

**'Behind the scenes': Stories of grandmothing
in the neonatal intensive care unit.
An autoethnographic, narrative study**

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'Behind the scenes': Stories of grandmothering in the neonatal intensive care unit. An autoethnographic, narrative study.

A thesis submitted in fulfilment of the requirements on the University of Wolverhampton for the degree of the Professional Doctorate in Health and Wellbeing

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Abstract

This study is concerned with listening to the stories of grandmothers who had a critically ill grandchild in a neonatal intensive care unit. There is a wealth of research on the parents of premature or sick babies, but the parents' parents are an ignored area in nursing and midwifery literature.

In July 2013, my grandson was born seven weeks early and became very unwell on day two of life. This left me questioning what stories other grandmothers would have to tell of having a sick grandchild. As a neonatal nurse, midwife and educator by profession, I felt a duty to explore this neglected area further. Using my own autoethnographic experience as a grandmother as a basis for this study, I interviewed five grandmothers in two inner city neonatal intensive care units in the West Midlands. My position as a grandmother/researcher with my specialist professional antecedents adds a unique insider perspective in this research.

Uniquely, I used a theme board to enable me to tell my own story, which then facilitated grandmothers to tell me their own story. From the rich data generated from those narratives, and to allow their stories to breathe, I crafted fictional stories as one stage of the analytical process. A hybrid methodology of performance autoethnography and narrative approaches has been used to explore this hard-to-reach group of women who are silenced when their grandchild is unwell and being cared for in a neonatal intensive care unit.

Continuing with a crafts-based analysis, a bricolage of grandmothers' stories was sewn together creating a patchwork quilt of their words. Their stories tell of 'getting there', 'getting in' and 'staying in'. What I discovered was that grandmothers act quietly 'behind the scenes', restricted by a 'border of technology as a barrier' and emerge as 'silent heroines'.

What grandmothers' stories tell have the potential to alter the way in which they are seen in the neonatal intensive care unit. I make recommendations for changes in policy and practice to allow these silent heroines to have a voice.

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'The beginning is the word and the end is silence.

And in between are all the stories'.

Kate Atkinson.

Acknowledgments

The inspiration for this project came when my grandson, Lenny Lumsden was born on 11 July 2013 at thirty-three weeks gestation. Lenny became critically ill the following day with Group B Streptococcal pneumonia and was transferred from a LNU to a NICU. My love and thanks go to Lenny who has been my motivation to complete this thesis.

My sincere thanks go to my son, Tom and his wife Sophie who have allowed me to tell my version of their son's journey throughout this project.

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Lastly, my husband Pete, who has been my solid foundation during my doctoral journey. Always knowing when to 'disappear'. Pete, I couldn't have done this without you.

Declaration of Anonymity and confidentiality

All fieldwork data presented in this thesis has been edited to preserve the participants' anonymity, therefore all names of people and places are pseudonyms.

Dedication

This thesis is dedicated to all grandmothers who have had or will have grandchildren in a neonatal intensive care unit. To those women, who by chance have spoken to me about being a grandmother; one in the hairdresser and one on a cruise, who I do not know, but I have not forgotten. Those from a close circle of friends, one who had premature twin grandsons and one whose daughter gave birth to a premature baby in England whilst on holiday from America. To Sarah, Lenny's other nanny who lived a similar experience to me, we are all joined by a special bond.

Vignette 1- Hilary Blue balloons

I'd had such a busy week. I didn't think it could get much worse. Little did I know! I was in the middle of a doctoral assignment, my daughter was getting married in two weeks' time, I had also foolishly agreed to make and decorate the wedding cake (with no prior experience!) and all my students' tripartite assessments were due to be completed in the next couple of weeks, my diary was full and bursting at the seams.

We arrived at the hospital, we could see that ambulance was at the entrance, the ambulance doors were open, and the ramp was down, "He's here" said Tom and we knew that he had arrived safely. We saw Lenny briefly who was being admitted by the NICU manager and a senior neonatal nurse. I had worked with them both and I had certainly seen Joy flap when she was stressed, today Joy was not flapping, and I felt immediately reassured and 'home'. We are sent to the parents' waiting room to wait whilst they did some more investigations, no balloons here unlike the postnatal ward. We wait and wait, watching the news on a constant loop; riots in Rio de Janeiro, bonfires in Northern Ireland and an attempt to remove the bid to withdraw from the EU (if only). I think they might have forgotten us.

Dr Kumari takes us to a quiet room to talk to Tom and me. He has sent for Dr John Rowan from another hospital to come and give a second opinion. The heat is unbearable, we go outside for some air and to wait for Sophie to arrive. As we are standing outside, Dr Rowan arrives, gives me a big hug and says, "you need to be a grandma now, not a nurse". This is actually easier said, than done. But from that point onwards, I make a conscious decision to take a step back, let Tom ask the questions, try not to look at Lenny with a midwife's eye, try not to analyse the monitors, and try not to offer advice- well, okay, I advise Sophie on hand expression of breast milk and that's it!

My son has grown from a boy to a man today. He is a father now and I am a grandmother.

Chapter 1

Introduction

1.0 Introduction

This introductory chapter provides the rationale, the aims, objectives and research question of this research project. The background to the study will also be explored as will my personal and professional antecedents. I aim to consider the process of a performance autoethnographic narrative enquiry of five grandmothers who had a grandchild being cared for in a neonatal intensive care unit (NICU¹). The narratives of **getting there**, **getting in** and **staying in** are the main patches in a patchwork of stories that emerge from their narratives. Additionally, **silent heroism**, **technology as a barrier** and being **'behind the scenes'** also thread their way throughout this thesis, as does the metaphor of weaving and fabric that will become clearer later in this work. The common visions of helpless, white haired old grandmothers are challenged along with the assumptions that grandmothers' stories tell of vulnerability and hiding out of sight.

1.1 Overview

It was my own unique grandmothering experience of having a critically ill² grandchild in NICU that was the catalyst for exploring this neglected and previously non-researched area. The aim of the study was to hear the stories of this group of women whose grandchildren were unwell and being cared for in a NICU.

Its objectives were to:

- 1 Explore grandmothers' experiences through their storytelling.
- 2 Identify the commonalities and differences their stories had to tell.
- 3 Consider changes that could be implemented in the practice setting as a result of research findings.

The decision to include my own story in this enquiry was made since I believe that I could not separate what I had personally experienced from what other grandmothers had or could potentially experience. Consequently, insider research

¹ The abbreviation NICU will be used throughout this thesis for simplicity.

² Critically ill, sick and ill are terms that will be used interchangeably throughout this thesis. Defined as a neonate who requires intensive or high dependency care in a NICU.

was an important consideration in this enquiry due to the distinctiveness of my own experience. A self-story is told 'in the context of a specific set of experiences' (Denzin, 1989a: 186) Therefore I positioned myself as a teller, centrally in the narrative that is given. My self-story was of and about the self in relation to my personal experience and was constructed as it was told. Situated as I am within my own story and not being able to separate what *had* happened to our family to what *was* happening to other grandmothers my subjectivity is declared here from the outset.

There is an absence of stories that grandmothers could tell about being in NICU, and I argue that this under-investigated area is examined further. Aligning myself to Frank (2010) I let the collective stories of grandmothers breathe. Their stories emerge from 'behind the scenes' to a telling of their own version of grandmothersing sick newly born grandchildren.

1.2 The Research Question

To date there is no body of knowledge concerning this group of women who are sometimes invisible to the nursing and medical teams treating their grandchildren. Using a performative autoethnographic and narrative enquiry approach, grandmothers' stories have the potential to give an important insight into the myth told of them and their experiences of being on the side-line of the care of their sick grandchild. Not since the early 1990s has any British research investigated a grandparent's perception of having a sick new-born grandchild in the NICU when McHaffie (1991; 1992) conducted a survey on the role grandparents played in NICU. Consequently, very little is known about the stories of grandmothers in this situation in contemporary nursing and midwifery literature.

My own experiences led me to question the narrative of others. My story may have been exclusive to me and my family but there could have been a common narrative. In addition to my personal interest, I felt a professional responsibility, as a nurse, midwife, teacher, researcher and grandmother that this under-investigated area was studied in order to raise awareness of and contribute the future of clinical practice.

This thesis sets out to address the following question:

'What stories do grandmothers have to tell about their experiences of having sick grandchildren who are being nursed in a Neonatal Intensive Care Unit?'

1.3 Rationale for the study

Grandmothers have many roles in society, first and foremost, they are mothers to their children regardless of the age of those children. When their adult children are in difficulty most will provide a stable and supportive foundation on which those adult children can lean (Dench and Ogg, 2002). There is some evidence supporting how grandmothers regularly serve as a mother's personal support system, nursing and counselling and providing emotional support (Kornhaber, 1996; Mitchell and Green, 2002) but this is usually associated with the well, term newborn baby. I would argue that grandmothers also assume these roles with fathers (their sons). Midwives have created a pathway of education and support that starts antenatally with expectant grandmothers becoming involved with their daughter's childbirth classes (Polomeno, 1999a, 1999b, 2000; Linn, Wilson and Fako, 2012; Tommy's.org, 2018) and breastfeeding support classes (Johnson, 2014). Grandmothers can also act as their daughter's birth partner during labour and birth, supporting her daughter or daughter-in-law throughout this crucial time. There was nationwide success with policy changes in North American hospitals regarding visitation of families to women in labour in birthing suites (Giganti, 1998) and this has discredited the usual arguments against open visiting such as infection control, confidentiality and getting in the way, which have been long-held excuses in UK birthing rooms. Being closely involved in her daughter's or daughter-in-law's antenatal activities and having a presence in the intrapartum period are a welcome development for grandmothers since many of them could be providing childcare once the baby's parent(s) go back to work. This intimate involvement and participation of grandmothers suddenly ceases as soon as the baby becomes ill and is admitted to NICU. The voices of grandmothers are silenced if the baby is sick and requires specialist care, the metaphorical door is closed to them being involved any further.

Grandparents remain an indispensable source of regular childcare assistance whilst their participation in the workforce also continues to grow (Gendell, 2008). There is a gender divide in that grandmothers participate in childcare more than

grandfathers particularly in northern Europe (Leopold and Skopek, 2014) which confirms my point that shutting grandmothers out of NICU is a wasted opportunity for them to support their families when they will be almost certainly doing so when the baby's parents return home and to the workplace. Grandmothers could be providing several years of childcare to their grandchildren in the future (Fergusson, Maughan and Golding, 2008), it is unknown that if there is a hiatus in their relationship with their grandchildren if they are premature or unwell and whether that will affect their long-term relationship. There is a general agreement that the engagement of service users is an important facet of research (Speers and Lathlean, 2015), therefore, grandmothers' views are valuable, and their voices should be heard, because at present there is no mechanism for listening to them.

1.4 Purpose and scope of the study

Given the background described, the purpose of this study was to listen to the storied narratives of grandmothers whose grandchildren were patients in a NICU. The intention was to bridge the gap in nursing, midwifery and medical literature. The purpose of this study was to create an awareness of grandmothering when there is a sick grandchild in NICU. The evidence supporting Family Centred Care (FCC) only concentrates on the parents and to a lesser extent, siblings; grandmothers' stories have the potential to add to the concept of FCC. It has been recognised that having a sick baby in a NICU is a stressful and worrying time for parents (Franck, *et al.*, 2005; Reid and Bramwell, 2010; Busse *et al.*, 2013; Mofleh Kawafha, 2018) and in acknowledging that grandmothers could be a source of support to the family it is important to discover more about their involvement. The purpose of the study is also to inform future research and debate around this area of interest.

1.5 Neonatal Provision

Neonatal care services are unique in that they cover a whole pathway of care. Neonatal units are set within fourteen newborn networks across the UK (British Association of Perinatal Medicine (BAPM), 2017). My concerns for grandmothers were influenced by the stark statistics that demonstrate the large number of babies admitted to a NICU which results in parents being separated from their newly born child and consequently, grandparents being separated from their adult

children and grandchildren. Crucially, not all preterm babies need to be admitted to NICU and they should only be admitted if there is a clear clinical need (Cescutti Butler, Hewitt-Taylor, Hemingway, 2020). The Atain project has been instrumental in keeping term babies with their mothers, rather than an NICU admission (NHS Improvement, 2018; Croucher and Puddy, 2019). Admission to a transitional care unit also reduces the need for preterm admissions to NICU, but the efficacy has been difficult to evaluate (Battersby, Michaelides, Upton and Rennie, 2017). Nevertheless, every year in the United Kingdom (UK) 100,000 babies are admitted to a NICU for specialist care (Bliss, 2019). This means that one in seven babies born in the UK require treatment because they are preterm³, term⁴ babies who are sick⁵. Low birthweight, prematurity and term admissions to NICU mean that potentially there could be 400,000 grandparents per year with 200,000 of those being grandmothers who will experience their grandchild being cared for in a NICU in an unwell or extremely unwell condition.

1.6 Family Centred Care

The British Association of Perinatal Medicine (BAPM) (2017) recommended support for parents during the stressful time their baby is in the NICU. BAPM (2017) outline clear guidance on the facilities NICU should provide to make parents' experience more tolerable⁶. These welcome recommendations are only for parents and not extended to grandparents who have been pushed into the wings by dominant medical and nursing models of care.

The POPPY project (Staniszewska *et al*, 2009) mentions siblings and other family members as an element to FCC, disappointingly nowhere in this report are grandparents mentioned as part of the family unit. There is a lack of attention to the parents' parents and consequently there is a gap in knowledge of truly family centred care. It is essential that the focus on the parents, however neonatal unit staff are falling behind their midwifery colleagues who have been significantly more inclusive towards grandparents in the antenatal, intranatal and postnatal

³ Preterm: born before 37 completed weeks gestation.

⁴ Term: born between 37-42 weeks gestation.

⁵ In 2016 there were 657,076 live births in England and Wales (The Office for National Statistics [ONS], 2018)

⁶ These include 24-hour access to the NICU with access also to food and drink without charge; kitchen facilities; overnight bed; shower facilities and a room for siblings to play are among the recommendations for parents under the term of family centred care (BAPM, 2017).

periods and see the partnership between parent and grandparent as a strong ongoing supportive unit (Johnson, 2014).

1.7 Mothering

All grandmothers are mothers and to have a perspective on grandmothering in this study, it is essential to engage in a discourse on motherhood since it is the foundation on which grandmothering sits. Mothering refers to the personal, individual experiences that women have in meeting the needs of and being responsible for their children. Conversely, motherhood refers to the context in which mothering takes place and is experienced (Miller, 2005).

The traditional ideology of mothering is based on expectations of full-time stay-at-home mothers, which perpetuates cultural stereotypes (Johnston and Swanson, 2006). Mothers who are not privileged by this dominant culture are set up to fail. Early feminist research and argument led to the mapping of the challenged landscape of mothering (Chodorow, 1978; Oakley, 1979). The meaning of childbirth is interlocked with a society's attitude towards women, both reflecting its economic system (Oakley, 1979). The experience of mothering and domestic labour borders on a predominant interest with male-defined institutions, marriage and the family. Importantly, these writers questioned the social processes that framed motherhood and confronted theories of biological determinism.

In early work focusing on experience and expectations of motherhood, attention has been drawn to assumptions made by women's 'natural' and 'instinctive' caring capacities (Oakley, 1979). It has been argued that such assumptions have neglected the circumstances, power relations and interests that have made women primarily responsible for mothering (Hays, 1996). This led to beliefs that 'women's mothering abilities are somehow natural, essential or inevitable' (Miller, 2007: 57). Many feminists agreed that the incompatibility between women's maternal and professional identities is a product of restrictive female roles imposed by patriarchy (da Cunha, 2012).

Even though household and living arrangements have changed in recent decades, ideologies of 'good' mothering continues. While divorce rates and women's paid employment have increased, women still do not have adequate day care, enough

support from male partners, and workplace challenges still persist (Chase, 2001). Therefore, it is women who still mainly care for children, although this should not imply that all women mother (Francis-Connelly, 2000). Mother work is focussed on protecting, preserving and fostering her children's growth and development, and that this work needs to be done within the framework of the socio-cultural group (Francis-Connelly and Sytniak, 2015). This is seen in Western countries where women prodigiously subscribe to the idea of 'intensive mothering', where child-rearing is interpreted as child-centred, expert-guided, emotionally absorbing, labour intensive and financially expensive (Hays, 1996: 8). The core of intensive mothering is the idea that only the mother possesses both the instinctive skills and the necessary knowledge to undertake the mothering work and in doing so, will determine the child's normal development and well-being (Hays, 1996). With this investment into her mothering role, her identity as a mother may be threatened when the baby is ill and will interfere with her ability to care for her child (Wilson, 2007).

Becoming a mother is a significant life event and each birth is a pivotal turning point in a woman's life (Prinds *et al.*, 2014). The transition to motherhood is an individual experience for each woman and her family (Parratt and Fahy, 2011). The transitional phase to motherhood can be significantly altered when a baby is born prematurely and separated from her by being nursed in a NICU (Shin and White-Traut, 2006).

1.8 Grandmothering

The transition to grandmotherhood is also a major life event, which alters the relationship grandmothers have with their own children and their partners and arouses complex emotions. Typically, the transition is a time of happiness, fulfilment and satisfaction, but it can be associated symbolically with the notion of 'getting old' since women also undergo the profound biological transition of menopause (Caldas-Coulthard and Moon, 2016: 312). As well as a marker of old age, becoming a grandmother implies a shorter future, social generativity, social status, seniority and social renewal (Erikson, Erikson and Kivnick, 1986). The identity of grandparenthood can be 'tenuous and ambiguous' and has few explicit norms in the role and function of grandparents in western culture (Reitzes and Mutran (2004: S213). Changes in society such as mortality, divorce, fertility and a greater proportion of mothers working means that grandparents have a greater

opportunity to fulfil grandparental roles (Tatterton and Walshe, 2018). Not all women want to be grandmothers for the reasons already cited. This reluctance may be due to a newfound freedom from their adult children, having a grandchild restricts this freedom. Women can be torn by differing emotions when they are told they are going to be grandmothers (Kitzinger, 1997). As with those traditional roles of mothering, grandmothers might be overwhelmed by the traditional grandmothering role, that they are not ready for.

When a grandchild is born who requires intensive care, it means that grandmothers, cannot transition into the role they envisaged and are forced to take a step back from grandmothering their grandchildren temporarily. Certainly, from the stance of a grandmother (of a sick grandchild) and whilst acknowledging that grandfathers' (of sick grandchildren) stories are equally rich and important and neither to ignore or marginalise grandfathers, this scholarly project solely focuses on grandmothers.

The role of kinship has a strong tradition in the structure and system of families (Dowdell, 2005). When a grandchild is born the family is restructured with all family members proceeding up the generational tree (Kornhaber, 1996). The child becomes a parent, and the parent is transformed into a grandparent. The birth of a child precipitates a major transition in the life of the family, with new parents creating a new role regarding their baby but they also develop ways of relating to their own parents (Bright, 1992). However, when there are complications with the baby's health that necessitates admission to a NICU, grandparents may not automatically make the transition up the generational tree for fear of the baby dying or being disabled along with concerns regarding their own son/daughter and son-in-law/daughter-in-law.

1.9 The Auto-Narrative

I have enjoyed a long professional career in nursing, midwifery and teaching. As a nurse and midwife in the 1980s and 1990s I worked in a sub-regional⁷ NICU where exciting developments were occurring, with the implementation of a transport team, development of a parent support group, clinical trials into artificial surfactants and preterm formulae. The development of teaching resources and

⁷ Sub-regional NNUs were equivalent to a level III unit before the reorganisation in 2001.

the validation of English National Board⁸ (ENB) neonatal course (ENB 405), with which I was heavily involved, paving the way for my transition into teaching in the years that followed.

My passion has always been with neonatal care and the development of students, midwives and post-qualifying professionals to enable them to deliver the best possible evidence-based care. I have proudly seen many of my former students become managers, matrons, network leads and advanced neonatal nurse practitioners (ANNP).

When my grandson was born in 2013, my professional training and experience had not prepared me for those coming weeks. It was the most frightening and emotional experience for all my family and whilst I possessed extensive professional knowledge, here I was, a grandmother, like so many others before me.

1.10 Insider research

The binary positions of insider or outsider do not account for anywhere between the two poles. '*The space in-between*' can only be occupied by the researcher (Corbin Dwyer and Buckle, 2009: 60). It is the 'middle ground' which qualitative researchers typically navigate (Burns et al., 2012). Certainly, as an academic researcher/grandmother it was in this minute gap between two poles where I sat. Objective knowledge rests on the researcher's ability to detach themselves from preconceived ideas about the social groups they study (West et al., 2013). Whether the researcher is an insider, sharing the distinctive role or experience under study with the participants, or an outsider to the camaraderie shared by participants, the personhood of the researcher, including her membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation. Being an insider is not enough; sound understanding occurs when the researcher moves across social and intangible boundaries of which they may or may not be conscious at different times during a study (Griffith, 1998).

⁸ English National Board for Nursing, Midwifery and Health Visiting was established in 1979 under the aegis of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) and was the approving body for post-qualifying courses.

When shared understanding and common experiences are discussed in qualitative research, the concept of insider/outsider status is commonly raised (Gair, 2012). As a nurse/midwife, grandmother and researcher, I needed to acknowledge my own multi-layered identity and consider the implications of my personal and professional characteristics on my relationships with research participants and colleagues (Leslie and McAllister, 2002). Pre-existing membership of a group can have its benefits, possessing insider midwifery knowledge was advantageous in the 'getting in' and 'fitting in' phases (Burns et al., 2012: 52; Singleton and Furber, 2014). I had certain insider knowledge of the NICU environment, and I was generally known and familiar to most of the nurses working on both NICU. This can be an added benefit because I could sense when the units were busy, when procedures were being undertaken, and when to keep my distance. The disadvantages were that often nurses wanted to engage in personal tête-à-tête which I had to disengage from to remain objective and to fulfil my role as researcher.

Holding membership does not denote complete sameness within that group (Corbin Dwyer and Buckle, 2009). There was also dissonance whereby I was also excluded to some extent. Having no direct access to enter the unit (NICU 1)⁹; to the staff room or nowhere to sit in NICU 2 and I had nowhere to change¹⁰. Membership of groups is complex and cannot be identified in defined terms (Simmons, 2007). Therefore, emic and etic perspectives are not absolutes and there would inevitably be certain aspects of my personality that would align me with the people being studied and other aspects that would emphasise difference (Corbin Dwyer and Buckle, 2009). In this instance, with my professional background, I was an insider to the profession and, as a researcher, an outsider to the organisation. My own experience was another illustration of the insider/outsider dichotomy; researchers are never completely inside or outside (Toy-Cronin, 2018). The descriptions that resonated with my experiences were those that acknowledge the complexity, fluidity and multi-dimensional nature of positioning relative to grandmothers.

⁹ Security and gatekeeping: NICU 1 had a reception area operated for most of the day. I had to wait to be allowed to enter the unit and I was given the access code for the office where I could leave my belongings.

¹⁰ I needed to change out of my outdoor clothes and the only place for me was the staff W.C. that I was given the digital code for.

The insider/outsider notion is particularly important in this research because I had lived my own version of what the women in the study were about to tell me. I wanted my story to be part of the storytelling, to encourage the grandmothers to tell me *their* own story. It is because of my common lived experience that I was located as an insider to the participant (Gair, 2012). Simmons (2007) advocates early rapport building as an advantage of insider research, consequently I made prospective participants aware of my own experience as a grandmother which encouraged an honesty and directness, opening up a connection and common ground (Singleton and Furber, 2014).

1.11 Storying the narrative

When I was a child, my mother would read me stories from books to my sisters and me. When I was able to read, I would go to the library regularly and read children's stories to myself and sometimes to my younger sisters. However, there was nothing quite like listening to a story being told, feeling safe and warm whilst my mother read to us. I am also a child of the 60's a 'signed up member of the Jackanory generation' who listened to stories on the radio and television (McHugh, 2007: 111). Stories need to be told. Who tells them, who listens to them, who makes sense of them and who retells them is dependent upon the stories themselves, what they express, what they mean and what can be gained and learned from them. Frank's (2010) retelling of 'Christmas Eve'¹¹ has been pivotal in my need to tell the story of my grandchild whose journey has been the catalyst for this research. Stories are meaningless and empty without anyone to hear them, and it was with interest that I sensed grandmothers' stories needed to be heard.

Grandmothers' stories in this study have been written as short performative story using the fictional novel 'Behind the Scenes at the Museum' (Atkinson, 1995) as a framework for the telling of their stories. Atkinson's (1995) fictional character of Ruby and her relationships with her mother, grandmother, aunt and sisters form the basis of how grandmothers' stories have been told in this study. What is seen in Atkinson's (1995) novel is solidarity within the female characters. Ruby's

¹¹ The story by Eduardo Galeano is retold by Frank (2010:4) and is entitled 'Christmas Eve'. 'The doctor was working late in the Children's hospital, he took one last look around and saw one of the sick children walking after him. He recognised the lonely, doomed child, "Tell someone..." the child whispered. "Tell someone I'm here".

grandmother (Nell) and great-grandmother (Alice) who both have a history, a life lived, and an influence although, not always positive, on their family. They do, however, have major contributions to make in the story and on Ruby's outcome. Cornwall's (2007) assertion that the myth that female solidarity and autonomy does not occur in reality is refuted in Atkinson's novel where Ruby's mother and grandmother are not always in harmony or solidarity with each other, but they do eventually grow to stand together in the face of tragedy and trauma.

There are a range of arts-based approaches to express findings (Casey, 2009; Lengelle, Meijers and Hughes, 2016) and I wanted to be creative in how I managed grandmothers' narratives even though it is relatively unconventional in nursing and midwifery literature. The writing and reporting of results are not just the final phase of the research process but also as a method of enquiry in itself (Richardson and Adams St. Pierre, 2005). Experimental autoethnography allows for the use of fiction in writing since it enables the preservation of anonymity based on real people and events and breaks down the barriers between art and science in research (Grant, 2010). Therefore, the grandmothers' narratives will be written in the style of short stories.

Imaginative-creative writing is the boldest departure from traditional academic writing, poetry, fiction and drama are examples of creative genre that is advocated as alternatives to traditional writing (Chang, 2008; Cross, 2016; Lengelle, Meijers and Hughes, 2016; Kolhatkar, 2017). These methods allow the writer to express the story in a less inhibited format, allowing readers to be actively engaged in interpreting those creative expressions. I will create unique stories for each grandmother and the audience waits for the story to commence, intrigued by what events will unfold. It is with sensitivity that the unique identity of each grandmother is maintained in each fictional piece I write. I have interwoven extracts of grandmothers' stories as vignettes that appear in between each chapter to illustrate their individuality and complexity.

1.12 Theme board

The verbal channel of storytelling is not always adequate (Karnieli-Miller *et al.*, (2017). Stories can be brought further alive with illustrations and pictures (Frith and Harcourt, 2007); thus, it was the medium of a theme board that helped me to bring my own story alive. My theme board was used primarily as a method of

telling my story pictorially and metaphorically. Initially it became an anchor on which to explain my experiences, thoughts and ideas to my academic supervisors. The visual theme board (Image 2: p58) can be invaluable in helping to verbally tell a story (Cross and Holyoake, 2017). I used this medium to tell grandmothers in this study *my* story and for grandmothers to tell me *their* stories, in turn it became a framework for their own narrative.

Theme boards or storyboards can be used to assist with the telling of stories in a creative and reflective manner (Lillyman, Gutteridge and Berridge, 2011; Lillyman and Bennett, 2012). Visual tools when combined with verbal interactions have the potential to foster a mutual understanding (Noël, 2015). It was important to me that I told my story verbally and with a pictorial image which drew me into developing a visual tool. The theme board I developed, depicted in this thesis tells my story of becoming a grandmother, my grandson is central to the other images since my story would not exist if not for him (full interpretation appendix 1). The theme board is ekphrastic in that it breathes words into mute pictures (Holman Jones, 2008). The theme board became part of performing my story to grandmothers and is fundamental to the methods of data collection in this study.

1.13 Structure of the Thesis

This thesis is comprised of six chapters.

Chapter one introduces the study discussing the aims of the research as well as stating the research question. The background to the study includes, the position of mothers and grandmothers within the family context, the rationale and scope of this enquiry are justified. The use of Atkinson's novel and my theme board have been introduced.

Chapter two offers a critical analysis of the available, relevant literature surrounding contemporary role of grandmothers, grandparents caring for well grandchildren, grandparents with sick grandchildren, grandparents visiting sick hospitalised grandchildren and performative autoethnographic perspectives of grandmothers.

Chapter three highlights the methodological approaches used in the study. A hybrid of two main methods, namely: performance autoethnography and narrative analysis are encapsulated in the discussion. I illuminate the use of a visual tool to highlight my own story within the research and the use of fiction as a medium to express my findings. My position and philosophical stances are argued. This chapter includes discourse around the ethical and professional issues within this study.

Chapter four offers my justification for the three-step analytical framework approach utilised within this enquiry, namely Atkinson (1995) and Frank, (2010) along with my own reflexions. I also use the metaphor of fabric as an explanation of the three-step approach. In this chapter, I address active listening and locating the narrative. A bricolage or patchwork quilt has been constructed by sewing the main patches together.

Chapter five presents the main findings from grandmothers' narratives. Here snippets of their stories are shown using a three-step analytical model. Three central patches have been elicited, **getting there; getting in; staying in** along with three further critical findings; **behind the scenes, technology as a barrier,** and **silent heroines**. In this chapter I also provide critical discourse around the main findings and the key features of grandmothers' stories. Implications for future practice are highlighted.

Chapter six draws together the conclusion of this thesis using Richardson's (2000a; 2000b) criteria of interpretive sufficiency. In this chapter, I discuss the strengths and weaknesses of the study and the impact this study may have in nursing and midwifery practice.

1.14 Chapter summary

In this chapter, I have introduced the study aims and research question to be addressed in this enquiry. I have discussed mothering and grandmothering as social and familial roles, introducing the concept of grandmothers with grandchildren in NICU. I was keen to introduce the UK neonatal service provision as a contextual parameter, alongside FCC and how both frame grandmothers' experiences. In this chapter, I have discussed how my professional and personal experiences have had a major influence on the study aims and research question. The use of a theme board has been introduced, juxtaposed with Atkinson's (1995)

novel. I have included vignettes of grandmothers' stories between each chapter to show how I developed their stories into fiction.

In the next chapter I synthesise the literature pertaining to grandmothers and grandparents. I have presented the literature thematically engaging in discourse around the main findings and how the literature has influenced my own study.

Vignette two- Rajinder

I cried for everyone

When they arrived in India after a nine-hour journey, the first thing my grandmother did was ring my mother. The first time she rang her there was no answer, she rang my father, again no answer. She knew that even if my mother was on another planet she would send her a text message, my grandmother was very worried. She rang my mother again, no answer, rang my father, no answer and even rang my uncle (my mother's brother), no answer- 'Shit! What is happening?' she thought. My grandmother was 5000 miles away, although to her it felt like 100,000 miles and no-one was answering her calls. After 3 hours of pacing the lawn my father responded, he said "Mom don't worry, Karishma is in the hospital, she is on oxygen, and they are going to take the baby out today. She has got a condition called pre-eclampsia". "What the Hell! What is going on?" Grandmother stood on that lawn saying to my great grandmother "What do I do, do I go back now? I've only just arrived". She was in turmoil; she didn't know what to do and was in tears. Crying her eyes out, her daughter is in a critical condition. My grandfather tells her not to worry, everyone else is there with them, he says "Just to take it easy". My grandmother was pacing, pacing, pacing the lawn 'Oh my God, what am I going to do'. My great grandmother says (as they do) 'go and sit down and pray she is going to be fine'. So, they did sit down and pray, and the next phone call came with the news that my mother was off the oxygen and that they were going to bring the blood pressure down. She was able to talk to Karishma thank God, she sounded like she had had 100 drugs in her body though. She said to my grandmother "Don't worry about me, enjoy your holiday". That was all she said. My grandparents had gone to India for two weeks but came back after a week. My grandmother could not stay any longer, she said to my grandfather "I'm going back" and he replied, "I'm coming with you". So, they flew back home because everything had gone pear-shaped.

Chapter 2

Policy and debate on grandmothering:

A literature review

2.0 Introduction

In the previous chapter, I introduced the subject of grandmothers set within the context of mothering theory. I introduced the aims of the research and the research question. In this chapter I situate the thesis within a range of policy and practice debate on grandmothering. Many of the studies reviewed, explore grandparents rather than grandmothers alone, since many of the findings do not single out grandmothers for specific interest. It is important to acknowledge at this point, the cultural differences in grandmothering in other countries.

This review of the literature aims to critically appraise the research that exists in the field of grandmothering in British society. An overview and critique of the theoretical arguments around grandmothering a sick grandchild, grandmothers and childcare, visiting sick grandchildren in NICU and autoethnographic studies of grandmothers will be given. The studies reviewed identify the gap in the literature that my research aims to respond to. The key features of the literature are synthesised into five themes.

2.1 Grandmothering in British Society

In British society the focus is on the nuclear family as the preferred family structure, and the role grandparents play within families is largely invisible and often overlooked (Hebblethwaite, 2017). There are 13.6 million grandparents in the UK today (ONS, 2019). In total, 30 percent of all women over the age of 18 are grandmothers (7.6 million), half of grandparents are under the age of 65 or working age (Smethers, 2015). Consequently, one in two people in Britain is a grandparent by the age 55 which is currently under state retirement age, at a time when many people in this age group are still in full-time employment. This contests the British stereotypical view of grandparents as being elderly and infirm. Grandparenting relationships are important to intergenerational exchange across the life course with grandparents offering a significant resource to parents (Wellard, 2012). Childcare provided by European grandparents can have a positive effect on grandparents' health and wellbeing (Danielsbacka *et al.*, 2019). Whilst

childcare is an important aspect of grandparents in Britain, it is not their only function, with many grandmothers engaging in activities with their grandchildren such as, sporting, educational, outings, going on holiday and offering emotional support (Moore and Rosenthal, 2015).

Grandparents are marginalised in their grandparental role when their grandchild is in NICU. It is interesting to note that there is no policy relating to grandmothers despite the growing importance of grandparenting. Indeed, from 2006 to 2017 there was a year-on-year increase from 2.7 per cent to 3.2 per cent of households with a grandparent as head of the household (i.e., caring for grandchildren) (ONS, 2019). Although grandparents play a pivotal role in family life, legislation and social policies often disregard their contribution to family support (Glaser, Monserrat, Waginger, 2010). It is estimated that there are some 200,000 family and friends caring for 300,000 children in the UK. However, because of the lack of data, these carers are largely invisible to policy makers and service providers (Peake, 2019).

Despite this invisibility, it is mainly grandmothers, the mothers' mother who is responsible for childcare (Wheelock and Jones, 2003). There is concern however, that the availability of grandparents as child-carers may be declining, due to increased geographical dispersion and regarding grandmothers, a rising employment rate amongst older women (Gray, 2005). The age that women and men can claim state pension has changed, meaning that they will be over 66 years of age before some are in a financial position where they can care for grandchildren (should they wish to) on a regular basis without being employed (The Pensions Act, 2011, 2014). State childcare provision in the UK is relatively poor compared with other European countries, with grandparents providing essential childcare that allows younger women to (re)enter the workforce. This has increased from 1.3 million to 1.6 million grandparents providing child-hours of childcare which is a 35 per cent increase from 2009/10 (Wellard and Iparraguirre, 2013).

