 2002). As noted in *Chapter Two*, although the field of Deaf Studies has done much research on Deafhood, culture and history, as well as on linguistics it often fails to connect peoples' experiences of being deaf to other aspects of their lives (Kusters et al. 2017). Equally, much social sciences research continues to maintain a focus on deaf people and their need and eligibility for services but does not elaborate on the interactions between service providers and service users (Young and Temple 2014). The value of exploratory research lies in its approach to expand upon such knowledge by unsettling and questioning what we know and to unearth nuances (Stebbins 2001). The need to understand the nuances of these shared experiences was highlighted in *Chapter Two*.

The literature review has identified a gap in knowledge regarding the experiences of deaf people and nurses. Therefore, the purpose of the proposed study is exploratory; studying an experience about which little is known. Rather than having a hypothesis to test, qualitative research approaches exploration with open-ended research questions (Holloway 2005). Aiming to explore and understand the social world, rather than predict, explain and control, the research questions are concerned with how people make sense of their world and experiences. Because of the clear need for more robust research into these experiences the research questions and objectives are:

Questions:

1. What are the experiences of deaf people who have interacted and received care from nurses?
2. What are the experiences of nurses who have interacted and provided care for a deaf person(s)?

Objectives:

1. To explore the perceptions that deaf people hold of their interactions with nurses
2. To explore the meanings that interactions with nurses hold for deaf people
3. To explore the perceptions that nurses hold of their interactions with deaf people
4. To explore nurses' values and beliefs about caring for deaf people

Critical creativity

While the exploratory nature of this study would commonly imply research situated in the interpretive paradigm, a critical creativity worldview embraces the need to blend assumptions from different research paradigms in order to answer most research questions (McCormack and Titchen 2006). Critical creativity is derived from Fay's (1987) critical theory. Critical theory has an explicit intent towards emancipation. With its roots in a Western European Marxist tradition, the aim of emancipation is "to liberate human beings from circumstances that enslave them" (Horkheimer 1982, p.224). Therefore, critical theory does not set out to simply explain and understand social contexts but aims to free people from circumstances of domination and oppression. Critical social science is concerned with the kind of action that arises from raised awareness or increased understanding that leads to a desire for people to address oppression and domination rather than action resulting from power or coercion. The literature critiqued in *Chapter Two* has highlighted themes of oppression and empowerment that consistently arise in literature related to the experiences of deaf people. Therefore, it is essential for this research to be positioned in a paradigm that is underpinned by principles of emancipation i.e., enlightenment from oppression.

Titchen and McCormack (2010) have critiqued critical social science, emphasizing its lack of explanation as to how a critical theory can be turned into action and the lack of acknowledgement of the moral and spiritual dimensions often involved in pushing out the boundaries of the known. In addressing this shortcoming, critical creativity blends being critical with being creative. The critical element involves an engagement in critical critique by de-constructing what we know then reconstructing it to develop new understanding and knowledge (Habermas 1974; Fay 1987). While this reflective re-construction of knowledge is a creative process in itself, being creative in the context of critical creativity also means using creative imagination and expression (Titchen and McCormack 2010). In the context of this study, critical creativity offers the opportunity to understand different types of practice epistemology and ontology in a way that can facilitate enlightenment for future action and subsequently improve the experiences and interactions between deaf people and nurses.

As emphasised in *Chapter Four*, it is our bodies that provide our perception and understanding of the world. As a paradigmatic synthesis in which the assumptions of the critical paradigm are balanced with creativity, critical creativity enables access to embodied, tacit knowing. Ellingson (2017) emphasises that despite decades of discourse among a range of researchers about the significance of the embodiment to research and sense making, many qualitative researchers still do not know how to intentionally embody their practices in ways that make their bodies a meaningful presence in their research. Research is always already an embodied communicative process (Ellingson 2017) and the body may therefore not be seen to require special consideration. However, Pink (2015) suggests that a sensory approach to research cannot be simply guaranteed or learnt from a book but can be developed through the researcher's intentional engagement with his or her environment. Embracing the creative has the ability to surface other forms of knowledge (embodied, tacit) upon which this research is rooted. The use of creative expression to facilitate critical reflection allows “synergy between cognitive and artistic approaches to critique” (McCormack and Titchen 2006, p.256). Gendlin (1993) emphasises the body’s capacity to attune to a situation and grasp significance before it is cognitively processed and reflected upon. Paying attention to this knowledge and trusting it are central to critical creative research (McCormack and Titchen 2006).

A hermeneutic approach

In the previous chapter, I explored my ontology and epistemology. These were underpinned by Merleau-Ponty’s (2012) work on embodiment. From my exploration of philosophy, I believe the essence of personhood to be dialogic (Buber 2009, Merleau-Ponty 2012), embodied (Merleau-Ponty 2012), ethical (Levinas 1969) and spiritual (O’Donohue 2000). Ultimately, I believe we perceive and come to know the world through our bodies. If the body mediates all experience of the world, as I believe it does, it is imperative that I explore the implications this has for the methodology and methods of this study. Hermeneutics (Gadamer 2013) as an approach to interpretation, in research and further afield, expresses the way an experience is lived in an embodied, relational and contextual way. Therefore, there are multiple layers of meaning involved in interpretation. I believe that Merleau-Ponty’s exploration of our engagement with the world is further enhanced by Gadamer’s (2013) hermeneutics, and vice versa. In this chapter, I will explore how Merleau-Ponty’s understanding of experience enhances the hermeneutic approach to understanding.

The term hermeneutic originates from the Greek term *hermeneuein* meaning to “interpret”. Hermeneutics is concerned with the practice or art of interpretation (Dallmayr 2009). Hermeneutics explores interpretation (meaning making) and understanding as central dimensions of human action and by extension, narrative. Originally used to interpret texts, the hermeneutic tradition shifted during the Romantic Era to focus more generally on the nature of understanding (Preston 2009). Heidegger (1996) proposed a hermeneutic phenomenology that placed emphasis on an existential analysis of *Dasein* that should replace traditional ontology. Therefore, from Heidegger’s perspective *Dasein* should replace traditional understandings of the world and existence. Heidegger (1996) believed that the temporality of our knowledge implies our finitude and the impossibility of attaining ultimate and absolute truths. Gadamer partly adopted this view of ontology, developing many aspects of Heidegger’s thoughts (Scheibler 2000). In line with Heidegger’s (1996) and Merleau-Ponty’s (2012) thoughts, Gadamer (2013) criticised the positivist notion that knowledge starts from the mind.

From a hermeneutic perspective, each person is believed to interpret the world from a different stance but none of these perspectives gives privileged access to “reality”. Human understanding is mediated through what Gadamer (2013) called historicity. This refers to linguistic, social and cultural traditions. In discussing Husserl’s (1978) notion of lifeworld, Gadamer therefore emphasised the situatedness of human encounter. Gadamer (2013) adopted the phenomenological concept of the ‘horizon’. The knower is bounded to his present horizons as the productive ground of all understanding. Shaped by the past in an infinitude of unexamined ways, the present situation is the known in which understanding is rooted. This is the meaning of the hermeneutical situation (Heidegger 1996). We, therefore, encounter the present moment from the horizon of experience shaped by past experiences and by cultural traditions that have formed the foundations of who we are and are becoming (Brockmeier and Meretoja 2014). In my own horizon, I am limited by that which I am familiar with and from which I draw upon to perceive. Therefore, the limitation of the horizon represents an openness to possibility inasmuch as it represents a perimeter, as it is not static and provides the conditions for potential future perceptions. This is similar to Merleau-Ponty’s (2012) belief that we cannot separate ourselves from that which we have already encountered and know but that it provides a basis from which to expand our understanding. Because the matrix of our understanding is always in flux, Gadamer (2013) believed that we are always understanding differently. Therefore, our meaning-making is always a reinterpretation of previous interpretations from a different point of view in that moment in time and space. As a result, another layer of historicity is added to the hermeneutics of understanding. The interpretation not only has a bearing on how we act and interact but is an act in itself and therefore changes the very world we live in. Similar to Merleau-Ponty’s (2012) belief that our perception of the world unfolds as we come into contact with it, Gadamer demonstrated that meaning making is entwined with being.

Gadamer (2013) understood our horizon as the place in which we can enter into further understanding. Thus, the process of dialectical understanding is a “fusion of horizons” (Gadamer 2013, p.317). Gadamer (2013) did not characterise a fusion of horizons as an attempt to escape or transcend one’s own lifeworld but rather to expand one’s horizon of understanding. To embrace the known and the yet to be known (McCormack and Titchen 2006). The fusion is an encounter, a point of contact. Therefore, for Gadamer (2013), the true locus of hermeneutics is the dialectical in-between. This contact is a new, ‘in-between space’ where a person sees themselves in the other and the other sees himself/herself in the person. This is not a place of permanence but of participation and movement. The fusion of horizons “changes constantly, just as our visual horizon also varies with every step that we take" (Gadamer & Dottori 2006, p.61). The fusion of horizons was therefore not understood by Gadamer as a harmonious merging or Hegelian synthesis[35], but as an engaged dialogic encounter. This relates to Buber's (2009) notion of holding ground while being open to the other. Buber (2009) believed that in the in-between space you do not abandon your own values, beliefs and perspectives but hold these while also listening and holding another person's values and beliefs (Friedman 1996).

Gadamer's (2013) hermeneutics tends to emphasise our embeddedness in a common world while also acknowledging the nuanced nature of our experience and encounter in it (Dallmayr 1993). Therefore, understanding does not entail a direct grasp of subjective intentionality but exhibits a struggle that Dallmayr (1993, p.6) describes as ambivalence and mis- or non-understanding. In the dialectical in-between, the idea of the hermeneutic circle is central to understanding. Gadamer uses Heidegger's metaphor of the hermeneutic circle "to describe the experience of moving dialectically between the parts and the whole" (Koch 1996, p.176). Gadamer emphasised that *Dasein*'s being is always being-with (Scheibler 2000) that underlines the fact that human beings are part of a web of socially defined concepts, roles, functions and interrelations. The hermeneutic circle is therefore an iterative spiral of understanding in which the relationship between the whole and its elements is made meaningful (Paterson and Higgs 2005). The interpreter must shift from understanding and imaginatively dwelling in the world of the participant to distancing and questioning the participant's world as other, engaging in cycles of understanding, interpretation and critique. Meaning therefore, does not reside solely in separate experiences but also in the wider context. This aligns with my relational and dialectical ontology.

Hermeneutics does not offer a methodology for conducting conversation but invites us to investigate our ways of being in the world with a strong focus on the personhood of each being who is in relation and participating with the other. Gadamer's (2013) hermeneutics was focused on the back-and-forth dialogue that exists in conversation. "To become always capable of conversation – that is, to listen to the Other – appears to me to be the true attainment of humanity" (Gadamer 1972, cited in Wierciński 2011, p.28). Therefore, for Gadamer the conditions for a hermeneutic conversation were a willingness to listen as well as a common language (Wierciński 2011). In his philosophy, language is the means by which this dialogue takes place. In contrast,

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[35] Hegel argued that the fusion of horizons could lead to a definitive synthesis which unifies two people (Ferrarin 2019).

from a Merleau-Pontian perspective, we understand and interact with the world not only through language but through our whole embodied interaction with it. Therefore, the back-and-forth dialogue that Gadamer (2013) writes about is also informed by our senses. Although the body and its role in hermeneutics is not emphasised in Gadamer's work, hermeneutics is embodied by its nature and incorporates the totality of dialogue. Therefore, I believe that Gadamer's (2013) hermeneutics implicitly includes embodied perception as developed by Merleau-Ponty (2012).

Hermeneutics does not request that we give up our particular standpoints to reach agreement with others but that we try to understand our particular standpoints in light of the understanding of the other (Wierciński 2011). The goal of conversation is neither to tolerate difference for the sake of diversity of opinions nor to support a forced agreement but to reach an enriched understanding. Hermeneutics therefore seeks understanding rather than explanation, acknowledges the situatedness of the interpreter, recognises the role of a person's positioning in interpretation, views inquiry as dialogic and is comfortable with ambiguity (openness rather than vagueness). These five characteristics draw attention to the philosophical underpinnings this approach offers. Such an approach has the potential to enable shared meaning to develop between the potential differing perspectives of the people participating in this study.

Underpinning my study with the philosophies of Merleau-Ponty (2012) and Gadamer (20013), the purpose is to achieve an exploration of experiences. The essence of the questions, according to Gadamer (2013), leads to the opening up of possibilities for meaning making. Rather than trying to put myself into participant's shoes and see things from their stance, I aim to reach a shared understanding through engagement. Methodology "describes the process by which insights about the world and the human condition are generated, interpreted and communicated" (Koch 1996, p.174). Therefore, this research will be characterised by the dialogical nature and dynamics of discovery that Merleau-Ponty (2012) and Gadamer (2013) wrote about.

Researcher positionality

In research, there is often a sense that the truth lies hidden beneath, waiting to be exposed if sufficient measures are put in place to ensure that methods are robust. Yet, the reality is that the act of shaping raw material is a creative act that reveals as much about the values and beliefs of the sculptor as it does about any other person's perspective (Paterson and Higgs 2005). Merleau-Ponty (2012) and Gadamer (2013) both emphasise that our understanding stems from our positioning in the world, therefore it is crucial for me to be transparent about my positioning and to critically question how meaning has been created (rather than uncovered) in this study.

The story of my positionality in the research began in *Chapter One*, in which I situated myself. I approached my study as a hard of hearing person, realising over time that I was culturally hearing in many of my thoughts and actions. Prior to commencing fieldwork, I often thought of myself as an outsider to the deaf community and an insider to the nursing community. As a hearing person, however immersed in the deaf world, I could not gain an instantly accessible understanding of the daily experiences of deaf persons. As Sutton-Spence and West (2011, p.423) have stated, “it is a daily battle of being aware that we do not understand, and often never can”. However, in practice these binary notions of insider/outsider often transgressed such boundaries (Dwyer and Buckle 2009). For example, through my limited BSL, I was often able to strike up a simple conversation with a deaf person that seemed to dissolve binary notions of ‘hearing’ and ‘deaf’ and allowed us to meet in the space in-between. Additionally, when engaging with nurses about my study, I often felt that they approached me as an outsider with my status as a researcher overriding my status as a nurse. This is an example of a reflection that I wrote about in relation to my positionality:

> “I am still not convinced that there is a fence that can never be crossed between the hearing and deaf world. I think there is some sort of continuum or different levels of understanding.” [Reflection Bridging the Gap Conference 27/11/17]

Das and McAreavey (2013) highlight that positionality is best understood as a dynamic phenomenon. Therefore, we are not permanently located according to a single status but feelings of insiderness and outsiderness overlap and intersect (Merton 1972; Wray and Bartholomew 2010). Therefore, researchers stretch the boundaries of the hypothesized insider-outsider dichotomy, or “work the hyphen” (Fine 1994, p. 31). Horsfall and Higgs (2011) describe the action of inhabiting different positions and boundaries[36] in research as boundary riding. Because my positioning (and belonging) in this study was not static, I will continue to write myself into the story of the research. As a novice researcher, there were many processes of becoming as I engaged with the research process and my horizons expanded. These expansions emerged from the interaction between myself and all the people I engaged with, as well as the social and the political situation in which the research occurred. Therefore, it was rooted in the collaborative process of meaning making in space and time

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[36] In this context Horsfall and Higgs (2011) defined boundaries as rules, conventions or taken-for-granted assumptions.

(Holstein and Gubrium 1995; Kusow 2003; Gadamer 2013). Dwyer and Buckle (2009) highlight that this space of being in “relation to” our participants can be a tensional, complex but also, a rich space. Through reflexivity, I will show the impact of my positionality in producing knowledge and therefore, acknowledge the politics of the ‘doing’ in my research (Corlett and Mavin 2018).

Reflexivity

The aim of reflexivity is to critically and constructively question understanding. Dewey (1933) emphasised that reflection is complex, rigorous, intellectual and emotional process. Dewey (1933) believed that experience involves participation, an engagement between an individual and the environment. Such experiences contain what Dewey referred to as continuity, a continuous flow of knowledge from previous experiences. Meaning making and knowledge production is therefore a continuous and cumulative process that fosters growth and is characterised by forward movement. For Dewey, reflective thinking fosters the development of open-mindedness, wholeheartedness and responsibility. These enable a habit of thinking in a reflective way. Dewey believed that because an experience involves interaction between oneself and the world, there is a change not only in the self but also in the environment as a result. Through interaction with the world, we both change it and are changed by it. Awareness and description of experience alone, however, is not enough, claimed Dewey. What is critical is the ability to perceive and then weave meaning among the threads of experience. Therefore, the value of an experience lies in the perception of relationships. This is where the role of reflection sits. The purpose of reflection is to make meaning, to formulate the relationships, make sense of and attribute value to the events in our lives. Rather than “mulling over” an event or experience, Dewey (1933, p.118) viewed reflection as “active, persistent, and careful consideration of any belief or supposed form of knowledge”. Social interactions for Dewey were therefore, a mode of praxis and imbued with ethical connotations.

Rogers (2002) has drawn four principles from Dewey’s writing about reflection:

1. Reflection is a meaning-making process that moves a person from one experience into the next with deeper understanding of its relationship with and connections to other experiences and ideas. It is the thread that makes continuity possible
2. Reflection is a systematic, rigorous, disciplined way of thinking
3. Reflection needs to happen in community, in interaction with others
4. Reflection requires attitudes that value the personal and intellectual growth of oneself and others.

Building upon Dewey's thoughts, Schön (1983) was interested in how professionals know through their practice. Schön (1983) believed the concept of 'professionalism' was too strongly linked to 'technical rationality'. Drawing from Polanyi's work, Schön (1983) believed that we often fail to acknowledge the significance of tacit knowledge in our work. For Schön (1983), tacit knowledge is the situated 'knowing-in-action' that forms the foundation for the action-related attitude that an experienced practitioner has. Schön (1983) called this 'reflection-in-action'. Schön (1983) claimed the work of practitioners is characterised by unique situations that demand professional frame making in which patterns of problems can be solved. Such thinking is not technical-rational, but is based on experience and involves meaning, emotion and perception. Schön's (1983) work is unique in that it places emphasis on a mode of reflection that extends beyond intentional cognitive reflection and draws attention to the embodied dimension. Kinsella (2007) calls this an embodied mode of reflection that arises through the body and is revealed in action. Schön (1983) claimed that drawing from a repertoire of experiences, practitioners can create understanding of new and uncertain experiences. In fact, we must draw our knowledge from restructuring and playing with past experiences. This knowledge-in-action is gained from engaging in and layering different levels and kinds of reflection (Schön 1983). Schön (1983) emphasised the importance of embracing creative ways of reflecting to avoid limiting our practice or becoming counterproductive. Both Schön and Dewey emphasise the inter-relatedness of self and world which must be the focus of critical reflexivity (Door 2014). Such thinking is compatible with Merleau-Ponty's (2012) and Gadamer's (2013) writing.

As mentioned previously the strengths of qualitative research lie in its attempt to carry out dialogue between different ways of being, to record and discuss complexity, detail and context. Reflexivity is a dialogical and relational activity that requires continual engagement between the researcher and others who are involved in the research process (Alvesson and Sköldberg 2009; Jones et al. 2013). Reflexive engagement entails critical self-reflection of the ways in which background, assumptions, positioning and behaviour impact on the research process takes place (Higgs et al. 2011). In this study, the internal process of critical self-reflection was supported by dialogue and critique of my research and critical questioning of my actions with my supervisory team and through my collaboration with the third sector[37]. These activities presented a tangible way of recording how the research unfolded and guarded against

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[37] This collaboration will be described in detail in *Chapter Five*.

premature closure of ideas. Taylor (1993) emphasises the importance of lingering with concepts that fall between being and nonbeing. He believed that through this inward turn reflection is brought full circle when pondering something it cannot yet comprehend. For Taylor (1993), this is when reflection bends back on itself and becomes reflexive.

Although, it is impossible to escape from the consequences of our positions by talking about them endlessly, we can articulate differing assumptions and agendas that contribute to multifaceted understanding. Person-centred qualities of openness, trust and dialogue were adopted to create a safe space that would nurture reflexivity and engagement (McCormack and McCance 2016). Such engagement involves every person at each stage of the research process from design to dissemination. Moments of reflexivity have been captured and woven throughout the remaining chapters to ensure coherence with my philosophical stance and methodology.

Working with minority groups

There are numerous minority groups, for example refugees, asylum seekers and Māori, who have historically been subject to experimental or intervention research. Traditionally researchers have taken a positivist approach to research, placing minority groups as other. As a result, such groups have been misrepresented, pathologised or problematised by research processes (Liamputtong 2010). This has often resulted in suspicion and fear of researchers among these groups. Several researchers (Wilson and Barton 2012; Heaslip 2016; Kotz et al. 2016) have documented the reluctance and limited participation in research of indigenous and ethnic groups. Because of the negative perception of the research process, which is based on history and personal experiences of cultural groups, such as the deaf community, researchers need to reconsider their research design to make it more culturally appropriate for these groups (Liamputtong 2010).

Often minority groups are labelled as hard-to-reach. However, the term 'hard-to-reach' is ambiguous. Countless challenges faced in defining, identifying and gaining access to certain cultural and linguistic minorities often contribute to researchers describing them as hard-to-reach (Tourangeau et al 2014). Because hard-to-reach groups are not homogenous, many different strategies have been discussed and employed to encourage engagement and participation (Smith 2012). Conversely, I argue that services and research may be 'hard-to-access' for people from minority groups. Therefore, rather than framing participants in a problematic way, I suggest that reaching and recruiting participants may pose challenges to researchers because they understand little about them and/or are not actively engaged with the community in which they wish to involve (Foehl 2011). From this perspective, researchers need to understand and overcome the barriers to accessing research that potential participants may face. Liamputtong (2010) highlights that it is important for researchers not to jump to conclusions that people from minority groups are unwilling to take part in research but to understand certain elements of research that are important for these groups. Because of historically negative perceptions of the research process, trusting the motives of the researcher and believing that the research goals will benefit their community are vital components when ensuring the research design is culturally appropriate. By being creative and flexible in the strategies for engagement with people, these barriers can often be overcome. Based on this discussion, I believe that researchers need to implement creative ways of thinking about how the values and beliefs of minority groups can inform methodologies and methods to enable meaningful participation.

Reconciling methodology with interpreting and language considerations

The triadic interaction

The extra layer of complexity that exists with the use of interpreters makes the integration of reflexivity in research essential (Temple and Edwards 2002). Researchers must acknowledge and examine the interpreter's meaningful contribution to the discourse of interpreted encounters (Roy 1996).

In the UK, there is a growing body of cross-language research conducted with people who speak little or no English. Interpretation, transcription and translation are everyday practices in such research (Temple 2002). However, the distinction between these processes is often unclear with most researchers using the terms interpreter and translator interchangeably. Interpreting enables communication produced in one language to be conveyed in another; transcription allows alternation between modalities such as the spoken to the written for another purpose, for example data analysis; translation ensures that statements are understood as expressions of the same meaning (Young and Temple 2014). Sign language interpreters do not fit neatly into either translator or interpreter category as their role involves conveying one language in another (interpretation) and an alternation in modality[38] (translation).

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[38] Modality refers to the mode of language expression being used, whether spoken or signed (Napier 2015).

Despite these complex processes being essential to cross-language research, discussions relating to the effects and challenges of employing interpreters and translators to address the language differences between researchers and participants are scarce (Twinn 1997). There is a small yet limited body of literature relating to best practices for researchers communicating through an interpreter (Temple and Edwards 2002). However, the specific implications of utilising interpreters and translators in the research process are rarely articulated. This is strange, given that qualitative approaches to research are immersed in traditions that acknowledge the importance of reflexivity and context (Temple and Edwards 2002). In research conducted with sign language users, debates about interpretation, transcription, and translation intersect with those concerning research with deaf people.

Epistemology and language in research

Researchers appraise language in a variety of ways depending on their theoretical or philosophical approach. Language perception in research ranges from a complete indifference to how language can shape a research narrative (Squires 2010). Researchers using positivist epistemologies often view language as a neutral medium through which meaning can be conveyed without difficulty across languages. Typical assumptions made during the processes of interpretation, translation and transcription include “accurate” interpretation via professional interpreters, “verbatim” transcription, and “correct” translation using back translation (Temple and Young 2014). Back translation is the ‘re-translation’ of a translated transcript into the original language and a subsequent comparison of the original version and the back translation to identify discrepancies (Behr 2017). This conventional best practice model of working with interpreters mirrors a mechanistic role in which the interpreter should not add or subtract from what the two parties, researcher and interviewee, communicate to each other. Additionally, the interpreter is thought to adhere to professional invisibility and complete linguistic and relational neutrality (Angelelli 2004). These impartial roles traditionally ascribed to interpreters are often presented as evidence of established validity in research. Those who do not reflect on their approach to language interpretation and translation are implicitly, if unintentionally, working with these positivist epistemologies (Metzger 1999). Such research claims a technically accurate interpretation has taken place.

In contrast, researchers who adopt epistemologies, other than those concerned with trying to objectively capture reality, reject the idea that language is simply a sign system that carries meaning (Temple and Young 2004). Alternatively, language is understood as a non-neutral medium that shapes the social world rather than passively reflecting it (Lewin and Silverstein 2016). This view challenges the traditional role of interpreters as neutral conduits of language by exposing the fact that interpreting is an interactive process in which a message is constructed out of the interplay of linguistic and social features (Wadensjo 1995; Angelelli 2004). Therefore, the relaying of a message faithfully, accurately and without personal or emotional bias is not always possible (Tate and Turner 1997; Metzger 1999). Researchers who embrace these views must acknowledge and examine the interpreter’s meaningful contribution to the discourse of interpreted encounters (Roy 1996).

While interpreting as a form of mediation across linguistic and cultural boundaries has been recognised for some time, discourse related to differing perspectives is relatively recent (Pöchhacker & Shlesinger 2002). Metzger (1999) proposes a triadic view of the interpreted interaction where all are actively engaged in the communicative event. This is a sociological stance in which people are understood to be social beings, engaging in a social context. From this perspective, interpreters are viewed as participants in the encounter and their input shapes meaning created in the triad (Metzger 1999). Therefore, rather than having an invisible or passive role, the interpreter acts as an active co-participant, while representing the words of others (Angelelli 2004). Bakhtin (1986) argues that from this perspective, language and meaning is continuously reproduced and recreated by being used. Therefore, researchers must be mindful that interpreting and translation processes are analytic in nature, mediating what is known, how it is known and who is seen to tell. It is crucial that the multiple truths and meanings of this knowledge are explored as language can be endlessly altered, manipulated and hidden for a multitude of deliberate and non-deliberate purposes (Roth 2013).

Interpreting

As explored in *Chapter Two*, deaf people inhabit a rich sensory world in which vision and touch provide awareness and orientation to the world (Bahan 2008). The significance of this sensory orientation does not simply account for the primary senses through which deaf people experience the world. Rather it is the basis upon which reality has form and substance for a deaf person (Merleau-Ponty 2012). According to Lane (1995), Padden and Humphries (2005) this common experience of thinking about, knowing about and understanding the world manifests itself in deaf culture. As explored in *Chapter Two*, the culture of deaf people has largely been overlooked by hearing people. Additionally, hearing people have often developed projections or metaphors for deaf peoples’ state of being. For example, it is common for hearing persons to assume that deaf people live in a world of silence. This notion is invalidated by the knowledge that deaf people do not experience or complain of “silence”. Moreover, as explored in *Chapter Four*, people who are profoundly deaf often hear noises of varying degrees and are highly sensitive to vibrations. The deaf poet Ilya Kaminsky (2019, p.79) writes, “The deaf don’t believe in silence. Silence is the invention of the hearing”. Such common misunderstandings about deaf people emphasise the different cultural points of reference between deaf and hearing people that may need to be mediated by an interpreter. This is quite significant for researchers engaging with the narratives of deaf individuals and questions current knowledge of the deaf perspective or the deaf point of view.

Although hearing interpreters cannot fully share in a deaf person’s reality that is created and experienced in a visual form, they will hold bicultural as well as bilingual knowledge (Napier 2002). Bicultural knowledge may include an understanding of the controversies surrounding deafness as a physical disability or a unique culture and what is meaningful to deaf people. Several writers have used ‘Frame theory’ to explain the inferences made by interpreters about what is meaningful to persons for whom they are interpreting (Hatim and Wilcox and Wilcox 1985; Mason 1990; Metzger 1999; Angelelli 2004). Frame theory refers to assumptions and judgements that interpreters make about what the other people in the triad mutually understand by using the contextual knowledge of both communities, their languages and cultures (Napier 2002). These assumptions incorporate the interpreters assumed knowledge about cultural norms and values. Application of such knowledge can support interpreters in making interpretation linguistically and culturally effective and meaningful for participants. Therefore, interpreters make specific language choices according to their frames of reference, what certain concepts mean to them, and inferences they make about what concepts will mean to the participants (Napier 2002).

Frame theory suggests that searching for linguistic and cultural equivalents does not equate to searching for directly translatable words in each language, as sociocultural contexts may alter the way certain expressions are understood. Napier (2002) suggests that the most appropriate and dynamic translation style to use, in order to apply the fundamentals of frame theory and perform effectively as a linguistic and cultural mediatory, is free interpretation. Free interpretation focuses on meaning as well as linguistic and cultural equivalence but not the form of the message. Literal interpretation or transliteration refers to a more literal rendition of the source. Interpreters can blend free and literal translation approaches as each translation style operates on a continuum (Metzger 1999; Napier 2002). The majority of recent literature on spoken and sign language interpreting advocates for a free, equivalence-based approach to interpreting. It is vital to explore how the interpreter interprets what they see by engaging in discussions on perspective.

Young and Temple (2014) suggest numerous features of the interpreter that may impact on the study; language affiliation and the range of possible ways to be bilingual, whether the interpreter is trained in research methods and concepts, their connections with communities of deaf people, and other possible considerations such as gender, class and ethnicity. However, the most significant discussion in Deaf Studies literature relates to the interpreter's identity as either a "Deaf" or "Hearing" person. Although interpreters may have a degree of cultural familiarity true membership in deaf society has a great deal to do with the actual shared experience of deafness. The difficulties of attributing insider and outsider positions are relevant here (Twine 2000).

As mentioned previously, early discussions of insider/outsider assumed that each status carried with it certain advantages and disadvantages. However, more recent discussions have unveiled the complexity inherent in either status and have acknowledged that the boundaries between the two positions are not clearly delineated. In Deaf Studies, this complexity is evident in the debate surrounding the concept of deafness. The discussion concerning Children of Deaf Adults (CODA's) is just one example of the many tensions that exist in attempts to establish and define deaf identity. Many CODA's grow up actively involved in a deaf community, naturally acquire BSL as a first language and embrace values of the deaf community. This raises the question as to whether they are entitled to a deaf identity. Attempts to create hegemonic ideals and answer such questions have resulted in exclusion and highlight the cultural and linguistic diversity of deaf peoples' experiences (Obasi 2008). However, it is important to acknowledge that many people who have grown up learning BSL but are hearing view themselves as 'Deaf (hearing)'; that is, as hearing people they align themselves with deaf people and their values (Napier and Leeson 2016).

The majority of BSL/English interpreters are not only audiologically hearing but also culturally "Hearing"[39]. The majority of society have not thought of themselves as "Hearing" and are consequently Hearing only in deaf spaces and contexts. Hearing refers to a way of thinking about, knowing about and understanding the world that

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[39] The use of a capital 'H' mirrors the notion, explored in *Chapter Two*, that those who are culturally deaf capitalise the 'D'.

stems from a visual-auditory orientation to the world. Sutton-Spence and West (2011) believe that a Hearing person working in Deaf Studies lives two lives: one as a deaf ally[40] and one as a hearing person. This experience has been described as a daily battle of being aware that Hearing people cannot fully understand as they cannot cross the border into the deaf world (Hoffmeister 2008). This study situates the interpreter beyond the dead-end spaces of identity politics and seeks to explore the notion of the space in-between (Sutton-Spence and West 2011). However, as a novice researcher it was vital to be aware of and explicate such political discussions before entering the field.

The effects and challenges of employing interpreters to facilitate communication between myself and participants are complex. Although issues of representation cannot be solved, I can be transparent about the decisions I have made and the effect that these have had on the outcome of the study. Interpreters were employed through Deaf Action's communication and interpreting agency. Deaf Action's agency is registered with The Scottish Association of Sign Language Interpreters (SASLI). In Deaf Action, the people who provide language and communication support to deaf people must also be registered with SASLI or the Nation Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD). Members of these bodies are registered with the Protecting Vulnerable Groups scheme and are expected to adhere to the regulatory bodies Code of Conduct and Practice (see Appendix 5). Each code of conduct has key components that include issues of confidentiality, interpreting skills and knowledge, impartiality and professionalism.

Relational Ethics

In the Deaf Studies literature, there has been an ongoing debate about what constitutes ethical research practice with deaf people (Pollard 1992; Pollard 2002; Young and Temple 2014). The overarching question posed in this literature is whether it is correct to assume that universal ethical principles are appropriate to apply to research that involves deaf people. In the existing literature explored throughout this thesis, there is a sense that the deaf community have been used by researchers for purposes that are unclear and that do not relate to the deaf persons' own well-being.

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[40] An ally is a person who actively advocates for and supports individuals or people experiencing oppression. Being an ally is an ongoing process of social justice. In deaf communities, allies contribute to the goals of the deaf community in positive and supportive ways. Historically, allies of deaf communities had paternalistic attitudes that focused on helping. More recently, emphasis has been placed on working with the deaf community rather than for them (Leigh et al. 2018).

This has placed the deaf community at risk of exploitation and harmful research practices, however unintended these practices might be (Harris et al. 2009).

Ladd (2003) advocates deaf-led research, in which methodological decisions are founded on uncovering deaf peoples' realities and understanding deaf ways of knowing. Remaining mindful of deaf peoples' visual, tactile form of embodiment, I needed to find ways of exploring and engaging in real life situations in a culturally sensitive way. Reflecting on aspects of positionality in conducting research with deaf people, Foster (1993) questions whether (i) a hearing researcher can select appropriate questions for study (ii) can appreciate deaf peoples' experiences and (iii) accurately represent their observations and perceptions in analysis. Fook (2002) highlights that dichotomous thinking implies binary and oppositional interests. Additionally, equating 'sameness' with 'equality' and 'difference' with 'inequality' denies the dialogical and relational nature of our being and knowing.

From a Gadamerian (2013) perspective, shared understanding comes from entering into dialogue. Understanding is therefore thought of as neither objective nor subjective but is participatory (Todres 2007). The aim of dialogue is not the perfection of knowledge but the complete openness for a new experience (Wierciński 2011). In response to Foster's questions, I believe that as a researcher, I must construct questions that are open to the experience of the person, allowing them to share what they believe to be meaningful. My intention was not to represent a deaf person's experience to others or to give them voice but to start a dialogue that can inform nursing practice. Without this dialogue, there remains a distance between deaf peoples' experience of healthcare and nurses' understanding. Therefore, the aim of this research was not the perfection of knowledge but the openness of a dialogue. Gadamer (2013) emphasised that a readiness for dialogue is a moral phenomenon in which I am willing to allow the other to challenge my own preconceptions (Vilhauer 2010). This points beyond neutral communication in the direction of ethical and political practice.

Many have argued for ways of rethinking research practice so that good intentions translate into action that live up to the nursing profession's own ethical statement. I took a stance towards ethics that is relational. Relational ethics offers a meaningful way to frame nursing practice and research (Gadow 1990). It involves understanding the decisions we make with the ultimate goal of human flourishing (eudaimonia) (Larkin et al. 2008). The relationship is the basic principle of a relational ethic and therefore requires a recognition of its moral significance in the decision-making process of those faced with complex ethical decisions (Sherwin 1992). Since relational ethics is about quality of relationship, it challenges researchers and Research Ethics Committees (REC) to move away from “solving the ethical problem to asking the ethical question” (Bergum and Dossetor 2005, p.9). This reflects Buber’s (2009) philosophy that even though our interpretations of events are conditioned through our being, by being in dialogue with a person’s experience we can gain a deeper, more meaningful understanding.

From a relational ethics standpoint, ethics is a way of being that cannot be acquired solely by learning general rules. Rather, it must be acquired through reflective, emotional and social practice that enables us to put our understanding of eudaimonia into practice (Gabriel and Casemore 2009). Such practice is rooted in our values and beliefs about ourselves and other people. These values develop in order to help us determine the kind of person we should be and how we should act. In the context of research, where the researcher initiates and often controls contact and holds professional knowledge, it is crucial that the researcher is open to the values and personhood of participants. This involves taking up a questioning attitude of radical, reflective attentiveness to the way in which we experience the world (Van Manen 2014) and returns us to Levinas’ (1969) thinking that we have a responsibility towards the other. Van Manen (2014) emphasises that ethical decision making tends to be understood theoretically as a technical process but that the actual lived experience may be more ineffable and difficult to grasp. In my experience, relational ethics involves privileging the *emergent* here-and-now relationship *between* (Buber, 2009) myself and the people I engaged with (Finlay 2015). It necessitated *openness* to the other while being willing to give of self and the *courage* to stay in the process (presence). Therefore, relational dynamics must be explored *reflexively* by taking a critical stance.

Methodological Rigour

As with all research, rigour is an essential methodological consideration in critical creative research. Judging the methodological rigour of a research study involves critically appraising the design and approach to determine the credibility or trustworthiness of the results. Differing perspectives on how to assess rigour in qualitative research continue to be debated in the literature. Finlay (2006b) argues that rather than there being a standard criterion against which to assess the rigour of qualitative research, the aims and epistemological assumptions that have shaped the methodology must be taken into consideration. As determined throughout this chapter, hermeneutics does not provide a method for understanding but aims to clarify the conditions through which understanding takes place (Gadamer 2013). Strategies used to ensure rigour in this research therefore included; researcher reflexivity, a transparent decision trail and engaging in relational ethics. While the philosophical and methodological principles of each of these were explored in this chapter, it is important to consider the practical application of each.

The application of these methods for ensuring rigour were somewhat intertwined in practice. Researcher reflexivity was achieved through the use of a reflexive journal and engaging in critical conversations with my supervisory team. This reflexive practice, alongside the writing of this thesis resulted in a transparent decision trail. Lastly, to ensure rigour of this research study I engaged in relational ethics. While the methods used to practically apply researcher reflexivity and record a transparent decision trail in this study are easily identifiable, the methods of engaging in relational ethics are less concrete. Rashotte and Jensen (2007) argue that we can practice relational ethics, and therefore methodological rigour, by paying attention to context, having an awareness of power differentials and embracing complexity. I believe that this is an attitude towards research that is apparent in the transparency of my decision making and through my personal writing style.

Conclusion

Underpinning my study with Merleau-Ponty's (2012) and Gadamer's (2013) philosophies, the purpose of this research is to achieve an exploration of experiences. In this chapter, I have drawn from my philosophical principles to design a methodological framework located in hermeneutics that will serve to guide my research. I have continued to position myself in the research and have explored the role of the interpreter. In the next chapter, I will set out and defend my methods showing how they fit in the research paradigm and how they flow directly from the methodological principles I have set out. The way in which relational ethics translated into my research practice will be explored in *Chapter Six*.

Chapter 6: Methods

Introduction

In this chapter, I share the story of the methods employed in the study. According to Gadamer (2013), the task of hermeneutics is not to develop a procedure of understanding, but rather to clarify the interpretive conditions in which understanding takes place (Kinsella 2006). This is the continual merging of meaning and understanding that takes place to form one's horizon. In research, this continual merging of meaning and understanding can be captured through engaging an ecologic sense of making connections (Koch 1996). As a novice researcher, I entered the field with a direction for exploration (research questions and objectives). However, the conversations I engaged in at every stage of the research guided me throughout. The expansion of my understanding and interpretation of this topic was therefore not restricted to the interviews and focus group I facilitated but ingrained in the whole of my practice as a practitioner, educator and researcher in the field. The term data implies objects of knowledge that are distanced from the analytic examination of them. However, as a methodological approach, hermeneutics encourages researchers to embrace an attitude that ponders an unfolding and evolving understanding throughout the whole of the research story (Van Manen 2014). Therefore, in each stage of the research there was potential for a continual opening into possibility. In this chapter, I will continue to share my unfolding understanding of this research and explore how such understanding led to decisions related to methods.

Collaborating with the third sector

As explored in *Chapter Five*, recognising the moral significance of my decisions was imperative to the ethical stance I took to this research. To ensure that dialogue that was respectful of deaf communities and their culture was opened, I believed that it was important to seek appropriate support for the development of the research design. One of the ways in which I believed my research could have been sensitive to the culture of the deaf community was to seek advice and guidance on the development of my methodological ideas. At the beginning of the study, I began to engage with third sector organisations and people in my institution who worked closely with the deaf community. The nature of this engagement was often initiated via email and followed by face-to-face meetings. Through this engagement, it became evident that having a deaf person or ally of the deaf community join my supervisory team would be invaluable in supporting me to navigate the methodological and ethical considerations of my study. This decision was aimed at having a participatory element to the research process in which local knowledge about the topic can inform the research process (Reason and Bradbury 2001). Such an approach can acknowledge and respond to the political aspect of producing knowledge (Breda 2014).

Sutton-Spence and West (2011) have emphasised the paradox of Deaf studies is that it continues to be dominated by hearing scholars. While the focus of Deaf Studies is to empower the deaf community and strive towards social change, attempts to empower might not always be experienced as empowering (McLaughlin et al. 2004). Due to limited finances, I was unable to invite a deaf person to join the supervisory team, as an interpreter would have been required to facilitate communication. I acknowledge that lack of funding for interpreters is an ongoing challenge that hinders deaf people from both accessing and being able to fully participate in research. This has implications for participatory research with deaf people as the purpose and process of this research is not actively owned by the deaf community. This presents a limitation to my study. After engaging with a number of people from third sector organisations that work closely with deaf communities, I invited a member of staff from Deaf Action to be part of my supervisory team. Fiona[41] is a qualified BSL/English interpreter and a member of staff at Deaf Action. The nature of our collaboration varied depending on the stage of the research process we were engaged in. For example, during the process of applying for ethical approval, we emailed back and forth regularly to discuss ethical concerns that were culturally specific. However, over the course of my whole study we engaged in face-to-face meetings or communicated via email and telephone after each supervisory meeting. In addition to inviting Fiona to be an advisor on my supervisory team, it was through Deaf Action that I booked BSL/English interpreters for engaging in community events/clubs and for carrying out the interviews with deaf participants. I also worked with Deaf Action to produce the study information video in BSL[42].

Temple (2002) emphasises that the employment of third sector advisors in research does not solve issues of representation per se but raises questions about how that person was chosen, whom they represent and how accountable they are. Rather than viewing them as recipients of services, much of the third sector's work is co-produced with deaf communities (Scottish Third Sector Research Forum 2016). Therefore, third sector organisations play a significant role in advocating for the deaf community. Fiona was asked to join the supervisory team because she was eager to engage with

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[41] Pseudonym

[42] The process of creating an information video in BSL will be described later in this chapter.

the study, held knowledge of the deaf community and challenged my thinking through critical questioning. Additionally, Fiona demonstrated that her values aligned with that of Deaf Action who seek to raise awareness of the needs and rights of deaf people, challenge discrimination and provide services to promote quality of life (Deaf Action 2018). Overall, Fiona identified strongly with the work that Deaf Action do and is passionate about meeting the needs of the deaf community. Fiona advised and challenged my thinking as I navigated my way through procedural ethics and fieldwork. Because the formal academic processes (ethics, progression points and presentation of my work) were all reviewed and assessed by hearing people, Fiona provided me with a way to anonymously ask for feedback from the deaf community on decisions regarding the research process. Examples of when and how this feedback was used to inform my research decisions will be given throughout the remainder of this chapter.

Ethical considerations

In *Chapter Five,* I identified relational ethics as a meaningful way to frame my practice as a researcher. This section focuses on how the principles of relational ethics were translated into the methods I employed. During the process of applying for ethical approval, I came to understand the two dimensions of research ethics that Guillemin and Gillam (2004) term ‘procedural ethics’ and ‘ethics in practice’. I have used these two dimensions to structure my discussion.

Procedural ethics

Obtaining local NHS Board Approval to undertake the research was an early step in the research process. Ethical approval for this study was granted by NHS South East Research Ethics Committee (see Appendix 6) Originally, approval was granted for a single centre study and later extended to a multi-centre study to include six NHS health boards. The decision to extend to five other health boards resulted from challenges in recruiting participants from the original health board. These challenges are explored later in this chapter. Once I was granted approval from the REC, I applied for the Research and Development (R&D) departments at the six NHS boards identified as potential areas for recruitment. Caldicott Guardian approval was also sought and granted (see Appendix 6) as I had originally intended to video record my interviews with deaf participants[43]. The process for obtaining ethical approval for this study was relatively smooth.

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[43] My decision not to video record interviews with deaf people will be explored later in this chapter.

Procedural ethics requires researchers to articulate to review boards the purpose of their research, the ways they will minimise risk of harm to participants and their data management practices. The completion of an application form for a REC can often be seen as a ‘tick box exercise’ or hurdle to overcome. As a novice researcher, I spent time reviewing the ethics application to ensure that I was responding to questions in “ethics-committee speak” (Guillemin & Gillam 2004, p.263) but also sought to balance this with the need to be flexible about decisions made in the field. This involved using language that is free of jargon and demonstrating my competence to carry out the proposed study. Additionally, I demonstrated a firm understanding of the historical and political contexts related to being deaf, including the significance of deaf culture and sign languages.

With an awareness of the implications of doing research across cultures, ensuring cultural sensitivity throughout the research process was my focus. However, in my discussion with the NHS REC, the ethical implications of engaging with participants from a different cultural and linguistic background went unaddressed. The REC’s focus remained on ensuring that universal ethical principles for researching vulnerable groups had been considered. Although universal ethical principles are well-defined in research, they often cannot be easily translated into practice in all cultures and communities (Msoroka and Amundsen 2018). For example, it is easy to state the ethical principle of ‘do no harm’ but what does it look like to implement that in research practices with deaf communities? Crasborn (2010) highlights that unintentional harm may be caused if deaf peoples’ culture and language is invisible in the research processes. This has previously led some deaf people to insist that identifiable data of them signing are used and their rights to anonymity waived (Crasborn 2010). Therefore, the principle of ‘do no harm’ cannot be translated into universal methods without the basic understanding of ‘harm’ being defined by dominant members of society (Smith 2006). By taking an ‘ethics in practice’ approach, I intended to avoid universalising ethical principles and to reflexively navigate the research process. This ethics in practice approach will be explored in more depth later in this chapter.

Working from a dominant (hearing) perspective, the REC suggested two amendments, during my review panel meeting, that I believed to be ethically problematic in the context of my study. Firstly, they requested that deaf participants were provided with written information sheets (as well as BSL versions) and secondly, that I inform deaf participants GP’s that they had participated in the study. Although these suggested amendments may appear harmless, they had ethical implications for which I sought guidance from Fiona. The first suggested amendment expressed a common misunderstanding that BSL is not a sufficient way of sharing information. By intentionally choosing to provide the information in BSL, I was not only seeking the most effective means of ensuring informed consent but was also acknowledging the language preferences and cultural-linguistic identity of potential participants (Temple and Young 2014). What was understood as best practice by the REC (providing information in written English) could have resulted in failure to create the best conditions for a person to make a decision about participation and denied BSL as a bona fide language. Therefore, providing a written English version of the study information could potentially suggest a lack of sensitivity and understanding by marking BSL as a lesser language. This could have had an impact on my relationships with potential participants, as it may have indicated to them a lack of understanding of their culture and language.

The second suggested amendment posed a problem in trying to recruit participants who may have a general mistrust of healthcare professionals (Kuenburg 2016). I therefore consulted with Fiona on this amendment. In our discussion we acknowledged the pivotal role of GPs in primary healthcare and in connecting people to other services. However, as research has shown, a large proportion of deaf people in the UK express a lack of trust of their GP (SignHealth 2014). To gain clarification, Fiona provided an opportunity for her deaf colleagues at Deaf Action to anonymously express how they would feel about their GP's being informed if they were participating in research related to healthcare. There was a strong response from Fiona's colleagues that they would be reluctant to take part in research if their GP were to be informed, as they felt this would breach confidentiality and anonymity. From my experience of applying for ethical approval, it appeared that certain stages of the procedural ethics process rendered deaf peoples' culture, their communities and their language invisible. Although the REC accepted the challenges I posed to their suggested amendments, my experience emphasised the problems with applying universal rules across all research contexts during the procedural ethics review process (Tilley and Gormley 2007).

The experience of completing the procedural ethics application and discussion with the REC emphasised to me the importance of finding balance between essential procedural ethics and relational ethics (discussed in *Chapter Four*). I realised the ethical significance of the cultural implications arising from my own positioning in relation to the research and the cultural knowledge I carry into the research context. I found the process of applying for procedural ethics triggered my thinking about potential ethical dilemmas that could arise during fieldwork. However, my discussion with the ethics panel felt distanced from the experiences of people I wished to engage with. While I focused on potential ethical implications of navigating between two cultures and languages, the ethics committee appeared focused on ensuring that somewhat fixed ethical standards were met. Ways of meeting such standards appeared to be prescribed with little attention paid to how ethical practices are shaped by the people I wished to engage with. Although many of these ethical dilemmas became visible only as the research proceeded, as a novice researcher I would have valued a discussion with the REC about what I anticipated to be the most significant potential ethical challenges.

Although at the time I was unsure of the relationship between the procedural ethics process and the day-to-day ethical issues that would arise in the doing of research, I came to view the procedural ethics process as a necessary step that provided a checklist of potential issues to consider. Additionally, it was a helpful step in the design of my research project, as it motivated me to make decisions regarding methodology and methods. However, on the whole I experienced what Guillemin and Gillam (2004, p.269) describe as the “gulf” between ethics committee’s approval of a research project and the reality of ethics in practice.

Ethics in practice

As emphasised in *Chapter Five*, I took a relational approach to ethics. The deaf community are often viewed as a vulnerable group (Singleton et al. 2014). Therefore, the REC was focused on the procedures that could be put in place to safeguard participants in the study. However, my main ethical concerns in this study were reliant on my understanding and openness to other ways of being that do not deny others their right to self-determination. Guillemin and Gillam (2004) name this dimension of ethics, ‘ethics in practice’ and relate it to the ethical obligations that a researcher has towards each person that they interact with during the study. Although no major ethical “dilemmas” may arise, researchers make every day ethical choices in the way that they relate and respond to people during fieldwork. Everyday actions during fieldwork can subsequently, have ethical implications (Guillemin and Gillam 2004). I therefore focused on being aware of “ethically important moments” (Guillemin and Gillam 2004, p.265) and having a language for reflecting on them (Komersaroff 1995). This took the form of free writing in my reflective journal and discussing ongoing ethical dilemmas with the people I was engaging with both in the field and in my supervisory team.

In research, the ethical responsibility ultimately falls on the researcher themselves and the potential for harm relates to the nature of the interaction between the researcher and the participant. Therefore, the need to relate to core ethical principles requires the critical engagement of the researcher and can never be a matter of applying a routine formula (Butler 2002). As stated before, research is undertaken from the researcher's positionality (horizon) and therefore, the values and beliefs of the researcher are woven into every decision they make. Reflexivity not only captures how knowledge is produced in the research but also the interpersonal aspects of research. In these aspects, lie the possibilities of respecting the autonomy, dignity and privacy of each person the researcher comes into contact with. In being reflexive, a researcher would not only be alert to issues related to knowledge creation but also ethical issues in research (Guillemin and Gillam 2004). Ethics and reflexivity are therefore active, ongoing processes that need to saturate every stage of the research.

An example of one ethically important moment that arose for me during recruitment was when a deaf person requested that we carry out an interview without an interpreter. I had attempted to secure a BSL/English interpreter twice for an interview with Lindsey[44] and was in the process of rearranging this for the third time, when Lindsey suggested meeting without an interpreter. At first, I felt uncomfortable about Lindsey's suggestion. My mind cast back to my NHS ethics application and I felt a sense of wrongdoing. However, Lindsey highlighted to me that she was comfortable communicating with me in BSL and through lip-reading because she had met me numerous times before and was familiar with my communication nuances. Therefore, we made a shared decision to carry out the interview without an interpreter. From the stance of a relational account of autonomy, although duties arising from potential vulnerability include protection from harm, the duty to protect must always be informed by the overall background aim of fostering autonomy (MacKenzie et al. 2014). Ethics in practice therefore provided me with the opportunity to frame my decisions in the context of social relationships and upheld a relational approach to ethics.

Inclusion & exclusion criteria

The inclusion and exclusion criteria of a research study identify characteristics that deem potential participants as eligible or ineligible to participate. Salkind (2010) emphasises that the selection of inclusion and exclusion criteria should be guided by the ethical and methodological principles of the study. Due to the exploratory nature

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[44] Pseudonym

of this study, the inclusion and exclusion criteria were not extensive but sought to identify people whose experiences could contribute to answering the research question. As this study was not concerned with aspects of audiological measurement, hearing thresholds did not need to be determined but rather a focus was placed on the use of BSL as a first language and/or language of choice. As with most research, changes to this study were made as the research unfolded. For example, one of the challenges I was confronted with during fieldwork was the constraints of the six-month timeframe in my inclusion criteria. It became evident that to recruit participants, I would need to be more flexible and change the timeframe. This resulted in the removal of a timeframe. The tables (6.1 and 6.2) below display the original criteria and final criteria with changes indicated in italics.

