Creating stories from parents' premature birth experiences to engender empathy in nursing students

JULIA PETTY Senior Lecturer in Children's Nursing,
School of Health & Social Work, University of Hertfordshire.

Submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctorate in Education.
October 2019

Acknowledgements

I would like to acknowledge and thank my supervisors, Professor Joy Jarvis and Dr. Rebecca Thomas for their invaluable support, time, advice and expertise for which I am truly grateful. It has been a privilege to learn from and be guided by them throughout the doctorate programme. Thank you for enabling me to become a researcher.

I would also like to thank my professional lead Lisa Whiting and the children's nursing lecturer team at University of Hertfordshire for their unwavering encouragement throughout the programme as well as my wonderful family, Clive, Leah and Luke, for their understanding and support.

Abstract

Introduction: In healthcare, stories are an evocative way to educate nurses about the emotional experiences of patients. Little is known however, about the impact of storytelling in neonatal nursing practice and education.

Aims: The aims were; to explore how parents of premature babies described their neonatal care experience; to develop digital stories informed by their narratives and to investigate how these may contribute to empathic learning in nursing students/staff.

Methods: Within an interpretive, narrative design using principles from constructivism, twenty narrative interviews with parents of premature babies were undertaken to collect their stories. Core story creation reconfigured the raw narratives to develop digital stories using the ASPIRE model. Thematic and metaphor analysis were also applied. Finally, a mixed methods approach investigated the perceived value of the stories for empathic learning with nursing students and staff in neonatal care.

Findings: Parents described their experience using a strong emotional narrative revealing important learning points for those caring for them. The use of metaphors was a common way to express emotion. Frequent metaphor clusters provided pivotal themes for the creation of digital stories. Four key themes emerged from the analysis: namely, the effect of digital stories on emotion and empathy, the perceived value of digital stories for learning and knowledge acquisition, the potential impact of digital stories on practice and the format of digital stories for representing emotion and evoking empathy. Overall, student nurses and staff evaluated the digital stories positively. It was clear that they were an effective way to teach others about emotional experiences of parents and had the potential to enhance empathy. Many participants indicated that stories may influence their practice by enhancing understanding of the emotional needs of parents.

Discussion: Digital stories appear to be an effective and evocative way of telling the stories of others and depicting their emotional experience from which we can learn. Emotions can be a source of knowledge, and digital stories representing the parents' experience and emotions may enrich empathic learning.

Conclusion: Value is placed on parent stories by students and staff in relation to enhancing empathic learning within the neonatal field. Digital stories can be one way of teaching emotional aspects of care that places the parents at the centre.

Creating stories from parents' premature birth experiences to engender empathy in nursing students

Contents

List of Figures

List of Tables

List of Boxes

Appendix

Page

PART 1:

Exploring narrative approaches and concepts

Chapter 1: Introduction

1.1 Preface

Welcome to my thesis which is an account of my journey of, 'Creating stories from parents' premature birth experiences to engender empathy in nursing students'. I start with why I have developed an interest in stories, storytelling and empathy and what led me to undertake this research.

As a children's and neonatal nurse, I have known for many years how important it is to be able to support parents of vulnerable, sick babies to help them through often dark times. As a nurse educator, I have also known that it is vital to teach others about the importance of understanding how patients feel, placing the child and their parents at the heart of care, a vital component within the context of person-centred neonatal care. However, I knew less about *how* to teach my students about others' feelings so that they could give more empathic care. Against the political backdrop of current healthcare policy, often driven by targets and statistics to measure outcomes, the patient at the heart of care can often be forgotten. I came to think therefore, how better to understand their experience than by listening to, in this case, the stories of parents?

So now, as a researcher, I have set out to find out how parents' stories can be used in a learning and teaching capacity, to promote empathy in nurses who care for premature babies and their parents. This of course must start with nursing students. As I started to read at the start of my journey, the words of others resonated with me such as Carl Rogers (1980: 116) who stated that, "We think we listen, but very rarely do we listen with

real understanding, true empathy. Yet listening, of this very special kind, is one of the most potent forces for change that I know". Similarly, Brown (2015) saw empathy as listening while at the same time emotionally connecting and communicating with others.

These views highlighted the importance of listening to parents. It wasn't until I began my research that I had the opportunity to *really* listen to parents and their stories. Before I start to detail what parents said and how their stories were used, I invite you to listen to and watch my own digital story which captures the essence of why this subject is so important and why I strive to enhance empathic learning and person-centred care for parents in the neonatal speciality.

My story, 'Into the Light' (Figure 1.1) highlights how my own experience has shaped the research I undertook. This introduces the concept of reflexivity and its importance from the very outset of the study. The study, the aims and reasons for undertaking it have personal importance for me as an educator, practitioner and researcher. In relation to the narrative paradigm, since I am a researcher seeking to understand others through their narrative, I needed to begin with my own story and to be transparent about my background and ideological assumptions (Bishop and Shepherd, 2011) as well as my own emotions and feelings (Collins and Cooper, 2014). As Ellis and Bochner, (2000) stated, revealing self through storytelling is a vulnerable but valuable act. Other writers agree with the need to be open about one's theoretical stance (Pithouse-Morgan et al, 2012), and this is seen to uncover the researcher's positionality and inner beliefs (Frank, 2002). Therefore, in agreement with such literature, it was necessary for me to make my 'self' and my own story explicit in this research study so that there is a better understanding of

how I approached my research questions and interacted with participants and data.

Therefore, at the start of my dissertation, I present my own digital story below.

Figure 1.1: 'Into the Light' - My Digital Story

http://www.patientvoices.org.uk/flv/1091pv384.htm
[Press control and click on the image or URL above to access the story]

1.2 Outline of dissertation

This dissertation is presented in two main parts: Part 1, 'Exploring narrative approaches and concepts' and Part 2, 'The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students'. Each part is comprised of various phases. Figure 1.2 outlines an overview of the whole study, including all these phases along with signposts to the relevant outputs produced throughout the research. The organisation of the dissertation follows the structure outlined in Figure 1.2 (first, left-hand column) chronologically. The use of colour (electronic version) further highlights the main phases: Part 1 (Blue), Part 2, Phase 1 (Purple), Part 2, Phase 2 (Green) and part 2, Phase 3 (Orange).

For Part 1 ('Exploring narrative approaches and concepts'), a general introduction followed by a discussion of the underpinning concepts and literature are covered in chapters 1 and 2 respectively. The overarching design of the study is discussed in chapter 3 which outlines the methodological approach for all subsequent phases. Ethical considerations are also addressed in chapter 3. The final chapter of Part 1 (chapter 4- 'Working with narrative: an initial study') focuses on an initial, small-scale study that was undertaken to explore a narrative approach to inform the main research methodology, in preparation for Part 2.

Part 2 ('The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students') focuses on three main phases in line with a conceptual framework adapted from Charon's (2001) narrative medicine model, outlined

in chapter 5. The three phases of the main study (attention to narrative, representation of narrative and affiliation with narrative) are covered in chapters 6, 7 and 8 respectively. Each of these phases has its own introduction, background, methodology, analysis, findings and discussion sections. A discussion in chapter 9 brings all the three separate phases of Part 2 together to a coherent whole, highlighting the implications for practice, dissemination of findings and future research, before concluding in chapter 10. Finally, supporting information is contained within the Appendix, comprising (in order of appearance); a summary of strategies to ensure trustworthiness in qualitative research (Appendix 1) , materials/raw data for the initial study (Appendix 2) and phase 1 of the main study (Appendix 3), extracts of a reflective commentary (Appendix 4), the COREQ checklist for reporting qualitative interviews (Appendix 5) and materials/raw data for phases 2 and 3 of the main study (Appendix 6 and 7), A full summary of training undertaken as well as dissemination outputs produced throughout the research can be seen in Appendix 8.

Throughout the dissertation, reflexivity was undertaken and is presented as first-person, reflective boxes within each chapter. Reflexivity refers to the researcher's need to be aware of how and why they are conducting their research and to recognise how their own beliefs and opinions about the topic under investigation might influence generation of new knowledge, data collection, interpretation or analysis. (Alvesson and Skolberg, 2017). By this, reflexivity has an epistemological element. It is seen as a necessary process in research of this nature to demonstrate credibility of the findings (Kingdon, 2005; Lambert et al, 2010; Newbury, 2011) and well documented as a way qualitative researchers should ensure rigor and quality in their work (Dodgson, 2019). It is seen by

Teh and Lek (2018) as being a gold standard for determining trustworthiness especially when dealing with the nuances of different groups of people.