In England, grandparents do not have an automatic right to see their grandchild; if there is family relationship breakdown and/or divorce, grandparents will have to apply to Her Majesties' (HM) court for permission to have contact with their grandchild (if it is being prevented). Conversely, in times of family crises,

grandparents can often, very suddenly become kinship carers for their grandchildren, with little or no support (Peake, 2019). I include these facts to illuminate the 'space in between' that grandparents, and especially grandmothers find themselves in and reiterate Reitzes and Mutran (2004: S213) notion that grandmothering is 'tenuous and ambiguous'. With no legal rights to see a grandchild but used as kinship carers when a crisis occurs, grandmothers are called upon when the need arises. The contributions they make to family life can be enormous and their stories can make a significant contribution to the way we think about them. In northern industrial cultures grandmothers are no longer icons (Kitzinger, 1997), grandmothering does not represent the pinnacle of a woman's achievement. Appreciating this view that grandmothering has been downgraded, led me to understand why grandmothers do not feature highly in academic literature and why the roles of grandmothers have been eroded to just being unpaid child carers.

Not all women will embrace the role of being a grandmother. Some will be reluctant to support their families by undertaking childcare responsibilities, so that their adult children can continue to freely continue with their careers and professional development. Grandmothers are often expected to baby-sit, childmind whilst their daughter is at work or on holiday and to be taken for granted (Kintzinger, 1997). Grandparents attempt to meet the expectations of continuing to work and being active in a variety of life domains whilst carrying out the traditional role of grandparent and expected to help care for their grandchildren (Noy, Taubman-Ben-Ari, 2016). Family stress, strain, health risk and depression can be a result of grandparents attempting to balance childcare, family responsibilities and working life (Musil et al., 2009; Lee, Clarkson-Hendrix, Lee, 2016), and this can lead to strain on spousal relationships, particularly when grandfathers do not support grandmothers in caring for grandchildren (Matez, Cooney (2009). Whilst these issues are important to the overall wellbeing of grandparents its should not be forgotten that it is also physically exhausting lifting, carrying and just be with grandchildren all the time (Goodfellow, Laverty, 2003). Alongside this are the challenges of unplanned babysitting requests and the delayed arrival of parents to collect their child can lead to tensions between grandparents and their adult children. Being a grandmother is not without its difficulties and stressors and this is often overlooked in the literature.

2.2 Search Strategy

To situate the current study within the context of the current body of knowledge, a literature search was undertaken with the intention of summarising previous works and identifying gaps and omissions (Grant and Booth, 2009). I am interested in storytelling and biography, my reading has been extensive and includes works of fiction, biography and poetics (see bibliography). My engagement with those wider works has made me absorb the literature in a way that has enabled me to read and critique academic 'stories' in view of their practical application.

Current attitudes surrounding grandmothers of babies in NICU has not been under consideration in this country for thirty years. This section provides an overview of the literature search methods employed in the search for theoretical arguments pertaining to grandmothers of sick babies. The review identified only a small number of studies that related specifically to grandmothers in NICU. Although gaps in the evidence base underpinning grandmothers' roles in acute neonatal illness, are evident, the abundance of evidence pertaining to parents creates an imbalance in FCC. This lack of robust evidence in this area creates a lack of specific policy on how grandmothers can be accommodated in NICU.

A search was carried out utilising the following electronic sources: CINAHL; EBSCO; ETHOS; MEDLINE and Google Scholar databases. After implementing the search methods, inclusion criteria were applied (table 1: p33). Search terms with Boolean operator AND was used, 'grandmothers' AND 'role'; grandmothers AND 'critically ill grandchildren'. I changed the search terms to 'critically ill grandchildren' AND 'grandparents'. Since both yielded few papers, I changed the search terms to; 'grandmothers' AND 'caring for grandchildren' and 'grandparents' AND 'caring for grandchildren'. Since few studies emerged from my original search, I widened it to 'grandmothers' AND 'sick grandchildren in hospital', and 'grandparents' AND 'sick grandchildren in hospital'. I also searched for 'grandmothers' AND 'visiting sick grandchildren' and 'grandparents' AND 'visiting sick grandchildren in hospital'. Finally, in an attempt to elicit appropriate methodological studies, I searched using 'grandmothers' AND 'autoethnography'.

In addition, my search for literature pertaining to accessibility to grandchildren in hospital, most specifically, neonatal units were accessed.

Inclusion Criteria	Rationale
Key words	Key words were essential to the inclusion criteria to confirm that the literature captured within the search addressed the topic under review
Primary research	Primary sources were included since it is my own interpretation of their work, have not been manipulated and are the most reliable sources.
Date of publication	Originally, I searched for research from 2000 onwards. For very specific neonatal research, I had to extend the search to 1980s. Since those early research articles have not been replicated elsewhere, I justify their use in this review.
Research whereby grandmothers were the major subject	Grandmothers were the most important focus of the review and allowed for specific results to be retrieved. However, since there was a lack of literature in this area, I expanded the term to include grandparents.
Peer reviewed	Peer review ensures that research findings are reliable since they have been appraised by experts in the field.
Worldwide	Initially only literature from the UK and Europe was included, however this yielded very few results. Therefore, the inclusion criteria were expanded to worldwide, English language.

Table 1: Inclusion criteria.

It was clear from the initial search that there was limited literature relating to grandmothers with sick grandchildren in NICU. Therefore, I also searched specific journals; 'Midwifery'; 'British Journal of Midwifery'; 'Journal of Contemporary Ethnography'; 'Journal of Narrative Theory'; 'Journal of Clinical Nursing'; 'Journal of Pediatric Nursing'; 'Qualitative Health Research'; 'Journal of Neonatal Nursing'; 'Neonatal Network'. The search strategy primarily comprised electronic database searches but also included 'snowballing', i.e. following up references and citations from key papers (Jacobsen, 2017). A hand search was also undertaken to ensure that all search methods had been utilised (Beecroft, Booth and Rees, 2015).

The landscape of research relating to grandmothers and grandparents is interesting to note; with ten studies from United Kingdom (UK); six from USA; six from Australia; four from Canada; three from Israel; two from Sweden; two from Denmark and one from New Zealand, Finland and Brazil. Becoming a grandmother can contribute to the positive functions of social integration and enhanced social status (Armstrong, 2003). Grandparents can also feel a sense of generativity, feeling that their lives are worthwhile and making a contribution to future generations (Thiele and Wheelan, 2008), therefore literature pertaining to these aspects of grandparenting was used in this review (appendix 2).

2. 3 Synthesis of research findings

Critical appraisal and analysis of all the studies which met the inclusion criteria were synthesised by using Beecroft, Booth and Rees (2015) critical appraisal tools. There was an eclectic mix of research methods, namely, twelve surveys; five phenomenological studies; four qualitative studies; three literature reviews; three secondary analyses; two autoethnographic studies; and one longitudinal study, explorative study, comparison study, one mixed methods and one narrative enquiry. I classified the literature into themes (Aveyard, 2014); I then revisited the literature on several occasions to determine whether the themes were sound (Evans, 2007). The main themes addressed in this chapter are in the following order:

1. Contemporary role of grandmothers
2. Grandparents and childcare
3. Grandparents with sick grandchildren
4. Grandparents visiting sick grandchildren in NICU
5. Performative autoethnographic perspectives of grandmothers

In this critical review I have attempted to unravel the interrelated strands of modern grandparenting. What has been challenging, is to find grandmothers' voices in the literature, what they have to say and who is listening to them. What is not clear are grandmothers' stories of their experiences of having grandchildren in NICU or the performance autoethnographic experiences of grandmothers. What is interesting, are attitudes towards older women, the changes that have taken place in society that devalues maturity and wisdom, seeing grandmothers as elderly and vulnerable. No more so than in the present COVID-19 pandemic when

grandparents are urged to stay safe and stay away from grandchildren, closing NICU to any visits from grandparents (Bliss, 2020; Scottish Perinatal Network, 2020). The consequences of restricting visiting can lead to anxiety, worry and uncertainty (Hegelius, Harada and Marutani (2021).

2.4 Contemporary role of grandmothers

Grandmotherhood is a social, cultural and uncontested biological category associated with ageing (Caldas-Coulthard and Moon, 2018). This cannot be separated from the climacteric, 'the end of mothering and the beginning of grandmothering' (Greer, 1991: 26) which is preceded by four other ages of woman, namely: infancy and childhood; adolescence and nubility; wifeness; motherhood. To set this review into the context of those five stages, clearly all women who have grandchildren will have transitioned through ages one to five and are still straddling three and four whilst moving into age five. Critically, being a grandmother does not mean the end of mothering as Greer (1991) argues, notably it signifies the changing of the mother role to include the next generation. Originally, in the painting by Baldung (1544), the sixth and seventh ages depict old age and death as the final two ages. Greer does not discuss the final two ages, leaving the reader in a state of confused limbo. Leonard's (2007) medicalisation of the seven ages does not add any clarity, including only 'active retirement' and 'later life' as the sixth and seventh ages. Greer (1991) fails to see that grandmothers are still mothers to their adult children and that mothering continues, despite the transition to grandmotherhood.

In western culture, becoming a grandmother can be a marker of being socially old (Armstrong, 2003). Excluding older women from NICUs is a continued reflection of how British culture values older women. There are mixed messages about women growing older in the 21st century, often meaning that the grandmothering role is vague in modern society, not fitting those societal norms that value youth rather than experience and wisdom. With age comes social invisibility, society does not value older women for their intellectual or moral qualities, but simply by their external appearance (Caldas-Coulthard and Moon, 2018). The obsession with younger women, their looks and celebrity mean that any women over the age of fifty, is generally ignored and forgotten.

'Older women belong at the heart of cultural and social debate, their voices have been allowed to become muffled and ignored and this represents, notwithstanding the lavish and visible attention given to the interests of younger women, a net diminution in women's position' (Dench, 2001: 10).

The paramount value of physical appearance in western culture is a determinant of female worth) with the attainment and maintaining an attractive youthful appearance often being central to their role and social standing (Haboush, Warren and Benuto, 2012; Hodgetts, Chamberlain and Bassett, 2003). One of the consequences of the ideology of ageism is invisibility, silence and stereotyping (Caldas-Coulthard, Moon, 2016; Moran, 2021b).

Not only does ageing bring with it a possible loss of beauty but it brings infirmity. Ageist stereotypes of disengagement and loss of function are addressed in research studies (Baird, Lucas and Donnellan, 2010; Ben Shlomo *et al.* 2010; Ben Shlomo, 2015; Moore and Rosenthal, 2015). An analysis of two large-scale national panel studies showed that life satisfaction did not decline over most of adulthood, with those between the ages of 40 and 70 showing a large increase in their life satisfaction, which is when most people will become grandparents. There is, however, a steep decline in life satisfaction amongst those over the age of 70, which is apparently due to loss of function and infirmity (Baird, Lucas and Donnellan, 2010). Participants in all four studies showed that they had a sense of living worthwhile, productive lives and had a positive sense of personal growth of being a grandparent (Baird, Lucas and Donnellan, 2010; Ben Shlomo *et al.* 2010; Ben Shlomo, 2015; Moore and Rosenthal, 2015).

Grandmothers specifically are highlighted by Moore and Rosenthal (2015) who discovered that they participated in a range of sporting, educational and leisure activities with their grandchildren. Encouragingly, grandmothers in this study were at their happiest when they were looking after their grandchildren and those least satisfied were grandmothers who spent no time with their grandchildren. These results emulate to an extent, the findings of Ben Shlomo *et al.* (2010) where they also discovered a positive personal growth of becoming a grandmother in their participants. The findings are extended to new grandparents, who were found to have higher levels of life satisfaction if they were in the younger age group and had higher levels of physical health and economic status (Ben Shlomo, 2015). The

survey approach is dependent upon self-report and therefore is affected by the motivation and ability of the respondents (Wagstaff, 2006). Data from surveys is superficial and is suitable for breadth of issue analysis rather than in-depth consideration of the topic and lacks the depth and richness of data collected by qualitative methods (Polit and Beck, 2018). Positivist approaches assume that human behaviour can be measured using the principles of physical sciences, but the appropriateness of this approach is questionable (Bowling, 2014). Gathering data from a large group of participants, does generate generalised viewpoints without any ability on the participant's part to add nuance or depth to their answers and is reductionist in nature (Parahoo, 2014; Hasson, McKenna and Keeney, 2016).

The standing grandparents have in British culture, is often one of indifference, disinterest, disrespect and disregard. This would not have happened if researchers had not detached older people from their family networks in the seventies and eighties (Dench and Ogg, 2002). The intergenerational role of grandparents is an important one and the synergies that develop between grandparents and grandchildren are increasingly important to families. Grandparents can and do contribute to society and for many they are still in employment and juggling myriad family commitments (Lumby, 2010). The possibility of exploiting grandmothers should not be forgotten (Scott, 2012). Not all grandmothers wish to be used as unpaid childminders, having already raised their own children. It is possible that they wish to have some long-awaited freedom from family responsibilities because they are 'plain exhausted' (Shakharova, 2021).

Investigating whether grandmothers have a sense of growth and worth does, I would argue, perpetuate the view that older women are seen as redundant to society by many people. The researchers wished to discover whether the women in their studies had any sense of satisfaction and engagement. As discussed previously, there is a transitional phase to becoming a grandmother (Armstrong, 2003; Kaufman and Elder Jr., 2003) but that transition should not devalue what mature, experienced, capable women are already doing with their lives. The nature and the role of grandmothers in Britain has changed over time. Older women are often viewed as being frail and vulnerable, even though grandmothers in these studies have been shown to live happy, energetic and interesting lives.

2.5 Grandparents and childcare

In continuing to discover more about grandmothers and their core roles in society, I discovered that many grandparents act as unpaid childcare providers for their grandchildren. A sense of understanding of the range of that childcare provided by grandparents in our modern multicultural society is needed. It is not known whether all grandmothers would wish to participate in the caring roles if their grandchildren were in hospital. There were no clear patterns from the Millennium Cohort Study (2008) indicating variances between ethnic groups in the use of grandparental childcare (Hansen and Joshi, 2008). Although, the marginally greatest users of grandparental childcare were Pakistani and Bangladeshi families, with Indian families at the lower end of the spectrum using grandparents the least for childcare.

Children in some ethnic groups were more likely to be co-resident with grandparents which suggests greater availability to provide childcare and with a greater number of living grandparents in white families; there was more potential for childcare in this group (Statham, 2011). Conversely, Bordone *et al.* (2020) showed that Indian, Pakistani, Bangladeshi and African parents were less likely to use (outside) childcare than white British parents. Among those from Black and Minority Ethnic (BAME) groups using childcare, the likelihood of using grandparental childcare was lower among white British groups. Caribbean parents were more likely to use childcare from outside the family than any other ethnic group but that childcare when used, was less likely to be grandparental care (Hansen and Joshi, 2008). Jamaican families in Britain rely on grandmothers to unify the family network by continuing to care for grandchildren and strengthens the maternal line (Plaza, 2000). Some of the differences can be explained by the proportion of working mothers across all groups and those who are single mothers. The critical points made here suggest that there are some slight differences amongst who provides childcare in Britain and ethnicity may have some bearing upon who takes care of children when parents are working. Large scale longitudinal studies can raise awareness of the subject area, but by their very nature, introduce bias (Hasson, McKenna and Keeney, 2015). The weaknesses of longitudinal studies are that in investigating similar subjects they can arrive at conflicting conclusions.

In a longitudinal study of families in Bristol, Fergusson, Maughan and Golding (2008) found that forty-four per cent of children were regularly cared for by grandparents at the ages of 2, 8, and 15 years. This is an increase by 10-15 per cent compared with previously cited studies (Plaza, 2000; Hansen and Joshi, 2008; Bordone *et al.*, 2020). There was some correlation between older mothers who were in higher paid employment and were less likely to rely on grandparents for childcare than younger women. It is wrongly assumed that children of older parents have older grandparents who may be less able to care for grandchildren, again reverting to ageist stereotyping of the older adult. Attrition is often a feature of longitudinal studies (Polit and Beck, 2018) and this study was no exception, with n= 8752 children remaining in the study from the original total sample of n= 14,472. This is a significant weakness; one of the other weaknesses of this study was the lack of ethnic minority groups in the final sample and therefore, the findings do not fully represent the wider population in the UK. Ferguson, Maughan and Golding (2008) fail to acknowledge that the high level of attrition could have altered the overall ethnic mix of participants. What this study does show is that a significant proportion of British grandparents do play a significant role in caring for their children.

It is challenging to understand why hospitals exclude grandmothers when it is seen in the literature that grandparents can become the lone carers of their grandchildren. Grandparents sometimes need to take childcare of their grandchildren in place of the children's parents (Backhouse and Graham, 2013; Lee, Clarkson-Hendrix and Lee, 2016). This could be due to a variety of factors but often because their own adult children were addicted to drugs and/or alcohol, were imprisoned or had mental illness and could not care for their children. Because of these reasons, grandparents, expressed shame and stigma of having to care for their grandchildren (Backhouse and Graham, 2013). Often informally caring for grandchildren without official recognition, grandparents felt that they had lost their children and were responsible for their problems and likened it to the feeling of grief of losing a child. Backhouse and Graham (2012) specifically make the point that, this grief did not attract the same degree of social support that the loss of a child through death might result in. Crucially, when grandparents raise their grandchildren, their rich narratives show the paradox of pleasure/pain, inclusion/exclusion, being visible/invisible.

Thrown into raising their grandchildren, grandparents as the sole carers for their grandchildren were often left feeling undeserving and silenced (Lee, Clarkson-Hendrix and Lee, 2016). Grandparents found it stressful to take full responsibility for their grandchildren's wellbeing as well as the stress of dealing with authorities and the lack of recognition and mirrors to an extent the findings from Backhouse and Graham (2012; 2013). This theme of stress is further extended to include violence or threats of violence towards grandparents when they assume custodial care for their grandchildren (Gair *et al.*, 2019). This leaves them vulnerable and lacking in support. Nevertheless, these qualitative studies also generated positive findings of raising grandchildren, spending time with them and having grandchildren as an integral part of their lives. The narratives also told of issues of identity such as disciplining grandchildren, where grandparents had lost the traditional grandparent role and struggled to be both parent and grandparent. The narratives of grandparents in these circumstances are an important way forward in this field since it gives a significant voice to people who may not have been heard before and focus on their perspectives (Freshwater and Holloway, 2015).

Grandparental care, whether it is unpaid childcare whilst the parents are out at work, or whether grandparents have custodial care of their grandchildren, there is a need to recognise the value of what they do in supporting their families within the framework of the British social system. There is little recognition and limited financial support for grandparents who undertake these responsibilities. Nevertheless, grandparents will undertake childcare for their grandchildren when needed and are a vital part of a child's emotional wellbeing none more so than when the grandchild is in hospital (Brødsgaard *et al.*, 2017)

The research shows that grandparents take care of their grandchildren so that their adult children can remain in employment. This is across all households and ethnic groups in the main, with those who are higher earners or single Black mothers, choosing paid childcare over grandparental childcare. It would have been useful to know whether grandparents agreed to those caring responsibilities, giving up their own time to do so and therefore are the weaknesses in these studies. There can be a loss of identity when that care becomes full-time. Acting in the parental role and not having the pleasure of being a grandparent can mean that grandparents are often invisible and silenced (Backhouse and Graham, 2012, 2013). Rather than saving grandmothers from the workhouse, in modern Britain,

grandmothers are saving their adult children from the shackles of full-time childcare.

2.6 Grandparents with sick grandchildren

When a grandchild becomes ill and is admitted to hospital, it disrupts the equilibrium within the family. Paediatric intensive care units (PICU) have a similar intensity to that of NICU in that the patient is critically ill. A study showed that the pain grandparents' feel when a grandchild is admitted to hospital is often more acute than other family members recognise, being able to visit their grandchildren in hospital alleviates some of the stress grandparents feel (Moraes and Mendes-Castillo, 2018). Grandparents visiting grandchildren in PICU were found to be 'finding themselves in a storm', one of suffering and pain. Here grandparents described feeling heartbroken to see their grandchild so ill. Grandparents were found to be suffering, breaking their hopes and dreams for their grandchildren. The approach was to generate theory as a product of the qualitative research process (Strauss and Corbin, 1994; Toles and Barroso, 2015). The trauma grandparents were experiencing can be heard in their narratives as 'fighting to be the anchor of the family'. As seen in previous discourses, information about a grandchild was a key factor in grandparents' understanding (Mitchell, 2007; Lee and Gardner, 2010). There was no exception here, where receiving information about their grandchildren's condition and prognosis was of utmost importance for grandparents in this study. Therefore, searching for information and wanting to feel included by healthcare teams was another significant finding.

Grandparents can play an important role of providing emotional and practical support for families affected by childhood cancer, but they are an under-recognised part of the family (Scheinemann, 2017). When a grandchild has cancer, it has been described as 'the worst experience' (Charlebois and Bouchard, 2017). As with Moraes and Mendes-Castillo (2018) the overarching theme in this study was that grandparents declared that the most difficult aspect of the whole experience was to see their grandchild so ill and there is a crucial need to understand more about this facet of grandparents' views. The child's suffering, the trauma and the pain was reported to be difficult to see (Charlebois and Bouchard, 2017). One of the most important grandparental roles was being able

to support the whole family, seeing themselves as the pillar of the family and mirrors Moraes and Mendes-Castillo (2018) study. Attempting to discover the lived experience (Holstein and Gubrium, 1994; Parahoo, 2014), the central themes generated by in-depth interviews, grandparents expressed the views that they were 'living the worst experience' and to 'feel supported'. However, grandparents in Charlebois and Bouchard (2017) study expressed the need for support for themselves and this was generally gained from their spouse or other friends and family.

The voices of grandparents are heard and are clearly articulated in these qualitative studies. Whilst grandparents were supporting their family during the hospitalisation of a grandchild, they themselves lacked support and resources, especially regarding their need to be included and informed by the healthcare team. Findler, Dayan-Sharbi and Yaniv (2014) conducted a comparative survey in Israel to ascertain the quality of life among grandparents whose grandchildren had survived cancer. Those grandparents' health and sense of coherence were all poorer than grandparents with healthy grandchildren. However, despite the physical and emotional toll taken by their grandchildren's illness there were also positive implications that may be a source of personal growth. Crucially, the study relied on subjective self-reports and social desirability that may have affected participants' responses and is a limitation of the study (Terry, 2015). The high degree of generalisability of survey data is increased by using statistical analysis. However, it does not allow for the human emotional factors to be considered, which is a weakness of survey data.

Grandparents find themselves in an untenable position when a grandchild has cancer. Grandparents of grandchildren with cancer wanted to 'trade places' with their grandchild, experiencing the feelings of unfairness (Moules *et al*, 2012a; 2012b). There are some similarities for grandparents with grandchildren with cancer and grandparents with a grandchild in NICU in that the grandchild's outcome is uncertain and their life is precarious. Moules *et al*. (2012a, 2012b) fail to point out that grandparents of older grandchildren with cancer will have an established relationship with their grandchild as opposed to a relationship that has only just begun. Nevertheless, there are some tenuous links between the two and both find themselves in a marginalised position when their grandchildren are in hospital.

Having a grandchild who has cancer can have some long-term consequences for grandparents who suffer from problems such as anxiety and depression. A diagnosis of cancer in a grandchild can affect grandparents' quality of life, particularly in the domains of physical, psychological, social relationships and their environment (Wakefield *et al.*, 2014). Using questionnaires to measure those four areas with grandparents, compared against a control group of grandparents with healthy grandchildren found that a grandparent whose grandchild did have a cancer diagnosis had a poorer quality of life, with reduced functioning than those in the control group. Grandmothers experienced worse quality of life and higher distress than grandfathers (Wakefield *et al.*, 2014). The response rate to the survey was 69.5 per cent in the cancer group and 67.5 per cent in the control group which borders optimal and suboptimal response rate that Wakefield *et al.*'s. (2014) fails to declare. Most responders in the study were female (62.9 per cent) which may explain the claim that grandmothers are closer to their grandchildren than grandfathers and will speak more openly about their feelings (Davey *et al.*, 2009) and therefore significantly affects Wakefield *et al.* (2014) claims.

Grandparents are fundamental to family support and are more likely to suffer stress and anxiety which could be reduced if more information about their grandchild's cancer was made available to them (Wakefield *et al.*, 2013). It is important to hear what grandparents have to say in this situation since their views could be applied to NICU grandparents. Grandparents in Wakefield *et al.* (2013) study also completed a questionnaire to measure their information needs. Disappointingly, whilst no qualitative data were available in these studies, the findings do show the need for information to avoid relying on second-hand data from the child's parents. The information from nonexperimental designs lacks depth and relies on superficial data rather than in-depth enquiry (LoBiondo-Wood and Haber, 2008). The information grandparents sought was about the chance of their grandchild's survival, information about their grandchild's specific cancer, treatment, procedures and medication. Interestingly, a 'knowing silence' was described by these grandparents, not being in receipt of first-hand information, backing off and watching from a distance, with a helplessness they could do nothing about (Moules *et al.*, 2012a; 2012b). This phenomenological study of sixteen grandparents did generate rich qualitative data of the lived experience, that sought to find meaning and critical truth in the essence of their experiences

(Polit and Beck, 2018). Critically though, Hermeneutic research does not involve an attempt to conserve individual stories of participants but tries to keep central to the topic or phenomenon itself (Moules et al., 2012a). This limits the individual voice by representing their experiences. Grandparents in this study described their suffering, but also, more positively, their ability to advise other grandparents who are in a similar situation, a finding that is not replicated elsewhere. This is similar to my point that there is a lack of information about grandparental stress when a grandchild is ill.

As previously debated, a life-threatening diagnosis in a child can throw a family into turmoil. This is seen when a baby is born prematurely or diagnosed with a congenital heart condition. Studies show that immediate contact with grandparents following a devastating diagnosis, precipitates immediate responses from grandparents who aim to be supportive to the family (Rempusheski, 1990; Hall, 2004a; 2004b; Ravindren and Rempal, 2010; Frisman *et al.*, 2012). Rather than fracturing the relationship between grandparents and their adult children as seen elsewhere, these studies discovered that grandparents offered practical help to support the parents of the ill child to maintain family unity. A grounded theory approach was undertaken with grandparents of pre-school children with hypoplastic left heart syndrome (Ravindren and Rempal, 2010). In recognising that a greater insight into a phenomenon is required (Harvey and Land, 2017), grounded theory in this instance has given a greater understanding of grandparents of grandchildren with rare congenital heart condition. A key finding of this study was for grandparents to maintain the parent-well child relationship, becoming advocates for their wellbeing. The siblings of ill children need care and support when their parents are intensely involved with their sick child, here grandparents stepped into the parent role with their grandchildren.

Likewise, supporting parents emotionally and practically during the hospital stay and after discharge was a key finding in Frisman *et al.* (2012) qualitative study where grandmothers' narratives were evaluated for main features, confirming previous accounts and identifying common elements (Holloway and Freshwater, 2007a). It was important for grandmothers to listen to the parents, supporting them without expressing their own opinions, setting them aside whilst simultaneously wanting to be happy about the newborn infant. Content analysis of interview data reduces the material by coding into manageable paraphrases

(Flick, 2014). This can lead to limiting the findings to a small number of themes. Importantly though, some of the grandmothers in this study had the experience of supporting the fathers and being present around the time of birth, grandmothers noticed that the fathers were in shock until the mother was stabilised; this is a significant finding and has not been reported elsewhere.

Support of parents with premature babies (by grandparents) does not necessarily have to be with the parents in person but support by telephone was seen to be sufficient (Rempusheski, 1990). This small-scale study used saturation as a justification for the small sample size which reduces the credibility of grounded theory (Bluff, 2006). The sample inclusion was restrictive including grandparents of 50 years and over; this will have eliminated many younger grandparents who could have contributed effectively to the study. Grandparents expressed themselves as having hope, being unprepared, anticipating the worst and not feeling like a grandparent. What is significant is Rempusheski's (1990) view that the grandparent becomes a client to NICU by virtue of being a member of a three-generation family when the team follows a family care model. The notion that grandparents become a client of the NICU rather than a visitor is a significant factor since this is not addressed elsewhere in the literature. Since this finding was identified thirty years ago, it is regrettable that grandparents are still not considered to be part of the family unit. As a gerontological nurse, Rempusheski (1990) could see the value of grandparents as part of the family unit.

Double concern was a key feature in a phenomenological study (Hall, 2004a, 2004b) where the lived experience of grandmothers with critically ill, small grandchildren was explored (Hall, 2004a). Grandparents were interviewed together in couples, with the findings extrapolated and presented separately. 'Hoping for the best', 'feeling helpless' and 'powerless' were expressions from both grandmothers and grandfathers. However, grandmothers discussed experiencing 'kindness and dismissal', feeling well-received at the NICU but at the same time feeling dismissed by a 'wall of nurses' who did not show a caring or understanding attitude towards them (Hall, 2004a: 65); this again perpetuates the bias against grandmothers. There are some parallels with Rempusheski's (1990) finding of 'having hope' and Hall (2004a) 'hoping for the best', where grandparents hoped that the baby would live, and once they were home, hoping they would not be damaged in any way and would live a healthy life. In recalling these feeling some

years after the event, it is possible that grandparents did feel very strongly about them at the time, or the feelings could have been exaggerated in their memory. The descriptions of the world from an insider perspective may be inadequate as an account of human behaviour. People cannot always explain their behaviour as it may be caused by other forces (Galvin and Holloway, 2015). In this case, those outside forces could be a spouse since grandparents were interviewed as a couple. It is problematic having a partner present in an interview who might influence the data and favour expressions of shared, rather than individual experiences of the phenomena (Norlyk, Haahr and Hall, 2016).

Family functioning can be altered when a grandchild has a life-altering diagnosis. Strain on parents and grandparental relationships occur because grandparents are sometimes on the periphery of care, when they feel that they should be more involved, with the aim of protecting their adult child. Wanting to be strong, the anchor of the family and protecting adult children and grandchildren was a common thread in the literature. Grandparents felt the need to support their families but also needed support themselves to deal with the challenges of having a very ill grandchild. Nowhere in the literature did grandparents feel well supported and often this was not a requirement, moreover they felt they wanted to support their loved ones in trying times. What remains unknown, is what their experience was at the time, rather than a retrospective recollection of events.

2.7 Grandparents visiting grandchildren in NICU

Grandparents are not included in the recommendations for family visiting and as previously discussed, not included in FCC in NICU. Early Scottish research in this area discovered that NICU nurses and doctors least liked working with grandparents than any other family member (McHaffie, 1991, 1992). Worryingly, only half of the nurses in this study cited establishing a relationship with the baby as a grandparental need. Similarly, doctors disliked working with grandparents; concerned that grandparents could undermine the parents' role with one consultant having a parsimonious view that, '*support without intrusion should be the motto*' (McHaffie, 1992: 282). Surveys to discover both lay (parents and grandparents) and professionals (nurses/midwives and doctors) opinions of support for families of very low birthweight (VLBW) babies and to assess the appropriateness of visiting policies in seven NICUs in Scotland. There was a clear

derisory consensus across all groups of professional and parent respondents that the principal role of the grandparent was to provide emotional support for the parents. Whilst postal surveys can elicit important information and are appropriate for producing descriptive data (Bowling, 2014; Terry, 2015); crucially, the differences and depth of interpretation and understanding cannot always be fully explored or generalised. Nevertheless, the research did show that grandparents would do anything to help so that parents could be with their babies, and this was viewed as an expression of care and concern (McHaffie, 1991). Being left out of family care leaves grandparents at the edge of their family's joint experience and troublingly, the needs of grandparents are highlighted with an example of a grandmother who only got the opportunity to see her grandchild twice before the baby died not having the chance to hold her (McHaffie, 1991).

Thirty years after McHaffie's (1991, 1992) study there are still NICUs that do not have flexible visiting arrangement for grandparents. Studies show that restrictions still apply in Scandinavian countries (Latva *et al.* 2007; Flacking, Breili and Erikson, 2019) where grandparents do visit their grandchildren. However, eighty per cent of grandparents (from 349 admissions) visited hospital to see their grandchild, with fifteen percent only visiting once (Latva *et al.*, 2007). Grandparents visited more frequently if the grandchild was first-born, or if the mother was younger and if visiting frequency of the parents did not correlate with the visiting frequency of other grandparents.

Rigid routine structures that are in place in hospitals meaning that visiting a sick child in NICU can be interrupted by the medical ward round (WR). The WR is an opportunity for families to have direct communication with the medical team caring for their sick babies, but they often find it intimidating. Being overheard and overhearing during the WR was a cause for concern for families (including grandparents) and was a relatively common occurrence (Bramwell and Weindling, 2005). Restrictions to visiting during the WR aim to minimise overhearing and confidentiality problems that can occur by excluding visitors during the WR. Parents are usually invited to hear and participate in discussions for their own baby (Bramwell and Weindling, 2005). Worryingly, approximately a quarter of grandparents believed that their visiting privileges had been restricted due to the WR (Blackburn and Lowen, 1985). Whilst there was some dislike for restricted visiting, grandparents were sympathetic to the reasons that the restrictions were

there to protect the infant and echoes McHaffie's (1991) findings of tolerance of the restricted visiting times.

In families where their sick child is small and/or premature, grandparents need to get to know their grandchild in the days following birth. Grandparents expressed concern for the parents as well as for the baby, not knowing the outcome and wishing to take away the pain for the parents. There is no doubt that McHaffie's (1991; 1992) work on social support in NICU paved the way for better grandparental visitation. As the least liked member of the family to work with, grandparents needed to visit their grandchild, in what was a potentially hostile environment to them. Anticipating the worst, emotional reactions and not feeling like a grandparent were findings in the early work of grandparental roles in NICU. Information needs arose with grandparents of small grandchildren, since they were not involved in consultations or medical WR and therefore the information they received was second-hand. However, a vulnerability can be seen to thread its way through grandmothers' narratives, on the side-line of care with limited access to their grandchild.

2.8 The performance autoethnographic voice of grandmothers

Since my own experience is fundamental to this enquiry, I searched for other grandmothers' stories of having sick grandchildren. I was curious to find if this had been reported before. In a short article, Gunn (2011) describes the pain and suffering she experienced as a grandmother through pregnancy loss. Her son and daughter-in-law were expecting triplets, one fetus died in the first trimester and another in the third. A baby girl was delivered safely but the acute loss of losing two grandchildren was hard to bear. Gunn (2011) makes the point that many others have walked the same path but how to survive the pain has not been published. Whilst this paper adds to an awareness of grandparents in this sad situation and the loss acute, it is the grandmothers' voice that resonates, which is powerful and influential.