Table 6.1 Inclusion and exclusion criteria for deaf people

Inclusion & exclusion criteria for deaf people	
Original inclusion criteria	**Final inclusion criteria**
Prelingually deaf adults (18 years old+)	Prelingually deaf adults (18 years old+)
People for whom BSL is their first language or language of choice	People for whom BSL is their first language or language of choice
People who have had experience of nursing care in the last six months	*People who have had experience of healthcare that they could remember*
Original exclusion criteria	**Final exclusion criteria**
People who are not prelingually deaf	People who are not prelingually deaf
People for whom BSL is not their first language or language of choice	People for whom BSL is not their first language or language of choice
People with incapacity	People with incapacity
People whose experience of nursing care has been in a mental health setting	People whose experience of healthcare has been in a mental health setting

Table 6.2 Inclusion and exclusion criteria for nurses

Inclusion & exclusion criteria for nurses	
Original inclusion criteria	**Final inclusion criteria**
Registered adult nurse	Registered adult nurse
Nurses who have cared for a prelingually deaf, BSL user in the past six months	*Nurses who have cared for a prelingually deaf, BSL user*
Original exclusion criteria	**Original exclusion criteria**
Not a registered member of the nursing team	Not a registered member of the nursing team
Nurses who have not cared for a prelingually deaf, BSL user in the past six months	Nurses who have not cared for a prelingually deaf, BSL user

This study originally aimed to explore the experiences that deaf people and nurses had of interacting with one another. However, the significance of BSL/English interpreters to healthcare relationships and my growing understanding of their active participation in such encounters resulted in a change to the study. A focus group of BSL/English interpreters was added. The reasons for deciding to include interpreters as true participants will continue to be explored and written into the remainder of this chapter. The following table displays the inclusions and exclusion criteria for interpreters:

Table 6.3 Inclusion and exclusion criteria for BSL/English interpreters

Inclusion & exclusion criteria for BSL/English interpreters
Inclusion criteria
A qualified BSL/English interpreter
An interpreter who has experience interpreting in a healthcare setting
Exclusion criteria
An unqualified BSL/English interpreter
An interpreter who has no experience interpreting in a healthcare setting

Negotiation of access

Access to sites

Permission to access the hospital sites and carry out the study was sought and granted from either the Director of Nursing, Interpreting and Translation Manager or the Equality and Human Rights Manager from each participating health board.

Gatekeepers

To meaningfully access potential participants from minority groups, researchers often need to identify gatekeepers who can act as mediators (Eide and Allen 2005). Lewin (1947) first coined the concept of a gatekeeper, describing them as individuals who ensure that information moves between individuals and groups based on social and cultural norms and values. Das and McAreavey (2013) argue that the overarching goal of the gatekeeping process is to protect and control access to a community. In this research, gatekeepers played a key role to accessing and recruiting potential participants because deaf communities often have a lack of trust for mainstream research (outside of Deaf Studies) (Wrigley 1997; Singleton et al. 2014). Therefore, due to my limited links[45] with the deaf community, I was reliant on gatekeepers' input. The key people I identified as being essential to connect with were employees of Deaf Charities, BSL/English interpreters, colleagues in my institution who had connections with the deaf community and NHS interpreting services.

Das and McAreavey (2013) emphasise that gatekeepers not only have the power to grant or deny access but may also heavily influence potential participant's decisions about whether to opt in or out of the research. By acting as cultural brokers and mediators, gatekeepers also assist researchers in becoming culturally competent (De Laine 2000; Liamputtong 2008). Engagement with gatekeepers presents the first encounter that requires researchers to negotiate and put ethical values into practice in the field. This brings to life the emerging and ongoing nature of relational ethics (McAreavey and Muir 2011). Such ethical decisions are prompted by an evaluation of gatekeeper's motives, questions about how routes of access may affect research participation and how the relationship between a gatekeeper and researcher is established and maintained (Das and McAreavey 2013). Crowhurst and Kennedy-Macfoy (2013) emphasise the lack of attention given to the complex dynamics in

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[45] My links with the deaf community all stemmed from the BSL course I was undertaking at Deaf Action during the time of my research.

which researchers engage with gatekeepers in practice. Due to this lack of attention, the impact that gatekeepers have upon the research process often goes undocumented. Seeking access via gatekeepers is approached as a historically situated, social and cultural process that embodies the power relations of the contexts in which it takes place (Crowhurst and Kenned-Macfoy 2013). Engaging with gatekeepers can, therefore, have personal and political implications.

In practice, I employed multiple approaches to connecting with gatekeepers. These included attending local events, consultations, information sessions, conferences and anything else that seemed relevant to my research and that might include members of the deaf community, BSL/English interpreters and service managers. Examples of these events include the European Forum of Sign Language Interpreters Conference, the NHS's British Sign Language engagement event and Deaf Actions Annual General Meeting. I continuously sought to expand my networks and to learn more about the deaf community and the people who worked with them. What I experienced from attending and participating at these events was a stark contrast between events hosted in hearing spaces that had agendas created by hearing people and those hosted in deaf spaces that had agendas developed by the local deaf communities. While events hosted by the deaf community and interpreters appeared to have constructive dialogue that was actioned, events held by the NHS often gave deaf people a platform to express their views without space for dialogue or actions for the future. Participation appeared tokenistic with deaf peoples' experiences being shared and then responded to in a defensive tone. The following observation, made during one of these events, reflects this concern:

> "Service managers are not listening to deaf community members. They respond to deaf peoples' questions by listing improvements implemented by the organisation to defend their services. The conversation feels disjointed." [Notes from NHS engagement event 09/05/17]

There appeared to be an illusion of engagement that in reality impeded dialogue and polarised deaf community members and service managers. Todres (2008) believes that such tokenistic engagement may highlight that policy makers value the bottom lines of their targets at the expense of responding to community specific concerns. In the face of such dynamics, the possibility of engaging dialogue fades away, giving place to a series of interrelated monologues. According to Freire (2017), a monologue is an oppressive statement about what is true and right that does not invite, or even tolerate response. Therefore, the potential for dialogue, an in-between space for ideas, values, beliefs and differences to meet (Buber 2009) is prevented. Despite this being my experience at engagement events, a number of the gatekeepers who work in Interpreting Services and NHS Diversity roles recognised the need for further research into the needs of the deaf community. They had themselves found it challenging to support the values and needs of deaf people in a system that is not designed with deaf people in mind. They expressed their work in relation to the deaf community as a constant learning curve in which they did not always "…get it right" but were "enthusiastic about creating the energy and resources needed for deaf and hearing people to work collaboratively" [Reflection 05/09/18].

Gatekeepers that I engaged with whom were BSL/English interpreters or whose worked was based in deaf charities often approached me with what appeared to be suspicion. Something that has been documented by hearing researchers elsewhere (Sheppard 2011), with protection of the deaf community being stressed as the reason for suspicion. Because of the history of researchers 'doing to' deaf communities, deaf people and those who work with them seek to know who researchers are, where they are coming from, and what their commitment to deaf communities is (Napier & Leeson 2016; Leeson et al. 2017). As reciprocity is a key value of deaf signing communities, Leeson et al. (2017) highlight that deaf people are often willing to engage with researchers who seek to bring about shifts in how deaf communities are understood and valued, provided there is ongoing dialogue with the deaf community and engagement across and beyond the life of the study. Recognising that I was a guest in the deaf community (O'Brien & Emery 2013; Napier & Leeson 2016; Leeson et al. 2017), I had expected gatekeepers to question my motivations. However, at times I felt that I was being cast as an oppressor (O'Brien & Emery 2013) by gatekeepers who asked me to focus my energy on researching my own profession. During the final phase of recruitment, I was advised by one gatekeeper to have "…no further contact with deaf people" [Reflective diary 19/10/18]. As a researcher, when such boundaries are encountered it is crucial to ask questions about why the boundary is there, what purpose it is serving and whose interests it is protecting (Horsfall and Higgs 2011).

In these communications, focus was often placed on the potential harm that could be caused to participants but also to the institutional relationships that gatekeepers had with the deaf community. As Das and McAreavey (2013) emphasise, gatekeepers must maintain their credibility with the community, ensuring that their relationships are not jeopardised. Viewing these gatekeepers as experts in their field, I initially did not feel confident to challenge these views. Therefore, I raised them in my supervisory team. Over time, I came to realise that this sensitivity was shaped by conflicts of perspectives between deaf and hearing people in both healthcare and research. As already mentioned, deaf people have been misrepresented, pathologised or problematised by research processes in the past. Additionally, gatekeepers may have other interests and may hold preconceived ideas of what constitutes meaningful research (Das and McAreavey 2013).

Although these suggestions were often disheartening and made me question my motivations, I continued to remind myself of a comment made during a conference I attended called Bridging the Gap[46]. During this event, a deaf person highlighted, to the BSL/English interpreters and Deaf Studies academics present, that actively spending time with deaf people was more valuable than passively learning about them. Therefore, throughout my engagement with gatekeepers, I continued to hold a view that interviewing nurses alone would provide me with one perspective, excluding deaf peoples' experiences and stories. This relates to Merleau-Ponty (2012) and Gadamer's (2013) belief that we can achieve an appreciation of otherness from the vantage of one's own lifeworld through dialogical engagement between different perspectives and modes of lived experience.

In summary, challenges that arose during my engagement with gatekeepers resulted in a tangible shift in power dynamics between myself and those who work more closely with deaf communities. Sutton-Spence and West (2011) have labelled this 'negotiating the legacy of hearingness' in which they state that:

> "As people who can hear, we are members of a powerful majority, but in Deaf Studies the balance is tipped and we find ourselves the minority working with and in an intrinsically powerful group of Deaf people and Deaf cultural practices." (Sutton-Spence & West 2011, p.429)

O'Brien and Emery (2013) have challenged this perspective, arguing that research and access to the deaf community continues to be mainly mediated by hearing people who work closely with the community. Therefore, the position of deaf people is far from powerful. Sutton-Spence and West (2011) highlight that there is "almost no debate about the tricky epistemological and ontological ground navigated by hearing people" (p.422) who wish to do research with deaf communities. Hoffmeister and Harvey (1996) emphasise that it is important for hearing professionals to work out their reasons for working with deaf people. However, rather than having to defend doing research with deaf people, Kusters et al. (2017) emphasise the importance of

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[46] The purpose of this annual conference is to bridge the gap between the deaf community and the academic community. More specifically for academics to find out what kind of research the deaf community would like to see and for the deaf community to see what kind of thinking goes into developing a research idea.

thinking and writing about positionality with the intent of being transparent. Additionally, in Deaf Studies Kusters et al. (2017) warn against defining hearing academics as monolithic oppressors. My motivations and positionality continued to be questioned from my initial contact with gatekeepers to the final write up of this thesis. I will reflect on this further in the final chapter of my work.

Through my experiences of interacting with gatekeepers, I came to understand them not as instruments in the field to move past, but as social actors that are embedded, participating in, and influencing relations of power. Additionally, gatekeepers provided much advice and discussion that contributed to “ethically important moments” (Guillemin and Gillam 2004, p.265). For me, engaging with gatekeepers was a dynamic process shaped by encounters (Crowhurst 2013) and involved more than just ‘access’. Gaining access was therefore regarded as an ongoing process that was negotiated at each level of contact. Power dynamics and researcher positionality (discussed in *Chapter Five*) hold significance for researchers working with gatekeepers to access participants (Das and McAreavey 2013). The impact that gatekeepers’ behaviour had on recruitment of deaf people to my study will be explored later in this chapter.

Setting

Due to the small close-knit nature of deaf communities, disclosing information about an individual’s diagnosis or the setting in which they were cared for may identify them (Temple and Young 2014). Therefore, with the aim of maintaining anonymity of participants, detailed descriptions of the settings in which nursing participants worked or deaf people were cared for are not provided. This study was situated in six health boards including NHS Lothian, NHS Greater Glasgow & Clyde, NHS Forth Valley, NHS Borders, NHS Lanarkshire and NHS Fife. These sites are not discussed independently so as not to identify specific clinical areas or participants. However, from within these health boards all major hospitals were included as potential recruitment sites.

Sampling

In this section, I will describe the sampling approach that I adopted to recruit participants. This was different for each group (deaf people, nurses and BSL/English interpreters) and the sampling of each posed unique challenges. McAreavey (2017) highlights that recruitment processes are frequently more complicated than researchers present in their descriptions. Recruitment is often complex because the process is both social and technical in nature (Clark 2010). My recruitment phase extended over 11 months and involved numerous approaches to engaging potential participants in the study. As a novice researcher, with little experience of gaining access to participants, I was unprepared for the complexities related to my chosen sample. These complexities were not related to being granted ethical approval by an ethics committee but were linked to the lack of information available regarding what clinical areas had cared for a deaf person and/or required a BSL/English interpreter.

Deaf participants

Deaf communities do not exist in a geographical location, as they are a linguistically and culturally defined group (Ladd 2003). As stated previously no concrete data or register of deaf people exists. Records that do exist are thought to be under-representative of the deaf population as they depend upon registration with the local social services department, which is completed on a voluntary basis (Deaf Action 2016). This presented a challenge to sampling.

As familial, social and professional networks amongst deaf people are extremely tight and overlapping (Ladd 2003), snowball sampling was originally thought to provide access to members of this population that other methods could not reach. As social media has recently begun to play a significant role in the lives of deaf people (Fisher et al. 2019), a BSL information video (see Appendix 7 for English script) was placed on various social media and charity websites that are associated with Deaf Action.

Fiona and I collaboratively developed the content of the BSL information video as a written English script. Following this initial development of the script, the content was critically revised by an employee at Deaf Action, who was fluent in BSL and English, and independent of the study. This revision enabled amendments to be made, ensuring that the information was linguistically clear and culturally appropriate. The final stage of the process was to translate the script into BSL and record it. The script was signed by a fluent BSL presenter who was video recorded by the multi-media and translation team at Deaf Action. I spent time with a member of the multimedia team as the video was edited which allowed me to be involved in the process. Despite the collaborative effort that had been put into producing a linguistically and culturally appropriate video, this method of recruiting participants was unfortunately not effective. Informal responses to this video on social media sites suggested that deaf people were suspicious of who I was.

Recognising that my status as a hearing researcher and a nurse may have caused deaf people to feel apprehensive about taking part, I decided to provide potential participants with an opportunity to meet me in their own community spaces. I therefore contacted organisers of deaf clubs across the six different regions to ask if I could attend deaf social events with an interpreter to meet people and share information about my study. With approval from the deaf club organisers, I visited deaf social clubs to introduce myself and engage with people about my study. In these spaces, I saw BSL and deaf culture come to life. People were often uninterested in formally taking part in the study but wanted to chat. As a BSL learner, deaf people often relaxed in my presence once they discovered I was learning their language. Upon finding out that I was a BSL student, the interpreter we were working with was often asked by deaf people to ‘turn off their voice’ so that the deaf person and I could engage in dialogue through signing. Although these visits to deaf clubs were valuable experiences for me to engage with deaf people face-to-face and often resulted in me gaining insight into deaf peoples’ lives, deaf people did not want to formally take part in the research. My recruitment of deaf people was further complicated by an email I received after my first two visits to deaf clubs.

Shortly after I began visiting deaf clubs, I received an email from a deaf community member, Peter[47], who was concerned about the ethical issues of me engaging with the deaf community. More specifically, Peter had two major ethical concerns. The first was that I was spending time at deaf clubs, which Peter explained are considered safe spaces for members of the deaf community. Due to the deaf community being dispersed geographically, deaf clubs are often a rare opportunity for community members to meet and interact with others that share BSL and deaf culture. Peter explained that these clubs are often seen as a quick and easy source of information for researchers with little being given to the deaf community in return. Cenoz and Gorter (2017) and O’Rourke (2019) write about the need for ‘breathing spaces’ (as introduced by Fishman 1991) or ‘safe spaces’ (Creese and Martin 2006) for minority languages. These are spaces in which one specific language is used, rather than other multilingual language practices in which languages are mixed. In the context of deaf communities, deaf clubs have been viewed as such spaces for a long time (De Meulder et al. 2019). De Meulder (2018) has noted that this is beginning to change as ‘new signers’ present a challenge to this concept because of their developing language practices. However, I recognised the need to respect the safe spaces in which deaf people can meet and socialise and therefore chose not to visit any more deaf clubs.

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[47] Pseudonym.

The second concern that Peter had was that the deaf community were suffering from consultation fatigue from the ongoing engagement with the Scottish Government regarding the BSL (Scotland) Act 2015. Hopeful that the BSL (Scotland) Act 2015 will improve access across all facets of life, deaf people may therefore have felt uncertain as to how a small-scale research study could have any impact on their experiences of healthcare. This sense of consultation fatigue was reported in the BSL users' response to the Scottish Government's efforts to engage the community in drafting the BSL National plan (British Deaf Association 2017) and is additionally mentioned elsewhere (Singleton et al. 2015; De Meulder 2017b). As mentioned previously, consultation fatigue is often a problem when communities are repetitively asked to engage in processes that are tokenistic and produce limited outcomes. Those who worked with deaf communities at different third sector organisations highlighted to me that deaf people have frequently shared their stories without seeing any impact of their involvement in outcomes. This reflection was written after one of my visits to the Scottish Sensory Centre:

> "Mary[48] explained that deaf people are often invited along to engagement events to share their experiences. This information is noted and put on a shelf. The next year they are invited back again to talk about the same things. This happens year after year and often they [deaf community members] get fed up, throw their arms up in the air and say 'I've told you this before'. No wonder there is a reluctance to take part in research. How many times must you tell your story before you are heard, acknowledged and responded to?" [Reflection 05/09/18]

Consultation fatigue leads to community engagement that can be an empty and frustrating process. Arnstein (1969, p.219) has labelled such tokenistic engagement a "window-dressing ritual" in which power holders go through the motions of consultation, but with no assurance that the concerns and ideas of the community will be taken into account. This echoed my reflections from the NHS engagement events I had attended. It is evident that such tokenistic engagement can result in people avoiding future participation.

Prior to my discussion with Peter, I had been unsuccessful in recruiting any deaf participants through visiting deaf clubs but had recruited two participants with whom I had previous connections. Although I felt welcome and chitchatted to many deaf people at deaf clubs about their overall experiences of healthcare, no one was prepared to share their healthcare experiences in a formal interview. Through my conversations with those who work closely with the deaf community, I came to

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[48] Pseudonym.

understand numerous reasons why deaf people might be unwilling to engage in the study. Firstly, deaf people have a general distrust of non-signing or not fluently signing researchers (Singleton et al. 2014; Young & Temple 2014; Kusters et al. 2017). Secondly, due to my limited connections with the deaf community, deaf people might be suspicious as to how the information will be used and whether it will affect their care in the future. In conversation with Peter, I developed a more targeted approach to recruitment in which I would recruit deaf people who either worked for deaf charities or had strong connections to them. Peter himself decided to take part in the research. This targeted approach resulted in the deaf participants in my study having similar characteristics as they all worked either for the Third Sector or in Social Care and were bilingual or fluent in BSL with a good understanding of English. As highlighted earlier, providing detailed demographics on deaf participants could identify them. However, it is important to note that all deaf participants in this study had similar characteristics. While the hermeneutic approach I have taken to this research does not aim to generalise research findings but to develop shared understanding, this raises questions as to how deaf people with diverse experiences of being deaf can be enabled to take part and inform research. I recognise this as a limitation of my study which will be discussed further in *Chapter Nine*. Deaf people who were interested in taking part were provided with the study information video via email.

The original snowball sampling approach to recruiting deaf participants wasn't totally ineffective. During the final stages of data collection, an interpreter who I had worked with both in this study and my teaching, asked for my contact details to pass on to members of the deaf community who she thought might be interested in taking part. Through being involved in the study, experiencing my teaching and seeing me at community engagement events I believe she saw that I was eager to engage both across and beyond the research study.

> "…she is starting to get a sense of what the study is about...something has changed in her understanding" [Reflective Diary 21/11/18].

I experienced a change in her approach from what Turner and Best (2017) call defensive interpreting to collaboration.

Nursing participants

Using established networks, convenience sampling was employed to recruit nurse participants to this study. Identification of potential participants was initially carried out with the help of NHS interpretation and translation service managers. This involved the service managers providing me with access to information regarding clinical areas that had required a BSL/English interpreter in each health board. Access to this information varied across different health boards depending on the managers' willingness to engage with the study and available statistics on the use of BSL/English interpreters. Many of the health boards did not have statistics regarding the level of demand for BSL/English interpreters and/or the areas that had requested them. This reflects the findings of the review carried out by Mapson et al. (2019) which highlights that records of BSL/English interpreting provision are often combined with spoken language booking, resulting in detailed statistics around use of BSL being unavailable. Managers from two out of the six health boards were keen to engage with the study and had up-to-date information on where BSL/English interpreter's services had been requested. Another board provided information on a three-month period of their usage of interpreting services.

Once I had information about clinical areas that had required BSL/English interpreters, I visited those areas to speak to nurses about my study. Each of these clinical areas were hospital based. Through this method of sampling, I recruited a small number of nurses to the study. However, from my engagement with the deaf community, I knew that many more nurses in each health board would have cared for a deaf person without having used a BSL/English interpreter. With information from interpreting services proving to be inconsistent, I decided to carry out ward-to-ward visits, at all major hospital sites in the six health boards, in search of clinical areas that I could potentially recruit nurses from. The decision to focus primarily on hospital sites, rather than community settings, was a practical one driven by the time restraints of this study. These visits to the hospitals involved me visiting each ward and asking nursing staff if they had cared for a deaf, BSL user. This provided me with an opportunity to engage with nurses face-to-face. I also contacted the clinical nurse managers in each health board via email and telephone, asking to attend charge nurse meetings at each site. Responses to these emails were not consistent but did result in me attending numerous charge nurse meetings to share information about the study.

In addition to carrying out ward-to-ward visits, posters (see Appendix 7) were placed in staff communal areas in the wards displaying information about the study and inviting nurses to take part. Nurses who had cared for a deaf person and expressed interest in the study were provided with a study information sheet (see Appendix 7). No participants were recruited via this method.

Interpreting participants

In *Chapter Five*, I explored the positioning of BSL/English interpreters in the triadic encounter and argued from Metzger's (1999) perspective that interpreters are active co-participants in the interaction. The initial objective of this research was to interview nurses and people who are deaf. Interpreters were not invited to "participate" as such because in my early interaction with interpreters and people who work closely with the deaf community it was strongly communicated that interpreters would not want to participate. The reason being that interpreters do not wish to speak on behalf of the deaf community or be their "voice". "Interpreters are just there to interpret" [Reflective diary 21/11/18] was a common message that was communicated by interpreters themselves. This suggested a "cloak of invisibility" (Llewellyn-Jones and Lee 2013, p.56) that interpreters take a neutral stance in the triad and was contradicting my reading relating to Metzgers (1999) view of interpreting approaches. As I began to work alongside interpreters, when visiting deaf clubs and interviewing deaf people, I began to observe and understand what participation of the interpreter in a triad meant. This was a relatively new experience for me. I began to understand that my relationship with them was important to the triadic interaction as we discussed the aims of the interview, negotiated the wording of research questions and checked in with one another after the interaction with the deaf person. Each time I worked with a BSL/English interpreter they actively shaped the interaction in a significant way. Therefore, as I progressed through the recruitment and data collection, I became increasingly aware of the importance of the interpreter's input in the interaction between healthcare professionals and people who are deaf. It became clear that my data would produce an incomplete picture of the nature of these interactions without the input of BSL/English interpreters as participants.

> "I hadn't [properly] questioned the idea that 'interpreters are just there to interpret'. This was something that Fiona emphasised at one of my supervision meetings - that interpreters will not want to reflect on the interviews afterwards as it was not their place to voice an opinion. They are there to translate, not participate in discussion or dialogue. However, I don't think the lines are that clear cut." [Reflective Diary 21/11/18]

Although I had originally highlighted the importance of interpreter's input (as interpreters) to the study, they had not originally been included as true participants. As I began to see a contradiction between my understanding of the interpreter's roles and the messages being communicated above, I sought theoretical explanation in the interpreting literature. Turner and Best (2017) developed the notion of 'Defensive Interpreting' that may be subconsciously ingrained as an automatic or deliberate response that maintains outdated messages in the interpreting profession. Therefore, despite extensive critique (Janzen and Shaffer 2008), the view of interpreters as an invisible conduit (the interpreter is there to interpret) has prevailed over time. Turner (2007) argue that the notion of the interpreter as invisible and disengaged ties into “institutionalised altruism” (Merton and Gieryn 1982, p.118). In essence, this notion suggests that what defines the profession is the adoption of selfless ethics. However, Turner suggests that this does not capture interpreter’s desire to advance social aims. Defensive practices would produce two-dimensional interpreting. However, in my work with interpreters, the act of interpreting appeared to be more of an art in which the presence of the interpreter was not static or invisible but depended upon moment-by-moment interaction and fluid role boundaries. The notion of the interpreter disengaged as a defensive behaviour has been thought to tie into the persistence of the conduit model (Hsieh 2006). As a result, Roy (1993) and Turner (2007) argue that no one really knows where to draw the line on the involvement of the interpreter in research. Additionally, Mole (2018) highlighted that sign language interpreters do not regularly have the opportunity to speak for themselves as the job often requires them to restrict expression of their own opinions.

BSL/Interpreters were recruited directly from Deaf Action. Through my contact with Fiona, information (see Appendix 7) regarding the study was provided to members of the interpreting team via email.

Maintaining momentum

During the recruitment phase of the research process, I encountered a challenge in establishing an understanding of the study amongst nursing staff. Over a period of 10 months, I engaged in ward-to-ward visits and managerial meetings, speaking to frontline and managerial nursing staff about my research topic. The purpose of this phase of fieldwork was to identify specific clinical areas in which deaf people had received nursing care and to recruit from these areas. While I was aware that challenges often arise during recruitment, I had not anticipated the confusion my research topic would cause nurses. The majority of nurses were unfamiliar with the concepts ‘British Sign Language’ and ‘sign language user’. Additionally, nurses were often unable to differentiate meaningfully between a person who is hard of hearing and a person who is a deaf, BSL user. Without a clear distinction, many of the conversations I engaged in involved an untangling of concepts related to deafness and subsequent language preferences to determine whether the person they had cared for was a BSL user or not. These conversations often required lengthy explanations in which many nurses appeared to be perplexed by the fact that BSL is a separate language from English. In these conversations, I therefore experienced the ongoing need to defend and raise the status of sign languages as bona fide languages.

In addition to the ward-to-ward visits, I had records of specific clinical areas[49] that had made use of a BSL/English interpreter in the past six months. Despite the records showing that a BSL/English interpreter had been booked for these specific clinical areas, nurses often appeared puzzled and could not recall a deaf, BSL user being cared for on the ward. In some wards this uncertainty extended to managerial staff. Responses to my question about whether or not a BSL user had been cared for in their clinical area often resulted in a variation of "I don't know they [deaf and hard of hearing people] all blend into one" [Response from Charge Nurse - Field notes 20/08/18].

Navigating my way through the hospitals, I often felt like a "wandering researcher". The dictionary's definition of wandering is "travelling aimlessly from place to place" (Oxford Dictionary 2019b). Although I set out with an aim to my hospital visits, it often did not feel directional or fruitful (messy). With nursing staff often being unsure about whether the person they had cared for used BSL as a first language, I was left wondering how the deaf person had experienced nursing care when staff were unclear about their first language and communication preferences.

With these conversations bringing little clarity as to whether a deaf person had been cared for in each clinical area, nursing staff often responded to my curious questioning with comments that explicitly or inexplicitly expressed a lack of applicability to or a lack of interest in the study. Recorded responses in my field notes included:

> "No, we don't get deaf patients here" [Fieldnotes 26/06/18]
>
> "None of the nurses here speak sign language" [Fieldnotes 04/07/18]
>
> "No, we had a deaf man a few months ago but he could lip-read" [Fieldnotes 20/08/18]
>
> "I can't say we do [get BSL users]" [Fieldnotes 21/08/18]
>
> "No but we're pretty good here" [Fieldnotes 09/10/18].

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[49] As stated previously two out of six of the health boards had up-to-date statistics regarding clinical areas that had required a BSL/English interpreter

I began to feel disheartened at the lack of engagement with the topic and level of confusion I was encountering in these conversations:

> “There have been many moments today when my sense of purpose has been questioned and depleted due to peoples’ confusion regarding the study. When explaining the study to staff a lot of people have responded with messages that suggest I have come to the wrong place to recruit, as deaf people wouldn’t require their services. Members of staff politely direct me towards ENT as that is where ‘they’ are likely to be.” [Reflection 24/09/18]

Despite the puzzled responses I received from nurse’s time and again, I continued to visit hospitals, ticking each ward off my list as I visited. At the time of this study, there was little information about how to go about carrying out research with the communities that I wished to engage with. Because of this, I often questioned my methodological decisions and wondered what more I could do to improve the sample recruitment size. Upon reflection, I was focused on *doing* in this part of the research and believed that successful recruitment relied solely on my effort and determination. In an attempt to achieve academic credibility through sample numbers, I had persevered visiting multiple wards in search of participants but had not been critically reflecting on what the conversations I was engaging in were revealing. I began to critically question what the conversations I was having were telling me about the context and culture of care. It was evident that the beliefs about deafness held by nurses was reflective of the biomedical perspective held in wider society. The numerous misunderstandings and myths about deafness, sign language and deaf communities suggested that the experiences of deaf people, both in and out with the healthcare environment parallel one another.

Participants

I originally intended to recruit six deaf people and 12 nurses to this study. However, as a result of challenges recruiting participants nine nurses, four deaf people and three interpreters took part. Among cultural groups who exist in small communities, identifying someone’s characteristics or occupation may cause them to be highly visible (Schank et al. 2010), consequently broadcasting their identity despite the use of pseudonym (Young and Temple 2014). The challenges of keeping anonymity for deaf participants in research have been well-documented (Harris et al. 2009; Young and Temple 2014; Kusters et al. 2017). Young and Temple (2014) emphasise that even generalised descriptors of deaf peoples’ characteristics, for example their job title, could identify them due to the size and socioeconomic characteristics of the community. Decisions regarding anonymity must therefore take into account peoples’ situated social position. For the purpose of this study, I have limited detailing the demographic characteristics of all participants to avoid unintentionally breaking confidentiality.

Nurses

The nine nurses who took part worked in a range of different settings that included hospital and community settings. The experience of these nurses also varied. Many of the nurses I interviewed were sharing their first and only experiences of caring for a deaf person. Others took part because they had a personal interest in the topic. Table 6.4 displays each nurse participants' clinical role, the strategy used to recruit them to the study and their knowledge of deaf communities.

Table 6.4 Characteristics of nurse participants

Name	**Clinical role and setting**	**Recruitment strategy**	**Knowledge of BSL/Deaf communities**
John	Advanced nurse practitioner working in acute care	NHS interpretation and translation statistics	No prior experience
Emily	Advanced nurse practitioner working in acute care	NHS interpretation and translation statistics	No prior experience
Jane	Staff nurse working in acute care	NHS interpretation and translation statistics	No prior experience
Adam	Staff nurse working in acute care	Ward visit	Fluent BSL user, deaf family member
Kelly	Staff nurse working in acute care	Ward visit	No prior experience
Rachel	Senior staff nurse working in acute care	Ward visit	Knowledge of basic signs
Sophie	Staff nurse working in acute care	Ward visit	Completed online deaf awareness training

Anna	Senior staff nurse working in acute care	Ward visit	Knowledge of basic signs, deaf work colleague
Beth	Health visitor working in community care	Snowball sampling	Completed basic BSL course and deaf awareness training

Deaf people

The four deaf people who took part in this study all held characteristics of what Holcomb (2013) terms the 'deaf elite'[50]. They were fluent in BSL, expressed having a good understanding of written English, a number were second generation deaf[51], held middle class jobs, worked in a job that actively promotes the awareness of deaf culture, and participated in local advocacy. In contrast to the deaf elite, the majority of deaf communities are made up of what the deaf communities call grassroots deaf. Those who are classed as grassroots deaf experience lower socioeconomic status in mainstream society as a direct or indirect result of language deprivation (Padden and Humphries 1988; Ladd 2003; Holcomb 2013). I use the notion of deaf elite in this research to highlight the different social constructs in deaf and hearing cultures, and subsequently the influence these can have on a person's behaviour. This may have implications for who feels empowered to take part in research and subsequently deaf epistemologies. The notion of deaf elite is further explored in relation to theory in *Chapter Eight* and the implications this has for the knowledge produced in this research is critiqued further in *Chapter Nine*.

BSL/English interpreters

Three BSL/English interpreters took part in a focus group in which they explored what it is they value about their profession. This provided rich data that meaningfully captured BSL/English interpreter's roles in interactions between a deaf person and hearing person who do not share a common language. The three interpreters who took part in the focus group study were recruited via Deaf Action. All were qualified BSL/English interpreters with varying levels of experience.

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[50] Holcomb (2013) describes people who are deaf elite as being second generation deaf, relatively well educated, hold middle-class jobs and actively participate in local and national advocacy.

[51] Second generation deaf refers to deaf people who have deaf parents but hearing grandparents. Therefore, they have acquired a sign language naturally from their parents (Deuchar 1984).

Consent

Pollard (2002) highlights that there are three specific ethical issues which become increasingly complex when carrying out research with deaf people: the use of deception, preserving the anonymity of research participants, and obtaining informed consent. As mentioned in *Chapter Three*, deaf people are commonly at an increased risk of what has been termed as ‘low fund of information’ (Pollard 2002). Fund of information refers to the accumulated knowledge individuals have from picking up facts through casual conversation and access to media (Young and Hunt 2011). Low fund of information may result in concepts such as ‘consent’ being unfamiliar. The process of informed consent is made increasingly complex when working with people who are deaf due to the visual nature of their first language because the informed consent is typically documented in written form. Additionally, sign language preferences and proficiencies differ widely in the deaf population. To avoid the possibility of information gaps or misinformation in this study, adequate communication arrangements, via a qualified BSL/English interpreter were made. The formal consent process was viewed as a consent conversation, in which I was sensitive to preexisting knowledge and the possibility of information gaps. Prior to this consent conversation participants were given time to watch the study information video for a second time. This also provided the interpreters with an opportunity to gain a better understanding of the research. After watching the information video, potential participants were encouraged to ask questions to ensure the study processes were understood.

In addition to gaining formal written consent from all participants (see Appendix 8), consent was viewed as a process that threads through the whole length of the research. Therefore, I continually looked for signs from participants indicating that they were happy for the conversation and engagement to proceed. The underlying conditions incorporated in process consent are informed flexibility, sympathetic presence, negotiation, mutuality and transparency (McCormack 2003; Dewing 2007). The process consent method contains five elements: background and preparation, establishing the basis for capacity, initial consent, ongoing consent monitoring and feedback and support. These elements are not linear but are fluid according to context and the people involved. The two fundamental questions that the researcher needs to reflect on can be summarised as ‘is this person consenting?’ and ‘does this person have (informed) appreciation of their consent?’ (Dewing 2007, p.15). Asking these questions involves the whole of the researcher’s ‘embodied sensibilities’ (Greenhough and Roe 2011, p.53). Process consent adds clarity to any informed consent that has been achieved and helps the researcher respond to any challenges about their decision-making processes. Additionally, informed consent is congruent with a relational approach to ethics in which ethical moments arise out of ongoing interactions during the research process.

Location & space

Interviews with deaf people were carried out at a location of the participant's choice. For all participants this was either their place of work or their local deaf club. Interviews with nurses were carried out at their place of work. More specifically, these conversations took place in offices and meeting rooms that were available. Reflecting the chaotic nature of the hospital, these conversations were occasionally interrupted by people also looking for a quiet space to talk to relatives or to make a phone call. The focus group with interpreters took place in a meeting room at Deaf Action's main headquarters.

As explored in *Chapter Two*, deaf people inhabit a rich sensory world in which vision and touch provide awareness and orientation. It should be appreciated that a core idea of Deaf Space is that sign language is primarily direct visual contact (Tsymbal 2010). The concept of 'Deaf Space' began at Gallaudet University as part of the development of a new communication center. The project team recognised that when deaf people gather they build a safe place for self-expression. Creating this space may involve rearranging furniture into a conversation circle and adjusting lighting to optimise visual accessibility (Lewis 2013). Language moves (quite literally) in this space through the spatial and temporal aspects of how sign language is produced. This Deaf Space allows culture to manifest itself in the physical world (Byrd 2007). In the triad (interpreter, deaf person, researcher), we negotiated the way the physical space we were in could best be set up for all those involved. This was a short discussion between the deaf person, the interpreter and myself that was routinely initiated by the interpreter. Over time, this discussion became integrated into my ways of working as I realised the significance of setting up the space for any kind of interaction. Therefore, creating a physical space in the environment that responded to our ways of being enabled a communicative space (Habermas 1972).

Data collection processes

Defining 'data'

As a methodological approach, hermeneutics inquiry assumes an understanding of research as an unfolding story (Van Manen 2014). The story is understood through data that reflects this unfolding. Data included my reflective field notes, interview transcripts, focus group transcripts and my creative expressions. McCaffery et al. (2012) suggest that the term 'data' implies separated objects of knowledge. From this perspective data collection is viewed as the process by which to capture these objects and analysis involves a distanced examination of them. However, the hermeneutic spiral suggests that interpretation and analysis is non-linear and open to ongoing interpretation (Gadamer 2013). In this research, the data were experienced and considered in a fluid manner, creating an ecological sense of the 'bigger picture'. Data were therefore captured at different stages of the research process, creating a continuum of data collection and analysis that stemmed from my initial fieldwork through to data analysis. Table 6.5 shows the research stage at which each method of data collection took place.

Table 6.5 Data continuum

Research stage	Recruitment	Formal data collection	Data analysis
Data collected	• Reflective field notes	• Semi-structured interviews • Focus group • Reflective field notes	• Creative expressions • Reflective notes

This data continuum will be explored further throughout this chapter. However, the following sections describe data collection methods that were utilised during the formal data collection period.

Semi-structured interviews and one focus group

Data were collected through individual semi-structured interviews and one focus group. Due to the exploratory nature of this research, I decided to engage in semi-structured interviews, with participants who were deaf and nurses, in the hope of generating deeply contextual accounts in which participants could explore what they believed to be meaningful (Ellingson 2017). With a focus on exploration of experiences, understanding, values and perceptions, each interview allowed for flexible, in-depth exploration of the topic. The flexible nature of a semi-structured interview was favoured as I was able to make use of interview topic guides (see Appendix 9) containing open-ended questions. In exploratory research, interview topic guides are often emergent i.e., they develop over the course of the study as preliminary interviews reveal emerging themes (Holloway 2005). To allow the interviews with deaf people to inform the interviews with nursing participants and vice versa the initial plan for research was not tightly prescribed and there was a degree of overlap between stages of data collection and data analysis (Sim and Wright 2000). The broad, semi-structured nature of the interview provided participants with the freedom to talk in-depth about their experiences (Dearnley 2005), ascribe meanings and explore new paths that emerge during the interview (Silverman 2011). The development of the interview topic guide for the interviews with deaf people was created in collaboration with Fiona to ensure that the questions were linguistically and culturally understandable and appropriate. Additionally, some of the BSL/English interpreters, who were interpreting during the interviews with deaf people, wished to see the interview guide prior to the interaction to clarify their understanding and ensure a fluid interpretation.

Approach to data collection

My approach to the semi-structured interviews was influenced by principles of narrative inquiry and emotional touchpoints (Dewar et al. 2009). In the interviews, I hoped to move away from a relationship of interviewer-interviewee to narrator-listener. This provided a conceptual shift away from the notion that interviewees have answers to the researcher's questions and towards the idea of narrators with stories to tell. As the listener, it was my role not only to attend to the story but to invite the story. Wengraf (2004) places emphasis on 'inviting narrative' believing that this allows the conversation to become less structured and more in-depth. Often people find it difficult to verbalise the stories that tap into the tacit understanding of experiences. As a result, stories can appear distorted due to rationalisation (constructing logical judgement) and reasoning (looking for reasons for beliefs, conclusions, actions and feelings) or information may be withheld because of negativity of rational thought (Van Lieshout and Cardiff 2011). Additionally, Freshwater and Stickley (2004) state that generally people do not have a rich emotional vocabulary. Therefore, it is crucial to enable people to move beyond bland statements of 'it was fine' and 'we managed'. Creativity can aid the surfacing of embodied, tacit knowledge (McCormack & Titchen 2006). Therefore, the role of creativity in research methods can facilitate exploration of peoples' experiences that might not be accessed by mainstream methods that rely on linguistic articulation (Higgs et al. 2007).

Dewar originally used emotional touchpoints to enable nursing staff to hear the voices of patients and families and learn about their experiences of care. By focusing on emotions related to personally meaningful moments (touchpoints) for patients and their families, staff were able to engage in ‘real’ dialogue that contributed to the uncovering of caring practices that are not easy to define. Dewar et al. (2009) emphasised the importance of picking up on cues and asking questions that relate to what the person is saying during these conversations to allow the person to decide what is important to focus on. By implementing a creative, yet less structured approach to conversation a more in-depth exploration of experiences is gained. In this study, I made use of Evoke cards (Stokes 2017) and The Bear Cards (Veeken 2012) to tap into peoples’ stories. This differed from Dewar’s use of emotional touchpoints in that pictorial cards were used to invite narrative by asking the participant to select cards that they felt related to their experience. This provided participants with an opportunity to reflect on their experience with the cards providing visual cues to trigger memories. Some participants used the cards as reference points to begin sharing their experiences while others made little reference to them. I often returned to these cards if the flow of conversation became stilted or I wanted to explore elements of a participant’s experiences in more detail. Therefore, the cards were used to invite story and to give the participants visual prompts that helped them to explore what was meaningful in their experiences.

I collected data with the interpreters through a focus group. Wenger (1999) draws our attention to the importance of communities of practice and the ways in which practitioners need to come together and share stories of practice so that they can learn from each other. Focus groups have the advantage of providing a social context for meaning making and tap into social processes of communication. With a focus on exploration of experiences, understanding, values and perceptions, the interviewer can allow for flexible in-depth exploration of the topic (Liamputtong 2010). The idea behind the focus group method is that group processes can help people to explore and clarify experiences and meaning in ways that are less accessible in a one-to-one interview. Group discussion is particularly appropriate when the interviewer has a series of open-ended questions and wishes to encourage participants to explore the issues that are meaningful to them by generating their own questions and pursuing their own priorities (Ellingson 2017).

My role as facilitator

My role in the focus group was to facilitate the group discussion. The focus group opened with an activity in which I asked participants to think about what it was that they value about their profession and choose Evoke card(s) (Stokes 2017) that resonated with those values. Using these cards, I invited participants to share their thoughts in the group. This encouraged an open discussion. Participants were encouraged to elaborate on their discussion through the telling of stories from their practice. In the focus group, I took on the role of facilitator and was actively participating in the discussion. I also had an observer present to take notes that would capture elements of the discussion that I may not have been able to observe as facilitator, as well as feeding back on my performance as a facilitator to improve my research and facilitation practice. Such non-verbal responses and reactions can carry information to supplement and on occasions contradict verbal responses (Halcomb et al. 2007).

In both the individual conversations and focus group discussion, I utilised nursing skills of listening and encouraging, allowing the narrator to introduce anything they felt to be important. This means that the initial plan for research was not tightly prescribed, and some phases of the process changed or shifted so that we did not cover the questions I had developed in the guides (Creswell 2014). Additionally, I was able to draw from my facilitation skills to 'hold the space' in the focus group discussion, through use of appreciative dialogue (Dewar and Sharp 2013). Appreciative dialogue can be facilitative by careful, curious questioning aimed at asking people to consider possibilities and connect with each other emotionally using affirmative language. Appreciative dialogue can support other people to become more facilitative (Dewar and Sharp 2013). This occurs in the context of relationships and plays out in our day-to-day conversations with one another. I implemented the principles of caring conversations (Dewar and Nolan 2013) in my appreciative dialogue, ensuring that the seven C's were at the forefront of my mind; *be courageous, connect emotionally*, *be curious, collaborate, consider* other perspectives, *compromise, celebrate.* I asked questions such as 'What do you think is going on here?', 'How does that make you feel?', 'What strikes you about this?', 'can you share a little more about that?', 'what is important to you?' Dewar and Sharp (2013) emphasise that through the nature of appreciative inquiry questions, we engage in a collaborative activity in which we become co-facilitators or facilitative participants. Questions that are developed from the seven C's facilitate the exploration of what matters to people.

Inviting narrative with the deaf participants was much easier than with the nurses. Deaf participants often shared "long stories, in detail" [Reflection 19/10/18]. Although storytelling in any community is an important way to pass on linguistic and cultural knowledge, signed stories have long been recognised in deaf communities as a cornerstone of deaf culture (Hall 1989; Rutherford 1993; Peters 2000). Sign Language in itself is how stories, jokes and poems are passed down through generations. Although this may be said for other languages, because sign language has no written form the sign language through which they are shared act as visual artefacts (Trahar 2013).

Originally, I had intended interviews with deaf people to inform the interviews with nurses and vice versa. However, due to the recruitment challenges discussed earlier in this chapter, I had interviewed most of the nurses before completing my first interview with a deaf person. Therefore, the interviews with nurses informed the interviews with deaf people. Additionally, all interviews informed my facilitation of the focus group as this was the final data set to be collected.

Data recording

All interviews and the focus group discussion were audio recorded with recordings transcribed by myself for analysis. Due to the visual nature of BSL, I had originally sought to video record the interviews with deaf people. However, during recruitment it became apparent, in my conversations with employees of deaf charities, that video recording might cause people to avoid participating.

> "…it can be really tricky to get people from the deaf community to do a video recorded interview. There is a formal element to the conversation they [deaf people] shy away from for fear of how/where that information will be used. Deaf people don't want anyone to get into trouble and don't want there to be negative consequences for themselves or anyone else if they return to the same hospital or clinical area" [Reflection 05/09/2018]

Therefore, I decided not to video-record interviews but to audio-record the interpreter's English translation of these interviews.

Creative hermeneutics analysis

In research methods, the process of data analysis aims to identify what is considered essential meaning in the raw data. This involves reducing, reorganising and combining the dataset so that the product of analysis is a creation that speaks to the heart of what was learned (Ely et al. 1991). Data from this study was analysed through a process of creative hermeneutics analysis (Boomer and McCormack 2010; Van Lieshout and Cardiff 2011). This was underpinned by Gadamer's (2013) philosophy of hermeneutics and Merleau-Ponty's (2012) philosophy of embodiment. Drawing from the hermeneutic spiral, analysis is understood as non-linear and is open to the possibility of ongoing interpretation.

Rather than viewing the analysis process through a linear framework, I understood analysis as involving layers of interpretation (Finlay & Evans 2009) that resulted in a ‘relational dance’ (Finlay 2006a). Therefore, analysis is a textured, back and forth engagement with the data that is often chaotic in nature (Finlay 2006a). In this study, data were collected through interaction with people. My assumptions (outlined in *Chapter One*) were the horizon of understanding from which I approached data collection. As I came to the analysis stage, I was aware of my knowledge of the data and initial analytic impressions that developed during data collection. These have been collected in reflective field notes (observations, reflexive journal entries, stories and conversations) throughout the recruitment and data collection period. Therefore, data analysis began as initial thoughts and interpretation and questions were recorded (Tuckett 2005). Archiving all records of this ‘raw data’ provided me with an audit trail and benchmark against which further analysis took place.

Finlay (2014b) argues that the main challenge for researchers engaging in analysis is to push beyond that which they already know from their horizon (experience and knowledge). Therefore, I aimed to come to an understanding that does not arise from simply interrogating the data but rather allowing my horizon to be questioned by the data (Boomer and McCormack 2010). One of the overarching questions I employed during analysis was: How do I relate to the data in my own being? By being open to concepts that I wished to understand and exploring meaning for the participants, this process brought to light prejudices that may need to be critiqued to encourage the formation of new meaning. This process facilitated a heightened awareness of self personally and professionally.

From a Merleau-Pontian (2012) perspective, my body enables me to experience and understand. Therefore, my body is the foundation of my interpretation and analysis. To approach analysis holistically, an attentiveness to my body was essential. Traditionally, thematic analysis has focused on using cognitive knowledge to draw out codes and themes from the data (Chadwick 2017). Through use of cognitive knowledge alone, researchers fail to acknowledge pre-cognitive knowledge that Merleau-Ponty (2012) writes about. Therefore, the fullness of our tacit knowledge and multiple ways in which the body shapes the way we think is denied or suppressed. Being mindful of the fusion of mind, body and spirit (explored in *Chapter Four*), it was important for me to find a way of analysing that would not silence the spirit or render the body invisible. Therefore, I used a range of approaches that would stimulate multiple intelligences in the analysis process. These will be woven into my findings chapter. In order for data analysis to be carried out in a systematic and transparent way I have developed a six-phase framework for the analysis of my data. It must be noted that these were not carried out in a linear fashion.

Presencing

Working from the premise that all knowledge is based on tacit knowledge and therefore derived from the senses, I wished to engage in presencing (Senge et al. 2011). Senge et al. (2011) explain that presencing blends the words ‘presence’ and ‘sensing’ and works through seeing from a deep source. I believe that presencing is directly related to the deep silence (Dauenhauer 1980) that allows stillness of dwelling in the body’s senses (Merleau-Ponty 2012). Gendlin (1993) writes about the edge of awareness in which he describes a felt sense at the edge of our thinking that we cannot yet think. By being with this felt sense through presencing, our bodies shift in how they are experiencing something and meaning is revealed. Such a felt sense stems from what we already know but opens up to new meaning. Therefore, rather than jumping into the type of “head work” that thematic analysis is often driven by, I wanted to engage with what my *whole* body might reveal about the data in stillness. According to Scharmer (2007) part of presencing involves “letting go” and “letting come” (p.179). This process does not happen through one prescribed activity but through a whole set of practices that quiet the mind. I created space for my body to let go and let come by doing full body scans[52], taking walks, practicing yoga and choosing to work in the countryside where I felt able to practice stillness. I engaged in these practices at different times during analysis bringing conscious self-awareness to and about the body (Leigh and Bailey 2013). This enabled the use of my body as a grounding of knowledge both pre-reflectively and reflectively (Smears 2009).

Dwelling

Hermeneutic analysis requires that the researcher dwell with the data. This phase involved becoming familiar with the material that I was working with and beginning to draw out overarching themes and patterns. Through ‘being with’ the data I aimed to sense the story through experiencing it in my wholeness (emotions, imagination, embodiment). Although familiarisation begins during data collection, it extends into the formal analysis phase allowing researchers to sense the essence of the conversation (Ely et al. 1991) and initial impressions to materialise. Finlay (2014a) engaged in a way of being in her research that employed concepts of embodiment to dwell with the data. Sensing into the meaning of things and noticing what comes from that space, she asked two questions of herself:

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[52] A full body scan involves mentally scanning yourself from head to toe to notice how the body feels. This method of meditation can provide grounding that helps to sync mind and body (Headspace 2019).

How is this engagement making me feel in my body?
What might that body sensation be saying?

Throughout data analysis I kept these overarching questions in mind and made time to pause and capture my felt-senses. When asking these questions, I searched for a word or image for the felt-sense I was experiencing. I then captured this using creative imagination and expression. During the transcription and analysis phase, I listened to the audio recordings of interviews and through a re-experiencing and re-embodying (Finlay 2014a) of the conversation, I recorded memos that answered these two key questions. This enabled me to enter into dialogue with my felt-sense. In listening to the transcripts, my body reacted to the emotion that lay beneath the surface of the encounter (Sharma et al. 2009). This emotion was captured in creative expressions and viewed as knowledge.

By dwelling with the data, implicit, layered meanings develop. Dwelling involves more than a passive pause in which we wait for meanings to somehow emerge. Instead, meanings are unearthed and themes are shaped. Giorgi (2009, p.131) emphasises that meanings are “detected, drawn out, and elaborated”.

Theming

Thematic analysis focuses on identifying and describing both implicit and explicit ideas in the data through holistically attending to the research data (Van Manen 2014). These are known as themes. Themes are often threaded throughout the collection of data or can be single meaningful accounts deemed significant to understanding the whole (Ely 1984). Van Manen (1990) emphasises that themes are recovered or embodied in the developing meanings and imagery of the data. Due to the exploratory nature of the study, an inductive approach to analysis was employed. Emphasis was therefore placed on what meaning was constructed from the interaction between myself (listener) and the participant (narrator/storyteller). As the purpose of this research is to explore a little-known phenomenon the analytic objectives were driven by the research questions and objectives. The questions and objectives embedded the values, and direction of inquiry, therefore framing how the data were viewed and ultimately determining which themes were worth tagging, defining and coding.