Reflexivity also has a personal element in relation to reflection, a key component of reflexivity (Roddy and Dewar, 2016). Finlay (2002) referred to introspection' of one's actions through the research process and of one's self, as well as intersubjective reflection relating to our relationships with others. Råheim et al (2016) regarded thoughtful, analytic self-awareness of ones' experiences and their impact throughout the research process as vital and this is done by reflection. In this study, it was therefore deemed as an essential part of being reflexive, hence the importance of threading reflective accounts through the whole dissertation.

Reflexivity also includes my learning journey that has taken place as a developing, new researcher. Part of this learning and development has been the opportunity to produce relevant outputs in the form of both digital learning resources and published articles (Petty, 2016a; 2016b; 2017a; 2017b; Petty et al, 2018a; Petty et al, 2019a; 2019b; 2019c; Petty and Treves, 2017), highlighted in Figure 1.2 (second, right-hand column) with added hyperlinks to enable the reader access to them. Regarding the publications thus far, these have imparted the benefits of not only disseminating the methods and findings of each stage of the study to a national and international audience but have also led to valuable, scholarly peer review feedback prior to acceptance and final publication in a range of relevant, peer-reviewed journals. An example of such feedback following peer review and revision of one of the papers (Petty et al, 2019c) is as follows: "An insightful research-based snapshot of premature baby parent perspectives which helps appreciate

the context and impact of their journey. The research approach taken contributes to the critique of qualitative research methods and how they can be used to illustrate experience. The associated videos provide a unique yet valuable alternative dissemination communication mode". The publications are outlined below. Each publication is sign-posted and explained at appropriate points through the dissertation chronologically.

Part 1: Chapter 2

Petty, J. (2016a). Learning from narrative to understand person-centred experience: a literature review. *Journal of Neonatal Nursing*. 22(6), 297-308.

Part 1: Chapter 4

Petty, J. (2017a). Creating stories for learning about the neonatal care experience through the eyes of student nurses: An interpretive, narrative study. *Nurse Education Today*. 48: 25-32.

Petty, J and Treves, R (2017). Development of a digital storytelling resource to support children's nursing students in neonatal care. *Nursing Children and Young People*. 29(2), 32-37.

Petty, J. (2016b). Appreciation of the neonatal care experience through the eyes of student nurses: The Development of a Storytelling learning resource. *LINK* (UH online journal). https://www.herts.ac.uk/link/volume-2,-issue-2/appreciation-of-the-neonatal-care-experience-through-the-eyes-of-student-nurses

Part 2: Chapter 6

Petty, J. (2017b). Emotion work in qualitative research: interviewing parents about neonatal care. *Nurse Researcher*, 25(3), 26–30.

Petty, J, Jarvis, J and Thomas, R. (2018a). Core Story Creation: Analysing narratives to construct stories for learning. *Nurse Researcher*. 24(4), 46-50.

Petty J, Jarvis J, Thomas R. (2019a). Understanding parents' emotional experiences for neonatal education: A narrative, interpretive approach. *Journal of Clinical Nursing*. 28(9-10), 911-1924.

Petty J, Jarvis J, Thomas R. (2019b). Listening to the parent voice to inform person-centred neonatal care. *Journal of Neonatal Nursing*. 25(3), 121-126.

Petty J, Jarvis J, Thomas R. (2019c). Using parent metaphors for learning about the neonatal care experience: an interpretive perspective. *Journal of Child Health Care* (online advanced publication)

The digital outputs that have been produced are also cross-referenced throughout the dissertation at relevant points. These comprise my own digital story ('Into the light'- Chapter 1), a digital storytelling resource ('Appreciation of the neonatal care experience through the eyes of student nurses' -Part 1: Chapter 4), a video presented at a 2018 learning and teaching conference ('Creating and telling stories in neonatal care') and a collection of eight digital parent stories ('Another World', 'On the Edge', 'Connections', 'Fighter', 'Our Salvation', 'The Long Haul Ahead', 'Out of the Darkness' and 'Bittersweet' - Part 2: Chapter 7). The final website developed to host all said digital outputs ('Stories from the Neonatal Unit' – NeonatalStories.com) is signposted in Chapter 9: Discussion. Links to all these digital resources are hyperlinked in Figure 1.2 that follows [Press control and click on the blue hyperlinks within Figure 1.2 to access both the publication abstracts and digital outputs].

.

Figure 1.2: Overview of the study's main stages and outputs

Study timeline	Digital outputs and Publications
PART 1: Exploring narrative approaches and concepts (Chapters 1-4)	
• Chapter 1: Introduction • Chapter 2: Underpinning theory and concepts • Chapter 3: Design and methodology • Chapter 4: Working with Narrative: An Initial study	My Digital Story: Into the Light Petty (2016a) Publication Appreciation of the neonatal care experience through the eyes of student nurses. Storytelling resource Petty (2016b) Publication Petty (2017a) Publication Petty and Treves (2017) Publication
PART 2: The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students (Chapters 5-10)	
PHASE 1- 'Attention to narrative' – Exploring the parent's experience (Chapter 6)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	Petty (2017b) Publication Petty et al (2018a) Publication Petty et al (2019a) Publication Petty et al (2019b) Publication Petty et al (2019c) Publication
PHASE 2- 'Representation of narrative' – Creating the parent stories (Chapter 7)	
• Introduction • Aims and research question • Background • Methods • Analysis • Outputs • Discussion	Digital Stories Creating and telling Stories in Neonatal Care Another World On the Edge Connections Fighter Our Salvation The Long Haul Ahead Out of the Darkness Bittersweet
PHASE 3- 'Affiliation to narrative' – The impact of stories on empathic learning (Chapter 8)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	The Value of digital stories in neonatal care- Your views. – Evaluation Survey Neonatal Stories Website

1.3 Background

It is important to learn about and understand parent experience in the neonatal care specialty within the context of narrative healthcare, so that student nurses and staff can potentially offer more empathic care. Story and storytelling may be one way to raise awareness and educate about parents' emotional experience and in turn, enhance empathic learning, the focus of this study. The theoretical framework of narrative inquiry within the interpretivist paradigm underpins the study from the outset using principles from constructivism in the crafting of stories for learning.

Premature birth and subsequent neonatal care have a significant emotional impact on parents (Aloysius et al, 2018a; Taylor, 2016), even linking to unfavourable psychological outcomes later, after discharge (Petty, et al, 2018b; Fowler et al, 2019). Therefore, there is a fundamental need for staff and students to have empathy so that they can be sensitive to parents' emotional needs. The concept of empathic learning in the context of this study, is to learn about and understand the emotional experiences of parents. This is in line with a person-centred approach to caring for others. In the field of neonatal care, listening to parents is a key element required for understanding their emotional needs as they go through challenging experiences and encounters which nursing students and staff can learn from.

The power of storytelling to teach us about the experience of others through narrative and to enhance empathy is well documented (Fairbairn, 2005; Hardy and Sumner, 2018; Patey, 2016). In healthcare education, stories are an evocative and compelling way to

represent the patient experience in line with an individualised person-centred approach to learning, where we place those in our care at the centre of attention and by doing so, learn about them to enhance our empathy. This is essential within the political background and context of healthcare that too often focuses on statistics and hard data. Hardy (2017: 5) in the following quote emphasises the important distinction between scientific and narrative-based healthcare: ''Statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system''. The latter part of this quote is congruent with Charon's (2006) concept of narrative medicine where health professionals come to a closer understanding of their patients through listening to their stories. By this, using our own perceptions and interpretations, we make sense of and come to some understanding of their experience in the form of meaning-making (Bruner, 1992).

Much has been written on the potential benefits of storytelling within many disciplines including healthcare (Kelly and Howie, 2007; Missel and Birkeland, 2011). One such benefit is the potential for stories to influence the care of patients in relation to transforming practice, which may include making a change and/or improvement in some way (Phillipi, 2010; Hardy and Sumner, 2018). However, less is known about the impact of storytelling specifically in the neonatal care specialty where understanding the parent experience is key to empathic and emotion-based learning, the focus of this study. In addition, little is known about empathic learning in neonatal care and how narrative can be used in an educational context to teach students and staff. Storytelling as a pedagogical strategy is under-used in this field of healthcare with greater focus directed to skills-based, clinical teaching and less on narrative based learning.