An autoethnographic portrait of her grandmother is given by Rambo (2005). In a layered account, the grandmother emerges as a cruel, dislikeable woman who showed no care or love towards her granddaughter. The rationale for this lengthy paper is not given but it would seem as though painting her grandmother into the narrative, expunges her from Rambo's (2005) life. Rambo (2005) loved her

grandmother, but she disliked her pettiness and her meanness. Personal memory is selective, and an overreliance can censor past experiences (Chang, 2008). What is disappointing is that the grandmother has no redeeming features unlike those in other studies where care, concern and love have been expressed but they have not had the autoethnographic platform on which to shout (Armstrong, 2003; Hall, 2004a, Ben Shlomo *et al.*, 2010, Frisman *et al.*, 2012, Moore and Rosenthal, 2015). Richardson's (2010) autoethnographic account of her relationship with her grandson, tells of detachment, attachment, distance, fear, dreams and complex relationships. The relationship with her daughter-in-law was a difficult one and when eventually, she leaves taking her son with her, it leaves Richardson (2010) wondering whether she will ever see her grandson again. Some parallels can be seen with Sims and Rofail (2013) study, who found that grandparents were devastated by the loss of contact with their grandchildren through divorce, their lived experience stories were grief-stricken and sad. There is no conclusion to Richardson's (2010) autoethnographic account, except the intense feelings of failure as a mother, feeling blame for earlier life decisions that had ultimately left her son without his child.

2.10 Chapter summary

The key findings of the literature are that there are very few outlets that facilitate grandmothers' storytelling in a world where grandmothers are caring for their grandchildren, are relatively young and have competing familial commitments. There is also a lack performance and creativity in contemporary storytelling research from the perspective of data collection and data presentation. There is little recognition of performance autoethnography in nursing, midwifery and social care research. Grandmothers and grandparents are often seen as elderly, victims or vulnerable and there is a distinct absence of biography in the stories that restricts their views from breathing.

The findings presented here are a product of my own interpretation. The current understanding of grandmothers is limited, clumped together with grandfathers, their individual experience and story is often missing. Nevertheless, grandmothers have made a contribution to research findings either individually, in a couple or within the family unit.

The striking feature of this review is the methodological foundation for many of the studies which were surveys utilising questionnaires. Whilst these can generate large volumes of data in breadth, if not depth, the individual voices of grandparents are not present. Nevertheless, trends and commonalities can be seen that can have an influence on that specific area of practice such as cancer nursing and PICU nursing. Phenomenological, grounded theory and narrative enquiry can generate rich data, which is in-depth and can reveal emotions, feelings, tell of pain and heartache and have given the grandparents the opportunity to tell of their experiences. No performance autoethnographic research has been found in this review of the literature. Grandmothers' stories have been illuminated in just under half of the studies reviewed. Whether interviewed with a spouse or alone, their words are critical to our understanding of what it is to be a grandmother caring for grandchildren or with sick grandchildren.

Owing to the gaps in my understanding of grandmothers in the literature and the limitations in methodological approaches I have identified, there leaves space for alternative methods and epistemological genres to be explored. Using my own professional biography and the autobiography of having a sick grandchild in NI will be the foundation for exploring other grandmothers' stories who find themselves in a similar situation to mine and will be addressed in the following chapter.

In light of the discussions raised in the literature, in the next chapter I will present an argument for the adoption of an amalgam of two methodological approaches. I will identify my position within this enquiry and discuss the use of a theme board as a vehicle for data collection. There will be discourse around the main ethical principles relating to this study and will conclude with a discussion on trustworthiness.

Vignette 3 Grace

I am far, and she is here

At the beginning of February Christine rang her mother Grace who was just eating pepper soup. “Mummy, I am in hospital, they tell me I am having delivery pains and I am having twins”. A shocked Grace left her food and immediately prayed and prayed on the rough mat. “God will protect you” she said to her. The doctors had told Christine that these babies were stable, their weight was better than the little grandson. Grace was prepared to come and look after those little ones and so again, they struggle, struggle to get the money to come to England and to change their tickets. She came on 25 February; it was a holiday period, and the ticket was very expensive. The way she saw it was, the babies were healthy, and they were surviving. By passing this difficult situation onto God, He gave her the strength to deal with this challenging time. But sometimes she felt that these things are too heavy, and she struggles to find peace. Why does her daughter have her babies in the winter? The snow is falling again, and the roads are all blocked, the hospital car parks are not clear, and it makes visiting more stressful than it already is. The bitterly cold wind cuts through Grace like a knife. Grace is not used to this weather at all, she can do nothing about it and just has to get on with it.

Chapter 3

The Methodology

3.0 Introduction

In the previous chapter I reviewed the literature which has informed the methodological framework I have adopted for this research. In this chapter I will rationalise my focus for the chosen methodological approaches. In discussing the methodology, I have produced an overview that establishes vital context and fundamental strategies that are different from the approaches utilised in the literature.

I aim to highlight how the adoption of an eclectic approach to the methods of performance autoethnography with narrative enquiry have both influenced and guided data gathering. I will make clear how I used the narrative interview to gather stories from five grandmothers bound within the environment of a NICU.

I will appraise how my own position as nurse/midwife, academic and grandmother within the field. As a practitioner-researcher, issues surrounding ethics and reflexivity will be clarified and finally, I will justify the use of Lincoln and Guba's (1985) four quality dimensions framework for addressing the quality assurance of this study.

3.1 Positioning myself in the enquiry

A researcher will deeply filter observed events through a particular stance (Emerson, Fretz and Shaw, 2001). This stance is reflected in the way in which, as a researcher, I identified with the grandmothers in this study and acknowledge the bearing my previous experiences may have on the outcome. My standpoint has been considerably influenced by those experiences as well as professional antecedents. These intimate associations between the kinds of positioning a teller does and the types of stories told in this study call for a view on positioning (Georgakopoulou, 2013; Parker-Jenkins, 2018). I am sympathetic to Frank's (2000) assertion that standpoints are not an option and thus my standpoint as a nurse, midwife, researcher and grandmother within this thesis is fully acknowledged.

An essentialist ontology views culture as something that has a concrete existence (Carter and Bolden, 2012). As a consequence of belonging to a particular culture, individuals obtain certain kinds of selves that are deterministic of who they are inside (Fuchs, 2001). An essentialist believes that all women are the same because of their shared biology (Fahy, 2008); however, in the context of midwifery practice, no two women are ever the same. An essentialist approach views the participant as a passive vessel of feelings and emotions but with good rapport, and with the right line of questioning, a narrative can be extracted from the participant by the interviewer (Holstein and Gubrium, 1995). I position myself as a post-modern, anti-essentialist in this enquiry, not wishing to categorise people because of their gender, and whilst grandmothers have the one same characteristic of having grandchildren, they are not the same as each other. From the anti-essentialist position, it is not the lived experience but rather a narrative, or story of experience that is of interest, filled with meanings, interpretations, additions and deletions (Reissman, 1993). Furthermore, narratives are told through the medium of language which also shapes the stories in significant ways (Carter and Bolden, 2012).

Challenging traditional assumptions about grandmothers puts me firmly in the postmodern epistemological stance, thereby accepting uncertainty and turning my attention to the fragments of lives, the minute events of everyday life, seeking to understand them (Silverman, 1997). Postmodernism questions traditional assumptions, deconstructing them, showing the ambiguity and contextuality of meaning (Borer and Fontana, 2012). This is displayed by a greater sensitivity to problems and concerns that have been scantily addressed in the past. Autoethnography offers a nuanced way of giving a voice to a person's experience (Ellis, 2004). In recounting my own feelings and combining the roles of interviewer and interviewee was an essential factor when seeking to talk to grandmothers. It was important to consider the use of performance, the telling of my story or a dramatized oral narrative, through the act of representation (Crawley, 2012). Inextricably linked by my experience to other grandmothers is a fundamental feature of my thinking, re-inhabiting the space I lived through in the early days of my grandson's life. The medium of critically reflexive methodology resulting in narrative of engagement with others and performance autoethnography (Spry, 2011), with its contextual strengths allowed me to move in and out of the

experience to develop an understanding of grandmothers' experiences. Certainly, excluding the actions of the listener can encourage essentialist thinking (Reissman, 2012); and was something I aimed to avoid.

It is the moveable and fluid characteristics of narrative methods that have allowed this enquiry to develop and contribute to the body of knowledge. It has enabled me to create an amalgam methodology of performance autoethnography and narrative enquiry that is unique to this study. There are several possible approaches to discovering the grandmothers' world with phenomenology and autoethnography having the most potential to underpin this enquiry. Grandmothers of NICU grandchildren do have a commonality in their experiences and will have a 'lived experience'. However, there are limitations to this approach as there can be a tendency to ignore the context of the research, the conditions in which data are collected and 'insider' perspectives may be inadequate as an account of human behaviour (Galvin and Holloway, 2015). Phenomenology can be criticised on epistemological grounds in that looking for order in experiences and between those experiences is objective and essentialist (Todres, 2005). The most the researcher can do is offer multiple perspectives from multiple positions and contexts (Holstein and Gubrium, 1994; Erikson, 2011). For these reasons, phenomenology was discounted for this enquiry, I required an approach that was less rigid, was more creative and allowed the context, intertextuality and textuality to be a fundamental feature of this research.

Any empirical evidence generated during a research project cannot be separated from the theoretical standpoint of the researcher. As a researcher I had some concerns with my professional and personal experience; firstly, that my story may have had an influence on how and what other grandmothers had to tell in their own story, and secondly, I was concerned that grandmothers may seek answers from me about their own situation. To overcome any concerns about interconnectedness in this enquiry it was crucial that I was critically reflexive and transparent throughout the process and acknowledged all my predispositions and assumptions (Avis, 2005; Forbes, 2008). Any acknowledgment of my stance maybe fundamental, but purposefully pointing out how narrative is the perfect approach for emphasising the reflexive, contextual and relative ontologies and methodologies and not a preoccupation with objectivity (Lincoln and Guba, 1985; Denzin, 1989b; Clandinin and Connelly, 2000; Holloway and Freshwater, 2007a).

Locating myself in relation to the participants in this enquiry illustrated the commonalities between both academic researcher and grandmother and can also show how they may have viewed the researcher (Image 1). My position and some of the shared biography I had with the grandmothers in the study, as Frank (2000) points out that taking a standpoint means to accept myself with what my biography shares with others. The underlying commonalities in our stories of being a mother and grandmother are female characteristics that are distinctive and individual to us all, providing a mutual understanding of what those female qualities are without being overtly expressed. How the researcher participates within the field reflects how they identify with the participants and ultimately becoming a character in the story being told (Emerson, Fretz and Shaw, 2001; Erikson, 2011) were shaped by my stance within this study. Undeniably I am part of the performance, and I am present within the whole of this work by bearing witness and by retelling the stories accurately and authentically.

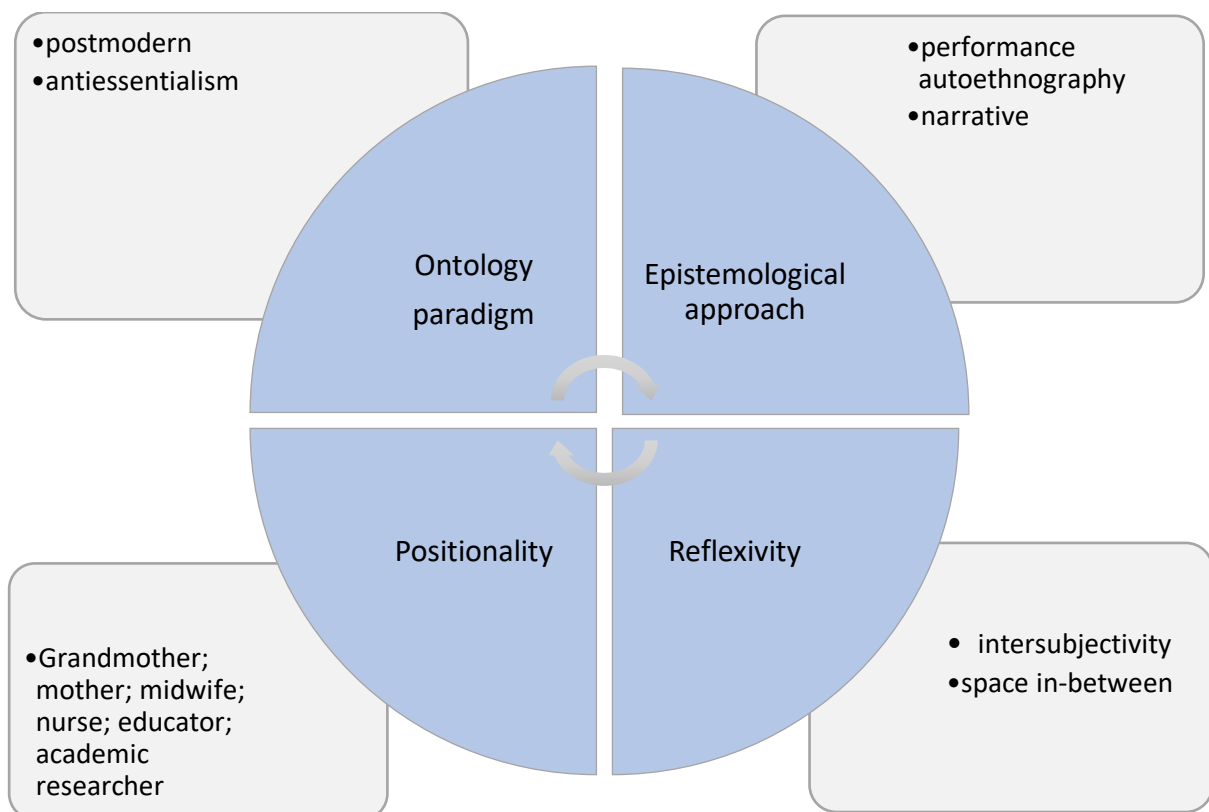


Image 1: My position within the enquiry (adapted from Pitard, 2017)

I can align myself with Beck's (2005: 419) notion of 'women helping women', in that I have the experience of working with women, for women and to women which cannot be separated from who or what I do or the research I was undertaking. Those relationships made with women are all individual and have likenesses to Ólafsdóttir's (2008: 195) 'close connections and emotional experiences' where midwifery care relies on strong emotions arising from close connections with women and her family. It is these relationships that can be identified as contemporary paradigms of midwifery practice (Hunter, 2001; 2004; Deery and Hunter, 2010; Kirkham, 2010). I have tacit intuitive knowledge of what other grandmothers may have experienced based upon my own personal and practice-based experiences, a sense of inner knowing and that sense of coming from the self. Being with woman and connected ways of knowing are fundamental to my position as a researcher.

3.2 Methodology

Individual perspectives from individual positions are a necessary feature of this research as well as individual experiences, the data needed to be less structured, there also needed to be more freedom to express the grandmothers' words. As a result, using a determinist approach and being able to create a methodology that is an amalgam of two approaches. There is a synergy between narrative and autoethnographic approaches, an emerging border between the two (Gubrium and Holstein, 1999). I make my case here for the fusion of two disciplines of research which is aligned with Denzin's 'seventh moment' (Denzin, 2001: 324). The current, or seventh moment of research in the 21st century is '*the methodologically contested present*' (Denzin & Lincoln, 2005: 1116). An amalgam of performance autoethnography (Conquergood, 1991; Denzin, 2014b) and narrative enquiry (Clandinin and Connelly, 2000; Frank, 2010) was created in an attempt at creating my own paradigm and with a 'contested present'.

Within this enquiry and to let the data breathe, making decisions throughout data collection about where, what and when data can be collected (Frank, 2010), I needed to be explorative and flexible. Autoethnography provides an inside viewpoint on everyday life through engagement with people, exploring human experience and social interaction (Skeggs, 2001; Sharkey & Larsen, 2005). The adoption of an autoethnographic approach to my enquiry is justified by the need

to engage with grandmothers whilst their grandchildren were still being cared for in NICU.

My 'auto' biography needed to be included since it was the bedrock of the encounters I would have with other grandmothers, being unable to separate myself from my own and their experiences (Denzin, 2003a; Smith and Gallo, 2007; Muncey, 2010; Spry, 2011). The words of Holman Jones (2008) are significant to me and captured the essence of what I was aiming to achieve in this study:

'Setting a scene, telling a story, weaving intricate connections among life and art, experience and theory, evocation and explanation...and then let go...'

(Holman Jones, 2008; 208)

Autoethnographers turn the analytical lens on themselves and their interaction with others (Chase, 2005). As a researcher using tenets of my own autobiography and within the boundaries of autoethnography, I aimed to write autoethnographically. Thus, as a method autoethnography is both a process and product. My own position mirrors Ellis' (2004) view of autoethnography which emphasises getting close to those we study, endeavouring to see the world through participant's eyes and conveying the experience authentically to their everyday life. Autoethnography as my epistemological stance places me as the grandmother researcher at the centre of the research with a heightened self-consciousness of the textual production (Plummer, 2001; Holman Jones, 2008; Ellis, Adams and Bochner, 2011).

Autoethnography expands and opens a wider lens on the world by creating a reciprocal relationship with audiences to compel a response (Holman Jones, Adams and Ellis, 2013). This approach helped me to understand how the kinds of people we claim or are perceived to be are influenced by interpretations of what we study, how we study it, and what we say about our topic. When writing an autobiography an author reflectively and selectively writes about past experiences, which is certainly true in this enquiry. Usually, with autoethnography the author does not live through these experiences solely to make them part of a published document, rather, these experiences are assembled using hindsight (Denzin, 1989b).

Autoethnography values the researcher's personal memory whereas ethnography relies on participants' memory with the addition of the researcher's memory of what was observed and heard in the *field* (Chang, 2008). I would argue that both are equally important firstly, my story when told, helped the grandmothers engage with *my* situation and secondly it became a framework for *their* own story. In addition, their stories helped me to make meaning out of experience and events. Nonetheless, I am conscious of the notion of bias with Denzin (2014a) stating that everyone's story has bias no matter how often the story is told. Without attempting to eliminate bias and create a framework for my storytelling, I produced and used a theme board (Image 2: p59) which helped me to frame my story pictorially so that I could tell the story as authentically as possible. The notion of bias is commonly understood to be any influence that provides a distortion in the results of a study (Polit and Beck, 2018). This is a term drawn from the quantitative research paradigm and is incompatible with the philosophical underpinnings of qualitative enquiry. Those carrying out qualitative research are an integral part of the process and the final product, and separation from this is neither possible nor desirable. Subjectivity does not infect the study, it enhances it (Muncey, 2010); it is the intention that my own subjectivity enriches this enquiry.

'Pentimento' is something that is painted out of a picture that later becomes visible again (Denzin, 2014b: 1). Stories are like pictures that have been painted over, untold and hidden, when told and shared, the stories are uncovered, and the paint is scraped away. My story was illustrated through a theme board enabling me to scrape the paint away from my own story to reveal a unique and individual experience. Montage and pentimento show images, blending my story, shaping and defining my experience. When both participants and researcher are part of the same larger (or smaller) society, this sharing may be amplified (Van Maanan, 2011). Certainly, in having had a similar experience to the grandmothers, the sharing of stories was amplified and compatible

I needed a way to express my autoethnographic process and to share my individual story. I used my theme board as a script or backdrop to the performance. I constructed my theme board in early 2014, after I had decided on the topic for my thesis and following the first meeting with my supervisors. I was able to use it to tell my supervisors my story. This then became a very important

The purpose of the performance (of telling my story) was to engage the audience (grandmothers) fully, so that performer and listener met in the liminal space that lay between them (Smith and Gallo, 2007). The performance paradigm insists on face-to-face encounters instead of abstractions and reductions (Conquergood, 1991). This situated me within the carefully negotiated and fragile face-work that is part of the complex and nuanced drama of everyday life. Touching the audience with an autoethnographic narrative to learn about the participants' lives was a focus of the two-way interaction I had with the grandmothers in this study (Carless and Douglas, 2010). I told my story to each grandmother and then invited them individually to tell me their story.

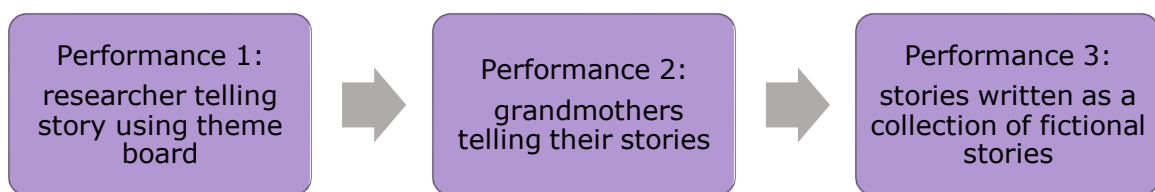
It was the female intergenerational stories that were of interest to me, taking narrative a step further by framing grandmothers' stories into an alternative genre, thereby strengthening the performative elements of this study (Hamera, 2011). This detailed description, is a performance that moves through mimesis (imitation) and poesis (creation) of the pictorial to the written word (Conquergood, 1992; Holman Jones, 2011; Hamera, 2013). Narrative fiction has the qualities of persuasion, situational empathy, assuaging, inspiration and sense-of-life experience (Kolhatkar, 2017). The layered text is one of not only putting myself into the text (Richardson and Adams St. Pierre, 2008) but including the grandmothers' narrative into the fictional style of writing.

My own ideas have parallels with Turner (1986) who used the conceptual lens of performance because it focussed on the creative, playful, imaginative, articulate expressions of ordinary people. Performance is an interpretive event involving actors, scripts, stories, stages and interactions whereas cultural performances are captured group events that are rooted in the flow of everyday life (Denzin, 2003b). The performance in this study can be seen in three stages (Image 3: p61):

1. The telling of my story using a theme board is a performance in its own right
2. The grandmothers used their own words to tell their story as a performance. Each story is unique, and the telling is a performance of its own
3. The transcription and writing the stories as a collection of fictional stories were also categorised as performances.

In bringing the past into the autobiographical present, I insert myself into the past and create the conditions for rewriting and hence re-experiencing it and re-telling it. Denzin (2006) entitles this as 'the narrator-as-dramatist' and is a facet of my recreating my story for grandmothers to hear. It is through the medium of the theme board and the telling of the story that this enquiry is based within the performance autoethnography paradigm.

Image 3: Three acts of performance



The second strand of methodology in this study is the essential element of narrative enquiry. Denzin's (2003a) eloquent words are aligned with my understanding of the importance of narrative:

'We live in narrative's moment. The narrative turn in the social sciences has been taken... Everything we study is contained within a storied or narrative representation' (Denzin, 2003a: xi).

There are two arguments for narrative enquiry, firstly, there is 'no other way of describing lived time other than in the form of narrative' and secondly, 'that narrative imitates life and life imitates narrative' (Bruner, 2004: 692). The culture of storytellers affects the stories they tell and therefore a person does not operate in a cultural vacuum (Holloway and Freshwater, 2007a). The culture of storytellers is an important aspect, and I was interested to hear how this would show itself in the participants in this enquiry. Notions of temporality through storytelling enable people to locate their 'now' experience in a context of 'back then' and 'not yet' (Holloway and Freshwater, 2007b: 704). It is the 'now' that was of interest and was the main reason for grandmothers to tell their stories whilst their grandchild was still being nursed in NICU. The 'backdrop' or scene setting where the stories

were to be told create a settled sense of place or the intersection of time and space (Baynham, 2015). This not only framed the performance of storytelling, but it also situated the stories temporality of the 'now' of the story. The social space where the stories were told was a conglomerate of situational context factors (Georgacopoulou, 2015). The location of the interview was not just a logistical tool but rather an integral part of the interview (Herzog, 2012).

Frank (2000; 354) is clear that although he uses narrative and storytelling interchangeably in his writing, he states that '*people do not tell narratives, they tell stories*'. Importantly, Atkinson (1997) argues that authors such as Frank (1995) will not produce sound research on the social world by shedding the social and replacing it with solitary voices. I would fervently argue here, that for this study it is the solitary voice that is the most significant one and I have taken the responsibility to tell the solitary story authentically and frankly. Each person's story can remain unique while being representative in that uniqueness (Frank, 2010). This is a noteworthy point; it is the uniqueness that is of interest in this enquiry but the representativeness of other grandmothers that could hold the key to changes in practice. The 'typical' story should not be discounted moreover, it should be embraced it in what Frank (2010) calls 'vivid' stories. The vividness of stories can connect lives to times, representativeness and uniqueness and are a '*turning point*' Bruner (1997:146; 1999: 8), and crucially, '*epiphany*' (Denzin, 2014a: 12) that are at the crux of grandmothers' stories.

When I listened to their stories it was evident that there needed to be a medium in which to develop their stories for them to be heard. It is the people or grandmothers who tell the stories, stories cannot tell on their own. Stories are told because something out-of-the-ordinary has happened and means that a response is required (Frank, 2010). That out-of-the-ordinary event being a sick grandchild in NICU meant that there were grandmothering stories to be told. The grandmothers in this study were not inhibited when it came to tell their story, they were fluent and articulate in the way they recounted their story to me. The life story turns the subject into an author, the author being the one who brings the story into existence (Denzin, 1989b; Tedlock, 2011). The grandmothers authored their own stories verbally and I set them within the context of a fictionalised story and allowed their stories to be told.

3.3 Reflexivity

To overcome any challenges with subjectivity of engagement, I endeavoured to conduct this enquiry with a close link to my positionality. In maintaining a reflexive journal (Rae and Green, 2016), I developed the capacity to think reflexively (Forbes, 2008; Doyle, 2013). I also had reflexive discussions with my academic supervisors. As part of data collection, I shared my theme board of symbolic images of the landscape of my experience. These reflexive activities helped me to critically look back on my own experiences and become more aware of my own story in relation to the participants.

Any evidence generated from a research project cannot be separated from the theoretical standpoint of the researcher. Reflexivity requires the researcher to operate on multiple levels (Etherington, 2004), acknowledging that as a researcher, I was intimately involved in both the product and process of the research endeavour. This serves to reinforce the need for critical reflexivity (Holloway, 2005; Doyle, 2013). In narrative research the context in which the study is conducted is particularly important when complex social phenomena are being investigated. In real-life settings or where prior knowledge, skills and expertise of those engaged in its conduct are likely to impact upon its outcomes (Dowling, 2006; O'Conner, 2011). With my pre-existing experience it was essential as a researcher that I had the ability to reflect back and forth on the research process, challenging my own perceptions and potential influences I may have upon it. To ensure integrity and trustworthiness of qualitative research, it is vital that there was a way to analyse how the subjective and intersubjective elements influences research (Finlay, 2002; Holloway and Freshwater, 2007a). Reflexivity offered me the tools as a researcher to overcome some of these concerns of the depth I was situated within this enquiry. There is no way to escape the social world in order to study it and it is further argued that it is not necessary to do so, that we must work with what knowledge we have (Hammersley and Atkinson, 2003).

3.4 Ethical considerations

In developing methodology and methods my attention was drawn to the decisions and choices that would affect participants in the choices I made during the data collection process. Although this study did not directly involve critically ill neonates, it did involve their families at a time when the babies were still unwell

and their future uncertain. As the narrator to their stories, I had the responsibility to ensure that I had authentically represented grandmothers' words whilst doing so within a recognised ethical framework. In the wider context, the participant may view the interview situation positively when a researcher with a professional authority shows strong interest in what they have to say (Kvale and Brinkmann, 2009).

Performance autoethnography does not escape ethical problems (Murphy and Dingwall, 2001). I acknowledge here that since my own story was clearly and deeply embedded in this study that I needed to reflect that when considering the role of others in our own experiences. There must be a balance to protect others and ourselves (Morse, 2002). Thus, I was mindful that 'my story' was also my family's story, my son and his wife and their critically ill son. The wider family were also intimately connected to and woven through the story I had to tell. The autoethnographer holds a demanding standard of '*ethical self-consciousness*' (Bochner, 2000: 271). I was aware that I was telling a personal and transparent account of the families' experience. Therefore, verbal permission was granted from Tom and Sophie to tell my version of our story to other grandmothers during this enquiry. Their names in my story have not been changed to ensure authenticity and realism.

Due to the potential vulnerability of the families, this enquiry called for an ethical positioning throughout (Hammersely and Traianou, 2012) (appendix 3: table of ethical process). One of the main ethical concerns surrounding this enquiry was gaining approval to conduct research in an NHS hospital setting. Permission was sought from the University of Wolverhampton, Faculty of Education Health and Wellbeing Ethics Committee before applying to the Research and Development Departments of two NHS Trusts via the Integrated Research Application System (IRAS). It is important to defend the ethical issues raised in a research protocol (Paniagua, 2014). My proposal was no exception and was subject to review at the Local Research Ethics Committee (LREC) which I attended in person to answer questions relating to the chosen methodology. The committee made conditions that I fully adhered to before full approval was confirmed.

There could be a potential discrepancy between the informal, private, intimate talk in conversation with the grandmothers and the ethical dilemma relating to

research control, power issues and knowledge ownership where there is exploitation of participants. A collaborative approach was required in this study (Murphy and Dingwall, 2001). In recognition of this potential discrepancy, I followed Karnieli-Miller, Strier and Pessach (2009: 285) conditions that participants must fully understand the meaning of the study and truly volunteer to participate in it. To assist in the process of ethical consideration I drew on '*contextualised-consequentialist*' model (Denzin and Lincoln, 1994:21) which consists of four principles, mutual respect, non-coercion, non-manipulation and with democratic values. This model required me to build relationships with the women of respect and trust and that were non-coercive and not based on deception. This was executed by introducing myself by my first name, giving a brief description of the study and highlighting that I also had been a grandmother to a grandchild in NICU. I gave the grandmothers and their families at least twenty-four hours to consider being interviewed by me (appendix 4: details of recruitment process).

Whilst narrative research does not pose the risk of physical harm associated with clinical research, it would be a mistake to think that it is risk free. Risk includes the probability and magnitude of negative outcomes (Beauchamp and Childress, 2013), and risk assessment involves the analysis and evaluation of probabilities of negative outcomes, especially harm. Being interviewed for example, often at length, in depth and on a sensitive topic, can be experienced as intrusive and distressing and raw emotions may arise (Holloway and Freshwater, 2007a; Gibson, Benson and Brand, 2012; Speers and Lathlean, 2015). This had been drawn to my attention by the University of Wolverhampton Ethics Committee who advised me to include a debrief prompt sheet to be used if a grandmother became inconsolable during her interview. Although there was no potential for harm during narrative interviews, there was the possibility that grandmothers might become upset as they recounted their story. In fact, every grandmother wept during her interview, though visibly upset at times, all regained their composure quickly and none required further psychological support. I gave each grandmother the debrief sheet if they should require further support. There were no breaches of confidentiality from grandmothers regarding any member of staff. Two of the grandchildren had been cared for in other hospitals before being treated at NICU

2. Where grandmothers refer to another hospital, I have changed the names of those hospitals in their stories to maintain anonymity.

Researchers may be affected by the accounts they hear in the field (Lillrank, 2012; Hoong Sin, 2018). The care of the emotional self is a great responsibility that researchers need to be aware of when working intensely with families (Deery and Hunter, 2010). This is an important point because being a nurse, midwife, grandmother and researcher who may be familiar with such intense experiences does not necessarily protect or prepare them as a researcher (Morse, 2007). This aspect of research ethics is not subject to any official governance when conducting interviews (Kirkham, 2008) and consequently I had to rely on my own professional capability. As a midwife I am experienced at working with women in a variety of settings and I can wholeheartedly sympathise with Hunter's (2001) expectations that the ways in which midwives interact with women, and how they manage the emotional aspects of these encounters, are crucial in determining the quality of the woman's experience. Midwives develop coping mechanisms to help them manage difficult situations (Kirkham, 1999; Deery and Hunter, 2010; Bharj and Chesney, 2010) and I am no exception. Subsequently I was emotionally affected by one experience on NICU 2 (appendix 5 'the baby who didn't die') to address the issues that arose, I wrote about it in my research journal and discussed the episode with my supervisor. This is a salient point, since the burden of living with and not sharing information obtained in the field could have resulted in there being a longer-term emotional concern (Mooney-Somers and Olsen, 2018). However, with emotional maturity, support, and professional resilience (Clohessy, McKellar and Fleet, 2019) and the sounding board of my supervisor, I was able to manage the emotional aspects of hearing stories in the field.

Originally there were three interview options that I had written into my proposal with the aim of giving grandmothers the choice of:

1. To be interviewed alone
2. To be interviewed accompanied by their partner
3. To be interviewed in a small group of other grandmothers

I was conscious that grandmothers with a very sick grandchild may be vulnerable and nervous about being interviewed as part of a research project. However,

stories can be useful devices for individuals to come to terms with their vulnerability (Holloway and Freshwater, 2007b). Vulnerable populations require extra protections as research participants (Matthews and Ross, 2010; Polit and Beck, 2018). In the clinical setting, I anticipated that participants might be shy, quiet, nervous or feeling emotional. I had sought to give grandmothers the option to have someone accompany them in the interview if they were feeling vulnerable (rather than not be interviewed at all). There are advantages of joint interviews, and they are a particularly appropriate method for studying complex shared experiences (Polak and Green, 2016). They can also offer valuable information about how couples co-construct shared experiences (Sakellariou, Boniface and Brown, 2013). Recognising that there are tensions between methodological and ethical challenges with joint and individual interviews because they can add to family distress (Norlyk, Haahr and Hall, 2016). The influence of a partner in interviews will affect the interview and may not be a true account of their experience (Taylor and de Vocht, 2011). There could also be power imbalances within the relationships (Braybrook *et al.*, 2017). There is potential for ethical dilemmas in interviewing couples together (Haahr, Norlyk and Hall, 2014), the balance between the wish to gain as much information as possible with compassionate questioning in their situation along with the need to avoid ethical problems around confidentiality (Mellor, Slaymaker and Cleland, 2013).

Likewise, interviewing small groups is not without its challenges, in that the data will always come from the group and not the individual. Compounded by the problems that one or more participants may remain silent throughout the interview and there is less opportunity to explore issues in detail because of the number of participants in the group (Bluff, 2006b; Flick, 2014). Whilst some participants might find the interview less intimidating than an individual interview, others may feel the opposite (Harvey and Land, 2017). Additionally, confidentiality may not be assured particularly where sensitive information is being shared (Doody, Slevin and Taggart, 2013). It was a relief to me that grandmothers were emotionally vulnerable but resolutely strong and chose to be interviewed without their partners and avoided this dilemma. Any research experience could prove positive or negative for the participant. However, an informal, intimate conversation could also provide a safe and positive opportunity for participants to describe their experiences to someone who is interested in listening to their experience

(Holloway and Freshwater, 2007a) and some may find the interview process therapeutic (Hammersley and Traianou, 2012). I was bound to act in the best interest of the grandmothers. It is the principle of beneficence that provides the participant with protection from harm (Terry, 2015).

Given the options available, all grandmothers chose to be interviewed alone. No grandmother wished to have their partner present and since so few grandmothers were ever available at the same time the third option became redundant. There were two reasons that I wanted to interview grandmothers on their own firstly, to hear the female voice of having a sick grandchild and secondly to hear her individual story, not a joint experience. Ethical concerns must be given higher priority than the methodology when interviewing individuals or couples (Norlyk, Haahr and Hall, 2016). To this end, all five grandmothers were given the same two interview options.