Ely et al. (1991) encourages the analyst to be playful during the code and theme development, comparing, contrasting and looking for links. Writing analytic memos during these processes supported coding and theme development. Memos are part of the initial theme and code generation process and act as understanding of themes in the form of free thinking (Ely et al. 1991). Through memos I noted initial thoughts, potential categories and connections. Memos allowed me to find a focus without committing prematurely to a particular perspective and so excluding options for analysis.

During analysis I wished to be sensitive to nuance and texture of the triadic engagement. Guests et al. (2014 p.122) suggest creating a method for tagging non-verbal cues in data. These includes body language/gestures, intensity of expression, and tone of voice. In this study, I wanted to note the meaningful contribution of nuances in the interpreted interaction. Acknowledging the triadic nature of the interpreter interaction, I wished to pay attention to how these unfolded. Young and Temple (2014) suggest numerous features of the interpreted interaction which may influence the research encounter. Many of these relate to the interpreter's background and connection with the deaf community. However, I believe that by listening to the audio recordings alongside reading transcripts and field notes, there may be meaning in the space shared by myself, the interpreters and the participants that could not be found by reading the transcripts alone. Finlay (2014a) describes this as re-experiencing the sense of it. Such engagement with the audio recordings and field notes from these encounters may result in the discovery of meanings that are not evident in the research transcripts.

Expression

A critical creative worldview (McCormack and Titchen 2006) assumes that embracing creativity can facilitate expression of tacit knowledge. Creative imagination and expression have been understood to blend embodied knowing and meaning into cognitive analysis (Higgs et al. 2007; Titchen and McCormack 2010; Senge et al. 2011). Therefore, working with creativity enables us to realise the essence of experience and through creativity, capture the power and meaning of that experience. Bortoft (1971) offers the analogy of an actor embodying his part in a play. This process is not simply the mechanical reading of “lines” but rather the actor gives himself to the flow and flux of the play. This avoids restricting oneself to the analysis of decontextualised words that runs the risk of missing something important (Finlay 2006a). Releasing from the formal processes of analysis that often involve “head work”, creativity can open to new ways of seeing and understanding. Therefore, understanding is enhanced by attending to the body (Finlay 2006a). Creative expression enabled me to reshape my understanding of the parts (unidimensional) into the whole. This presented a web of connections and relations between the parts

(Simons and McCormack 2007). In analysis, I used paint and authentic movement to express my understanding of data.

The purpose of the authentic movement was to capture the meaning of the data as a whole. Therefore, the process of engaging in authentic movement took place after analysis of the individual transcripts (parts). Whitehouse (1979, p.2) who originated the process described it as “movement-in-depth” which is based on Jung’s (1916) concept of active imagination. Authentic movement is thought to bring unconscious, tacit understanding to conscious awareness through movement. Therefore, it can reveal embodied, intuitive knowing by following the lead of the body (Pallaro 1999; Horsfall & Titchen 2009). Working in pairs, one person moves with eyes closed following the lead of the body, while the other witnesses. The witness watches with uncritical eyes to support through ‘being there’ existentially and empathetically (Titchen et al. 2011).

I chose to practice authentic movement on the beach with a critical companion[53] (Titchen 2000), Niamh. When we arrived at the beach, Niamh and I spent time in a silent walk that enabled us both to connect to our senses and to the space. After grounding myself, I danced out the data in authentic movement with my eyes closed and Niamh observed. Once I had finished, Niamh drew out what movement she had seen in the sand to provide a visual from which we could have a reflective conversation. We then had a reflective conversation that was recorded and transcribed (see Appendix 10). This brought the themes to life as a whole.

Refinement

This phase involved the refinement of themes. Raw data were used to guide confirmation of themes, with verbatim extracts being selected to represent them. Themes were detailed with a description and amended based on evidence from the data. Relationships among the codes and themes were then displayed and questioned. The act of identifying themes in text, among other components of the data analysis process are highly interpretive acts. Therefore, there is always a need to always refer back to raw data and select extracts based on their ability to exemplify the intended concept and ensure that themes are grounded (Guest et al. 2014).

Reflection

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[53] Titchen (2000) defines critical companionship as a helping relationship in which a more experienced facilitator accompanies another person on an experiential learning journey, using methods of ‘high challenge’ and ‘high support’ (Johns’ 1997) in a trusting relationship.

Transparency of process is critical to ensuring the validity and reliability of hermeneutic analysis. Engagement in reflective and reflexive processes that enables heightened awareness of meanings as they evolve is therefore essential. Schön's (1983) and Dewey's (1933) approaches to reflective practice, explored in *Chapter Five*, were key to this process as I unearthed assumptions and made new meaning. This facilitated an exploration of the relational process between me and participants as a means to understanding more deeply. Reflection is undertaken, not as a self-indulgent activity but as a way of gaining further insight into our embodied, intersubjective world (Finlay 2014a). Therefore, reflexivity is a continual process of reflection upon interpretations of our own experiences and others experiences, to move beyond previous understandings (Finlay 2013). This active, critical way of thinking and doing leads to an understanding of the fusion of horizons between researcher and participant (Gadamer 2013; Finlay 2014b).

This method of analysis facilitated a dialogue with myself in which multiple inner perspectives were critiqued. Unlike the linear presentation of each phase above, the analysis phase was dialogic and therefore involved free movement between phases. Benner (1994, p.116) believes that researchers engage in "cycles of understanding, interpretation, and critique", viewing all interpretations as complete but never ending.

Conclusion

In this chapter, I have shared the methods employed in the research study to clarify the interpretive conditions through which understanding took place. I have emphasised that understanding does not simply emerge during analysis but is constructed throughout each stage of the research process. Therefore, I have storied this chapter with the intention of being transparent about how my relationships with others developed and my understanding during fieldwork unfolded. I was aware that potential participants might be challenging to locate and access due to the lack of sampling frames available for research with deaf people. I have articulated the challenges I faced in the fieldwork and how I overcame them with the guidance of those who work closely with the deaf community. While some of this has involved me making practical decisions, in the timeframe of the study, I believe I have shared a clear audit trail of how I have applied the methods in generating and analysing the data. In *Chapter Seven*, I will now present the themes and subthemes developed from the analysis.

Chapter 7: Findings

Introduction

This chapter presents the story of my conversations with nine nurses, four deaf people and three BSL/English interpreters over a period of approximately seven months. The purpose of this research was not to understand participants' experiences as isolated cases but as social beings. Therefore, rather than separate the three groups (nurses, deaf people and BSL/English interpreters), I share the overall picture that has developed from my interaction with all people who engaged with this research. This reflects my philosophical and methodological stance and is true to my experience as a novice researcher in exploring the parts (individual narratives) and whole (context) of the story. Interlinked and overlapping to varying degrees, the subsections of this chapter provide a structure for synthesising the themes and core narratives that emerged through the research process. In keeping with the ethical principle of anonymity, each person who took part has been given a pseudonym to prevent them from being identified. These pseudonyms are displayed in table 7.1 to help the reader to navigate the findings chapter. Additionally, I have used abbreviations in the text when referring to quotes to help the reader identify the source (See table 7.2).

Table 7.1 List of participant pseudonyms

Psuedonym	**Background**
Carly	Deaf person
Lindsey	Deaf person
Hayley	Deaf person
Peter	Deaf person
John	Registered Nurse
Emily	Registered Nurse
Jane	Registered Nurse
Adam	Registered Nurse
Kelly	Registered Nurse
Rachel	Registered Nurse
Sophie	Registered Nurse
Anna	Registered Nurse
Beth	Registered Nurse
Harry	BSL/English interpreter

Tina	BSL/English interpreter
Cat	BSL/English interpreter

Table 7.2 Abbreviations used in the text to identify the source of the data

The source of the data	**Abbreviation used in the text**
Deaf person	DP
Registered Nurse	RN
BSL/English Interpreter	INTERP

The nature of the data

The parts

As highlighted in *Chapter Six*, the expansion of my understanding and interpretation of the social context of this research was not restricted to the interviews and focus group I facilitated but was integrated in the whole of my practice as a researcher in the field. Data went beyond participant's experiences to include meetings, ward-to-ward visits, networking at conferences and ad-hoc conversations in an attempt to understand the experiences shared in the wider social, cultural and political context. Therefore, the narrative of the findings is intertwined with examples of direct quotes and extracts from multiple data sources (i.e., field notes, interview transcripts, reflective diary entries) as well as other sources through which a number of people and stories have been introduced in *Chapter Six*.

In *Chapter Six,* I shared the different ways in which creative methods were used to analyse data in this study. Through re-listening to each interview, I re-embodied (Finlay 2014a) the conversations and captured my tacit understanding of each interview in a painting. These paintings allowed me to capture what I believed could be missed through simply reading the transcripts and will be used to display my interpretations of the data. In a reflective discussion with my supervisor Brendan, I identified the contrast between the themes that I had drawn out of the analysis process and the colour/vibrancy of the paintings I had created. We discussed what this reflected and how it told a story of the juxtaposition of the themes (whole) and each nurse's desire to provide person-centred care and be sensitive in the care they provided (parts). This juxtaposition is useful as it allows the complexity of experience and meaning, which would have otherwise remained invisible, to be revealed. This complexity of experience may be key to understanding the experience itself. These pictures will therefore be woven throughout my findings chapter along with the authentic movement.

The whole

Although the participants in this study were not known to each other, their stories are located in the wider context of the relationships between hearing healthcare professionals and deaf people. Therefore, the findings from this research rest neither on singular relations between various parts, nor on a presumed congruence between parts and whole. Rather, paradoxes and contradictions are acknowledged and explored, while at the same time identifying shared meanings (Manley et al. 2008). Drawing from and moving between the whole of the research story and the individual parts reflects the nature of the hermeneutic circle (Gadamer 2013). I focused on the insights that I gained from the stories themselves and from the interplay among different narratives, interpretations and reflections. As highlighted in *Chapter Five*, the philosophical position of critical creativity embraces the multiple realities that are honoured and included at the same time (Koch 1996). Each part or component of the hermeneutic circle has been analysed before being reintegrated into the whole. Rather than understanding resembling a closed circle, Paterson and Higgs (2005) proposed a hermeneutic spiral in which understanding is ongoing and evolving. The hermeneutic spiral acknowledges the historical and social context in which understanding of the present is formed and situated. Therefore, this chapter seeks to illuminate the stories in their social, political and historical context.

Figure 7.1 Authentic Movement

The picture in Figure 7.1 is an image representing the movement I made in the sand during the authentic movement, introduced in *Chapter Six*. My critical companion Niamh and I shared our experiences of and learning from the authentic movement in a reflective dialogue which can be seen in Appendix 10. I have chosen to share this part of the process at the beginning of this chapter because it captures the whole of the research story from which the parts unfold. The image represents the kind of movements that I made and the connections I made between the movement and research experiences, in my reflective dialogue with Niamh. From this dialogue the four main themes of the research were drawn out: *The Unknown, Borders, (Im)possibilities* and *Authentic Engagement*. These themes and subthemes represent the research process and the findings from analysis. I will use different elements of the authentic movement reflective dialogue to introduce each theme. In Table 7.3 I present the themes and sub-themes that will be described below. In vivo themes are enclosed in inverted commas.

Table 7.3 Themes and subthemes

Themes and sub-themes
The Unknown

The ‘façade’ ‘Underneath’ ‘Layers’
Borders ‘The same old story’ ‘I was invisible’ ‘I’m just deaf’
(Im)possibility Stuckness Visual people
Authentic engagement Shifting perspectives ‘Little things make a big difference’ ‘Between us’

The Unknown

This theme reveals *The Unknown* into which participants appeared to enter when engaging with people or practices that were new to them. Nurse participants were often caring for a deaf person for the first time. Deaf people were often entering into the healthcare system with little knowledge of how the system functioned and/or how to navigate it. For deaf people, *The Unknown* was experienced as a lack of information regarding their healthcare being made accessible to them and healthcare professionals being unaware of their language and care needs. For nurses, *The Unknown* reflected their lack of awareness of deaf peoples’ unique care needs and the different approach to care that these needs necessitated. As a result of nurses’ ignorance and deaf people not being able to communicate their needs or their experiences, a *Façade* existed whereby nurses believed their approach to caring was effective. However, deaf people expressed that *Underneath* they felt their experiences of care were negative. The interpreter participants indicated that the relational dynamics between healthcare professionals and deaf people are influenced by complex *Layers*. These *Layers* relate to power dynamics, language ideologies and constructions of deafness that often manifest in the social space. The interpreters expressed managing these *Layers* through a repertoire of techniques that they integrate into the interpreted event. Each of these subthemes and their connections to *The Unknown*, will be articulated and explored in the following reflection and analysis.

In the authentic movement, this theme is situated in the following reflective observation and photograph:

> “…a spiralling that didn’t seem particularly controlled and sometimes ended up in what looked messy.” [Authentic Movement 2/04/19, p.3]

Figure 7.2 Authentic Movement – The Unknown

The ‘Façade’

Through conversations with various healthcare professionals[54] during recruitment, I came to recognise the numerous misunderstandings about deaf people that were present amongst clinical staff in the hospitals I visited. The following reflection from my fieldnotes demonstrates that many nurses believed that deaf, BSL users would not be cared for in their clinical area:

> “When explaining the study to staff a lot of people have responded with messages that suggest I have come to the wrong place to recruit, as deaf people wouldn’t require their services. Members of staff politely direct me towards ENT as that is where ‘they’ are likely to be.” [Reflection 24/09/18]

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[54] During my ward-to-ward visits, I naturally engaged in conversations with multiple members of the healthcare team, including nurses, doctors and allied health professions.

This reflection conveys an understanding amongst many nurses at the recruitment sites that deaf peoples' needs would be met elsewhere, mainly in audiology or an Ear, Nose and Throat (ENT) department. This understanding indicated a biomedical focus on a person's deafness and failed to acknowledge that deaf people encounter a wide range of health challenges that are not a direct result of being deaf[55]. Additionally, as discussed in *Chapter Six* during recruitment the majority of nurses were unable to differentiate meaningfully between a hard of hearing person and a deaf, BSL user. As a result, these nurses did not think that caring for a deaf person would require any unique considerations. I was interested in how these understandings of deafness might manifest in the care environment and influence nursing practice. The importance of maintaining a focus on the caring experiences therefore became apparent to me.

In the interviews, before encouraging exploration of experiences in depth, I invited nurses to share their general experiences of caring for a deaf person. Showing an enthusiasm for inclusive practice, some nurses voiced the importance of approaching care with principles of equality and inclusion. John commented:

> "You just want to get everything right because… you want it [service] to be working and be as inclusive to everyone and you don't want something to go wrong just because this person happened to be deaf." [John RN, p.3]

For others, the espoused values of equality and inclusion were equated with providing care that "doesn't change at all" [Jane RN, p.3]:

> "…whether a patient is deaf or whether a patient can hear normally they just get treated exactly the same so yes, you might have to take your time a little bit more with a deaf patient but they're still a patient at the end of the day, so the treatment you give them, the time, anything like that, it doesn't change." [Jane RN, p.14]

While it was not clear whether Jane had an awareness of the differences between a deaf and hearing person, Jane appeared to associate equality with sameness and failed to acknowledge the different needs of the person she was caring for. Such a statement standardises care as acontextual and suggests a 'view from nowhere'. Jane was therefore expressing an objective approach to her practice that did not acknowledge what equality and inclusion might look like for an individual. I got the sense that Jane was trying to express what was articulated in my interview with

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[55] It is important to reiterate that many of the health challenges deaf people experience, may be related to the social determinants of health of deaf communities explored in *Chapter Two*.

Sophie - that there is "…nothing wrong with being deaf" [Sophie RN, p.13-14]. While this perspective may aim to promote equal practice and avoid labelling, it prevented Sophie and Jane from critically questioning how a deaf person's differences can be valued and their specific needs identified and responded to. Without such critical questioning, nurses may fall back on assumptions about how to provide effective care to a deaf person.

Such assumptions were apparent in my ward-to-ward visits during recruitment in which I recorded numerous responses from healthcare professionals that were similar to this comment:

> "We had a deaf man a few months ago but he could lip-read." [Fieldnotes 20/08/18]

This comment indicated that the nurse believed lip-reading was an effective way to communicate with a deaf person. While this deaf person may have been skilled in lip-reading, as explored in *Chapter Three*, only 35-40% of what is communicated verbally can be effectively lip-read, with guesswork determining the rest. Therefore, the assumption that deaf people can effectively engage with healthcare professionals through lip-reading is unlikely to be true. Nevertheless, such an assumption was echoed in my conversation with Kelly who stated:

> "She [deaf person] managed lip-reading with the consultant and anything else she just wrote down but she did get 90% of what he [consultant] was saying as long as he kind of slowed down." [Kelly RN, p.7]

This assumption that the deaf person was effectively communicating through lip-reading and written English appear to create a *Façade* in which healthcare professionals believed the person was understanding and making meaning out their healthcare experiences. This *Façade* was familiar to the interpreters, as Cat indicated in the following statement:

> "Quite often the nurses and the other staff have said 'Oh this person, they've been fine at lip-reading, they understand what we're saying'. 'OK, question mark'." [Cat INTERP, p.55]

The *Façade* observed by interpreters and indicated by nurses suggested a need to question ways of communication, caring and understanding.

One nurse, Anna, reiterated these *Façade* issues, reflecting on an experience in which her assumption that the deaf person she was caring for understood her healthcare experience was challenged by a complaint from a family member. This complaint exposed her assumptions and Anna emphasised that a *"façade*" [Anna RN, p.1] had existed in which she ignorantly believed her care practices were effective:

> "Honestly, on the façade it was like everything was all hunky dory, it was all peaceful." [Anna RN, p.1]

This *Façade* indicated that due to nurses' lack of knowledge and understanding of deaf peoples' visual orientation and language, nurses may not be adapting their practice to address deaf peoples' unique needs.

Shedding light on what mechanisms may underpin and maintain the *Façade* between deaf people and nurses, the interpreters and deaf people who participated highlighted that many deaf people use "the deaf nod" [Harry INTERP, p.25] to pretend they understand what is happening in their healthcare experiences. This was understood as a common habit among deaf people that Carly believed stemmed from:

> "…worry that, actually, the doctor will think they are stupid if they have to ask for clarification." [Carly INTERP, p.15]

This reflects Goffman's (1963, p.87) notion of 'passing for normal' in which covering and passing strategies are used by people to minimise their experiences of stigma. Emphasizing the effect the deaf nod could have on understanding, Harry stated that:

> "…with this deaf nod people will smile and go 'yeah, yeah, yeah I've got it' and they haven't. They've got no idea which leg is about to be removed. So, it's a big issue. I've had someone going for an angioplasty, the surgeons sat down and explained it all and I signed it all and the [deaf] persons [signing] 'great, great, great' and the surgeons smiling. However, this person wasn't informed. 'Have you got a picture you could show him?' And then he [deaf person] went 'oh shit, that looks a bit scary.'" [Harry INTERP, p. 25].

Furthermore, Hayley emphasised that:

> "It's very difficult to know, even [for] interpreters whether when a person nods, if it's actually a nod of full understanding or just going along with it. I know interpreters will ask for clarification but for healthcare professionals to actually know is almost impossible." [Hayley DP, p.15-16].

These reflections demonstrate the potential negative consequences of the *Façade* to deaf peoples' understanding of healthcare and subsequent care and treatment. Additionally, the deaf nod may maintain the *Façade* and healthcare professionals' belief that their approach to caring for a deaf person is effective.

There were exceptions to the objective view that nurses often articulated. With a sense of uncertainty about how to care for a deaf person, John and Emily curiously questioned, "…what's our kind of contact going to be like?" [John RN, p.2] and "How is this going to go? How are we going to manage?" [Emily RN, p.4]. While John and Emily did not have previous experience or knowledge of caring for a deaf person, their critical questioning prevented them from falling back on assumptions associated with standardised or procedural care. Additionally, two of the nurses, Beth and Adam had previous experiences of engaging with deaf people and BSL skills, Adam as a fluent sign language user and Beth with a basic understanding of BSL. These insights enabled them to critically question and adapt their approach to practice when caring for a deaf person. This will be further explored in the theme *Shifting Perspectives*.

'Underneath'

In my conversations with nurses during interview, although there initially appeared to be a *Façade* in which some nurses believed that the person's needs were being met, contradictions emerged once they moved beyond the initial superficial exploration of their experiences. Sophie reflected:

> "..they [deaf person] could interact and they could see us but they couldn't really understand what we were saying but they could lip-read. It was still quite hard from a nursing point of view." [Sophie RN, p.2-3]

This reflection holds a contradiction in itself, as Sophie suggests that the deaf person could lip-read effectively yet couldn't understand. Thus indicating the interpretations of effectiveness of communication approaches were ambiguous in themselves.

Without a common language to complete an initial nursing assessment, Jane indicated that she observed the abilities and needs of the deaf person she was caring in the following manner:

> "We had to do an initial nursing assessment. Checking the patient's cognitive abilities, how they mobilise, how they manage in the house and things like that…We were just kind of waiting for him to get up off the chair to see how he walked." [Jane RN, p.4]

Further reflecting on this situation Jane stated:

> "It was hard, you did want to ask him [deaf person] questions but you kind of felt like you were taking a step back." [Jane RN, p.18]

Jane's reflection indicated that she was carrying out an assessment of the deaf person's needs by relying heavily on distanced observation, suggesting that care was provided in a different way. This also echoed Carly's experience that it is "very rare" [Carly DP, p.6] for a healthcare professional to engage them in a conversation. Peter shared his experience of healthcare professionals observing him, making judgements and decisions for him and the lack of autonomy he experienced when his daughter was in hospital. He recalled reading his daughter's bedside medical notes in a search for information and stated:

> "...there was some reference to me and my wife. Saying things, like for example, 'Dad seems concerned' but they never ask me if I was concerned or not but they'd [doctor] made an assumption, said 'Dad seems concerned' but of course I was concerned, nobody had asked me how I felt, nobody had discussed anything with me. They were just looking at me, they were assessing me as a person without even asking me a question and making a decision for me, and I was disappointed to read that and I was disappointed of their perspective of me, their perception… They couldn't communicate with me because I'm a deaf person. They didn't even try. It was just 'Dad seems concerned' and I thought where does that come from? How have they decided that?" [Peter DP, p.6]

While Peter had initially sought to find information and understanding of what was going on in his daughter's medical notes, he uncovered assumptions that healthcare professionals were making about him through their distanced observations.

Due to lack of effective communication with healthcare professionals, deaf people similarly made sense of their healthcare experiences through observations. As a result of having little engagement from healthcare professionals, Hayley shared that she experienced:

> "Three hours of constantly looking around for people coming out in case I missed that name call, you know and the stress that that put on me and I'm also trying to look after my son." [Hayley DP, p.6]

Similarly, Lindsey shared the problems that arose for her when she was not informed of what was going on while waiting in A&E and a curtain obscured her visual means of obtaining information:

> "I found it really worrying. What's going on? Why's she [nurse] not coming back? You know and not being able to hear everything. [Hearing] people can pick up what's going on but you can't see a lot. If anybody comes in, anybody talks don't hear what's going on. So, we do miss out a lot." [Lindsey DP, p.3]

Thus, Hayley and Lindsey were intensely observing the space they were in and the people they engaged with, trying to pick up on visual cues to make sense of what was going on.

Across the interviews with all participants who were deaf, there was similar evidence of subtle social cues, indications of auditory signals and other visual cues that provided fragmented information. This often led deaf participants to resort to guesswork or filling in the blanks to make sense of their environment and the people in it. Auditory information that hearing people take for granted, such as verbal announcements made in waiting areas and overhearing healthcare professionals talking, were highlighted as being critical for navigating healthcare environments. Peter shared how despite being at his GP surgery for 10 years, healthcare professionals continued to expect him to navigate the healthcare system through auditory means:

> "Maybe 10 years ago, I moved GP and the nurse there would come out and she would shout my name of course. Yeah, she would shout 'Peter'. Of course, as a deaf person, I'm anxious. Have I missed my name? Have I missed my appointment? And that still continues. They know I'm deaf, but they still do it." [Peter DP, p.2]

It appeared that the healthcare environment was therefore viewed as a 'hearing space' which deaf people found challenging to navigate. These findings indicate that despite healthcare professionals often believing that deaf people are understanding their healthcare experiences, *Underneath* the *Façade*, they often remained in *The Unknown* and "…didn't know what was happening" [Peter DP, p.13] due to information not being made accessible for them.

In contrast to the deaf nod explored in the subtheme *The façade,* all the deaf participants in this study expressed confidence in making known to healthcare professionals that they were deaf and would need adjustments. For example, a tap on the shoulder instead of a name call in a waiting area. However, it was apparent that all experienced what Lindsey described as being "on edge" [Lindsey DP, p.8] as healthcare professionals often did not act on these requests. As a result, Peter explained, "I have to constantly educate them [healthcare professionals]" [Peter DP, p.2]. Similarly, when reflecting on her care for a deaf woman Beth commented:

> "I think she [deaf person] put a lot of effort into managing professionals in the health service." [Beth RN, p.10]

This suggests that despite informing healthcare professionals of the adjustments they require to fully access and navigate their healthcare experiences, routine practices may not be adapted.

While it is evident that the contradiction between *The façade* and what was happening *Underneath* the superficial care experience caused emotional stress for deaf participants, there was also evidence of deaf peoples' physical needs not being met. Peter shared his experience of being unsure if he could ask or how he could ask for help with washing and dressing during a period in hospital:

> "…it was hard for me to get out of bed and wash and shower and things like that but at the same time I never asked for somebody to help me. I just wasn't sure if I could, if I was allowed to get out [of bed] for a shower because I'd never been given that information." [Peter DP, p.13]

Similarly, two of the nurses who took part, Sophie and Anna, shared experiences of finding out that, contrary to their understanding of the situation, the deaf person they were caring for had unmet physical needs that they were unable to communicate with nursing staff:

> "It was friends and family that, you know, that could sign and they were saying, 'she's had the same night dress on for two or three nights' or 'she's been in pain' or 'she doesn't understand why she's getting the antibiotics'." [Anna RN, p.1-2]

As a result, Anna reflected that nursing staff had been unaware that for the deaf person "…underneath it was just turmoil" [Anna RN, p.1] because they were in pain or did not know how to ask for assistance with their personal care. Such moments of awareness were upsetting for Sophie and Anna and they shared how it felt emotionally:

> "[I] just felt like I'd let the patient down because I didn't know how to do sign language. So, I felt I should have learnt sign language, even a tiny bit to understand because sometimes when you're explaining something you think they're just going to understand you and they don't. He wasn't understanding." [Sophie RN, p.3]

> "I felt, we [nursing staff] felt we'd totally failed the lady." [Anna RN, p.3]

Such realisations appeared to be moments of crisis for Anna and Sophie that highlighted hidden assumptions. These assumptions included beliefs they held about the deaf persons' understanding of their healthcare experience and their ability to make their needs known. This draws attention to the need for an awareness of how navigation of hospital experiences may be different for deaf people.

For Anna and the wider nursing team she was working with, being made aware that their approach to caring for the deaf woman was ineffective triggered critical reflection of their practice. Viewing the complaint as an opportunity to improve their practice, Anna stated that:

> “We wrote to them [family] and asked them to come in and said ‘this is what we’re going to be changing or are trying to change’… At first, we were like ‘Oh god, we were trying to do our best and blah blah blah’ but then we thought no, no we can learn from this.” [Anna RN, p.15]

By inviting the family of the deaf woman to participate in a conversation about how care could be improved in the future, the team were informed about a local charity that could provide support to nurses caring for a deaf person. Additionally, this experience triggered Anna to think about how nursing teams can gather and share information related to an individual’s unique communication nuances from family members:

> “We’ve [nursing team] got this thing called a magic board. So, it’s meet and greet and forward communicate. So, we try to speak to every relative in the ward, if the patient wants, just to give a quick update. It’s usually at visiting time, you know, you’re going and saying [to the patient] ‘have you told them [family member] how well you have done at physio today?’ or whatever and that way maybe the daughter will say, ‘he’s really really deaf, so you need need to…’ or ‘his sights not very great so…’. So, you get these snippets [of information].” [Anna RN, p.17]

Thus, Anna’s experience of receiving a complaint not only triggered critical reflection but was a platform for transformative action in her future practice.

From my early interpretations, I could therefore see a mismatch between nurses’ perceptions of deaf peoples’ care experiences and the deaf peoples’ personal experiences of care. Without an opportunity to enter into dialogue, nurses and deaf people were often experiencing multiple realities with little shared knowledge and understanding. As a result, I felt a sense of “I” and “them”, rather than “we” and “us” in the narratives. This highlighted a deaf/hearing divide in which little shared meaning was being developed. Without a common language, both nurses and deaf people were often observing one another and making interpretations from actions and feelings about what was going on. Therefore, what was seen, felt and imagined appeared to form the foundation of their perception. Without dialogue to negotiate and challenge these interpretations, I got the sense that rather than living an experience together, nurses and deaf people were distanced from one another in the interactions.

‘Layers’

In contrast to what has been explored in this theme so far, in the focus group with interpreters, Cat and Harry expressed a belief that healthcare settings are often collaborative spaces. Cat expressed that the healthcare environment is "quite a cooperative environment normally… by the very nature of it" [Cat INTERP, p.7], while Harry stated that "people will try and align with one another" [Harry INTERP, p.18]. Viewing themselves as allies[56] of both deaf and hearing people, the BSL/English interpreters who took part in this study, provided me with a different lens through which to see the interactions between nurses and deaf people. The interpreters expressed being situated in a unique position, the intersection between hearing and deaf worlds, in which they made sense of the complexity of the encounter between a deaf person and a nurse. From this position the interpreters expressed having an understanding of many *Layers* that influence the engagement between hearing people and deaf people.

Expressing their role in the triadic interaction as participative, Harry explained:

> "We're not just external, we are participants in a conversation, co-creating the meaning with everybody else." [Harry INTERP, p.6]

Further exploring the influence that they could have on the interpreted event, the interpreters expressed their role in the co-creation of meaning as involving communication and cultural mediation. Harry emphasised that "…as well as managing information, we're managing relationships" [Harry INTERP, p.5]. Managing relationships in an interpreted interaction was expressed as requiring an awareness of the shifting power dynamics that exist in the healthcare interaction and assessing whether the power dynamics are favourable for effective communication and an effective encounter. In the following discussion, Tina expressed the weight of responsibility that this role holds:

> "Harry: …often you're the most powerful person in the room because you are the only person who knows both languages. We decide who gets to speak and when, a lot of the time but actually we've got the least power because there's a medical professional with all their medical knowledge and a patient with all their life knowledge. We take over the power sometimes
>
> Megan: How does that feel as an interpreter?

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[56] For a definition of an ally, see *Chapter Two.*

> Tina: It’s a terrifying responsibility. Especially because you’re everyone's voice so if you misinterpret something, the effect that it can have is huge. So, it's a massive responsibility and it’s quite a duty to get it right.”
>
> [Focus Group INTERP, p.4-5]

From this discussion, it appears that the nature of the power dynamics was seen as being imbalanced and shifting in the triad. Therefore, power was understood by the interpreters not as static or dwelling with one person in a given situation but as constantly under negotiation. Harry expressed making a conscious effort to recognise the power imbalances in the triad and to facilitate balance:

> “…we’re often pulled in two directions. Pulled between invisibility, which is quite an old model of interpreting and being an ally and that constant pull of, I have something that I would like to add. Is it my role? Can I add this? Should I add it?” [Harry INTERP, p.24]

This emphasises the complexity of interpreters wanting to challenge misunderstandings or perceptions and knowing when it is appropriate to do this. Additionally, this suggests that the management of relationships and power dynamics in the interaction does not simply rely on knowledge of two languages but on an understanding of the complex relationships in which the conversation is taking place. Cat further reiterated this, stating:

> “Sometimes it’s the sort of attitudes of the people you’re trying to work with. It’s not actually the context of the communication. It’s the other bits around it.” [Cat INTERP, p15]

With an awareness of both language and cultures, the interpreters spoke at length about complexity of managing power dynamics that exists “between an oppressed language and a dominant language” [Harry p. 37], a minority group and an oppressed group and people that hold differing views of deafness. This understanding juxtaposed many of the nurse’s expressions of a neutral approach to care, suggesting that the power dynamics at play in relationships are often invisible and unconscious, and potentially unexamined by healthcare professionals. Therefore, much of interpreter’s work involved looking beyond the immediate meanings of peoples’ linguistic actions, considering the position (values, beliefs, and understanding) of the people they were interpreting for and managing the various implications these had for the encounter.

All the interpreters spoke about having a repertoire of “tactics” [Cat INTERP, p.15] or a “toolbox” [Tina INTERP, p.17] to help them manage a diverse range of situations in which they needed to make a “fix” [Cat INTERP, p.16] or “repair” [Harry INTERP, p.40]. These repairs were choices made to help correct the imbalance of power and/or cultural misunderstandings. However, the effectiveness of managing such situations was emphasised as being heavily reliant not only on having cultural knowledge but also on understanding the people they were working with to enable shared meaning to develop. The interpreters highlighted this element of interpreting as being the most challenging part of their work with Harry describing it as sometimes feeling “lumpy” [Harry INTERP, p.16]:

> “Harry: Sometimes it’s my skills. Sometimes I don’t understand the patient.
>
> Cat: Do they want to be understood or not?
>
> Harry: When I come out thinking ‘I didn’t do well’, ‘I didn’t perform well’. Obviously, I have to make sure everyone is safe before I leave the room but sometimes that feels very lumpy.
>
> Cat: And do you think that’s just their actual communication or do you think it’s their aims were not what you expected?
>
> Tina: A combination?
>
> Harry: A whole combination.”
>
> [Focus Group INTERP, p.16]

This highlighted the complexity of grasping a sense of who each person is in the interpreted encounter.

When able to grasp a sense of another person and express their character and personality effectively in the interpreted event, Tina believed that enabled those in the triad to feel connected to one another. However, emphasis was also placed on accepting that sometimes “people have different aims and different intension” [Harry INTERP, p.17] that can result in lumpiness. Harry and Tina further discussed this stating:

> “Harry: …sometimes we just have to interpret the clash, the disagreement and allow people to sort it out for themselves
>
> Tina: Some people just don’t get on… so no matter how well you set up a situation or how well you interpret with good intention… it’s just not going to be perceived well. So, there’s a lot of background that sort of… you’ve just got to let that conversation take its course.”

[Focus Group INTERP, p.18]

Because an interpreter's main role is to facilitate a smooth interaction, repairs or fixes were described as being blended into the interpreting process. However, this was viewed as challenging to achieve while simultaneously interpreting and could result in interpreters being "really prickly with [hearing] people" [Harry INTERP, p.32]:

> "Because sometimes I'll be interpreting a situation and it's not quite working, they're [healthcare professional] looking at me when actually it would be better to look at the patient. I'm going to have to make a repair and my head says 'actually it's OK to ignore me, I won't be offended. If you maybe could just speak to the patient that might just work a little bit better for you both' but because I'm interpreting at the same time, everything is happening at high speed, what comes out of my mouth is 'look at the patient!' which is prickly to the point of offensive. And that's not what I mean to happen at all." [Harry INTERP, p.40]

This highlighted the importance of nurses understanding the role of a BSL/English interpreter to allow for an effective interaction. Additionally, this reinforced the notion that much of the work of interpreters is hidden from healthcare professionals as they do not see or recognise the repairs or fixes being made.

The interpreter's role in facilitating shared understanding and meaning involves mediating both linguistically and culturally. Shared understanding does not come about purely through direct translation of language from English to BSL or vice versa but is woven into the complex relationships in which the conversation is taking place. Therefore, all the "bits" [Cat INTERP, p.15] that happen around the translation of language are significant to the development of shared meaning and understanding in the therapeutic relationship. In the focus group, the interpreters began to unravel the *Layers* that are involved in this. As mentioned earlier, these *Layers* will be interwoven into the remainder of this chapter.

Summary

In summary, this theme acknowledged that nurses, deaf people and interpreters are often entering into *The Unknown* in their interactions with one another. Often unable to differentiate between someone who is hard of hearing and someone who is a deaf, BSL user participants who are nurses often did not hold knowledge of language or cultural differences that exist between hearing and deaf people. As a result, they did not view their care for a deaf person as requiring alternative approaches to practice.

With little understanding of deaf peoples' unique care needs, a *Façade* existed in which nurses believed their routine approaches to care were effective. *Underneath* the *Façade*, both nurses and deaf participants indicated that communication with one another was a major challenge. Without a common language through which to communicate, deaf people and nurses appeared to remain in *The Unknown* with observations of one another being the primary means to make meaning out of their interactions. Relying on observations alone resulted in fragmented communication or misunderstanding of one another and the care experience. Due to this lack of effective communication deaf participants needs often remained unmet.

The misunderstandings between deaf people and nurses were viewed by the interpreters as made up of complex *Layers*. Such *Layers* relate to linguistic and cultural differences, constructions of deafness, ideologies and power dynamics that often define the relationships between deaf and hearing people. The interpreters perceived their role in the interpreted event as managing these *Layers* and misunderstandings to enable effective communication between deaf people and healthcare professionals. However, by managing such misunderstandings, questions arise as to whether or not the *Façade* remains or should be addressed through consideration of the layers of practice described by interpreters.

Borders

In the authentic movement, the spiralling out of control that resulted from entering into *The Unknown* created a border, indicating a boundary between deaf people and nurses in their interactions. The following reflective account illustrates my interpretation of these *Borders*:

> “Megan: …when nurses or deaf people are talking about coming into contact with one another there seems to be that kind of spiralling out of control of “how does this work?”, “we’ve never done this before”. Maybe not so much for the deaf people but for the hearing people but I think the deaf people still feel that sense of “oh, here’s another hearing person who isn’t sure how to be with me, how we’re meant to be together, or who we’re meant to be together”. And there’s that kind of spiralling and chaos. I think that in itself creates a boundary-
>
> Niamh: that’s where I saw- In your expression I think I saw retreat and disconnection.”
>
> [Authentic Movement 2/04/19, p.4]

Figure 7.3 Authentic Movement – Borders

In this theme, I will explore the nature of the *Borders* and how they influenced the relationship between deaf participants and nurses. The subtheme *The same old story* describes how deaf peoples' experiences of healthcare were recurrently negative with their communication needs remaining misunderstood and unmet. Without an effective way of communicating and having the opportunity to engage in social activity in the hospital, all deaf people in this research appeared to have experienced their sense of self and identity being denied. This is explored in the theme *I was Invisible*. Lastly, the theme *I'm just deaf* reflects deaf peoples accounts of healthcare professionals making assumptions about them and their needs based on the biomedical understanding of deafness. This created a space of separation, difference and distance that marked the boundaries between the deaf world and hearing world. It is important to note that for some, the border between the deaf world and hearing world was seen as being a place of engagement and enrichment. This will be explored in the final theme.

'The same old story'

This subtheme reflects deaf peoples' accounts of recurring negative experiences of healthcare and engagement with healthcare professionals. Several deaf participants shared their stories with a sense of frustration that when interacting with services and people in the NHS, "…it's always the same old story" [Peter DP, p.21]. The majority of care experiences shared by deaf people were negative in their nature. Indicating that these negative experiences were not isolated events, but that deaf people experience continuous challenges Hayley stated:

> "I'm deaf and my family are deaf and they've had terrible experiences. My Mum's had terrible experiences and so has my family and so I know how hard it must be for people stuck in these situations." [Hayley DP, p.4]

With broader insights into the healthcare experiences of deaf people from his personal connections with the community, Adam also recognised deaf peoples' enduring negative experiences of healthcare:

> "…they've [deaf people] told their stories for a long time and here we are in the 21st century and we still have a problem dealing with this sort of thing. We still as a society, don't know how to react to a community that is no different from us other than the fact that they can't hear us. You know what I mean? So, I would imagine that the deaf community is just fed up." [Adam RN, p.27]

The sense of frustration expressed in these conversations echoed my reflections from engagement events in *Chapter Six* where I highlighted that deaf peoples' stories are often shared but not heard, acknowledged or responded to meaningfully by NHS organisations.

The main concern for all deaf participants were the communication barriers they experienced. Peter, for example, emphasised that "communication is always a problem" [Peter DP, p.1]. Communication barriers were faced by deaf people across the whole healthcare system. They identified obstacles, as both patients and family members, in finding accessible ways of booking appointments at reception, in receiving urgent call backs after blood tests and when interacting with healthcare professionals directly. Lindsey shared her experience of having to book an interpreter to speak to a receptionist because of continuous lack of understanding of her communication needs:

> "…the [reception] desk is quite high and I'm quite small. I'm not joking, it's up here *gestures to chin* and the receptionist never stands up for me. She could stand up for me because I'm quite small. I've never needed an interpreter for reception but this time I had to which is ridiculous really. Normally I'm quite confident but that person… she's not making an effort." [Lindsey DP, p.12-13]

Having the option of an interpreter to facilitate communication in healthcare environments was emphasised as crucial to all deaf participants, with Peter emphasizing "Interpreters are important for me" [Peter DP, p.1]. An interpreter was viewed as fundamental to access, making meaning and enabling autonomy.

However, a number of challenges to accessing interpreters were highlighted. These included the current lack of interpreters and healthcare professionals independently making a decision about whether or not an interpreter was needed with Hayley emphasizing:

> "…very rarely it seems that nurses book interpreters for appointments in the hospital and that's been my experience for a long time." [Hayley DP, p.3]

As a result of healthcare professionals failing to book interpreters, Hayley further reflected that:

> "…it feels like I'm always fighting for [deaf] peoples' rights and their language rights and interpreters and it's a bit of a conveyor belt of requests." [Hayley DP, p.28]

This sense of needing to advocate for the wider deaf communities' linguistic rights was reiterated by all deaf people who took part. This suggests that the historical challenges of gaining access to services and healthcare in BSL continues to be a challenge for deaf communities.

Many nurses made decisions regarding the use of an interpreter based on their own assessment of how effectively they believed the deaf person could communicate via lip-reading and written English. Many did not appear to recognise that by communicating via written and spoken English that deaf people would be communicating in their second language. Sign language was therefore seen as a dialect of spoken English. Methods of communication were often chosen because they were misunderstood as being a variation in delivery of a shared language. The misunderstanding that BSL is a variation of the surrounding spoken language reiterates the power imbalance between the two languages explored in *Chapter Two*. Harry highlighted that these power imbalances continue to exist stating:

> "BSL and English are my two working languages and they're both of equal importance. However, BSL has a much lower status." [Harry INTERP, p.36]

This lower status was evident in the terminology used by nurses when they spoke about BSL and BSL/English interpreters, "Sign Language person" [John RN, p.5] and "like a person to come in and sign" [Jane RN, p.5]. The lower status of BSL, alongside nurse's belief that it is a variation of English can lead to a failure to recognise the need for an interpreter. This subsequently contributes to the negative experiences of deaf people in healthcare.

It was not clear whether nurses deemed themselves as more capable of assessing the needs of the deaf person than the person themselves or if they simply did not have an effective way of asking the deaf person about their communication needs. However, it was clear that deaf people are often not enabled to express their needs and as a result are treated as passive recipients of care. This was apparent in the following reflection by Peter:

> "I felt they [nurses] didn't try at all, they didn't ask 'how can we communicate?' for example. They didn't want to put the work in to see if they could match my communication style, my communication abilities." [Peter DP, p.7-8]

When given the option of having an interpreter, each deaf person made decisions about whether or not they wanted one depending on the context of the healthcare situation. Recognising the shortage of interpreters, some deaf people were happy to engage with healthcare professionals they were familiar with without an interpreter:

> "So, when I go to the asthma clinic for example, I don't get an interpreter because I do the normal procedures, we talk about the computer, it's very straightforward, we talk about the results so there's nothing really complex. When I go to the dentist, I use my wife. It's so easy and it's straightforward and I'm comfortable with that." [Peter DP, p.2]

> "Remember I don't lip-read everyone but because they think I can speak very well, they think I can lip-read but that's not the case." [Lindsey DP, p.15]

These reflections indicate that having the autonomy to choose communication preferences in different situations was important to Peter and Lindsey. In the focus group, Harry touched upon the importance of respecting a deaf person's choice. Sharing a story about a situation where he turned up to interpret for a deaf family during end-of-life care and the patient's wife said "What are you doing here? I didn't ask for you" [Harry INTERP, p.7-8]. In this situation, the deaf man's daughter decided to interpret for her family and Harry acknowledged:

> "The daughter wants to be in the room with her Mum and Dad. There wasn't any decision [to make]. The doctor could have insisted on it. But you know what, I'll be at the end of the corridor if anybody wants me. Respecting the wishes of a grieving family." [Harry INTERP, p.7]

With a diverse range of communication skills and abilities across the deaf community, making a choice regarding ways to communicate was therefore expressed as personal and contextual.

While the deaf people who took part in this study appeared to be confident in requesting interpreters, Peter and Hayley stressed that the older generation in the deaf community are often reluctant to ask for interpreters. There was a sense that some deaf people have been made to feel that they were being a burden for requesting an interpreter and therefore avoided doing so:

> "When I was growing up, obviously I have a deaf family and my family said 'aw, you know, don't worry about interpreters, its private when it comes to the NHS. You know, health things should be private and don't need an interpreter'." [Peter DP, p.1]

> "They're [parents] both deaf and they never use interpreters. They don't ask for interpreters, they just say 'oh no, no it's fine. I don't want to bother anybody. Just write it down, it'll be OK'." [Hayley DP, p.15]

I experienced this attitude myself during recruitment when a charge nurse described her experience of caring for a deaf person as a "nightmare because she required an interpreter and cost the hospital a fortune" [Fieldnotes, 22/10/2018]. The potential impact of this perspective is that *The same old story* could persist with deaf peoples' communication needs continuing to be misunderstood and unmet.

Despite BSL being the preferred method of communication, in the absence of an interpreter, all deaf participants in this study appeared confident in their abilities to communicate with healthcare professionals through a combination of written English, gesture and facial expression due to being bilingual:

> "Deaf people are different. They have different struggles. Some are OK with English. Actually, I'm good with English, you know." [Peter DP, p.4]

However, it was emphasised by all four deaf people that the linguistic abilities and English literacy levels of the wider deaf community are diverse and therefore, communicating through written English will not be appropriate for many deaf people. Hayley shared an example of a deaf person she knew who had "poor language acquisition" [Hayley DP, p.6]:

> "He can't read English at all, doesn't understand fingerspelling, there are no lip patterns, he can't lip-read, it's a bit more like mime. If I was to use fluent BSL, it wouldn't be understood [by him]." [Hayley DP, p.7]

This comment reflects the literature explored in *Chapter Two* and *Three*, which highlighted the diverse language skills of people in deaf communities. Sharing a story of how this deaf person has experienced challenges when interacting with the healthcare system Hayley stated:

> "So they [deaf person] were going back to the hospital again and again and they had stomach pains but they weren't understanding [their diagnosis] and they [healthcare professionals] didn't book interpreters for the appointments, not once and, as I say, they were in A&E every single night and they never ever booked an interpreter for this client and it's their [healthcare professionals] fault that the client kept coming back because they weren't understanding the information and when I was involved they [healthcare professionals] wrote it all down and I was saying, the person can't read, they don't understand it in English and they were like 'I thought they did', you know. So, you know the visits to A&E, the same stories getting explained every single night." [Hayley DP, p.7]

These accounts indicate that effective communication for deaf people is unique to each person and situation. The findings explored in this theme suggest that deaf peoples' language and communication needs are often misunderstood or not responded to. As a result, healthcare professionals often make decisions on behalf of a deaf person as to what constitutes effective communication. The findings indicate that addressing what is going on *Underneath* could enable healthcare professionals to move beyond the *Borders* created by the negative healthcare experiences of deaf people.

For Peter, recurrent negative experiences of the NHS have led him to view healthcare in a practical way:

> "I think now as I've grown up and I've matured, I'll be honest, I've a low expectation of it [NHS] now because if I go to hospital or I got to an appointment, that engagement will be minimal. You know, that rapport you build will be minimal. You know, it's really practical. They [healthcare professionals] will resolve the issue and then I go out. So, I go in, have the problem solved and then I leave. I think that's the way I look at it now." [Peter DP, p.1]

This suggests that while the care Peter received may address his physical needs, it does not acknowledge or value the psychosocial dimensions of health or caring elements of healthcare practice. Therefore, healthcare professionals care for Peter has reflected the biomedical model.

The consequences of nurses not recognising deaf people as having unique linguistics needs resulted in deaf people often having no means of effectively making sense of their experiences and/or expressing themselves. Subsequently, deaf people described the negative impact this had on comprehension of diagnosis, adherence to treatment and ability to make meaning from the experience. For example, when expected to lip-read during a consultation, Carly misunderstood a diagnosis when she lip-read a doctor mouthing a word beginning with the letter C and thought she had cancer:

> “…with the terminology, in medical terminology it's very confusing and a lot of it can go over your head, you don't understand it.” [Carly DP, p.17]

The deaf participants and the interpreters described numerous experiences of deaf people “taking medication at the wrong times” [Carly DP, p.15], being diagnosed and having no understanding or a misunderstanding of diagnosis due to medical jargon being communicated via written or spoken English. This indicates that the ineffective communication during the treatment of deaf people can have vast consequences.

‘I was Invisible’

A sense of invisibility in healthcare emerged as a result of the boundary that developed between deaf and hearing people. Peter, Carly, Hayley and Lindsey all shared experiences in which they felt invisible when interacting with healthcare professionals. Feelings of invisibility were triggered by social exclusion and lack of meaningful engagement and participation in care decisions. As a result, deaf peoples’ social identities were often not acknowledged and responded to by healthcare professionals. I painted the following image (Figure 7.4) after my interview with Peter which captures the essence of this subtheme.

Figure 7.4 Can you see me?

Deaf people frequently experienced what Lindsey described as the “natural reaction” [Lindsey DP, p.5] of healthcare professionals speaking directly to a hearing member of the family or an interpreter about their health and well-being, rather than directly to them. This was exacerbated by family members and interpreters occasionally being treated as having a “parenting role or a caring role” [Carly DP, p.11]. Lindsey stated:

> “If my husband was there, they [healthcare professionals] would speak to my husband instead of me and that is something they shouldn’t be doing.” [Lindsey DP, p.5]

Similarly, Carly expressed:

> “There should be interpreters there but there’s not so I need to get what I can from this conversation, but they [healthcare professional] would just speak to my dad or other family members and they wouldn’t focus on me at all. I felt very excluded from these conversations.” [Carly DP, p.19]

These accounts show that deaf peoples’ social roles can be affected by healthcare professionals communicating with family members instead of the deaf person. In the focus group, Cat emphasised that feelings of exclusion are not isolated to healthcare experiences and that:

> “Lots of people in the deaf community have felt excluded throughout their lives.” [Cat INTERP, p.36]

In an inpatient setting, in the absence of family or an interpreter, the accounts of deaf people indicated that they often experienced exclusion in the form of physical and social distance from healthcare professionals. For instance, Peter observed nurses engaging with other patients in the ward and bypassing his bed space:

> “They [nurse] didn’t inform me about anything. The nurse would come and chat to other people but not to me. She just passed me by and I can understand why because obviously she wouldn’t have sign language knowledge but it was boring. I mean I was bored to death every day.” [Peter DP, p.11]

Peter’s experience appeared to result in lack of participation in the social interaction in hospital, creating a boundary that prevented him from feeling connected to the wider social world. He therefore stated “I was really isolated, lonely, all on my own” [Peter DP, p.10]. Similarly, reflecting on her experiences of being in hospital Lindsey stated “It’s a lonely experience” [Lindsey DP, p.7].

Feelings of isolation and being on the *Borders*, appeared to result in actions that had potential for further negative consequences. For instance, because of this feeling of exclusion from the social world, Hayley expressed a preference for a side room as an inpatient:

> "…when you've got hearing people around you, you don't know what they're saying, it's quite stressful, you know." [Lindsey DP, p.30-31]

This may indicate that Lindsey opted to remove herself from the hearing space as a means of self-protection.

Opportunities for deaf people to engage in authentic social interaction were limited to visiting times, when family could visit or when an interpreter was booked. However, as explored in the subtheme *The same old story* interpreters were rarely booked. Therefore, it was evident that deaf people could spend long periods in hospital without any meaningful interaction in their first language.

The social isolation caused by being excluded from the social aspects of care appeared to subsequently have a negative impact on Peter's mental wellbeing and resulted in little motivation to care for himself physically:

> "[I was] very, very low, I think I felt really low in terms of my mood. I didn't shave whatsoever; I couldn't be bothered. I didn't really wash in that way." [Peter DP, p.13]

Peter's lack of motivation to physically care for himself may suggest that the social isolation he experienced started to have a negative impact on his self-worth.