With the above in mind, the study aimed to create stories, using processes of emplotment and core story creation, applied to the interview narratives from parents of premature babies who had spent a significant period in the neonatal unit from birth to being discharged home. The stories depicted their trajectories through early birth of their babies and the subsequent neonatal care experience. The study then aimed to explore how these stories, represented through a digital storytelling platform using key metaphors on which to base each story, could be used to educate nursing students and neonatal staff about the emotional care of babies and families. In turn, it finally aimed to investigate the potential effect of the digital stories on empathic learning, to ascertain the potential impact on person-centred nursing practice.

To summarise thus far, literature supports the link between stories and enhanced empathy within healthcare (DasGupta and Charon, 2004; DasGupta, 2007; Williams and Stickley, 2010; Frank et al. 2015). It was proposed in this study that assigning meaning to parent narratives following story creation could lead to an enhanced understanding in the learner about the parent's emotional experience, in turn potentially leading to more empathic, person-centred care.

1.4 Exploring Key concepts

Within the preface and introduction, key concepts have emerged that are important to define at the outset, to enable the reader to understand their meaning and context for the remainder of the text. These are depicted visually in Figure 1.3. They are then outlined and explained within the context of the current study in Table 1.1. These concepts are threaded through the dissertation and interlink in various ways. They served to inform the evidence base by providing key terms for literature searching, which is discussed in the next chapter and subsequent ones thereafter. In addition, the interconnecting concepts introduced below are analysed in greater detail in later chapters where applicable.

Figure 1.3: Key concepts

Table 1.1: Defining and explaining key concepts

Narrative inquiry: The study of individuals' experiences through narrative and how their physical, social and cultural environment impacts and shapes the narratives they tell of their experiences (Haydon et al 2018).
Interpretivism: A research approach that argues truth and knowledge are subjective, as well as culturally and historically situated, based on people's experiences and their individual interpretation and perception of these experiences (Ryan, 2018).
Constructivism: A theory of how people learn by constructing their own understanding and knowledge of the world through experiencing events and reflecting on these experiences. They are active creators of their own knowledge (Dewey, 1938; cited by Clandinin and Connelly, 2000).
Neonatal care: A healthcare speciality that refers to the care of sick and/or premature newborn babies and their families. Nurses, doctors and allied health professionals provide continuous support twenty-four hours a day (National Health Service (NHS) England, 2019). A neonate refers to a baby in the first twenty-eight days of life although this period of time varies from birth until discharge. In this text, the terms 'neonate' and 'baby' are used interchangeably. The same applies to the terms 'premature' and 'preterm' to describe babies born less than thirty-seven weeks gestation.
Narrative healthcare: Healthcare that is delivered to patients by those who acknowledge, interpret, and act on the stories of others (Charon, 2001). This contrasts with the traditional, scientific model that more commonly uses data and objective outcome measures to guide patient care and service development.
Experience: Events or occurrences that are encountered by people from which they interpret, make meaning from and learn to understand the world.
Meaning-making: The understanding of a phenomena. Narratives are an individual version of reality and are at the heart of all 'meaning-making' (Bruner, 1992).
Knowledge: An understanding of something (for example, facts, information, descriptions) acquired through experience or education by perceiving, exploring or learning. Narrative learning leads to acquisition of narrative knowledge, defined as that obtained from the narration of an experience (Dow, 2006).
Transformative learning: The process of constructive and meaningful learning that goes beyond simple knowledge acquisition and supports critical ways in which learners consciously make meaning of their lives (Mezirow, 2000; Simsek, 2012) to bring about change that can impact on practice (Kroth and Cranton, 2014).
Story: Stories are narratives that are sequential and temporal. They are comprised of people that interact, within a specific context or situation and a plot. As well as a sequencing of events, there is also a form of meaning-making about experience that

occurs. Stories mean something to the teller (Bruner, 1996; 2014) and the listener which may be interpreted differently by both.
Storytelling: The art of writing or recounting events to others. Storytelling in a narrative healthcare context is said to connect practitioners to their clinical practice on a more emotional and empathic level (Pallai and Tran, 2019).
Digital Story: Short videos that combine stand-alone and first or third-person narratives combining a variety of multimedia and presented on a digital platform (Moreau et al, 2018).
Digital Storytelling: The art of recounting events to others through digital media that combines images, music, story and voice (Haigh and Hardy, 2011).
Core Story creation: A method of managing and reconfiguring raw data obtained from narrative interviews (Emden, 1998) to construct stories for learning.
Emplotment: A process where narrative is assembled into a plot, a method of narrative analysis synonymous with Bruner's (1991) narrative 'structuring' consisting of actions, events and happenings.
Representation: The description or portrayal of narrative or experience.
Metaphor: When something is regarded as representative or symbolic of something else. In a healthcare context, metaphors are a figure of speech commonly used by patients as ways to express complex thoughts, feelings and emotions by the transference of one term to another (Southall, 2013).
Empathy: A complex concept that involves the ability to understand and share the feelings of another, comprising different components (Jeffrey, 2016). Affective empathy is the ability to subjectively experience and share in another's feelings. Cognitive empathy is the ability to identify and understand another person's feelings and perspective. Behavioural empathy is defined as action taken in response to the internal experience of cognitive and/or emotional empathy (Tamayo et al, 2016).
Empathic learning: Learning about and understanding the emotional experiences of others, in order to give better care. This concept may also be called emotional learning.
Parent experience: Events or occurrences that are encountered by parents who have had babies in neonatal care for a given time.
Person-centred care: Focusing on the person and being sensitive to their needs as a central part of care, rather than the needs of the service (Royal College of Nursing (RCN), 2016).

Chapter 2: Underpinning theory and concepts

This chapter examines the background literature that underpins the study's key concepts (Table 1.1). Firstly, literature supporting narrative inquiry and constructivist theory within the interpretivist framework is discussed to provide a historical and epistemological context. The background analyses evidence relating to the definitions, use and value of stories within both the education and healthcare arenas generally. The concepts of person-centred care, empathy and the study of experience within nursing and neonatal nursing specifically is discussed as well as a focus on the nature of story and story creation.

2.1 Theoretical framework

The study, 'Creating stories from parents' premature birth experiences to engender empathy in nursing students' is set within the overarching theoretical framework of narrative inquiry. This core theoretical approach underpins the study in its entirety where the focus is on the individual's experience which is shaped, expressed and enacted through narrative. Moreover, it is the individual's *perceptions* of experience that forms their narratives; how they tell their stories to others and themselves, how they make sense and meaning of this experience. The meanings taken from experience change over time and depend on the context and situation an individual finds themselves in. By this, narrative inquiry is the study of the perception of the experience of an individual and how their physical, social, and cultural environment impacts and shapes the narratives they tell of these experiences (Haydon et al 2018). For this study, understanding experience relates to that of the parent within the neonatal care environment.

Clandinin and Connelly (2000) refer to narrative inquiry as an approach that uses field texts, such as stories and autobiography, journals, field notes, letters, conversations, interviews and life experiences as the units of analysis, to research and understand the way people create meaning in their lives in narrative form. The approach includes storytelling as a methodology. Within this, the story is the focus of study. In other words, narrative is not only an approach to research, but it is also the phenomenon being studied. Robert and Shenhav (2014) describe the 'umbrella narrative' as being both the nature of the approach used and the object under study. Narrative inquiry, in an educational context, centres on how individuals make sense of their experience, their world and their own self from which themselves or others can learn (Connelly and Clandinin, 1990; McDrury and Alterio, 2016).

Narrative research sits within the interpretive paradigm where the notion of interpretation means the discernment of meaning. Interpretivists emphasise understanding the 'meaning' individuals place on their actions (Weaver and Olson 2006; cited by Welford et al, 2011) and how meanings may differ from person to person. The goal of interpretive research is to understand and find meaning in experience from multiple perspectives and so theory emerges inductively. Interpretivism argues that truth and knowledge are subjective, as well as culturally and historically situated, based on people's experiences and their individual interpretation and understanding of these experiences (Ryan, 2018). It has been argued that interpretivism raises a question of how to develop an objective science from subjective experience (Denzin and Lincoln, 2017). However, in qualitative research such as this, the aim is not to be objective since the

focus is on understanding and interpreting human experience; subjectivity therefore is an inherent part of such research.

Both narrative and interpretivism are congruent with the perspective of constructivism, where meaning-making is central, and an emphasis is placed on construction of knowledge. Bruner's paper 'narrative construction of reality' discussed narrative 'structuring' and how story *making* is central to creating an understanding of the world and people within it (Bruner, 1991). This theory is very relevant to the current study that seeks to explore and understand parent's 'reality' by constructing meaning from their narratives and in turn, to construct stories. Berger and Luckmann (1991: 27) concur and believe that ''everybody lives in a world of some sort'' and that knowledge is produced through the social construction of reality. Such theory sees learning as an active, not a passive process, where knowledge is constructed, based on personal experiences in which people have different interpretations in how they generate knowledge, based on their past experiences and context. Social constructivists emphasise the collaborative nature of learning and the importance of the social context. Abolafia (2010), for example, spoke of narrative construction on a par with sense-making which occurs during interactions with each other and McAdams (2006) stated that stories exist to be told in social contexts for people to create meaningful understandings.