Voluntary participation into any enquiry and informed consent should be given freely without coercion (Kvale, 1996; Darlington and Scott, 2002). I ensured this by giving an invitation letter and participant information sheet to parents and grandmothers during a period of visitation at least 24 hours before the interview was arranged to take place. The opportunity to ask questions where there was a lack of clarity is important for informed consent (Marzarno, 2012). This period was allowed to give grandmothers and their families time to discuss it freely, without interference and to make a joint decision on whether to participate in the study. Written informed consent was sought firstly from the parents of the sick baby because the story being told would have elements of their own experience and their permission was an essential condition from LREC. Secondly, written informed consent for the interview to be recorded was gained from each grandmother herself (steps in the recruitment process are clearly identified in appendix 4). The right to withdraw at any time (Kvale and Brinkmann, 2009) was assured and grandmothers were reassured that withdrawal from the research would not affect their grandchild's care or treatment. In the event no-one asked for further information and no grandmother withdrew from the study once written consent had been obtained. Over the data collection period I approached a total of eleven grandmothers requesting their participation; one cancelled the appointment before consent was signed, two women declined, one baby was transferred to

another hospital, one grandmother did not make further contact and one baby sadly passed away (RIP †) resulting a total of five grandmothers.

Five grandmothers agreed to tell me their story. The narrative interviews took place in a private room in NICU, and once I had told my story which took approximately twenty minutes, grandmothers recounted their stories which were up to forty minutes in length.

Confidentiality arises from the right to privacy and disclosure of information from the participant that had the potential to be sensitive (Punch, 2014). Anonymity and confidentiality were assured in the information letter to the participants. Bound by the Nursing and Midwifery Council (NMC) Code (NMC, 2015) confidentiality and anonymity were maintained by using pseudonyms to replace the participants' names. Even when measures have been taken to anonymise participants they could still be identified if their quotes were used with pseudonyms and demographic data (Morse, 2007). I did not gather any demographic data from grandmothers; I only knew them by their first names and did not have access to their grandchild's medical records. As a member of a professional group, I was expected to conduct myself in accordance with the norms of the group. This is because a role within that professional group (nurse/midwives) comes with its own cluster of rights and duties, powers and permissions (Toy-Cronin, 2018). I was also very aware of my outsider status (to NICU) and that I did not have any access to any medical or nursing records to refer to. Whilst my insider knowledge was vast, I was an outsider as a researcher. In addition, I was concerned about breaching any confidentiality. Attempting to maintain confidentiality, grandmothers' identities and those of the research locations were safeguarded, to this end the names of the NHS trusts were not disclosed and are referred to as NICU 1 and NICU 2. Confidentiality has been maintained by not divulging names or places to anyone other than my supervisors (Tod, 2015; Harvey and Land, 2017). However, these persons have not been able to link the data with the participants.

I interviewed grandmothers an hour before visiting time; this ensured that they still had protected time with their family, and it meant that staff were not aware who I was interviewing and assisted in maintain confidentiality. NICU staff are

well-rehearsed at maintaining confidentiality of their patients, the parents and other family members and are bound by The Code (NMC, 2015).

The Right to Privacy is a necessary condition for maintaining the relationship of trust and respect (Beauchamp and Childress, 2013). It was essential that grandmothers felt safe to talk to me as a grandmother/researcher away from the cot side. A comfortable private room on each NICU was allocated for the purpose of the interviews to ensure privacy and confidentiality and to avoid interruption (Karnieli-Miller, Strier, Pessach, 2009; Tod, 2015). Consent forms were revisited, and the structure of the interview and recording were made clear before commencement. The ethical considerations outlined by IRAS, LREC and Trusts' guidelines were followed diligently in terms of storage and protection of data. I had considered how I presented myself in NICU and I asked for unit managers' guidance on how they expected me to be dressed¹².

3.5 Data Collection methods

Data were collected in two similar NHS trusts NICU 1 and NICU 2. Both were chosen because they were situated in areas of cultural and social diversity meaning that there was the possibility of recruiting grandmothers from a range of backgrounds. I designed a poster (Appendix 6) and hung several in prominent places in each NICU to advertise my research and call for participants. From the five grandmothers I interviewed, only one contacted me through this medium, the other four were recruited by me speaking to them at the cot-side¹³. It is important to note here that I approached grandmothers with extreme care. I was aware of the precarious nature of sick babies, and I always had a conversation with the lead nurse before I engaged with any grandmother (details of recruitment process: appendix 4).

In narrative research the sample is usually chosen for convenience and or purposively (Iphofen, 2005). I chose a convenience or opportunistic sample because there were very few grandmothers visiting their grandchildren who were readily available and who met the inclusion criteria. There was the risk that the

¹² On NICU 1, I wore my university midwifery teacher's clinical uniform. On NICU 2, I had to change into surgical scrubs (as do all staff). On both NICU, I wore a university badge stating, 'midwife researcher'.

¹³ Aware that baby's conditions change on an hourly basis, I always approached the lead nurse when I arrived at each unit and always asked if there were any families that I should specifically avoid so that I would not infringe upon their visiting time.

sample would not reflect the characteristics of the population (Harvey and Land, 2017), however a lack of grandmothers visiting was data in itself. The criterion for convenience refers to those cases that are the easiest to reach under given circumstances (Patton, 2002). A convenience sample was chosen for the reasons discussed below. What was important to me was that the participants had a story to tell and were willing to give their time freely to recount it to me. How people are accessed for research purposes remains a practical problem (Iphofen, 2002). With the emphasis being on obtaining different perspectives from participants (Polit and Beck, 2018).

As already alluded to, one of the major problems I encountered when entering the field that affected my sampling method was that there were no grandmothers. I randomly visited both NICUs during afternoon and evening visiting times, Monday to Friday and at weekends. One nurse commented '*you need to come after 7 O'clock, all our grandmothers are working*'. This was an important point, I had assumed that because my workplace had given me the flexibility to visit my grandson frequently, it was clearly not the case for other grandmothers. After 19 days of visiting both NICU, I interviewed the first grandmother.

The metaphorical images in the theme board I had created are powerful representations of my personal story and resonated with other grandmothers in the course of my research (Image 2; p59: appendix 1). This approach aligns itself to the *performance* in performance autoethnography where the researcher uses their own experiences to consider and examine interactions between their self and others (Savin-Baden and Major, 2013). There is a cautionary note that:

'Taking the threatening path of personal disclosure, the researcher treads a cliff edge' (Finlay, 2002: 532).

I could have had the potential in focusing on excessive self-analysis rather than focusing on the grandmothers. This aspect cannot be overlooked; I needed to ensure that the focus of each interview was on the grandmother herself once my own story had been told. I could have written my story and asked grandmothers to read it however, the performativity of the telling is significant and as Denzin (1989b: 43) asks '*where in the text of the story is the author*'? In telling a story with the use of a theme board (Edgar, 1999; Cross and Holyoake, 2017), it allowed *me in my story* to be heard.

For grandmothers to join me in my space it was important to connect with them on a very personal level. The life story interview brings forth the voice and spirit of the storyteller within life as-a-whole context and achieves the most equitable interpersonal exchange as possible (Atkinson, 2012). Self-disclosure concerning the personal experiences of the researcher often initiates authentic dialogue and opens an opportunity to re-examine their own interpretations and beliefs (Arvay, 2003). In revealing my story to grandmothers, demonstrated that they were not alone on their journey and that I had experienced something similar, the opportunity for them to step inside the personal world of the storyteller.

Researchers interacting with people in clinical areas in times of crisis, should be mindful that their time is precious and limited, particularly since visiting time is so limited (Morse, 2007). The time of the interview was mutually arranged with each grandmother to coincide with them visiting their grandchild. I was sympathetic to grandmothers' needs to be able to visit as normal and be with their loved ones. I arranged with four of the grandmothers to meet an hour before visiting time so that my time with them did not encroach on their time with their grandchild. I arranged to see one grandmother on a Saturday morning, outside of normal visiting times but still in the NICU to comply with ethical approval stipulations of where the interview should be conducted. When I first approached grandmothers at the cot-side, I found that they were willing to tell me part of their story before any formal arrangements had been made. It is these by-chance and informal stories that are important to the initiation and the overall relationship between the participant and researcher (Clandinin and Connelly, 2000).

Interviews are a key principle of autoethnography (Munhall, 2012), narrative enquiry (Holloway and Freshwater, 2007a) and performance autoethnography (Denzin, 2003b). For grandmothers to engage in storytelling, the narrative interview was employed. This is the simplest form of interviewing where participants are asked to share their experiences and are uninterrupted by questions (Holloway and Freshwater, 2007a). This method is well planned and prepared but does not use a rigid structure. From Czarniawska's (2004) three ways of collecting stories, it was the third type that I employed; a story specifically asked for by the researcher attempting to access the thoughts and feelings of the grandmothers. Asking participants to tell their story in their own way means that the grandmothers' intentions are uppermost to the interview (Anderson and Jacks,

1991). After I had told my story first with the use of a theme board, I invited grandmothers to tell me their account of their own experience which also formed part of my observations of them during the interview process (Angrosino, 2008). The initial question should be broad enough to trigger a long story (Holloway and Wheeler, 2010), consequently, I asked grandmothers 'can you tell me your story?'. Thus, giving them control over the interview and as much time as they needed to tell their story.

3.6 Trustworthiness

Bricoleurs seek alternative ways of justifying their interpretive choices rejecting positivist notions of internal and external validity (Kincheloe, 2004a). Indeed, among the difficult problems faced by investigators committed to interpretive practices is deciding whether an interpretation is credible, truthful and whether one interpretation is better than another (Schwandt, 1986). Lincoln and Guba's (1985) post-positivist paradigms namely, credibility, dependability, confirmability and transferability addresses those limitations of positivist research offering ways of assessing the quality of narrative analysis. Lincoln and Guba's (1985) framework will be used to address issues of quality in this analysis (table 2, p74). A further criterion of trustworthiness is whether the narrative evokes emotion in the reader (Duffy, 2012). I would argue that the narratives of grandmothers in this study, do indeed, evoke emotion. I was bound to successfully defend interpretations of emotional narratives into the post-positive paradigm of trustworthiness (Schwandt, 1986; Frank, 2004, 2010, 2016; Sandelowski, 2006).

Table 2: Four dimensions criteria (Lincoln and Guba, 1985, after Forero *et al.*, 2018).

Rigour Criteria	Purpose	Original strategies	Strategies applied to this study
Credibility	To establish confidence that the results from grandmothers are true, credible and believable	<ul style="list-style-type: none"> • Varied engagement with each setting. • Interviewing process and theme board. • Peer debriefing. 	<ul style="list-style-type: none"> • Established contact with both sites. • Researcher had insider knowledge and experience of sites. • Researcher had required knowledge and skills to perform role.
Dependability	To ensure the findings of this enquiry are repeatable if the enquiry occurred within the same cohort of participants, context and researcher.	<ul style="list-style-type: none"> • Rich description of the study methods • Establishing an audit trail. • Three step approach to analysis. 	<ul style="list-style-type: none"> • Developed track record of the data collection process. • Field notes • Verbatim transcripts from digital recordings. • Debrief records
Confirmability	To extend the confidence that the results would be confirmed or corroborated by other researchers.	<ul style="list-style-type: none"> • Reflexivity • Epilogue and prologue 	<ul style="list-style-type: none"> • Reflexive journal. • Theme board • Lens of interpretation
Transferability	To extend the degree to which the results can be generalised or transferred to other contexts.	<ul style="list-style-type: none"> • Purposeful sampling 	<ul style="list-style-type: none"> • Detailed verbatim transcripts • Individual fictional novels (Atkinson) • Contextuality • Intertextuality. • Thick description.

My approach to analysing the narratives in three steps has been a lengthy process and has resulted in my being immersed in the data providing a way of exploring, describing, re-telling, and teasing out the multiple threads that make up the distilled patchwork of meanings. Peer debriefing is a technique of establishing credibility with an expert peer reviewer who scrutinises transcripts for trustworthiness and credibility (Sandelowski and Barroso, 2007). I chose not to use member checking to ensure trustworthiness, instead expert peer debriefing was conducted with my first supervisor. This enabled 'honesty' in the transcripts and the basis for interpretation was explored. Debriefing should offer catharsis and allow the researcher to clear their mind of emotions that may cloud their judgment (Lincoln and Guba, 1985; Morse, 2015). However, I would justify that my emotional attachment to the narratives could not be separated and in effect, adds to the context and intertextual basis of their interpretation. My engagement with grandmothers was established quickly, with a mutual connection. It is those relationships and rapport that lead to descriptions of human experiences that are immediately recognised by others who share the same experience (Cope, 2014).

For these reasons, I chose not to give the transcripts back to grandmothers for member checking. Returning scripts to the participants (for member checking) runs the risk of participants correcting or re-telling their story (Czarniawska, 2004). Indeed, participants may not recognise their own stories or understand the form of language used (Sandelowski, 1996). Whilst this aspect may be the case, there is the risk that participants may alter, add to, or reject the transcript (Czarniawska, 2004). It is not clear why a participant should be given the opportunity to change her mind; it is not required for any other type of research (Morse, 2015). Member checking is not practical, it can constrain the researcher (Birt *et al.*, 2016) and if the participant does not agree with the analysis, it puts the researcher in a difficult position. Stories, phrases, words, manners of speech are not static; they all continue on their own trajectory (Crowther *et al.*, 2017). I wished to have a 'here and now' account of grandmothers' stories not one that was changed on a different day because their situation had changed or that they had forgotten to talk about something during their storytelling. Member checking was developed when qualitative researchers were trying to gain recognition for the rigour in their work alongside more traditional positivist researchers (Birt *et al.*, 2016). For these reasons peer debriefing was my chosen method of

establishing trustworthiness and authenticity. Context in this respect along with reflexivity awards the findings of this enquiry credible (O'Connor, 2011).

The maintenance and clarity of an audit trail so that dependability can be assured is seen to be one aspect of trustworthiness (Holloway and Freshwater, 2007a; Morse, 2015). This was achieved by keeping field notes, an interview diary and records of debriefing with my supervisor. The conditions in which the interviews were undertaken have some bearing on what was told, conditions in hospitals change (Connelly, 2016). This could have had an influence on the way the story was told on that day, at that time and whether those stories would be the same the day before or the day after, and if it would affect the dependability of the data will never be known. However, my treatment of the data has been consistent with each story, with the same robust analytical processes applied. Dependability of this study has been attempted but is subject to many variable circumstances that may mean that the narratives could be altered but the treatment would remain the same.

There is a view that 'the only generalisation is, that there is no generalisation' (Lincoln and Guba, 1985: 114), I found it a challenge as a qualitative researcher to make generalisations. To establish transferability of findings it is the responsibility of the researcher to ensure that the reader can make inferences about extrapolating the findings to other settings (Polit and Beck, 2018). This is achieved by the thick descriptions in the narratives being written as a fictional story, adding both contextuality and intertextuality to the narrative as one aspect of the three-step approach of analysis. Context is crucial in narrative research and in describing and applying in detail the analytical process (Lincoln and Guba, 1985; Holloway and Freshwater, 2007b). Therefore, I have enabled potential applicators to make that transferability due to the clarity of the data analysis.

Attempting to assure quality standards in a post-positivist enquiry, trustworthiness, in this study has been assured by applying Lincoln and Guba's (1985) four- dimensions criteria to the study findings. The clarity of how the main patches have been reached using a reflexive journal, field notes, interview diary, expert peer debrief, the theme board, verbatim transcribing and thick description have demonstrated transparency and thus, achieved meaning and trustworthiness.

3.7 Chapter summary

In this chapter I have discussed my position as a researcher within this study and have addressed the data collection methods. I have also recognised the needs of grandmother's voices to be heard using a unique hybrid methodology of performance autoethnography and narrative enquiry. The strict ethical considerations of interviewing grandmothers in two NHS NICU have been discussed and justified. The interconnection between my position as a grandmother with a sick grandchild within this enquiry and the need for reflexivity has also been made. The use of a theme board in the interviewing process has been highlighted and arguments made in using such a medium for the purpose of performance within this study. I have debated quality assurance methods in this enquiry and how they have been achieved.

In the next chapter I will discuss the analytical framework I employed to analyse five grandmothers' stories. I will show how the metaphor of the fabric of their stories combined with my own story can be intertwined and sewn into a patchwork quilt, with central patches, layers and a border.

Vignette four: Melissa

I'll send him back ready to be a dad

Melissa quickly packed a bag that included a nightdress; two pairs of Marks and Spencer (Collection) trousers; three blouses; some comfortable shoes; a coat; a cardigan and underwear (again M and S); as well as the book she needed to finish. She drove non-stop for four hours, the only thing that kept her awake was BBC Radio Four- The Film Programme; Inside Science; The News; The Archers and Front row all kept her company on the long drive to the Midlands hospital where Christian, Ellen and the new baby were. By the time she arrived at 8 O'clock in the evening she was pretty shattered. She eventually managed to park her car and after negotiating the hospital entrance that was surrounded by luminous yellow looking patients in wheelchairs smoking their last cigarettes of the day, she arrived at the Neonatal Intensive Care unit where her granddaughter was being cared for. She found her son there, who fell onto her weeping. All of the family, everybody was terrified. Baby Iris and Christian were together, and his wife was extremely ill in another part of the hospital. The midwives had been very kind in trying to help him, but he is very young, only twenty-five. He went from "I'll let you know when you can come" to crying on Melissa's shoulder saying to her, "I'm so glad you're here".

Chapter 4

Analysis: Quilt making

4.0 Introduction

In this chapter I share the unfolding narratives of five grandmothers, namely, Sarah, Rajinder, Grace, Melissa and Susan, using a three-step analytical re-storying model. Since performance underpins the methodological framework of this enquiry, I was determined to align the analysis with the performative elements of the methodology. I discovered that choosing, justifying and applying an analytical strategy were not without its challenges. Therefore, the process and choices I made in developing an analytical model will be shared and justified in this chapter.

The analytical process is not necessarily linear or organised and reassuringly, there is no right or wrong way and no standard formula for success (Lathlean, 2015). The aim of this chapter is to defend the use of a three-step approach to analysis of the data. Firstly, writing grandmothers' narratives as a fictional story using Atkinson's (1995) novel 'Behind the scenes of the museum' as a basis for my writing. Secondly, Frank's (2010) Acts of Interpretation to frame grandmothers' stories and thirdly to defend how my own story relates to the grandmothers in this study. The chapter concludes with an introduction to the main data findings in the form of a patchwork quilt.

4.1 The Analytical Process

Offering grandmothers the opportunity to tell their stories *to* me and *with* me created the chance for the mutual exchange of experiences. Here there was an entering of each other's spaces and the valuing of the telling of our stories together. The richness of grandmothers' narratives cannot be underestimated, their frank and detailed stories required sympathetic and respectful interpretation. In performing my story with the aid of my theme board, grandmothers entered *my space*; grandmothers then told me their stories and I entered *their space*. The reciprocated sharing of each other's spaces meant that their stories could be told freely and establishing a rapport can help participants and interviewer have a shared understanding (Darlington and Scott, 2002). In experiencing a similar road

to the grandmothers, the original contribution I make to the body of knowledge is underpinned for all six of us by biographical routes (Denzin, 2014).

To think *about* a story reduces its content, to think *with* a story is to experience it affecting one's own life and to find in that effect a certain truth of ones' life (Frank, 1995). This is not just an empathic knowing, more a felt, embodied experience that made for a mutual understanding (Etherington, 2005). The genre of family stories was available as performed stories (Hyvärinen, 2015) and in this study were performed by grandmothers in their own way, chronologically, detailed and eloquent. Each story was an individual account of a very personal experience. However, not all stories fit into strict models of analysis therefore, I created a new three-step approach to show the stories in the creative genre (Image 4).

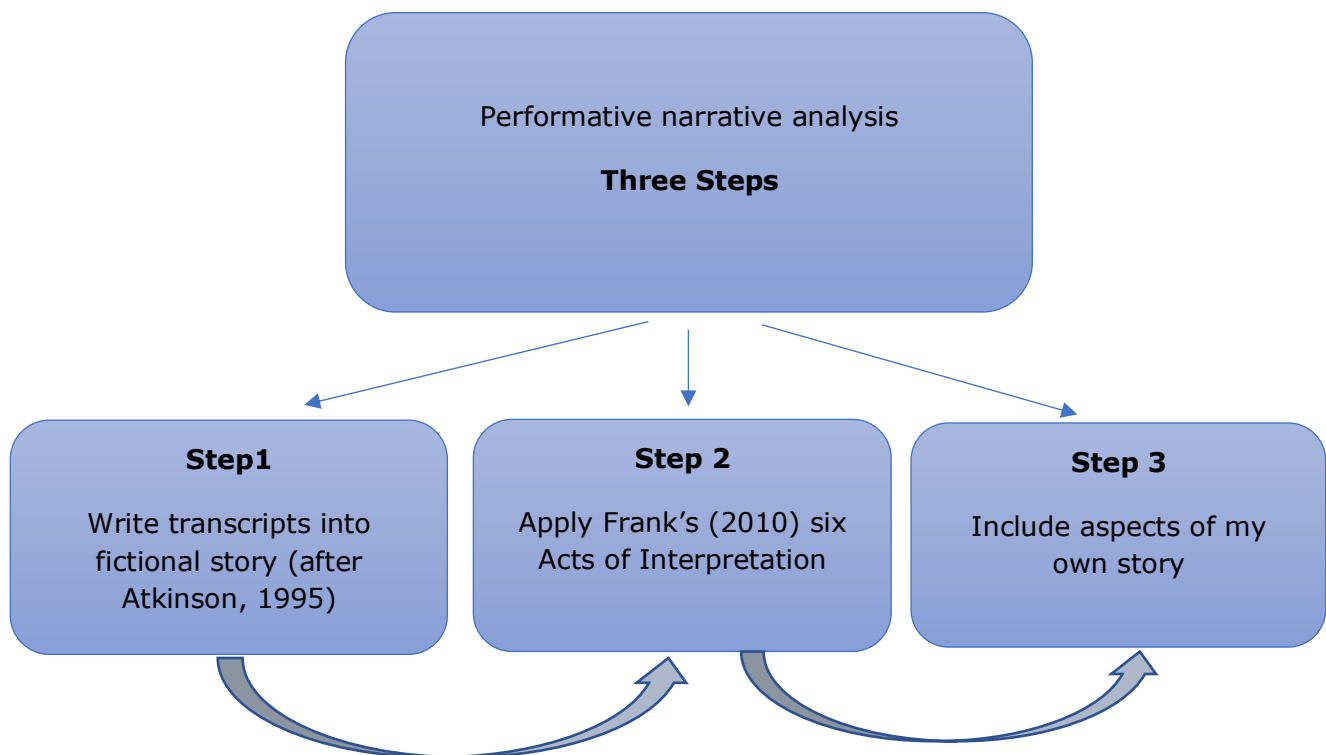


Image 4: three analytical steps.

Narrative researchers can be regarded as impresarios, encouraging the creation of aesthetic and artistic performances through the telling of life stories (Duffy, 2012). I created the three-step approach so that the performance was not lost in my interpretation, more it continued through in fictional stories and my own story. Communication of the story is dependent upon three elements, namely the story,

the narration and the audience. Who listens and hears or reads to the stories are as important as who tells them (Chase, 2008). Therefore, the analysis needed to be sympathetic and aesthetically effective. There is some variation within the performative approach the use of poetry, artwork, drawings, drama and photographs have been used (Holman Jones 2008; Casey and Webb, 2018; McGarrigle, 2018; Stavropoulou, 2019). However, these authors do not cite the use of fictionalising the stories as a means of presentation. Whilst there is little of it in the literature, I followed Reissman's (2006) ideas of contemporary interpretation, to support my ideas of fiction as a technique of presenting grandmother's stories.

Interesting stories are always the key to engagement (Radiano *et al.*, 2017) and in creating fictional stories, it allowed me to engage in an analytical process that required an in-depth understanding of the transcripts. The use of prose, poetry, images (Berridge, 2008) or the art of the novel that can tell us about another's experience can be pointed and precise (Ungar, 2011); as well as the use of lyrical writing to create experiences of events (Brinkmann, 2009). I required a medium to express grandmothers' narratives that illuminated the complexity and individuality they held. Writing grandmothers' stories as a work of fiction I was able to encapsulate the drama and how their stories define reality in this fresh and creative medium and formed the first part of my literary analysis (Tedlock, 2011; Kolhatkar, 2017). Creatively writing fictional accounts with attention to literary style is factually accurate (Tedlock, 2011). The application of the three analytical steps enabled me to see the big picture by constructing fictional stories (Atkinson, 1995), and in using the Acts of Interpretation (Frank, 2010), I have been able to reduce the pieces or 'small story' of the patchwork to a whole sewn-up quilt or 'big story'.

I started my analysis by reading and re-reading the transcripts from the interviews and crafting stories from them in the style of Atkinson (1995). I required the narratives to represent the individualised story of each grandmother. I used Polkinghorne's (1995) ideas of narratives as stories, this way I could craft stories from the narratives as a linguistic form that preserves the complexity of human action and its relationships with temporal and environmental contexts. The methods I employed in the analysis of narratives sought to analyse the stories for the experience they contain, eliciting threads from the stories and the

relationships between them. It was important to analyse the stories as a work of fiction, for me to encapsulate the drama and the emotion they contained.

Giving voice to stories that can be difficult to tell, can be achieved by fictionalising them since this method can help examine voice, marginality and understanding (Davis and Warren-Findlow, 2011). It was the creativity in producing stories as a step in the analytical process that generated ideas. The standards for scholarly fiction should evoke aesthetic pleasure, understandings derived from narrative coherence and verisimilitude, and an enhancement of emotional resources (Banks, 2008). Grandmothers' narratives themselves contained drama, emotion and expression, and could have been presented without any fictional treatment. I have extended the editing and re-writing of their stories, taking them one-step further in fictionalising and developing the characters that are central to the stories themselves (Müller, 2017). The characters in the narratives were sculpted from the contributions the grandmothers made using their own stories and including other family members in their narratives. In writing the stories in this way, I have aligned myself with D'Angelo's (2009) first mode of intertextuality which is adaptation; this is the change of medium from interview transcripts 'the data' to fictional stories and has enabled me to 'show' grandmothers' stories in an alternative way. Adaptation in this context is the recasting of rhetorical text into a new form (D'Angelo, 2009).

I will justify here the use of Kate Atkinson¹⁴ as a contemporary novelist who enables her readers to gain a deep understanding of both contemporary and historical understanding of social life, thereby making a significant contribution to my analytical reasoning. There are parallels between Brinkmann's (2009) use of Houellebecq and my use of Atkinson's 'Behind the Scenes' style; I would argue their writing of human lives, experiences and sufferings enable us to learn from their characters than from more traditional forms of empirical research. This type of artful emotional documentary discourse has emerged as a powerful literary genre, infused with rhetoric and metaphors (Davis and Warren-Findlow, 2011; Tedlock, 2011). Certainly, passages from fictionalised narrative can be evocative

¹⁴ Kate Atkinson won the [Whitbread](#) (now Costa) Book of the Year prize with her first novel, [Behind the Scenes at the Museum](#). Her 2013 novel [Life After Life](#) won the South Bank Sky Arts Literature Prize, was shortlisted for the Women's Prize, and voted Book of the Year for the independent booksellers associations on both sides of the Atlantic. It also won the Costa Novel Award, as did her subsequent novel [A God in Ruins](#) (2015).

and are an embodied and personal understanding of the subjective experience (Rhodes and Brown, 2005) grandmothers recalled. In addition, for Grace's story the novel of Ngozi Adichie¹⁵ has been nominally drawn upon to illustrate her African narrative.

Using Atkinson's (1995) style of writing to represent grandmothers' narratives gave me a freedom to express their words and to develop a plotline in-keeping with their individual story. What developed from the narratives were, voice, fictions and performance. These stories became my analytical foundation, from which Frank's AOI (2010) were then applied.

4.2 Three steps of analysis

There is more to a story than 'telling a good yarn' (McCormack, 2009: 142). Because of the 'yarn', I am drawn to the image of woven fabric as a metaphorical illustration of the emmeshed strands I have used to analyse the narratives (image 5). The image shows how those threads combine to make a complete piece of fabric. Elements of that fabric will later become a patchwork quilt:

- The **Selvedge** depicts Atkinson's (1995) 'Behind the Scenes' that threads through the fabric anchoring all the fibres together, preventing fraying and acting as a binding. Without the selvedge the fabric of analysis will fall apart.
- The **Warp** is my story that is the stationary longitudinal threads of the fabric and is the foundation of the fabric.
- The **Weft** is the interwoven threads that are drawn in and inserted over and under the warp threads of 'Acts of Interpretation' (Frank, 2010).

¹⁵ Ngozi Adichie, C (2017) Half of a Yellow Sun is set in Africa which is where Grace lives. I referred to this novel for Grace's story to compliment her African culture.

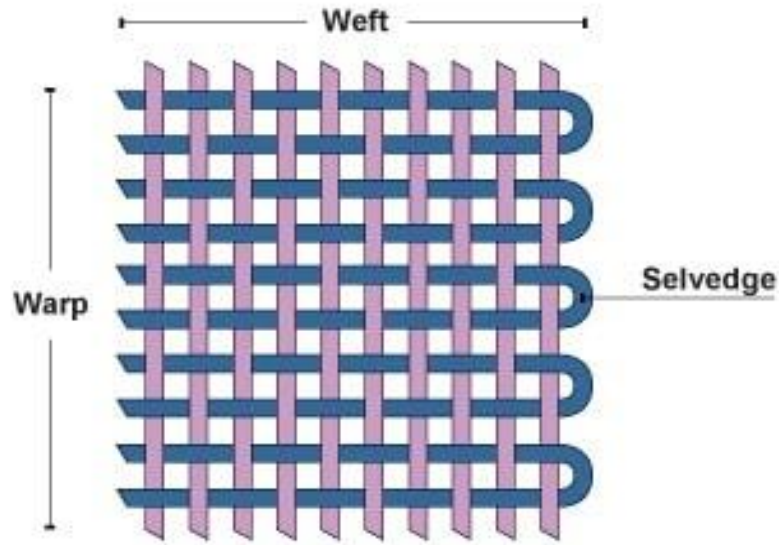


Image 5. The fabric of analysis

Step one: Stories written as fiction (The selvedge).

In writing grandmothers’ stories into fiction, I took the stance to write some stories from another’s perspective (table 3) which interconnects with Frank’s (2010) Acts of Interpretation (table 4: No 2: p86). I was also influenced by McHaffie’s (1994) novel, *‘Holding On?’* which tells the story of a baby in NICU from the perspective of the people involved in his care¹⁶. A representational quote from the interview text that epitomised each woman’s experience was placed alongside it (Beal, 2013) becoming the title for her story.

Narrator of grandmothers’ story¹⁷	Title of story
Rajinder’s story told by herself	<i>I cried for everyone.</i>
Susan’s story told by her daughter	<i>The face my husband sees.</i>
Grace’s story told in the third person	<i>I am far, and she is here.</i>
Melissa’s story told in the third person	<i>I’ll send him back ready to be a dad.</i>
Sarah’s story told by herself	<i>A roller coaster.</i>

Table 3: narrators and titles of grandmothers’ stories

¹⁶ Consultant, nurse, mother, chaplain.

Creative analytical practices, including literary devices drawn from fiction, allow the social researcher to better portray real events (Grant, 2010). Multiple perspectives of a story begin the translation (Frank, 2010). The retelling of a story from another point of view can shift a central character to the periphery or vice versa (Frank, 2010). I was careful to ensure that each grandmother remained central to her own story even when told from this alternative perspective. The writing of fictional stories became the first step of analysis which is where I discovered that there were similarities, differences and strands in each story, revealing both the individual and collective nature of experience (McCormack, 2009). The use of fictional methods should not be synonymous with falsehood, arguably, it facilitates telling tales in a dramatic and enjoyable way (Grant, 2010). The distinction between fact and fiction can be muddled (Clandinin and Connelly, 2000); therefore, I have been meticulous in my interpretation of the narratives that the fundamental fictional story is a faithful reflection, without embellishment of what grandmothers said. There is an inescapable responsibility of authorship when representing participants' lives (Richardson, 1990), and it was imperative that I adhered to this responsibility in my fictional accounts. In using fabric as a metaphor for the analysis, I make the point that this does not mean that stories were fabricated.

Step two: Acts of Interpretation (The Weft).

If the stories are defined with a beginning, middle and end that reveal grandmother's experiences, narratives can take many forms, in many settings, before many audiences and with various degrees of connection to actual events or persons. Thus, themes, principal metaphors, definitions of narrative, defining structures of stories are often described poetically and artistically and are context bound (Manning & Cullum-Swan, 1994). All of which all have an important bearing on the fictional stories I created. Interpretation in its hermeneutic and dialogical tradition (Frank, 2010) is, less a matter for me of decoding stories than seeing all the variations and possibilities inherent in the grandmothers' stories. I have opened myself up to these possibilities of the fictional story and in my analysis of grandmothers' stories and is more of an ongoing dialogue with the story.

Frank (2010: 97) coins the phrase 'dialogic narrative analysis' which led me to apply Frank's (2010) six Acts of Interpretation (table 3) where the interpretive

framework encouraged me to look at grandmothers' narratives in considerable detail. In my contribution to the analytical framework, I have used these six steps as lenses in which to interpret grandmothers' stories to look for commonalities in those fictional stories. I have not used the steps in sequential order rather, in a random fashion depending on each individual story itself and I have named them for the purpose of this analysis, '**Lens of Interpretation**' (LOI). Where any of the steps have been applied within the analysis, I have created a table of how and where Frank's LOI are applied in the analysis (table 4). Frank's (2010) six Lens of Interpretation (1-5) can be seen woven through the findings in the following chapter (a more detailed analysis of Frank's LOI is in Appendix 7). To address the sixth LOI '*appreciate the story and storyteller*', a poem was written (Sherwin, Cross, Holyoake, 2014; Stenhouse, 2014; Edwards, 2015; Cross, 2016; Cross and Holyoake, 2017) (appendix 8) for each grandmother to illuminate her personal experience.

Frank (2010) Lens of Interpretation (LOI)
1. Telling stories through images- seeing the story off the page
2. Telling the story from another character's perspective- imagining their possibility
3. What are the details that might have been omitted? - there is no presumption of a hidden text to be uncovered
4. The differences between the storyteller and the analyst-interpretation finds a better beginning in difference
5. Slow down- listen and wait. Not only in the interview but also when interpreting the stories- go for a walk.
6. Appreciate the story and the storyteller (write letters/poems- but not sent).

Table 4: Frank's Lens of Interpretation.

Step 3: My Story (The Warp)

A story can only be subjective, offering a perspective on experienced reality (Holloway and Freshwater, 2007). My story or the warp in metaphorical terms, underpins the fabric of grandmothers' stories. Here, my story is not separated but as stationary tension threads that is a constant feature throughout. Deep-seated memory as a process of continuous construction (Smorti, 2011) allowed me to tell my story of being a NICU grandmother, openly and authentically. Autobiography

is a text of power relationships that can be problematic (Berry, 2004). However, when I listened to the recordings, I realised that I had told five slightly different versions of my own biography in my interactions with grandmothers. My story did not fundamentally change, and in the telling of it, the theme board was an anchor on which to hang my story. However, when I listened back to the recordings and re-read the transcripts, each grandmother reacted differently to my story and some interjected with their own thoughts or experience along the way, Rajinder is an example:

- 'As you do, yeah'.
- 'There's nothing you could do'.
- 'I know, I know the feeling'.
- 'Try to keep yourself busy'.