The sense of social distance expressed by deaf participants was echoed by both Jane and Kelly as they shared the challenges they experienced in trying to get a sense of who the deaf person was that they were caring for. Jane explained that "…[chit-chat] was restricted because you didn't want to bombard this man with questions" [Jane RN, p18]. In the following extracts Rachel and Beth reflect on the significance of such mundane conversations:

> "Normally you know we are in and out. Under normal circumstances we're in and out, we're meeting all the members of the family, we're making them tea, we're having wee chats with them, we're getting to know them. I never felt I got to know him [deaf relative]." [Rachel RN, p.7]

> "…I suppose one of the things that I found intriguing was trying to understand my client's personality or both my clients' personalities because I think when you hear a voice, a voice tells you such a lot of contextual information. So particularly someone's state of mind perhaps, perhaps just all the sort of idiosyncrasies I suppose. I think when somebody uses sign language or maybe when somebody speaks a language that's not your first language it would take a while to understand their personality because I suppose you don't know how they're using their words." [Beth RN, p.9-10]

The absence of chit-chat or small talk, which often appears mundane and superficial, was emphasised as being the source from which nurses begin to develop a picture of someone's life. Kelly highlighted the challenge of "catching her [deaf person's] personality" [Kelly RN, p.19] in her interaction due to lack of idiosyncrasies that are usually captured in someone's voice. The content of that dialogue, as well as the idiosyncrasies of how people communicate, were both highlighted as being valuable sources of information. This suggests that rather than being inconsequential, small talk essentially forms the foundation of relational practice from which person-centred care can be provided. Mundane, everyday chit-chat is therefore a powerful relational and clinical resource, which was not available to deaf people in the care settings described.

Despite some nurses articulating that they would be "happier if I'd been able to actually have a conversation" [Rachel RN, p.22] with the deaf patient or the deaf family members, there was sense that such nursing care did not justify the use of an interpreter:

> "Well, I don't know if it [having an interpreter] would have been helpful or not. I don't know how much we [nurses] would have got out of that." [Rachel RN, p.9]

> " …I think if he was going for any sort of procedure then they [doctor] would have got an interpreter, like a person to come in and sign definitely but in terms of everyday nursing, no." [Jane RN, p.5]

While it is unclear why Rachel and Jane did not believe nursing care justified the use of an interpreter, there is an apparent contradiction in their desire to have a conversation and lack of use of interpreters. This contradiction perpetuated the lack of connection and sense of invisibility expressed by the deaf people.

In contrast, the interpreters who took part emphasised that they frequently spend time with their deaf clients as a "completely social thing" [Cat INTERP, p.56] because they recognised that it may be the deaf person's only opportunity to communicate in their first language. Cat expressed that because she gets booked for an interpreting job for a fixed time period, she is happy for healthcare professionals to make use of her time:

> "You think well I'm here anyway so I would always, at the nurses [desk], ask if anybody else is wanting to do anything else while I'm there cause sometimes people just want to know tea and coffee preferences and things like that… I would usually say to staff 'is there anything else that you want to do while I'm here?' Just cause that's an opportunity." [Cat INTERP, p.31]

Cat therefore recognised the significance of social interaction, particularly informal interaction that uncovers information about a deaf person's idiosyncrasies as being beneficial to the care of the deaf person.

As well as having a lack of social contact while engaging with healthcare professionals or in hospital, deaf participants shared experiences in which their social roles and identities as Mum, Dad or daughter were denied to them through lack of engagement with healthcare professionals. This appeared to be the most stressful situation for participants as they were concerned about a loved one's health and unable to participate in care decisions. This was apparent in Hayley's reflection:

> "I had to take him (son) to A&E because he wasn't right and it was bronchitis and there was no interpreter. Nothing at all and I was in hospital for five days with my son. You know, he was in hospital and I stayed with him for five days. They actually asked me to leave the room at one point and the nurse got all masked up and put a pinny on and 'what on earth are they doing? That's my baby' and I could hear my baby crying and I could see through the window and they were doing some kind of test and they were just seeing if it was swine flu, you know, and I didn't even know that. I didn't even [know] beforehand that that's what they were doing but afterwards they said, 'no he's ok but we were just checking'. They should have told me beforehand. It was a relief because he was fine and it was bronchitis and he ended up staying there for five days but to not approach me and say this is what we're doing, this is the plan. Nothing at all, I felt like I was invisible, an invisible Mum. That's what I felt. I don't want the kids to see me stressed so I'll just try and ignore it, switch off from that and move on and that's tough to do as well when you're feeling left out." [Hayley DP, p.31-32]

For Hayley, her role as a mother was denied her by the healthcare staff and she was unable to participate in decisions about her child's care. As mentioned in the subtheme *Underneath*, Peter similarly felt that his role as father was denied as he spoke about reading his daughter's bedside medical notes to establish what was happening.

In the focus group with interpreters Cat shared an example of the potential consequences of deaf people not being enabled to support and participate in their loved one's care:

> "Sometimes the deaf person feels that they're not really getting included in the discussions because everything is happening so quickly. They're not really getting a chance to be on board and people are like 'I'll tell you later, we're just sorting it out and it's grand'. They don't get to be involved in the decision making, especially when it's end of life stuff. And we [interpreters] are not always booked that often for that because it's not the patient [who is deaf], and perhaps it's not the next of kin…I suppose [it's] overprotection in a way, Like 'let's not bother

> them, let's not tell them' and then they don't realise that [their] Mum or Dad is actually going to die." [Cat INTERP, p.9-10]

Without information being shared regarding their own or their loved one's care, these accounts indicate that deaf people are unable to actively participate and are potentially left feeling a sense of depleted personhood. These notions of being excluded and invisible were occasionally echoed in my conversations with nurses:

> "So, I picked this one [Evoke card] just because like I say it's mostly darkness and the person might feel like they're maybe not seen enough or not, that sounds a bit silly saying not heard enough but just feeling like they're a bit isolated in the darkness. Not knowing maybe what's going on really." [Jane RN, p.7]

> "…they [deaf person] communicated that they had felt they were in the shadows." [Sophie RN, p.2]

While Jane and Sophie indicated that the deaf people they were caring for were feeling isolated, this realisation did not appear to trigger any changes in their care. This may indicate that they had accepted that social isolation is the norm for a deaf person or that they were unsure how to address this. However, there is little evidence to back up these claims.

'I'm just deaf'

This subtheme relates to differing views of deafness that were apparent in interviews with deaf people and nurses. Deaf participants' stories were often dominated by feelings of frustration as to how deafness is perceived and the consequences of these perceptions. Differing views of deafness were evident in my conversations with all participants. These surfaced not only in the choice of language that participants made but also in their actions. Differing perceptions of deafness between nurses and deaf people appeared to contribute to the sense of 'being on the *Border*' if they were incongruent.

In the interviews, nurses often appeared hesitant as to what language to use to express deaf peoples' differences. However, words and expressions such as "disability" [Kelly RN, p.8] and "dull of hearing" [Anna RN, p.6] reflected the biomedical perspective. Additionally, some nurses projected other disabilities onto the deaf person they were caring for, describing "bold print" [John RN, p.9] text and "braille" [Kelly RN, p.10] as being helpful for the deaf person, despite no indication of the need for these. Such biomedical discourse suggests conceptual dualisms such as abnormal/normal, disabled/non-disabled without attention being given to what it means to be deaf to an individual. Carly's reflected on her experience of such dualisms stating:

> "It's almost like I've got another disability. I'm just deaf, I just need an interpreter for communication, but I think they'll [healthcare professionals] be using the medical model and I'd be classed as disabled." [Carly DP, p.5]

Thus, it appeared that Carly was being marginalised and exposed to biomedical constructions of deafness that she did not identify with. Similarly, Peter reflected on assumptions that healthcare professionals had made about him. He shared an experience of being referred to additional services for support that he had not asked for or that did not directly relate to the nature of his hospital appointment or admission:

> "I got a letter, and it was from speech and language therapy… and they said they had concerns about my daughter and her language development because obviously her parents are deaf, so they assumed and I thought 'OK fair enough' but they didn't ask or inform us or want to discuss the referral or anything… I just thought why on earth would you assume that? I really lost it… I went to the appointment anyway and they were lovely, they were lovely and we discussed it and they said your daughter does not need any speech and language therapy whatsoever. Yes, her parents are deaf but they're very knowledgeable, they understand the environment, they're raising her correctly, bilingual. So, I was really annoyed because the nurse had, you know, the department had made an assumption and OK, in a way you think OK, I could argue that they were just trying to be nice and say that we need support but actually we didn't [need it] and nobody actually asked us or discussed it with us, they just made an assumption and sent a referral. So that underlines again, that assumptions are all around us." [Peter DP, p.9-10]

The nurse in this story had evidently made assumptions about Peter's ability to support and make decisions about his daughter's language development. This illustrates Peter's experience of paternalistic actions and motives of healthcare professionals. While these may be rooted in good intentions, they subjected Peter to professional control and subsequent unnecessary contact with additional support services.

The impact of these perceptions of deafness on the caring relationship became apparent in deaf peoples' reflections. Conflict and tension were often evident in the relationships between deaf people and healthcare professionals when their beliefs about deafness did not align and there was no means by which to effectively discuss how deafness was experienced. Peter reflected on how this made him feel stating:

> "…it's like patronising really, because it's like you're a deaf person so therefore you need support. You need a social worker to help you get through life. I know we said that everybody is different but actually most deaf people know about

> equipment, yeah, they know how to organise that themselves. You know, you don’t always need a social worker to get through life.” [Peter DP, p.9]

For the deaf people, attitudes and views towards deafness were tangible in their healthcare encounters through the way that nurses choose or choose not to engage. Lindsey stated:

> “I can see they [healthcare professionals] feel uncomfortable with me” [Lindsey DP, p.12]

This indicates that despite assumptions and perceptions of deafness not being verbally articulated, they are expressed and sensed through embodied action. Peter believed that such behaviour of healthcare professionals expressed:

> “Having a fear of somebody that’s different from you.” [Peter DP, p.22]

Similarly, Adam had witnessed this in his practice and described it as the “…undertone of the hearing community thinking that there’s something different” [Adam RN, p.14] and being unsure how to approach a deaf person. As a result, he stated that:

> “I think inherently if you’re not sure about something you’ll just avoid it and I would probably go as far as to say the deaf community probably suffer from poorer care just as a result of people being a bit like ‘aw I don’t like in there’ or ‘what am I going to do?’.” [Adam RN, p.18]

This suggests that healthcare professionals may physically distance themselves from deaf people and reflects Peter’s experience of healthcare professionals passing by his bedspace. Such attitudes and prejudices influenced deaf peoples’ desire to engage with the healthcare professional. Carly and Lindsey both expressed feeling lack of motivation to make an effort if the healthcare professional evidently felt uncomfortable with them. This suggests that deaf people may retreat into themselves if a sense of trust and safety necessary to develop therapeutic relationship is not present.

This subtheme indicates that the attitudes that nurses held towards deafness had a powerful influence on their behaviour and subsequently the way in which the deaf person experienced care. The biomedical model of deafness continues to have a negative impact upon the experiences of deaf people with assumptions being made about their capabilities and needs. The assumptions of the biomedical model were tangible to the deaf people in this study and often resulted in deaf participants appearing disempowered. Such disempowerment had the potential to create a boundary between them and the healthcare professionals caring for them.

Summary

The interpretations related to the theme *Borders* indicated that due to the misunderstandings between deaf people and nurses, a figurative border can develop between them. Therefore, while they are physically in the same space this does not always result in coming to know and understand one another or develop shared meaning. This can create a space of separation, difference and distance that marks the boundaries between the deaf world and hearing world. The subtheme *The same old story* suggests that deaf peoples' language and need for access to information in BSL is often overlooked. The findings of this subtheme indicate that without access to healthcare information in BSL, there is significant potential for harm to be caused due to deaf people misunderstanding diagnosis and treatment. The subtheme *I was Invisible* indicated that as a result of lack of shared language and social interaction between deaf people and others in the healthcare setting, deaf people often feel invisible. Due to the feelings of invisibility, lack of access to information in BSL and nurses' approach to caring, the findings indicate that deaf people are often forced into the position of passive recipient of care. Lastly, the subtheme *I'm just deaf* suggested that the biomedical construction of deafness is dominant in nurses' practices with assumptions being made about deaf peoples' capabilities and needs.

(Im)possibility

This theme relates to the lack of potential and possibility for authentic engagement that some nurses felt as a result of not being able to communicate verbally with the deaf person they were caring for. This often caused a *Stuckness* in which a fixation on lack of common language restricted connection and movement toward a space of encounter. In the authentic movement this presented as:

> "…a space, an actual physical space that you moved into once or twice that seemed very closed off, which is that circle (photograph) and quite restrictive in that you didn't seem to be able to move in it at all." [Authentic Movement 2/04/19, p.3]

Figure 7.5 Authentic Movement – (Im)possibility

This reflects the mind-set that many participants found themselves in when they encountered the sense of separation, difference and distance. The subtheme *Visual People* describes deaf peoples' different ways of being and knowing that influence their navigation of healthcare systems, interaction with healthcare professionals and understanding of healthcare information. While this subtheme describes barriers that deaf people encountered in understanding their healthcare experiences, it also presents alternative approaches that enabled them. The name of this theme*, (Im)possibility* therefore represents movement from a focus on obstacles and barriers to a place of potential connection.

Stuckness

As mentioned previously, five of the nurse participants had never met a deaf BSL user before. Although some of the nurses expressed that their physical nursing care remained the same, being unable to use their spoken English created a problematic situation that was unfamiliar to them. As a result of being unable to use spoken English to communicate, there appeared to be a freeze or *Stuckness* in which some nurses felt there was little they could do beyond physically caring for the person. This relates to the relational elements of care. The *Stuckness* I sensed and heard in nurses' narratives appeared to extend from feeling deskilled. For some this was voiced explicitly while for others it was tangible in the effect this had on the nature of their relationship with the deaf person. In this position of *Stuckness*, Kelly fixated on the lack of common language between her and the deaf person stating:

> “I mean, I don’t know British Sign Language so how am I going to communicate with the patient?” [Kelly RN, p. 3]

Similarly, Rachel expressed:

> “We [nurses] can communicate with people who have had strokes, we can communicate with people who’ve got dysphasia, people who’ve got dementia but this wee population *long pause* it’s frustrating. You’re very, very limited in what you can do.” [Rachel RN, p.21-22]

In this *Stuckness*, Kelly and Rachel reflected very little on their experiential knowledge and existing skills that could contribute to a meaningful interaction. Communication was therefore equated with language without attention being given to alternative ways of communicating relational elements of care. Rachel communicated a deep frustration with this situation:

> “…it was really frustrating for me and you feel so stupid. Do you know if you get to this stage of your life and this stage of your nursing career and not being able to communicate with somebody that's deaf.” [Rachel RN, p.22]

In trying to problem solve, Kelly expressed a disbelief that BSL was a deaf person’s only way of communicating:

> “…there must be something else d’you know, to have been deaf since she was born, she must have other ways of communicating. Most people do and I presume have some other form of communication, it can’t just be British Sign Language. They must have some other way of communicating.” [Kelly RN, p.3]

For Kelly and Rachel, there appeared to be a sense of impossibilities or lack of potential for their relationship with the deaf person to develop. Additionally, in her attempt to problem solve, Kelly appeared to frame BSL as problematic, reflecting dominant language ideologies and the lower status of sign languages.

In many of the conversations with nurses in which I sensed a *Stuckness* in their relationship with the deaf person, I found it challenging to enable them to move beyond this. At first, I thought this was purely a reflection on my facilitation skills as a novice researcher. Although I believe this contributed, there was also a certain element of acceptance from some of the nurses that this is simply deaf peoples’ reality. For example, Jane appeared to have little to reflect on when asked what was important and meaningful in the interaction between her and the deaf person. Additionally, she expressed that there was nothing about her approach to caring that changed over the course of the two days she was caring for a deaf man:

> “Megan: Can you pick some words or emotions that you could use to describe your experience of first meeting the man you cared for and then think about how that experience changed over the course of your interaction?
>
> Jane: I don’t think it changed or was different. No. I think it can be difficult and I guess you have to have a lot of patience, but I don’t think it changed. No, I wouldn’t say that it changed over the course of the two days I looked after him.” [Jane RN, p. 13]

It appeared that Jane was uncertain how her actions or approach to practice could change to influence the care experience. Later, Jane voiced that support for nursing staff to care for a deaf person might be helpful. This may indicate that Jane believed there was potential for a more effective approach to care but did not know what shape or form this would take or how to explore this potential.

As well as BSL being viewed as problematic, some nurse participants appeared to project the communication challenges faced in the interaction onto the deaf person. By using words and phrases that framed the communication barriers as belonging to the other person they failed to recognise the communication challenge as reciprocal. For example, Jane stated that:

> “It obviously took a while for him [deaf person] to understand [through lip-reading].” [Jane RN, p.4]

Rather than viewing lip-reading as the issue due to its ineffectiveness, Jane appeared to problematise the man’s ability to lip-read. Similarly, Kelly reflected on her experience of the deaf woman she was caring for having a prolonged stay in hospital:

> “So obviously with her being deaf and she had other disabilities as well, they did prolong her stay an extra 24-48 hours or she would have been away home. Her being deaf did make it more, not difficult but it did prolong her stay.” [Kelly RN, p.1]

Here Kelly and Jane appeared to be problematising the deaf person rather than thinking about what conditions might enable the deaf person to participate in their care or make it more efficient. This may suggest a primarily biomedical understanding of access rather than a collaborative and participatory approach in which language barriers are viewed as social challenges.

When Kelly expanded on the deaf person's prolonged stay in hospital, there were numerous reasons for delay in discharge including lack of common language, nursing staff's uncertainty about how best to communicate, lack of availability of a BSL/English interpreter, unfamiliarity of the situation and poor documentation. Kelly highlighted that the person's communication preferences "…weren't getting communicated between us [nursing staff]" [Kelly RN, p.2]. Although Kelly stated that's "our fault, that's us as nursing staff" [Kelly RN, p.3] there continued to be a sense that the person's deafness was the problem rather than a communication challenge that existed *between* the deaf person and nursing staff.

A moment of self-awareness of unexamined prejudices and biases was triggered for Kelly when she realised that she had made an assumption that the deaf woman she was caring for couldn't read or write. Kelly came to realise that she had not attempted to ask the deaf person how they could communicate because she had seen a barrier and thought it could not be overcome:

> "I'd passed a judgement before I'd even met my patient. Just from seeing my handover" [Kelly RN, p.14].

Kelly acknowledged that:

> "In the future, I would definitely ask 'How will I communicate with you. How will you find it easiest to understand what I am saying to you' and just go from there." [Kelly RN, p.15]

While this realisation presented Kelly with an opportunity to communicate healthcare information through written word, she appeared unaware of the cross-cultural ground that she was continuing to occupy after this realisation. Without such knowledge, ongoing critical questioning of self and practice did not appear to occur. Potential cross-cultural tension was therefore hidden, and no space made for dialogue and negotiation. For Kelly the sense of freeze or *Stuckness* appeared instantly resolved when she realised she could communicate with the deaf person through written English. So much so that she made the decision to cancel her request for a BSL/ English interpreter:

> "…it [written communication] moved things on so much quicker because we spent 4 or 5 hours thinking how are we going to tell this women about post-operative instructions and when the follow up [appointment] would be? I was thinking 'oh my god, this woman is going to stay in for 48 hours just to wait on an interpreter and she's perfectly fine'. Obviously, it keeps the consultants happy, they've got beds opened up for the next patient coming in." [Kelly RN, p.11]

Kelly's reflection highlights the demanding workforce pressures and time constraints as including the "…background priority of the ward and the patients that are waiting in A&E" [Kelly RN, p.8]. Therefore the challenges that existed in the practice setting may have hindered Kelly from moving beyond the *Stuckness* to engage more meaningfully with the deaf person. This may suggest that nurses cannot reconcile their own value system with the outcomes delivered in their organisation or that unspoken expectations construct impossible scenarios in which healthcare professionals are caught. The picture I painted after the interview with Kelly (Figure 7.6) reflects the business of the clinical area she worked in and the pressure I sensed she felt to maintain the flow of patients through the clinical area, potentially to the detriment of effective and meaningful connection with the deaf person.

Figure 7.6 Whirlwind

Although the sense of *Stuckness* appeared resolved for Kelly, without the deaf person's account it is unclear how effectively they understood the information provided to them in English. Therefore, Kelly found a means (written English) to help her communicate discharge information but that did not necessarily enable her to communicate effectively or meaningfully with the person. Kelly appeared to gain control of the task of communicating information but whether or not this opened up a space in which the deaf person could effectively participate is not known. The participating interpreters highlighted that this oversimplification of resolving communication challenges is common and can result in healthcare professionals believing they are effectively communicating while the deaf person remains in *The Unknown.* Cat explained that it is often not until the healthcare professionals see a deaf person communicating in their own language that they may question these beliefs:

> "…they [nurses] realise that there's suddenly this full communication happening and they're telling you that their sister is going to come in because they've forgot their charger for their phone and blah blah blah blah blah and you're just getting all this information. They just see this person that's just a different person all of a sudden because they can communicate." [Cat INTERP, p.55-56]

This again reiterates the challenges of knowing if a deaf person is fully understanding what is being communicated with them as highlighted in the subtheme *Layers*.

Visual people

While many of the nurses focused on the importance of linguistically communicating with deaf participants, all deaf participants emphasised the significance of visuals to understanding and meaning making. This not only related to exchange of healthcare information but to navigating healthcare systems, relating to people and being enabled to participate in all elements of their healthcare. The deaf participants spoke about being visual people, emphasizing how crucial visual information is to their communication, orientation and understanding because as Hayley emphasised "…that's how we use language" [Hayley DP, p.17]. Adam indicated that deaf peoples' visual orientation to the world is "…a different way of thinking about things" [Adam RN, p.39] that impacts how meaning is shaped, presented and represented.

As explored in the subtheme *Underneath* the hospital was often experienced as a hearing space. Expanding upon this Carly emphasised that healthcare environments are challenging to navigate visually, with complex signage and few images to represent different departments and facilities:

> "There are so many different departments in the hospital and people don't necessarily know what these departments are. You know whether it might be pictures next to what the department are to make things more visual. For ENT, maybe there could be a visual next to that with a small picture an ear, nose and throat…it [the hospital] needs to be a bit more visual so that people know and feel more comfortable about going to the right department or navigating their way to the right department through the hospital." [Carly DP, p.17]

Carly’s comment suggests that physical healthcare environments are designed from the perspective of the hearing ‘norm’ with little attention given to alternative ways of navigating them.

As visual people, deaf participants also highlighted the importance of visual information to facilitate effective healthcare assessments and understanding when receiving healthcare information that included medical jargon or concepts unfamiliar to them. Many of the routine assessments in the healthcare setting were noted as being insufficient for adequately assessing a deaf person’s needs. For example, use of a numerical pain scale was emphasised as being problematic due to its reliance on numerical rating:

> “Numbers don’t show that [pain intensity] and they’re not the best way to actually find out how somebody is feeling cause when people say 1 to 10, [the deaf person thinks] ‘what are you using numbers for?’, they don’t see how numbers are linked to pain. It is quite meaningless actually.” [Hayley DP, p.21]

This indicates that standard approaches to assessment that are used with hearing people may not enable a deaf person to effectively express their experiences of health and illness. While the consequences of assessing a deaf person’s pain using numerical values is unknown, inadequate assessment may compromise diagnosis and treatment.

Suggesting solutions, Hayley reflected on the importance of providing visual information expressing:

> “Something visual to give them [deaf person] an idea of what is actually happening in their body. That is part of the deaf language.” [Hayley DP, p.17].

Additionally, Hayley and Carly emphasised the importance of healthcare staff to think visually when providing instructions such as time and dose of medication. Giving examples of a “…drawing or some kind of diagram” [Carly DP, p.16], Carly emphasised that that these visual things can “support deaf patients to understand information for their appointments” [Carly DP, p.16]. In the hospital, healthcare professionals were seen to rarely use visual aids to facilitate understanding.

Lack of visual information was stressed by some as being extremely problematic for deaf people who have low English literacy levels coupled with poor BSL language acquisition. Reflecting on one of her client’s hospital experience, Hayley described a "gap" [Hayley DP, p.11] in which materials and visuals to support understanding is often missing for deaf people:

> "So there seems to be a gap, because he [deaf person] wasn't able to get the materials and visuals that he needed to support his understanding of his medication." [Hayley DP, p.11]

Further reflecting on this gap, Hayley stated that interpreters and social services often had to create the visual resources to support this deaf person's understanding. This indicated that healthcare professionals were not recognising the need for visual materials. Hayley shared how one deaf person was affected by the lack of visuals to back-up his understanding:

> "…they [healthcare professionals] said you know, 'reduce sugars and change the way that you eat' but there was nothing visual for this client. They gave him a list of 'don't do this, don't do that'. They [client] just didn't understand that at all. So basically they were eating the wrong foods and still suffering and still having to go along to A&E." [Hayley DP, p.7]

This reveals the negative consequences that can result from healthcare professionals not understanding and responding to deaf peoples' visual orientation to support their understanding.

There were limited examples of how healthcare professionals had used visuals to communicate and support a deaf person's understanding. For example, Hayley told of a GP using a skeleton to give her visual insight into bone structure and an occupational therapist who gave one of her client's pictures to enable them to engage visually in therapy:

> "…there was one [doctor] that did use a skeleton and I thought wow, that was really impressive. When you actually just show me what's going on it gives me that insight so that I know what's happening." [Hayley DP, p.18]

These insights indicate that visual information can enable and empower deaf people to understand and make meaning out of healthcare information. Therefore, as Hayley reiterated "…for every deaf person there should be something visual" [Hayley DP, p17].

This resonated with the interpreter participants discussion regarding the importance of visual communication. In this discussion, participants stated that for many deaf people visuals are vital to grasp understanding of diagnosis, treatment and care. As healthcare professionals were seen as being hesitant to use visuals, the interpreters spoke about using their smart phones to find videos and pictures on the internet that would visually explain procedures or conditions to enhance their explanations:

> “Sometimes the communication is just not working so you have to try everything in your toolbox…to the point where you’re getting your phone out and you’re going *points* ‘this date here’ or pointing to the body part or using photos or symbols or gestures or using everything in your toolbox to try and get over what’s [being communicated].” [Tina INTERP, p.17]

As well as visuals being important in the healthcare setting to provide deaf people with information regarding diagnosis, treatment and care, visuals were expressed as being important for a therapeutic relationship to develop. Tina explained that:

> “Deaf people are very visual so a twitch of the eyebrow, a hearing person might not catch but we would. Or a deaf person would immediately catch that and we would know that that tiny little movement can display a lot even if nothing is signed or said…70% of sign language is in the body, not just the hands.” [Tina INTERP, p.24]

This comment suggests that deaf people may be highly attuned to what non-verbal communication is expressing due to their visual orientation to the world. Expanding on this Adam emphasised that:

> “[Sign language] is based as much on facial expression as it is on signing. You can get by a lot by communicating your facial expression.” [Adam RN, p.2]

Tina and Adam’s comments indicated that facial expression is a significant part of sign language and deaf peoples’ communication. While this may not be useful for communicating complex medical information, it challenges the notion explored in the subtheme *Stuckness* that nurses and deaf people can communicate very little without a shared language. Therefore, there may be potential for enhancing care through greater attention to facial expression and body language.

Awareness of deaf peoples’ visual orientation and language was also evidently fundamental in the triadic interaction. For example, working between two modes (spoken and visual) in the interpretation of words such as “anaesthetic”, required interpreters to visually demonstrate how and/or where the anaesthetic was to be administered. Therefore, visual understanding was a pre-requisite for interpreting such information accurately. Such information could enable the placement of signs in the sign space to accurately reflect the administration route and location an anaesthetic would be given on the body.

Emily's first experience of working with a BSL/English interpreter gave her some insight into the visual nature of BSL and how she could contribute towards an accurate translation of healthcare information:

> "They [interpreter] were clarifying if I wasn't being specific enough. For example, I said 'I'm going to give a local anaesthetic' and the interpreter clarified by asking 'Is that an injection?' Yes, it is but of course I never thought to say that." [Emily RN, p.4-5]

Although these details may seem trivial, the interpreters discussed the distress that some of their deaf clients had experienced when the nature of the sign they had used did not accurately reflect the reality of their experience. These were examples of providing information which is "linguistically correct but meaning wise badly badly wrong" [Harry INTERP, p.46]. Tina and Harry reflected on their own experiences of providing information that was visually incorrect:

> "I was interpreting for somebody who went in for an operation and they told me the next time I saw them, they said 'oh, they put a mask over my face and I was terrified, I didn't realise what they were doing and I got really scared' cause they thought it was an anaesthetic *signs injection* but nobody had said anything about putting an oxygen mask on them. So they freaked out because that little bit of information had been missed." [Tina INTERP, p.47]

> "I signed that for Entonox recently, I signed gas and air *signs mask over face*, actually it's not like that at all you bite on the [tube] and the person got something they didn't expect cause they expected gas *signs mask over face* and actually they got *signs biting down on tube*." [Harry INTERP, p.46]

These examples highlight that interpreters are often relaying information that explains and anticipates what is to come prior to medical procedures and interventions. In these situations, there was a sense of weightiness with regard to the responsibility of having to provide accurate information in advance because the deaf person may not have an interpreter to clarify information when the procedure or intervention is being carried out. In these situations, interpreters expressed relying heavily on the healthcare professional to provide accurate and detailed information. The interpreters spoke about asking questions to clarify their visual understanding of healthcare information:

> "…are you going to put a mask over their face? Is it going to be in their hand? Like, what exactly is going to happen?" [Tina INTERP, p.48]

While the interpreters emphasised situations in which they clarified their visual understanding, they also emphasised that there are situations in which they did not know what to ask because they were not trained healthcare professionals. This reiterates the need for effective relationships between interpreters and healthcare professionals, which have historically been underdeveloped.

Summary

In this theme, I identified that a lack of shared language often limited the capacity of nurses to communicate. This resulted in a *Stuckness* in which they were unsure how to develop a relationship and gain a sense of who the person was that they were caring for. Unable to use familiar practices of linguistic engagement nurses expressed feeling deskilled. The lack of shared language became a barrier not only to the relational element of care but also to the effectiveness of physical care. In the subtheme *Visual People* deaf people expressed that having knowledge about the visual nature of their understanding of the world could provide healthcare professionals with a different approach to their care. Providing visual information and communicating via visual means was expressed as essential to deaf peoples' navigation and understanding of their healthcare journey. However, the hospital environment and healthcare professional's common communication methods were often viewed as lacking visual information. Healthcare professional's understanding of the visual nature of BSL was also viewed as crucial to accurate interpreting.

Authentic engagement

In the authentic movement this theme was expressed as playfulness and spiralling that drew me back to the line (border). The movement was energetic and crossed the line. This theme relates to a releasing of the *Stuckness* when the possibilities identified in the previous theme are realised and embodied. A praxis spiral was identified in the authentic movement that also relates to this theme. Over time, some nursing participants discovered ways in which they could relate to and engage with the deaf person. In these moments of connection, the *Border* between deaf and hearing worlds appeared to become less well-defined and I saw the potential for relational practice and authentic engagement. Beth emphasised that this space is not without misunderstanding and controversies or difference, but that shared meaning is possible.

> "Niamh:…well you can see they're praxis spirals. But I thought it looked playful and very intentional in the way that you were moving.
>
> Megan: I think I could feel this (praxis spiral) in very, very specific interviews that I've done where people have had a previous interest in the deaf community and BSL and that little bit of knowledge prior to engaging with someone that is deaf and even a little, tiny glimpse into the deaf community has allowed them to be very curious about how to engage with someone who has a very different culture

> from them. And realising that it's not just that they're deaf. Realising that that means a lot more than they just can't hear. Realising that they view the world differently and actually from just having that little bit of insight it makes them question everything that they do in their practice."

[Authentic Movement 2/04/19, p.5]

Figure 7.7 Authentic Movement – Authentic Engagement

Shifting perspectives

As explored in the subthemes *I was invisible* and *I'm just deaf,* deaf participants described healthcare professionals as embodying a biomedical perspective in their practice. In contrast to viewing deafness from this biomedical perspective, all deaf participants viewed their deafness positively, reflecting the sociocultural perspective of deafness explored in *Chapter Two*. Deaf culture and deaf awareness were concepts mentioned by all deaf participants in this study. Healthcare professionals were often described as having no deaf awareness with Carly expressing "I can tell quite quickly if someone is not deaf aware" [Carly DP, p.4]. When asked what deaf awareness meant to them, most deaf participants were quick to share negative experiences in which healthcare professionals had little awareness of deaf ways of being and knowing. Emphasizing the importance of understanding different values and beliefs inherent in these perspectives of deafness Carly stated:

> "I think that hearing culture is very different from deaf culture and people don't know that. People just think, you know, you're just a deaf person, you've just got a hearing loss." [Carly DP, p.30]

Due to lack of awareness of these differences, deaf participants highlighted having to continually educate healthcare professionals. This was evident in Hayley's comment:

> "I'm just re-explaining 'it's deaf culture, its deaf culture'." [Hayley DP, p.28]

In contrast to the subtheme, *I'm just deaf*, deaf participants therefore expressed characteristics of being deaf that marked deaf people as different from hearing people. The paradox presented by these two statements "*I'm just deaf*" and "It's deaf culture*"* indicates the importance of what Adam described as "understanding what it [deafness] is or what it isn't" [Adam RN, p.21].

Amongst nurse participants in this study there were varied levels of knowledge and understanding of the differences between deaf people and hearing people. Most participants were unaware of deaf culture and how BSL differed from English, while others had a basic understanding or expressed being "aware of the culture" [John RN, p.5]. Although many of the nurses appeared to be embodying a biomedical framework in their approach to caring for a deaf person, a shift from this perspective was apparent in the data.

Some nurses realised over time that the person they were caring for did not view their deafness as a disability or deficit. For example, Kelly stated that the person she was caring for:

> "…probably doesn't even realise [deafness] is a disability anymore because she's had it that long." [Kelly RN, p.8-9]

This indicated that Kelly had begun to question what the 'norm' was for the deaf person she was caring for. However, there was no indication of how this may have influenced her practice.

For Anna and Sophie, a shift in their perspective occurred due to complaints they received regarding the unmet care needs of the deaf person. These complaints highlighted to them that their routine approaches to care, such as use of a numerical pain scale for assessment were not adequate or effective. For Sophie this realisation triggered a curiosity and questioning as to how deaf people may express pain in a different way:

> "I want to be able to treat somebody as a whole person, to understand everything about them and also understand people that are deaf sometimes communicate differently when they're in pain." [Sophie RN, p.10]

Sophie began to reflect on her practice and how she had misunderstood the effectiveness of her approach to pain assessment. Following this moment of realisation, Sophie engaged in an online deaf awareness course. These actions showed Sophie's desire to expand her understanding of how a deaf person might experience and express health and illness differently. However, the challenge of trying to change ingrained perspectives and routine practices was highlighted by contradictions that arose in Sophie's description of how she communicated with the deaf person after the deaf awareness training:

> "Megan: So how did you communicate with them [deaf person] before the interpreter came in?
>
> Sophie: Just as I would with any other patient, just explained everything and he could lip-read so he understood things, but he just, when he was trying to communicate things back he said 'oh I don't really understand what you're saying'. So, we did manage to communicate, we managed to tell him about post-operative [care] and he completely understood but it was just better to have somebody else that could use sign language just cause there are so many things after an operation that you need to know." [Sophie RN, p.3]

While Sophie had been informed that communicating with the deaf person in English was not effective, she returned to this familiar way of interacting. This highlighted the difficulty of imagining alternatives to ingrained understanding and practices, suggesting that rather than simply being actors or instruments performing a routine, routine practices are embodied acts that often display taken for granted norms. From these accounts it is evident that rather than being moments of realisation that wholly transformed practice, Sophie and Kelly experienced moments of curiosity that empowered them to question elements of their practice. In the authentic movement this was seen as the beginning of playfulness which will be explored in depth in the next subtheme. These findings suggest that curiosity may facilitate nurses questioning of their ways of thinking and practicing that has the potential to enable more culturally sensitive approaches to care.

For two of the nurses Beth and Adam, having knowledge and understanding of BSL, deaf culture and having previous interactions with deaf people enabled transformation of their practice from routine approaches to care to culturally responsive care. For Adam, growing up with a deaf family member meant that interacting with deaf people and using BSL was an ordinary and regular experience for him. In contrast to nurses' responses to deaf people explored in the subtheme *Stuckness*, in which BSL was problematised, Adam recognised BSL as a bona fide language:

> “I look at it [BSL] just as I would a foreign language. Yeah, they [deaf person] can’t hear but it’s somebody who doesn’t speak English. I view it as a language difference. I can’t speak for the deaf community, but I think that’s probably what they see it as well. You know, there’s nothing wrong with them, they just can’t hear you.” [Adam RN, p.15]

Therefore, Adam recognised that BSL was crucial to deaf people accessing and understanding their health and care. While this perspective was not a new ‘shift’ in Adam’s thinking, his experiential knowledge of BSL enabled him to understand the significance of linguistic access and prompted him to prioritise this in his care. Adam noted deaf people feel relieved when they meet a nurse who has some understanding of the deaf community and believed that his family links to the deaf community instantly “creates that rapport” [Adam RN, p.7] with a deaf person. Therefore, although Adam acknowledged that his understanding was “somewhat limited” [Adam RN, p.18], his personal experiences provided him with a different frame of reference to those who had no connections to the community and potentially fell back upon assumptions. This provided him with insight into the deaf world that I captured in the painting Figure 7.10.

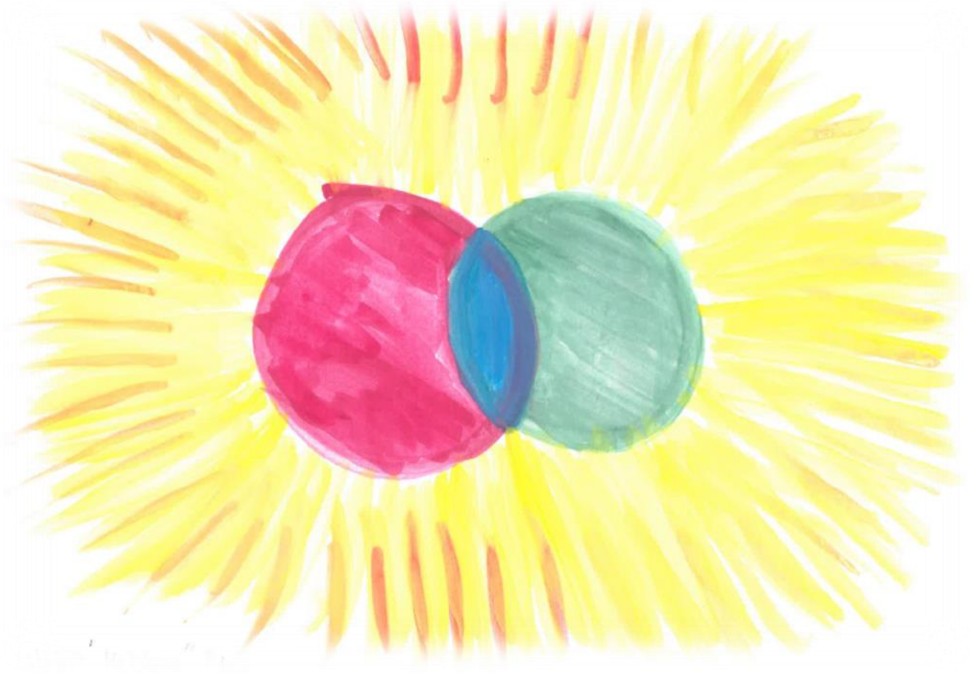

Figure 7.10 Meeting of worlds

While Beth had less frequent contact with deaf people, she had engaged in a BSL course and formal deaf awareness training 10 years prior to caring for a deaf person.

Reflecting on the impact formal deaf awareness training had on her understanding and perspective of deafness Beth stated:

> “What really struck me was all the deaf awareness content from the class I’d been to as part of the sign language course sort of came back to me.” [Beth RN, p.2]

Beth allowed her familiar acceptance of the world and practice to be questioned by being open to trying to understand how the deaf person was experiencing her care. Beth described this as being able to “stretch myself” [Beth RN, p.20] beyond that which she already knew from experience and established knowledge. This went beyond moments of curiosity to enable taken for granted practices to change and culturally sensitive care to develop. This was evident with the following narrative she shared regarding her conversation with a client about her baby’s hearing status:

> “I remember us having conversations in my broken sign language around what are your hopes and expectations around the hearing test and I think what I tried to do was listen without prejudice but understand that a hearing test has a very different meaning to a family who use sign language as their first language than it might do to a person who has become deaf, or a hearing person. So I remember when they got the hearing test results, well I knew the hearing test results because they come back before you do the first visit but it’s really interesting, normally when I would see a family that weren’t deaf, normally I would say ‘oh the hearing test results have come back and everything's fine, I imagine you feel relieved’ or I’d say ‘that’s good’ but when I went to see this family I said ‘oh, I see the hearing test results have come back and she’s hearing. How do you feel about that?’ and I suppose it’s little things isn’t it, like that I’d like to think are important.” [Beth RN, p.13-14]

Through this reflection, Beth displayed that she was able to develop praxis in which she brought together her prior knowledge of BSL, deaf culture and new understandings, then reflected in action and committed to her engagement with a moral intent. This is further illustrated in the following reflection:

> “When the baby was born, the fourth child. You know, I asked for her name and I wrote it down and I said ‘oh, does she have a sign name?’. This is a little bit of deaf culture I knew about, but my understanding really increased. So, she [deaf person] said ‘oh no, we don’t give sign names at birth, it’s given to you from within the community and it’s given to you at a time when people know who you are’. I suppose as your personality develops. I said, ‘Oh gosh, I didn’t realise that. What are your sign names?’ and they were brilliant. I found it a really enriching experience.” [Beth RN, p.16]

Beth’s basic knowledge of the differences between hearing and deaf cultures triggered a curiosity about what might be important to the deaf person she was working with. This curiosity led to an expansion of her understanding and illuminated different characteristics of deaf and hearing culture. Rather than these differences creating a barrier or border between Beth and the deaf person, there appeared to be a meeting of two worlds. I captured this meeting of worlds in the picture I painted after my interview with Beth, naming it ‘*Merging of margins’* (Figure 7.9).

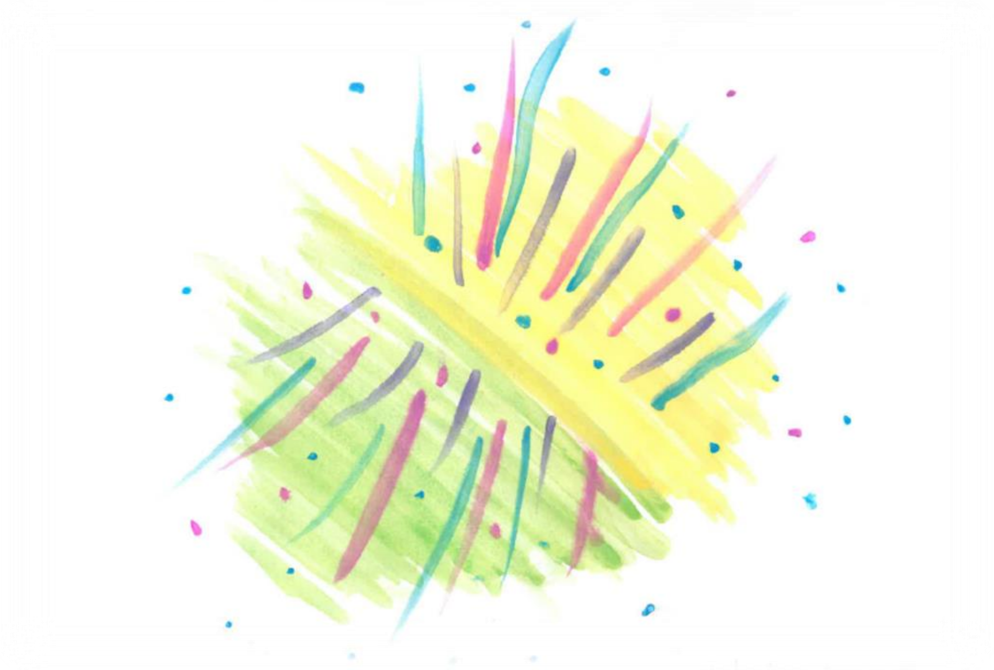

Figure 7.9 Merging of margins

These stories triggered a response from Beth in which she stated:

> “… you begin to think about who you are as a professional, what you represent to a deaf family and how that might determine the care you provide. So, thinking about the power relationship that exists between the two of you, thinking about the meaning of words like ‘hearing test’ and ‘deafness’.” [Beth RN, p.17]

Beth therefore remained curious and attentive to the world of the family she was working with, believing that health and well-being might have a different meaning to a deaf person. Beth believed that this awareness and sensitive approach to caring for the deaf family laid a foundation of trust that allowed her and the deaf family to collaborate with one another. This is displayed in the following reflection:

> “I’m guessing that the family maybe understood what was going on, that I was trying to understand I suppose, the deaf world and be respectful of that.” [Beth RN, p.5]

These findings suggest that understanding and attending to a deaf person’s everyday ways-of-being may be required to develop culturally sensitive care and authentic engagement. Beth and Adam’s reflections resonated with Lindsey’s experience of interacting with healthcare professionals with basic BSL skills. She believed this “makes a difference” [Lindsey DP, p.14] and makes her feel “more comfortable to approach" [Lindsey DP, p.14] another person. This indicates the influence of values and attitudes that individual nurses hold about deafness, that they not only shape the way they approach engagement with a deaf person but also significantly shape the quality of relationship between deaf people and healthcare professionals.

Reflecting on how nurses may access knowledge that can inform culturally responsive care, Beth expressed a belief that it is in nurses' power to educate themselves stating:

> "It's in our [nurses] power to educate ourselves about somebody's world and about culture and be equipped." [Beth RN, p.18]

However, as emphasised at the beginning of this subtheme and demonstrated in Sophie and Kelly's accounts, for those who had no prior contact with the deaf community the shift in perspective they experienced transformed their thinking but not their actions. This may suggest that a greater understanding of the different *Layers* that influence the relational space between nurses and hearing people may be required to trigger a perspective shift that can transform practice.

The value of taught deaf awareness courses was highlighted by a number of deaf participants as having the potential to enable healthcare professionals to shift their perspectives of deafness. However, Peter believed that such courses "presented their own problems" [Peter DP, p.4]. Peter highlighted what he believed to be a problem with taught deaf awareness in which peoples' ways of engaging with one another becomes restricted by following a set of rules:

> "It means that people always follow a set of rules, these fixed rules and they say 'oh, I have to do this. I have to do the other' and there's more than one way to do something. I think that, you know, sometimes there is a problem with that because that can create its own difficulty because people are individuals. Deaf people are different. They have different struggles." [Peter DP, p.4]

This indicated to me that prescribed ways of engaging with deaf people, that is often inherent in decontextualised training programmes, may fail to acknowledge and respond to deaf peoples' diverse ways of being. A narrow understanding of deaf culture and deaf being may therefore be harmful as healthcare professionals need to relate to the people they are working in the context of a specific situation.

'Little things make a big difference'

Although all deaf participants expressed the importance of having access to information about their health and care to help them make sense of their healthcare experiences, they also emphasised that in their interactions "little things… make a big difference" [Lindsey DP, p.8]. These little things related to the emotional and relational elements of care that humanised their healthcare experience. Peter described these little things as the "basic niceties" [Peter DP, p.7] that can make the difference between a positive and negative experience of care. These little things were simple gestures:

> "…she [nurse] was smiley, she was friendly, she was relaxed you know, she summoned me into the room with a nice gesture. In general, she used gestures and body language." [Carly DP, p.10]

> "If there's no verbal communication, for example, that doesn't matter. It's about, you know, gesturing. Those basic niceties, those basic things, writing down 'you OK?', 'you worried?' You know something as basic as that, in really plain English would have allowed that type of communication to start to develop and grow and so there are different ways." [Peter DP, p.7]

Such embodied engagement could be described as a routine part of nursing care but appeared to be crucial to conveying a nurse's sense of openness and availability to deaf participants. These findings contrast with the negative experiences described in the theme *Borders*, implying that relational acts, facilitated through authentic engagement break down the borders described and reduce the possibility of a negative experience of care. After my interview with Carly, I captured the contrast between her experiences of nurses who engaged in the 'little things' and those who did not (Figure 7.11). The left-hand side of this picture captures the humanising affect that the 'little things' such as gesture and facial expression had on her. In contrast the right-hand side reflects the dehumanising affect that is reflected in the subthemes *I was Invisible* and *I'm just deaf*.

Figure 7.11 It's the little things

This image illustrates that when deaf people were engaged with through small acts, they felt seen and responded to. Therefore, making embodied relational connections appeared to acknowledge the personhood of the individual and enable authentic engagement. Because many of the little things were conveyed not simply through words but through gesture and bodily movement, the significance of the whole body in giving shape and form to what nurses do and how they do it appeared significant.

While many of these moments of embodied engagement appeared to be unplanned, Emily was intentional about engaging relationally with the deaf person she was caring for through her body language:

> "So, I went to introduce myself to him whilst he was on the ward and gave him our leaflet and I felt he didn't want to look at me. He wanted to look into space or his sister, who was not quite translating but for him but communicating with him. And I wanted him to look at me because I wanted him to see that I was a kind, friendly face so he would see me, recognise me next time. I wanted to shake his hand, so I had to really go out of my way to make him look at me which I felt… I didn't know if that was the right thing to do." [Emily RN, p.1-2]

This suggests that Emily felt it was important for her to show the deaf person she would be caring for that she was friendly by using facial expression, gesture and touch. Emily described making decisions about how to engage with the deaf person:

> "Just instinctively, I literally thought I'd like him to look at me so that when he comes in again, he would recognise who I was the next time. I wanted him to

> look at me and see me smiling. That's what I wanted to achieve actually." [Emily RN, p.3]

Although communicating with a deaf person was unfamiliar to Emily, she appeared to practice using embodied knowledge and skills that she could apply to this new situation. Similarly, Anna stated that when communicating with someone who you do not share a language with, you "…improvise because you don't always have all the right things" [Anna RN, p.10]. For Emily and Anna this engagement was a process of "trial and error" [Anna RN, p.23] or toing and froing to find ways of engagement that were effective. I captured this toing and froing in the kite image I painted after relistening to my interview with Emily (Figure 7.12) and named it '*Dancing in the wind*'.

Figure 7.12 Dancing in the wind

This painting conveyed the playfulness and rhythm of this toing and froing that I sensed in Anna and Emily's reflections. For Anna, who worked on a stroke unit this appeared to be a familiar practice of blending gesture, verbalising and using other visual cues to explore how to most effectively communicate with someone. This indicates that nurses from specific disciplines may be more familiar and comfortable using and/or articulating how they use their bodies to communicate.

While Emily and Anna had an awareness of the significance of embodied communication to engage authentically, as explored in the subtheme *Stuckness* some nurses overlooked these elements of their practice, focusing on the frustration of not having a common language. This inattentiveness to simple actions or gesture does not indicate that the nurses had not incorporated these into their care but may suggest that they are subconscious actions, difficult to articulate and therefore not reflected upon. Adam touched upon this, stating:

> "I spend a lot of my time, a lot of the work I'm doing just now em, is in human factors. You know soft skills, nontechnical skills, communication, how we work as teams and stuff like that but you never really think about communication other than you know, in the sense of verbal English. You never really think about and you know, to be honest I don't really think about how we would use nontechnical skills to the deaf community." [Adam RN, p.39]

However, it was evident in many of the nurses interviews that they did not consciously think or reflect on their communication outside of the use of language. Therefore, many felt they "…couldn't really convey much information other than a cup of tea" [John RN, p.15]. Despite this, I was able to gain a sense of care that some nurse participants were expressing through their body language and use of gesture in the interview. This sense of care was particularly prominent in my interview with Rachel. Rachel expressed a deep frustration at not being able to *tell* a deaf relative how she felt when his wife was dying, stating:

> "It's really difficult as a nurse not to be able to communicate with somebody, really difficult. I don't know how that man's feelings about how we do things. Is he in emotional distress? Do you know, does he think we're doing a good job? Does he need more from us? There's no feedback coming from him. We were just doing everything we thought we could." [Rachel RN, p.7-8]

Despite this account indicating that Rachel believed she could not communicate much with the deaf person, after re-listening to this interview, I painted a picture (Figure 7.13) and named it '*Warm embrace'*.

Figure 7.13 Warm embrace

This picture was accompanied by the following reflection:

> "As I was speaking to Rachel today, I realised she was struggling to verbalise how she interacted and connected with the deaf person she was caring for. I listened to her talk about the frustrations of not being able to use language to communicate. However, in the telling of the story, she was embodying how she had physically connected and engaged. She sat up right, leaned into me and used gesture. Her eyes were expressing a desire to connect. How can I enable people to express the connections we make through our proximity, energy, the way we hold ourselves and what it says about how we feel about the other?" [Reflective diary 28/09/19]

Despite having little evidence that the man Rachel was caring for felt her intentions, I sensed that Rachel would have communicated a sense of care and availability through her body. However, Rachel was so fixated on the fact that she had no means of relating to the deaf person verbally that she did not acknowledge the other ways in which she used her body to communicate her care. This suggests a privileging of language that neglects the capacity of the body to relate in other ways.