These ideas are relevant to the current study that focuses on learning about parents' experiences within the neonatal care context which cannot be undertaken in isolation. In other words, we construct knowledge about the parent experience by listening to and

placing their voice at the centre. Learning from and with others, in this case parents, was at the core of this research.

In relation to healthcare specifically, Charon (2007: 97), a prolific writer on the concept of narrative medicine proposes that, human beings …. ''absorb, interpret, and respond to stories'' from others, resulting in narrative knowledge; that is, knowledge obtained from a narration of an experience (Dow, 2006). From an ontological perspective, people see the world through narrative: it is their reality. Interpretivism assumes multiple situated realities in which context gives meaning to phenomenon and 'truth' is viewed from multiple perspectives and realities (Levers, 2013). Interpretive research recognises that the participant, or in this case, the parent, is the expert and that there is no single ultimate or correct interpretation of their reality.

Epistemologically, the creation of knowledge through narrative, is seen from the perceptions of experiences of parents in neonatal care. Meaning-making occurs by attempting to understand their reality. A key theme arising here is that of *experience* and learning from this experience; using narrative to understand it. Within neonatal care, narrative inquiry for this study refers to that of the *parents'* experience since we cannot explore that of the baby themselves. Making sense of experience in this specific field of healthcare and what nurses can learn from this experience to influence their practice with babies and families is a core focus.

2.2 Historical context of narrative and storytelling.

It is important to consider relevant literature from a historical perspective to understand the epistemological foundations of narrative and how it has informed current thinking. Narrative inquiry is an interpretive approach to research in education (Hall and Powell, 2011), social sciences and in the case of the current study, in healthcare and nursing. It emerged as a discipline from within the broader field of qualitative research in the early 20th century. The analysis of narratives has developed since this time when researchers started to question empirical, more traditional research methods which up until then, were more prevalent. At this time, postmodernism questioned the more scientific assumptions of rationality and truth. The view emerged that knowledge is value-laden, and reality is based on multiple perspectives (Holloway and Freshwater, 2007; Ryan, 2018). Instead, a focus was placed more on truth grounded in life experiences involving social interaction between humans, emphasising the social nature of knowledge creation. This epistemological context of narrative and storytelling has been articulated historically across various disciplines including philosophy, psychology, education, anthropology and importantly for this study, healthcare.

Starting with philosophy , the narrative paradigm was proposed by 20th century philosopher Walter Fisher (1985) who believed that meaningful communication was a form of storytelling and that individuals experienced and comprehended life as a series of ongoing narratives, each with its own conflicts, characters, beginning, middle and end. Ricoeur (1984, 1992) also spoke about humans interpreting what they do in life through the creative power of narrative. Ricoeur's narrative theory presented a way of understanding oneself through the activity of emplotment or mimesis, which refers to

how a person collects events and actions into one meaningful story. Understanding these apparently disconnected events is by means of the plot (Ricoeur, 1992). Narration illuminates human action and experience and highlights temporality, a core feature of a plot. Relating this to the neonatal field, it is the individual world of the parent that is of interest and the story that emerges from their experience and journey through the neonatal unit, which here can be seen as the temporal 'plot' of events.

In the field of psychology, the above philosophical concepts were reiterated. Gerrig (1993) spoke of human lives being represented by experience of 'narrative worlds'. He said even a brief story told can swiftly remove us from our day-to-day reality and we can 'disappear' into the narrative worlds of books and films. Some narratives are created out of fact, some out of fantasy, some are intended to communicate truths; some communicate emotion which may only make a brief impression while others may be more memorable and moving in an emotional sense. It is the latter that is of interest to the current study in that the aim was to explore the link between storytelling and person-centred care comprising the concepts of empathy and empathic learning by understanding the emotional experiences of parents in neonatal care.

In line with this concept of 'narrative worlds', Bruner's (1991) 'narrative construction of reality' postulated that humans organise experience and memory of what happens to them mainly in the form of constructed, '*storied*' narratives. Narratives are an individual version of reality and are at the heart of all 'meaning-making'. Similarly, the psychologist, Polkinghorne (1988; 1995: 183) focused on the concept of meaning and maintained that "human beings exist in three realms; the material realm, the organic realm, and the realm

of meaning". He defined "narrative" as a story relating a series of events. Influenced by Ricoeur, he saw narrative as the fundamental instrument of the human sciences. The notion of 'instrument' places narrative into a research context as something to be studied. He believed narrative accounts have a unique explanatory power. The current study aims to harness this power in relation to how we can use parents' stories to explain, teach and enhance empathic learning within the neonatal field.

The integral link between narrative, experience, story and storytelling in line with interpretivism is summarised very succinctly by Baldwin in the *Story Catcher*: ''Story is the narrative thread of our experience – not what literally happens, [but] what we tell each other and what we remember" (Baldwin, 2007: 44). This emphasises the significance of perception in the telling of one's experience to others, perception being a subjective phenomenon that differs from person to person offering different interpretations. Moreover, Baldwin's view of a thread in relation to narrative highlights the importance of using a plot to tell a story. The potential for different interpretations also applies here in that what happens in a story, the events that occur and how they are experienced and 'storied', is explained differently by different people. What could be seen as the same event could be experienced and storied differently by different people and at different times. This important area of discussion; that of perception and interpretation is returned to later at relevant points.

2.3 Narrative in education

Narrative, or more specifically, learning from narrative has a key role within education as a discipline. John Dewey (1938), a philosopher of experience and an educational theorist, saw storytelling as a key characteristic of human experience of the world. His theory was based on peoples' lives being enacted in storied moments of time and space, involving interaction with others and continuity within a temporal context (Dewey and McDermott, 1981). Dewey used the metaphor of a three-dimensional (3-D) space approach to narrative, as a way to find meaning in experience. His model involved the terms interaction (personal and social), continuity (past, present and future) and situation (experience in a certain place). Any narrative inquiry therefore is defined by this 3-D space. A narrative inquirer would consider temporal dimensions of experience relating to the movement of looking backwards and forwards, inwards and outwards locating it within a particular place (s), in a personal and social context. This approach also suggests that to understand people, we need to examine not only their personal experiences, but also their interactions with others. Dewey's approach has had a profound influence in the study and practice of narrative inquiry in many disciplines including education. The fluidity in storytelling, moving from the past to the present, was at the heart of his theory of experience.

Clandinin and Connelly's (2000) development of narrative inquiry as a research methodology was deeply shaped by Dewey. As educationalists who referred to themselves as narrative researchers, they strongly believed in the power of narrative and its benefits for teaching and learning. Like Dewey and Bruner, they also regarded

narrative as being the best way of representing and understanding experience. Their model of story, based on the work of Dewey, was also one of a 'three-dimensional narrative inquiry space' framework comprising continuity / temporality (past, present, future: start-body-end), interaction (personal and social) and place (the situation). In research terms, Clandinin and Connelly (2000) saw these dimensions as vital to pursue within narrative inquiry in seeking to understand experience of others.

Within an educational context, storied accounts of peoples' experience over time must be perceived, reflected upon and understood for us to learn from them. As explained previously, perception is an important concept to emphasise since it differs from person to person within interpretive inquiry. In addition, reflection is also a necessity for learning, about one's own or others' experience. Moreover, it is a central element of nurse education where there is a significant onus placed on learning from experience. Indeed, within education, Connelly and Clandinin (1990) as narrative inquirers, regarded reflection as an essential element of storytelling about one's own individual experience. We reflect on, then narrate our experience by telling our story and by doing so learn from this which may impact on our practice; for example, this may lead to making improvements or adjustments to what we do in our practice and place of work.

Furthermore, reflection is also important for learning about others. Some authors argue that it is a vital part of healthcare delivery (Charon, 2001; Sanders, 2009; Murphy et al, 2018) particularly in the context of narrative healthcare. Reflection has an epistemological component in that it assists health professionals to gain insight into the

worlds created by patient stories and their situations. Schon (1991) spoke of the importance of the 'reflective conversation' which is used commonly within nursing to understand the lived experiences of both patients and staff, for individuals to learn from them and develop professionally and personally. The importance of reflection in the generation of stories about one's experience was reiterated by Moon (2013) and McDrury and Alterio (2016) who argued that through emotional and reflective engagement with individual perspectives, storytelling can bring about learning that involves transformation of how learners view themselves and others, which could lead to change in practice. Similarly, Anderson et al (2012) found that the engagement with digital stories specifically, promoted meaningful reflection in health professionals relating to their practice with patients.