Whereas Grace, listened and nodded, rather than speaking, both are examples of the 'gestured duet' (Finlay, 2012). Whilst their reactions were all different the main autobiographical content of my story remained the same, but the words and order were slightly altered each time.

In analysing an autobiographical text (Keats, 2013), I have opened and presented strands that were integral to my story and were reflected to some extent in grandmothers' narratives. The differences between my biography and the participants were that I had a clinical understanding of my grandson's condition where they did not have such a clear perception, in addition, my grandson by now was three years old and well. An example of how I applied all stages of the analytical process the data can be seen in table five (p 88).

It could be, in searching for patterns or teasing out of a text the common threads, the real stories of human beings are not lost (Franzosi, 1998). It is crucial in the analysis of grandmothers' stories that they remain whole and are not fractured in my analysis. Snippets of those stories though provide common patches that when sewn together create a patchwork quilt and are presented in chapter five. Representing interview transcripts is a crucial consideration and includes retaining the situated nature of the participant's experience, highlighting the individuality and complexity of a life and includes the multiple voices of the researcher and participant (McCormack, 2004). In my analysis of grandmothers' narratives, I looked for common threads in each story. I did not want the threads to become

generalisations since this would make grandmothers fade into support roles. Rather than overarching categories, a downwards reduction yielded a different kind of text (Clandinin and Connelly, 2000). I aligned myself to Atkinson and Delamont (2008) who advocate looking for common properties, recurrent structures and recognisable genres.

Table 5: Steps in the analytical process.

Original Interview text	Step 1. Fictional story (Atkinson) The Selvedge	Step 2. LOI (Frank) The Weft	Step 3. My story The Warp
<p>Nobody knew what was happening and he is a first-time dad, holding a newborn baby and said, "please come mummy". I live 4 hours away. I got in my car and drove. I got here at about 8 O'clock in the evening and Christian just fell weeping on me. All of them, everyone was terrified.</p>	<p>Melissa quickly packed a bag that included a nightie; two pairs of Marks and Spencer (Collection) trousers; three blouses; some comfortable shoes; a coat; a cardigan and underwear (again M and S). She drove non-stop for four hours, the only thing that kept her awake was BBC Radio Four- The Film Programme; Inside Science; The News and The Archers all kept her company on the long drive to the Midlands hospital where Christian, Ellen and the new baby were. By the time she arrived at 8 O'clock in the evening she was pretty shattered. She found her son there, who fell onto her weeping. All of the family, everybody was terrified</p>	<p>1. Seeing stories off the page</p> <p>3. details that might have been omitted.</p> <p>5. slow down- listen and wait.</p>	<p>I also had a journey to take both physically, emotionally and metaphorically when my grandson was born and has parallels with the women in this study.</p> <p>We arrived at the hospital, we could see that ambulance was there at the entrance and the ambulance doors were open and the ramp was down; 'he's here' said Tom and we knew that he had arrived safely.</p>

4.3 Active listening

The analytical process begins with the researcher immersing themselves in the interview data to gain detailed insights (Tamalge, 2012; Noble and Smith, 2013). In listening to the digital recordings of the women's voices and reviewing the transcribed stories facilitated reflection of the 'emotional heat' of the moment (Holloway and Freshwater, 2007a), linking my memory of that account. I was mindful that my own history using my theme board preceded each grandmother's story. This is in-line with Georgakopoulou's (2017) notion of the story-opener or story-prefacing devices thus, presenting a shared experience and showing grandmothers that I understood their situation and potential story. Grandmothers in this study did use story-openers as Georgakopoulou (2017) describes. These are usually a time or place to an event and how that event needs to be understood and is illustrated by Grace:

“I came here first when she was pregnant with the first one and she told me ‘mummy I am pregnant’. I was in Africa, so I says “Okay, I will buy a ticket to go to England”” (Grace).

Listening to my retelling of my own story helped me to gain a perspective and focus of the experience and reminded me of the reasons the stories grandmothers were about to tell me would be invaluable to this study. The self-story positioned me at the centre of the narrative (Denzin, 1989a). I had been concerned that when researching incommensurable stories, I might have wanted to take sides or have a particular opinion that supports one set of stories over another (Etherington, 2004). However, I was reassured when listening that this was not the case and an objective understanding of each of the women's personal social contexts developed as her story unfolded. The retelling of stories raises the question of who owns the story with the blurring of ethical concerns and negotiated relationships (Clandinin and Connelly, 2000). In the retelling of grandmothers' stories, I have been careful to re-tell them in such a way that they would still recognise their story as their own. However, it is the retelling of stories that become a principal analytical technique (Duffy, 2012).

It is the meaning that storytellers select of the stories they tell to convey the meaning they intend the listener to take from the story (Hill Bailey and Tilley,

2002). (Re)presenting the transcribed words as prose echoes Cross (2016) who created poems from the spoken word, the process in this study is similar involving culling and playing with words, phrases and segments to arrive at an '*evocative distillation*' or *fictional story* (Cross, 2016: 9). Listening to narratives with reflexive learning, critical thinking requires the listener to uphold and discover the contextual and intertextual elements of stories (Kehler, 2016).

4.4 Locating the narrative

Initially I located stories in the narratives which were obvious, transparent and clear. Within each story there was a beginning (orientation) and an end (coda) (Reissman, 1993). These are the boundaries to each story, and each also includes abstract (summarising the point), an evaluation (highlights the point) and a series of linked events mostly organised chronologically rather than thematically (Bell, 2009). A story recounts a discrete set of events with '*sequential and temporal ordering*' (De Fina, 2003: 13) and spatial ordering, *where* a sequence of events unfolds (Reissman, 2012). Storytellers often take time to add descriptions of people, places and other details to give context to their story (McCormack, 2004); and whilst these elements do not offer much in the way of interpretation or explanation, they do add to the overall picture of the story and the narrative process. If participants believe that this detail is important to tell (Phoenix, 2008) then as a researcher I believed it was necessary to attend to it in their versions of their story

Stories can include all aspects of an experience, can have elements missing or aspects of the story taken out and put back in again until the correct fit is found (Frank, 2010). The researcher will not always know what is missing, exaggerated or incorrect, therefore recognising these factors made me aware that grandmothers' stories may be incomplete or embellished. Storytellers make narrative decisions on what to include and leave out of a story, the style of narration, the place where the story is told and the audience (Harvey *et al.*, 2000). The *narrated* refers to actors, characters, scenes in stories, the *nonnarrated* is everything not included in the story, and *disnarrated* are elements that are narrated in the story but did not actually happen (Vindrola-Padros and Johnson, 2014). Here I make the case that *disnarrated* is where grandmothers have hinted at something within their story but have not fully engaged with it. The *disnarrated* is a useful analytical tool as points to storytellers' views of what is acceptable or

desirable in their worlds (Vindrola-Padros and Brage, 2017). Applying this theory to grandmothers' stories, all grandmothers included characters and scenes, so all stories were fully *narrated*. Grace omitted to tell me that her own daughter had been born prematurely, therefore she had a *nonnarrated* aspect to her narrative. Melissa hinted that her daughter-in-law's parents were unhappy that she had stayed overnight with the baby in NICU and thus aspects of her story is *disnarrated*.

To provide a more coherent account, I reorganised the story data via temporal ordering into a more chronological sequence, resulting in the narrated story having a structure, a beginning, middle and end which has analytical implications textually, contextually and intertextually (Polkinghorne, 1995; Tomkinson, 2016). Language is central to the analysis of an interview, it functions to construct individual identity (McCormack, 2004; Dibley, 2011). Looking through the lens of a researcher I needed to examine three language features, namely:

1. What is said

Word groupings or phrases (of course; it was natural that); signal a request for understanding (you know?); words that make space for thought (umm); specialised vocabularies (specific to their community); metaphor and imagery. This is illustrated in Susan's story:

'I felt I was swimming alongside my son'

2. How it is said

Active/passive voice; speech functions (questions; statements; exclamations); personal pronoun (we, I, you); occurrence of internal dialogue (I said, then I said). This is observed in Rajinder's story:

"She's got this condition- pre-eclampsia. What the Hell! What's going on innit?"

3. What is unsaid

Includes periods of silence, tone, speed of delivery, inflections, emotions and hesitations. Grace demonstrates this in her story:

"It's just like...it's just like...the same".

Consistent with the ethos of this study, I felt it was important to remain faithful to the grandmothers' voices and re-present their stories using their words and colloquialisms whether Black Country dialect, African dialect, estuary English or a combination of cultural language used. In keeping the grandmothers' voices distinct I believe that the real power of each unique experience has been captured. (Melissa's story is told in full in appendix 9). From the threads in each story, I grouped them into patches to create a quilt of findings.

4.5 The patchwork quilt of findings

The metaphor of fabric as an analytical structure in which grandmothers' narratives were synthesised. Taking this metaphor of fabric one step further, I have created a patchwork quilt of the main patches from grandmothers' narratives, showing the stiches and sewing together that I identified in those narratives. The three patches are:

Central Patch 1: Getting there (to NICU)

Central Patch 2: Getting in (to NICU)

Central Patch 3: Staying in (NICU)

Sewn alongside the central patches to create a patchwork quilt are six other patches, namely, 'journey', 'maternal instinct', 'emotion', 'stepping in and stepping back', 'coping' and 'life goes on' (image 6: p93). Extracts from the fictional stories I developed are sewn to the central patches. Each central patch is bound by a prologue paving the way for those extracts to unfold and are concluded with my own reflexions drawing attention to the complexity of the grandmothers' stories (McCormack, 2004). Subjectivity is not a contaminant in research (Etherington, 2004). Therefore, I have addressed my own subjectivity within the text reflexively, showing my self-awareness and self-exposure, holding myself accountable to the standards of knowing and telling.

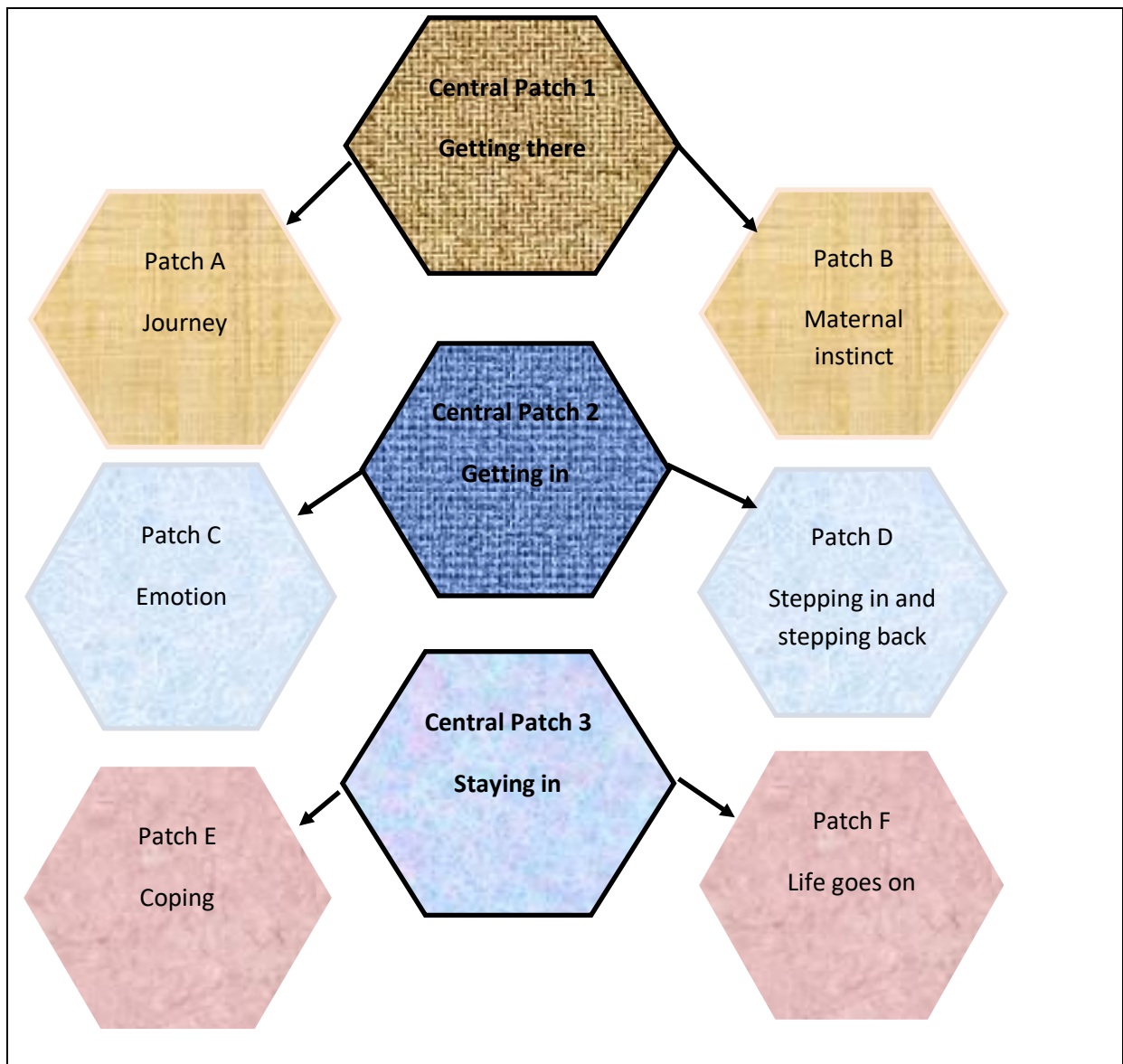


Image 6: Emerging pattern of patches.

4.6 The layout

4. 6.1 Patches

From placing the patches together in a pattern, I have been able to sew together some commonalities I found in grandmothers' stories, so that they appear in this basic structured template. I ultimately have sewn together all the patches to form a full quilt-like piece (image 7: p97). Aligning myself to Wickham (2007), I used the skills of needlework and have arranged the patches into a metaphorical quilt which has parallels to Mishler's (1999) love of crafts. These metaphors resonate

with me, and I have felt drawn to these symbols whilst aiming to place all the patches of grandmothers' stories and sewing them into a finished quilt. Recurrent content can be identified when narrators retell the same story even if they use different words, but recurrent storylines are often embedded within different types of stories (Phoenix, 2008). In this study three central patches were discovered which act as anchors to the raw edges of other patches and are sewn together into the quilt of grandmothers' stories.

4.6.2 Texture

The patches are made from textured fabric, illustrating nuances that gives the quilt intricacy and shows how grandmothers' stories have density and complexity. By analysing the elements of experience, the handling of time, contextualising the role of the storyteller, and the integration of these factors it is possible to trace developments in the texture of personal stories (Dixon and Stratta, 1986). The patches themselves have boundaries and it is the blending of texture and structure that shows the stories are more evocative of the complex experiences of each story (Todres, 2008). The fullness and richness of stories create a layered and textual quality to the quilt, showing that grandmothers roles have many layers and tiers. Complexity does not mean complicated or chaotic, it is more dynamic, self-organising and adaptive (Downe, 2010). Grandmothers in this study were in a state of flux and constant change as the condition of their grandchild altered. This led to a density to their stories that were not linear but constantly changing, which adds to the texture in the fabric of their stories.

4.7 Bricolage

By interpreting and analysing the data I discovered that I had become a *bricoleur* in reworking the stories into a different and artistic form (Wibberley, 2017). Mythical meaning-making bricoleurs combine their imagination with whatever knowledge tools they have at-hand in their repertoire, with artefacts such as stories and images (Levi-Strauss, 1966). Bricoleurs use the tools available to them to complete a task (Kincheloe, 2004b), as a keen sewer, knitter and embroiderer, I was able use those tools both physically and metaphorically to sew together the patches of grandmother's stories. The quilter stitches, edits and puts the patches together this draws the patches together in a pattern or an interpretive experience (Denzin and Lincoln, 2011). Bricolage implies the fictive and imaginative elements

of the presentation of formal research (Kincheloe, McLaren and Steinberg, 2013). As an artist combines pieces of pictures (theme board), texts (stories) or fabrics (quilt) to create a new and original illustration (Kinn, *et al.*, 2013); I have created a patchwork of those bodies of text to give artistic flourish to the narrative. There are also parallels here with Atkinson's (1995) style of writing since there are multiple voices, different textual and contextual formats, the non-sequential ordering of her chapters that eventually draw together the central patches of the story to expose a secret, a mystery or hidden tale.

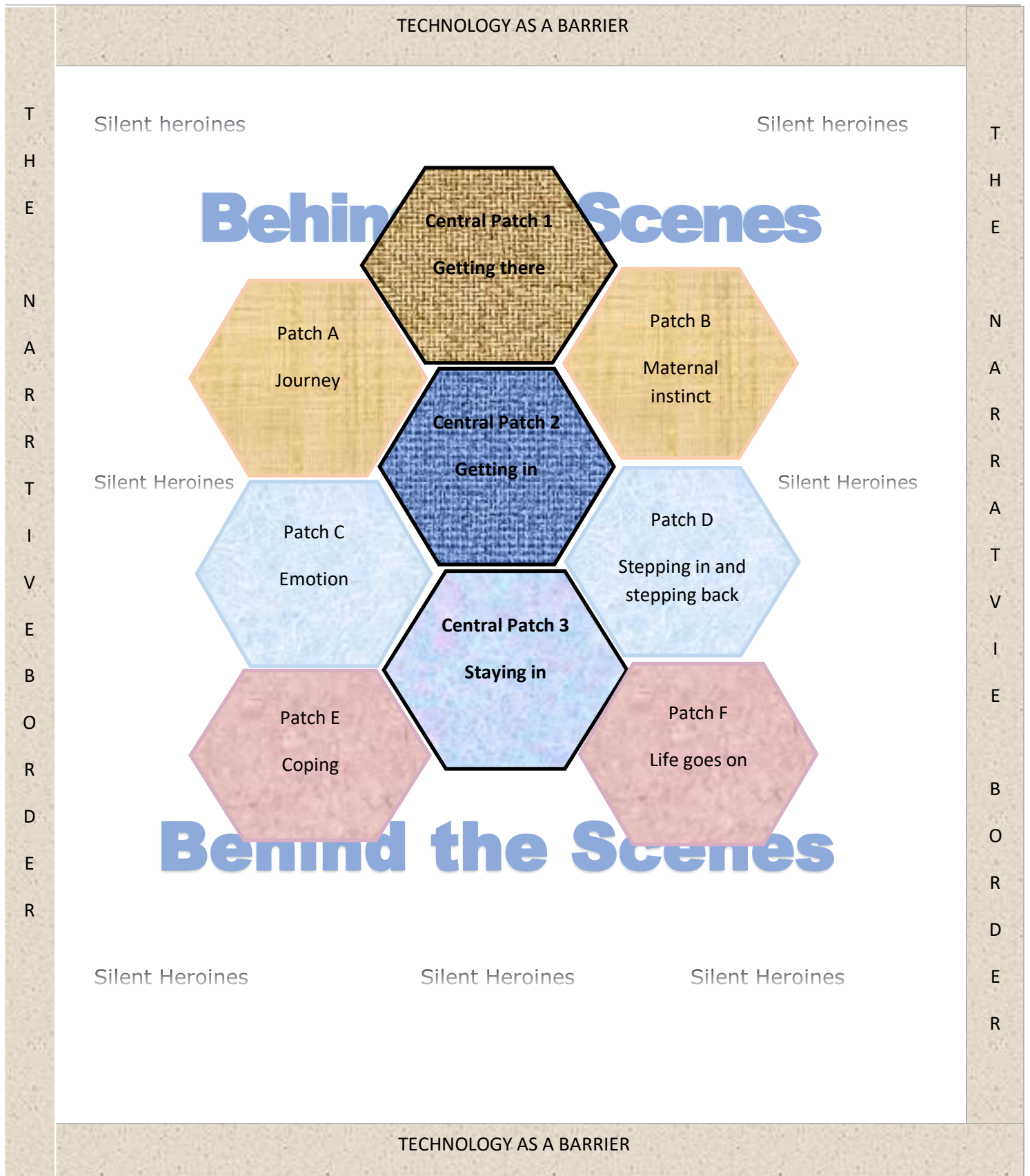
A narrative bricoleur will have the understanding that research is an interactive process shaped by personal history, gender, social class, profession, autobiographical images, insights and interpretations (Denzin and Lincoln, 1994; Keats, 2013). Using my personal insights and interpretations, I was able to produce a set of interconnected images in a performance text. Using an eclectic approach to analyse the stories places me as a bricoleur tinkering with the construction, reconstruction and assemblance of the quilt, interacting with the patches and readjusting them. This has resulted in a dense, complex, reflexive collage-like creation that reorganises pieces to construct new meaning and looking for '*new messages*' (Levi-Strauss, 1966: 20). New patterns emerge and new shapes are reflected on the page created by the bricoleur (Richardson, 2000b) where I found profound human drama playing out in the creative narratives. The two images of the patchwork depict how the montage of grandmothers' narratives have been placed, arranged and then sewn together. A patchwork quilt has three layers, the top, the wadding and the backing, this metaphorical quilt has embedded within its wadding, the notion of '*behind the scenes*'. The border of the patches is '*technology as a barrier*'. Embedded in what they do in the background, without fuss, without drama emerging as '*silent heroines*' which I have sewn into the layer that is the backing.

4.8 The Narrative Border

The narrative arc is the backbone of the story (Blume, 2019) and is usually formed of a common structure namely, staging, plot progression, and cognitive tension (Boyd, Blackburn and Pennebaker, 2020). The backbone of grandmothers' stories in this study was of their experiences of having a sick grandchild in NICU and how the technology was a barrier. Storylines that develop from narratives or stories

can build a rich picture of the field of study (Greenhalgh *et al.*, 2005). Thus, it was from those storyline narratives I identified the major patches and ongoing similarities and differences within the stories, which all included elements of staging, plot progression and tension. There was, I discovered when listening to them over again, a hidden yarn or the *disnarrated* of the technological barrier. In searching for the narrative arc in grandmothers' stories I also found a border (Bishop, 2012; Kingdon *et al.*, 2019). Bricoleurs seek to find what is absent (Kincheloe, 2004b), and in searching for the absent, I found the unspoken and implied. What was common to the grandmothers' stories was 'technology as a barrier' that was implied in their narratives. The restrictions that are applied to grandmothers when they visit their grandchild are present throughout all narratives. The metaphor of a border to the quilt not only depicts the border or focal structure of the fabric of the stories but also as a physical border to be passed in gaining access to their grandchild.

Image 10. The completed patchwork quilt.



4.9 Chapter summary

In this chapter I have justified a three-step approach to analysing the data using Atkinson (1995) (selvedge), Frank (2010) (weft), my story (warp). In interpreting the grandmothers' narratives, I acknowledge the context in which I talked to grandmothers, one of a professional and as a grandmother like them, working outwards from my biography to understand the biography of other grandmothers.

Sarah, Rajinder, Grace, Melissa and Susan all had their own individual version of having a sick grandchild as was my own, there were some commonalities, but each of their circumstances were unique. From their stories I created three central patches:

Central Patch 1: Getting there (to NICU)

Central Patch 2: Getting in (to NICU)

Central Patch 3: Staying in (NICU)

What also emerged in my analysis of the data, from what was not overtly stated in the stories was that grandmothers were '**silent heroines**', constrained by a boundary of '**technology as a barrier**' and always '**behind the scenes**'.

In the next chapter, I will present the findings that emerge from the patchwork of their stories and discuss them within the wider literature. I will address how the findings relate to practitioners in the NICU environment.

Vignette 5 Susan

The face my husband sees

My brother, Edward named after a royal prince (and treated like a prince in my honest opinion) has just become a father. The baby is very poorly and on an intensive care unit. Trust my brother to do something like this, as if my mother Susan hasn't got enough on her plate at the moment. She is working full time in a senior role, is on call and now this has happened. Susan has been transported back 30 years to when I was born and has brought all that emotion back to her. It has been "pent up for years" she says, a very emotional week indeed and restored all her old feelings. She can see that a lot has changed over the years, the monitors and equipment are different, but she has found herself checking the monitors for signs of any change, just like when she had me. Susan is now going through what Betty had with me-history repeating itself. Her face is a mask at the moment, the one she shows to us (calm and serene) and the one my dad sees (anguish and worry), they are quite different faces. She only trying to protect us but on she goes, like a balancing act actually, one minute she is with my brother and his girlfriend because they are so distressed and the next trying to support my dad. Poor dad his mom, my nan has had to go into a hospice this week for palliative care and he's had to deal with that mostly on his own because Susan's at the hospital with William. The family's a bit split at the moment it's quite a traumatic week because both Susan and Dave are still working full time and they've had a brief discussion about it, still supporting each other but worried that they will start to burn out after splitting themselves into so many portions. But Susan wants to take the load of worry from William, she has to protect her children, she is so like Betty, so maternal and strong, those motherly instincts cannot be shifted.

Chapter 5

The Evidence, Findings and Discussion

5.0 Introduction

In the previous chapter I discussed the three steps I employed in the analysis of the data. From that analysis I created a pattern of patches from the fabric of grandmothers' stories, that when sewn together became a patchwork quilt of grandmothers' stories.

In this chapter, I aim to present and evaluate the interconnections between the central patches from grandmothers' stories. Returning to the literature, I will provide critical discourse around the main data findings. I have combined the findings with the discussion, rather than two separate entities to show the seamless interconnectedness. Therefore, I have designed this chapter so that the main findings are not lost in the discourse but are fundamentally woven into the fabric of the stories.

Contexts exist in lives and contexts exist in writing lives (Smith, 1994). To put grandmothers' words into context, I have written explanations before and after their quotes to give the words meaning and to set them into context. If stories are retold for brevity, they lose their concrete meaning, thus becoming a quote that stands alone without purpose. An 'opening scene' whereby presenting a scene to catch the reader's attention shows that the hero and her doings are important and exciting (Bowen, 1968: 21), have credibility and meaning (the narrator of each story has been identified in table 3: p84).

5.1 Central patch 1: Getting there

All grandmothers in this study had a compulsion to be by the side of their adult son or daughter when their grandchildren were born, and this is where their personal journey began. The strict visitation arrangements of NICU did not deter grandmothers from travelling to the hospital to be with their adult families. Melissa was at home in the south of England when her son asked for her help, Rajinder was on holiday in India and Grace was at home in Africa. Three women travelled great distances to the hospital. Susan and Sarah lived close by and despite their work commitments travelled to the hospital as soon as they were

able. I also had a journey to take both physically, emotionally, and metaphorically when my grandson was born and has parallels with the women in this study.

Patch A: Journey

Melissa's granddaughter had been born and was initially well, but Melissa's daughter-in-law was in a seriously ill condition in the Intensive Care Unit (ICU) with no diagnosis or prognosis¹⁸. It is common practice when the mother is on ICU for her baby to be cared for in the NICU. Melissa's story begins:

'Christian was a first-time dad, holding a newborn baby and said, "Please come mummy". He had always used that maternal pronoun in times of crisis, Melissa knew it was a bad sign'.

Melissa felt the need to be with her son and new granddaughter and had to drive alone for 4 hours to get to the hospital

'By the time she arrived at 8 O'clock in the evening she was pretty shattered. She eventually managed to park her car and after negotiating the hospital entrance that was surrounded by luminous yellow looking patients in wheelchairs smoking their last cigarettes of the day. She arrived at the Neonatal Intensive Care unit where her granddaughter was being looked after. She found her son there, who fell onto her weeping. All of the family, everybody was terrified'.

Rajinder was on a long-awaited holiday in India when her daughter needed an emergency caesarean section. Rajinder's story begins:

'She had gone to India for two weeks but came back after a week. She could not stay any longer, she said to my grandfather, "I'm going back" and he replied, "I'm coming with you". So, they flew back home because everything had gone pear-shaped'.

Drawn by her maternal instinct to sacrifice her long-awaited holiday and travel home, she was, like Melissa, catapulted centre-stage into a scenario she had not envisaged.

Grace lives in a country in Africa, her daughter Christine lives in England with her husband and two children. Grace had saved the money to buy flight tickets so that she could travel and stay with her daughter when she had had her first and second babies. Unexpectedly Grace needed to make the journey for a third time.

¹⁸ Melissa told me that Ellen was later diagnosed with hyponatraemia and recovered after 48 hours following delivery. All women in labour are at risk of hyponatraemia (defined as blood serum sodium <130mmol/l). Complications include headache, agitation, confusion, seizures and death. (NHS Resolution Early Notification scheme, 2019)

“Mummy, I am in hospital, they tell me I am having delivery pains and I am having twins”. Grace was prepared to come and look after those little ones and so again, they struggle, struggle to get the money to come to England and to change their tickets. She came on 25 February; it was a holiday period, and the ticket was very expensive’.

Despite the considerable expense and the distance and it being the third time in three years, Grace was prepared to travel as soon as she could to be with her daughter and her premature twins.

Susan is a manager of a care home and on twenty-four-hour call. She went to the hospital when her daughter-in-law was in labour and was there at the birth of her grandson. By the side of her adult child.

‘Susan has felt like she has been swimming alongside her son this week, supporting him and his partner. At the same time, she has been protecting us all, like a lioness ‘protecting her pride’ as she says’.

Sarah went to the hospital to visit her daughter and granddaughter. She was struck by the normality of other families.

‘We came to see her, and we could see all these balloons and you know, babies coming out and I was obviously remembering my own experience’.

Women in this study had already ridden their own journey of motherhood and were embarking upon their next generational phase, the journey into grandmotherhood. The extracts in this patch capture the weight of duty that grandmothers experienced in travelling to be with their adult child. Regardless of where they were in the world, all grandmothers made a huge effort to travel to be beside their family when their grandchild was born. Grandmothers had been unprepared for their grandchild’s admission to NICU, nevertheless there was a visceral need to get themselves to the hospital.

Patch B: Maternal instinct

The maternal cord in all five stories show a strong maternal urge. The maternal instinct is a thread that runs through all the stories and includes guilt and bonding. Although Susan lived quite close to the hospital where her son’s baby was born and she did not have to travel far, she expressed the need to be with her son during the time her grandson was in the NICU.

‘Susan wants to take the load of worry from William¹⁹, she has to protect her children, she is so like Betty²⁰, so maternal and strong, those motherly instincts cannot be shifted’.

Sarah’s story has elements of this too.

‘I really felt that I wanted to take her home and protect her, but I knew I couldn’t and it’s my maternal instinct- you know’.

Despite the distance and expense, Grace’s words are powerful and demonstrate that strong maternal urge.

‘When she is in Africa and her daughter is here, she feels her heart is full of pain for her because as she says, ‘my heart is full of pain because I will be far, and she is here and says, “mummy I need you” and I know that she really needs me’.

Melissa experienced a challenging time in trying to get to see her granddaughter. Her daughter-in-law was still in ICU and her parents were exhausted and needed to sleep and Christian was also on the point of collapse from exhaustion. She describes the situation.

‘They were grieving actually, and no-one knew if they would ever have Ellen back or if they did, would she be herself? So, Melissa had promised she would stay at the hospital all night, she would check on Ellen and check on the baby’.

Melissa had managed to spend the night by her granddaughter’s cot side whilst other family members had some much-needed rest. When the news came that her daughter-in-law was recovering, she instinctively knew that she needed to take a photo of the baby to her.

‘She knew how important it was for mothers to bond with their babies and showing her pictures of the baby might be helpful. When Melissa got to the intensive care unit, she was pleased to see that Ellen was awake’.

Sarah talked about wanting to hold her granddaughter.

‘And then we popped in to see the baby for just a few minutes because we felt she needed to rest, we just wanted to love her (hold her)’.

Susan, having had her own premature baby was concerned that the mother and baby would not bond, because the baby had not been out of the incubator for a cuddle.

‘She feels really sorry that William and Gemma can’t love their baby and knows how important it is for them to hold him. In fact, Susan can’t wait to hold Edward herself,

¹⁹ William is Susan’s son.

²⁰ Betty was Susan’s grandmother, who raised her when she was a child.

according to Susan, 'she has empty arms' and will not be able to hold him until he comes home'.

Here Susan shows that she is more concerned with her daughter-in-law holding the baby, knowing that it can have a detrimental effect on the bonding process. Susan did also express dismay that she could not hold her grandson.

Grandmothers are mothers first and foremost, the emotional pull of needing to be with their adult children was strong. For three of the grandmothers, resilience was an important factor which enabled them to travel long distances to be by their child's side during the critical time when their grandchild was ill. All grandmothers expressed the feeling of fear, not knowing what the outcome would be. Frightened that the situation was fragile and could change quickly, three grandmothers knew from their own personal experience²¹ that their grandchild's condition was precarious at times. Grandmothers had a strong determination to support their child during this time and made every effort to be with them.

5.1.1 Critical discourse: Getting there

Maternal instinct can be seen in the narratives, explicitly spoken about or implied. Regardless of their personal situation, grandmothers were supporting their families with fortitude, visiting their grandchild in the afternoons and evenings when they could, 'being with' their adult child in a time of need. Based on a life-course perspective and linked family lives, women are important providers of intergenerational support and care (Das, de Valk and Merz, 2017). Grandmothers are key figures in giving practical support to their children and grandchildren and are in accordance with the notion of 'women as kinkeepers' (Goody, 2004). Intergenerational ties and linked lives play an important role in mobility choices in general but more especially when that mobility is thrust upon the waiting relatives as seen with the grandmothers in this study. In early life, attachment bonds ensure that the infant maintains proximity to the caregiver (Magai, 2008). That early attachment occurs during pregnancy, as maternal-fetal bond and is an emotional response to the growing life within, this develops further as the pregnancy becomes more tangible (Sandbrook, 2010). This theory adds to Bowlby (1969) and Ainsworth's (1967) ethological work on maternal-infant attachment which demonstrates that in secure situations, infants developed more protected

²¹ Susan and Rajinder had had preterm babies themselves; Grace had already had preterm grandchildren.

relationships with their mothers than those where the mothers were described as insecure or avoidant (Weinfield *et al.*, 2008). It is the early relationships in childhood that can have a long-term effect on lifespan development (Mooney, 2010). These theories are significant and have contributed highly to the development of FCC in NICU. Mothers provide the 'haven of safety' for the developing infant (Ainsworth, 1967). The grandmothers in this study are mothers to their adult children, the attachment they express in their narratives is clear to hear, those early bonds continuing with their children and with their grandchildren.

As the child grows into adulthood, they move further away from the caregiver, although the caregiver retains that safe haven if the child experiences distress (Magai, 2008). Calling for their mothers' help in a time of distress, grandmothers' adult children needed *their* mother to be with *them*, although they were not ill, their children were and as parents, they were in a period of distress. There is no reason to think that a child's attachment to his or her parent wanes once adulthood is reached, or that a parent does not continue to offer a place of safety to her adult offspring when needed (Ainsworth, 1989). The durable bond is a positive attachment between parent and infant and once well-established, this link is almost indestructible (Goulet *et al.* 1998). It is the power of this link that counters the urge to give up during difficult times and connect the parents to their child once the bond of dependence has diminished. The adult children of grandmothers needed them, and *they* needed to be with their child during the critical phase of their grandchild's illness. Being a mother involves embodied, visceral experiences and responsibilities for meeting the needs of another dependent human being (Miller, 2005). These responsibilities continue when the offspring is an adult. There are parallels with the notion of intensive mothering, where only mothers believe they possess the necessary knowledge to undertake mothering work (Hays, 1996). Grandmothers may possess the same belief that only they have the experience to support their adult child in time of need.