'Between us'

The title of this subtheme was an original in vivo code identified during analysis of the research. It reflected the reciprocal and participatory relationship that one of the nurses, Beth developed with the deaf person she was caring for and was extracted from this short account:

> “I was thinking, oh gosh, we must have between us been able to fashion enough communication skills to get past the functional part of the relationship and actually do what I think is the real job of nursing which is the relational part.” [Beth RN, p.7]

Beth cared for the deaf family she was visiting over a period of three years. She described developing a “helping relationship” [Beth RN, p.5] with a family who she visited over this time. Recounting her initial relationship as “functional” [Beth RN, p.4], Beth emphasised the importance of an interpreter in enabling her to develop an understanding of the family she was working with:

> “…in the early days when we didn’t really know each other and I was, I didn’t feel very confident about using sign language, we used the interpreter quite a lot. So particularly in the early visits when you’re getting to know a family or as part of the nursing assessment, I suppose there are quite a lot of questions that you need to find out about them. Their family’s access to resources, the children's health and development, some assessment of their parenting ability. We do that with all families but that requires me being a competent communicator to be able to elicit that information from a family. So, the interpreter was absolutely invaluable to help me understand who they were as a family and then to make an assessment of any needs that would arise, and I think as well, it was useful for the family to ask me lots of questions.” [Beth RN, p.4]

Beth viewed her initial contact with the family as crucial to establishing the basis for an effective relationship that enabled her to understand how their world was constructed. To do this effectively Beth recognised that both she and the deaf person required an interpreter to complete an effective nursing assessment and exchange information accurately. Beth expressed that once she “got over the business of them [family] being new” [Beth RN, p.5] they established ways of communicating effectively between them and began to use an interpreter less. This involved relying on a combination of methods to communicate including her basic sign language, gesturing and finger spelling. However, Beth continued to negotiate the need for an interpreter with her client ensuring that this was an option available to both of them:

> “…it felt OK not to use an interpreter. I always offered her an interpreter ‘would you like me to book an interpreter?’ and there’d be times when she’d say, ‘can you come round at this time, I’ve booked an interpreter’.” [Beth RN, p.14]

This negotiation of the need for an interpreter suggests the sharing of power as Beth made these decisions *with* the person rather than *for* them. Additionally, she acknowledged that one or both of them might feel the need for an interpreter at certain appointments.

While Beth had a basic understanding of BSL and utilised this to communicate with the family she was caring for, she described being able to continue to develop a picture of who the family were by paying attention to the deaf persons whole embodied being. Therefore, while having a basic understanding of BSL was key, Beth also emphasised a wider sense of relatedness through the body. This involved being attentive to the "whole picture" [Beth RN, p.12] and becoming familiar with the "idiosyncrasies" [Beth RN, p.9] of her client's nonverbal behaviour to understand what's being communicated. Consequently, the texture of the signed communication and knowing a person, in the sense of their personality and character, were interconnected. This kind of knowledge was viewed, by Beth, as harder to get through an interpreted dialogue as it was obscured by the interpreted event:

> "…the interpreters are great in that they'll interpret the words and the emphasis on words but it's not the same as tuning in and I want to say listening, listening with my eyes." [Beth RN, p.10]

This revealed a belief that coming to know a person is not solely dependent upon language but is wholly embodied.

John and Emily similarly developed a collaborative and participatory relationship with the deaf person they were caring for. Despite having no prior contact with a deaf person, John and Emily recognised that the person could guide their practice to ensure the care they provided was culturally sensitive. John expressed:

> "I was worried about etiquette and not doing… not speaking to him at the right time and things like that and I actually said to him look if I do something wrong just give me a clip around the ear." [John RN, p.5]

Although there was an element of fear of doing something wrong evident in John's statement, both he and Emily expressed that when caring for the deaf person they were "taking his lead" [Emily RN, p.17]. John and Emily therefore acknowledged that there were gaps in their knowledge of how to effectively care for a deaf person but that they were willing to learn from and be guided by the person. Therefore, rather than providing one way care, Emily, John and Beth developed a partnership in which the experiential knowledge of the person was acknowledged and valued. In contrast to providing a view from nowhere explored in the subtheme *The façade*, this approach revealed an understanding that each person in the care environment comes to the interaction with differing beliefs and values that stem from their life experiences. Entering into such a partnership allowed Emily and John to move past the routine approaches to care that were evident in other narratives.

The significance and value of Emily and John's openness to learning from the deaf person they were working with became apparent in how the deaf person responded to them. Both had experienced a lack of engagement from this deaf man when they first introduced themselves to him with Emily stating:

> "I went to introduce myself to him whilst he was on the ward and gave him a leaflet. I felt he didn't want to look at me. He wanted to look into space…Afterwards I spoke to his sister and she said that if he doesn't want to talk then he won't look at her so I thought, right that was maybe him choosing not to talk to me." [Emily RN, p.2]

While this reflection suggests disengagement of the deaf person, over time, both Emily and John expressed they developed rapport and trust with the man. Emily shared the contrast between this initial disengagement and how the deaf person responded after she had cared for him and he was later readmitted for further treatment:

> "I waved and I said hello and he was very encouraging for me to come in and just see him and he was actually able to tell me that he was sick and what not. It was just a two-minute interaction, but it was nice. He recognised me and we were able to have some form of communication." [Emily RN, p.10]

The contrast between the deaf person's initial lack of engagement and subsequent enthusiasm to interact with Emily suggests that her openness to learning from him had enabled a relationship to develop.

In reflecting on their experiences, both Beth and Emily emphasised the experiential knowledge that the deaf person had of communicating without a shared language and how their relationship had benefited from it. In contrast to some of the nurses who expressed a disbelief that BSL could be a deaf person's only way of communicating, Beth and Emily both recognised how "expressively communicative" [Emily RN, p.1] the deaf people in their care were. Beth described her client as being "a communication magician" who she believed had "built a repertoire of communication skills that really outweighed [hers]" (Beth RN, p.6). She spoke of her clients "brilliant facial expressions" [Beth RN, p.12] and "receptive skills" [Beth RN, p.6] that contributed to her client's communicative skills being superior to hers. After completing the interview with Beth, we further discussed deaf peoples' communication skills and I reflected on this conversation in my diary:

> "After the interview, we [Beth and I] had a short reflective conversation in which she described nurses as thinking they are great trees of communication and

> that often we feel sorry for deaf people because they are unable to use their voice. However, through learning BSL and how deaf people utilise their bodies to communicate, we realise that deaf people are the great oaks of communication and we are just a tiny blade of grass'." [Reflective diary 29/11/18]

While recognising that there are a diverse range of communication abilities in the deaf community, this reflection suggests that while nurses believe themselves to be good communicators, placing focus on spoken voice may result in neglect of the whole body. Reflecting on their experiences of caring for a deaf person, both Emily and Beth acknowledged that they did not know how the deaf person they cared for had perceived the interactions. However, reflecting on what had previously been only an implicit and inarticulate embodied sense of her relationship with the deaf person Beth expressed:

> "So when I think about it now, I think oh that was such a privilege to be able to work with each other to get to that stage in our relationship." [Beth, p.7]

While I recognise the limitation of not having the specific deaf person's perspective of these experiences, these accounts suggest that openness to learning and shared meaning making has the potential to provide more positive experiences of care for deaf people.

Summary

In this theme, I identified an approach to practice in which some nursing participants recognised the potential to connect. In the subtheme *Shifting perspectives* the importance of understanding the differences between the deaf and hearing culture to enable shared understanding to develop was identified. It was apparent that differences could be illuminated without a hard border forming if there was an openness to understanding differences from the alternative perspectives. Adam and Beth's experiences suggested that the boundary sites where different worlds and perspectives meet can be fertile places where shared learning takes place. The subtheme *Little things make a big difference* highlighted that despite not having a shared language the relational and emotional elements of care could be communicated through nurses using their body. Some nurses intentionally pursued this connection in their practice and embodied a responsiveness towards the deaf person. This often involved improvising and testing out different ways of engaging with the body that would enable shared meaning. Acknowledging the complexity and ambiguity of engaging in this way, it was acknowledged by participants that at times meaning can be lost or misunderstood. However, deaf participants expressed that communicating through *little things* such as use of gesture, facial expression and movement had the potential to humanise their healthcare experience. The last subtheme *Between us* showed that some nurses were able to develop collaborative relationships with the deaf person. These relationships valued the knowledge and experiences that both the nurse and deaf person brought to the relationship. Such reciprocal and participatory relationships have the potential to provide positive care experiences for deaf people.

Conclusion

This chapter has explored and interpreted the findings of this study in which I engaged with nurses, deaf people and BSL/English interpreters to explore their experiences of interacting with one another. Key findings are taken forward to the subsequent discussion in *Chapter Eight*.

The series of themes and subthemes that developed from the data indicated that there is often a mismatch between deaf peoples' and nurses' experiences and understanding of their interaction. Without a means to articulate and develop shared understanding, nurses often engaged in familiar approaches to care that did not acknowledge or respond to deaf peoples' unique needs. Deaf peoples' accounts of healthcare were therefore predominantly characterised by negative experiences with ineffective communication being the main challenge. Without an understanding of sign language and deaf peoples' diverse language need, nurse's routine reliance on written and spoken methods of communicating often prevailed.

The findings of this study draw attention to the ways in which nurses might better understand what being deaf means to an individual. The different conceptualisations and understandings of what it means to be deaf that nurses articulated and embodied, suggest a predominantly biomedical perspective that viewed deafness as a disability or impairment. As this perspective did not align with deaf peoples' own experiences of being deaf, their stories were dominated by feelings of frustration with the attitudes and assumptions of healthcare professionals. There was evidence of this creating divisive boundaries between nurses and deaf people that prevented an effective relationship from developing. Although these biomedical views were often not voiced by nurses, they were tangible to the deaf people through nurses embodied actions. A shift in perspectives from that of the dominant biomedical perspective to understanding what deafness meant for an individual occurred for a number of nurses. Such a shift triggered a questioning of nurse's approaches to practice. While this questioning was often limited, the ability of the nurse to be open to and curious about the deaf person's world resulted in a transformation of their thinking. In these relationships, rather than differences creating a border or barrier they had the potential to enable authentic engagement in which a deaf person's everyday ways-of-being were acknowledged and responded to.

Nurses expressed a desire to build relationships with the deaf person for whom they were caring. Such desire suggests an emotional commitment to care. However, unable to use familiar ways of engaging through language, some nurses felt limited, expressing a lack of potential for their relationship with the deaf person to develop. This caused a *Stuckness* in which familiar ways of engaging were not adequate. Nurses often lacked effective ways of asking the deaf person about their communication preferences, making decisions about what was effective communication and whether interpreters were required. Despite feeling limited by lack of common language many nurses did not book interpreters. These situations sometimes caused nurses to problematise the persons deafness and BSL, framing the communication barriers as belonging to the deaf person. In contrast, some nurses identified the need for an interpreter to establish the basis of a caring relationship. Beyond the need to communicate via language, deaf people emphasised the significance of embodied engagement to enabling a relationship with nurses to develop. While some nurses appeared fixated on the need for language, often overlooking the capacity of the whole body to communicate others intentionally pursued such a connection in their practice. Such embodied engagement appeared to humanise the healthcare experience for deaf people, emphasizing the significance of the whole body in developing relational practice.

A key argument in this thesis is that people have the potential to open up communication through embodied knowing. The findings have drawn attention to the visual nature of deaf peoples' embodiment that enables them to perceive, understand and express themselves. The visual nature of deaf peoples' understanding of the world therefore has the potential to underpin effective approaches to caring for a deaf person. However, healthcare environments were frequently experienced by deaf people as hearing spaces in which auditory information was privileged and provided navigation, understanding and formed the basis of relationships with professionals. With little or no access to this auditory information, deaf people were excluded from autonomously navigating healthcare systems and understanding and participating in their care. This suggests that deaf people were systematically disempowered and disadvantaged due to lack of recognition of their visual nature and language. Feelings of invisibility and isolation were expressed by deaf participants, suggesting that the disempowerment felt has the potential to impact a person's sense of self.

While not always explicitly acknowledged by participants, notions of power featured throughout the findings. There was evidence that the power dynamics between nurses and deaf people were influenced by the difference in language status between BSL and English, conflicting conceptualisations of deafness and the influence these had on nurses' decision making. The interpreters recognised the ever present and changing power dynamics between healthcare professionals and deaf people. In the triad, interpreters viewed part of their role as managing these power dynamics through fixes and repairs. However, there was evidence that the power dimensions at play often go unnoticed and therefore unexamined by nurses. This appeared to be a result of lack of understanding of the wider social context in which deaf peoples' health and care is situated. While the majority of deaf people experienced feeling disempowered by healthcare professionals, there was also evidence of deaf people being empowered. By recognising the deaf person's life experiences as valuable, collaborative relationships developed in which shared meaning and decision making were prioritised. Nurses being open, curious and aware of how they used their body as a communication 'tool' enabled an embodied engagement. This potentially opened up a space of encounter, a fertile ground, where care became relational, collaborative and participative.

Chapter 8: Discussion

Introduction

In the previous chapter I outlined the findings from the research that developed through four main themes and 11 subthemes. In this chapter, I present the conceptualisation of my findings from the research. I will explore the relationships between each theme identified through my analysis of data and the significance in relation to existing theory. Here I draw from Fay's (1987) critical perspective that we learn from theory through our embodied and experiential practice, rather than simply learning about theory. Therefore, we learn about ourselves in terms of theory. Shotter (1993) also reminds us that the way we should primarily use theory is to generate new links and enrich our thought and action rather than establish one truth. In this chapter, I synthesise the findings, in relation to theoretical literature, to present and critically examine my key arguments. The theorisation is shaped around the notion of the in-between space which is the broad outcome of this thesis. This notion stems from Buber's (2009) ontology in which the self is located in relationships. The space in-between represents the social, relational and physical space between people.

Returning to the aims of the research, I sought to explore nurses' and deaf peoples' experiences of interacting with one another. Moving beyond my research objectives of exploring perceptions, meanings and values that each person holds in the encounter, in this chapter I critically question the context in which these interactions take place. Therefore, the relationship between historical, social and political contexts that influence these interactions are exposed. Drawing from Husserl's (1978) notion of lifeworld, I identify how deaf peoples' and nurses' embodied lifeworlds and horizons are constituted. In doing this, I return to my philosophical underpinnings of embodiment to show the significance of embodiment to each lifeworld. I then illuminate an understanding of the space in-between these lifeworlds and how it is constructed and examine the tensions that arose in my findings. In this chapter, I argue that BSL/English interpreters are situated in a unique position, the intersection between these worlds, and often understood as 'bridging the gap'. However, while there is an unquestionable need for interpreters in the healthcare setting, I argue that access is much broader than linguistic participation. In this chapter, I identify and explore social injustice and critically consider why these injustices are perpetuated or remain unnoticed. Additionally, I identify what social and structural changes can address these injustices. While I show in this chapter that I have met the research aims, questions that arose from the findings and the further work that is required to address these are also detailed.

The embodied lifeworlds

There is overwhelming evidence in this study, as shown in the theme *Authentic Engagement* that the embodied lifeworld of both deaf people and nurses are fundamental to understanding the interactions between them. As introduced in *Chapter Four*, Husserl (1978) believed that our lifeworld is our sense of meaning that develops socially and culturally. It therefore denotes the perspective or 'horizon' (Gadamer 2013) that people have of the world that arises out of everyday experiences. The common lifeworld of a person relates to the common senses or meanings constituting their "form of life" or natural attitude towards the world. According to Ashworth (2006), lifeworld encompasses a person's sense of self, embodiment, relations with others, spatiality and temporality amongst other dimensions. As shown in *Chapter Four*, Merleau-Ponty (2012) has been particularly influential in illuminating the significance of the body in understanding a person's lifeworld. He argued that grounding of everyday life experiences in the body should be accounted for. From this perspective, the physical nature of the body is significant to embodied experience as it creates a perceptual field. To understand how the space in-between nurses and deaf people is constructed, the embodied lifeworld of each needs to be understood. Figure 8.1 illustrates the main dimensions of each lifeworld that were identified in the research interpretations. This includes the wider context in which both lifeworlds and the in-between space are situated.

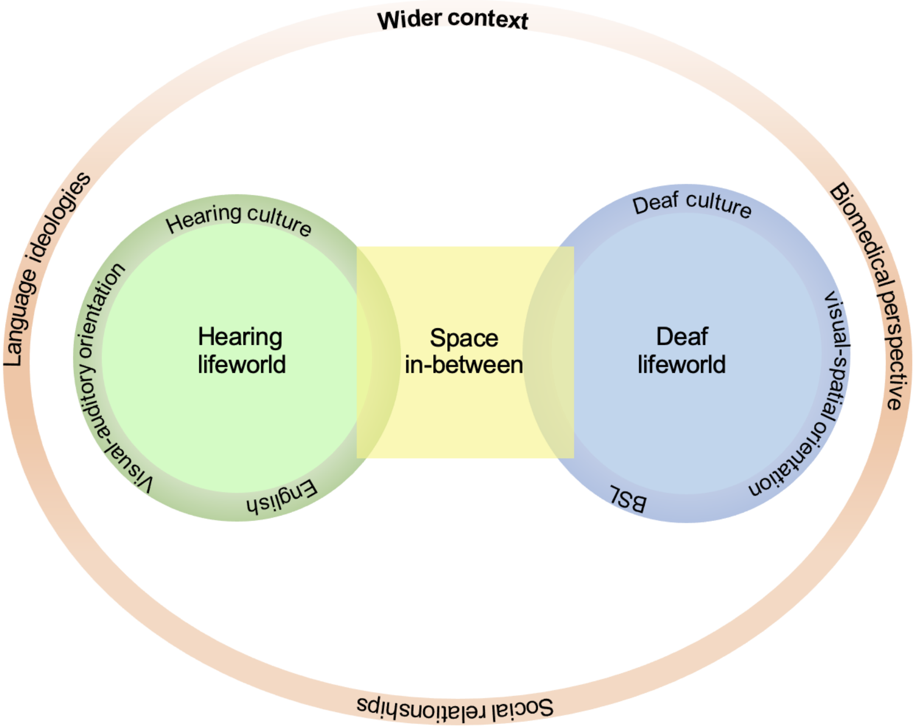

Figure 8.1 Lifeworlds

Merleau-Ponty (2012) argued that our sensations are the basic units of our perception. Therefore, our everyday involvement with the world is shaped through our sensory engagement with the existence of things. The deaf participants in this study expressed having an alternative visual-spatial engagement with the world to that of hearing people. This visual-spatial orientation to the world became evident in the subtheme *Visual People* in which deaf participants expressed the need to communicate, orientate themselves and understand healthcare through visual means. Having a visual orientation was not only expressed by Hayley as the way that deaf people use language but understood by Adam as a completely different way of thinking about things to that of a hearing person. Therefore, this visual orientation leads to different ways of being and knowing that were expressed by Hayley and Carly as being part of deaf culture. In this study, healthcare professionals' approach to care often did not acknowledge or respond to deaf peoples' visual way of being and knowing. Examples of nursing assessment tools, information about body functions and healthcare instructions that were given in English were viewed as difficult to comprehend as they did not provide visual understanding. Reflecting on the significance of providing visually accurate information during the interpreting process, the interpreters provided insight into how meaning takes shape in a visual way for deaf people. This related to notions of iconicity and signed space. Iconicity involves a perceivable link between meaning (what is communicated) and form (the way it is communicated) (Brien 1992), while signing space refers to the placement of objects, people and places in the 3-dimensional space in which sign language is used (Fekete 2017). Both iconicity and signing space draw attention to how meaning takes shape and is expressed in a visual-spatial way. While O'Brien and Kusters (2017) argue that all deaf people are not visually oriented to an equal or similar extent, or in the same ways, the biological state of being deaf is clearly central to understanding deaf peoples' embodied lifeworlds (Friedner 2012). These findings are reiterated by the Jongen et al. (2013) study in which the need for a more nuanced understanding of how deaf people can be empowered to understand and use healthcare information was highlighted.

Primarily visual in nature, deaf peoples' sensory orientation is unique in that it differs from the majority of society whose primary senses are visual-auditory. The findings of this study emphasised that the hearing lifeworld is the dominant social and cultural world that defines audiological hearing as the 'norm'. Perception is visual-auditory with spoken and written word being inherently valued as the primary way of communicating. In the findings, the hearing lifeworld of nurses became evident in the systems of language and social practices that existed in their reflections. These often reflected taken-for-granted practices that did not recognise or respond to deaf peoples' visual-spatial orientation. Such discourses and social practices that operate in nursing evidently reflect those embedded in the dominant society (explored in *Chapter Two*). The main social practice that characterised nurses' hearing lifeworld was the use of spoken English to communicate. These finding are significant as they emphasise nurses' assumptions that everyday actions and practices are based on shared embodied perceptual capacities. Additionally, they draw attention to the potential limits of a nurse's own horizon as a hearing person (Gadamer 2013). This raises the issue of how misrecognition of deaf peoples' visual-auditory orientation may present a major obstacle to social justice in healthcare relationships.

Young et al. (2020) argue that it is essential to recognise that by emphasizing deaf peoples' being as a different or changed sensory orientation to the world, a phonocentric point of view is taken in which the primacy of sound and hearing is understanding as the 'norm'. I do not wish to define sight and hearing as completely separate sensory modalities, as this does not align with my understanding of sensory pathways explored in *Chapter Four*. Additionally, I am not implying that the people who are visually orientated and auditorily orientated are indefinitely "at odds with one another" (Friedner & Helmreich 2012, p.73). However, in this study the need to differentiate between different worlds and ways of being was emphasised in the theme *Borders*, where we saw a boundary develop between deaf people and nurses when deaf peoples' embodied lifeworld went unacknowledged. Therefore, the theory (Merleau-Ponty 2012; Gadamer 2013) indicates that negative healthcare experiences described by deaf people could be addressed through acknowledgement of sensory orientations. Such acknowledgment may enable nurses to respond to deaf peoples' lifeworlds and subsequently construct spaces of authentic engagement.

In his exploration of *Dasein* (being-in-the-world), Heidegger (1996) conceived a person's being in two possible modes: authentic being and inauthentic being. Heidegger's concept of authenticity is concerned with a focus on knowing and attending to our everyday ways-of-being in order to see our true self and our unique potential. Authenticity at its most basic is a characteristic of genuinely being a person (Higgs et al. 2011) and communicating oneself (Buber 2009). Linking the notion of authenticity to the notion of an embodied lifeworld, authentic being relates to inhabiting embodied everyday ways-of-being. Such authentic and inauthentic being is experienced in relation to things and others (Heidegger 1996; Gadamer 2013). In the subtheme *I was invisible*, we saw that when deaf peoples' authentic being was suppressed or denied by healthcare professionals they experienced a loss of personhood. For example, Lindsey reflected on feeling like an invisible Mum when she was not enabled to participate in her daughter's care. This experience can be understood as an 'I-It' way of relating to a person, which Buber (2009) believed diminished authentic ways of relating. For Peter, this depleted sense of self resulted in him lacking motivation to care for himself physically. In contrast, an 'I-Thou' relationship acknowledges the uniqueness of an individual's lifeworld and enables authentic being. This contrast was highlighted by Cat's description of healthcare professionals often seeing a 'different person' when a deaf person is enabled to express themselves authentically, through BSL.

The notion of authentic engagement and being is directly connected to Gadamer's advocation of openness to new understandings. Gadamer (2013) argued that a person cannot detach themselves from their horizon (that which is familiar) and therefore it can become a limit to their understanding of the world and others. However, a person's horizon is also a necessary basis from which their understanding has the potential to expand (Merleau-Ponty 2012; Gadamer 2013). According to Merleau-Ponty (2012) and Gadamer (2013), such expansion occurs when we come into contact and participate in the world and with others, enabling horizons to fuse. Nevertheless, as seen in this study we can have contact with others without a fusion of horizons occurring. This was evident in the research interpretations which suggested that nurse's routine approaches resulted in social distancing, lack of understanding of the healthcare experience and at times ineffective physical care for the deaf person. Therefore, there may be 'contact' between nurses and deaf people without dialogue in which negotiation and shared meaning can develop (Gadamer 2013). Consequently, deaf participants expressed experiencing feelings of frustration, distrust of healthcare professionals, uncertainty and healthcare needs that remained unmet.

In practicing from their own horizons, we saw that nurses often believed their ways of approaching care were sufficient to enable authentic engagement. This relates to Fay's (1987) notion of false consciousness in which a person's understandings of a situation is false or incoherent. In other words, in the prevailing ideology, the generally accepted version of how things are and what is 'real' or 'true', the possibility that things could be otherwise does not arise. Fay (1987) argued that this may result from inattentiveness to the uniqueness of a situation, which calls for new and different action. Fay's (1987) theory therefore highlights how nurse's taken-for-granted practices can become internalised, exercising subtle dimensions of power that are relatively invisible. This draws attention to the need for nurses to become critically aware of their own lifeworlds, as well as ideologies embedded in healthcare contexts and how these may constrain their way of thinking and practicing. In this chapter, I identify evidence from this study that draws attention to how these lifeworlds meet in the space in-between and how this space can be divisive or a place of potential.

Summary

In this section, I have argued that to understand how the space in-between nurses and deaf people is constructed we need an understanding of the lifeworld of each. The lifeworlds of deaf people and nurses are firmly rooted in social structures and exhibit extreme differences. Returning to Merleau-Ponty's (2012) belief that our sensations are the basic unit of our perception, I highlighted that deaf people have a primarily visual-spatial orientation that is brought alive through BSL and deaf culture. Alternatively, nurses have a visual-auditory orientation. Due to nurses' visual-auditory orientation being the dominant embodied position, deaf peoples' alternative embodied orientation often goes unrecognised in healthcare settings. This has the potential to restrict deaf peoples' authentic expression of their embodied everyday ways-of-being. While deaf people have an understanding of the hearing lifeworld from living in a society predominantly hearing society, the interpretations suggest that nurses need a better understanding of the deaf lifeworld. This may have the potential to address the oppression and social injustice that deaf people often experience in healthcare settings.

Inauthentic engagement in the space in-between

Benner (1994) argues that most of our knowledge of the lifeworld is not linguistically articulated. However, it manifests as a system of values and experience that define choices and ways of acting (Habermas 2015). In this section, I will use evidence to demonstrate the ways in which embodied practices of healthcare professionals construct spaces of healthcare delivery that are dominated by narrow ways of thinking and practicing. Constructing them from their own lifeworld, deaf ways of being and knowing are often restricted and subsequently the potential for authentic engagement in the space in-between different lifeworlds is closed down.

Hearing spaces

Theory suggests that there is a conflict between hearing and deaf lifeworlds, which was evident in the being and doing of healthcare professionals described in the findings. One of the main conflicts is how lifeworlds are negotiated and understood in the physical space that healthcare occurs. Massey (2005) argues that conceptualisations of space in the social sciences and especially in human geography[57] have become detached from physical space and are often seen as relative and relational abstractions of space rather than as a realistic representation of it. This returns me to a question posed by McLevey (2016) in *Chapter Three*: In what ways might a physical space open up perceptual possibilities for some bodies and close down possibilities for others? To answer this question, it is crucial to examine what the findings of this research illuminate about the physical and social space in which deaf people and healthcare professionals come into contact.

Healthcare facilities are physical structures and environments. From this study, it is evident that deaf people often experienced the physical structure and arrangement of healthcare systems as exclusionary spaces. In the subtheme, *The same old story* deaf people described written English signage, high reception desks that made lip-reading difficult, and reliance on auditory call systems as rendering healthcare spaces inaccessible to them. This is backed up by evidence from the literature review, which indicates that challenges to accessing healthcare services begin the moment a deaf

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[57] Human geography is a social science discipline that adopts a spatial approach to understanding aspects of the human social world. Therefore, human geographers think about how things exist in space, believing that everything that happens occurs in a certain space and time (Jones 2012).

person wishes to make initial contact with a service (Reeves et al. 2003; Kyle et al. 2005). Designed by, and therefore, for people who are hearing (auditorily orientated) such structural ‘norms’ often fail to account for difference and unintentionally makes it challenging for ‘others’ to navigate. In his sub-theory ‘the body’, Fay (1987) argued that the way that time and space are structured controls the bodies and the bodily movement of the people who occupy it. Therefore, the people who move through the hospital do so in pre-established ways (Fay 1987). This naturalises or normalises certain bodies, while problematising others. From a sociological perspective, Goffman (1963) maintained that to experience stigma is to have a marker placed on you that removes you from the default category of ‘normal’ and places you in the ‘other’. Such sites of exclusion draw boundaries that distinguish who can participate and who cannot. Linking this to notions of Deaf Space (Tsymbal 2010), deaf peoples’ authentic being and self-expression (through BSL) is evidently hindered by physical structures, but also by the pre-established and unquestioned movements of the people they come into contact with.

My research findings illuminated that when deaf people enter into a hearing space their embodied positioning shifts in an attempt to navigate it. This is a result of the expectation for deaf people to conform to ‘norms’. Peter shared that after 10 years of being registered at the same GP practice, he continues to have to respond to a verbal name call in the waiting area despite asking for a tap on the shoulder. Lindsey similarly experienced her request for staff to make adaptations being refused when receptionists at her GP practice would not stand up behind their desk to enable her to lipread. This resulted in her having to book an interpreter to communicate with reception staff. As a result of having to conform to the ‘norm’, both Lindsey and Carly expressed feeling on edge in healthcare settings as they are constantly looking around for fear of missing an auditory call for an appointment. This expectation for deaf people to shift their bodily positioning indicates that the social order is taken for granted and viewed as ‘truth’ or reality. Therefore, healthcare staff may assume that many of the challenges faced by deaf people are simply ‘the way things are’. Horrill et al. (2018) argue that consistent negative experiences of access for minority groups draws attention to biomedical perspectives of access that place responsibility on an individual. Such an attitude is challenged by the disability model, explored in *Chapter Two*, which argues that the challenges deaf people face are a result of how normalcy is constructed (Davis 2017). Viewing access as a social responsibility and form of social relationship, shifts the responsibility onto healthcare professionals which means they have a significant role to play in improving access.

The evidence indicated that the embodied practices of healthcare professionals not only function within spaces, but also construct spaces between patients and themselves. Healthcare professionals do not merely occupy spaces of healthcare but create different spaces of power through their interactions as embodied spatial beings. Therefore, the relationship between healthcare professionals and their patients creates what Benner (1994) describes as a disclosive space that can be constricted or safe. To create a safe disclosive space, space must be understood as constructed through social relationships. Levinas (1969) understood this process of disclosive space development as an ethical responsibility, and one which has the potential to enable or disable conditions of possibility.

This section draws attention to how the healthcare space both shapes and is shaped by the people interacting in it. Therefore, I argue that both the physical and social space are affected by the cultural values, norms, knowledge and beliefs that pattern social interaction and determine how people use and react to the environment. By identifying how the physical and social space creates divisions or opens up possibilities in the space in-between deaf and hearing lifeworlds, we can begin to imagine how to pursue spaces that open out ways of being, as opposed to a space which is designed for a single way of being-in-the-world (McLevey 2016).

Biomedical constructions of deafness

As explored in *Chapter Two*, understanding of ‘deafness’ and ‘deaf being’ have developed over time, with the importance of deaf ontologies and epistemologies more recently being highlighted as significant to understanding deaf people (Kusters et al. 2017). However, evidence from this study supports the argument made by Sachez (2017) that developing constructions of deafness are firmly located in Deaf Studies with limited impact on those outside of this discipline. Evidence from across recruitment and data collection suggested that biomedical constructions of deafness remain dominant in the healthcare setting with deafness being problematised. This reductionist, pathological lens was implied by healthcare professionals directing me towards ENT to locate deaf people during recruitment. Additionally, throughout recruitment and in the subtheme *I’m just deaf* biomedical constructions of deafness were evident in the language that was used by nurses to refer to deaf people. Notions of disability suggested that nurses viewed deaf people as impaired and dependent. Additional disabilities were also projected onto deaf people by two of the nurses, Kelly and John, who suggested resources such as braille and bold print being helpful. For Peter, a nurse’s assumptions about his ability to support his daughter’s language development led to her being referred for speech and language therapy without him being informed. This draws attention to the professional control that deaf people can be subjected to when decisions are made for them based on biomedical assumptions about their abilities and needs.

Differences in terminology often indicate deliberate choices and perspectives, therefore expressing ideologies. These constructions do not simply offer different definitions of what it is to be deaf but privilege one way of being over another. Such attitudes translate into day-to-day social practices (Fay 1987). As well as healthcare professional actions demonstrating this biomedical perspective, Carly and Peter expressed being able to sense the embodiment of the biomedical discourse through healthcare professionals' discomfort with their perceived differences and the physical distance that they seemed to maintain from them. Therefore, it is evident from this study that nurses internalised ideological concepts and if they had not considered them, embodied the values that are inherent in these concepts. By the very nature of their hearing lifeworld, nurses aligned with hearing practices without critique, unless something or someone prompted them to analyse these practices and reconstruct them (Gadamer 2013).

These findings are significant as they suggest that dominant constructions and ideologies of the biomedical model, explored in *Chapter Two,* continue to inform healthcare and nursing practices. Therefore, through the way that healthcare practitioners act towards, relate to and engage with a deaf person they often name the world from a certain perspective (biomedical) that is fixed and not open to alternative understanding. Such approaches to care often did not acknowledge or respond to the deaf person's lifeworld but drew them into a medical frame of reference and resulted in disengagement from the person. Lindsey displayed an intentional disengagement by opting for a side room to remove herself from the hearing space. Fay (1987) argued that when a person cannot represent themselves authentically in relationships, and when their experiences are not heard or responded to by the other person, they may detach from the situation. This detachment and the challenges it poses to authentic engagement have been clearly illustrated in this research.

Language ideologies

In the subtheme *The same old story*, we saw that deaf peoples' healthcare experiences were characteristically negative due to communication challenges. Evidence from deaf participants' and interpreters' accounts in this study identified that in the wider deaf community in Scotland there are a range of language abilities. These abilities range from minimal language skills that Hayley described as resembling mime, to being bilingual in BSL and English. While the deaf participants in this study indicated that they were bilingual in BSL and English, they raised the issue of language dysfluency, low fund of information and low literacy levels in the deaf community. As summarised in the subtheme *Underneath*, nurses found it challenging to ascertain an individual's language needs and abilities without being able ask them verbally. Peter and Carly similarly expressed that it was uncommon for healthcare professionals to ask them how they could effectively communicate with one another. With uncertain and ambiguous understanding of an individual's language needs and lack of understanding of BSL as a bona fide language, nurses often resorted to using written or spoken English to communicate. The hierarches of power that tend to place sign languages below spoken languages therefore became apparent when BSL was viewed as a dialect of spoken English (Lane 1999).

The potential consequences of ineffective communication and dialetizing of BSL was highlighted in a story shared by Hayley, in which one of her deaf clients repeatedly and inappropriately attended A&E because healthcare professionals were not providing information regarding his diagnosis and plan of care in an accessible language (BSL). These findings are significant as they emphasise that despite the effort of the BSL (Scotland) Act 2015, sign languages continue to be misunderstood and hold a lower status than English. The consequences of this are far reaching in healthcare settings. This reflects the literature explored in *Chapter Two,* in which I discussed the negative consequences dominant language ideologies continue to have on deaf communities. There continues to be a failure of policy to achieve acknowledgement of deaf peoples' language and healthcare rights.

Understanding deaf peoples' communication abilities and needs was further complicated by what Goffman (1963) calls passing behaviour. Evidence from this study identified that deaf people use strategies of pretending to understand, such as the 'deaf nod'. Goffman argued that such behaviour aims to avoid the stigma of being deaf by "passing for normal" (p.87). This notion is concerned with the control of information, "to tell or not to tell, to let on or not to let on, to lie or not to lie, and in each case, to whom, when and where" (Goffman 1963, p.57). As summarised in the subtheme *Layers* such behaviour can reiterate misunderstandings related to effective communication and also promote the idea that the deaf person is a skilled lip-reader and/or English literate. Harry emphasised the potential consequences of such behaviour, giving an example of a deaf person going for surgery without knowing what procedure they had consented for. The research interpretations suggested that while interpreters may recognise such behaviour due to their understanding of BSL and deaf culture, healthcare professionals are unlikely to identify it. While all the deaf participants in this study indicated that they felt confident to make their needs and abilities known to healthcare professions, Goffman (1963) emphasised the high level of anxiety that this process can cause for a deaf person “in living a life that can be collapsed at any moment” (p.87).

In the subtheme *The same old story,* I identified evidence that having a BSL/English interpreter was important to enable all deaf participants to access healthcare. A number of different attitudes towards booking and utilising BSL interpreters were evident amongst nursing participants. While Beth and Adam understood an interpreter to be crucial for effective communication to take place, Rachel and Anna both expressed a belief that it was appropriate to book an interpreter for medical updates or for surgeons to gain informed consent for procedures, yet not to provide everyday nursing care. This may indicate that higher value is placed on technical medical care over relational nursing practice. Alternatively, it may indicate that when thinking about an opportunity to make understanding and navigate the space in-between, nurses often did not recognise how interpreters can facilitate this in their practice. Evidence from this study also suggested that nurses’ reluctance to utilise interpreters may be a result of communication challenges between deaf people and healthcare professionals being framed as belonging to the deaf person. Therefore, a deaf person’s deafness and inability to use spoken English became the central issue and was problematised. This was evident in Kelly’s account in which she attributed the deaf persons’ inability to use spoken English and difficulties in booking an interpreter as resulting in a delayed discharge. Napier et al. (2018; 2019) have highlighted the tendency of hearing people to see necessity, ownership and relevance of the interpreter ‘for’ the deaf person rather than for all. Such behaviour that problematises sign languages and its users contributes to the maintenance of the low status of sign languages through language shaming (Haualand and Holmström 2019). This highlights the audism experienced by deaf people in which healthcare professionals hold beliefs and exhibit behaviours that express prejudices towards them (Humphries 1977).

Irrespective of which perspective a healthcare professional held towards booking interpreters, it was common for healthcare professionals to make a decision regarding the need for an interpreter without involving the deaf person in the decision-making. While these decisions often appeared to be based on understanding of BSL and beliefs about whether nursing care justified the need for an interpreter, Kelly’s account also highlighted constraints such as time pressures, financial and organisational priorities as having an influence. Therefore, nurses may at times feel relatively powerless, recognising what ‘ought’ to be done without the authority to put it into practice. This reflects healthcare discourses of maintaining order, routine and efficiency at the expense of relational nursing care (Horrill et al. 2020). Despite often viewing the interpreter as ‘for’ the deaf person, as seen in this study, the decision of whether or not an interpreter was ‘needed’ was often made by healthcare professionals. Such actions reflect discourses of dependency and paradoxically renders the means of communicative access as a means of reinforcement of inequalities created through power and knowledge (Napier et al. 2019). The uncertainty of linguistic access and social participation reinforces structural-level discrimination that prevents deaf people from exercising personal agency (Young et al. 2020). This reflects the ongoing challenges that have resulted from The Disability Discrimination Act 1995, explored in *Chapter Two*, in which the responsibility of choosing reasonable adjustments for a disabled person remains with the service provider. The deaf peoples’ narratives of their experiences highlighted the usually silent consequences of a healthcare professional’s decision to ‘get by’ without an interpreter.

While in *Chapter Two*, I challenged the notion that access to healthcare for deaf people can simply be equated with linguistic access via an interpreter, it is evident that linguistic access remained a priority for deaf people in this study. Therefore, I argue that the option of having an interpreter should always be available to deaf people to enable effective communication in healthcare interactions. While Mapson et al. (2019) have indicated that there may be a shortage of BSL/English interpreters in Scotland, this study has illuminated a need to further understand nurse’s decision-making processes in relation to utilisation of BSL interpreters for nursing care. Such understanding should address the power or lack of power held by nurses in relation to linguistic access to healthcare.

Hidden power dynamics

In this chapter so far, I have argued that healthcare spaces are organised social contexts. In this section, I draw attention to how authentic engagement is not only influenced by power operating in the social structures of healthcare contexts but also in the relationships between individual nurses and patients. Therefore, power operates on a structural (macro) and an interactional (micro) level. Drawing from Bourdieu’s (2020) concept of habitus, the different socialized norms or tendencies in both hearing and deaf culture guide behaviour and thinking. In the findings of this study, we saw that deaf people experienced distinctive power differentials in deaf and hearing communities, often feeling disempowered in the latter. In looking at habitus relationally, power differentials are influenced by the social structures (fields). Bourdieu’s (2020) theory contends that a member of a minority community may demonstrate power within that community as a result of a shared habitus. However, the same person may feel powerless outside of that community as a result of a habitus that oppresses their norms, values and behaviours. As explored in *Chapter Six,* the deaf participants who took part in this study can be viewed as deaf elite. Despite holding ‘elite’ social statuses and subsequently exercising power in deaf communities, we saw that these did not transfer into participants experiences in hearing communities. While often not acknowledged in the literature, the physical body and its interaction with the world is vital in the creation of habitus (O’Brien 2021).

The relational nature of the space between hearing and deaf lifeworlds draws attention to how the body and embodied practices act as a site and source of power in the context of healthcare. While the interpreters alluded to the changing power dynamics in healthcare settings, these appeared to be hidden from nurses. This reiterates the findings of the literature review, in *Chapter Three*, that showed healthcare research normalise the operations of power making them often invisible to the people who are embedded within those structures. Power is therefore not always wielded consciously or intentionally.The themes explored so far indicate that practitioners should consider how, despite believing themselves to be driven by ideals of equitable care, they may continue to exert professional power through using language and embodying practices that emphasise a biomedical model of care. In the subtheme *The façade*, we saw how nurses appeared, perhaps naively, to believe in nursing as apolitical, a neutral practice in which everyone is treated the same. This was expressed by Sophie when she stated that all patients receive the same care and treatment irrespective of who they are. Jane similarly indicated that a person’s deafness would not influence the care given. This attitude objectifies deafness as a condition rather than a way of being. Although these perspectives may aim to promote equal practice and avoid labelling, objectifying deafness in this way suggests it is something that happens to a person, rather than being part of the person (Temple and Young 2014). As a result, the deaf person’s lifeworld may be disregarded in the process. This exposes a “dilemma of difference” (Minow 1990, p.19) which arises when it is necessary to decide whether to act on difference by acknowledging it and responding to it or overlooking it with the intention of promoting equality and social justice.

The challenge of overlooking or misunderstanding a deaf person's differences and lifeworld, is that nurses fall back on their own understanding and assumptions to guide their practice. Therefore, the narrowness with which deaf people are viewed through the biomedical construction of deafness can be used as an instrument of oppression through maintenance of dominant values and power structures (Cody 2006). Heidegger (1996) argues that when the maintenance of another's authenticity is not a priority in caring practices there is a danger of stepping into the place of the other and meeting their needs on behalf of the other. In this study, such an imbalance of power was most evident when decisions regarding language choices were made by healthcare professionals on behalf of the deaf person. Without active participation in decisions being made regarding their communication needs, deaf people were placed in a passive position. This illustrates how 'care' in a healthcare relationship may be influenced by a power differential between the 'professional' nurse and the 'passive' patient. Evidence from the subtheme *I was invisible* indicated this may result in deaf people involuntarily adopting a passive role in which they are not actively engaged in making decisions regarding their care. This was expressed by all deaf participants as being excluded and therefore unable to maintain their normal social roles or identities. Although the definition of paternalism is continually under discussion, in the context of this study, it is evident that paternalism exists when decisions and presumptions are made for deaf people without engaging them in the conversation. This reflects the active debate in current healthcare literature which explores how power is intertwined with practices of compassion, like caring in nursing (Barnett 2016). Critical theory emphasises that such social structures are typically not open to challenge or critique, even when it sustains injustices and harm, as compassion is considered inherently good and unquestionable (Chinn 2018).

The power relations exposed in the following experiences highlight another way that disengagement and inauthenticity is instigated. In the subtheme, *The same old story* we saw that deaf people have been sharing their stories of need for access to healthcare in more culturally and linguistically appropriate ways without any meaningful change. This also reflected my experiences of tokenistic engagement of deaf people at NHS engagement events during recruitment (see *Chapter Six*). The evidence from this study shows that despite the efforts of deaf people to advocate for their rights, having to repeatedly accommodate to the hearing world often resulted in deaf people not feeling powerful to change anything and resigning. Such resignation was evident in Peter's low expectations of healthcare in which he had accepted that his relationships with healthcare professionals would be task-orientated with minimal social engagement. On a broader scale, this resignation was also evident in the consultation fatigue that I identified during recruitment as a potential reason for deaf people not wanting to participate in the study. These findings are significant as they suggest that while deaf people have increasingly found a ‘voice’ from which to express and advocate for their rights, their voice is often not responded to by wider society and when engaging with healthcare professionals. Therefore, I argue that attention needs to be paid to the social relationships in which power is exercised, with nurses taking a more critical approach to their practice by examining the value basis of their care.

With an understanding of the power structures at play in the space in-between and acting as allies for deaf people, the interpreters viewed part of their role as balancing the power dynamics between healthcare professionals and deaf people. Managing power dynamics, language ideologies and different conceptualisations of deafness happened through what the interpreters called ‘fixes’ or ‘repairs’. Although Harry acknowledged that interpreters sometimes “interpret the clash” [Harry, p.18] between different lifeworlds, correcting the imbalances of power and/or cultural misunderstandings were often blended into the interpretive act. This draws attention to the potential invisibility of the cultural mediation to the other participants (deaf person and nurse) in the triad as the interpreter aims towards a smooth interaction. Therefore, while fixes may be made to rebalance power dynamics in the interpreted encounter, paradoxically such power dynamics may remain hidden to healthcare professionals. These dynamics could also place the interpreter in a position of holding too much power unbeknownst to both the healthcare professional and deaf person. This emphasised the ongoing tension between notions of interpreter invisibility/neutrality and participation/co-construction of meaning that stem from different models of interpreting. Mole (2018) has similarly highlighted that due to the blending of cultural mediation into the interpretive act invisible privileges may remain invisible to healthcare professionals. While I argue that the interpreted event may not be the place to allow power dynamics to be exposed and examined, these findings emphasise a need for healthcare professionals to recognise and understand the knowledge, beyond linguistics, that interpreters hold. Such knowledge has the potential to facilitate nurse’s awareness of the *Layers* that contribute to power dynamics. This may subsequently facilitate navigation and understanding of the space in-between.

In this section, I have shown that while the shifting power dynamics in the relationships between deaf people and healthcare professionals are tangible to deaf people and interpreters, they often remained hidden to nurses. Despite remaining hidden, power is exercised through the biomedical discourses, ideological beliefs and assumptions that manifest in nurses' practices. This emphasises the need for greater awareness amongst nurses of the wider political context and power structures through which care takes place and in which they are located. Effective and appropriate care for deaf people may be premised on a need, first, for nurses to recognise the existence of such power dynamics.

Language/body split

This section draws attention to the language/body binary that prevented nurses from knowing or articulating how they could engage meaningfully with the deaf person beyond language. Despite many nurses expressing that nursing care did not justify the need for an interpreter, the subtheme *Stuckness* paradoxically captured some nurse's fixation on lack of common language to communicate. This fixation was predominant in Kelly and Rachel's reflections, with both expressing a frustration at not having a common language through which they could get to know the deaf person. Knowing a person was therefore understood as accessing a person's 'inner world' through an accumulation of explicit information, understanding and clarification that articulates the experience of others. Habermas (1972) articulates such approaches to knowledge that is concerned with how others see their worlds as 'practical interests'. Such interests can enable practitioners to think about what the care they provide might mean, or be perceived to mean, by the people they are caring for (Hewitt-Taylor 2015). While these findings are significant as they suggest that nurses expressed a desire to engage in relational care, Kelly and Rachel reflected very little on alternative ways of communicating relational intent. These findings imply a language/body binary that privileges language in nursing practice. Such privileging not only undervalues the embodied elements of nursing practice but also separates the deaf person from their embodied identity. Therefore, the deaf person was seen as someone to be known as separate from how they are known (through their embodied being). As personhood is fundamentally embodied (Merleau-Ponty 2012), separating the person from their embodiment may oppress authentic being.

My interpretations indicate that this fixation on language caused an unsettledness for Rachel and Kelly in which they felt deskilled. Dewey (1933) was interested in the notion of perplexity in which a person is blocked when encountering a situation which does not yet make sense. In such a situation, one's routine habits and rituals are unable to overcome and provide a readymade, known answer to a "problem". Therefore, the individual experiences unsettledness. This unsettledness can produce motivation to inquire and be curious. However, being caught in the web of perplexity can occur if there is a lack of motivation or a lack of time to inquire. By reacting to new situations by downloading habitual ways of thinking, limited learning occurs due to the view of the world remaining familiar (Senge et al. 2011). Schön (1983) believed that this led to narrowness and rigidity in practice. From this perspective, nurse's knowledge is understood as static, with fixed skills and lack of acknowledgement of creative and intuitive embodied knowledge that can enable them to engage beyond language. Therefore, the need to be skilful may suppress a nurse's capacity to be in a caring relation with a deaf person. The unsettledness that nurses experienced was understood by Peter as a contributing to the physical and social distance that he experienced from healthcare professionals. These findings indicate that nurses embodied this unsettledness in their interactions, and it created a barrier to authentic engagement.

While linguistic content and features enable expression of self and identity, from a Merleau-Pontian (2012) perspective, focus on language alone fails to account for the expression of self through the whole body. Schön (1983) believed that we often fail to acknowledge and be attentive to the tacit understanding in practice. Therefore, our encounters are viewed as instrumental exchanges of information, with no role for embodiment. Approaching care from this framework, effective communication can be conceptualised as ensuring efficient information exchange between patients, their families and other healthcare professionals (Loftus 2015). This is however, an impoverished attempt to capture the complexity of communication in the clinical encounter. There is potential to move beyond this instrumental and task-orientated understanding, through exploration of such complexity (Benner 1985).

Summary

By viewing healthcare as a social space and social relationship, the assumptions, positionality and culture of healthcare that create or perpetuate poor access to healthcare for deaf people have been identified. In this section, I developed a number of key arguments that draw attention to nurses' perspectives and practices that can inhibit deaf peoples' authentic being. It was evident from this study this was often a result of nurses working in the boundaries between deaf and hearing worlds without an awareness of the difference between two different worlds or with a fixed perspective of what it means to be deaf. Therefore, nurses were often unaware of the dominant social constructions of deafness they were working from. This resulted in ineffective approaches to care that did not respond to a deaf person's lifeworld. Subsequently, healthcare spaces were experienced by deaf people as restricting and divisive.

Constructing spaces for authentic engagement through embodied practice

So far in this chapter, I have argued that healthcare spaces are relational and therefore constructed by the social actions and practices of people in them. The findings have illuminated how healthcare spaces can naturalise certain bodies (hearing), while problematising others (deaf). Therefore, deaf people often experience such spaces as exclusionary. In this section, I will address the question posed by McLevey (2016): how can we begin to imagine and pursue spaces that open out ways of being, as opposed to a space which is designed for a single way of being-in-the-world? I will focus on what the findings illuminated about how nurses can intentionally construct spaces that enable participation and shared meaning to develop. Construction of the space in-between involves nurses framing their practice as wholly embodied. This necessitates attention to the embodiment of both the deaf person and the nurse. I will argue that by approaching the space in-between in this way, there is potential to enable authentic being for both the nurse and the deaf person, as they acknowledge and respond to one another’s lifeworlds. While each person is experiencing the encounter from their own lifeworld, there is an openness to possibility and potential for a fusion of horizons. Such approaches may contribute to developing emancipatory and empowering approaches to caring for deaf people. In this section potential implications of the study for nursing practice, education and future research will be outlined.

Acknowledging and responding to deaf peoples’ embodied language practices

There is overwhelming evidence that constructing safe disclosive spaces (Benner 1994) that deaf people can participate in relies on nurses and deaf people having a means to authentically engage and communicate with one another. The findings of this study emphasise the need for social justice to help reduce inequalities in accessing healthcare by empowering deaf people to understand and critically engage in their healthcare. A major contributing factor that disabled deaf people in this study from engaging and participating in their healthcare, was that BSL continues to be misunderstood and viewed as a lesser language. Reiterating the findings of the literature explored in *Chapter Two*, a number of factors were identified in the findings as contributing to the low language status of BSL. These related to historical views of language as spoken and written. As explored earlier, the findings of this study indicated that the impact on deaf people is significant and oppressive. To address this problem, the research interpretations suggest there is a need for NHS organisations and the healthcare professionals who work in them to commit to understanding and removing the barriers that prevent deaf people from accessing healthcare in linguistically appropriate ways. This has the potential to shift understanding of access from a biomedical perspective that holds the deaf person as individually responsible to access as a social responsibility (Horrill et al. 2018; Jongen et al. 2018).