There is an important link therefore between narrative and transformative learning specifically. Kroth and Cranton (2014: 2) stated that when educators use stories, they are much more meaningful to the learner than other forms of more ''academic or detached'' means of teaching. Both the person telling the story and the learner are drawn into the experience, they learn from it and this learning has the potential to be transformative. This was described as on a par with Mezirow (2000), as a deep shift in one's perspective during which one can become more open-minded and discriminating in bringing about change.

Transformative learning is consistent with the principles of constructivism, where the learner is an active, not passive learner and who creates and interprets knowledge that is

rooted in personal experience. Individuals actively construct meaning from their own experiences and view the same event differently to others. Similarly, transforming practice is an active process. In addition, theorist Dirkx (1998) articulated the importance of meaning in the process of learning and how we construct that meaning within the learning experience. Knowledge is not just something to be taken in by the learners; rather, it arises when making sense of novel experiences. To be meaningful, what is learned is personally significant in some way. Such learning can contribute to fundamentally new ways of seeing and understanding experience, potentially being more able to influence practice. This was articulated by Jarvis et al (2004) who suggested that story not only motivates and engages the learner but has the power to produce a deep level of understanding with clear links to the potential for influencing practice. Edwards (2013) linked the temporal element of stories with the potential impact on practice. She stated that looking backwards from a story to examine the present as well as looking to the future, can bring about a possible change or transformation in practice which she linked closely with the role of story within nurse education.

Lindsay and Schwind (2016) summarised the links between narrative, reflection and learning very competently within the context of education in healthcare. Taking up Dewey's model and Connelly and Clandinins' views that that experience is relational, temporal and situational, this has the potential to be educational. These authors believed that when experience is reflected upon and reconstructed, it has the potential to reveal and construct knowledge relating to the human aspects of care. This is congruent with the expectation that nurses are both reflective practitioners as well as knowledge-makers. They also considered narrative inquiry as a means of enhancing, not only the

quality of care, but the quality of experience of those in our care by educating staff about their patients.

Influencing and changing practice when there is need for improvement or advancement of new knowledge is a vital part of current healthcare policy. In neonatal care specifically, practice implications of transformative learning relate to the part that storytelling may play in enhancing narrative knowledge of parents' experience, empathic learning and in turn, how this may potentially influence person-centred care of parents and families. The chapter now discusses the part that storytelling has within healthcare, particularly nursing with a specific focus on neonatal care.

2.4 Narrative in healthcare and nursing

Narrative within the healthcare arena has its roots within the field of anthropology and has gained prominence with various writers since the 1970s (Geertz, 1973; Czarniawska, 1998; Bateson, 2000; Macintyre, 2001). Its study has accompanied an increasing appreciation of the practice of writing about social and cultural reality. Rapport (2004: 317) spoke of the ontology underlying narrative and states that narrative is present in every age, place, speciality and culture; ''It is simply there, like life itself''. These anthropologists argued that narratives are a primary embodiment of our understanding of the world, of experience and of ourselves. Parallels can be seen with the views of theorists cited earlier from other disciplines: It is in, and through, various forms of narrative emplotment that we give meaning to our lives. This meaning changes over time

and between people, contexts and cultures, again highlighting the personal element of narrative and storytelling within an interpretive approach.

The term 'narrative medicine' is one that has been used by key writers who advocated the power of story within healthcare. Seminal work in the field of narrative medicine was undertaken by Kleinman (1989), a physician who became an anthropologist and Good (1994), also an anthropologist who wrote about the medical profession, both highlighting the key place of narrative in understanding the patient and his/her illness. They and other scholars cited here chronologically, Geertz (1973), Young (1976), Sontag (1979), Bruner (1991), Millard (2010) and Clifford (cited by Song, 2017), shaped medical anthropology's scholarship on illness narratives and the politics of writing about people's experiences of health and illness.

An example of this was demonstrated through the clinical work of Kleinman (1989) who was aware of the significance of medical histories, referring to the 'tale' of complaints becoming the text that must be 'decoded' by the practitioner. Kleinman's anthropologic training led him to recognise that illness narratives must be contextualized, and that each patient brings to the practitioner their own story. That story embeds the disease in meanings that make sense only in the context of a particular life. *The Illness Narratives* text (Kleinman, 1989) told stories of sickness within this premise. Other writers within the medical profession have undertaken similar work and have demonstrated the importance of narrative to their field by storytelling both about themselves and others in their care, with the intention of readers to learn from these accounts (Coles, 1989: Frank, 2013). All these writers agreed that one way to learn, is to listen to patient stories, shown

to elicit thought, reflection and enhance the learning experience in relation to humanistic understanding (Cole, 2009).

Frank (2013), for example in an account of his own illness, aimed to amplify and connect voices that told stories about suffering, offering the health professional a view from the patient's perspective. He argued that illness narratives are not merely accounts of symptoms but a mechanism through which people become aware of and make sense out of their experiences. A transformation takes place from something lived into something interpreted which can be given structure and meaning through the dialogue that takes place between the patient and physician. "Narrativization" therefore can act as a reflexive, therapeutic, and even a transformative mechanism for people who have experienced illness or, as in this study, parents who have spent many weeks or months living in a neonatal unit alongside their unstable, vulnerable baby with an uncertain outcome.

Greenhalgh and Hurwitz (1998) focused on the benefits of narrative to both healthcare and education and the link between the two. This is relevant to the current author's own underlying position as both health professional and educator. Greenhalgh and Hurwitz (1999) saw illness narratives as providing a medium for the education of both patient and health professional and this is particularly significant in the current climate where patient stories are increasingly being used in the public arena with the aim of teaching compassionate and empathic care. The authors theorised that narratives are memorable, grounded in experience and encourage reflection within the context of a patient centred

agenda. This message can be applied to the field of neonatal care where parents are at the centre.

Charon (2006), an American doctor, offered a personal account written about how she discovered narrative medicine and what she felt could be achieved from and by it. The patient approach or, more aptly for the current study, the *person-centred* approach to healthcare as introduced by Greenhalgh and Hurwitz (1998; 1999) is reiterated powerfully by Charon (2001) who illustrated her writing with real stories not only from her own journey and reflections from working as a doctor but from the perspectives of her patients. Charon (2006) argued that narrative medicine derives its aim from an ethical and imaginative impulse to inhabit and be with others through the phases of attention, representation and affiliation. Paying attention and listening is then followed by representation, usually writing the medial case history. The attention paid to medical stories of illness combined with representational reconstruction in medical narratives results in the final movement: affiliation. Affiliation registers the ethical impulse to act on the patient's behalf. We shall return to this model later regarding the conceptual framework for this study.

Charon also saw the importance of acquiring 'narrative knowledge' that is grounded in experience from the patient's perspective, believing that this contributes to *humanising* medicine. This is in stark contrast to the cost and data driven medical based model of healthcare seen for example in the United States (US) where a humanistic approach to care can be lost. As Murphy et al (2018) emphasised, narrative medicine makes a

significant shift theoretically away from the medical model that is grounded in dualism, where mind and body are separate entities. Conversely, narrative medicine is non-dualistic and therefore more holistic and humanistic. Mullan et al (2006) provided a compilation of personal essays / stories from the US healthcare system and included a story that told the account of a new doctor working in the neonatal unit for the first time who experienced a wide range of powerful emotions and reactions to the care of tiny, vulnerable preterm neonates on the edge of life. This personal perspective brings to light the issues of reflecting on one's practice and experience within this speciality. Such stories are rare within texts in the neonatal field although two have emerged in the UK recently (Segal, 2019; Gordon, 2019). These are particularly relevant as they are written by mothers with premature babies who write about their neonatal care experience. They highlight the highs and lows of their experience and the accounts are often deeply emotional. A limited number of digital stories are also available through parenting websites such as BLISS and *Patient Voices*, but these only capture a still snapshot of narrative, rather than relaying a story over time. While these still have great value and the potential to represent the parent experience, it is the notion of a 'storied' approach that the current study aims to build on, to address the significant gap in narrative work in this field.

The common message from writers in narrative medicine is that narrative and storytelling have an integral role in everyday life, both in health and sickness. They call attention to the inherently narrative structure of the patient experience from which we

can learn. There is significant potential value of using storytelling to enhance learning about the patient experience within the narrative healthcare context.