Parents instinctively view themselves as their child's protector, needing to maintain a calmness, rally strength and sometimes develop a sense of control (in times of need) (Bourdeanu and Cannistraci, 2018). These young adults were independent and autonomous and yet, when *their* babies were ill, as new parents they looked to their mothers for support. All grandmothers in this study responded

promptly to their children and demonstrated all three dimensions regardless of where they were geographically.

The natural bonding process is threatened when an infant is born preterm or sick and in need of intensive care (Mäkelä *et al.*, 2018). Care provided in NICU aims to overcome the barriers of separation and attempts to empower parents to become partners in the care of their baby, encouraging bonding ties. Whilst the postnatal mother is encouraged to care for her baby as often as possible, one of the critical attributes to motherhood in NICU includes a diminished opportunity for mother-infant interaction because of the imposed structure of care (Cescutti-Butler, Hewitt-Taylor, Hemingway, 2020). Two grandmothers in this study expressed concern regarding separation, one regarding her daughter sleeping in the postnatal ward where other babies were a constant reminder to her daughter that she did not have her baby with her. This can cause stress in mothers when they are separated from their baby (Turner, Chur-Hansen and Winefield, 2015). Grandmothers were separated from their own adult children and grandchildren because they had other responsibilities to deal with and because of the boundaries put in place by NICU. They were behind the scenes intentionally and unintentionally, separated, waiting in the wings for either permission or the opportunity to close the gap of separation.

My reflexions

When my grandson became very ill on day two of life and needed to be transferred from a LNU to a NICU, it meant that it left me to drive my son to the receiving hospital. We had a steady journey that took about forty minutes. The distance does not compare with Rajinder, Melissa and Grace who all travelled further but the anxiety and concern I felt was great and on a par with them. It was a journey as a mother I had to make and there was never any question that someone else would drive Tom to the hospital. It was a journey, in those circumstances that no one else, except a mother could make.

5.2 Central patch 2: Getting in

As already shown in the narratives, grandmothers went to great lengths to get to the hospital to be with their child and grandchild. Once their grandchild was born and being cared for in NICU grandmothers needed to see for themselves that the baby was doing well so that they could support their child and child's partner

during that time. Within the limitations of visiting times, they were able to visit, sit, wait and stare whilst parents and nurses were engaging in the care of the baby. All grandmothers had other family, jobs and responsibilities that they needed to attend to as well as visiting their grandchild. In addition, the parents needed supplies, clean clothing and food. Other grandchildren needed caring for and accommodating all these tasks were important to them.

Patch C: Emotion

Grandmothers' stories were strong and full of emotion. Caring and worried grandmothers described how, at the beginning of their grandchild's admission to NICU how they had been very concerned for their child and grandchild. Rajinder cried the most out of all grandmothers in her narrative:

'She didn't know what to do for my mummy or how she could help her. In fact, she worried so much and cried so much that she couldn't cry anymore'.

Sarah also talked about the emotion of having a sick grandchild:

'It was hard, very hard. I was just choked, absolutely choked and she said to me "when you see her, don't cry because she's only small and it will start me off". And even if she'd been an eight-pound baby I still would have cried because she's my first grandchild and I'm proud of her. I was trying my best to hold it back, but it was awful, absolutely terrible, it really was. I felt like I wanted to take her home and protect her'.

In a similar vein, Grace had the feeling of 'getting on with it'.

'It is only Grace who can handle all of these things she says to her daughter, "Your father he doesn't have the heart to deal with all these things". And even though she is here because her baby daughter is having 4 babies to care for and she feels her pain'.

Being far away from her husband means that Grace takes the full burden of looking after her family in England as they seemed to go from one crisis to another.

Rajinder worried not only about her grandson and her daughter but also her elderly mother.

'My great-grandmother said "don't worry, he'll be fine" but at the same time my grandmother was very worried about my mummy and my great-grandmother. A whole cycle of worry in fact'.

Although Melissa was very worried about the situation, she managed it in a different way.

'Basically, Melissa did what she always does in these sorts of situations, she tried not to be emotional, just deal with it'.

Susan hid her feelings from her family and only revealed her true emotion to her husband once they were at home.

'Her face is a mask at the moment, the one she shows to us (calm and serene) and the one my dad sees (anguish and worry), they are quite different faces'.

For Susan and Rajinder, it was like going back in time.

'Susan has been transported back 30 years to when I was born and has brought all that emotion back to her. It has been "pent up for years" she says, a very emotional week indeed and restored all her old feelings. She can see that a lot has changed over the years, the monitors and equipment are different, but she has found herself checking the monitors for signs of any change, just like when she had me'.

'As if she didn't feel guilty enough, being on holiday when I was born. She felt guilty because of what my mother had been through. It was like history repeating itself, my grandmother wasn't sure if my mother had had the same condition as her, although it probably was (a family friend thought so too). The doctor had been asking my mother about my grandmother's medical history and they have said that my mother has "inherited that from her mum"'.

The intergenerational position of grandmothers meant that three had mothers still living. Both Sarah and Rajinder's mothers had played a significant part in caring for *their* daughters when they were children. What was upsetting and worrying for them was that they were not allowed to visit their great-grandchild because of the restrictions in place in NICU.

Some grandmothers in this study did not dare or want to think about the grandchild until the mothers' health was stable. Grandmothers also said that they did not want to burden or worry the parents with their own questions and thoughts. Mothers, daughters, grandmothers, great grandmothers anxious about the baby, their child, their mother, a perpetual cycle of unease. In taking the weight of strain themselves, grandmothers worried about their children and their grandchildren. The emotion they felt in telling their stories was evident in their interviews but rather than be consumed by worry, grandmothers busied themselves to relieve the anxiety they felt. Susan's *'the face my husband sees'*, demonstrates vividly how she tried to hide the worry from her son and his partner, only finally letting her mask slip when she was at home with her husband.

Patch D: Stepping in and stepping back

Whilst parents were with their baby in NICU for most of the day, they required the support of someone who could provide food, look after their other children and undertake some household tasks for them. The grandmothers in this study all rose to those responsibilities. They also felt that they needed to take a step back since these were their adult children with a husband, wife or partner, now parents themselves. Grandmothers believed they had to let their offspring have their own parental responsibilities and to do so as their mother, they needed to let that happen.

“Can you do us something to eat Mum?” my mummy would ask, and the washing needed to be done. So, every day she travelled in my car to the Central hospital where I was (for the first few weeks) and it is a 100-mile round trip every day to see me and my mummy, to take the clean, ironed washing and take the dirty washing away, she also brought food with her’.

As seen in Rajinder’s story, grandmothers visited their grandchildren during designated times and in addition brought food, supplies, clean clothes and did so willingly. Since the parents were at their child’s side for most of the day, they relied on their families and particularly grandmothers to support them in this way. Although the need to be with their grandchild was paramount, providing support in other ways was also an important feature.

Melissa experienced a challenging time in trying to get to see her granddaughter. Her daughter-in-law was still in ICU, her son was exhausted and needed to sleep. Melissa had promised she would stay at the hospital all night, she would check on her daughter-in-law and on the baby. This proved to be more difficult than she imagined, grandparents are not allowed to stay on the unit overnight, so Melisa had to persuade the staff that she would be unobtrusive and not get in the way.

‘Grandmothers are not supposed to be there overnight, not supposed to be there without a parent being there as well. So, Melissa made herself very friendly and small and tried not to get in the way and just had to ask “Can I just sit? Christian won’t go to sleep, she’s only just been born, and I can’t leave her on her own”’.

In using persuasive justification, Melissa could stay overnight but could not pick her granddaughter up and cuddle her, she could not feed her, these were the nurses’ jobs. There appears to be a limited amount of flexibility in visiting arrangements and when one parent is critically ill, the other is too tired to function and the family strongly believe that the baby should not be alone, some

allowances had been made but were limited to the grandmother sitting by the cot-side.

Sarah's daughter had her baby at 31 weeks gestation due to pre-eclampsia:

'I was glad I'd got the weekend off because she'd had her baby on the Friday night and because it had been such a rush, she hadn't got anything with her, she'd got nothing for herself, nothing for the baby and so it was a mad dash round town to Mothercare and Boots the next day so that I could get nappies, nighties and clothes and stuff for her and the baby (although it was very hard to find anything to fit a 2lb 2oz baby)'.

Grace postulated that once the twins' conditions were improving, she would be more settled.

'She will carry on cleaning and doing the laundry, a lot of laundry. Cooking, she cooks most of the time and looks after the other two little ones. The boy is starting to walk now so they are both a bit of a handful'.

Grandmothers wanted to protect their adult child as already discussed but they also recognised that their child was a parent and caring for their baby was their responsibility. Four grandmothers discussed this in their narratives.

Being practical by undertaking household tasks, providing food and supplies and helping with other children was something that grandmothers were willing to undertake. This practical support reduced the burden for their adult child gave the grandmothers in this study something useful to do and contributed to the wellbeing of their child so that they could actively be a parent to their sick baby. Recognising that they needed to take a step back once the main crisis was over, grandmothers although still visiting, were holding-on, whilst letting go.

5.2.1 Critical discourse: Getting in

Mothers with a sick child express their emotions such as guilt, sadness, blame and shock (Holmes, 2004). As mothers themselves, grandmothers also expressed some of those emotions in their narratives. Worrying about a situation they could do little to change was a common thread in all grandmother's stories. Not knowing the outcome of their grandchild's condition in the early days following admission left grandmothers emotional and highly anxious, discussing worrying in their narratives.

The position of grandmothers within the family system often seem to carry implications for providing support through a protectiveness, once closer than

anyone else to the parent-child unit but at the same time removed from it. For parents, care seems to consist of fretting and fussing and worrying and is the glue that keeps a mother affixed to her child (van Manen, 2002), a normal phenomenon and one in which mothers wish to take the worry away from their child. Not only do parents wish to take the burden of worry, but they also worry *about* their adult children (Hay, Fingerman and Leftowitz, 2007; 2008). Similarly, mothers cite their spouses and mothers as being the most important sources of support when they have preterm babies (Noy, Taubman-Ben Ari and Kuint, 2014). Mothers find grandmotherly support helps reduce their anxieties, gives them emotional stability and decreases the physical burden (Matsui and Yumi, 2018). Grandmothers in this study were not specific about what their concerns were, although they worried about their child because they could see how tired and fatigued, they were, which is highlighted by Melissa's concern for her son.

I saw that grandmothers in this study demonstrated 'triple concern', since they discussed either their own mother or mother-in-law (Sarah, Susan, Melissa and Rajinder) or other adult children (Melissa, Susan and Grace) in relation to their current situation. The 'sandwich' generation are mid-life adults who take care of their descendent and ascendant relatives (Grundy and Henretta, 2006; Aazami, Shamsuddin and Akmal, 2018), this clearly puts all grandmothers in this study into this category. The demands from such an intergenerational position can mean competing priorities (Igarashi *et al.*, 2013) which Rajinder and Sarah most definitely discussed. Melissa was very worried about her adopted daughter as well as two sets of great-grandparents. The grandmothers in this study did not want to over burden their adult child with their own worry, withholding their own anxieties and recognising that it was enough for the parents to worry about their own children, much less bear the weight of worry of grandparents.

It is important in the early days following admission to NICU, that parents get to know their infant, developing a fundamental relationship with their child and understanding their parenting role (Staniszewska *et al.*, 2012; Melançon *et al.*, 2020). Open visiting policies for parents helps facilitate this with protected time just for parents. Mothers are never completely alone, that they were 'mothering in public' because there is always someone (healthcare professional) in the background (Hall and Brinchmann, 2009). Nevertheless, this precious time gives mothers and fathers the opportunity to focus on their relationship with their baby,

concentrate on their baby's needs, and learn how to care for them in partnership with their baby's nurses (Browne and Talmi, 2005). Grandmothers put everything aside to be supportive to the parents, and their loving concern was much appreciated by the parents (Hall, 2004a). This finding correlates with the grandmothers in this study, without explicitly verbalising so in their narratives, their very presence in NICU showed that loving support.

Grandmothers in this study also stepped away or stepped back, recognising the need for their adult children to manage their own responsibilities. Identifying that they needed the space to become a parent, grandmothers in this study demonstrated that they could and would take a step away in order for those parental relationships to develop.

My reflexions

My experience differed from the five grandmothers in this study. I was known to the medical and nursing staff in NICU. I had taught many of the nurses on the neonatal intensive care course and taught with several of the staff on the Newborn Life Support (NLS) course as an instructor. I was in a privileged position of knowing the staff as well as knowing about the condition my grandson had and the treatment he required. This though was a double-edged sword, knowing the consequences of his condition was frightening. I felt I was one-step ahead, anticipating complications that may ensue.

'Getting in' though was the same experience for me as it was for the other grandmothers. Adhering to strict visiting times, staring through the incubator portholes at a grandson I did not know and could not hold nor touch. I could not relieve my son and my daughter-in-law so that they could have a rest, a shower, eat food since one of them always had to be with me when I visited.

5.3 Central patch 3: Staying in

It was important to grandmothers that once they had visited their adult child and grandchild in NICU, that there were able to continue to do so despite their other family and commitments. Three of the women in this study had full-time jobs, one volunteered in the public sector, and one did not work. All grandmothers had other children, all had husbands and four mentioned their own mothers in their stories. The grandmothers in this study had many other responsibilities that they were

managing during their grandchild's stay in NICU. To 'stay in' and keep visiting, grandmothers had to juggle their responsibilities so that they could be by their adult child's side.

Patch E: Coping

Coping with having a sick grandchild in NICU was a common patch for all grandmothers in this study and all dealt with the stress that the situation brings with stamina and resilience. When I looked for common patches in the narratives, I found that for three of the grandmothers, Grace, Rajinder and Melissa, praying and a faith in God played a very important role in helping them cope with their situations. All three discussed their faith as a way of helping them during their crises. Sarah and Susan did not make any reference to faith in their narratives. Thus, whilst this was not common to all five because of its importance and significance to three women, its inclusion is justified.

During the night that Melissa stayed with her granddaughter. The staff gave her the message that her daughter-in-law had regained consciousness.

'Then miraculously at about 5.00 in the morning, Ellen had regained consciousness, seventeen hours after the delivery of her baby. Their prayers had been answered. The nurse in ICU called the neonatal unit to tell the family the news'.

Rajinder prayed from the time Karishma was admitted to the hospital.

'She does believe in God and all she could do was to pray, so that's what she did, she went to the temple and was praying, praying, praying and praying at home and while she's at work. Her mother-in-law in India did a very special prayer for the me and my mummy'.

Rajinder was advised by her mother-in-law to pray for her daughter.

'She was pacing, pacing, pacing the lawn "Oh my God, what am I going to do". My great-grandmother says (as they do) "go and sit down and pray she is going to be fine"'.

Similarly, Grace also talked about God and putting her faith in Him. When her grandsons were born prematurely, she received the news by telephone.

'Her son-in-law said, "I got bad news, my wife, she is in the hospital with delivery pain and the doctors told her they wanted to deliver by Caesarean section". Grace was distraught she knelt down on the mat with her husband, and they prayed and after they had finished praying, she phoned Christine. She was in hospital, and she was crying, and Grace said, "don't cry my baby, I am far, just put everything on God"'.

For Rajinder, Grace and Melissa praying, and worship played a very important role during their experience. For them, their beliefs were a constant in their lives and regardless of what religion they followed, prayer was a source of comfort and solace during their worrying and stressful time. Three grandmothers in this study gained great strength from prayer and their belief in God. This gave them a focus and concentrated their thoughts, giving them a sense of peace knowing that God would protect their family and themselves. Susan and Sarah did not discuss prayer or faith in their stories but although this was omitted the assumption cannot be made that prayer and faith did not have a part to play for them. Sarah and Susan told of how they coped with their situations. Susan needed to keep busy:

'Forever the practical one Susan, who is so like Betty²² that way, says, "give us your stuff, lets' do this"'.

Sarah found that she had so many questions she could not ask and had to make the effort to keep those questions to herself.

"As I said, you have to take a back step, and she's like my youngest, and so it's very difficult for me".

As well as praying, Rajinder and Grace described other coping mechanisms.

Rajinder returned to work even though her husband disapproved. Not knowing how to deal with the situation, she needed some normality back in her life.

'She is trying to keep herself busy at work because sometimes, you know, she just wants to run away from it because, she's just had enough, she can't worry anymore, her head is splitting'.

Grace too felt overwhelmed, she struggled at times, especially because the winters were cold, and she was not used to it.

'But sometimes she felt that these things are too heavy, and she struggles to find peace. Why does her daughter have her babies in the winter? The snow is falling again, and the roads are all blocked, the hospital car parks are not clear, and it makes visiting more stressful than it already is'.

Coping with their individual situation was unique to each grandmother, with three putting their faith in prayer, one keeping busy and one taking a step back helped them to 'stay in'.

²² Susan's grandmother, who raised her.

Patch F: Life goes on.

I was struck by other commitments grandmothers had as well as caring for their adult children in times of crises. These responsibilities did not go away whilst their grandchildren were ill, life was 'going on' around them with work and family issues that they were also dealing with, a balancing act that they delicately managed to achieve.

Grace was worried about her daughter and the babies. She also had concerns about one of her sons, her phone rang several times during her interview.

'These are not all of Grace's worries. The situation at home is not good, she has got a son he is twenty-eight and they are always calling her about him, what can she do? Her phone rings all the time with family in Africa ringing her about him. Her son doesn't listen to her anyway, he likes drugs and beer, all that sort of thing which are not good. Even now whilst she is in England, she is worried about him.

Susan also had additional worries, she was working full-time, was on-call and her mother-in-law was ill.

'It's like a balancing act actually, one minute she is with my brother and his girlfriend because they are so distressed and the next, trying to support my dad. Poor dad his mom, my Nan has had to go into a hospice this week for palliative care and he's had to deal with that mostly on his own because mom's at the hospital with William'.

Life was carrying on for Melissa, her husband had arrived back home from his business trip and as due to visit the following day. Melissa's concerns came later. She coped with the initial crisis and the situation was settling now but had some worries over her daughter.

'Her daughter Hannah will arrive tomorrow; she is seventeen and was adopted from Thailand when she was eleven months old. Melissa is not sure how it will be for her, how she will be around the new baby, she knows that Melissa and Peter didn't adopt her until she was eleven months old, and she knows that the day she was born was the day her family abandoned her'.

Sarah was now driving her daughter to the hospital.

'My son-in-law had to go back to work yesterday for money reasons, which I know most parents have to do but it's hard because she's on her own now'.

Rajinder went back to work, despite arguments with her husband.

My grandmother told my grandfather "I can't be there anymore with Karishma, looking at her in this situation, I can't do it, its tearing me apart. I want to go back to work, to see my own patients (at least they make me laugh) and it's a different

atmosphere. My Grandfather was not pleased, he told her “You’re kidding, aren’t you?”

All five grandmothers had other family and work responsibilities during their grandchild’s stay in NICU. Three grandmothers worked full-time and balanced working with being with their child and grandchild. Sarah and Susan had senior roles and had to ensure that their employment needs were met, and that other staff could cover their work when they were not there. Rajinder decided to return to work and had to cope with the tension from her husband and the need to have some normality in her life. Grandmothers felt an enormous weight on their shoulders that they were unprepared for. However, with the strength of prayer, determination and love for their child, they shouldered the burden willingly, prioritised their responsibilities and stayed where they needed to be.

5.3.1 Critical discourse: Staying in

Coping strategies of grandmothers with grandchildren in NICU range from keeping busy to visiting as often as possible. Women often use coping mechanisms such as seeking emotional support, religious coping and venting emotions (Aftyka *et al.*, 2017). Three grandmothers in their narratives discussed praying as a way of coping with having a sick grandchild, I was drawn to their openness to discuss what is usually a private act. Spirituality are beliefs that sustain and support the individual through times of difficulty which includes illness (Albaugh, 2003; Hollywell and Walker, 2008). There is the indication that private prayer is used by a significant number of people for coping within health-related contexts (Kurtz, 2012; ap Siôn and Nash, 2013). Grandmothers in this study did not suddenly turn to prayer only in adversity, for them it was part of their fundamental religious belief system. There is no scientific evidence to support the effects of prayer with health, coping and healing (Dusek *et al.*, 2002; Masters and Spielmans, 2007) and prayer can be conducted in private in any situation (Blaszko Helming, 2011). Whilst Grace talked about praying on the floor at home with her husband, Rajinder prayed in the Temple, Melissa was not explicit about where she prayed, yet none of the grandmothers discussed using hospital chaplaincy services for prayer, which would indicate that they would pray when and where it was necessary.

Prayer is a way of coping with stressful life events, people who use prayer in this way could be characterised as engaging in passive coping processes that fails to utilise more active or direct coping strategies (Masters and Spielmans, 2007).

Nevertheless, prayer and its effects on coping and increasing quality of life should be acknowledged (Abu *et al.*, 2019). Prayer and coping (with their grandchildren's illness) play a part in grandmothers in this study who used prayer in their everyday lives, it was fundamental to their being. Having a faith was extremely important to them, otherwise they would not have discussed it so openly. In their narratives it was not clear what or who they were praying for, Rajinder prayed and the next news she had was that her daughter was 'off oxygen and the blood pressure was coming down' and Melissa felt very strongly that it was her role to 'pray them through it'. It is well-recognised by people of all persuasion pray to 'God' for help or mercy at times of great threat (Hollywell and Walker, 2008).

Praying can help lower anxiety (Dorn, 2006; Hollywell and Walker, 2008), whether praying helped grandmothers by lowering their own worries is not known but their spirituality did aid their coping at times of crisis. This does not mean that they relied on prayer alone to improve their child and grandchild's situation, they did not passively expect prayer to solve all their problems since they actively engaged in supporting their adult child practically and emotionally. Rather, prayer was fundamental to their own wellbeing which helped them deal with their own predicaments and crises.

Resilience is an important aspect, and grandmothers all coped differently with their situations. It is self-efficacy that helps people deal with certain situations, giving them the strength to continue (Carter, 2014). Self-efficacy was seen to help grandmothers cope with their unique situation. As well as praying, Rajinder went back to work, Susan made herself busy and Sarah took over driving her daughter to hospital to help cope. Resilience is associated with a commitment to care and emotional upheaval and transition back to daily lifestyles and rhythms (Carr, 2014). Grandmothers in this study were far from that shift but in maintaining a sense of normality, they were helping themselves and their families with that transition.

The final patch to sew into place is one of life carrying on, other responsibilities needing attention and other commitments to adhere to. Expecting a new baby in the family should be a time of joy and expectation. When the baby is born too early or is unwell it disturbs families' plans, routines and hopes into chaos and distress. Maternity leave will commence for mothers as soon as they have their

baby²³. This means that they can spend time in NICU with their baby, partners though return to work following a period of paternity leave that is variable in length depending on their employment²⁴. Parents of infants admitted to NICU are believed to experience high levels of distress, increased anxiety and depression and trauma, mothers during this time need their families (Obeidat, Bond and Callister, 2009). Parents may be worried about managing the needs of other children at home or concerned about workplace responsibilities (Tallon, Kendall and Snider, 2015). Therefore, a dependence of new mothers on their own mothers for support, with female kinship holding dual edged potentials of practical and emotional care (Mitchell and Green, 2002). Certainly, career-patterns among women work their way through the whole family cycle. Some grandmothers support their families financially or practically and some do both (Dench and Ogg, 2002). As discussed previously, the grandmothers in this study were part of the sandwich generation, having other family commitments, work pressures, husbands and other children. Juggling life, work, family commitments as well as having a sick grandchild was something that grandmothers managed to do despite 'life going on' outside the realms of being a grandmother.

Managing the demands of ageing parents, an adult child and the worry of their grandchild puts grandmothers in a challenging position. Grandmothers in this study did not fit into the stereotype of an ageing, grey-haired woman who sits in a rocking chair knitting (Janelli, 1988, Karp, 2000; Sawchuk, 2009). They were relatively young; Melissa's narrative was specific:

'She was so looking forward to being a grandma even though she had said to them when they got married, "Don't make me a grandma before I'm 50" and here she was 49 years of age, a grandmother'.

The intergenerational responsibility of looking after other grandchildren was only discussed by Grace, who was looking after her two grandchildren whilst her daughter and son-in-law were with the premature twins. Grandparents are often involved with caring for other siblings when parents are in NICU with their sick baby (Ravindren and Rempel, 2011; Moules *et al.*, 2012). This takes a burden of

²³ Statutory Maternity Leave starts the day after the birth if the baby is born early (gov.uk.)

²⁴ Statutory Paternity Leave is 1 or 2 weeks paid Paternity Leave.

responsibility away from the parents, knowing that their other children are being cared for whilst they are away from home.

Caring for older parents or loved ones whilst still caring for partly dependent adult children and this intergenerational responsibility is reasonably common (Grundy and Henretta, 2006), and can add to increasing stress levels and health issues (Do, Cohen and Brown, 2014). This was very much part of grandmothers' concerns in this study. Rajinder was pulled in several directions:

I didn't know whether to go and see my mother because she is quite sick with arthritis and asthma, in fact, she can't breathe without an inhaler and then Karishma is asking "Mum, what time are you coming?"

She was working full time and trying to meet the needs of all family members. Susan had had to pass the responsibility to her husband to care for his own mother who was going into a hospice when normally that is something she would have organised. There was 'never enough time in the day' to truly fulfil their roles adequately as the middle generation woman (Steiner and Fletcher, 2017). Interestingly, none of the grandmothers discussed being tired but did discuss not knowing which way to turn and how to fit everything into their day. Life was going on around them as they attempted to metaphorically juggle the balls in the air.

My Reflexions

As each grandmother wept during her interview, I also cried with them. Their situations similar but also very different from mine but it brought back those emotions to me, buried not very deeply, I found. My empathy with them was clear for them to see, I had walked in their shoes, had a similar experience and we were bound by a common thread.

At the suggestion of the nurses my grandchild was baptised by the hospital chaplain in NICU prior to his transportation to the second NICU. I have no faith and prayer does not feature in my day-to-day life. However, the event of baptism was both a comfort to me and my family but also a realisation that he may not survive the journey. I did not pray for the remainder of his stay on the NICU, more I put all my faith in the medical and nursing teams that were taking care of him daily. I do know that intercessory prayers were said, and candles lit by other family members and by friends on my grandson's behalf. This, I found comforting.

5.4 Behind the scenes

I am drawn to the metaphor of a museum as a place where objects and artefacts are exhibited. I see grandmothers' narratives as important artefacts and myself as a curator who assembles and presents them for public viewing. Atkinson's (1995) novel saves minutia, detail of the bigger story that might be lost and gives them value. I view myself as also being behind the scenes, saving small stories, preserving them and presenting them as the bigger story.

Aligning myself to Atkinson's (1995) work occurred early in the analytical process, I did not discover until much later in this process, that the title 'behind the scenes of the museum' had a meaning I could apply to the findings of this study because 'behind the scenes' has parallels with how grandmothers' function when their grandchild is ill in NICU. My own story also has elements of being 'behind the scenes' since it is a stationary part of the fabric that is the foundation for grandmothers' stories. I found when re-reading the transcripts that without my own 'behind the scenes' narrative, grandmothers would not have told their own story as they had.

The central wadding of 'behind the scenes' is the fundamental composition of quilt on which the patchwork of stories is anchored together. Hidden in every story is the work of grandmothers filling the gap between the patchwork and the backing. Functioning in a quiet and unobtrusive way, allowing their child's life to function amid the disorder that is created when their grandchild is born preterm or is unwell. Functioning so that they protect their child from the rigours of daily life. Functioning so that their grandchild can have their parents by their side. Functioning so that the family's journey is smooth and uninterrupted. Functioning, shouldering the worry and maintaining a mask of serenity.

Grandmothers in this study, without their knowledge, without expressing as such, the non-narrated, were always behind the scenes. Whether this was supporting their child and grandchild or behind the scenes hidden by a metaphorical cloak of invisibility. Middle-aged women are often invisible, not because they are absent but because their participation is not reported (Randell, 2017; Caldas-Coulthard and Moon, 2018). Grandparents are often seen as the great 'forgottens' of sociology (Attias-Donfut and Segalen, 2002). There are two aspects to the great 'forgottens' which is that the image of grandparents is generally unattractive

because they are associated with old age and the devaluing of older people, and the weak stereotype of grandparents do not make them attractive subjects. The grandmothers in this study were not absent but available, ready to support, willing and able, but largely ignored. Phrases such as, “Can I just sit?”; “we just wanted to love her”; “I wish I could give her something better than this”, shows that grandmothers wanted to be involved but had to wait on the side-lines of their grandchild’s care.

I am drawn to the parallels with mythological women in the fabric of their stories. The Tewa Pueblo Indian legend of Spider Woman, grandmother of the earth who is a preserver of life, a weaver of webs, a mentor and helper to those who struggle on the journey (Murdock, 1990). There are links with the notion of the mentor ‘who appears at the outset of a journey, equipping us in some way for what has come, a midwife to our dreams’ (Daloz, 1990: 18). The grandmother spider teaches her children and grandchildren, prepares them for the journeys they are about to take and what to anticipate. Two grandmothers (Susan and Rajinder) in this study had travelled their own journey of having a preterm baby, Grace’s daughter had had two preterm babies prior to the birth of premature twins. The grandmothers acted like the Tewa Pueblo Indian Spider woman by drawing on their prior experience all three could help guide their adult-child through the journey they were travelling.

The grandmothers in this study were called by their children to ‘be with’ *them* on their own journey of becoming a parent. By sewing the patches of stories together, I became aware that grandmothers needed to ‘be with’ *their* child, the ‘being with’ each other during times of stress was important to both child-mother and mother-child relationship. ‘Being with’ may just be a mindful presence (Dowd, 2018) for those mother-child-grandmother relationships, although that supportive presence can represent a powerful and concentrated involvement (White, Walker and Richards, 2008). Four of the grandmothers in this study were not present when their grandchild was born. It was not clear from grandmothers’ stories whether that had been the intention and since four of the births were too early for a birth plan to be in place²⁵, they had missed the chance to ‘be with’ their adult children when their grandchildren were born. Instead, they came to ‘be with’ their children

²⁵ Birth plans are usually discussed and written with the woman’s midwife at 36 weeks gestation.

and grandchildren at the earliest opportunity. Melissa's narrative describes being in the background perfectly.

'Melissa was worried for Christian, basically he didn't eat for 24 hours and actually Melissa said, "right I'm taking him away now, I'm going to feed him". She brought him back fed, with his sandwiches for the day and his bag for the baby and she 'sent him back ready to be a dad'.

My interpretation of their narratives is that grandmothers' function behind the scenes at every stage whether it is in the 'getting there', the 'getting in' or 'staying in'.

5.5 Technology as a barrier

Bordering the patchwork quilt of stories is a physical boundary that hinders access to grandchildren. Grandmothers are predominately obstructed by barriers hidden in their narratives. Grandmothers did not talk to me about technology specifically, it was more hidden in their narratives, the non-narrated. Drawing on my own experience I knew that there was a physical barrier between me and my grandson. I have called this 'technology as a barrier' or physical and metaphorical walls that prevent direct access to a family member put in place because of safeguarding, infection control and convenience. There is no doubt that the safety of babies in NICU is paramount, that their confidentiality, dignity and privacy is maintained, risk is assessed, and families are assured that security of these small, sick human beings is sustained (Cameron, 2010). Current COVID-19 restrictions of social distancing and mask wearing by parents have another added barrier and could have potential long-term effects on human connection and attachment (Green *et al.*, 2020).

Open visiting for parents encourages parental involvement and collaboration with the healthcare team and attempts to reduce parental stress levels and promote FCC (BAPM, 2017; Vohr, 2019). Parental visiting and involvement in the care of their baby needs to be carefully balanced with the need for developmental care (DC)²⁶ (Altimier and Boyle, 2019). This allows for clustering of care, positioning and handling, safeguarding sleep, minimising stress and pain and promotes infant-parent bonding (Lubbe, van der Walt and Klopper, 2012; Givrad *et al.*, 2020).

²⁶ Developmental care: interventions which counteract sensory overload or deprivation such as, reducing stress responses or providing positive sensory experiences (Reid and Freer, 2010).

The NICU may not provide the kind of healing environment that promotes the therapeutic process and a sense of wellbeing (Nichols, 2014). NICUs can be cramped, overcrowded, noisy, poorly lit environments lacking in efficient ventilation. Not only do these conditions have an adverse effect on staff (Rochefort and Clarke, 2010), they can also be draining for grandparents. There are certainly challenges in even providing comfortable seating areas for parents when they want to be at their baby's cot-side (Al-Motlaq, 2018). The design of NICUs in the 1970 and 1980s were planned as multi-patient rooms (Floyd, 2005), hospitals have since had to adapt NICUs to meet the needs of much sicker and more premature babies than they were originally designed to do (Vohr, 2019). This leaves the physical space compromised and therefore a barrier to effective care by the parents (Allermann Beck *et al.*, 2009) and does not accommodate grandparent visiting easily.

If the environment is not conducive to FCC, then attempting to access the baby in the environment is also a challenge (image 8: p126). I became aware that there are several rituals that grandmothers need to perform before they could see their grandchildren. The door to the unit is a gatekeeping device which allows access to the unit within certain rules (Allen *et al.*, 2015). Whilst Allen *et al.* (2015) study is in relation to the maternity unit, there are parallels between the maternity unit and NICU where the locked door maintains a geographic integrity and hence some form of control over the activity within the unit. This may not always be intentional and where a receptionist is not available, it is the nurse who answers the intercom and opens the door (Lee *et al.*, 2014). If the nurse is occupied in caring for a patient there may be considerable delay before the door is opened (Williams, 2019). The nurses' station can also act as a barrier, encountering 'backstage' behaviour' at the nurses' station leaving visitors feeling marginalised and excluded (Underwood, 2017). In addition, if the medical ward round²⁷, nursing handover or medical procedures are taking place, grandparents could be excluded from entering NICU until they have been completed (Bramwell and Weindling, 2005). The rules in NICU are not always uniformly enforced however, leading to confusion and irritation by parents (Williams *et al.*, 2018).

²⁷ Parents are encouraged to be present for discussions of their own baby during ward rounds (Caldwell *et al.*, 2019; Bradford-Duarte & Gbinigie, 2020) However, they are often asked to wait outside when other babies are being discussed in an open ward design NICU to avoid breaches in confidentiality.