The denial of access to healthcare information in BSL indicates that while the intention of the BSL (Scotland) Act 2015 and local NHS plans are to encourage the use of BSL in Scotland, dominant views prevail. While the outcomes of the implementation of the BSL (Scotland) Act 2015 are yet to be reported, the findings of this study suggest that its impact in healthcare may be minimal as there continues to be a gap between policy aims and the practices of healthcare professionals. This reiterates the ongoing discussions that the BSL (Scotland) Act 2015 may be merely symbolic with a wider commitment to implementing the act required from organisations such as the NHS (De Meulder and Murray 2017; Lawson et al. 2019). There is a need for NHS health boards to commit to addressing attitudes towards BSL and subsequent practices at organisational level in order to reinforce and sustain behaviour changes in healthcare professionals (Jongen et al. 2018). This would include a need to expand cultural competency beyond individual practitioners to include healthcare policies and staff at all levels of the system. For this to be effective, deaf people need to be actively participating in the development of local policy plans for NHS services. Such participation would challenge dominant perspectives and foster relationships between local deaf communities and policy makers in healthcare. This may result in greater utilisation of BSL interpreters, increase healthcare resources available in BSL and increase the awareness of deaf peoples' need for visual resources to help them navigate their healthcare experiences.

While I have argued that recognition of BSL as a valid language is necessary to improve deaf peoples' experiences of healthcare, evidence from this study highlights the diverse language abilities of people in the deaf community. Therefore, the findings of this study reiterate the argument that provision of sign language interpreters is not a quick fix for complex language issues (De Meulder and Haualand 2019; Young et al. 2019). This study illuminates the difficulty that healthcare professionals may experience in collaborating with deaf people to determine how to effectively communicate. Potential language dysfluency combined with covering and passing strategies (Goffman 1963), such as the deaf nod, may provide healthcare professionals with false reassurance that their communication approaches are effective. However, Peter stressed that fixed procedures that determine healthcare professionals cannot communicate healthcare information without an interpreter may deny an individual the option of using alternative communication methods. This indicates that strict compliance with protocol, that is governed by rules and instrumental action, does not facilitate individual needs and circumstances. The research interpretations indicate that healthcare professionals need contextual understanding of the diverse language abilities in the deaf community that is crucial to informing care. This may enable healthcare professionals to respond knowingly and recognise the need for individualised communication plans. Such plans should be made in collaboration with the deaf person, taking into consideration their contextual language choices. The use of sign language interpreters therefore has to be understood in the context of individual language and modality choices.

The evidence from this study supports the findings of the literature review that access to interpreters and information in BSL in healthcare settings is a key concern for deaf people. However, De Meulder and Haualand (2019) argue that if the provision of an interpreter is uncritically equated with healthcare access and inclusion, an ‘illusion of inclusion’ develops with little attention given to that which happens in and beyond the interpreted encounter. Therefore, utilisation of interpreters has constraints (De Meulder and Haualand 2019). The evidence from the findings indicate that a more nuanced understanding of how deaf people can be empowered to understand and participate in healthcare is needed. Such an approach needs to take into consideration the visual nature of how deaf people construct knowledge, the language diversity in deaf communities and the strengths of BSL, such as iconicity, that may have the potential to empower deaf people to actively participate in decisions about their health and care. The visual-gestural nature of sign language is evidently key to understanding how deaf people can be enabled and empowered to access healthcare. However, while the findings of this study indicate that deaf peoples’ visual-spatial orientation needs to be acknowledged and responded to, examples of how healthcare professionals can creatively facilitate a visual understanding, beyond the utilisation of BSL/English interpreters, were limited. As emphasised in *Chapter Three*, research has shown that when adapting healthcare instruments for deaf people, there are fundamental linguistic adaptations that need to be taken into account, with careful attention being paid to the difference between spoken language modes (auditory-oral) and sign languages (visual-spatial). Therefore, to ensure that English language-based materials are avoided, deaf peoples’ visual orientation needs to be prioritised in adapting materials and assessments (Anderson and Wolf Craig 2018). Rather than these challenges resulting in deaf people and their language being problematised, further research that focuses on how to enable deaf people to obtain, process and use healthcare information is required. The findings of this study suggests that by embracing iconicity and utilising visuals, there is increased potential for deaf people to gain a full understanding of healthcare information. This places a shared responsibility on those on the receiving end of health communication and those responsible for communicating health information (Horrill et al. 2018).

The findings of this study identified research evidence that supports the need to look beyond linguistic access, to question how the social space and social relationships between deaf people and healthcare professionals can be places of authentic engagement. Beyond the need for interpreters to facilitate effective exchange of healthcare information, this research illuminated the interpreter's contribution to the management of such relationships. In the subtheme *Layers*, we saw that BSL/English interpreters act as linguistic and cultural mediators as well as managing relationships in the triad. Therefore, much of interpreter's work involved looking beyond the immediate meanings of peoples' linguistic actions, considering the position (values, beliefs, and understanding) of the people they were interpreting for and managing the various implications arising from the encounter. BSL interpreters hold knowledge of both lifeworlds and how the space in-between can be a place of authentic engagement. However, the research interpretations suggest that the invisibility of these elements of interpreter's work may result in such knowledge remaining situated in the interpreting profession. As shared meaning-making is a process understood to be profoundly social and collaborative (Wenger 1999), I believe there is potential for knowledge exchange across disciplines (nursing and interpreting). Communities of practice (Wenger 1999) can allow for such shared meaning and a greater understanding of one another's role to develop. Specifically, such dialogue could enable nurses to grasp the complexities of the interpreting role, creating an awareness of what is going on beyond what they see and hear in the interpreted interaction. This may illuminate wider contextual influences on the encounter and would enable nurses to act 'knowingly' in the triad. Additionally, it would enable nurses to gain greater insight into deaf lifeworlds and how to facilitate authentic engagement beyond the interpreted event.

Valuing embodied being, knowledge and practice

As emphasised throughout this thesis, Merleau-Ponty (2012) and Gadamer (2013) believed that an expansion of our horizons can occur when we come into contact and participate with the world and others, enabling horizons to fuse. In the section *Language/body split,* I discussed how a number of nurses in this study viewed this point of contact as being solely linguistic. However, the research interpretations discussed so far have illuminated how nurses' whole embodied practices contribute to the construction of the space in-between being either constricted or safe (Benner 1994). In this section, I provide specific insights from the findings that emphasise the need for nurses to be aware of how both their own and deaf peoples' embodied lifeworlds can inform practice. Such awareness has the potential to enable authentic engagement.

In the subtheme *Little things make a big difference*, Peter and Carly described nurses who had a particular way of engaging them in their encounters that allowed a connection to be made. Emphasizing the significance of simple acts such as a smile, a gesture and friendly non-verbal communication these accounts suggest that a certain embodied approach conveyed a nurse's openness to engagement. My interpretation of Carly's experiences (painting *It's the little things*) of engaging with nurses who embodied such acts indicated that Carly felt seen and responded to in these encounters. Taylor (1994) defined such pre-reflexive acts of professionals as 'ordinariness in nursing', believing that interacting with others in genuine, ordinary ways could enable authentic engagement and humanise healthcare experiences.

While it could be argued that the simple acts experienced by Carly and Peter are pre-reflexive practices, two of the nurses, Anna and Emily, reflected on intentionally engaging with the deaf person through embodied practices. With a focus on the unfamiliarity of interacting with a deaf person, Emily described not knowing if the embodied approach she used to engage with the deaf person was the 'the right thing to do' the first time she met them. Despite this, Emily expressed moving towards and engaging with the deaf person intentionally and intuitively, indicating a sense of familiarity. Therefore, while the overall situation of engaging with a deaf person was unfamiliar, the findings indicate that there may have been be certain elements of the professional practice situation that were familiar. Schön (1987) argued that these familiar elements enable professionals to orient themselves in a practice situation and respond appropriately. Such familiar movement is not derived from technique that is rigid and calculated but rather it is flexible and improvised (Kinsella 2015). Therefore, the research interpretations suggest that Emily displayed professional artistry in which a practitioner exhibits their knowing through their embodied actions (Schön 1987). Schön (1987) believed that professional artistry occurs in indeterminate zones of practice that are characterised by complexity, uncertainty and unpredictability in which healthcare professionals encounter new situations. Reflecting the uncertainty of such encounters, my interpretations of Emily's engagement with the deaf person (painting *Dancing in the wind*) suggested that there is a playfulness to such practice. Emily shared how this approach to engaging with the deaf person appeared to transform their response to her from closed and disengaged, to friendly and responsive. These interpretations indicate that the aim of authentic engagement is not to achieve full or complete understanding but to express an attentiveness and openness to the other through embodied practice. This entails embracing the ambiguity of a new situation.

The difficulty in articulating such embodied practice became evident in my own struggle to facilitate nurses' reflections and in nurse's lack of attention to these elements of their practice. These challenges are widely documented in the nursing literature related to embodiment (Benner 1985; Lawler 1998; Draper 2014). From the research findings, I identified numerous reasons why articulating embodied knowledge may be challenging. Firstly, drawing from the language/body binary that nurses often expressed in this study, such embodied knowledge and practice may be undervalued in nursing. Secondly, the nurses in this study who reflected on such embodied practices were based in specialist roles. This may indicate that they were more skilled in such embodied practices or placed greater value on such practices. Alternatively, it may suggest that they were more skilled at reflecting on these elements of their practice. Lastly, my own interpretation (painting *Warm Embrace*) of how Rachel would have authentically engaged through embodied practices and her lack of acknowledgement of these elements of her practice, suggests that these may be hidden from the very practitioners who demonstrate them. Therefore, although nurses may not find it easy to articulate everything they do in their practice, there may be more that they implicitly understand that could be articulated if they only knew how (Taylor 1995; Shotter 2010). This relates to the notion that embodied knowledge manifests and is contained in the action of professionals in their practice situations. It is embedded in practice and unfolds in the course of action.

The significance of nurses' embodied emotions in actively shaping authentic engagement was apparent in the findings of this study. While clinical decision making has traditionally been viewed as a rational and cognitive process, little attention has been given to how the emotions of practitioners might influence this process (Kozlowski et al. 2017). In this study, nurses expressed a desire to build relationships with the deaf person for whom they were caring. In *Chapter Seven*, I emphasised that such desire suggests an emotional commitment to care. Moving beyond a desire and commitment, the findings also indicated the value of nurse's emotional responses to deaf people and application of this emotion in decision making. While Rachel's emotional commitment to care became apparent to me in her bodily form and movement, Emily's intuitive decision making was driven by her emotional desire and commitment to care. The research findings therefore suggest that nurses' emotions can contribute to and actively shape the ‘I-Thou’ relationship by providing nurses with an awareness of, or attunement, to their own and others feelings that enable appropriate responses to others and can facilitate practice choices (Titchen 2019).

In response to the research interpretations discussed so far in this section, I believe attention needs to be paid to silenced dimensions of practice that have previously not been thought of as legitimate forms of knowledge or understanding but are alive in all healthcare contexts. This presents what Lawler (1998) describes as a challenge in adapting tacit means of understanding human beings into tangible nursing practice. I argue that there is a need for nurses to reflect on and give voice to these aspects of their work. This would enable nurses to explore how bodies interact relationally, in time and space, through proximity, distance and movement (Kinsella 2015). Despite embodied knowledge being difficult to articulate due to its tacit nature, the research findings suggest that when it is purposeful and intentional the impact is felt by patients. While the interactions reflected on in this study may have been brief, there is overwhelming evidence as shown in the subtheme *Little things make a big difference* that such moments were remembered as humanising the care experience for deaf people.

As well as illuminating the significance of nurses’ embodied practices, the findings drew attention to the need for nurses to recogise and respond to deaf peoples’ embodied experiences and lifeworld. In the subtheme *Shifting Perspectives,* we saw that understanding a deaf person’s embodied lifeworld, including their visual language and culture enabled Beth to reflexively question the basic assumptions and ideologies that underpinned her everyday practice. This not only resulted in her recognising the need for a BSL/English interpreter to facilitate effective communication but led to her recognising how the deaf person’s embodied ways-of-being may contribute to their values, beliefs and perception of health. This enabled Beth to be sensitive to differing values that her client might hold when engaging her in conversations about topics such as her baby’s hearing test results. By critically reflecting on the meaning of the hearing test for the deaf family, Beth’s attention was drawn to the moral nature of her questioning, judgement and decision making (Levinas 1969). Such critical reflection enabled perspective transformation and action as Beth became aware of the assumptions and presuppositions inherent in her usual approach to these conversations (Mezirow 1991). Therefore, while it is not enough to simply take note of another person’s lifeworld or being in the world, it can provide guidance for action that facilitates praxis (McCormack and McCance 2010).

To live and act as intentional practitioners, Mezirow (1991) claimed that we must explore the values, beliefs, knowledge and personal assumptions on which action is based. Critical reflection, accompanied by critical discourse, can enable this. However, Heidegger (1996) argues that we only become aware of our values when they are challenged either positively or negatively. This relates to Gadamer’s (2013) understanding that from a person’s own horizon, they are limited by that which is familiar. While a person’s horizon may be characterised as a limit to their understanding, it also represents an openness to possibility, as it is not static or fixed. For many of the nurses in this study, their biomedical view of deafness framed their approach to caring for a deaf person and this remained unquestioned. Therefore, power was at play, manifesting in the routine practices of nurses who ‘articulated’ that power unknowingly (Fay 1987). However, for those nurses who had insight into deaf peoples’ lifeworld, such as Beth, dominant structures were illuminated, and a curious questioning of practice was triggered. Therefore, Beth was able to engage in critical reflection both in her practice (reflection in action) and in the interview (reflection on action) (Schön 1983). Thus, the research interpretations suggest that knowledge of a deaf person’s lifeworld, including their language and culture is a prerequisite for such reflexive practice.

While Beth reflected on how her knowledge of deaf culture and BSL contributed to her reflexive practice, questioning also occurred as a result of her embodied engagement with the deaf person. In the subtheme, *Between us* we saw that this participation involved both ultilising an interpreter and Beth ‘listening’ with her eyes. Understanding the deaf person’s lifeworld was therefore not something that happened cognitively inside of Beth, but it unfolded as she came into embodied contact with the deaf person (Merleau-Ponty 2012). This emphasises that a person cannot be known separately from how they are known (through their embodied being) (Gadamer 2013). Therefore, this section raises questions as to how nurses can ‘listen’ to the bodies of the people that they are caring for. This is not about getting beyond the need for language but finding a way to listen to the bodies that are always present in practice (Chadwick 2017). Therefore, rather than an openness to hearing the other’s ‘voice’ in an encounter, attention must be paid to personhood that is fully embodied (Young et al. 2019).

The research interpretations indicate that there is need for nurses to have knowledge and awareness of their own and deaf peoples’ embodied lifeworld. This includes having an awareness of the values and ideologies that each hold and how they translate into embodied ways of being. In the subtheme *Shifting Perspectives*, Peter claimed that such knowledge and understanding of deaf peoples' lifeworld cannot be gained from attending formal deaf awareness training, believing that this led to rigid practice that did not acknowledge the uniqueness of each person. These research interpretations draw attention to the need for active engagement between nurses and deaf people in nursing education and practice. Such engagement may provide the space for nurses to gain knowledge and understanding of deaf peoples' embodied lifeworlds through active participation. This would not only provide an awareness of the wider political context and power structures through which care takes place but also provide an opportunity for nurses to practice an attentive awareness to embodied engagement as it is lived out rather than as it is conceptualised or theorised (Van Manen 2014). Fay (1987) argues that such embodiment of theory is necessary for transformation of a perspective and subsequently action.

Summary

In this section, I have drawn attention to the need for nurses to have understanding and awareness of their own and deaf peoples' embodied lifeworlds. Such knowledge has the potential to highlight the wider context and power structures through which care takes place and in which nursing practice is situated. This may enable nurses to reflexively question the basic assumptions and ideologies that underpin their practice. In recognising the significance of a deaf person's lifeworld, nurses may adapt their practice to enable deaf people to authentically engage in their healthcare experiences. Such authentic engagement not only relies on participation through use of BSL but a wider embodied engagement with healthcare professionals.

Conclusion

In this chapter, I sought to provide a robust analysis of the data interpretations in relation to relevant theory. The discussions support movement towards an embodied understanding of the space in-between deaf people and nurses. The space in-between represents the social, relational and physical space between nurses and deaf peoples' lifeworld's. Such space is constructed through embodied being and practices. Practicing from their own horizons and often situated in the positivist biomedical view of deafness, nurses in this study often embodied hearing cultural norms and values. Such taken-for-granted practices often force deaf people to act and relate in ways that are incongruent with their lifeworld. This results in inauthentic engagement and a space that is restricting and divisive. The tension that results presents a need to understand how nurses and deaf people can authentically engage in the space in-between. The findings pointed to there being a need to adapt current approaches to practice by moving away from traditional and apparently narrow ways of working with deaf people.

The research interpretations drew attention to the need for nurses to become critically aware of their own embodied lifeworlds, as well as ideologies embedded in healthcare contexts and how these may constrain their way of thinking and practicing. This can provide the foundation for reflexive practice in which nurses recogise and question their own positioning. Subsequently, nurses can step out of taken-for-granted values and beliefs that underpin their practice. This has the potential to address the unequal power dynamics between deaf people and nurses. It is through this process of reflexivity that the potential for authentic engagement is realised. When deaf people are enabled to engage authentically, the boundaries between lifeworlds become blurred and the space in-between becomes a place of potential where new and shared understanding can develop. Such authentic engagement requires an openness to new understanding and a willingness to embrace ambiguity in the encounter. Moral doing or praxis can flow from such understanding.

The significance of nurses' embodied practices to the construction of an in-between space became apparent in this study. This relates to how nurses use their bodies to interact relationally. The research interpretations suggest that nurses hold embodied knowledge which they can bring to unique or uncertain situations. Such practices reveal professional artistry in the midst of action. This does not necessarily involve cognitive reflection but an embodied mode of reflection. While the research interpretations illuminated the significance of nurses' embodied practices, I identified numerous potential challenges to articulating these. This indicates a need for more attention and value to be given to these elements of nursing practice.

It is evident from the research interpretations that BSL needs to be recogised as a bona fide language and utilized in healthcare settings to empower deaf people to access healthcare. This is a social responsibility that requires both NHS organisations and the healthcare professionals who work in them to commit to removing communication barriers that deaf people may experience. This necessitates contextual understanding of the language ideologies that oppress sign languages and the people who use them and recognition of the diverse language abilities of people in deaf communities. Recognising BSL/English interpreters as linguistic and cultural mediators, I have argued that there is need for greater collaboration between interpreters and nurses. This has the potential to raise nurses' awareness of the invisible elements of interpreters' roles that involve managing the power dynamics and different perspectives. Such collaboration could enable knowledge exchange that provides nurses with a greater understanding of the context in which their relationship with the deaf person is situated. Beyond the need for interpreters, the research interpretations illuminated a need for a more nuanced understanding of how deaf people can be empowered to navigate and understand healthcare. While it is evident that deaf peoples’ visual-spatial orientation is key to developing such understanding, further research is required to explore this in more depth.

Chapter 9: Conclusion and research impact

Introduction

In the previous chapter, I discussed the findings from the study and positioned them in the context of existing theory. I articulated the new knowledge that the study has contributed to the field of Deaf Studies and nursing. Taking a critically reflective approach, in this chapter I will reflect on the 'doing' of the research and the insights I gained both professionally and personally. I will offer a reflection on my positionality as a nurse, researcher, educator and hard of hearing person, including my plans for future research. The strengths and limitations of this study will be considered. Lastly, my impact plan and plans for dissemination of this research will be described. As Gadamer (2013) emphasises, in attempting to understand we do not move towards final objective knowledge. Therefore, the findings from this thesis are not a search for complete knowledge but have captured something meaningful that expresses the experiences of participants. Additionally, some of the complexity, ambivalence and ambiguity in the interactions of nurses, deaf people and BSL/English interpreters have been captured.

Reflections on the research process

This doctoral research process has demanded engagement in the process of self-reflection and responsiveness to my own personal and professional identity. Titchen and McCormack (2010) highlight that in the addition to knowledge creation, there is a concern for transformation of self in research. Mezirow (1991) argues that critical reflection about oneself is the most significant learning. At the beginning of this thesis, I acknowledged my belief that nursing is a relational practice in which relationship forms the foundation of caring. In the doing and writing of this research, I came to realise that I was pursuing a deeper understanding of relational practice. Upon reflection, I often had not felt supported to develop my understanding of relational practice or enhance my relational capacity in my formal education or clinical practice. While the significance of relational practice was evident in the humanistic values of the nursing profession, it appeared this was something that was expected to already be part of me and my professional identity. However, in my clinical practice I often felt constrained by the dominance of task-orientated and mechanistic approaches to care that failed to reflect the significance of relationship as a foundation for caring. While I believed that people are inherently relational and hold capacity for relational connection, I felt myself being socialised to think and practice in certain ways that prioritised doing rather than being.

The process of doing this research has provided me with the space and support to explore, articulate and critically reflect on my understanding of relational practice. This has moved me past a focus on being interpersonally skilled through the refinement of behavioural communication skills, to an appreciation of the complexity of peoples' connectedness, the development of relational awareness and an interest in the movement of relationship. While this requires an attention to self and others, it also necessitates an understanding of the wider context in which care takes place. In this research, de-constructing the wider context in which deaf peoples' care is situated required me to cross cultural, linguistic and disciplinary boundaries. As I reflectively explored (*Chapter Six*), some of these boundaries at times felt restricting, challenged my intentions and could have led me to pursuing a much narrower focus on nurses' experiences alone. However, as the research unfolded, I developed the understanding and courage to articulate and justify why such boundary crossing is necessary. This has ultimately laid the foundations for collaborative working across disciplines (nursing and BSL/English interpreting) and communities (deaf and hearing) in my practice as an educator and nurse. Through my own practice and experience of boundary riding in this study, I have come to realise the value in seeking out and questioning boundaries in research.

Throughout the research process I have continued to develop an awareness of how embodiment is central to developing meaningful relationships in my work. The focus of embodiment became significant during the formation of the philosophical underpinnings of this study. While I had been actively engaged in embodied practices including nursing, massage therapy and yoga up until that point, I had never before critically reflected on how significant embodiment was to my personal and professional ontology and epistemology. Personally, this critical reflection brought me to an awareness of how my narrative as a hard of hearing person was imbued with notions of abnormality that I adopted from my experiences of audiology services. Disrupting and reconstructing that narrative has enabled me to redefine my deafness as part of my embodied experience of the world and others that forms my horizon. This personal perspective transformation has also influenced my practice as a nurse and educator, as I have developed a deep curiosity about how people experience the world in embodied ways. Rather than a narrow focus on how illness disrupts bodies, I am interested in how peoples' embodiment influences the social and relational space that we engage in. My experiences and the findings of this research have raised my awareness of the embodied nature of practice that is often taken for granted and rarely articulated. This relates to the intuitive and aesthetic knowledge that gives people a sense of what, when and how to act.

While writing this thesis, I transitioned into a new role as a nurse educator. My research journey has significantly influenced my approach to teaching and learning. DeLuca et al. (2015) argue that an absence of the body in nursing education raises questions about the ways that the body of the nurse and patient are understood and taught in the education of nursing students. Although such understanding and knowledge is often described as tacit and/or ordinary, the ideals of relational practice and human valuing are often embodied in these everyday activities and actions. These beliefs have significantly informed my approach to teaching and learning. With a focus on critical thinking and shared dialogue, I believe that people can understand the nature and essence of their caring practices by articulating and capturing the knowledge embedded and embodied in them. I am passionate about learners developing reflective skills that enables articulation of such caring practices. As the understanding of how relational practice is effectively operationalised in practice continues to grow, I am interested in how a focus on embodiment can contribute to practical knowledge, procedural knowledge and theory-in-use.

In addition to thinking about how I teach about the body, I have also considered my teaching practices. Although pre-registration nursing education programmes in Scotland require an equal balance of theory and clinical practice learning (Nursing and Midwifery Council 2018), I believe the mode through which theory is delivered requires revision. Emphasis on vision and sight in education is evident in lectures where students are often expected to remain still for long periods of time solely looking and listening. Howes and Classen (2014) state that this mode of learning is perceived as a “prerequisite for academic success” (p.2). However, in cultures where education is a more active process involving all of the senses and bodily movement, looking and listening is only part of the educational process. Such considerations may lead to changes in the practical design of learning activities and the way that they support embodied interactions in learning environments. In my own practice as an educator this has translated into an active learning approach that prioritises social and communicative processes in the application of learning (Dewing 2010). This requires a focus on designing learning activities that are collaborative and promote participation so that students are not simply developing ‘cognitive knowledge’ but are engaging with embodied cognition. Discovering and embodying such active ways of learning often requires students to un-learn traditional learning methods to embrace more creative approaches. Attending to how bodies interact, move in space, engage in rhythms, work with geographies and ecologies, may enable learners to consider more deeply how bodies interact in space and time (Kinsella 2015). Reid and Mitchell (2014) believe that such approaches enable educators and learners to embrace their bodies as resources that hold a repertoire of practices. I believe such embodied social learning enables students to develop embodied knowledge and practices that are valuable to their clinical practice.

While believing that embodiment is central to my practice as a nurse, current philosophical and theoretical understandings of embodiment fail to account for how embodied practice takes shape. Therefore, questions remain for me about how to translate the theoretical and philosophical insights related to embodiment into practice. While I believe there are no concrete answers, I continue to experience the challenge of describing the essence of embodiment in practice that is tangible both to me and others. This has been identified as a key challenge in describing the essence of professional artistry (Frost 2020). Therefore, in my practice as a nurse and educator appreciation of tacit ideas, knowledge, thoughts and feelings have become key to enabling both myself and others to appreciate and consciously develop an artistry. This involves bringing tacit and embodied processes into cognitive awareness to help professionals learn to exercise judgement in the midst of messy practice situations. Believing, from my own experience, that the cultures that students experience during their time at university and in practice education have the potential to define their personal and professional identity, I hope that my approaches will facilitate ongoing reflective practice that continues post qualification.

In *Chapter One*, I introduced the disorientating dilemma I experienced that led to me pursuing this research. Taylor (2000) argues that rather than a single disorientating dilemma, a much wider range of experiences results in transformative learning. Critically reflecting on my learning from the process of this research has enabled me to see how my own personal and professional identity has transformed.

Limitations

Context of care

While the deaf participants in this study shared their experiences of a range of healthcare contexts, it is important to note that the majority of nurse participants were recruited from secondary care settings. I therefore acknowledge that the findings will be impacted and potentially limited by the focus on the acute care context. The findings indicate that the physical and social space in which healthcare takes place can facilitate or restrain authentic being and engagement. I believe future research would benefit from including nurses' experiences from a broader scope of care contexts including primary and secondary care. This may provide greater insight in to how the social practices and physical structures of different care contexts can contribute to the space in-between deaf people and nurses.

Privileging of voices

A limitation of this study relates to the social status of the deaf participants involved. As previously discussed in *Chapter Five*, all deaf participants in my study were deaf professionals who could be viewed as deaf elite (Holcomb 2013). Although De Meulder (2017b) emphasises that the number of deaf professionals in the UK has steadily increased, it is evident that such people are not representative of the majority of the deaf population. While the aim of this study was not generalise the findings, the ongoing privileging of professional voices in research with deaf people has been highlighted as an issue by Murray (2017). This relates to Ladd's (2003, p.136) concept of the 'deaf subaltern' and 'subaltern-elite' that situates ordinary people in relation to the elite group who hold positions of power. In *Chapter Five*, I explored potential reasons why a more diverse group of deaf people were not recruited to this study. This included: gatekeeping, mistrust of researchers and hearing people, and consultation fatigue. This has implications for the findings of this research because a more nuanced understanding of deaf peoples' experiences may have been gained by including experiences of people who are situated as grassroots deaf. This limitation raises questions as to how people situated as grassroots deaf can be enabled and empowered to access and take part in research. Reflecting on my own challenges in recruiting deaf participants and issues of research being 'hard-to-access', I believe there is scope for research to be developed that enables greater participation of a more diverse group of deaf people. Such research would need to be collaborative and participative, supporting research that is guided by deaf epistemologies and ontologies.

Involvement of participants in the research design

A second limitation of this study is the lack of involvement of deaf people in the design of the study. Due to a combination of my limited BSL skills and the financial limits of this study, it was not possible to recruit a deaf person to join the supervisory team or to utilise a participatory methodology. Such participation would have allowed deaf people to contribute to the development of the research process. In *Chapter Six*, I acknowledged that lack of funding for interpreters is an ongoing challenge that hinders deaf people from both accessing and being able to fully participate in research.

Additionally, I acknowledged that the questions and objectives of this study were developed from my own positioning and perspective. However, to redress the power imbalances evident in research with deaf people, future research should be participatory with people from deaf communities contributing to the development of each stage of the research. Such participatory approaches are more likely to produce culturally sensitive research methods that enable deaf people to meaningfully take part (Liamputtong 2010).

Strengths

Philosophical underpinnings

The main strength of this research lies in the clear articulation and application of my philosophical underpinnings. Striving for epistemological and ontological authenticity, my philosophical underpinnings demonstrated and clarified the framework that guided my ways of *being* and *doing* in the research. Therefore, the philosophy shaped every part of the research process from the initial planning through to the discussion of the research findings. Applying the philosophical underpinnings drawn out of Merleau-Ponty's (2012) philosophy of embodiment not only opened up opportunity to engage in creative research but enabled me to be responsive to the alternative ways of being and knowing of deaf people. I believe that this contributed significantly to ethical sensitivity in my research and the development of new insights into the relationship between deaf people and nurses. I believe that having a firm understanding and being transparent about the philosophical underpinnings of my research enabled the development of a rigorous research methodology (Dewing et al. 2017).

New knowledge developed through boundary riding

Another major strength of this research is its unique contribution to knowledge. As highlight throughout in *Chapter Three* much of the empirical research that has been carried out with deaf communities has been situated in the biomedical perspective, privileging positivist traditions. Such knowledge based only on 'objective' research findings stripped of context is problematic resulting in 'incomplete epistemologies' (Reimer-Kirkham et al. 2007). Therefore, contextual evidence and knowledge, attending to the social historical, and political contexts of health, are key to avoiding the reproduction of such knowledge. I believe that new knowledge was generated in this study from riding the boundaries of different professions, communities and research methodologies. Staying within the boundaries of my own profession would have been safer. However, it would not have allowed new and meaningful collaborations to develop. The evidence from this study adds depth and breadth to existing knowledge and provides insights regarding the complexity and multiplicity of attributes that influence deaf peoples' experiences of nursing care. Chinn and Kramer (2008) propose that this type of knowledge leads to emancipatory knowing that can enable structural and social change at a local level. Creating such knowledge is critical to enacting social justice which I believe to be a social and moral responsibility in nursing practice.

Rigour

As a novice researcher, guided by Gadamer's (2013) philosophical hermeneutics, I recognise that this research was undertaken from my positionality (horizon). Research approached from such a perspective continues to be criticised for lacking methodological rigour and introducing researcher bias. Therefore, attention must be paid to how methodological rigour has been established. Finlay (2006b) argues that choosing criteria for establishing rigour in research must take into consideration the aims and epistemological assumptions that have shaped the methodology. As the basic tenet of hermeneutics does not provide a procedure for understanding but aims to clarify the conditions in which understanding takes place (Gadamer 2013), the rigour of this research has been established through researcher reflexivity (Koch 1996). Throughout this thesis, I have intentionally used a more personal yet academic writing voice with the intention of narrating the story of my research. This has enabled me to capture and be transparent about my positionality. Rather than my positionality remaining fixed, I have traced its movement as my understanding of the topic transformed and expanded. From this perspective, the whole research process is a reflexive exercise. Therefore, rigour has been achieved by clarifying the conditions in which understanding and interpretation took place.

Research dissemination and impact plan

The Research Excellence Framework (2019) states that researchers need to ask how their research contributes by evaluating it against two key criteria; the significance and reach of the research on the economy, society and/or culture (Stern 2016). Reed (2018) claims that the order in which a researcher contemplates these two criteria is crucial because without tangible meaning and value (significance), the scale or reach of impact is irrelevant. Therefore, in developing a plan for dissemination and impact, I have intentionally focused on the significance of my research in local communities where I believe people can benefit from the study in meaningful ways. By initially focusing on achieving significant impact on a local scale, the potential for extending the research impact in the future is enhanced (Anderson et al. 2009). The table in Appendix 11 identifies past, current and proposed research dissemination and impact activities. Reed (2018) believes there are five principles underpinning research impact: design, representation, engagement, early impact, and reflection and sustainability. To maximize the potential for achieving impact, I have taken each of these into consideration while impact planning.

Design

Although generating new knowledge is viewed as the intent of research, to have impact it must also be shared in meaningful ways that enables it to be applied in the real world (Reed 2018). The traditional approach to research impact focuses on creation of research outputs, particularly peer-reviewed articles. While academic publications are important for professional knowledge exchange and practice development, a broader relational approach is more likely to build social networks that can affect positive social change (Ozanne 2017). Therefore, in designing impact goals and identifying objectives related to knowledge exchange activities, attention needs to be paid to the exchange process while keeping the end goals in sight. In creating impact goals and knowledge exchange activities, I adopted a relational approach that reflected the methodology employed in this research (*Chapter Five*) and my belief that shared understanding comes from entering into dialogue (Gadamer 2013).

Representation and engagement

Representing the needs and priorities of those who will use and benefit from research involves identifying and nurturing key relationships with those to whom the research relates (Reed 2018). This includes an awareness of who has the power to enable and disable the research process to achieve impact. This principle relates to the social context in which the research takes place. In *Chapter Four* and *Five*, I identified key relationships with different communities, organisations and individuals that could potentially benefit from this research. These include; third sector organisations, NHS interpreting and translation managers, nurses, gatekeepers, BSL/English interpreters, deaf people and deaf communities. The impact plan reflects my intent to continue to develop these relationships and build long-term, two-way and trusting relationships with those to whom the research relates so that we can ideally co-create new knowledge together. This is not about ‘knowledge transfer’, which implies a one-way exchange of information but having a two-way dialogue (Reed 2018). To date, this approach has enabled me to engage meaningfully with the collaborative development of services and educational activities beyond the life of the research project. In my teaching, I have collaborated with colleagues in the Hearing Sciences Division at QMU and Languages and Intercultural Studies at Heriot-Watt to facilitate workshops that support nursing and interpreting students to learn with and from one another through simulated scenarios. Each of these have the potential to impact relationships and understanding between professions.

In *Chapter Five*, I emphasised that the findings of research often do not reach deaf communities because dissemination is invariably through written means (Orfanidou et al. 2015). In this study, research findings will be available to deaf people in physically, culturally, and linguistically accessible ways by taking into consideration the most appropriate method of knowledge exchange.

Early impact

Generating early impact in this research study was a challenge for me as a novice researcher. As discussed in *Chapter Five*, I faced many challenges to accessing deaf communities. Consequently, engaging these communities in early and ongoing impact planning was difficult. Throughout this thesis, I have highlighted the often-rigid boundaries of different communities (deaf community and BSL/Interpreting community) and professions. This raises questions as to how researchers can engage in early impact when working with marginalised groups. Due to the collaborative relationships that have been established through this research study, I believe that early impact planning in future research activities may be easier.

Reflection and sustainability

Reflection and evaluation of research impact is key to learning how to successfully deliver impact (Reed 2018). The time lag between the completion of this research and certain forms of dissemination, such as academic publication, will require reflection and evaluation of these routes to impact in the future. However, in taking a relational approach to knowledge exchange and impact, I must also reflect on the social networks that have developed through this study and how these are key to sustaining impact. As shown in the impact activity table (see Appendix 11), there are numerous activities that have resulted from networking in this research project. While many of these activities might not be seen as direct impacts of the research findings, they are impacts that have resulted from the research process that demonstrate a commitment to establishing connections with the people I have collaborated with beyond the life of the study. I will continue to track the impact of this research through the impact plan and my ongoing reflective practice.

Concluding remarks

The process of undertaking this research and writing this thesis have been professionally and personally transformative. My most recent reflection on the whole process clarified my beliefs about my own research and practice. While there are questions remaining as to how nurses can better articulate and value embodied practice, I hope this thesis offers new directions and ways of exploring, understanding and theorizing about embodiment. Most importantly, I hope it contributes in some way towards creating spaces for healthcare that are safe, inviting and socially accepting of deaf people. In closing this chapter and this thesis, I share a picture (Figure 9.1) which I painted at the end of data analysis and named 'Letting go and letting come'.

Figure 9.1 Letting go and letting come

While this thesis is an ending of sorts, it is also an opening up of new lines of questioning and inquiry. This image illustrates that while my doctoral journey is coming to an end, the process and findings have provided direction for exploration in the future.

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Appendices

Appendix 1: Published literature review

Nursing Practice
Review
Hearing impairment

Keywords: Deafness/Hearing impairment/Communication

●**This article has been double-blind peer reviewed**

A literature review revealed that health professionals' communication with Deaf people is often inadequate, leading to lack of understanding and putting patients at risk

Meeting Deaf patients' communication needs

In this article...

- **Deaf people's communication preferences**
- **Communication methods used by health professionals**
- **Risks posed by ineffective communication**

Authors Megan Dickson is research assistant; Ruth Magowan is lecturer, both at Queen Margaret University, Edinburgh. Ruth Magowan is also paediatric specialist nurse.

Abstract Dickson M, Magowan R (2014) Meeting Deaf patients' communication needs. *Nursing Times;* 110: 49, 12-15.
Effective communication between nurses and patients is a vital part of safe and effective nursing care. However, few health professionals receive training in how to communicate with Deaf people; as a result, attempts to communicate with Deaf patients is often inappropriate and undertaken without knowledge or understanding of their communication needs. This article examines the literature on ways in which Deaf patients experience communicating with, and receive care from, nurses.

DEFINITIONS

● **Deaf**
In the context of this article and in conjunction with Deaf cultural beliefs (Ladd, 2003) "Deaf" with a capital D refers to people who are prelingually deaf and for whom sign language is the first language and language of choice

● **Prelingually Deaf**
The term prelingually Deaf is used to describe people who lost their hearing before they acquired a language (Gilchrist, 2000)

British Sign Language has been recognised as a distinct minority language in the UK since 2003. This means the rights of its users are protected under both equality and disability legislation.

Estimates of the number of Deaf people in the UK who use BSL as their first or preferred language range from 50,000 to more than 100,000, and are often quoted without rationale or basis (*British Deaf News*, 2013). Ladd (2003) noted that the confusion of medical and cultural criteria make it difficult to ascertain the exact number of people in the Deaf community. For many years Deaf people have been "invisible" or undercounted in national statistics, making it difficult to plan services to meet their needs. The Deaf community also falls outside most other models of culture and ethnicity (Lane, 2005). There has been continuing discrimination within the NHS and the Department of Health to provide accessible and culturally appropriate healthcare (Powell, 2014).

To guarantee compliance with the Disability Discrimination Act 1995 (DDA), healthcare providers should ensure Deaf patients have access to certified BSL/English interpreters to facilitate communication with health professionals. This enables nurses and other health professionals to obtain accurate and complete medical histories, explain treatment effectively and gain Deaf patients' trust and confidence. Absence of an interpreter can increase the risk of misdiagnosis, medical error and non-adherence to treatment.

There is a dearth of nursing literature concerning Deaf people; many of the articles available are dated and anecdotal, most are not British in origin and may not, therefore, accurately represent the nature

5 key points

1. **Lack of effective communication with hearing people disables Deaf people, not their deafness**
2. **People whose first language is British Sign Language find contact with the NHS problematic**
3. **There is little evidence to guide nurses in communicating with, and caring for, this group**
4. **Deaf awareness training outlines the cultural differences between Deaf and hearing people**
5. **More research into Deaf people's experiences of care is needed and may be key in justifying compulsory deaf awareness training for all nursing staff**

Sign language is key to Deaf patients fully understanding what is said in a consultation

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BOX 1. **REASONABLE ADJUSTMENTS IN HEALTHCARE**

The Disability Discrimination Act 1995 requires healthcare providers to make three types of adjustment to remove barriers that make services difficult for people with disabilities to access or use services, providing it is reasonable to do so:

1. **Change aspects of service provision such as:**
   - Policies
   - Rules
   - Practices
2. **Adapt physical features of healthcare facilities such as:**
   - Steps and stairs
   - Passageways and paths
   - Entrances and exits
   - Internal and external doors
   - Toilets
   - Signs
3. **Provide auxiliary aids or services such as:**
   - Portable induction loops for people with hearing aids
   - British Sign Language interpreters
   - Information in alternative formats, such as Braille or audio CDs
   - Extra staff assistance

of nursing Deaf people in the UK. The lack of nursing literature may indicate that this group has not been thought to require special consideration. However, knowledge that is culturally relevant and reflects their lived, contextual realities and concerns is crucial to effectively nurse these patients (Lopez and Willis, 2004).

Access to healthcare

Legislation such as the DDA and the Equality Act 2010 demonstrate a commitment to eliminate discrimination, reduce social exclusion and make services more accessible for the Deaf population. The DDA introduced the concept of "reasonable adjustment", which requires service providers to take "reasonable" steps to remove barriers to accessing services (Box 1).

It is seen as good practice to include service users with disabilities in the process of considering what adjustments are appropriate, although service providers make the decisions about which to implement. For Deaf people, however, the major barriers are:

- Lack of recognition;
- Acceptance and use of sign language in all areas of life, and
- Lack of respect for their cultural and linguistic identity (Ladd, 2003).

In Scotland a mixed-methods study assessing the extent of access to public services in BSL by Deaf people found no instances of direct access to public service through BSL (Kyle et al, 2005). Participants reported frustration when contacting hearing services and considered contact with the NHS the most problematic, as well as the highest priority, public service.

Reeves et al (2003) evaluated access for Deaf people to primary and accident and emergency services in the north west of England. None of the 22 studied services had a visual patient call system, relying instead on patients responding to verbal calls; in two cases these came via public address systems. While managers said Deaf patients would be approached when it was their turn to be seen, only 27% of receptionists claimed to use this procedure.

Although 68% of the managers indicated their unit had a system for obtaining BSL interpreters, many had no experience of booking any, suggesting they were rarely used. Six departments (27%) used staff members with signing skills to interpret for Deaf patients; three of these staff were qualified to BSL Level 2, while one other was working towards that.

One unit was seeking funds for Deaf awareness training and for a staff member to learn BSL. Out of the 22 departments studied, 21 (95%) felt that access for Deaf people could be improved via Deaf awareness training (Reeves et al, 2003).

The findings of Reeves et al (2003) highlight that the difficulties experienced by Deaf people trying to access healthcare begin at reception, where their need to communicate and orientate themselves and to have an interpreter often goes unrecognised. The study also suggests that their problems arise from staff not understanding their communication needs. A major strength of this study is that data was collected, video recorded and analysed directly in BSL by a Deaf researcher, preserving its BSL nature and avoiding misinterpretation.

Literacy and health-related vocabulary

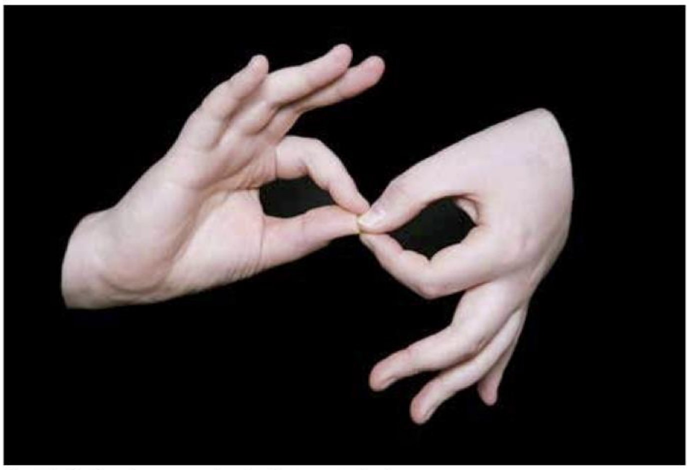
Communicating through spoken or written English poses many challenges to Deaf people, as there is no written form of BSL, and it differs from English in grammar and syntax (Kyle and Woll, 1985). Linguistic studies have also demonstrated only 30-45% of the English language is discernible through lip reading – contextualisation and guessing determine the remainder (Lieu et al, 2007; Barnett, 1999; Conrad, 1977a).

Although not a reflection of their intelligence, Conrad's (1977b) seminal research noted that the average reading age of Deaf adults is that of a nine-year-old. Berkman et al (2011) noted that the likelihood of accessing, processing and understanding health-related information is strongly associated with levels of literacy in adults, yet in the absence of a BSL interpreter, health professionals often resort to communicating with Deaf patients in writing.

Deaf people are commonly at an increased risk of what has been termed a "low fund of information"; this refers to the knowledge individuals accumulate from picking up facts and common-sense understanding through casual conversation and access to media (Young and Hunt, 2011). Coupled with low levels of literacy, this often leads to knowledge deficits about illnesses, their symptoms and causes, treatment options and risks, medication and preventive care.

Although printed materials about health topics may be available to Deaf adults, the information may not be written at a level appropriate for them, putting them at a considerable disadvantage. This has serious implications for the process of obtaining informed consent and the consequent safety of Deaf patients. Few rigorous evaluations of health literacy-related interventions for Deaf people have been carried out.

Pollard and Barnett (2009) explored health-related vocabulary knowledge in a sample of 57 Deaf people in the US. Participants were asked to complete a modified version of the Rapid Estimate of Adult Literacy in Medicine (REALM) screening instrument (Davis et al, 1993), which requires users to read a list of 66 health-related vocabulary terms and indicate their level of comprehension. Although 81% of participants possessed college degrees, almost a third (31.6%) produced scores that were considered below the level of understanding of a 14-15-year-old, which is considered indicative of low health literacy.



The British Sign Language sign for "interpretation"

Alamy

Words that were not understood included "obesity", "constipation" and "smear". The study did have limitations, as Deaf people often indicate they have understood healthcare information to avoid embarrassment (Ubido et al, 2002). The sample was voluntary and highly educated, so the results cannot be generalised.

Healthcare experiences

Steinberg et al (2006) conducted four semi-structured focus groups exploring the healthcare experiences of 91 Deaf adults in the US. Participants expressed communication difficulties, with a recurrent theme of fear of the consequences of miscommunicating. Positive experiences were characterised by the presence of medically experienced certified interpreters, health professionals with sign language skills, and doctors who made an effort to improve communication. However, alternatives to the use of certified interpreters, such as lip-reading and written communication, were common.

Parise (1999) conducted semi-structured individual and focus group interviews exploring the healthcare experiences of 10 Deaf participants in Quebec. Participants expressed feeling alienated, rejected and powerless when in contact with health professionals due to ineffective communication methods used. They found lip-reading and writing to communicate health issues laborious, overwhelming and emotionally draining, and identified the provision of a certified interpreter as creating a sense of ease in healthcare encounters.

Participants in Steinberg et al's (2006) study spoke of bringing family members to healthcare appointments to interpret, but feeling excluded from these conversations. They also noted that this method of facilitating communication compromised their privacy. This supports the findings of a descriptive pilot study by Wright (1993) in the UK, in which participants who used ad-hoc interpreters, such as family members, felt they were being *spoken about* and not *spoken to*.

Inadequate interpreting services leading to using family and friends increases the risk of medical error and is fraught with legal and ethical problems.

Steinberg et al (2006) stated that many participants who felt negatively about their healthcare experience had limited knowledge of their legal rights and/or complaints procedures in the healthcare system. Similarly, the British Deaf Association (2012) stated there is a paucity of knowledge about how legislation works and how it can be enforced within the UK Deaf community.

These two studies reinforce the findings of Gilchrist's (2000) US study exploring 11 Deaf adults' experiences of communicating with nurses, what health meant to them, and their attitudes towards nurses. Participants expressed a need to see signing, gestures, facial expressions and body language to make sense of their environment. Without being able to visualise words (through use of an interpreter) they noted that communication was diminished.

Participants described feeling proud to be Deaf and part of a tight-knit community with its own language. When in contact with nurses, however, they felt objectified because of their deafness and felt that no caring or compassionate connection developed. They emphasised that not all Deaf people understand written English, nor do they feel they need or want to. Participants also viewed nurses as living in doctors' shadows, and said nurses did not clarify any situations for them despite participants communicating a desire to be informed and empowered to take control of their health.

Inaccurate translation threatens the credibility and therefore trustworthiness of results, so a central concern of cross-cultural research is the development of cultural understanding and translation procedures. Parise (1999) and Gilchrist (2000) both required the use of interpreters to carry out their interviews, and to present the limitations of their studies. Threats to the validity of each of these studies emerge from the analysis being undertaken in a language that is not that of the participants. As detailed descriptions of the translation process were not provided it is unclear how far removed they are from the original data.

Another limitation of these studies and that of Steinberg et al (2006) lies in the nature of the sampling method. All relied heavily on "snowball sampling"; this is used where no sampling frame exists (Bowling, 2009) and accesses human networks to gather a sample or identify potential participants. The method is most effective when contacting hidden or hard-to-reach groups (Grove et al, 2013), but while it is the most common, effective way of obtaining samples from the Deaf community, it may not provide a sample that is representative of the Deaf population (Padden and Humphries, 2006).

Snowball sampling involves a researcher locating a few participants with the necessary criteria and asking for their assistance in contacting others with similar characteristics. Despite the potential for sampling bias, the evidence from these studies of Deaf people's access to healthcare is consistent; when anecdotal reports are taken into account, the evidence is also consistent over time suggesting that little has changed despite implementation of the DDA.

Deaf awareness

Many of the studies reviewed concluded that Deaf participants most valued being able to communicate in their preferred language with someone who is aware of the cultural differences between Deaf and hearing people. There are currently no plans to train health professionals en

"Nurse revalidation is likely to be a game changer for the profession"

Debra Moore › *p26*

masse in BSL, which highlights a discrepancy between patient preferences and the services available in the UK (Middleton et al, 2010).

Despite attempts by the UK government to offer patient choice and a willingness to meet their communication needs, it is not feasible for the NHS to train health professionals to the level required to fluently communicate with Deaf patients in BSL, due to the small size of this patient group. In the absence of health professionals who can sign adequately, Deaf awareness and access to certified BSL interpreters should, therefore, be a priority. The Department of Health (2005) recommended that all NHS frontline staff receive Deaf awareness training to enable them to respond appropriately and sensitively to the needs of Deaf people, providing a more accessible service and supporting compliance with the DDA.

Hoang et al (2011) carried out a study in the US to establish a link between knowledge about Deaf culture and Deaf patients, and completion of a Deaf Community Training (DCT) programme that incorporated elements of Deaf culture and linguistics. The results indicated that DCT significantly increases participants' capacity to care for Deaf patients, reducing health inequalities.

However, in a survey assessing US doctors' knowledge and beliefs regarding communication with Deaf people, although almost two-thirds (63%) knew that effective communication with Deaf patients is achieved through use of a certified interpreter, only 22% used this more frequently than other methods of communication (Ebert and Heckerling, 1995). Writing was the most frequent method used to communicate with a Deaf patient and was used in 34% of encounters despite only 32% of participants believing it to be effective.

Conclusion

There is clearly a lack of public and professional awareness of the barriers to healthcare services that Deaf people encounter. Their communication preferences are often ignored and they are expected to "get by". Although deaf awareness can improve health professionals' knowledge of how to appropriately and effectively communicate with Deaf patients, even if they know and understand Deaf patients' communication needs, health professionals often resort to inadequate methods such as lip-reading and writing. This does not reflect current NHS strategy that promotes person-centred care (McCormack and McCane, 2010).

There is a dearth of recent British literature on Deaf people's experiences of healthcare, but anecdotal evidence suggesting they often experience ineffective communication with health professionals has remained consistent over time. The lack of nursing literature may indicate that this linguistic group has not been thought to require special consideration. Further study of Deaf experiences of nursing care may help to justify provision of compulsory Deaf awareness training for all nursing staff. To effectively nurse Deaf patients it is important to develop knowledge that is culturally relevant and reflects their lived, contextual realities and concerns.

Further research could add to the literature, suggesting the need for national guidelines on the provision of translation and interpreting services within the NHS, to secure high-quality interpreting services for Deaf patients. Information on complaints procedures should also be made accessible to BSL users so they can highlight issues such as inadequate facilitation of communication and lack of adherence to legislation such as the DDA.

As the communication needs of the UK population continue to change, it is essential that nurses are educated to provide culturally responsive care that is sensitive to the needs of minority ethnic groups such as the Deaf community. As Montgomery (1981) stated:

> *"There are few places where it is more inconvenient or even dangerous to be misunderstood than a busy hospital ward."*

Better communication is not an option; barrier-free communication is regarded as a basic human right and vital to patient safety. Nursing Deaf patients needs to become a more inclusive relationship, in which patients are affirmed as partners rather than recipients of care; the recognition of, and adherence to, language preferences is vital to achieving this person-centred approach. **NT**

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Appendix 2: Diagnosis of hearing loss

To diagnose loss of hearing, an audiologist carries out a range of tests to quantify hearing in terms of the degree, the type and configuration of the hearing loss. With regard to degree of hearing loss, hearing levels are quantified in decibels (Kramer and Brown 2019). The following table shows the descriptors related to severity of loss.