2.4.1 The nature of story in healthcare

The chapter now turns to the specific concepts of story and storytelling. A story can take different forms; for example, written, digital or verbal accounts, non-verbal, symbolic or image-based stories, chronological journeys or single incidents. All of these can be considered in the context of the healthcare experience (Pallai and Tran, 2019) as well as having a key role to play in the contribution to learning. To facilitate learning in line with constructivism, so closely aligned with narrative research, one must construct stories that enable people to learn about others' experience.

The terms, story, storytelling and narrative are often used interchangeably within the literature. However, there are important distinctions that require clarification. As outlined in Table 1.1, chapter 1, narrative is defined as a spoken or written account of experience (Rashotte, 2005) whereas story is a series of connected events that takes a reader with them comprising a start, main body and a conclusion. This may be true or fictitious (Wright et al, 2014). Paley and Eva (2005) conceptualise this distinction in relation to a 'narrativity ladder': i.e. the increasing complexity from a simple narrative or account of a single event up to a more convoluted, causally related story involving an interweaving plot and key players. Narrativity is therefore on a continuum with 'story' being at the high narrativity end. It is also said that a story is designed to elicit an emotional response from, or form a connection with, the reader (Denning, 2000;

Edwards, 2013) while narrative is not necessarily a sequence of connected events with this aim in mind.

The notion of stories eliciting emotion is relevant to the current study and was highlighted very clearly by Edwards (2013: 61) who stated that they affect the "humaneness" of people directly. Stories are constructed to reflect the needs of individuals to express their experience in a way that makes sense to them, particularly compelling if the experience has strong ''emotional resonance''. We can potentially be changed or influenced by the emotions within a story. She later referred to the impact of the affective aspect of stories arguing that emotional learning is powerful, due to it being reflective and transferable. Here, connections between story, emotion and transformative learning are highlighted. Jarvis (2005: 9) also spoke of the resonance of stories that can be experienced when we hear or read a story that has strong emotional content. This could result in changing our actions in professional practice due to emotion mattering to us as humans. If something matters, one may be stimulated to think differently, take on new ideas and to act to improve practice.

In healthcare, attending to stories based on the narratives of patients, carers or parents has been shown to be an effective way for health professionals to hear and see some of what they experience emotionally and to be able to empathise with them (De Vecchi et al, 2016; Hardy and Sumner, 2018). In the neonatal field, it is reported that emotional care is not always optimal by parents (Russell et al, 2014; Blackburn and Harvey, 2019); hence the need for improvement in this area. On the part of the storyteller, in this case the parents, telling stories may open up many emotions and enable us to understand them

better, a fundamental part of being able to deliver improved, empathic, person-centred care that focuses on humanistic, emotional as well as physical needs. The links between story and emotion, the concept of emotional learning and the potential impact of stories on this is addressed again in later chapters.

Another important distinction in the discussion of story, is that between 'real' (patient's first-hand accounts) and fictional (imaginary) stories, to which there are associated advantages and disadvantages. Research has shown how real stories can be developed using narratives collected from patient interviews about their experience. Literature has documented how the use of these can promote meaningful reflection and learning about illness experiences (Haigh and Hardy, 2011; Stacey and Hardy, 2011; Corbally and ONeill, 2014). Real stories to depict experiences provide a powerful resource as already highlighted by Charon (2001). Charon believed that by using real stories, narrative competence is developed by the learner listening to them, leading to both an increased recognition of the patient experience and to more humane, ethical care. Wright et al (2014) also acknowledged that real stories may be seen by the reader or listener as more credible than fictional ones. However, the challenge of acquiring real stories can be an issue; difficulties may arise with consent, confidentiality, and the willingness of patients to talk about their personal experiences.

This may be where fictional accounts that simulate real-life experiences can be a more feasible approach. Research has explored the use of fiction, either completely fictitious stories or stories based on real events or patient experience. Fictional 'vignettes', defined

as brief evocative descriptions, accounts or episodes to teach key points to learners, can be developed from patient accounts, taken from actual cases. Studies that have explored vignettes have found them to be of value as a way of illustrating the patient's perspective (Hughes and Huby; 2002; Spalding and Phillips, 2007; Kelly and Howie, 2007; Paddam et al, 2010). The advantage of using fiction is that it approaches the material in a less restricted way and consequently communicates its content differently. To explain, where factual stories and descriptions describe what is the case, fiction expresses what could be, or at least what is imaginable. Another advantage is that fiction can relay important points about experiences when individuals are reluctant to disclose candid or personal feelings and strong, challenging emotions. They can also unravel the complexities that would otherwise only be covered by lengthy interviews taking considerably more time.

The potential value of using fiction is highlighted by Hoggan and Cranton (2015) who explored its role in promoting transformative learning, discussed earlier, in higher education settings with a group of one-hundred-and-thirty-one undergraduate and graduate students from two universities in the United States. Qualitative analysis on participants' written reflections were performed following a learning activity that included the reading of a fictional short story. Findings consisted of the three categories: the role of fiction in promoting change, new perspectives, and the fostering of critical reflection, all important elements within the context of higher education in which nurse education is positioned. The authors concluded that the types of learning described were consistent with processes that promote transformative learning. Although this study was

not undertaken in healthcare, it shows how the use of fiction can promote learning and is useful to inform the current study in view of the aim to create stories for this purpose.

As a counter argument, Lorem (2008) pointed out the potential for fictitious stories in putting the credibility of the narrator at stake, in that fiction cannot truly replicate real experiences and is only hypothetical. Fictional stories are not exactly the voice of the patient themselves as spoken by them directly. Authenticity makes a story believable and really draws the reader in to another's world. Therefore, it is an important consideration when working with peoples' narratives. However, Nolan (2018) reminded the reader that research of this nature is not dealing with 'objective truth' and that a story can still be authentic if it is *based on* others' experiences and this allows us to better explore the nature of human emotions. In addition, it is better to accept that *both* real and fiction have much to offer, each with different criteria for what leads to learning. Edwards (2013) proposed they do not in fact conflict and can be combined to exemplify the role of story in learning. Therefore, taking advantages from both types of story for the current study, the aim was to write part- fictional stories based on real life experiences. Moreau et al 's (2018) literature review on the use and value of digital stories in healthcare concluded that the creation of patient stories by a third party appeared to enhance health professionals' learning. The data for the co-creation of patients' stories alongside health professionals, as well as the creation and use of health professionals' own stories suggest that it is more beneficial in terms of learning rather than the sole viewing of patients' stories by health professionals. In other words, learning from someone telling the story of another appears to be beneficial to learning. Moreover, fiction is not as

widely used within healthcare research as real stories, opening an opportunity to explore this further.

A final distinction to highlight is between the different formats in which stories can be presented to the user. There are many ways in which a story can be 'told' and in which someone's experience can be represented; for example, using written text or digital media, through images, film or other arts-based formats. The method chosen for this study was to use digital media to present the stories. The rationale and associated evidence for this decision is addressed in chapters 7 and 8.

2.4.2 The value of storytelling in healthcare

In the context of narrative healthcare, a story is a uniquely human experience through which patients make sense of past or present experience, convey emotions and tell other people (Haigh and Hardy, 2011) during their healthcare encounter. Stories are seen as a potent way to expose professionals to human experience and to learn about this to encourage the development of sensitive, individual and compassionate care (Charon, 2007; Hardy, 2007; Stacey and Hardy, 2011). In healthcare, the benefits of storytelling have been demonstrated in relation to educating others about the lived experiences of patients (Charalambous and Beadsmoore, 2009; Thomas et al, 2009; Missel and Birkelund, 2011) and how it can influence professional learning (Christiansen, 2011). There is an emerging interest in how stories are used by health professionals to learn how best to care for their patients and understand their experiences. The text has already referred to the *Patient Voices* work which refers to the 'humanising healthcare' project. Hardy, the

lead on this project stated that the "intention is to establish a collaboration that aims to humanise healthcare using storytelling to illuminate the patient experience, inform education, promote co-production of healthcare … and generally make the world a better place" (Hardy, 2007: 22). Hardy's 2007 action research study analysed the value and effectiveness of the *Patient Voices* website and concluded that patient digital stories conveyed key emotional messages to health professionals that have the potential for transforming and humanising healthcare delivery. Lambert (2018) agreed with the value of story to this end, saying that statistics only inform us how the system experiences the individual, whereas stories tell us how the individual experiences the system. In line with this, narrative can be used in Charon's view, to equip the medical or nursing student with the ability to perceive suffering and be empathic. There is often such a question in relation to healthcare education as to whether humanistic qualities such as empathy can be taught. In Charon's view, exposing students to stories and lived experiences of their patients could enable them to understand illness and hospitalisation / care from the perspective of the patient and so facilitate the potential for enhanced empathy.