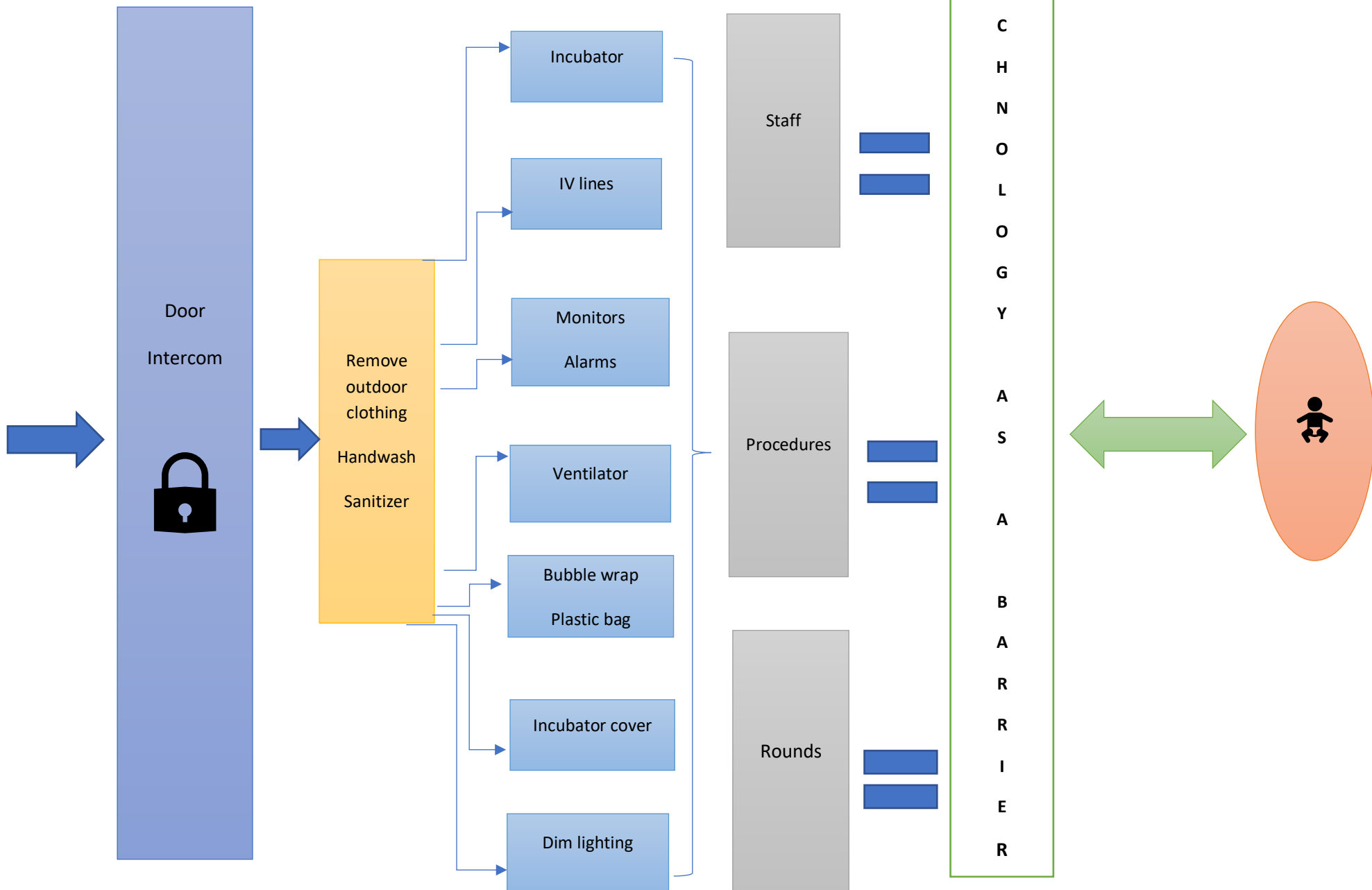
Getting through the door is the first major obstacle for parents and grandparents and links to the patch of 'getting in'. Osafo (2014a, 2014b) describes being an unwelcome visitor to NICU, in this case the visit was in a professional capacity not as a relative. Nevertheless, barriers were in place as she attempted to observe babies for academic purposes. The removal of outdoor clothing, washing hands and applying sanitiser are the second and third rituals to be undertaken. These are unquestionably important tasks and are embedded in the prevention of infection in neonatal care and their use cannot be over emphasised (Helder *et al.*, 2010; Hartz, Bradshaw and Brandon, 2015); although these explicit rules can be very frustrating for parents (Baird *et al.*, 2015). The incubator is another physical barrier and is surrounded by myriad technological paraphernalia and finding the neonate inside who may be covered in more high-tech equipment. The technological environment has been described by nurses as 'alien' and a cause of stress (McGrath, 2008; Feeley *et al.*, 2019). Fathers found the NICU environment created a physical barrier to their involvement in care (Feeley, *et al.*, 2012). Grandparents will find this type of technology a barrier to viewing and caring for their child and grandchild (Tunlind, Granström and Engström, 2015).

This world of ritualistic practice, rules and boundaries is one of tension for visitors who find themselves in the midst of an environment purported to be supporting families when their grandchildren are extremely unwell, and their adult children are exhausted with worry. Culturally scripted behaviours that do not allow rigid rules to be broken to accommodate individual cases can be a great cause of unnecessary stress for all concerned (Waring, Harrison and McDonald, 2007). Certainly, social bonding and mutual support can be affected where there are rigid hospital visiting rules, customs, practices and policies resulting in a damaging and prolonged liminality (Underwood and Rhodes, 2018). However, Sarah was unfazed by the limitations to visiting commenting; "if you've got a really poorly baby you don't want other people coming in a walking around, you know, you just want it quiet". Flexibility in visiting arrangements can have a positive effect and enables families to connect and support their critically ill relative (Mitchell and Aitken, 2017).

The rituals and structural challenges associated with visiting a loved one in hospital such as removing outdoor clothing (Underwood and Rhodes, 2018) was not necessarily seen as a barrier to the grandmothers in this study. The vision of their

grandchild surrounded by technological devices, with painful cannulae inserted into tiny hands, endotracheal tubes inserted and connected to a ventilator, arterial lines into the umbilicus and a feeding tube inserted into the nose is a sight no grandmother wants to see. Their faces difficult to see, their grandchild covered in life-saving technology that also acts as a barrier to their relationship. In Sarah's words, 'I'm like, where is she?' would ring true for every grandmother who meets her grandchild in this way.

Image 8: Technology as a barrier.



5.6 Silent Heroines

Whilst hero is considered an androgenous term and has been used in Campbell's (1990) writings of the hero tale where he uses the term in a non-binary way. I was also influenced by Thomson and Downe's (2013) hero's tales of childbirth using Campbell's theory to underpin their finding, of power, inner strength and courage. However, the female noun of heroine is more appropriate when presented with the following definitions:

1. a woman admired for her courage, outstanding achievements or noble qualities.
2. the chief female character in a book, play or film, who is typically identified with good qualities and with whom the reader is expected to sympathise. (Cambridge Dictionary, 2021)

It is the combination of both definitions that resonate and apply to the women in this study

The backing of the patchwork quilt when sewn in place completes finished object, holding the other layers together. In listening to the stories of grandmothers, I became aware that regardless of their personal circumstances, educational background, age or employment grandmothers appeared to take on the mantle of mentor and heroine automatically without their knowledge. Grandparents do have heroic qualities and their stories contain drama and experience (Kornhaber, 1996). The drama grandmothers spoke about, the layers of differing experiences are epiphanies (Denzin, 2014). I came to realise that rather than being vulnerable or victims, the grandmothers in this study were heroines. An unspoken patch that was silently woven throughout their story was being a mentor and a heroine that came naturally to them; behind the scenes, caring, supporting and being there.

The basic image of mythology is a woman and her child where there is mystic participation between the mother and the child and the child and the mother, is the final happy land, meaning that women do not need to make the heroic journey, since they are already in that place (Campbell, 1990). The true goal of the heroine is to become the all-powerful archetypal mother therefore, they set out on missions to restore their traumatised families (Frankel, 2010). Grandmothers in this study did indeed set out on their journeys to support their shattered families,

as mothers first and foremost. Heroines work as hard as any hero, they just do it 'without swords' (Frankel, 2010: 51). Certainly, women do not need to be warriors to be a heroine although, those who are, are more likely to be remembered (Colthran, Judge and Shubert, 2020).

The transition to grandmotherhood and wise women is a major shift for grandmothers, now matriarchs, teaching and nurturing the next generation. For most of the time that their baby was in NICU the parents were alone or with their partner with no other visitor present. At times though, and as expressed by two adult children, both needed their mother's presence; 'Please come Mummy' (Melissa's son Christian) and 'Mummy, I need you' (Grace's daughter Christine). Grandmothers came when asked, dropped everything and arrived to be with their adult child silently, without fuss, heroes without capes.

In Greek mythology there are many heroes who are almost exclusively men, who were mainly involved in fighting opposing armies or mythical creatures. Female fighters such as Amazons, Artemis, the Greek goddess of the hunt, Athena the armed warrior goddess and helpers of many male heroes (Isaccs, 2016). These seemingly strong women are described as warriors but not as heroines. To destroy the myth of inferiority, a woman needs to carry her own sword of truth (Frankel, 2010). As each woman dispels the myth of female inferiority, she becomes a role model for others (Murdock, 1990). Frankel (2010) highlights the point that grandmothers are not warriors by birth, they have married into the tribe, meaning that women sometimes must take on male attributes in order to become a heroine in her own right. Grandmothers will fight for the rights and wellbeing of their adult children and grandchildren. They do this without assuming male attributes.

Achilles the warrior and hero of the Trojan war could not have gone into battle without a woman behind the scenes. This woman was Briseis who quietly brought Achilles his food and wine, did the weaving with other women and sewed his battledress ready for war (Boyle, 2008; Fry, 2020). Briseis tells the women's story in the battle for Troy (Barker, 2018; Barker, 2021); without drama she silently went about her daily business sewing, weaving, cleaning to prepare Achilles for the battles he was about to enter. Briseis also supported other women, caring for them and their newly born children (Barker, 2021). Grandmothers in this study

possess the same qualities as Briseis, preparing her adult children for the journey they were continuing, behind the scenes, stalwart, dignified, reliable and noble.

The grandmothers in this study embody the characteristics of Athena, teacher of skills and mentors to their children, a love that is quietly strong and protective, heroic without glory or grandeur. And of Briseis, quietly weaving together the threads of a garment ready to be worn by the hero. Grandmothers in turn, silently facing the metaphorical battle they met when their grandchild was ill, when their own adult child needed maternal support, they are the true heroines who put their child and grandchild's need first, juggling their lives, work and family amid this stressful, emotional situation, and doing so without swords.

Grandmothering a grandchild in NICU has many facets; from being a mother, mentor, teacher, supporter, helper and nurturer. Grandmothers do these many roles whilst holding down jobs, being wives to their spouses, mothers to their adult children, grandmothering other grandchildren, being a friend, sister and daughter. The complex nature of being a grandmother is hidden beneath the quilt of their individual story. Patchwork itself is a metaphor for how their roles of being a grandmother are fragmented yet sewn together by a unique and individual complex experience.

5.8 Implications for practice

Despite the plethora of interest in FCC, there is nothing in the FCC framework that includes grandmothers as part of the family unit. Parents who have a critically ill child in NICU want to spend as much time with their baby as possible, extending their attachment and getting to know their offspring. For parents to spend time in NICU there needs to be someone 'holding the fort' and 'behind the scenes', that person is often the grandmother(s). Being behind the scenes often means that grandmothers are invisible to NICU staff, in the background, not intruding, taking care not to overstep the mark. Grandmothers are though, a valuable source of support to parents which is often not acknowledged by staff. Their contribution is invaluable and has the potential to be more valuable if they were allowed to come to the forefront. Neonatal Networks, Bliss, BAPM and managers should look forward to including grandparents in their policies regarding FCC and look to their midwifery colleagues who have made great strides in welcoming grandmothers

into their antenatal education classes, to be birthing partners to women and supporting them through the postnatal period.

At practice level the findings suggest the need for nurses, midwives, doctors, support workers to appreciate that for parents to visit their baby in NICU, there may be one or two grandmothers diligently and unobtrusively working behind the scenes caring for other grandchildren, cooking, cleaning, transporting, providing emotional and financial support. Grandmothers may also have other commitments, elderly parents, other family members requiring support and have careers of their own.

5.9 Chapter summary

In this chapter I have discussed the findings of the study within the wider literature and have applied a focus on grandmothers as the real heroines when their grandchild is in NICU. I have retold grandmothers' stories within the central patches of **getting there, getting in and staying in**. Grandmothers in this study were always **behind the scenes**, bordered by **technology as a barrier** and developing into **silent heroines** on their joint journeys with their families.

The contribution this chapter makes to the body of knowledge is multi-layered. Telling stories through the medium of fictional stories adds light and shade to the stories grandmothers had to tell. The knowledge elicited from those stories shows how they support their adult child, have genuine concerns for their family and arise as heroines providing a solid foundation on which everyone can lean.

In the next chapter, using Richardson's criteria (2000a; 2000b) for evaluating this study; I will draw together the findings of this enquiry and make recommendations for those who care for sick babies in a NICU.

Vignette five- Sarah

A rollercoaster

It's happened! They've kept her in. Her blood pressure is really high, and she is only 31 weeks. The placenta is breaking down and she's been rushed into theatre for an emergency caesarean. All of this I've learned over the phone, because she's at the hospital and I'm at home. I feel very isolated and very worried for my daughter and granddaughter, it's been the worst experience of my life, a real rollercoaster in fact! I'm being like a mad woman keep ringing her, texting her, "any news?" , "what's this and what's that?" and I can't help myself coz I'm so concerned about them both, so it's still early days, she still tiny and I want to know if she's growing, if she's put any weight on and if she hasn't why not, you know she's having her milk, why isn't she putting on any weight those sorts of things you know it's erm it's very hard. I'm like, I want to ask all the questions, but I've have had to take a step back I was going to ask the questions but it's not my place to, but I think I've been very good, I like to think I have!

Chapter 6

Conclusion

6.0 Introduction

This study has generated rich stories from a small cohort of grandmothers who had sick grandchildren as inpatients on one of two inner city NICU in the West Midlands. The findings show that despite barriers (intentional or otherwise), grandmothers, rather than victims are the real heroines in the family when a small baby is born; is unwell and their parents are doing their best to support him or her in an environment that is alien and frightening. This chapter draws the findings of this research together by returning to the objectives and addressing Richardson's criteria (2000a; 2000b; table 6). Included in this chapter is how I have answered the research question and indicates the strengths and limitations of the enquiry. I will reflect upon what I have learned from undertaking this study and what I might do differently in the future.

1. **Substantive contribution**- does the piece contribute to our understanding?
2. **Aesthetic merit**- is it artistically shaped?
3. **Reflexivity**- is the author held accountable to standards of knowing and telling?
4. **Impact**- does it generate new questions?
5. **Expresses a reality**- is it a true and credible account?

Table 6: Richardson's criteria

6.1 The research question

'What stories do grandmothers have to tell about their experiences of having sick grandchildren who are being nursed in a Neonatal Intensive Care Unit?'

In asking a simple question an abundance of rich data was generated. From my professional background, I knew that grandmothers were a marginalised group of visitors to NICU, but it was not until I experienced first-hand and had my own story that I became interested in what other grandmothers might have to tell me. From my standpoint of midwife/nurse, researcher, mother and grandmother, my

intention was to get close to the subjects so that they could recount their living story. I achieved that with a handful of grandmothers who had a story to tell. This study has highlighted and listened to grandmothers' stories, opening the way for them to have a voice, for grandmothers to be accepted and valued by the staff caring for their grandchildren.

6.2 Strengths and Limitations

Although there have been a limited number of studies on this subject, there is little interest in UK literature to address grandmothers' experiences of having a grandchild in NICU. My own story has provided a prologue for their stories using a theme board as a framework for the re-telling of my story. I have listened to their stories and have found several commonalities that weave through the patchwork of their narratives. I am confident that what they told me on the day I interviewed them was an exact account of what had happened to them, with no manipulation or agenda.

Strengths

My own story is pivotal in this enquiry. Had Lenny not been born at thirty-three weeks gestation and contracted GBS and had I not had the professional experience of a nurse and midwife; I would not have had a story to tell. Talking to grandmothers in this study confirmed that I had not imagined that having a preterm grandson was a traumatic and worrying experience. Having specialist knowledge had not prepared me for being a grandmother to an unwell grandchild (Giles and Hall, 2013). And, in listening to grandmothers' stories, I could hear that there were aspects of their experiences that had similarities and variances to mine.

Using a combined hybrid methodology facilitated my own experiences to stand alongside those of the participants in this study. Performance autoethnography or the opportunity to participate in others' lives gives this study a depth of understanding and used my own experience as a basis for the study (Hammersley and Atkinson, 1983). The use of a theme board to pictorially tell my story became a foundation for grandmothers' storytelling. Finally, narrative analysis looking for meaning in the stories, finding similarities and differences between them (Bruner, 2004).

There is no doubt that Frank's work (2010) has been crucial in this work in allowing grandmothers' stories to be heard. Framing those stories in the style of Atkinson (1995) has given nuances to the stories that were there in the telling but were accentuated using this novel approach. Grandmothers' commitment to this project meant they spared some precious time away from their grandchild to tell me their stories. They all bared their soul to me, told me their story, wept, laughed and joined me in that collective space of being a grandmother in NICU. Their vivid, detailed narratives contained vital, personal elements that I have lovingly crafted into their own personal account.

Limitations

From the birth of this project, I have been concerned about the possibility of bias in the work since the inspiration came from my own experience. I considered telling my story *after* grandmothers had told me theirs in an aim to reduce some bias. This felt erroneous, I believed that in sharing my own story would show grandmothers that I was the same as them, this had happened to me, although again, the introduction of bias was potentially problematic. I was concerned that the rapport I had started to build with them at the cot-side might be lost with a clinical 'tell me your story' approach. To address this, I have attempted to be transparent about my approach.

This study presents the narratives of grandmothers within a limited timeframe and may be useful in changing practice policy. There is no suggestion that the findings are transferable to other NICU in the UK. Caution should be taken when interpreting the results due to the small sample size.

Grandmothers are a hard-to-reach group and despite sitting and waiting in NICU for hours on end, it was three weeks before I found a grandmother visiting at all. In my naivety, I assumed there would be several grandmothers present during the allocated visiting times. Eventually I was able to recruit the first grandmother. I justify the small sample size of five grandmothers in this study. The group of grandmothers were homogeneous in that they were all in heterosexual married relationships but heterogenic in terms of cultural backgrounds. Acknowledging these variations is an important aspect in narrative research (Holloway and Freshwater, 2007).

As seen in this study, grandmothers are frequently 'behind the scenes' and therefore do not visit their grandchild often due to other family commitments. This resulted in a small sample size and although I am more than satisfied with the stories they told; it was a frustration that there were so few available. Although their stories generated a large volume of data to analyse, more stories could have added further to the rich and diverse data I gathered.

I chose not to engage with professionals to elicit their views on grandmothers in NICU, although on reflection, their views would have been extremely valuable. I did consider this once I had interviewed two grandmothers but since this meant gaining separate ethical clearance, I decided not to pursue this further. There was interest from nurses and consultants when I discussed my project with them, therefore this is an avenue that could be considered in the future.

Using Richardson's criteria of interpretive sufficiency (2000a; 2000b), I will address these individually.

6.3 Substantive Contribution

This study aimed to listen to grandmothers' stories and has been achieved. My personal contribution is made using a three-step approach to analysis, that culminated in the three main patches: getting there, getting in, staying in. Moreover, the treatment of the findings has added to the contribution to my understanding. Grandmothers could have been viewed as vulnerable, as victims in NICU, the poor elderly women who can only visit when permitted, who cannot touch their grandchild and who do not have a voice or any choice. The epiphany (Denzin, 2014a) came when I realised that these strong women were silent heroines, 'behind the scenes' doing what they could with love and generosity. Silent because they supported their adult child and grandchild unconditionally, without fuss or drama and do so whilst juggled other commitments and responsibilities. Heroines because they travelled long distances but also travelled the journey with their family. Being 'behind the scenes' appeared to come naturally to grandmothers, undertaking practical tasks, providing emotional support and feeding their adult child so that they could function at a basic level when being with their sick baby.

The technology that is keeping their grandchildren alive also acts very effectively as a barrier to the early relationship grandmothers can have with them. Accessing

NICU can be a daunting experience for any visitor especially those with a loved one inside. The formality and ritual that accompanies visiting a grandchild needs to be factored into the time it takes to get to the cot-side. The barrier of technology locks grandmothers out of NICU physically and metaphorically, whilst mostly unintentional, the gatekeeping process only serves to create frustration and disappointment. The border of technology came exclusively from non-narrated aspects of grandmothers' narratives as well as my own experience. Uncomplaining, they waited their turn, obeyed the rules and held their adult children's hands. The exception to this was Melissa who pushed the boundaries and stayed overnight when it was thought that her daughter-in-law would not survive. An exception to the rule that Rajinder could not navigate, her own mother, having to go home without seeing her great-grandson.

6.4 Aesthetic Merit

I have attempted to shape this study with artistic flair. Due to word constraints, I have not been able to present all grandmothers' full stories within this thesis. What I have presented are carefully chosen facets of their stories that are crafted to bring character, plot and emotion to them. Telling some stories from the viewpoint of another has given an alternative perspective from that of the participant which has added nuance and shade to the narratives (Frank, 2010). Concrete experience, intimate detail, careful editing, vivid pictures, feelings, conversations that feel like real life and most importantly, that the story is worth fighting for and one that encourages compassion and empathy are standards that are achieved in the heartfelt-ness in their interpretation (Ellis, 1999; 2000).

There are authors other than Atkinson (1995) that I could have considered using to frame grandmothers' stories. I did ponder the use of *The Revenant* by Michael Punke, that tells of a long and arduous journey, and unimaginable human endurance. However, this was a male narrative and was violent in places and after a period of reflection, I decided against it. I had also read other novels by Atkinson and considered 'Life after life', however, 'Behind the scenes at the museum', became the book that encompassed the images I wanted to portray.

The use of the theme board has artistically shaped this thesis. Simple but effective pictorial images that tells my story without words. Utilising this in my re-telling of my story created a performance, one I could perform again and again. I do not

profess that my theme board has any artistic merit, but it does provide a portrait that reveals my experience, my story and when dialogue is added a performance that it sincere and genuine (appendix 1).

The combination of my theme board, the performance, the re-storied narratives and the structure and design of this thesis do contain aesthetic merit, a work that values the expressions of grandmothers' stories in a unique and aesthetically pleasing manner.

6.5 Reflexivity

My position in this enquiry is four-fold; mother; grandmother; midwife; student researcher and from the position of each, I have approached this enquiry with enthusiasm, resilience and a dedicated determination. My position is a key feature of this study with a strong interconnectedness with the grandmothers. I did not expect to build such a rapport with them, but on reflection, my years of experience as a midwife and teacher had led me to this point, where I was able to 'click' with grandmothers from the outset.

Reflecting on the processes within this study, I would consider whether I would again apply through NHS ethical procedures to gain access to grandmothers. This laborious process took almost a year before appropriate approval was granted. Whilst I am now satisfied that I developed sufficient resilience to pursue this line of approval, there were times when I considered gaining access to grandmothers via an online forum such as mumsnet or attempting to find grandmothers from within my workplace who had had a sick grandchild in NICU. This would have made the process simpler and less arduous, however, the quality of data I gathered by sitting and talking to grandmothers in NICU and whilst their grandchild was still unwell, was exceptional. The critical element of being in that time and that space was central to this study and would not have been achieved with an online interview.

I understood that using a narrative approach would generate a large volume of data. I also knew that transcribing and analysing said data would be time-consuming. I underestimated the time and effort that these processes would take, additionally, creating stories from grandmothers' narratives was also a lengthy process. However, this formed an essential aspect of the analytical process and was invaluable in my getting to know the participants all over again. Through my

own lens of knowledge and experience I could shape the stories using a literary style. However, including '*everything except the kitchen sink*' can be very tempting for the researcher (Etherington, 2014: 54). I became very attached to the stories once they were written and have been tempted to include everything in this thesis. It has been painful to remove valuable quotes from the finished work, but more importantly, the inclusion of those that remain reflect the narratives concisely and clearly.

A good story promises to expose what is hidden (Ungar, 2011); I have attempted to show the hidden, non-narrated through fictionalising grandmothers' narratives. It is not a substitute for the academic methods I have used but in using fiction to express grandmother's words and telling them from different people's perspective has meant that other voices are also heard. I could have used a more conventional approach to the findings, presenting them as isolated transcripts, thematically presented. I wanted to produce a study that was more artistic, had more flair, and pushed the boundaries of qualitative research in nursing and midwifery arenas.

6.6 Impact

This study has generated knowledge about grandmothers with a grandchild in NICU that has not been explored in the UK. In the execution and writing of this study, I have begun to generate new questions that this study has not achieved since they were not part of this enquiry. The questions that have arisen for me are:

1. What are grandfathers' experiences of having a sick grandchild in NICU? Whilst I made a conscious decision not to include grandfathers' views and opinions in this study, there is no doubt that their contribution to families during times of crisis would be worthy of investigation. On my visits to NICU as part of my data collection process, I spoke only to two grandfathers. They are another hard-to-reach group who also have other commitments and responsibilities. Nevertheless, data from the male perspective would create more awareness that could, in turn, effect policy.
2. Gaining an insight into HCP views on grandparents would add to the body of evidence. McHaffie's survey in the 1990's concluded that HCP in NICU least liked working with grandparents than any other family member. There are many versions of grandparents (adoptive, step, same sex) that can

add to the confusion on who is permitted to visit. A clearer picture from HCP perspective may give them an appreciation of what grandmothers do and could do, not just looking after other siblings and bringing food to their adult child.

3. I am interested in the stories adult children of grandmothers would have to tell. I have painted a picture in this thesis whereby relationships were good between grandmothers and their children, there was mutual respect and a common goal. This may not be true for all families, and some may argue that their mother or mother-in-law should do more, some may be irritated by interference from grandmothers, some grandmothers may live some distance away and cannot be involved. What are the stories of those parents where their baby is in NICU, where they do not have extended family on who to lean?
4. There is the possibility that grandmothers and grandfathers can offer valuable support to their child when they have a grandchild in NICU. Since this generation of support has no voice, no real role to play in FCC, it would be interesting to ascertain grandparents' views on how they could make a difference.

6.7 Express a reality

It has been an honour to listen to the stories of grandmothers in this study. Their stories were overwhelming at times, their honesty, integrity and their resilience were admirable. I have attempted to be faithful to their words throughout this study and the use of Atkinson's (1995) style has allowed me some artistic licence, but their fundamental stories have remained an authentic account of their narratives. The credibility lies in my interpretation of their narratives expressing reality, embodying a fleshed out, embodied true and credible account (Richardson, 2000b). Listening to grandmothers' stories, I could hear the pain, worry, joy, heartache, love and passion in their voices. I have conveyed those emotions in my re-writing of them in the hope that readers are as moved by their words as I was.

Credibility also lies in my own story, the profound truthfulness of it. I have shown my own story in this enquiry from the outset, laying it open, not hiding it away but celebrating it as an essential aspect of this study. The words of Richardson (2010: 17) ring true to me; 'Oh, dear, it is *my son-my son-* who is jeopardy now...'

Experiencing the same feelings, I rallied the family and played my part and I have declared this loudly from the outset adding to the credibility of this work.

6.8 Recommendations

Those caring for sick neonates should:

- Recognise that grandmothers are *mothers* themselves first and foremost and have 'triple worry'.
- Challenge policy makers to include a more flexible schedule of visiting for grandmothers. When the partner resumes work following paternity leave or when the mother is single, think about grandmothers becoming a named partner who can also have open visiting allowances.
- Challenge policy makers to investigate the possibilities of providing a comfortable waiting area for grandparents, that provides some comfort and privacy, recognising that they work behind the scenes in many ways.
- Understand that some grandmothers may be providing childcare when the mother returns to work. Think of ways in which grandmothers can be included in individualised FCC and in discharge planning education, to help extend attachment with their grandchild.
- Encourage grandmothers to help mothers with breastfeeding, expression and storage of breastmilk. This may require individualised support and education.
- Consider working with leading charities to develop a grandparent booklet that provides relevant information and recognises their place in FCC.
- Facilitate grandmothers to hold their grandchild, in the presence of a parent when the baby's condition allows. Fill those 'empty arms'.

7.0 The final chapter

“When I visited my grandson in NICU, I was apprehensive, excited and fearful, not knowing what the future held for him or his parents. As a mature woman I have experienced many life events, this being yet another to be stored into my memory to be taken out and re-told from time to time. What of Rajinder, Grace, Susan, Sarah and Melissa, have they had more grandchildren? Have they had to travel their journey once more? I will never know. And what became of me? I have since had three more grandchildren, Lenny’s little brother was born in 2016, he also needed a month of care in NICU. My granddaughter was born to my daughter in 2019, required no NICU admission, a completely different experience that has made me reflect on how much, as a grandmother, I missed with the first two boys. As grandmothers our collective stories have informed this project allowing our stories to be told to a wider audience”.

“The sky begins to dry a little, the air seems to lighten. I am at home, over the threshold. I am alive. I am a precious jewel. I am Lenny Lumsden”. (Atkinson, 1995:333).

8.0 Postscript

My fourth grandchild, Connie was born in May 2021. At four weeks of age, she was admitted to a children’s ward after experiencing seizures. She was subsequently diagnosed with a rare genetic condition namely, 1P36 deletion syndrome. During her hospital stay, due to Covid 19 restrictions I was prevented from seeing my daughter and granddaughter. Here, I found myself, once again *behind the scenes*. My experiences of being a grandmother and the findings of this study will continue to challenge those caring for small, unwell babies and for them to think about the wider family’s involvement.

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Appendices

Appendix 1 Theme board explanation

This image is not very clear, but it is of some knitting; I had begun to knit a cardigan for the unborn baby. I stopped knitting when he was born, and I have never finished it.

Central to this story is Lenny. I have placed him firmly in the centre of this theme board

This image depicts me holding onto my son who I know must sink or swim in this situation. I can stay afloat, can he?

This is how I imagined the birth of my first grandchild to be, balloons, cards, the metaphor of swimming in clear water.

This is the fragility of the situation. Knowing that he was very ill and not knowing what the outcome would be.

This image is me looking out, from afar.

This corner depicts my daughter's wedding that was due to take place two weeks after Lenny was born. The cake, party food, wine, barbeque, a hat.



This image is of me with the weight of the world on my shoulders

This corner of the board is of a phone, books, work and me trying to juggle everything.

This is my brain, too full and needing a rest.

Here I am, not knowing what to do or which way to turn. This is how I felt most of the time.

Central also to my story and acting as a foundation on which everything else rests is my husband (otherwise known as Badger).