Diagnosis	**Range of hearing**	**Impact on person**
Normal hearing	Below 20dBHL	
Mild hearing loss	20-40dBHL	Difficulty following speech in noisy situations
Moderate hearing loss	41-70dBHL	Difficulty following speech
Severe hearing loss	71-95dBHL	Severe difficulty following speech without a hearing aid
Profound hearing loss	Over 95dBHL	May require hearing aids, cochlear implants, sign language and lip-reading

(British Society of Audiology 2018)

Hearing loss is often not curable, but hearing aids and sound amplification devices may improve hearing function. People who experience a hearing loss can be provided with a hearing aid free from the NHS to correct and compensate for the deterioration (Tate Maltby 2019). These are offered to people whose loss is more than 40 dBHL as this is the level of loss that the World Health Organization (WHO 2020) define as significantly disabling for adults. However, Tate Maltby (2019) argues that although hearing loss may be suspected, there is a commonly a gap of two to five years between an individual noticing the problem and taking action. Additionally, Action on Hearing Loss (2019) estimate that only 40% of people who could benefit from hearing aids have them. Research (David and Werner 2016) suggests that stigma plays a part in lack of use and rejection of hearing aids. Brown and Pullin (2019) argue that hearing aids are a stigma symbol (Goffman 1963) that highlights a shift from ‘normal’ to ‘other’. They therefore argue that the promotion of hearing aids as ‘discreet’ reflects the biomedical assumptions or belief that hearing loss is socially unacceptable and should be concealed.

Appendix 3: Critical appraisal tool

Literature reference:

Type of literature: research paper, policy document, book, other:

Relevance to research/thesis:

Study design:

Main focus of the literature - research question and objectives:

Details of participants or group to which the literature is relevant:

Methodology & methods employed

Findings:

Summary of key points:

Quality of the literature (strengths & limitations):

Relevance to thesis:

Other comments:

Appendix 4: Evidence table

Author(s)	**Aim/purpose of the research**	**Method/background**	**Key findings**	**Comments**
Cooper et al. (2003) UK	To examine mental health professionals contact with deaf people and knowledge of deafness, in relation to their attitudes towards people who are deaf	**Methodology** Quantitative **Methods** 121 qualified mental healthcare professionals Questionnaire that included: • 6 questions to assess the amount of contact participants had experienced with people who are deaf • 22 item Attitudes Towards Deaf People Scale (Cooper et al. 2004) • 10 multiple choice questions assessing participants	Knowledge of deafness did not correlate with attitudes towards deaf people (*r=0.150, p=0.119*) Professionals attitude scores did correlate with amount of contact with deaf people of equal or higher status (*rho=0.250*) Professionals attitude scores did not correlate with amount of contact with deaf people of lower status (*rho=0.061*) Participants who had deaf awareness training had a more positive attitude (*p<0.05*) towards deaf people than those who did not	The 'Attitudes Towards Deaf People Scale' was developed by the researchers following an examination of literature and a focus group of six deaf people (Cooper et al. 2004) The significance of correlations was ambiguous due inconsistent reporting of p values 'Status' was not defined by the researchers

		knowledge of deafness Analysed using Pearson's correlation and Spearman's rho		
Ferguson-Coleman et al. (2013) UK	To explore how deaf peoples' knowledge about dementia and access to services is mediated by their minoritised cultural-linguistic status	**Methodology** Inductive, qualitative design (broadly phenomenological) **Methods** Purposive sample 26 deaf people without dementia 3 Deaf-led focus groups • Deaf people over the age of 60 without dementia (n=11) • Deaf people aged 18-60 working in professional roles (n=6) • Members of deaf community aged 18-60 (n=9)	Participants were concerned about poor levels of knowledge and understanding of dementia amongst deaf community Primary care services were recognised as first port of call for dementia related concerns There was a widespread mistrust of primary care services because of failures in communication and lack of cultural competence Mainstream support services (healthcare and third sector) were viewed as being ill-equipped to respond to the needs of deaf people with dementia Translation into BSL is crucial but not always sufficient for understanding	Researcher profiles: dementia care expert (hearing, no BSL), deaf BSL user, hearing BSL user Researchers aimed to achieve culturally meaningful participation Researcher who is deaf, BSL user carried focus groups

		Thematic analysis underpinned by phenomenology	Attention to culturally preferred means of engagement with information is vital The content of information is best presented utilising formats that embrace deaf peoples' visual understanding Cultural values and practices require consideration when raising awareness and building understanding of dementia	
Gilchrist (2000) USA	To describe and interpret prelingually deaf peoples' experiences of communicating with nurses, the meaning of health, and their attitudes toward nurses	**Methodology** Qualitative, hermeneutic phenomenological methodology inspired by Van Manen **Methods** Purposive sampling Participants: deaf men n=6, deaf women n= 5 Semi-structured interviews Thematic analysis	Healthcare information was obtained primarily from the deaf community and friends Interpreters required to enable effective communication for both nurses and deaf people Deaf people expressed feeling left in the dark with little information about their health and care Decisions regarding use of interpreters are personal and contextual Interpreters were often not used by nurses. Written English and lip-reading were often utilized by	ASL/English interpreter employed

		Researcher engaged in bracketing	nurses and misunderstood as effective ways of communicating Nurses often engaged in routines activities without engaging with the person Some nurses went ‘out of their way’ to engage with the person The significance of nurses communicating via their whole body was emphasised	
Gilmore et al. (2019) UK	**Objective 1** To evaluate the impact of ‘Sign Language and Communication Tactics’ training on attitudes toward and knowledge of deafness **Objective 2** To explore whether such changes in attitude and knowledge persist over time **Objective 3** To explore ways of including deaf	**Methodology** Mixed methods evaluation **Methods** Objective 1 & 2: Questionnaire Attitudes to Deafness scale (Cooper et al. 2004). 22-item instrument with Likert scale Objective 3: Focus groups Participants: 2nd year medical students at	**Objective 1** Students who completed the course had higher knowledge scores ($p=0.03$) and more positive attitudes ($p<0.001$) than those in the control **Objective 2** No significant difference in either knowledge or attitudes scores in those who had just completed the course (p=0.34) and those who had completed it in the past (p=0.88) **Objective 3** Students suggested that deaf awareness training should be:	‘Sign Language & Communication tactics’ developed collaboratively between Action on Hearing Loss staff and QUB medical educators. Training involved: • 17 three-hour long BSL classes • 2 deaf awareness sessions • 1 session to develop an online BSL medical dictionary Statements viewed as inherently positive or negative attitude towards deafness

	awareness training into an undergraduate medical curriculum	Queen University, Belfast Completed course (n=29) Control (n=24) Control extended (n=33) Previous medical students who had completed course also took part (n=70) Statistical analysis conducted using SPSS software	Interactive Demonstrate good and bad practice Involve deaf people Involve sign language interpreters	At baseline, the sign language group had more positive attitudes (*p<0.01*)
Hoang et al. (2011) USA	To evaluate the effect of a Deaf Community Training (DCT) programme on the cultural competency of medical students Hypothesis: The DCT medical students will demonstrate greater knowledge of deaf culture and deaf people than the non-DCT	**Methodology** Quantitative evaluation **Methods** Recruitment purposive sampling Participants: non-DCT faculty n=130 Non-DCT students n=211, DCT students n=22	The hypothesis was supported DCT students has significantly higher over knowledge scores (p<0.01)	DCT programme involved: • 2-year training • Self-paced reading materials related to deaf culture • ASL classes • Residential ASL/deaf culture immersion programme • Completed research projects related to the deaf community

	medical students and faculty.	Survey: 6 multiple choice questions, 28 true-false questions Statistical data analysis conducted using SPSS software		The survey was based on a review of literature and guidance from a deaf community advisory group Participants in the DCT received an $8,000/year stipend.
Jensen et al. (2013) USA	To increase the deaf community's access to ovarian cancer knowledge by evaluating the effectiveness of an educational video To test the videos capacity to enable deaf people to acquire and retain cancer knowledge and the subsequent behavioural changes that result. **Hypothesis 1** Deaf women would have significantly lower baseline General, Ovarian and Total Cancer knowledge	**Methodology** Quantitative evaluation **Methods** Development of educational video involved extensive review process: • Script written by medical expert • Review of script by ASL linguistics, consultants from Gallaudet University, third sector and a panel of community members to ensure cultural alignment and English vocabulary that could easily be	**Hypothesis 1** *General cancer knowledge subscale* there was a significant difference between deaf and hearing women's baseline (*p=0.2*) *Ovarian cancer knowledge subscale* there was a significant difference between deaf and hearing women's baseline scores (*p<0.001*) *Total cancer knowledge score* (sum of two subscales) there was a significant difference between deaf and hearing women's baseline score (*p<0.001*) **Hypothesis 2** Both groups significantly increased from pre- to post-test in all 3 surveys:	The notion of 'closing the gap of knowledge' appear ambitious considering the number of factors that contribute towards that gap Survey pilot tested with deaf & hearing women Community-campus partnership between Moores UCSD Cancer centred, Deaf community services of San Diego, Inc., Bovee Productions, Gallaudet University & the association of the deaf Videos had open captioning and detailed graphics Detailed description provided of how video was created and the challenges of translating a spoken language into a sign language highlighted. Deaf

	scores than hearing women **Hypothesis 2** Both deaf and hearing women’s knowledge would increase from pre- to post-intervention **Hypothesis 3** These knowledge increases would be equivalent across groups **Hypothesis 4** Deaf women’s post-intervention scores would equal or exceed hearing women’s baseline scores.	translated into existing ASL vocabulary • Forward and back translated • Signed by native ASL signers • Reviewed by deaf community members Participants Deaf n=55 Hearing n=52 Pre- and post-intervention (video) Cancer Knowledge survey Statistical analysis conducted using SPSS software	*General cancer knowledge*: Deaf women (*p=0.034*), hearing women (*p<0.001*) *Ovarian cancer knowledge*: Deaf women (*p<0.001*), hearing women (*p<0.001*) *Total cancer knowledge: D*eaf women (*p<0.001*), hearing women (*p<0.001*) **Hypothesis 3** Hearing women displayed a greater mean change in knowledge compared to deaf women in all 3 surveys: *General cancer knowledge:* Hearing women (*M* difference=0.8), deaf women (*M* difference=0.4) *Ovarian cancer knowledge*: Hearing women (*M* difference =5.8), deaf women (*M* difference=3.5) *Total cancer knowledge:* Hearing women (M difference = 6.6), deaf women (M difference 3.9) Hearing women continued to have significantly higher general,	community members, interpreters and medical professionals all part of this process. ASL signs for certain medical terminology missing. Such terms were given special consideration and carefully explained. All research processes (study information, consent) were offered is ASL For two of the questions on the Ovarian Cancer Knowledge subscale the deaf participants scores were statistically significantly worse after watching the educational video – raises questions about how to effectively produce educational healthcare videos for deaf people Major limitation – 38% of the deaf participants reported previous involvement in a cancer related education programme. Therefore, this sample may have above the average access to cancer information compared to the wider US deaf population.

			ovarian, and total cancer knowledge than deaf women post-intervention (*p<0.001*) **Hypothesis 4** Deaf women's post intervention score for 2 of the surveys was significantly greater than hearing women's pre-intervention score Ovarian cancer knowledge score (*p=0.004*) Ovarian cancer knowledge score (*p=0.021*) There was no significant difference between post intervention deaf and pre-intervention hearing women's General Cancer Knowledge score (*p=0.555*)	Over 50% of the deaf population had a higher education degree. This is not reflective of the wider deaf population and suggests that deaf women with lower levels of education may experience ever greater health disparities. Additionally, raises questions about how to make research accessible for deaf people.
Kyle et al. (2005) Scotland	To explore access to public services in BSL by deaf people	**Methodology** Mixed methods **Methods** Purposive sampling Individual semi-structured interviews n=80	There were no instances of direct access to public services in BSL Participants reported frustration in contact with hearing services (contributed to marginalization) Adjustments (written English, expectations to lip-read) caused difficulties when in contact with	Deaf researcher All data were collected and analysed in BSL

		Focus group discussions n=45 Thematic analysis	hearing people. These were not viewed as solutions Provision of a registered BSL/English interpreter was the main priority of deaf people The insufficient numbers of BSL/English interpreters was highlighted by participants Participant's priority was that more hearing service providers were able to sign	
McKee et al. (2011) USA	To investigate the risk perceptions of cardiovascular disease among deaf, ASL users	**Methodology** Qualitative **Methods** Purposive sampling Participants: deaf people n=22 4 Focus group discussions Open ended, semi-structured questions (video recorded) Thematic analysis	*Knowledge* of cardiovascular health varied widely. Numerous areas of inconsistency or misinformation *Barriers* to communication and language posed a major challenge to accessing health education & effective communication with healthcare professionals *Facilitators* of cardiovascular health such as exercise, access to information *Practices* to reduce salt intake, avoid stress and to exercise were reported	Bilingual researchers (5 deaf, 1 hearing) Participants all fluent in ASL Themes were identified under 5 domains. These domains were drawn from past focus group involving national study of underserved hearing groups Poor knowledge of family history noted

			Dissemination sources of health information were identified as media, ASL-accessible health videos and medical websites, ASL fluent medical professionals	
McKee et al. (2015) USA	To translate, adapt and develop an accessible health literacy instrument in ASL To assess the prevalence of inadequate health literacy among ASL users	**Methodology** Cross sectional design **Methods** Translated, adapted and validated Newest Vital Sign (NVS) which assesses health literacy based on a person's ability to answer 6 questions about a nutrition label Deaf Health survey – to collect demographic information Comparison of ASL-NVS with the Peabody individual achievement test-revised (PIAT –R) reading comprehension subtest Adapted Wagner's Heart Disease Fact	Deaf participants were more like to have lower scores in the NVS assessment ($p<0.01$) and PIAT-R ($p<0.01$) Deaf participants had fewer correct answers for the heart disease knowledge assessment ($p<0.001$) The correlation between cardiovascular health knowledge and health literacy scores was higher for the deaf people than for the hearing ($p<0.01$) Researchers concluded that ASL-NVA is a useful health literacy instrument for deaf ASL users	The NVS incorporates aspects of numeracy, document literacy, and reading literacy Production of the health literacy instrument: Translation work group – not noted who was part of this group Creation of a computer-based survey to supply questions ASL-NVS survey piloted – not noted who was part of this pilot Modifications made based on feedback received from pilot

		Questionnaire to assess basic cardiovascular knowledge Participants recruited from health fairs, community locations, through distribution of flyers and information through community organizations Participants: Deaf people (n=166) Hearing people (n=239) Statistical analysis conducted using SAS version 9.2		
Parise (1999) Canada	To explore what is it like for deaf persons to seek health care To explore what strategies and resources do deaf people use in order to meet their health needs	**Methodology** Exploratory – anthropological perspective **Methods** Purposive sampling	*Separate worlds* participants expressed struggling to navigate their way around the healthcare system. The healthcare system was a source of alienation and suffering. Healthcare professionals were seen as having biomedical views of deafness	Study conducted in collaboration with Montreal Metropolitan deaf community centre and the Canadian deafness research and training centre Hearing researcher who had basic LSQ and ASL

		Open-ended interviews & focus groups n=10 Thematic anaylsis	*Communication* the deaf persons voice is often not heard or responded to. Inadequate means of communicating (written/spoken word) are often used. Communication was viewed as the link between both worlds	Qualified interpreter facilitated communication Pilot study conducted to test effectiveness of the interview guide
Patel et al. (2011) UK	To determine the short-term impact of CVD health promotion and assessment on 10-year CHD risk scores estimates amongst deaf people Hypothesis: a significant reduction in CHD risk score following health promotion intervention.	**Methodology** Pilot study – assessing short term impact of cardiovascular health promotion **Methods** Recruitment via local deaf club Participants: deaf people n=42, 20 of which were followed up at 6 months due to being high-risk subjects Cardiovascular health assessment Risk of developing CHD was estimated using algorithm – Framingham Heart Study	Participants found to be at high CVD risk did not achieve reduction of risk following health promotion intervention. The study highlighted important considerations for the design and delivery of CVD health promotion amongst deaf, sign language users The design and delivery of CVD health promotion specific to deaf people requires further study	Health screen programme – tailored for local deaf community by: • Involving local community to develop & advertise the health screening events • Use of interpreters & multi-lingual staff who could assist participants to make informed choices Does this result in a “tailored” programme? Parts of the assessment were self-reported e.g., history of cardiovascular disease, diabetes Researchers problematized BSL:

		Significance of results communicated to participant by a physician specializing in cardiovascular medicine, including CVD risk reduction advice Statistical analysis SPSS		Sign language appears to be underdeveloped – no sign for cholesterol. Challenging to deliver health promotion due to limited vocabulary
Pinilla et al. (2019) Germany	To explore deaf peoples' perceptions of non-communicable disease and diabetes prevention, health information access and communication barriers	**Methodology** Qualitative with social constructivist approach **Methods** Recruited via local deaf community 15 individual semi-structured in-depth interviews in German Sign Language (GSL) Transcribed into English and analysed using thematic content analysis	Four themes & 10 subthemes: **General diabetes perception** Signs for diabetes differ according to underlying concept of diabetes Diabetes knowledge depends on personal experience and social environment Diabetes is perceived as a private and personal issue **Health information seeking behaviour** Learning from friends and or having the disease influences level of knowledge	One member of the research team was a CODA & fluent in GSL The linguistic structure of sign language was identified as requiring consideration when planning and designing educational activities for deaf people

			Main source of health information is the internet **Learning about prevention** Parents and peers are most important health promoters Acute change in a personal health condition is a trigger to change health behaviour **Persisting communication barriers** Sign language is the preferred way of communicating & deaf culture should be taken into consideration Healthcare professionals should use a sign language interpreter Healthcare professionals should use supportive communication strategies	
Reeves et al. (2003) UK	To evaluate deaf peoples' access to primary care and A&E services in the North West of England	**Methodology** Mixed methods evaluation **Methods** Five health boards	**Communication** 54% deaf people expressed a preference for communication support via a qualified interpreter 31% preferred a family member or friend	Interpreters present for all research processes involving deaf people

		Region wide survey of A&E units 6 main strands of research: Semi-structured interviews with deaf people n=98 Interviews with GP managers n=31 Interviews with 22 A&E managers Visual assessments of facilitates at 22 A&E units	17% had qualified interpreter with them at their last GP appointment (self-arranged) 16% had never considered using an interpreter or did not know how to book one **Modes of communication** Of the 57 people who saw their GP alone: 47% used speech as part of their communication 88% attempted to lip-read the GP 70% communicated in writing 81% of GPs responded in writing 1 GP had a BSL qualification and communicated via sign language **Quality of Communication** 52% felt that most or everything had been clear 32% thought some information was clear 16% understood very little	

			Where communication was effective, participants described GPs behaviour as being helpful for meeting their communication needs – speaking slowly, using basic English & enhancing with gesture Substantially smaller percentage of Deaf people felt able to ask all the questions they wanted (*$p<0.001$*) or were confident that the doctor had given them the correct care (*$p<0.001$*) Despite there being no direct questions related to medication, 26% of deaf participants expressed concern about a prescribed medication. E.g., being given medication without an explanation, consuming medication intended for external application Deaf participants significantly less likely to hold positive views about their GP. Less likely to agree that their GP: listens to them (*$p<0.001$*) treats them with courtesy and respect (*$p<0.001$*)	

			does not make them feel they are wasting their GPs time (*p<0.001*)	
Sacks et al. (2013) USA	To increase the deaf community's access to cancer knowledge by evaluating the effectiveness of an ASL educational video To compare deaf and hearing men's pre-test general cancer and testicular cancer knowledge before and after viewing the same educational video **Hypothesis 1** Deaf men would have significantly lower pre-test knowledge in general, testicular, and total cancer knowledge compared to hearing men **Hypothesis 2** Deaf and hearing men's general, testicular and total cancer knowledge	**Methodology** Quantitative evaluation **Methods** Development of the educational video was identical to Jensen et al. (2013) Recruitment – snowball sampling Participants: Deaf men n=85, hearing men n=90 Pre- and post-intervention knowledge survey on general and testicular cancer information Statistical analysis conducted using SPSS software	**Hypothesis 1** Deaf men had significantly less cancer knowledge than hearing participants (p<0.01) **Hypothesis 2** Both hearing and deaf men's knowledge significantly increased in all 3 tests *General cancer knowledge:* Deaf men (*p<0.001*), hearing men (*p<0.01*) *Testicular cancer knowledge:* Deaf men (*p<0.001*), hearing men (*p<0.001*) *Total cancer knowledge:* Deaf men (*p<0.001*), hearing men (*p<0.001*) **Hypothesis 3** *General cancer knowledge* Deaf men showed greater mean change in knowledge (*M* difference = 0.42) compared to hearing men (*M* difference =0.30)	Community-campus partnership between Moores UCSD Cancer centred, Deaf community services of San Diego, Inc., Bovee Productions, Gallaudet University & the association of the deaf 54 minute, graphically enriched video that features ASL signers Detailed description provided of how video was created and the challenges of translating a spoken language into a sign language highlighted. Deaf community members, interpreters and medical professionals all part of this process. ASL signs for certain medical terminology missing. Such terms were given special consideration and carefully explained.

	would increase from pre- to post-test **Hypothesis 3** These knowledge increases would be equivalent across both groups **Hypothesis 4** Deaf men's post-test scores would equal or exceed hearing men's pre-test scores		*Testicular cancer knowledge* Hearing men showed greater mean change in knowledge (*M* difference = 3.52) compared to deaf men (*M* difference = 3.04) *Total cancer knowledge* Hearing men showed greater overall mean change in knowledge (*M* difference = 3.82) compared to deaf men (*M* difference = 3.46) Hypothesis not supported **Hypothesis 4** Deaf men's post-test scores equaled or exceeded hearing men's pre-test scores	
SignHealth (2013) UK	To understand the demographic profile, health, lifestyle and access to public services of deaf people in the UK	**Methodology** Quantitative - descriptive **Methods** Purposive sample via third sector organization Online survey	51% participants communicated with a healthcare professional through an interpreter 86% of participants would prefer to communicate via an interpreter 46% participants communicated with healthcare professionals through written English. No participants preferred this method of communication	Online questions provided in English and BSL Questionnaire piloted with members of the deaf community to ensure that it was linguistically and culturally appropriate

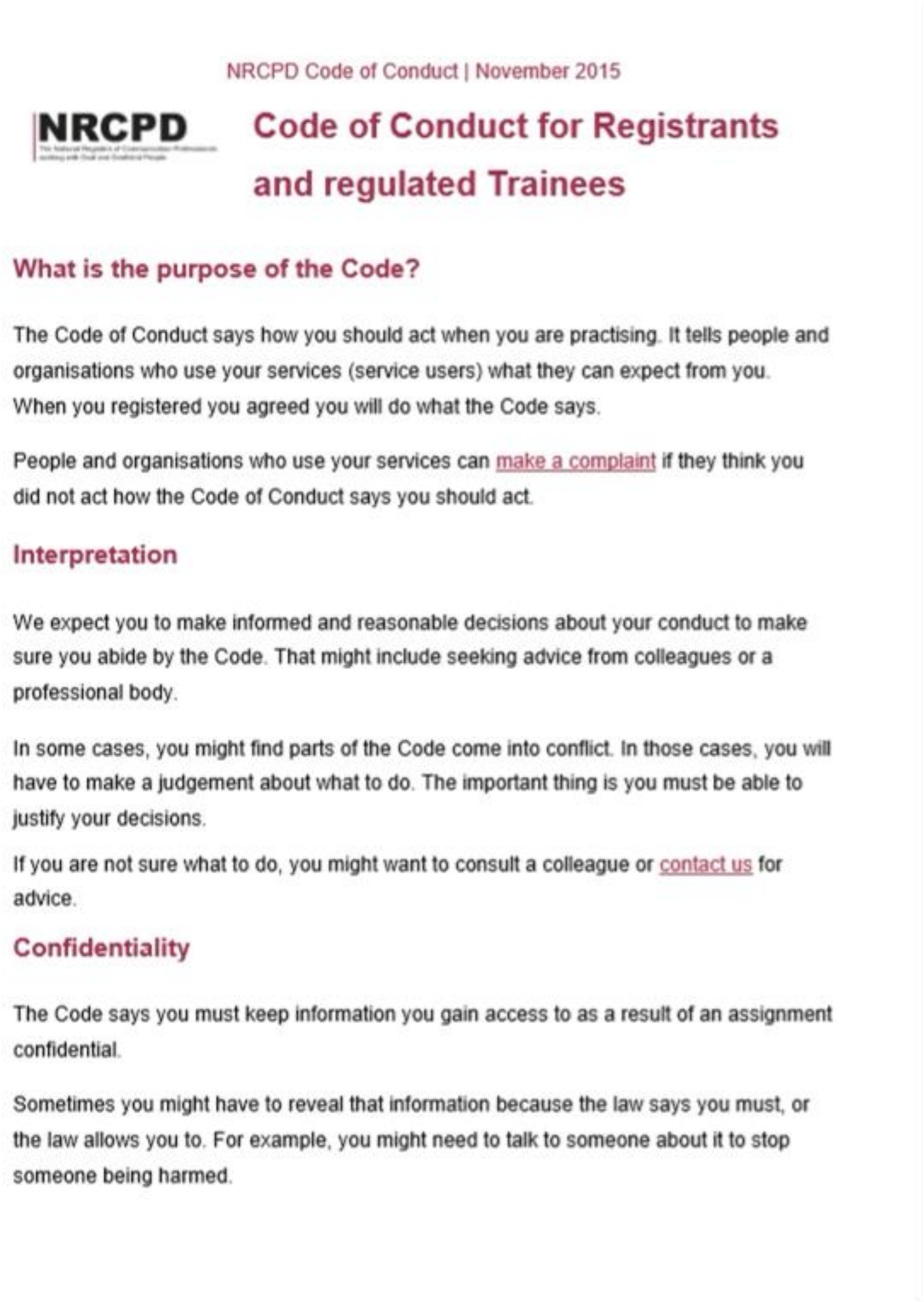
		Participants: deaf people n=533 Statistical analysis	23% participants communicated with healthcare professions through spoken English and lip-reading. No participants preferred to communicate in this way 17% use family and friends to communicate. 3% prefer to communicate this way	
Steinberg et al. (2006) USA	To better understand the health care experiences of deaf people who communicate in American Sign Language (ASL)	**Methodology** Mixed methods **Methods** Four semi-structured interviews Health questionnaire Participants recruited from local deaf communities in 3 cities and distribution of flyers Participants: Deaf people n=91 Thematic analysis	**Communication challenges** Poor quality of healthcare communication. Lipreading and written communication often employed despite being viewed as inadequate by deaf people. Syntax differences between languages and medical jargon contributed to challenges of communicating via written word. Difficulty using telephone-based communication resulted in participants going directly to the emergency department Communication improved when facilitated by a qualified interpreter who had medical experience. Family member often used as ad hoc interpreters which leads to deaf person feeling excluded	Qualified interpreters ultilised Researchers acknowledged the limitations of anaylsing English translations Participants were more highly educated than the average deaf person

			Some participants had positive experiences of communicating with practitioners with sign language skills **Emotions elicited by healthcare experiences** Many participants expressed strong emotions about their healthcare experiences. Recurrent themes: stress, fear of miscommunication and the consequences of highlighting inadequate communication. Mistrust and frustration when in contact with the healthcare system – that they are cared for differently than hearing people & that interpreters are only for them rather than for both participants in the conversation **Suggestions for improvement** Deaf awareness training Deaf people educating healthcare practitioners to show them how much information they are missing Understanding the need for interpreters	

			Other positive experiences Healthcare professionals who took time to explain and used visual aids	
Witko et al. (2017)	Aim: To investigate deaf New Zealand Sign Language (NZSL) user's quality of access to health services Objectives: To identify accessibility issues from the perspectives of NZSL users in general To document the perspectives of healthcare professionals working with deaf people Use the findings to develop NZSL policy for the sub-region	**Methodology** Qualitative **Methods** *Deaf participants and family members*: Focus groups n=32 Individual semi-structured interviews n=9 Online survey n=15 *Healthcare professionals*: Focus groups n=57 Semi-structured interviews n=2 Online survey n=65 Thematic analysis	Key issues report: Sensory barriers to managing appointments and navigating the healthcare system Inconsistent interpreter provision Lack of informed consent for treatment via communication in NZSL Limited access to general health information in NZSL Reduced ability of deaf patients to understand and comply with treatment options Common methods of communication – ad hoc interpreters, written and spoken word Feeling disempowered by lack of interpreter provision Some nurses were described as 'deaf friendly' – taking time to write	Deaf steering group co-designed the research framework and methods, and validated findings Interviews facilitated in NZSL by hearing and deaf NZSL users

			things down, gesture and improvise strategies to communicate Feeling devalued by comments or behaviours that reflect the medical model	

Appendix 5: BSL/English interpreters code of conduct



NRCPD Code of Conduct | November 2015

NRCPD

Code of Conduct for Registrants and regulated Trainees

What is the purpose of the Code?

The Code of Conduct says how you should act when you are practising. It tells people and organisations who use your services (service users) what they can expect from you. When you registered you agreed you will do what the Code says.

People and organisations who use your services can make a complaint if they think you did not act how the Code of Conduct says you should act.

Interpretation

We expect you to make informed and reasonable decisions about your conduct to make sure you abide by the Code. That might include seeking advice from colleagues or a professional body.

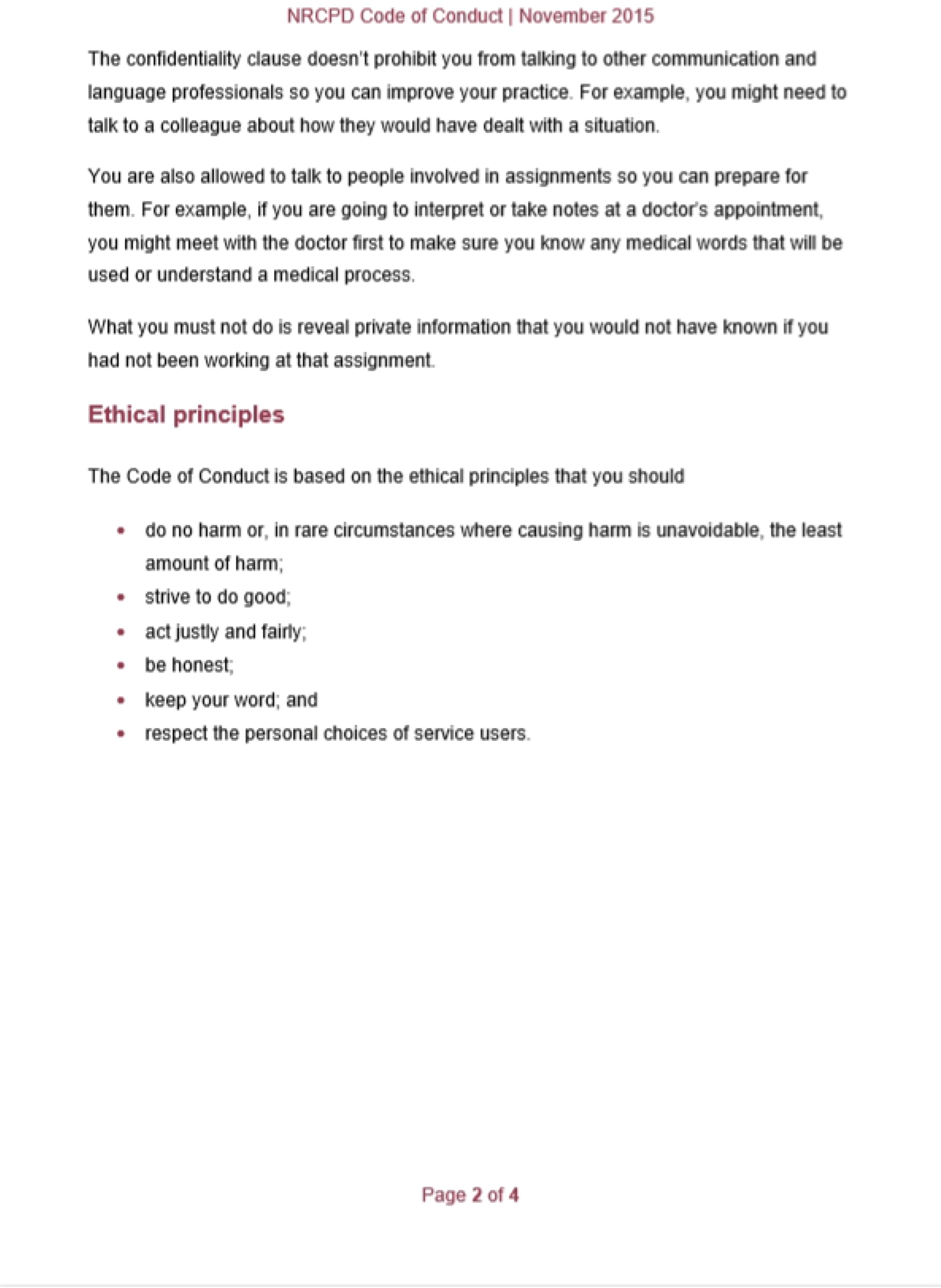
In some cases, you might find parts of the Code come into conflict. In those cases, you will have to make a judgement about what to do. The important thing is you must be able to justify your decisions.

If you are not sure what to do, you might want to consult a colleague or contact us for advice.

Confidentiality

The Code says you must keep information you gain access to as a result of an assignment confidential.

Sometimes you might have to reveal that information because the law says you must, or the law allows you to. For example, you might need to talk to someone about it to stop someone being harmed.



The confidentiality clause doesn't prohibit you from talking to other communication and language professionals so you can improve your practice. For example, you might need to talk to a colleague about how they would have dealt with a situation.

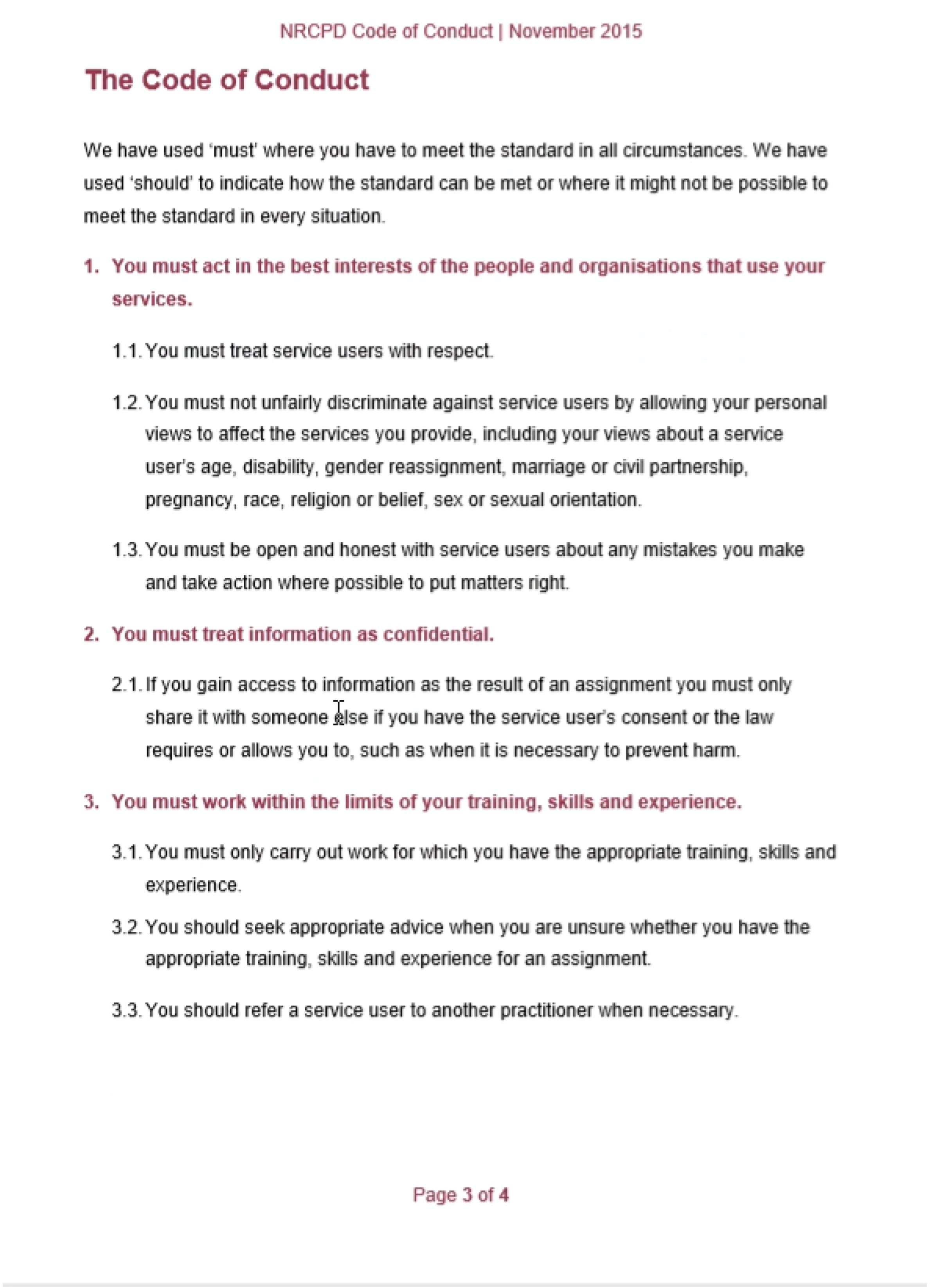
You are also allowed to talk to people involved in assignments so you can prepare for them. For example, if you are going to interpret or take notes at a doctor's appointment, you might meet with the doctor first to make sure you know any medical words that will be used or understand a medical process.

What you must not do is reveal private information that you would not have known if you had not been working at that assignment.

Ethical principles

The Code of Conduct is based on the ethical principles that you should

- do no harm or, in rare circumstances where causing harm is unavoidable, the least amount of harm;
- strive to do good;
- act justly and fairly;
- be honest;
- keep your word; and
- respect the personal choices of service users.



The Code of Conduct

We have used 'must' where you have to meet the standard in all circumstances. We have used 'should' to indicate how the standard can be met or where it might not be possible to meet the standard in every situation.

1. **You must act in the best interests of the people and organisations that use your services.**

    1.1. You must treat service users with respect.

    1.2. You must not unfairly discriminate against service users by allowing your personal views to affect the services you provide, including your views about a service user's age, disability, gender reassignment, marriage or civil partnership, pregnancy, race, religion or belief, sex or sexual orientation.

    1.3. You must be open and honest with service users about any mistakes you make and take action where possible to put matters right.

2. **You must treat information as confidential.**

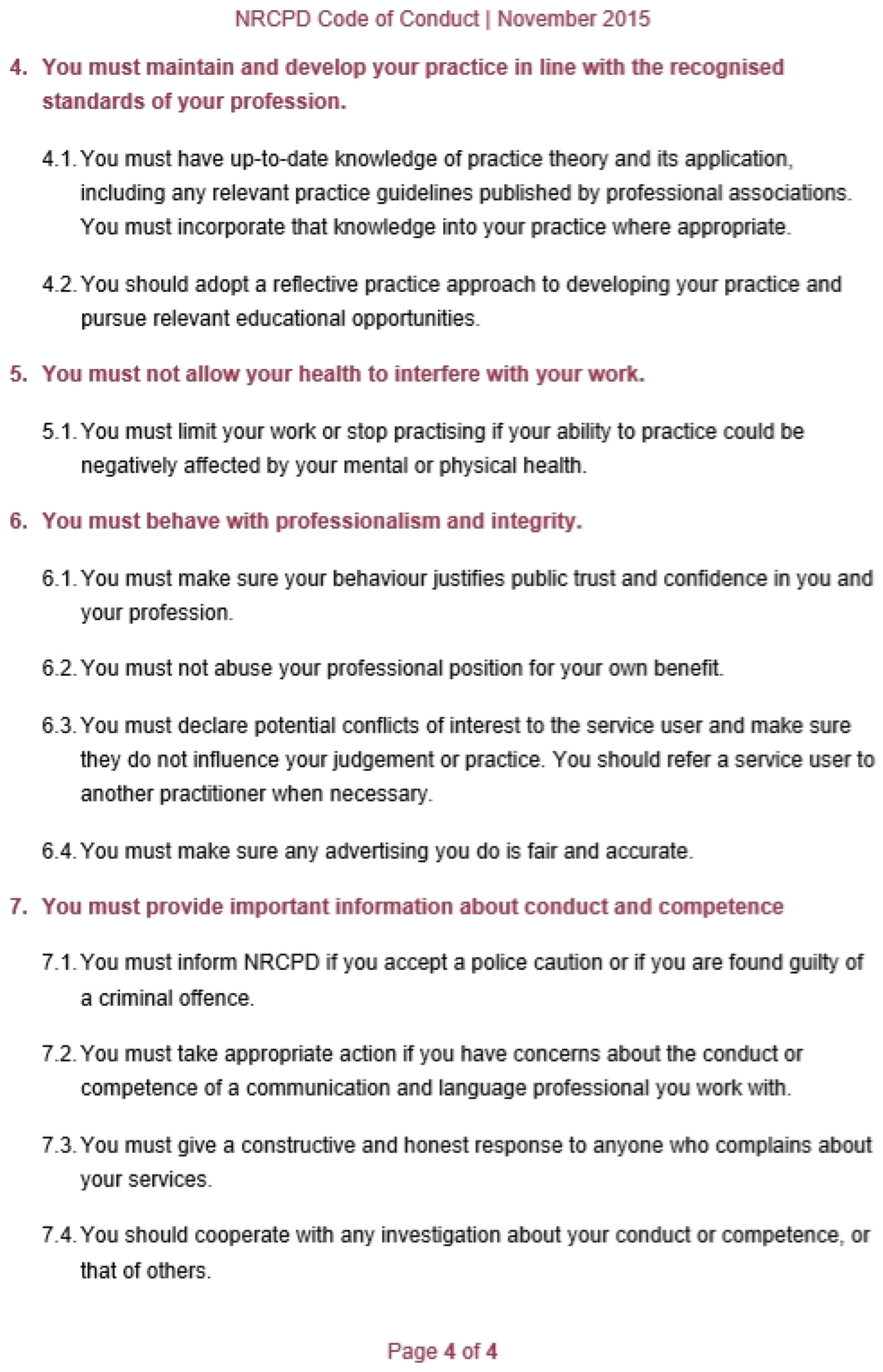
    2.1. If you gain access to information as the result of an assignment you must only share it with someone else if you have the service user's consent or the law requires or allows you to, such as when it is necessary to prevent harm.

3. **You must work within the limits of your training, skills and experience.**

    3.1. You must only carry out work for which you have the appropriate training, skills and experience.

    3.2. You should seek appropriate advice when you are unsure whether you have the appropriate training, skills and experience for an assignment.

    3.3. You should refer a service user to another practitioner when necessary.



4. **You must maintain and develop your practice in line with the recognised standards of your profession.**

    4.1. You must have up-to-date knowledge of practice theory and its application, including any relevant practice guidelines published by professional associations. You must incorporate that knowledge into your practice where appropriate.

    4.2. You should adopt a reflective practice approach to developing your practice and pursue relevant educational opportunities.

5. **You must not allow your health to interfere with your work.**

    5.1. You must limit your work or stop practising if your ability to practice could be negatively affected by your mental or physical health.

6. **You must behave with professionalism and integrity.**

    6.1. You must make sure your behaviour justifies public trust and confidence in you and your profession.

    6.2. You must not abuse your professional position for your own benefit.

    6.3. You must declare potential conflicts of interest to the service user and make sure they do not influence your judgement or practice. You should refer a service user to another practitioner when necessary.

    6.4. You must make sure any advertising you do is fair and accurate.

7. **You must provide important information about conduct and competence**

    7.1. You must inform NRCPD if you accept a police caution or if you are found guilty of a criminal offence.

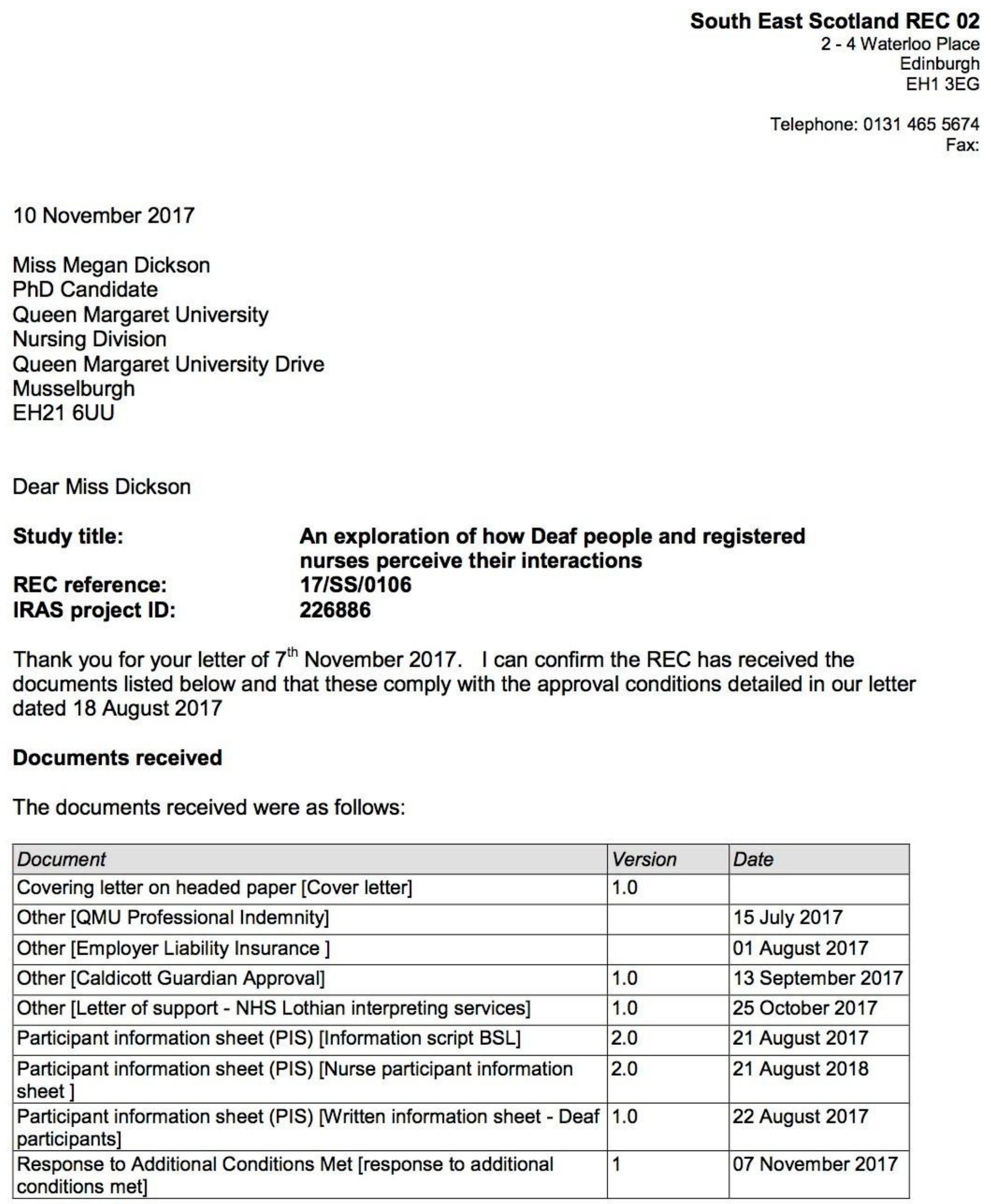
    7.2. You must take appropriate action if you have concerns about the conduct or competence of a communication and language professional you work with.

    7.3. You must give a constructive and honest response to anyone who complains about your services.

    7.4. You should cooperate with any investigation about your conduct or competence, or that of others.

Appendix 6: Ethics information

Ethics permissions



South East Scotland REC 02
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

Telephone: 0131 465 5674
Fax:

10 November 2017

Miss Megan Dickson
PhD Candidate
Queen Margaret University
Nursing Division
Queen Margaret University Drive
Musselburgh
EH21 6UU

Dear Miss Dickson

Study title:	**An exploration of how Deaf people and registered nurses perceive their interactions**
REC reference:	**17/SS/0106**
IRAS project ID:	**226886**

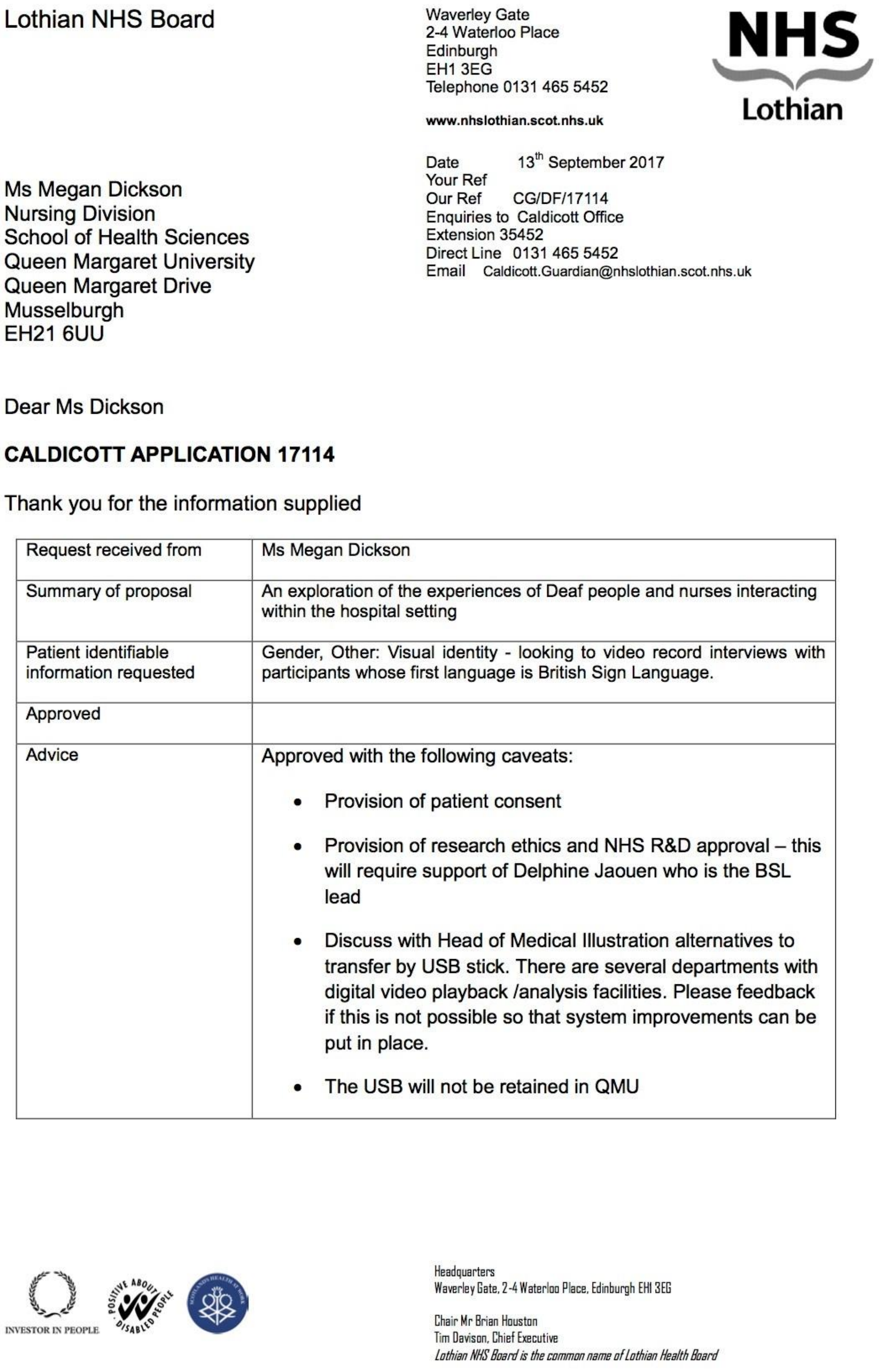
Thank you for your letter of 7th November 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 August 2017

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Cover letter]	1.0	
Other [QMU Professional Indemnity]		15 July 2017
Other [Employer Liability Insurance]		01 August 2017
Other [Caldicott Guardian Approval]	1.0	13 September 2017
Other [Letter of support - NHS Lothian interpreting services]	1.0	25 October 2017
Participant information sheet (PIS) [Information script BSL]	2.0	21 August 2017
Participant information sheet (PIS) [Nurse participant information sheet]	2.0	21 August 2018
Participant information sheet (PIS) [Written information sheet - Deaf participants]	1.0	22 August 2017
Response to Additional Conditions Met [response to additional conditions met]	1	07 November 2017

Caldicott Guadian Approval



Lothian NHS Board

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 465 5452

www.nhslothian.scot.nhs.uk

Date 13th September 2017
Your Ref
Our Ref CG/DF/17114
Enquiries to Caldicott Office
Extension 35452
Direct Line 0131 465 5452
Email Caldicott.Guardian@nhslothian.scot.nhs.uk

Ms Megan Dickson
Nursing Division
School of Health Sciences
Queen Margaret University
Queen Margaret Drive
Musselburgh
EH21 6UU

Dear Ms Dickson

CALDICOTT APPLICATION 17114

Thank you for the information supplied

Request received from	Ms Megan Dickson
Summary of proposal	An exploration of the experiences of Deaf people and nurses interacting within the hospital setting
Patient identifiable information requested	Gender, Other: Visual identity - looking to video record interviews with participants whose first language is British Sign Language.
Approved	
Advice	Approved with the following caveats: • Provision of patient consent • Provision of research ethics and NHS R&D approval – this will require support of Delphine Jaouen who is the BSL lead • Discuss with Head of Medical Illustration alternatives to transfer by USB stick. There are several departments with digital video playback /analysis facilities. Please feedback if this is not possible so that system improvements can be put in place. • The USB will not be retained in QMU

Yours sincerely

Professor Alison McCallum
Director of Public Health & Health Policy

Appendix 7: Study information

English information script

About researcher

Megan Dickson

PhD student at Queen Margaret University, Edinburgh

I am a nurse and am interested in learning more about the interaction between Deaf people and nurses. I am interested in the topic because as a student nurse I witnessed poor communication between a healthcare professional and a Deaf person. I recognised that this experience was frustrating for both the Deaf person and the healthcare professional. I hope that these interactions can improve in the future

Research

I am doing this study for my PhD project in partnership with Deaf Action. I would like to invite you to take part in this study. Please watch all the information and decide if you would like to share your story.