Placing the patient at the heart of the story is the essence of 'person-centred' care, which shall now be discussed.

2.4.3 Person-centred, empathic care

Person-centred care is embedded within the paradigm of holism that seeks to ensure that all needs of individuals accessing healthcare services are met with respect and that care is grounded in values and personal preferences (Delaney, 2018; Feo et al, 2018).

Tekiner (2017) suggests that narrative medicine is parallel to patient-centred care that focuses on the person's needs and goals, placing them at the centre of that care (Haydon et al, 2018; Santana et al, 2018). This makes narrative inquiry particularly suitable to explore a patient's or parent's experience of healthcare as it explores an individual approach. The narrative of a person with a health problem is a recount of the personal experience of their situation, influenced by events, environment and other people. The connectedness between these dimensions is observable in the final narrative and can provide a rich detailed view of how they understand that experience.

Person-centred care within the neonatal context requires further explanation to highlight the nuances of this speciality. Neonatal care is a distinct area of children's nursing and one that involves a wide variety of diverse skills and knowledge areas (Department of Health, UK, 2009; Turrill, 2014; National Health Service (NHS), 2019). The implications of premature birth and the subsequent neonatal care along with the often-protracted 'journey' through the neonatal unit, is one that offers huge opportunities for learning for students and staff working within this field. Neonatal intensive care is a practice area where nurses care for the complex needs of babies with a variety of conditions (Spence et al, 2016). Curricula for education of nurses commonly focuses on these physical conditions along with associated clinical care. However, learning about this specialty should be more than clinical and practical skills. Imperative for true, holistic understanding of the baby and family is for practitioners to address the psychoemotional needs of parents and close family members so that care is person-centred. This highlights the place for story and a narrative approach to healthcare. Little is known about the

integration of person-centred, emotion based education into nursing programmes, particularly so within the neonatal field (Petty, 2014).

As person-centred care is about focusing care on the person rather than the needs of the service (RCN, 2016), the personal requirements relating to the baby and family, should be central to care delivery (Draper and Tetley, 2013). While person-centeredness as a concept has been explored in certain nursing fields (Schwind et al, 2014; Laird et al, 2015), within the field of neonatal care, it is largely viewed within the remit of *family-centred* care. The acknowledgment of parents' personal experiences within a family context potentially increases one's understanding and compassion (Weis et al, 2015). It is therefore essential to ensure that those in our care, the babies and their families, lie at the heart of care delivery. It follows then, that a person-centred approach to education and learning must be true to this central principle.

Empathy is one such person-centred concept that is central to the current study, highlighted previously by the work of Charon and her narrative medicine outlook. Cooper (2011) has also written extensively on empathy but this time within education, starting her text with an explanation of its importance to society. She stated that an understanding of society comes with experience and that empathy can and should be part of that education. Empathy has been defined in Chapter 1 and is an attribute that involves an understanding by the practitioner of the experiences and perspectives of the patient. Spiro et al (1993) present a collation of essays on empathy and how this can be taught and enhanced in healthcare professionals, emphasising the importance of shared experiences and feelings between them and their patients. A question arising within

these texts was whether you can teach professionals aspects of person-centred care such as empathy? In other words, can you educate others to be empathic in the same way that you can teach them to perform clinical tasks and technological processes? This question pertaining to empathy education (Tavakol et al, 2012) along with the other relevant literature including research that has explored the use of stories or narratives to enhance empathic care in various ways (DasGupta and Charon, 2004; Shapiro et al, 2004; 2006a; 2006b; Rosenthal et al, 2011) is discussed further in Chapter 8.

2.4.4 Narrative research in neonatal nursing care

Within the literature thus far, work has mainly emerged from the medical profession and the adult nursing field that has explored learners' perspectives on the use of storytelling for teaching and learning (Hughes and Huby, 2002; Paddam et al, 2010; Wright et al, 2014). Research on storytelling in the field of neonatal nursing is lacking. Some studies however, have explored neonatal *experience* (Wigert et al, 2006; Fegran and Helseth, 2009; Uhl et al, 2013; Dellenmark-Blom and Wigert, 2014; Russell et al, 2014; Wigert et al, 2014; Blackburn and Harvey, 2018; 2019). Common elements of such work are that they are, in the main, interview-based studies adopting a qualitative approach to explore parent experiences of neonatal care. It is worth considering a selection of these studies to give the reader a taste of narrative work that has specifically explored the emotional element and experience of neonatal care.

To start, a study by Wigert et al (2006) aimed to describe mothers' experiences when their full-term baby was cared for in a neonatal unit. Ten mothers were interviewed six

months to six years after their experience in a neonatal unit. Key themes that emerged were exclusion and participation. A feeling of exclusion dominated when a new mother felt lack of interaction and a sense of not belonging to either the maternity care unit or the neonatal unit. Conversely, when a feeling of participation dominated, a continuous dialogue existed between the mother and staff and she then felt more positively cared for as a unique person with specific needs, congruent with 'person-centredness'. While there was a varied and wide time period in which interviews occurred, the implication of these results for nurses is that they can learn from mothers' narratives in relation to the importance of decreasing their experience of exclusion and the need to increase their feeling of participation.

Fegran and Helseth (2009) explored both parents' and nurses' experiences of the parent-nurse relationship focusing on when a preterm baby was hospitalised. This study used both participant observation and in-depth interviews with six mothers, six fathers and six nurses in a Norwegian thirteen-bed neonatal unit. It was found that that the neonatal unit context was thought of as a highly technological environment where human interaction and emotional closeness were identified as significant needs. This showed how narratives can reveal deep rooted, humanistic elements of experience, against the backdrop of the challenging neonatal environment, so emphasising the importance of person-centred care.

With a similar aim of exploring parent experience, Dellenmark-Blom and Wigert (2014) undertook a descriptive study in relation to neonatal home care following neonatal unit admission. The main finding was that parents experienced neonatal home care as an

inner emotional journey fraught with barriers and turmoil, from having a baby to finally feeling like they were a parent, which took significant time to fully achieve. These findings mirrored those from more recent studies on parent experience, undertaken by the author concurrently to the present study (Petty et al, 2018b; Fowler et al, 2019). Various themes emerged as important: namely, the parents' experience of leaving the hospital environment, establishing independent parenthood, maturing as a parent and processing experiences during the period of neonatal care. This concept of journey is consistent with that of story, a series of transitions over a course of time through which one narrates their experiences.

Russell et al's (2014) study also explored parents' experiences during hospitalisation with their premature babies through interviews with mothers *and* fathers. Although parents' evaluation of the adequacy of care in the neonatal unit was not the aim of these interviews, all parents spoke spontaneously and at length on this topic. Generally, parents were satisfied with the care on the neonatal unit in relation to their involvement and looking after their own baby, having easy access to them and they highlighted the challenges of expressing breast milk as one specific example. They were also satisfied with staff competence and efficiency, communication, experience, confidence, information and explanations. An area of satisfaction also related to the interpersonal relationships with staff including receiving sensitive and emotional support, reassurance, encouragement and the importance of being made to feel like an individual. Provision of information, emotional support for parents and increasing involvement in the care of their baby were emphasised by parents as important in their experience of personal-related care.

Penultimately, Wigert et al (2014) aimed to describe parents' experiences of communication with neonatal staff. Families were interviewed, and it was found that parents experienced communication with the staff as essential to the psychological management of their situation. Attentive communication gave the parents relief in stressful circumstances. In contrast, lack of communication contributed to feelings of loneliness, abandonment and unwanted responsibility, which added to the burden of an already difficult situation. This study stands out as it put forward what can be learnt by health professionals who are in a unique position to help parents cope with their emotions. Opportunities for good communication between parents and staff should be developed as early as possible.

Finally, a recent study further supports the above findings relating to parent experience. Blackburn and Harvey (2018) performed a mixed methods study using an online survey and parent interviews to explore their experiences of early neonatal care and education provision for children born prematurely. From analysing two-hundred and-nine survey responses and thirteen interviews with twelve mothers and one father, themes that arose related to contact and bonding in the hospital setting, experience after discharge, participation and inclusion in parent groups and the transition to school. Certainly, findings suggested that there is a potential detrimental effect on the bonding process from having a premature baby leading to higher chance of having post-traumatic stress disorder. A significant theme threaded through the interview narratives was a perception by parents of a, ''different kind of normal''. A later paper by the authors (Blackburn and Harvey, 2019) reported specifically in relation to exploring the information and support needed by parents and the effect on emotional health. An important finding was that

support systems did not offer adequate emotional support to parents, placing extra stress onto the family at a time when they are already dealing with the unexpected event of premature birth. Again, findings relating to deficits in emotional support are also supported by Petty et al (2018b) and Fowler et al (2019).