This image depicts me upside down in a sea of information

Appendix 2 Data extraction tool

Author and date	Title	Publication	Design/methodology	Sample	Data collection method	Method of analysis	Findings	Country
Blackburn, S., Lowen, L. 1986	The impact of an infant's premature birth on the grandparents and parents.	Journal of Gynecologic and Neonatal Nursing. 15 (2), 173-178	Postal survey	83 grandparents; 50 parents.	Questionnaire	Content validity	Hospital visiting activities; information sources; emotional reactions.	USA
Rempusheski, V., F. 1990	Role of the extended family in grandparenting: A focus on grandparents of preterm infants.	Journal of Perinatal and Neonatal Nursing. 4 (2), 43-55.	Grounded Theory	15 grandmothers	Interviews	Thematic analysis	Not feeling like a grandparent; anticipating the worst; acting to protect; learning a new language.	USA
McHaffie, H. E. 1991	Neonatal intensive care units: visiting policies for grandparents.	Midwifery. 7 , 122-132	Survey	Nurses/midwives n=265; doctors n=63; families n=93	Questionnaire	SPSSX	Professional least liked working with GP, dissatisfied with existing policies for GP; parents were dissatisfied with policies for GP.	United Kingdom
McHaffie, H. E. 1992	Social support in the neonatal intensive care unit.	Journal of Advanced Nursing. 17 , 279-287.	Survey	93 families	Questionnaire	SPSSX	More was expected of GM than from GF. Maternal GM were key figures	United Kingdom

Appendix 2 Data extraction tool

Armstrong, M. J. 2003	Is being a grandmother old? Cross-ethnic perspectives from New Zealand.	Journal of Cross-Cultural Gerontology. 18 , 185-202	Qualitative	30 women	In-depth interviews	Thematic analysis	Seniority and social status; social renewal; social integration;	New Zealand
Hall, E. O. C. 2004	Double concern: Grandmothers' experiences when a small grandchild is critically ill.	International Pediatric Nursing 19 (1), 61-69.	Phenomenology	7 couples	Interview	Thematic analysis	Double concern; being there no matter what; being in the midst of life and death; Constant worrying.	Denmark
Hall, E. O. C. 2004	A double concern: Danish grandfathers' experiences when a small grandchild is critically ill.	Intensive and Critical Care Nursing. 20 14-21.	Phenomenology	7 couples	interview	Thematic analysis	Double concern; caring and coping; being in the midst of life and death.	Denmark
Bramwell, R., Weindling, M. 2005	Families' views on ward rounds in neonatal units.	Archives of Disease in Childhood Fetal & Neonatal Edition 90 , F429-F431	Survey	86 respondents	Short interview	SPSS package	Over 50% overheard conversations about other babies; Concerns were expressed only by those who had overheard; parents and families had little information about ward rounds; confidentiality was a concern for some.	United Kingdom

Appendix 2 Data extraction tool

Latva, R., Lehtonen, L., Salmelin, R. K., Tamminien, T. 2007	Visits by the family to the neonatal intensive care unit.	Acta Pædiatrica 96 , 215-220	Retrospective survey of medical records	210 maternal records data	Medical records survey	Mann Whitney Test SPSS package	Mothers visited 6.7 days per weeks, fathers 4.8 days per week; 92% siblings visited; 80% grandparents visited.	Finland
Fergusson, E., Maughan, B., Golding, J. 2008	Which children receive grandparental care and what effect does it have?	Child Psychology and Psychiatry 49 (2), 161-169.	Longitudinal study (aspects from)	8752 families	ALSPAC		44% of children were regularly cared for by GP	United Kingdom
Hansen, K., Joshi, H. 2008	Millennium Cohort Study Third Survey: A User's Guide to Initial Findings	Centre for Longitudinal Studies	Analysis of Millennium Cohort Study	15,246 families		Repeated analysis	Working mothers used grandparents for childcare approximately for 18 hours per week	United Kingdom
Baird, B., Lucas, R., Donnellan, M. 2010	Life Satisfaction Across the Lifespan: Findings from Two Nationally Representative Panel Studies	Social Indicator Research. 99 , 183-203.	Analysis of two (German and British) national panel studies.	40,000 subjects with seven sub-samples	Comparison of two studies	Meta-analysis	Life satisfaction does not decline over much of adulthood, although a large decline in satisfaction in the over 70s was found.	United Kingdom
Ben Shlomo, S., Taubman-Ben-Ari, O., Findler, L.,	Becoming a grandmother: Maternal grandmothers' mental health,	Social Work Research. 34 (1), 45-57.	Survey	N=102 maternal grandmothers	Questionnaire	Repeated multivariate analysis	Personal growth; active involvement with grandchild;	Israel

Appendix 2 Data extraction tool

Sivan, E., Doliz, M. 2010	perceived costs and personal growth							
Ravindren, V. P., Rempal, G. R. 2010	Grandparents and siblings of children with congenital heart disease.	Journal of Advanced Nursing. 67 (1), 169-175.	Qualitative	15 grandparents	Interviews	Open coding.	Stepping in as needed; safeguarding relationships.	Canada
Richardson, L. 2010	Jeopardy: A grandmother's story	Symbolic Interaction. 33 (1), 3-17	Autoethnography	1 grandmother	Creative non-fiction	Symbolic interaction		USA
Gunn, J. 2011	The Grandparent's Journey.	Neonatal Network. 30 (4), 273.	Personal reflective account	Set of grandparents			Emotion, pain, grief.	USA
Backhouse, J., Graham, A. 2012	Grandparents raising grandchildren: negotiating the complexities of role-identity conflict.	Child and Family Social Work 17 , 306-315	Qualitative study	34 Grandparents	In-depth interviews using 2 questions	Three-layer thematic analysis	Pain/pleasure; myth/reality; inclusion/exclusion; deserving/undeserving; visible/invisible; voiced/silenced.	Australia
Frisman, G. H., Erikson, C., Pernehed, S., Mörelius, E.	The experience of becoming a grandmother to a premature infant- a balancing act,	Journal of Clinical Nursing. 21 , 3297-3305.	Qualitative	11 women	Interviews	Qualitative content analysis	Emotional experiences' a new role;	Sweden

Appendix 2 Data extraction tool

2012	influenced by ambivalent feelings							
Moules, N. J., Laing, C. M., McCaffrey, G., Tapp, D. M., Strother, D. 2012	Grandparents experiences of childhood cancer Part 1: Doubled and Silenced.	Journal of Pediatric Oncology Nursing. 29 , 119-	Phenomenology	12 women; 4 men (four couples were interviewed together)	Interviews	Hermeneutic analysis	Speed at which life changes; out of sync; knowing silence; life on hold; quest for normalcy; helplessness; GP needs.	Canada
Moules, N. J., Laing, C. M., McCaffrey, G., Tapp, D. M., Strother, D. 2012	Grandparents experiences of childhood cancer Part 2: The need for support.	Journal of Pediatric Oncology Nursing 20 , 133-140.	Phenomenology	12 women; 4 men (four couples were interviewed together)	Interviews	Hermeneutic analysis	Loving double; it's the right thing to do; the irony of inverse energy; standing by; changing relationships/	Canada
Backhouse, J, Graham, A. 2013	Grandparents Raising their Grandchildren: Acknowledging the Experience of Grief	Australian Social Work 66 (3) 440-454	Narrative Enquiry	34 Grandparents	Interviews	Three-layer narrative analysis; Narrative analysis	GP demonstrate grief and loss when caring for GC as a replacement parent. Loss of identity and being invisible were key findings	Australia
Findler, L., Dayan-Sharabi, M., Yaniv, I.	The overlooked side of the experience: Personal growth and quality of life among grandparents of	Journal of Family Social Work. 17 , 418-437.	Survey	56 grandparents and 60 control GP	Questionnaire Post traumatic growth	MANOVA	Lower sense of coherence; support and past experiences of the Holocaust	Israel

Appendix 2 Data extraction tool

2014	children who survived cancer.				inventory (PTGI) WHO QOL BREF-SOC scale		contributed to personal growth.	
Wakefield, C. E., Drew, D., Ellis, S. J., Doolan, E. L., McLoone, J. K., Cohn, R. J. 2014	'What they're not telling you': A new scale to measure grandparents' information needs when their grandchild has cancer.	Patient Education and Counselling. 94 , 351-355.	Survey	87 grandparents	Questionnaire	SPSS& SAS	Grandparents need more information to reduce 'second-hand' information; GP strongly endorse the need for an information booklet	Australia
Moore, S. M., Rosenthal, D. A. 2015	Personal growth, grandmother engagement and satisfaction among non-custodial grandmothers	Aging and Mental Health. 19 (2), 136-143	Survey	1205 grandmothers	Survey (91% participated online)	ANOVAs	Positive sense of living a productive life; engaged with grandchildren; wide range of activities.	Australia
Lee, E., Clarkson-Hendrix, M., Lee, Y. 2016	Parenting stress of grandparents and other kin as informal kinship caregivers: A mixed methods study.	Children and Youth Services Review. 69 , 29-38.	Mixed methods	303 caregivers	Survey and focus groups	t-tests and x2 tests	Children's wellbeing; relationships with birth parents; stress of dealing with authorities; additional stress	USA
Charlebois, S., Bouchard, L.	"The worst experience": The experience of grandparents who	Canadian Oncology Nursing Journal	Phenomenology	8 grandparents	Semi-structured interviews	Thematic analysis	Living the worst experience; having to support: A crucial role for grandparents; to	Canada

Appendix 2 Data extraction tool

2017	have a grandchild with cancer.	17 (1),					feel supported to better carry on.	
Moraes, E. S., Mendes-Castillo, A. M. C. 2018	The experience of grandparents of children hospitalized in Pediatric Intensive Care Unit.	Revista Da Escola De Enfermagem Journal of School of Nursing- University of São Paulo 52 , e03395, 1-8	Grounded Theory	9 grandparents (2 GF; 7 GM)	Participatory observation; semi-structured interviews	Comparative analysis	Finding themselves inside a storm; fighting to be the anchor of the family	Brazil
Rambo, C. 2018	Impressions of Grandmother. An autoethnographic portrait.	Journal of Contemporary Ethnography. 34 (5), 560-585.	Autoethnography			Stories of grandmother		USA
Flacking, R., Breili, C., Eriksson, M. 2019	Facilities for presence and provision of support to parents and significant others in neonatal units.	Acta Pædiatrica 108 , 2186-2191	Cross-sectional survey	34 NICU	Statistical analysis	Chi-square test + Fisher exact tests SPSS version 23	Restrictions on visiting for parents; siblings; grandparents; other relatives and friends in 50% of NICU	Sweden
Kelada, L., Wakefield, C. E., Doolan, E., Drew, D., Wiener, L.,	Grandparents of children with cancer: a controlled comparison of perceived family functioning.	Supportive Care in Cancer. 27 , 2087-2094.	Controlled comparison study	Grandparents of children with cancer (n=89); grandparents of healthy children (n=133)	Family assessment device	IBM SPSS V25	GP with children with cancer reported poorer family functioning; the impact of cancer extends beyond the immediate family	Australia

Appendix 2 Data extraction tool

Michel, G., Cohn, R. J. 2019								
Bordone, V., Evandrou, M., Vlachantoni, A. 2020	Ethnicity and grandparental childcare in the United Kingdom	Ageing and Society. 40 , 713-734.	Literature review	Data from Understanding Society survey	Synthesis		Ethnicity and grandparental childcare;	United Kingdom

Table of ethics process

Date	Committee	Amendments	Approval
<p>6 October 2014</p>	<p>University of Wolverhampton, Faculty of Education, Health and Wellbeing, Ethics Committee: documents submitted:</p> <ul style="list-style-type: none"> • Invitation letter to parents • Invitation letter to grandmothers • Information sheet for parents • Information sheet for grandmothers • Consent form to interview for parents • Consent to interview for grandmothers • Consent to audio recording parents • Consent audio recording grandmothers • Research protocol • Risk assessment 		
<p>23 November 2014</p>	<p>University of Wolverhampton, Faculty of Education Health and Wellbeing, Ethics Committee.</p>	<p>Information sheet 'Interviewing you' – seems an inaccurate title when the info sheet is for the parent not the grandparent – this needs tightening up.</p>	

Appendix 3 Table of ethics process

		<p>Remove footnotes from the info sheet and consent forms and make limits of withdrawal clear.</p> <p>Include a debrief sheet with more information about supports available – these are mentioned in the ethics form but not in the study materials</p> <p>Clarify recruitment venues as mentions more than one but on New Cross by name.</p> <p>Need to consider potential upset to participants more and include what steps will be taken during and after data collection should this occur.</p>	
23 November 2014	Amendments submitted		21 January 2015
February 2015-August 2015	<p>Integrated Research Approval System negotiated- all documents submitted including:</p> <ul style="list-style-type: none"> • Research passport • University liability certificate • Occupational health certificate • CV • Reference from line manager 		
7 August 2015	Integrated Research Approval System (IRAS)	Proportionate review not acceptable. Full REC meeting attendance required.	

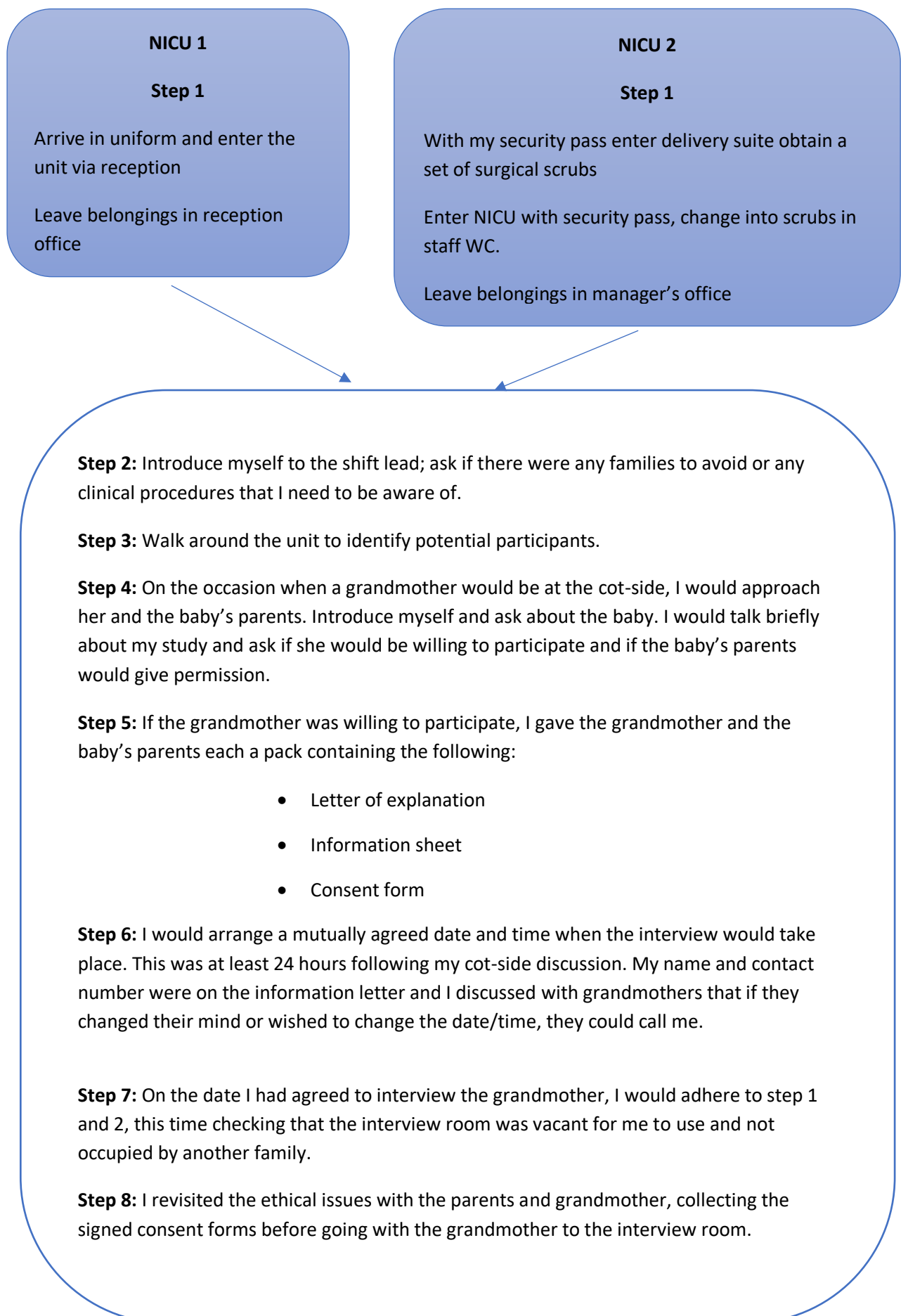
Appendix 3 Table of ethics process

<p>25 August 2015</p>	<p>Introduction to Good Clinical Practice eLearning (Secondary Care)</p> <p>Certificate</p>		
<p>16 September 2015</p>	<p>Attended Research Ethics Committee (REC) in Birmingham before a panel</p>	<p>1. The following changes to the protocol are required:</p> <p>a) It must be clear how cultural patterns will be measured in the study.</p> <p>b) The criteria for the grandmother must be clear e.g. are they required to be parent/legal guardian of either the mother or father.</p> <p>c) A clear definition of a 'sick' neonate must be given, and the inclusion/exclusion criteria must clearly define the level of illness that would prevent the grandmothers of a child being approached.</p> <p>d) It must be clear how audio recording will be transcribed and when they will be destroyed.</p> <p>e) The term 'grandfathers' should be amended to 'grandmother's partner' throughout.</p> <p>2. The following changes must be made to the information sheets:</p>	

Appendix 3 Table of ethics process

		<p>a) It must be clear that grandmothers cannot participate if parents do not give consent.</p> <p>b) Participants must be informed how they can access a copy of the study findings, if they wish.</p> <p>c) It must be clear how audio recording will be transcribed and when they will be destroyed.</p> <p>d) The term 'grandfathers' should be amended to 'grandmother's partner', as applicable throughout.</p> <p>3. With regard to the consent form for the interviews, the point relating to use of the audio recordings must be amended so that it is clear they will not be played to anybody outside of the research team.</p> <p>4. You are required to provide an information sheet and consent form for the partners of grandmothers, to obtain their permission to audio record the interview.</p>	
30 October 2015	Amendments submitted	Full approval	2 November 2015
8 March 2016	R & D Local NHS Trust 1	Full approval	8 March 2016
29 April 2016	R & D Local NHS Trust 2	Full approval	29 April 2016

Steps in the recruitment process



The baby who didn't die

Tuesday:

Visited the NNU tonight, I spoke to a grandmother whose grandchild was in ITU and was ventilated. She was interested in participating in my study and had intended ringing me when she was feeling 'more herself'. Before I could give her the written information, she had taken her daughter who had become unwell to the ward. I waited but she did not return.

Thursday:

I arrived at 17.00, the baby's name was not on the board. When I asked about the baby a nurse said she had gone to Sheldon hospital 'for Nitric' but would be back tomorrow.

Sunday:

I asked the shift lead about the baby as the name was not on the board again. The nurse went away to ask and came back to tell me that the baby had unfortunately passed away yesterday. I felt very sad. I was upset for the family and thought about them all the way home and what if that had happened to us.

Thursday:

I arrived at 18.00, the ward manager asked if I had managed to recruit any grandmothers. She also asked if the grandmother from last week had been interviewed. I said that the baby had died, she said no, we sent two babies to Sheldon hospital, and it was the 23 weeker that had died, the other had returned to the unit and was discharged yesterday.

I was delighted that the baby had not died but I was upset that I had missed an opportunity to speak to this grandmother. I could have visited on Tuesday but didn't.

Do you have a grandchild in the Neonatal Intensive Care Unit?

Are you interested in taking part in a research project?

Hilary Lumsden is a former neonatal nurse/midwife who is interested in finding out more about grandmothers' experiences of having a sick grandchild on the NICU.

Hilary will be recruiting grandmothers for her study in.....
For more information you can email [REDACTED] or ring [REDACTED]



Appendix 7 Table: Lens of Interpretation (LOI)

Grandmother	LOI 1 Telling stories through images	LOI 2 Telling the story from another's perspective	LOI 3 Details that are omitted	LOI 4 Differences between storyteller/analyst	LOI 5 Slow down- listen and wait	LOI 6 Appreciate the story and storyteller
Rajinder	Discussed worry as in theme board image.	Rajinder's story is told by her grandson.	There is no presumption of any text to be uncovered.	Rajinder was a new grandmother to her grandson who was born prematurely. This was new experience for her. Rajinder had had her own daughter at 28 weeks gestation. This was a story on its own that she told me before telling me about the grandson.	Listened intently to my story, agreeing with certain points; adding a few comments.	Thanked me for my time. Said telling her stories had helped her. Will pursue applying for her medical records to understand how pre-eclampsia had affected her own pregnancy.
Sarah	Talked about balloons as they are in the theme board	Sarah's story is told in the first person.	Susan and Sarah did not discuss prayer or faith in their stories, although this was omitted the assumption cannot be made that prayer and faith did not	Sarah was a new grandmother to her granddaughter. Her daughter had pregnancy induced hypertension and had her baby by	Listened carefully and quietly.	Thanked me for listening to her.

Appendix 7 Table: Lens of Interpretation (LOI)

			have a part to play for them.	emergency caesarean section.		
Grace	Discussed looking on from afar.	Grace's story is told in the first person.	I learned from Grace's daughter that she herself had been born prematurely and wondered if her mother had mentioned this in her story. She had not mentioned this to me and therefore her story has details that are omitted. This was a by-chance encounter and anecdotal in nature. I have used this anecdotal evidence to illustrate the fact that not all stories are complete and that some have missing or irrelevant elements.	This was Grace's 3 rd experience of being a grandmother. Each time she had travelled from Africa to support her daughter and her grandchildren. There the 2 nd and 3 rd pregnancies had resulted in premature babies being born.	Quietly listened, nodding throughout.	Thanked me for listening. Her daughter also thanked me for listening to her mother.
Melissa	Discussed the fragility of the situation in reference to the theme board.	Melissa's story told in the third person.	There is no presumption of any text to be uncovered.	Melissa was a first-time grandmother. She had not expected to be involved in the siltation she found herself in because her son had originally not wanted any interference. He called his mother	Listened with interest.	Thanked me for listening to her on a Saturday morning.

Appendix 7 Table: Lens of Interpretation (LOI)

				when the situation became too much for him to bear.		
Susan	Talked about a balancing act and protecting your pride. Used theme board image.	Susan's story is told by her daughter.	Susan and Sarah did not discuss prayer or faith in their stories but although this was omitted the assumption cannot be made that prayer and faith did not have a part to play for them	This was Susan's 3 rd grandchild, but the first one to need NICU care. Susan had had her own daughter prematurely. She told me her story of being a young unmarried mother to a preterm baby.	Listened intently, interrupted a couple of times to add her own comments.	Thanked me profusely. Said she had really enjoyed talking to me.
Hilary	My story did not fundamentally change. The theme board was an anchor on which to tell my story	I told my story in the first person.	Left out some medical terminology that was not necessary	The differences between my biography and the participants were that I had a clinical understanding of my grandson's condition where they did not have such a clear perception, in addition, my grandson by now was three years old and well.	Write as short stories. My own story was told in five slightly different versions. Listening again to grandmother's narratives was an important task in the analysis since some time had elapsed since I had heard them.	Poems Letters of thanks that I wrote immediately after the interview and handed it to each grandmother before I left NICU.

Appendix 7 Table: Lens of Interpretation (LOI)

				My reflexions.		
All grandmothers	Storytellers often take time to add descriptions of people, places and other details to give context to their story (McCormack, 2004) and whilst these elements do not offer much in the way of interpretation or explanation, they do add to the overall picture of the story and the narrative process.	Telling stories form others' perspectives McHaffie (1993) gives texture and nuance to the finished story.	The unseen unheard, excluded or nonnarrated stories (Vindrola-Padros and Johnson, 2014). Grandmothers are predominately obstructed by barriers hidden in their narratives.	There were differences and similarities with all six of us.	All grandmothers were given at least 24 hours to consider their storytelling. They all had the option of withdrawing from the process. All were living through their personal experience.	Grandmothers did not engage in any written correspondence with me. All grandmothers appreciated my story and thanked me for the opportunity to tell theirs.

Analysis using Frank's Lens of Interpretation.

**Frank (2010) Lens of
Interpretation- Six; write poems
(not sent)**

Rajinder

I couldn't cry any longer
I went back to work for a rest
My husband was not very happy
I thought it was all for the best.

I prayed to the Almighty a lot
Because I was so distressed
It helped me to know what I was doing
Was making me feel very blessed.

Melissa

When you son calls you crying
'Please come Mummy' he said
I'll drive to the ends of the earth
Because your words just filled me
with dread.

You were so tired and exhausted
All night you had not been to your bed
Go to sleep and get some rest
You look awful with eyes that are all
red

I will stay here whilst you sleep
My steps I will carefully tread
But don't be too long son
I need to go out for some bread.

Susan

When I had your sister, I was a young
naïve child
My grandmother Betty was my mentor
and guide
I'm doing the same for you, when all is
said and done son,
We are only protecting our pride.

Grace

Don't cry my baby, I love you

I am far, and you are here

I will get there, don't worry

Even though the cold is biting

And the snow is on the ground

I will get there, don't worry

The airfare costs a fortune

We scrape together what we can

I will get there, don't worry

Your brother is such a burden

Leaving him will be a strain

I will get there, don't worry.

The babies are miles away

Travelling again to see them

I will get there, don't worry.

Sarah

Tiny

Where is she?

So little but perfect

Hidden

By wires and plastic

Tubes and lines

Fragile

Don't touch her

She might break

Poem for the grandmothers who were not there.

I came again to see

If anyone wanted to speak to me

No nannies are here

All busy at home

With grandchildren two and three

Another fruitless visit today because unlike me

No nannies are here

All busy at home

Washing up

And cooking the tea.

Melissa's story

I'll send him back ready to be a dad

Melissa Baker had just finished her 2-hour stint at HM prison Birchfield where she volunteered in the library once a week. It had been a challenging morning and she was wondering whether she should keep going week in week out, she was finding it so draining and demanding. Still, she felt it was a worthwhile thing to do though and even if her visits only helped one inmate, it was worth it as far as she was concerned. Melissa still had several jobs to do that day including shopping for a wedding gift for her friend's daughter's wedding, weeding the garden and fitting in the book club later on (she still had the last chapter to read). Her husband, Peter was away on business in the Middle East and wouldn't be home for another week, which meant she had time to fit all of these things into her day without worrying about Peter, besides, she liked to keep busy. Her younger daughter Hannah was at school and although she needed to be back for her, the day was very much her own.

Then she got a WhatsApp message that would change her day; *'Lovely baby, just been born. Ellen extremely unwell'*. Melissa knew her daughter-in-law was in labour and was excited about the baby being born, she had been kept up to date throughout the labour whilst at the prison today, but this was totally unexpected and worrying news. She went home straight away to sort a few things out there.

Melissa's son, Christian had never been diagnosed with autism, but there was a lot of it on her side of the family and so the family all assumed that Christian was on the spectrum somewhere. Melissa had definitely noticed certain traits in his behaviour, such as his decision making, his emotions and when things that don't go to plan for Christian, they are very hard for him to cope with. And so, one of the things he was doing during his wife's pregnancy and doing that in advance was laying down the rules. His way of coping with the pregnancy was to read a book called *'How to be a good dad'*. He set rules for Ellen and for the family; he stated, 'short cuddles and you won't be allowed to come until after the baby is born'. Melissa thought it was better not to argue with Christian and took the attitude that when the baby does come, he'll realise it is quite different. After all, she was his mother and understood how his mind worked.

And so, Melissa and Peter had been pushed away, the other grandparents would be there at the birth, but Melissa was just keeping her distance, waiting. Theirs is a very Christian family and so they were praying every day, Melissa felt very strongly that it was her role to pray them through it. Anyway, Ellen was very late going into labour, almost 2 weeks late; they thought this baby would never arrive! Melissa was so looking forward to being a grandma even though she had said to them when they got married, 'Don't make me a grandma before I'm 50' and here she was 49 years of age about to be a grandmother. Ellen was booked into the midwifery led unit, which was fantastic, a home from home place to have the baby. Although it was a very long labour, all seemed to be going well. Ellen's mother, Judy, WhatsApp's Melissa

whenever she was taking a break and so even though she wasn't there Melissa did feel involved, hearing how things were progressing. And then the bad news came.

It wasn't very clear to Melissa what had happened, but Ellen had experienced a massive seizure straight after having the baby, it was completely out of the blue following a healthy, normal pregnancy. As soon as the baby girl was delivered, she was put onto Christian's tummy, the cord was cut, and Ellen was transferred to the Intensive Care Unit on the other side of the hospital. Christian called Melissa on her mobile. He was beside himself with worry. Ellen's parents, Judy and Michael were with her in ITU, nobody knew why she'd had a seizure, what had happened to her and why she hadn't regained consciousness. Christian was a first-time dad, holding a newborn baby and said, 'Please come mummy'. He had always used that maternal noun in times of crisis. Melissa knew it was a bad sign.

Melissa quickly packed a bag that included a nightie; two pairs of Marks and Spencer (Collection) trousers; three blouses; some comfortable shoes; a coat; a cardigan and underwear (again M and S); as well as the book she needed to finish. She drove non-stop for four hours, the only thing that kept her awake was BBC Radio Four- The Film Programme; Inside Science; The News; The Archers and Front row all kept her company on the long drive to the Midlands hospital where Christian, Ellen and the new baby were. By the time she arrived at 8 O'clock in the evening she was pretty shattered. She eventually managed to park her car and after negotiating the hospital entrance that was surrounded by luminous yellow looking patients in wheelchairs smoking their last cigarettes of the day as she arrived at the Neonatal Intensive Care unit where her granddaughter was being looked after (Footnote i). She found her son there, who fell onto her weeping. All of the family, everybody was terrified and baby Iris was on the unit as a lodger, not expecting there to be anything wrong with her, this was just a routine admission. Iris and Christian were together, and his wife was extremely ill in another part of the hospital. The midwives had been very kind in trying to help him, but he is very young, only twenty-five. He went from 'I'll let you know when you can come' to crying on Melissa's shoulder saying to her, 'I'm so glad you're here'.

Ellen on ITU was in a very bad state, she didn't recognise anyone for a very long time. It turned out that Ellen had very low sodium levels (footnote ii) and that was the cause of her seizures. The baby also had low sodium levels as well as an infection, so she was really quite poorly as well. Basically, Melissa did what she always does in these sorts of situations, she tried not to be emotional, just deal with it. Ellen's parents Judy and Michael were sent away to sleep, after all they had been awake for the whole 30-hour labour. They were grieving actually, and no-one knew if they would ever have Ellen back or if they did, would she be herself? So, Melissa had promised she would stay at the hospital all night, she would check on Ellen and check on the baby.

Christian was in quite a state as you might imagine, in that he wouldn't leave the baby because her mother hadn't even held her. He was just incoherent with exhaustion, so he was persuaded that he could sleep in a spare parent's room if Melissa could stay with the baby. This she found out was a complete no, no on this

particular unit. Grandmothers are not supposed to be there overnight, not supposed to be there without a parent being there as well. So, Melissa made herself very friendly and small and tried not to get in the way and just had to ask 'Can I just sit? Christian won't go to sleep, she's only just been born, and I can't leave her on her own'. It was Christian's feeling that Iris must have family with her. Yes of course the nurses were there but Christian is very family-minded, and he couldn't walk away from his baby knowing that family were not with her. 'You know how he is' said Melissa to no one in particular. He couldn't hand Iris over to a stranger, he was suddenly the sole parent, and he couldn't leave her without knowing that someone from the family was with her. Melissa said to him 'If they will let me sit with her, I will love her as much as you and Ellen'.

Once Ellen had been diagnosed with hyponatraemia, the doctors needed to do some investigations on Iris to rule out any other medical problems, she was now symptomatic and showing some signs of deterioration. Christian found it very difficult to consent to a lumbar puncture, his tiny, new baby and they wanted to puncture her spine, to him it was terrible, and Melissa found it hard to try and persuade him to let the doctors go ahead. The only way he would allow it to happen is if Melissa was allowed to be present throughout the procedure. She knew the answer would be no, but she had to ask anyway. It was then that she rang her brother Jeremy who is a GP, she asked, 'should we consent to this or not?' and he replied 'Yes, you should'. And it is a good job that the test was carried out because it did turn out that she had a little infection that mightn't have been picked up until later. It was all right in the end, but it was really hard for Christian to take it all in.

And so, Melissa spent the night by her granddaughter's cot, which she found very difficult. She was not allowed to handle her, not allowed to feed her, the nurses had to do all of those things. Melissa thought in this situation where no one knew what was happening with her mum, Iris had never been held by her mother, the father is young and exhausted and needed to sleep. It seemed very sad that that Melissa couldn't hold her and feed her. She would have liked to have told Christian that she had done those things. Then miraculously at about 5.00 in the morning, Ellen had regained consciousness, seventeen hours after the delivery of her baby. Their prayers had been answered. The nurse on ITU called the neonatal unit to tell the family the news, Melissa though was the only one awake, she had been sitting all night by her granddaughter's side in a small space by the cot, in a room with other very sick babies. The night had been long and had dragged into the early hours, the nurses had been busy all-night monitoring and caring for the other babies. A very small premature baby had been admitted into the same room at about one O'clock in the morning. It was busy with medical and nursing staff, an x-ray machine was bought in and then a scanner and eventually, it was a bit quieter again once the emergency was over. Melissa saw a very worried father visit his new baby and she felt sorry for him and the responsibility he was now facing.

Melissa walked to the ITU where Ellen was being cared for to see how she was. It was such a long way, she had no idea this was such a vast hospital, she later found out that the hospital was famous for its very long quarter of a mile corridor. She had to

walk out of one part of the hospital and into another building, it was dark and slightly forbidding and much further than she expected it to be. This part of the hospital was much older (dating back to 1889 actually) and eerily quiet at that time in the morning. Because it was such a long way Melissa knew it would be impossible to get the baby to Ellen and so she took photographs of Iris on her phone so that she could show them to her. She knew how important it was for mothers to bond with their babies and showing her pictures of the baby might be helpful. When Melissa got to the intensive care unit, she was pleased to see that Ellen was awake. Ellen couldn't remember anything about what had happened to her, she could only recall the first part of her labour and was completely blank and very confused, she didn't understand why Melissa was there and didn't even recognise her. Melissa was delighted that she had come round but by the time she eventually got taken to the neonatal unit Iris was 24 hours old. It was very, very hard for everyone.

Then Judy and Michael were back on the scene after their sleep. Judy had very clear ideas about what she wanted to happen and how she could help Ellen with breastfeeding which Melissa thought was really good and very important but again as a Grandmother Judy was not allowed into the unit except at certain times and the only way that Iris would get a breastfeed is when Ellen was wheeled there in a wheelchair and then that might not be at grandparents' visiting time. Ellen was finding it very difficult to breastfeed and Judy desperately wanted to help her but if she was not allowed into the unit, it made the whole process very difficult. When it was grandparents' visiting time, Judy was not even allowed to hold Iris to help position her at Ellen's breast, which everyone thought was ridiculous. Added to this, Judy was very slightly miffed that Melissa had been allowed to stay overnight with Iris and that an exception had been made. Poor Melissa, she had done what she thought was right and now had upset Judy, she couldn't win.

And then suddenly Melissa was free! She went to sleep at Christian's house and woke up knowing that both Ellen and Iris were on the mend. She has had an awful dream though and woke up in a hot sweat, she has dreamt that she is running the London marathon and has done no training whatsoever, she doesn't even have any suitable shorts and is in such a panic because she is nearly at the starting line! She realises that this must be an anxiety dream, not that she believes in any of that dream analysis nonsense, but it has left her feeling a little unsettled. She goes into Christian and Ellen's kitchen and is now much more comfortable and very much in her element, she puts a load of laundry in the washing machine and prepares sandwiches that she can take to the hospital for her son and his wife. She goes to the supermarket and buys food and makes several 'healthy' meals that she freezes for when they come home as well as baking a Victoria sponge and a Swiss roll. She changes the bed sheets and washes them too; she cleans the bathroom and vacuums up the stairs. Melissa is at her best when she is busy helping, it stops her from thinking about the situation at the hospital.

When she visited the hospital later that day, the crisis seemed to be dissipating; Christian had had a good night's sleep and could visit both his wife and daughter. This meant that the family could take a step back a little bit because they were not

needed as much now. Whilst she is walking into the unit, Melissa overheard a nurse talk to another nurse 'That grandmother was only allowed to stay the night because she's posh!' Melissa was horrified. Was that what they really thought of her? She is shocked, she had never considered herself to be posh, yes, she had been to university and had a master's degree and her husband had a good job, but she had never thought of herself as posh. She talked differently from people around here because she lived on the south coast but that was all. What a shame, she was under the impression that she had got on quite well with the staff, how very disappointing.

To give them credit though, Melisa had a lot of admiration for the nurses, their care had been absolutely faultless. They have helped Christian look after his baby very well, very, very patient with him to help him give the bottle to Iris. But then again very firm, when Melissa tried to help Christian change the baby's nappy, she was told off by one of the nurses, Joyce who said, 'You have to learn to do it yourself, you will have to do it when you get home, your wife will need to rest!'. Melissa thought this was quite good, no sex discrimination there just because he wasn't the mum didn't make any difference, he was a parent after all and was helped to do those things himself. The other thing Melissa thought was very good was the breastfeeding co-ordinator, when that kicked in on the intensive care unit, they were able to express some colostrum and take it to the NNU to feed Iris with. Melissa though that was excellent, she knew how very important breastmilk was for babies and especially for those who were unwell.

Ellen meanwhile had spent a day on ITU and was now being looked after on the maternity ward. This meant that Christian could be with her for most of the day. Melissa hadn't really seen her since she was in ITU because her parents had been dealing more with her care whilst Melissa had dealt more with the baby and actually supporting Christian because everyone seems to forget that these dads need support. Melissa thought that when the crisis happened, he was left with no support and Judy and Michael just seemed to forget that Ellen had a husband. For them to see their daughter so ill, they tended to treat her like a child, even an adult child, they become a child again and they seemed to have forgotten that her husband should also have been part of the family as well. Melissa was worried for Christian, basically he didn't eat for 24 hours and actually Melissa said, 'right I'm taking him away now, I'm going to feed him'. She brought him back fed, with his sandwiches for the day and his bag for the baby and she 'sent him back ready to be a dad'.

Melissa realised that she needed to take a step back now and let Christian be a dad. Judy and Michael have gone home for a couple of days to recover but will return. Melissa can now see the new family unit develop- that bond is there and is hard to break. It has been very hard for Ellen as well; she has even commented that Christian has bonded with the baby more than her. However, Ellen's milk has now come in and she is feeding the baby well, they should be alright by tomorrow and Melissa will go home. Meanwhile Peter has flown in from his business trip and Melissa's other son has arrived to offer support. This is a bit of normality for Christian having his family around him. His sister Hannah will arrive tomorrow, she is seventeen and was adopted from Thailand when she was eleven months old. Melissa is not sure how it

will be for her, how she will be around the new baby, she knows that Melissa and Peter didn't adopt her until she was eleven months old, and she knows that the day she was born was the day her family abandoned her, so for her it is different emotional thing, but she is coming for a visit.

The whole experience has left the family reeling and it will be nice for them to have a little bit of normality now. It was shocking and came completely out of the blue, a healthy pregnancy, they are all in a state of shock. And although the staff have been brilliant, really kind, that rules are so rigid. Melissa thinks that first night she could have been assumed to be mum, since mum wasn't there, and no one knew honestly if she would survive, and Melissa would have ended up being mum!