Aims of the study

To gather information about your experiences of receiving nursing care. To understand how you feel about the care you have received.

Reasons for the study

We know that those whose first language is BSL rarely meet healthcare professionals who share their language or who have appropriate Deaf awareness training. Therefore, communication exchanged between healthcare professionals and Deaf people is often compromised. As an outsider of the Deaf community (bilingual, non-Deaf) the nurse's view of the world is primarily hearing. Without knowledge and understanding of the interaction that take place between Deaf persons and nurses the quality of care can be compromised. We want to know about your experiences of interacting with nurses. We would also like to know if your interaction with nurses has had an effect on you as a person.

What the study will involve?

I will be carrying out interviews with Deaf people and nurses to explore their perceptions of interacting with one another. Nurses, within NHS Lothian, who have cared for a Deaf person, will be invited to take part. I would like to interview you with the help of an interpreter. This interview can take place either in your home or at a venue of your choice. The questions I ask during the interview will be open to allow you to speak about what is important to you. The interview will be video recorded. After the interview I will take some notes after I leave.

Using the information

Within this study we will take steps to achieve anonymity and confidentiality Making data 'anonymous' means removing information that makes it easy to identity someone. Examples of information that might help to identify people: age, gender, job, diagnosis. Every effort will be made to ensure that the data you provide cannot be traced back to you in the final report. You will be given a substitute name in all of the work. Confidentiality relates to the protection of the data collected. Information that could identify you will stored on a secure electronic file or be kept in a locked cabinet at Queen Margaret University. This information will be viewed by myself, my supervision team and the interpreter present at your interview [Pictures of research team inserted]. Confidential or identifying information about you will only be shared outside the research team if we believe there is a risk to you or to others. The information I collect will be used for this study only. The information I collect will be stored safely at Queen Margaret University until the study is complete (Estimated Dec 2019). The information that I collect will be used to write a PhD thesis. The information that I collect will be published when the study is over. The published information may include quotes from you. You are free to ask me to exclude certain information from publication.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you can leave the study at any point. If you leave the study you can request that any information gathered is not used for the study and it will be destroyed. Whatever your reason for leaving the study it will not affect you or your future care in any way. I will tell you if there are any changes to the study. You will not be asked to attend any additional meetings after the interview.

Benefits of taking part

By taking part in this research you will be helping to improve nursing care for other people who are Deaf. You will have a chance to tell your story about your care.

Risks

It is unlikely that there will be risks if you take part in this study. If you appear distressed or ask me to stop the interview I will do so. I will provide immediate support alongside the interpreter we are working with.

Thank you for taking the time to watch this video. If you are interested in participating in this study and would like more information please contact:

MDickson1@qmu.ac.uk

Support contacts

If you would like to discuss the study, withdrawn or have any concerns please contact:

Independent contact
[redacted]

Study supervisor
Dr Anne Williams
Lecturer in Nursing
Queen Margaret University

0131 474 0000
AWilliams@qmu.ac.uk

Researcher
Megan Dickson
PhD Candidate
Queen Margaret University
0131 474 0000
MDickson1@qmu.ac.uk

Advisor
[redacted]

Complaints

If you have concerns about the research and wish to make a complaint please contact:

NHS Lothian Patient Experience Team
Waverly Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

Telephone: 0131 536 3370

Thank you for taking the time to read this information. If you are interested in participating in this study and would like more information please contact:

MDickson1@qmu.ac.uk

Participant information sheet for deaf people

Queen Margaret University
EDINBURGH

Participant Information Sheet

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

About me

My name is Megan Dickson. I am a PhD student at Queen Margaret University, Edinburgh.

About the study

I am undertaking an explorative study that seeks to explore the perceptions that Deaf people and nurses hold of their interactions with one another.

Aims of the study

1. To explore the perceptions that people who are Deaf hold of their interactions with nurses
2. To explore the effect that interaction with nurses has had on the identities of Deaf people
3. To explore the perceptions that nurses hold of their interactions with people who are Deaf
4. To explore nurses values and beliefs about caring for people who are Deaf

Reasons for the study

For Deaf people, all contact and interaction with the NHS takes place in a hearing led context where speech is the dominant mode of interaction. Deaf people see this as something of an alien world where they are unable to express themselves and attain fluent, two way communication. Nurses often have little experience of interacting with a person who is Deaf. This results in them experiencing significant language and cultural barriers when caring for a person who is Deaf. We wish to better understand what can support a communicative relationship between a nurse and a person who is Deaf.

What will the study involve

If you agree to participate in the study you may be involved in:

Individual interview

I will be carrying out individual interviews. This will involve me asking you questions about your experiences of caring for a person who is Deaf. The conversation we have during the interview will be audio-recorded. Questions will be open to allow you to speak about what is important to you. I may take notes during the interview. The purpose of the interview is to explore your experience of interacting and providing care to a person who is Deaf.

Focus group

I will be carrying out a focus group with eight registered nurses. This will involve a group discussion. I will ask open end questions to support the focus group discussion. The purpose of the focus group is to further explore themes generated from the individual interviews.

Inclusion and exclusion criteria

Definition of terms

Prelingually deaf – refers to those who has lost their hearing before the acquisition of a language
Deaf – deaf with a capital 'D' refers to those for whom BSL is their first language and language of choice

Inclusion criteria for nurses

- Registered adult nurse
- Nurses who have cared for a prelingually Deaf, BSL user within the past six months

Exclusion criteria for nurses

- Not a registered adult nurse
- Nurses who have not cared for a prelingually Deaf, BSL user within the past six months

Using the information

- The information that I gather will include audio-recordings of the interviews and focus group as well as notes

- The information will be used to create themes related to the interaction between nurses and Deaf people

- The information that I collect will be used for this study only. It will not be reused for any other academic work

- Any information that could identify you will be kept in a secure electronic file or storage cabinet at Queen Margaret University

- All identifiable and confidential information will be stored in Queen Margaret University until the study is completed and academic award has been granted (estimated December 2019) in accordance with the Data Protection Act and QMU guideline

- Myself and my university supervision team will be the only people with access to the identifiable and confidential information

- Confidential or identifying information about you will only be shared outside the research team if we believe there is a risk to you or to others

- Information collected during this study will be published in academic journals and at conferences during and following the completion of this study

- You will be assigned a substitute name in all published material to ensure that you are not identifiable

- I will not include any confidential information that could put you at risk of identification in any published material

Risk to confidentiality

- Due to the small number of people who are Deaf within Scotland you may be identifiable as a group of nurses when information is published. In order to avoid individual identification I will ensure omission of NHS working site details.

- If you have concerns over any information shared with me you are free to request that it is not published

Do I have to take part?

- No. It is up to you to decide whether or not to take part

- If you decide not to take part in the study it will not affect you or your circumstances in any way

- If you do decide to take part in the study you are free to withdraw from this study at any point

- If you choose to withdraw from the study you can request that information gathered is not used by the researcher, and it will be destroyed

- If you choose to withdraw from the study you do not need to provide an explanation
- I will inform you of any changes to the study

Benefits of taking part

- It is hoped that your participation will benefit you by facilitating reflection on practice
- It is hoped that you participation will facilitate the exploration of potential approaches to caring for people who are Deaf for you and other nurses in the future
- It is possible that your participation will improve the care of people who are Deaf in the future

Risks of taking part

- It is unlikely that there is risk involved in this study process
- If any concerns are raised regarding the study I will stop the interview/discussion until they are resolved
- If any concerns are raised regarding harm to you or the other study participants appropriate support services will be informed

Support Contacts

If you would like to discuss the study, withdrawn or have any concerns please contact:

Independent contact
[redacted]

Study supervisor
Dr Anne Williams
Lecturer in Nursing
Queen Margaret University
0131 474 0000
AWilliams@qmu.ac.uk

Researcher
Megan Dickson
PhD Candidate
Queen Margaret University

0131 474 0000
MDickson1@qmu.ac.uk

Advisor
[redacted]

Complaints

If you have concerns about the research and wish to make a complaint please contact:

NHS Lothian Patient Experience Team
Waverly Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

Telephone: 0131 536 3370

Thank you for taking the time to read this information. If you are interested in participating in this study and would like more information please contact:

MDickson1@qmu.ac.uk

Recruitment poster for nurses

Have you experienced caring for a person who uses British Sign language to communicate?

Participate in a study about the experiences of nurses and Deaf people interacting.

What is the goal of the study?

This study aims to explore the perceptions that people who are Deaf hold of their interactions with nurses and the perceptions that nurses have of caring for people who are Deaf.

For Deaf people, all contact and interaction with the NHS takes place in a hearing led context where speech is the dominant mode of interaction. Deaf people see this as something of an alien world where they are unable to express themselves and attain fluent, two way communication.

Nurses often have little experience of interacting with a person who is Deaf. This results in them experiencing significant language and cultural barriers when caring for a person who is Deaf. We wish to better understand what can support a communicative relationship between a nurse and a person who is Deaf.

You are eligible to participate if you:

- Are a registered nurse
- Have cared for a person who is a Deaf, British Sign Language user in the past six months

What is involved in the study?

If you decide to participate in the study you may be involved in an individual interview or a focus group. Both the interview and focus group will focus on exploring your experiences of interacting and providing care for a person who is Deaf.

If you are interested in participating or would like to receive further information about the study please contact:

Megan Dickson
PhD Candidate at
Queen Margaret University
Email address: MDickson1@qmu.ac.uk
Telephone: 0131 474 0000

Queen Margaret University
EDINBURGH

Participant information sheet for nurses

Queen Margaret University
EDINBURGH

Participant Information Sheet

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

About me

My name is Megan Dickson. I am a PhD student at Queen Margaret University, Edinburgh.

About the study

I am undertaking an explorative study that seeks to explore the perceptions that Deaf people and nurses hold of their interactions with one another.

Aims of the study

5. To explore the perceptions that people who are Deaf hold of their interactions with nurses
6. To explore the effect that interaction with nurses has had on the identities of Deaf people
7. To explore the perceptions that nurses hold of their interactions with people who are Deaf
8. To explore nurses values and beliefs about caring for people who are Deaf

Reasons for the study

For Deaf people, all contact and interaction with the NHS takes place in a hearing led context where speech is the dominant mode of interaction. Deaf people see this as something of an alien world where they are unable to express themselves and attain fluent, two way communication. Nurses often have little experience of interacting with a person who is Deaf. This results in them experiencing significant language and cultural barriers when caring for a person who is Deaf. We wish to better understand what can support a communicative relationship between a nurse and a person who is Deaf.

What will the study involve

If you agree to participate in the study you may be involved in:

Individual interview

I will be carrying out individual interviews. This will involve me asking you questions about your experiences of caring for a person who is Deaf. The conversation we have during the interview will be audio-recorded. Questions will be open to allow you to speak about what is important to you. I may take notes during the interview. The purpose of the interview is to explore your experience of interacting and providing care to a person who is Deaf.

Focus group

I will be carrying out a focus group with eight registered nurses. This will involve a group discussion. I will ask open end questions to support the focus group discussion. The purpose of the focus group is to further explore themes generated from the individual interviews.

Inclusion and exclusion criteria

Definition of terms

Prelingually deaf – refers to those who has lost their hearing before the acquisition of a language
Deaf – deaf with a capital 'D' refers to those for whom BSL is their first language and language of choice

Inclusion criteria for nurses

- Registered adult nurse
- Nurses who have cared for a prelingually Deaf, BSL user within the past six months

Exclusion criteria for nurses

- Not a registered adult nurse
- Nurses who have not cared for a prelingually Deaf, BSL user within the past six months

Using the information

- The information that I gather will include audio-recordings of the interviews and focus group as well as notes
- The information will be used to create themes related to the interaction between nurses and Deaf people

- The information that I collect will be used for this study only. It will not be reused for any other academic work
- Any information that could identify you will be kept in a secure electronic file or storage cabinet at Queen Margaret University
- All identifiable and confidential information will be stored in Queen Margaret University until the study is completed and academic award has been granted (estimated December 2019) in accordance with the Data Protection Act and QMU guideline
- Myself and my university supervision team will be the only people with access to the identifiable and confidential information
- Confidential or identifying information about you will only be shared outside the research team if we believe there is a risk to you or to others
- Information collected during this study will be published in academic journals and at conferences during and following the completion of this study
- You will be assigned a substitute name in all published material to ensure that you are not identifiable
- I will not include any confidential information that could put you at risk of identification in any published material

Risk to confidentiality

- Due to the small number of people who are Deaf within Scotland you may be identifiable as a group of nurses when information is published. In order to avoid individual identification I will ensure omission of NHS working site details.
- If you have concerns over any information shared with me you are free to request that it is not published

Do I have to take part?

- No. It is up to you to decide whether or not to take part
- If you decide not to take part in the study it will not affect you or your circumstances in any way
- If you do decide to take part in the study you are free to withdraw from this study at any point
- If you choose to withdraw from the study you can request that information gathered is not used by the researcher, and it will be destroyed
- If you choose to withdraw from the study you do not need to provide an explanation

- I will inform you of any changes to the study

Benefits of taking part

- It is hoped that your participation will benefit you by facilitating reflection on practice
- It is hoped that you participation will facilitate the exploration of potential approaches to caring for people who are Deaf for you and other nurses in the future
- It is possible that your participation will improve the care of people who are Deaf in the future

Risks of taking part

- It is unlikely that there is risk involved in this study process
- If any concerns are raised regarding the study I will stop the interview/discussion until they are resolved
- If any concerns are raised regarding harm to you or the other study participants appropriate support services will be informed

Support Contacts

If you would like to discuss the study, withdrawn or have any concerns please contact:

Independent contact
[redacted]

Study supervisor
Dr Anne Williams
Lecturer in Nursing
Queen Margaret University
0131 474 0000
AWilliams@qmu.ac.uk

Researcher
Megan Dickson
PhD Candidate
Queen Margaret University
0131 474 0000
MDickson1@qmu.ac.uk

Advisor
[redacted]

Complaints

If you have concerns about the research and wish to make a complaint please contact:

NHS Lothian Patient Experience Team
Waverly Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

Telephone: 0131 536 3370

Thank you for taking the time to read this information. If you are interested in participating in this study and would like more information please contact:

MDickson1@qmu.ac.uk

Queen Margaret University
EDINBURGH

Information Sheet for Interpreters

Thank you for agreeing to take part and interpret within this research study. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please contact me if there is anything that is not clear or if you would like more information.

About me

My name is Megan Dickson. I am a PhD student at Queen Margaret University, Edinburgh.

About the study

I am undertaking an explorative study that seeks to explore the perceptions that Deaf people and nurses hold of their interactions with one another.

Aims of the study

1. To explore the perceptions that people who are Deaf hold of their interactions with nurses
2. To explore the effect that interaction with nurses has had on the identities of Deaf people
3. To explore the perceptions that nurses hold of their interactions with people who are Deaf
4. To explore nurses values and beliefs about caring for people who are Deaf

Reasons for the study

For Deaf people, all contact and interaction with the NHS takes place in a hearing led context where speech is the dominant mode of interaction. Deaf people see this as something of an alien world where they are unable to express themselves and attain fluent, two way communication. Nurses often have little experience of interacting with a person who is Deaf. This results in them experiencing significant language and cultural barriers when caring for a person who is Deaf. We wish to better understand what can support a person-centred relationship between a nurse and a person who is Deaf.

What will the study involve?

Interviews with participants who are Deaf

I will be carrying out individual interviews with participants who are Deaf. This will involve me asking participant's questions about their experiences. The interview will be video-recorded. Questions asked will be open-ended to allow participants to speak about what is important to them. I will take notes after the interview. The purpose of the interview is to explore the participant's experience of interacting with and being cared for by nurses.

Interviews and a focus group

I will also be carrying out individual interviews and a focus group with registered nurses. The purpose of these activities is to explore nurse's perceptions of caring for a Deaf person.

Your participation

As I am not fluent in BSL I will need the help of a BSL/English interpreter to provide information about study to potential participants, carry out the interviews and clarify meaning during the analysis stage. You may be involved in one or more of these stages within this study. Here is more information about each stage:

Consent conversations

To help potential participants make an informed decision about whether or not to take part a consent conversation will be arranged to provide information regarding the study. During the consent conversation the potential participant will be provided with information about the setup of the interview, recording of data, use of data and confidentiality. Information will be provided in plain English and translated in to BSL. Being sensitive to preexisting knowledge and the possibility of information gaps participants will be encouraged to ask questions whenever they are uncertain about the study process. Potential participants will be given one week to decide whether or not they would like to participate in the study. Respect for autonomy will be practiced by allowing potential participants to make a free, independent and informed choice.

Interviews

Interviews with Deaf participants will take place in their home or in a private venue of their choice. Interviews will be video-recorded for analysis. Prior to the interview we will have a short discussion regarding the interview topic guide and what questions I wish to ask. To allow for a flexible exploration of the topic the topic guide will not be tightly prescribed. Following the interview I may wish to have a short discussion with you to clarify meaning from the interview.

Analysis

During the analysis stage I will transcribe the recorded interviews into written English. However, the videos will not be discarded once transcription has taken place. You may be asked to watch clips of the recorded data with me to clarify meaning and support the analysis of data.

Your contribution to knowledge

Within this study I hope to uncover Deaf peoples' realities and perceptions of their experience of being care for. The research team are attempting to carry out dialogue between different ways of being (Deaf/Hearing) and to appreciate the complexity of the relationship between the two. As an outsider of the Deaf community (bilingual, non-Deaf) my view of the world is primarily hearing. I am working in collaboration with Deaf Action to make decisions that make it possible to link, but not reduce one perspective to another. Your meaningful contribution and cultural familiarity is valued by the research team.

Support Contacts

If you would like to discuss the study, withdrawn or have any concerns please contact:

Independent contact
[redacted]

Study supervisor
Dr Anne Williams
Lecturer in Nursing
Queen Margaret University
0131 474 0000
AWilliams@qmu.ac.uk

Researcher
Megan Dickson
PhD Candidate
Queen Margaret University
0131 474 0000
MDickson1@qmu.ac.uk

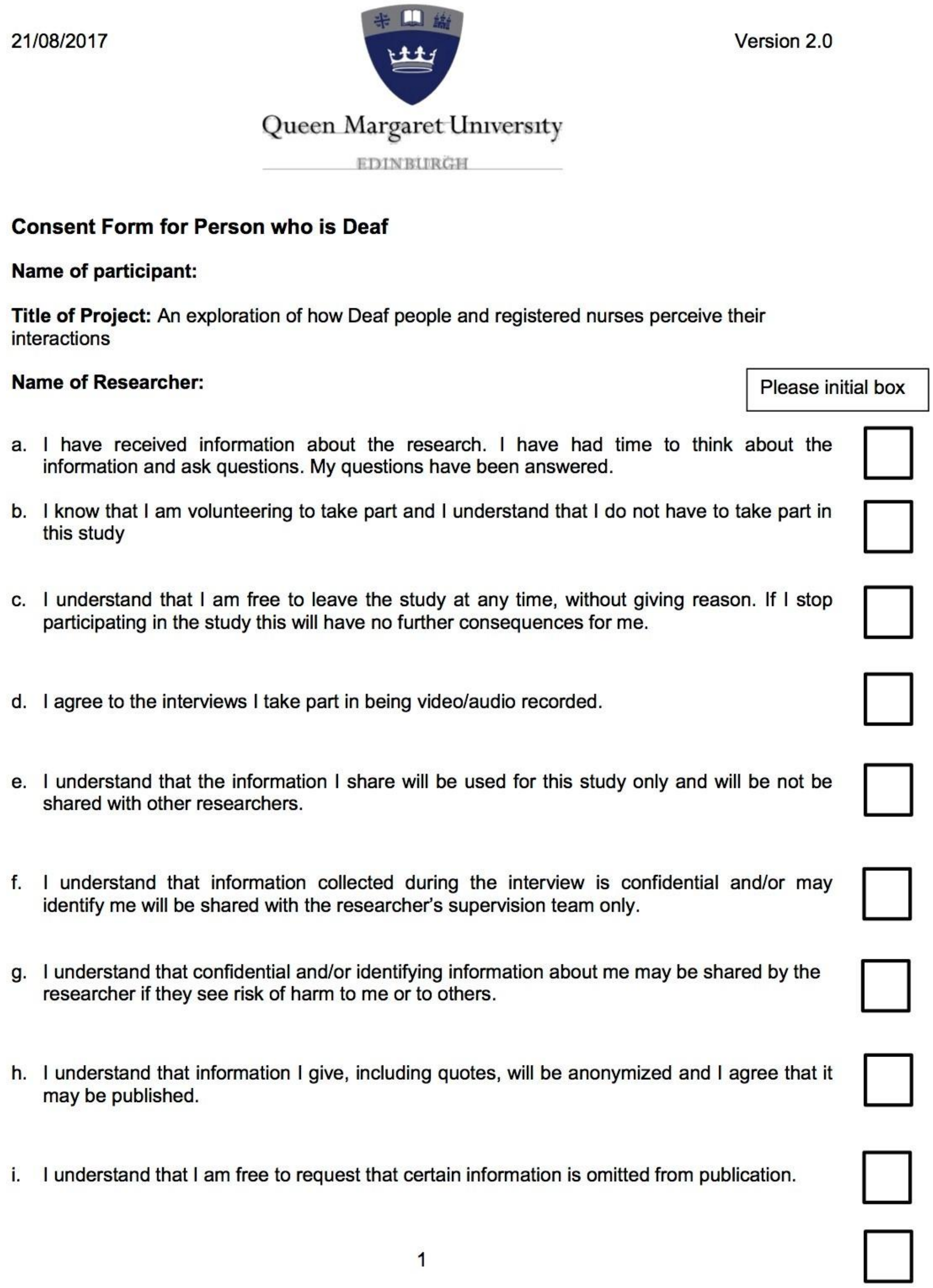
Advisor
[redacted]

[redacted]

Thank you for taking the time to read this information.

Appendix 8: Consent forms

Consent form for deaf people



21/08/2017 Version 2.0

Queen Margaret University
EDINBURGH

Consent Form for Person who is Deaf

Name of participant:

Title of Project: An exploration of how Deaf people and registered nurses perceive their interactions

Name of Researcher:

Please initial box

a. I have received information about the research. I have had time to think about the information and ask questions. My questions have been answered. ☐

b. I know that I am volunteering to take part and I understand that I do not have to take part in this study ☐

c. I understand that I am free to leave the study at any time, without giving reason. If I stop participating in the study this will have no further consequences for me. ☐

d. I agree to the interviews I take part in being video/audio recorded. ☐

e. I understand that the information I share will be used for this study only and will be not be shared with other researchers. ☐

f. I understand that information collected during the interview is confidential and/or may identify me will be shared with the researcher's supervision team only. ☐

g. I understand that confidential and/or identifying information about me may be shared by the researcher if they see risk of harm to me or to others. ☐

h. I understand that information I give, including quotes, will be anonymized and I agree that it may be published. ☐

i. I understand that I am free to request that certain information is omitted from publication. ☐

1 ☐

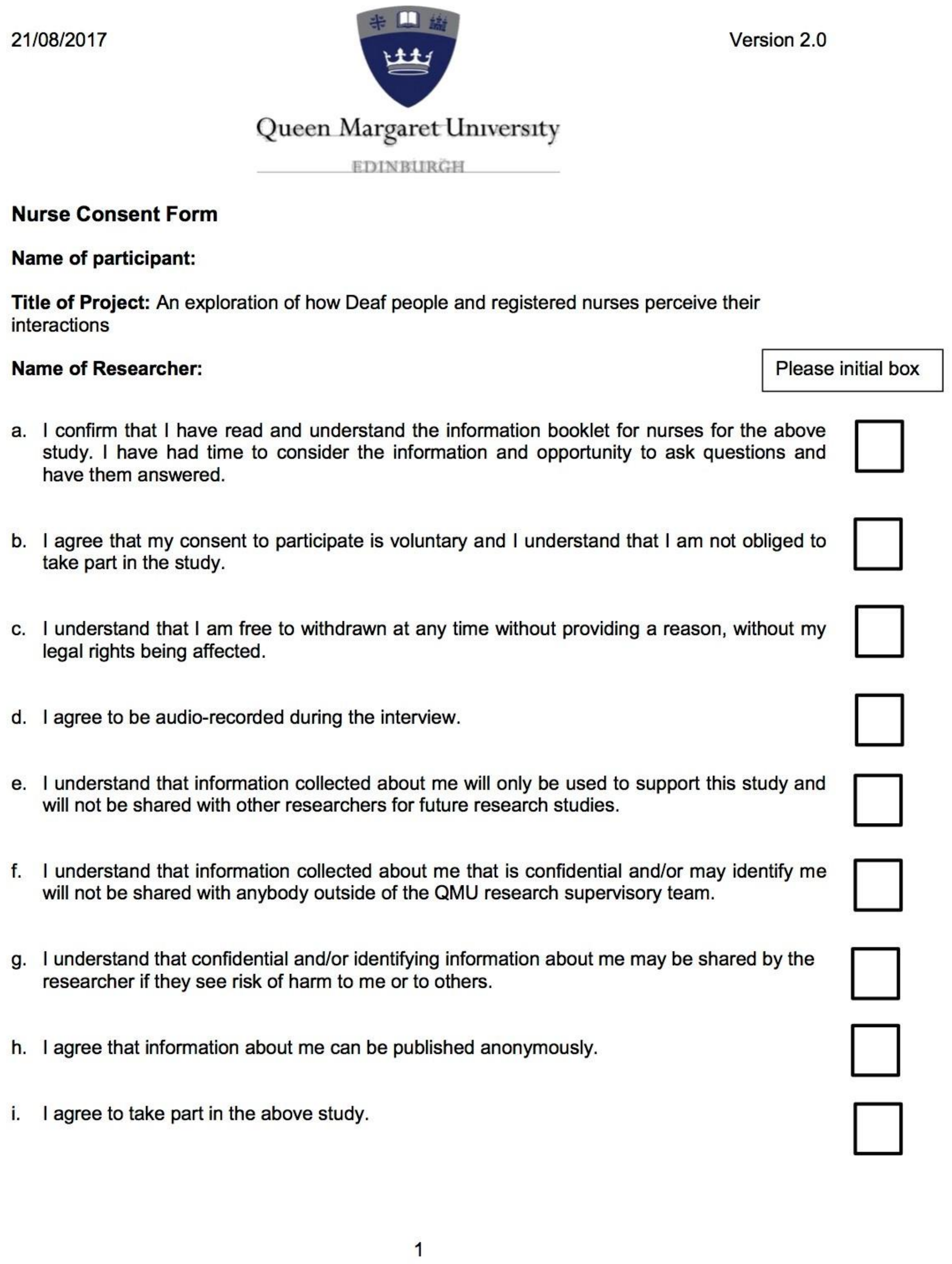
j. I voluntarily agree to take part in this study.

Date:	Name:	Signature:

I hereby confirm that I have explained the above research to Mr/Mrs/Ms………

Date:	Name:	Signature:

Consent form for nurses



21/08/2017 Version 2.0

Queen Margaret University
EDINBURGH

Nurse Consent Form

Name of participant:

Title of Project: An exploration of how Deaf people and registered nurses perceive their interactions

Name of Researcher:

Please initial box

a. I confirm that I have read and understand the information booklet for nurses for the above study. I have had time to consider the information and opportunity to ask questions and have them answered. ☐

b. I agree that my consent to participate is voluntary and I understand that I am not obliged to take part in the study. ☐

c. I understand that I am free to withdrawn at any time without providing a reason, without my legal rights being affected. ☐

d. I agree to be audio-recorded during the interview. ☐

e. I understand that information collected about me will only be used to support this study and will not be shared with other researchers for future research studies. ☐

f. I understand that information collected about me that is confidential and/or may identify me will not be shared with anybody outside of the QMU research supervisory team. ☐

g. I understand that confidential and/or identifying information about me may be shared by the researcher if they see risk of harm to me or to others. ☐

h. I agree that information about me can be published anonymously. ☐

i. I agree to take part in the above study. ☐

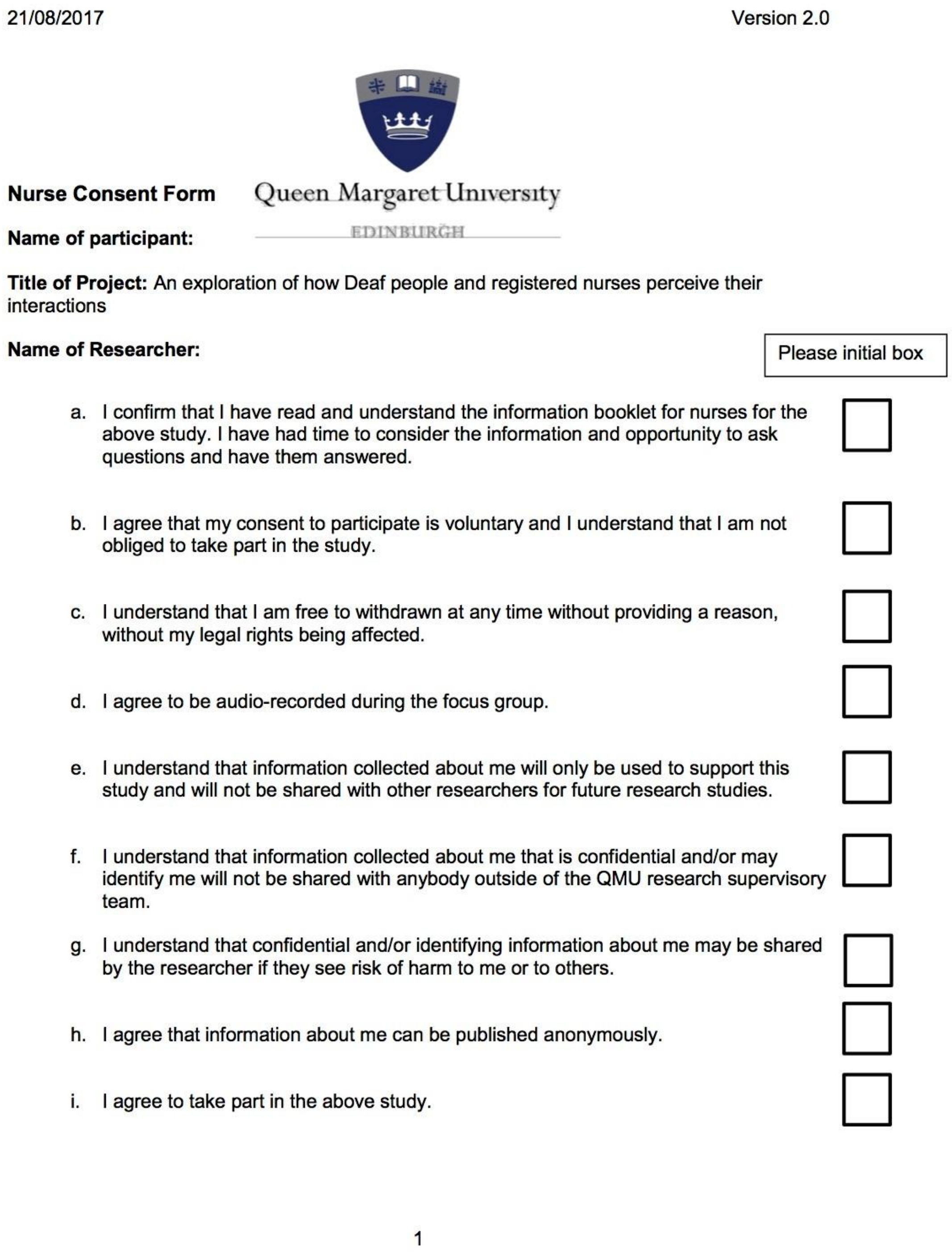
1

Date: Name: Signature:

I hereby confirm that I have explained the above research to Mr/Mrs/Ms……..

Date: Name: Signature:

Consent form for interpreters



21/08/2017 Version 2.0

Nurse Consent Form Queen Margaret University EDINBURGH

Name of participant:

Title of Project: An exploration of how Deaf people and registered nurses perceive their interactions

Name of Researcher:

Please initial box

a. I confirm that I have read and understand the information booklet for nurses for the above study. I have had time to consider the information and opportunity to ask questions and have them answered. ☐

b. I agree that my consent to participate is voluntary and I understand that I am not obliged to take part in the study. ☐

c. I understand that I am free to withdrawn at any time without providing a reason, without my legal rights being affected. ☐

d. I agree to be audio-recorded during the focus group. ☐

e. I understand that information collected about me will only be used to support this study and will not be shared with other researchers for future research studies. ☐

f. I understand that information collected about me that is confidential and/or may identify me will not be shared with anybody outside of the QMU research supervisory team. ☐

g. I understand that confidential and/or identifying information about me may be shared by the researcher if they see risk of harm to me or to others. ☐

h. I agree that information about me can be published anonymously. ☐

i. I agree to take part in the above study. ☐

Date: Name: Signature:

I hereby confirm that I have explained the above research to Mr/Mrs/Ms……..

Date: Name: Signature:

Appendix 8: Interview topic guide

Topic guide for interviews with nurses

1. Please tell me about your most recent experience of caring for a Deaf person

2. What did you understand about caring for a Deaf person prior to this experience?

3. How did you and the Deaf person express yourselves within the interaction?

4. What sense of connection or relationship did you feel you had with the Deaf person?

5. How did the interaction(s) with the Deaf person make you feel?

6. What did you value when you were providing care to the Deaf person?

7. Did the interaction with the Deaf person have any impact on you as a person?

8. What would be important to you in the future when providing nursing care for a Deaf person?

Topic guide for interviews with deaf people

1. Please tell me about the most recent nursing care you have received

2. How did you and the nursing staff express yourselves within the interaction?

3. What sense of connection or relationship did you feel you had with the nurse(s)?

4. How did the interactions with nursing staff make you feel/impact you?

5. What did you value about the nursing care you received?

6. In what way were the nursing staff available/present?

7. Did you feel you were being seen and understood by the nursing staff?

8. In what way were you able to make sense of your healthcare experience?

9. Did the interaction with the nurse/nursing staff have any impact on you as a person?

10. How did the space in which you were receiving care impact on your interactions?

11. What would be important to you in the future when receiving nursing care?

Focus group guide

Introductions & warm up activity

Introduce yourself & tell us what the best thing about 2018 was

Explain study rationale and aims:

- Study aims to explore how nurses and deaf, BSL users perceive their interactions
- Why – for deaf people all contact with NHS takes places in a hearing led context – spoken English is used within our interactions. This can be a hard place for BSL users to navigate if they are unable to express themselves in their first language. Additionally, most nurses have little experience of interacting with a person who uses BSL to communicate. They can experience significant barriers when caring for a deaf person.
- I want to better understand what can support a communicative relationship between nurses and a person who is deaf
- It is hoped that this study will improve the care of people who are deaf in the future, therefore benefiting both nursing staff and members of the deaf community
- How – interviewing deaf people, BSL users and nurses who have cared for a deaf person
- Challenges – engaging with the deaf community (potential reasons - consultation fatigue, trust, limited BSL skills) & recruiting nurses (potential reasons – misunderstanding re study, recruitment process – small population, large workforce)
- Benefits of capturing interpreter's experiences - deaf individuals have a vast array of experiences within healthcare that interpreters have been part of and witness of. Interest in different stories (nurse, deaf person and interpreter) within the interaction. Interpreter's stories could support and strengthen the study.

Creative activity

Often when we attempt to reflect within a focus group setting it can be helpful to do something creative first to enable us to tap into the experiences we want to explore. I have brought along cards. I want to invite you to think about your experience of interpreting and pick out a card or number of cards that represent what being an interpreter means to you (why you do it, what your motivations and values are). Ones that stick out for you. You can use these cards as a starting point to share your experiences.

Invitation to share cards

Enabling questions:

Can you tell me a bit more about that?

What does….. mean for you?

How would you know if….?

What does that really mean?

What could you do….?

What sense are you making of….?

What do you think would happen if…?

It sounds as though you are feeling… can you tell me more about it?

Themes

I will take note of themes that I believe are emerging in the discussion. At the end of the focus group, I will ask the participants to take a look at the themes and to add to them if they believe I have missed anything.

Final activity

Evaluation – how you found this activity & what learning you will take away from

Appendix 10: Authentic movement script

Niamh: I think if I describe the kinds of movements that I saw first of all and then what I connected them with. Would that be helpful?

Megan: Yep, please.

Niamh: so this is why I drew it, because these are the things that I saw. So I saw a kind of, like a spiralling that didn't seem particularly controlled and sometimes ended up in what looked messy, which is that (photograph). And a kind of drawing into yourself and- I don't think I would describe it as withdrawn but an aloneness, but a choice in that aloneness. But a very intentional aloneness that brought you to a line and seemed to keep happening at the same point of a line that you never crossed.

Niamh: I saw some really out of control retreat back but some playfulness in the retreat that looked like a spiralling in a really beautiful way. And that movement and intentionality seemed to draw you back to the line, which you looked quite excited about and energetic towards.

Niamh: and then there was a space, an actual physical space that you moved into once or twice that seemed very closed off, which is that circle (photograph) and quite restrictive in that you didn't seem to be able to move in it at all.

Niamh: And then I saw a lot of movement up and down, playful movement across all of the line that you were creating and boundaries that you were crossing. And then a beginning to kind of break the boundary (photograph) and an incredible peacefulness and stillness at the end. Yes!

Megan: Wow, authentic movement works!

Niamh: yes it does (sniff)

Megan: I definitely can see all of those things in my research data for sure.

Niamh: Do you want to talk through particular parts of it? because there are- it might remind me of things that I saw but haven’t said already.

Megan: Yeah… it’s funny because I saw.. the one thing that I was thinking about coming here was how I capture all of your data when you have to embody so many different parts of it. So you’re embodying a lot of different narratives and stories. So actually doing this makes you realise that a lot of people are living the same narratives just in different ways. So I guess form my data, when nurses or deaf people are talking about coming into contact with one another there seems to be that kind of spiralling out of control of “how does this work?”, “we’ve never done this before”. Maybe not so much for the deaf people but for the hearing people but I think the deaf people still feel that sense of “oh, here’s another hearing person who isn’t sure how to be with me, how we’re meant to be together, or who we’re meant to be together”. And there’s that kind of spiralling and chaos. I think that in itself creates a boundary-

Niamh: that’s where I saw- In your expression I think I saw retreat and disconnection.

Megan: Mhmm.. and it definitely makes both people within that interaction retreat and actually a lot of the time the deaf person retreats back into themselves because they just think “ugh, are we here again? Is this really my responsibility to make this situation work again?” and it can be quite heavy for them. Because it’s not just to do with them. It’s to do with the community that they care about. And that’s quite heavy- the weight on their shoulders.

Megan: but then, in between those- I don’t know. Even in that situation there are moments of connection and engagement and beauty and that idea of playfulness.. when both parties realise, not necessarily in terms of deaf hearing, they start to connect as people. They start to realise “oh, this is achieveable!”, “this isn’t as…

DOG CAME TO PLAY

Niamh: Hey Pal!

Megan: - “this isn’t as hard as… this isn’t as difficult as it could be”… It’s not a dead end…

Niamh: It’s not impossible?

Megan: Yeah, it’s not impossible. And you see those little glimpses of connection even when people are talking about it and they very much embody those moments when they’re talking about it as well.

Megan: What was this (photograph)? This was a space that I kept moving to?

Niamh: Yeah and it wasn’t necessarily a helpful space. It was like a movement between the line and that space that nothing really happened in, that felt quite heavy and laboured.

Megan: Yeah, I think there are a lot of times when I’ve been talking to people having those conversations when they haven’t been able to voice to me what it is they do when they’re doing routine tasks and stuff, which seem like key moments when you could really engage with someone. And I don’t- they often don’t quite express… nothing really happened there if you know what I mean? And actually when I’ve interviewed deaf people they’ve said that moments that I think are really important as nurses, for example when you give your tablet in the morning, it’s a key moment to find out how a patient I feeling or what's going on for them. And that that is when a lot of people within my data feel like they haven't been engaged with. They just feel like they're just another patient but they've watched nurses engage with everyone else in that moment and it's kind of like a lost opportunity or to make someone feel like the day is going to be okay…

Niamh: and so no movement happens

Megan: Yep

Niamh: I found that very sad and I found myself wanting to cry and I'm kind of feeling like I want to cry thinking about that and I found it very, very and watching it, and watching you move between those spaces.

Megan: And then there have been moments within the data when there has been such beauty as well and such special moments when they've been having realisation when they've been reflecting on their experiences as well. But it- I don't know. There is a lot of sadness in it as well and a lot of frustration. From everyone, myself included.

Niamh: I was going to ask you where you fit in that as well, because it seemed to me that while you embodied the data, a lot of what I was feeling was coming from you as well. Can we walk over here? So this is the part of it that it thought- well you can see they're praxis spirals. But I thought it looked playful and very intentional in the way that you were moving.

Megan: I think I could feel this (praxis spiral) in very, very specific interviews that I've done where people have had a previous interest in the deaf community and BSL and that little bit of knowledge prior to engaging with someone that is deaf and even a little, tiny glimpse into the deaf community has allowed them to be very curious about how to engage with someone who has a very different culture from them. And realising that it's not just that they're deaf. Realising that that means a lot more than they just can't hear. Realising that they view the world differently and actually from just having that little bit of insight it makes them question everything that they do in their practice. And it means that they nurse that person in a very different way because it means that they need to ask questions and they need to be curious to feel like they are doing a good job. And actually that's turned into something really beautiful for *them* as well. They've voiced that, that it was special and they felt proud after it. and as well that's what it feels like nursing is about so it's really rewarding for people when they do that. But actually they just need that little bit of information to get that spiral (praxis) started.

Niamh: what's the feeling that you get when you read those parts of the work?

Megan: excitement, joy, I guess just a happiness that the deaf person will go away from that experience feeling a lot lighter coming in. hopefully. I guess lightness is probably a good word because a lot of the other interviews have felt really heavy and a lot of the other conversations were… you kind of wonder how both people have gone away feeling about it and nurses have quite often voiced that they just felt like they failed or they have let someone down but also the deaf people have felt failed and let down and almost end up feeling a bit world weary because they have to put a lot effort in to get people to engage with them. And when you're ill you don't really want to have put that effort in.

Niamh: and aren't necessarily able to put the effort in.

Megan: yeah and actually they end up feeling extremely vulnerable. But what's interesting as well is that this happens- this praxis spiral isn't just about the nurses I don’t think. A lot of the deaf people that I interviewed are advocates for their whole community and they seem to be able to advocate for other people. Because a lot of them, their job is to be an advocate. And they seem to be able to flourish and advocate for others within their jobs but when it comes to really personal experiences where they are trying to be an advocate for their family or for themselves- it’s a different experience and it’s personal and… I don’t know… you don’t have the same opportunity to stand up for what you need and for your rights- for your language rights as well. Those kinds of things.

Niamh: It’s an interesting and very stark contrast. There didn’t seem to be a middle ground in your movement and there doesn’t seem to be a middle ground in how you’re describing it either. I actually did see something that I didn’t say at the beginning [of our conversation] which was exactly what you described. It was the direct opposite of what you describe in that circle, which was heavy and laboured. It was lightness, in that you were literally jumping around and it created movement. You started to move towards that line and you started to move forward but you returned to this space. To this intentional and space of positive energy quite frequently after that, in a way that you didn’t return to the other ones [spaces].

Megan: I think I’ve been searching for a middle ground in my data and- hello again [it’s the dog!!!]. Yeah I think I’ve been searching for that middle ground but it seems to be that people need… they’re either grasping it or they’re not and for the deaf person they’re either having a really bad experience or- I think they tend to focus on the bad experiences because they’re quite- I want to say, hurtful experiences? And they struggle to highlight experiences that maybe have been the middle ground, which is understandable…

Niamh: Maybe there isn’t a middle ground… so, what about you?

Megan: Where am I in this? As a researcher, as a person, as a movement?

Niamh: I guess as a movement… let’s go with that.

Megan: I think I could feel myself in all of the movements. I think I’ve wrestled with all of these emotions that I’ve embodied when I’ve spoken to people and I’ve felt when they’ve been speaking to me. I think I’ve felt a lot of this bit- this… not so much the total chaos but the sort of spiralling but messy (photograph) and unsure where it’s going. Because I’ve been very unsure of how I’m meant to be with people. Maybe I’m the middle ground. I feel like I can very much embody and feel what everyone in feeling in all of the different situations that I’ve come across but trying to make a connection between them. Trying to make a connection between the two extremes and trying to work out how nurses can do that as well without just feeling like they need to be educated as well. I think in my interviews I really struggled with that idea of having a conversation rather than asking questions because I didn’t want to just start educating people on- not so much on what they should have done, but what information might have been helpful for them to have and that might have made an impact on the kind of engagement that they had with the people they were caring for. But then one of the last interviews I did was the most beautiful interview with a nurse who did have that little bit of background knowledge and some of her thought process before she even went a met the person she was going to be working with in the community was just totally fascinating. It made her question what she should wear, whether she should use her sign language, whether it was appropriate because she only had a very basic level… but actually she ended up having a very playful relationship with the person she was working with because they began to understand one another and she described that as that being quite difficult at the start. Because you have to pay quite a lot of attention to the way that people speak and she doesn’t know sign language well enough to know that there's… of to recognise accents and ways of signing and how big your signing space is and things like that. But actually as time went on she began to realise what was normal for that person. What was their normal way of signing and how did that feel different when that person was anxious.

Niamh: without actually having a comprehensive knowledge of communication in a normal way for them?

Megan: Yes. And that made me realise that I guess her tiny bit of insight is what makes a difference between those two contrasts of chaos and something like this (praxis spiral) that's really beautiful and…

Niamh: or spiralling that's not unintentional but is not directional.

Megan: Yep. Yep, and I guess that's where that idea of playfulness and curiosity come in. you just need a little tiny bit of information to get that started. To know that being deaf means a lot more than what you first think it means.

Niamh: I've one more question. I pointed out at the very beginning that there was a definite sense of drawing towards self and aloneness (not loneliness) and it seemed to be an intentional movement. I wonder what you think about that?

Megan: I was thinking about this last night actually. I always thought that it was the deaf person that felt isolated and lonely in the kind of situations that I've been talking to people about. And they have. But at the same time I've started to recognise that nurses have felt extremely lonely in their experiences and haven't really felt that supported in that they just kind of have to come up with ideas to make the situation work alone and haven't felt able to talk about it and have just been expected to manage. And at times that's been embarrassing for them and they've realised that they've jumped to huge conclusions about deaf people and realised that there are actually ways of communicating that they hadn't thought about. I think this process- I think there's lots of loneliness in this process- in the whole research process. I think I felt lonely in that there were people who I thought were going to be really supportive of what I was doing and they turned out not be. Trying to engage with a community who have a lot of people protecting them has been quite lonely. But then there's been lonely- but also working in a supervisory team who don't have any knowledge of people I'm going to be working with- who've been really supportive, but again it's me bringing all of the information to the table. But in all that there's been really special moments when those barriers of deaf/hearing, researcher/nurse, have been broken down and it makes you realise why you're doing what you're doing.

Niamh: And that's what I was beginning to see in the breaking down of the line. I also am aware that you have chosen in your process to be alone for this part of it and it seems that you have found some peace in it and I said that. That at the end you seemed very peaceful but you were very far away from me and you were- you had found stillness but it didn't look any different to the other times that you had retreated but it felt different.

Megan: yep, I think I have found some peace in- I think I have been very focused on making sure that I am getting through the research process right. Like am I doing what I'm meant to be doing when I'm data collecting, when I'm recruiting. Have I ticked all these boxes? Have I done everything I'm meant to be doing? Have I done enough? Why am I not getting more participants? And I'm just kind of realising, and I've been told this the whole time, that that's something to write about and that it says a lot- it speaks volumes, when it's really difficult to recruit or when people don't want to engage with you and just realising that there's a lot of valuable stuff in this and that engaging with this kind of community and finding the space between you and them is all about relationship and that takes time. So if people don't want to engage with you or seem quite harsh in the way that they speak or act towards you there are reasons behind that and they're not normally… well in this situation, haven't been personal reasons. That there's a history there and that- I don't feel like I have to work really hard to get in anymore. That's what I was trying to do- I was trying to probe and prove myself. Whereas now I think 'let's just be me'. Be someone that values relationships and engagement and be who you want to engage when you let go.

Niamh: and that's where that stillness comes from?

Megan: yeah..

Niamh: So it's an intentional stillness then. Wow

Appendix 11: Research dissemination and impact activity

Research dissemination and impact activity	Type of activity	Activity details	Audience	Date	Type of impact*
Member of interview panel for Promoting Equal Access to Services (PEAS) project. PEAS was an internship for newly qualified BSL/English interpreters run by Heriot-Watt university in partnership with police Scotland and the NHS.	Interviewing	Contributing to the development of interview questions from a nursing perspective. Developing a simulated scenario in collaboration with two deaf people for candidates to role-play Interviewing candidates alongside academic BSL/English interpreters Role playing a practice nurse in a simulated scenario	• Academic staff who are BSL/English interpreters (interviewers) • Graduates of BSL/English interpreting course (interviewees)	2018	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change Other social
Member of interview panel recruiting BSL/English interpreters to a local health board	Interviewing	Developing and reviewing interview questions from a nursing perspective and to ensure they align with values of deaf communities and interpreting profession Interviewing candidates alongside staff from a local interpreting and translation service	• NHS interpretation and translation service managers (interviewers) • BSL/English interpreters (interviewees)	November 2019	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change

					Other social
NHS Lothian nurse director meeting	Research dissemination and local engagement	Meeting attendance, research presentation and discussion	• Nurse directors (NHS Lothian) • Service leaders	September 2021 *Delayed due to coronavirus*	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change Policy
EdSign Lecture. EdSign is a series of lectures on deaf issues. It is organised by an Edinburgh based academic and community group. These lectures are open for members of the public and are delivered in both English and BSL	Research dissemination and local engagement	Research presentation that is interpreted into BSL Discussion with deaf community members	• Deaf communities • Qualified BSL/English interpreters • Trainee interpreters	September 2021 *Delayed due to coronavirus*	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change Other social
BSL version of findings	Research dissemination	A signed, BSL video providing a summary of findings will be	• Deaf communities	September 2021	Understanding and awareness

		placed on Deaf Actions Facebook page and twitter		*Delayed due to coronavirus*	Attitudinal Cultural Other forms of decision-making and behaviour change Other social
NHS Lothian Interpretation and Translation services meeting	Research dissemination and local engagement	Research presentation and discussion	• Service leaders • Qualified BSL/English interpreters	August 2021 *Delayed due to coronavirus*	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change Policy
Planned publication	Research dissemination	Research findings	• Plan to direct towards national nursing audience	Ongoing	Understanding and awareness Attitudinal Cultural Health and wellbeing

					Other forms of decision-making and behaviour change Policy
Planned publication	Research dissemination	Research methodology and methods	• Plan to direct towards researchers	Ongoing	Understanding and awareness Attitudinal Cultural Other forms of decision-making and behaviour change
Embedding research findings in undergraduate nursing curriculum	Facilitating learning	Module workshops: Sensory and embodied knowing in practice A person-centred approach to caring for a deaf person and working with an interpreter (practical simulation) Creativity in research Deaf Awareness Session	• Undergraduate nursing students • Undergraduate BSL/English interpreters • Deaf communities	Ongoing	Understanding and awareness Attitudinal Health and wellbeing Other forms of decision-making and behaviour change Other social

Web-based communication	Dissemination and impact	• Research Gate profile • Social media presence – Twitter • Blog post for The Limping Chicken (deaf blog)	• Nurses • Researchers • Deaf communities • Public engagement	Ongoing	Understanding and awareness Attitudinal Health and wellbeing Other forms of decision-making and behaviour change Other social

*Based on Reed's (2018) categorisation of types of impact that include: understanding and awareness, attitudinal, economic, environmental, health and wellbeing, policy, other forms of decision making & behaviour change, cultural, social, capacity of preparedness