A strong emotional content is threaded through the above studies. Another consistent point or finding was that emotional support for parents was often lacking, requiring improvement. These studies are revisited along with further research in Part 2 (main study) relating to parents' emotional experience and the need to teach this to enhance empathic learning and potentially contribute to improved person-centred care of parents.

2.5 Critique of story

While appreciating the potential value of narrative, one must also acknowledge limitations and potential tensions that exist between narrative approaches to educational research and traditional methods. Polkinghorne (1988:35) summarised this clearly by asserting that there are two kinds of human rationality: "narrative rationality", which leads us to ''understand synoptically the meaning of a whole, seeing it as a dialectic integration of its parts'', and another kind, which uses objective, quantitative methods. Empiricists maintain that narratives explain events only to a very limited extent. However, while scientific methods serve the natural and biological sciences within healthcare and medicine, they do not catch the meaning humans make of actions

and experience. Capturing such meaning within the healthcare arena is vital to understand the perspective of the patient.

In addition, while narrative is valued for the insights it offers into the experience of others including patients, Woods (2015) pointed out concerns about the truth-value of narrative and the extent to which we can trust that people's stories of illness accurately describe what it was really like, returning to the question of authenticity. Whether or not we accept narratives as a viable source of information is based on the question of how they constitute truthful descriptions of an event or life story (Lorem, 2008). In other words, one can ask, how can one be sure that someone's story is a true reflection of what happened? Also, often an institution may regard narrative as a readily accessible truth: e.g. regarding parents' responses to a situation; but this can be problematic due to assumptions that may not consider different perspectives or interpretations. In relation to the notion of truth, there is always some doubt when it comes to interpretivism. The inherent subjectivity of what stories mean to those analysing them influences the authenticity and truth behind any findings that emerge.

However, it may be wrong to doubt the truth of what parents have said, since as acknowledged earlier, stories are based on peoples' *perceptions* of what they experience. In other words, their stories are *their own* truths based on *their own* perceptions. One person may have said something but if the parent heard something else, then that is their understanding, their interpretation of the story. As Winterton (1997) stated (cited by Haigh and Hardy, 2011: 409): ''Stories are always true; it's the facts that mislead".

In addition, stories and the underlying meanings can change according to the audience and how the storyteller wishes to present themselves. Stories are said to be written to present self and experience in a particular light. Meaning could also potentially change if peoples' narratives are used in a research context for the creation of stories; they may be reconfigured, adapted and / or altered in various ways which may then not be a true representation of a person's experience. Possible misunderstandings may arise if narratives are interpreted or used differently to the original intended story, hence the need to ensure reflexive rigour is applied to qualitive, narrative research. Paley and Eva (2005) suggest that it is important not to confuse the emotional persuasiveness of the story with the objective accuracy of the narrative, and so they recommend undertaking ''narrative vigilance''. This is the action or state of keeping careful watch for possible misunderstandings and misconceptions.

Another critique concerns individuality. Strawson (2004), for example, criticised Bruner's view of how humans live by narrative and that we are defined by our narratives of ourselves, alongside his claim that we create or invent the self specifically by "writing" and "storying" it. She questioned if this is true and whether we do create ourselves. She asks: Is the narrative view a profound and universal insight into the human condition? This may depend on the type of person one is, and it may be true enough for some but not so for others. Some people may indeed be intensely narrative and self-storying while others may not be, and these individuals may have little sense of, or interest in, their own history, nor have any wish to give their life a certain narrative shape. This implies that we are not all the same and that a narrative reality does not apply to everyone.

A final critique of story centres on knowledge: while narratives derived from patient encounters are a source of knowledge, they are not the only one. Lorem (2008) warns of a potential over-reliance on narrative in that knowledge can also be generated from facts and science. Kalitzkus and Matthiessen (2009: 84) noted; ''Narrative is not the only thing that counts in medicine: by no means is it meant to devalue medical knowledge". Also, to concur with Strawson (2004), there are patients who are ''not interested in telling their story or sharing their innermost feelings, and not every topic raised in a consultation calls for detailed narrative exploration".

The points of critique discussed above are often associated with interpretive research, hence the need to optimise rigour which includes having a transparent, reflexive approach. Box 2.1 contains a personal reflection on the literature highlighting some key points to ensure reflexivity was applied from the outset of the study.

Box 2.1: Reflection: The Literature

It has been highlighted how some writers have commented on limitations with the term 'story' raising questions about the potential for biased interpretations and whether peoples' accounts are true. Stories are framed for a specific purpose, so it was essential for me to critically reflect on the issue of authenticity. On the one hand, stories situated in fantasy and fiction may raise issues about the question of truth and authenticity. However, they can also present a 'truth'; for example, they can be metaphorical as in the case of fantasy or with fiction, they can represent the essence of experience. Misunderstandings of interpretation may arise due to the individuality, context and prior knowledge of the person listening or attending to stories and unconscious influences upon stories that are produced may come into play.

Such issues may problematise the truth-content of patient's or in my case, the parents' reporting.

Other questions for critique came to light during my analysis of the literature. Regarding narrative healthcare, for example, is it appropriate for institutions to follow a purely narrative based approach or should it be warier of its modes of investigation, particularly when these may be used to develop services? Conflicts may exist in relation to external questioning around data and rigour of information-gathering by other means; hence, an institution may then overly rely on patient accounts to understand, deliver or plan care. Relevant to this point, I was very drawn to the critique from Kalitzkus and Matthiessen (2009: 84) who cite Launer (2002): '' Disease, disability, deprivation, and death are not stories. They are facts. Professionals, who get carried away by narrative ideas to the point where they forget this, are not safe''. Narrative healthcare literature, therefore can ignore the limits of narrative. People may have experiences that do not fit neatly into a storyline or an organised, plot of what happened. Moreover, there are human experiences beyond narrative such as non-verbal, gestural or more intuitive modes of communication that are also important within nursing care that can contribute to meaning-making and interaction with others.

One other issue was whether it was right to see experience in relation to a rigid, scripted notion of what a good, straight, linear story should be. Addressing these issues contributed to a reflexive approach to my study and is further discussed in future chapters.

2.6 Summary

To summarise this chapter, there are integral links between narrative and story with empathy, emotion and experience, particularly important when considering the parent within the neonatal unit who undergoes a significant trajectory of events over a course of

time. Consideration of these interlinking concepts was undertaken within the context of a narrative, interpretive theoretical perspective and an underpinning constructivist epistemology.

These important links were summarised by Caldwell (2012) who spoke of the views of Pink (2008), describing story as having context enriched by emotion where meaningful information is passed down to others. Distinguishing it from factual information that lacks an emotional impact, a story is more likely to elicit emotion, a critical element that makes information relevant, memorable and particularly relevant for teaching others. For Pink too, storytelling is an art modality that demands interpretation. As human beings, we author our lives by creating or constructing narratives that reveal our world and ourselves. That is, we live our stories. Listening to each other's stories helps us to show empathy and better connect to one another. Remembering a story is more powerful than recalling facts. The Health Foundation (2016) agreed, stating on their webpage that ''we respond to stories, particularly when there is emotional detail, and remember information given in story form much more vividly''. This all emphasises the capacity and potential of story to educate. In this way, storytelling can be a pedagogical tool that can teach us about the emotions of others.

Finally, the link between narrative and learning in neonatal care was published by the author in a peer-reviewed journal (Petty, 2016a) titled; 'Learning from narrative to understand person-centred experience: a literature review'. The objective was to explore literature that focused on the narratives of parents and nurses with a view to evaluating their value for enhancing learning about person-centred nursing care in the neonatal

field. Purposive sampling of the literature, applying inclusion and exclusion criteria revealed a final selection of nine studies for review. Analysis of the selected literature found that attention to narratives of both parents and nurses revealed important insights into the lived experiences of this challenging environment providing an effective vehicle for students and nurses to learn about these experiences within a compassionate, person-centred approach to the care of neonates, parents and staff. The paper concluded that there is a place for the integration of narrative in the form of storytelling into teaching and learning strategies that capture the experience of those within the neonatal field that can be used to support education about person-centred neonatal nursing care.

Chapter 3: Design

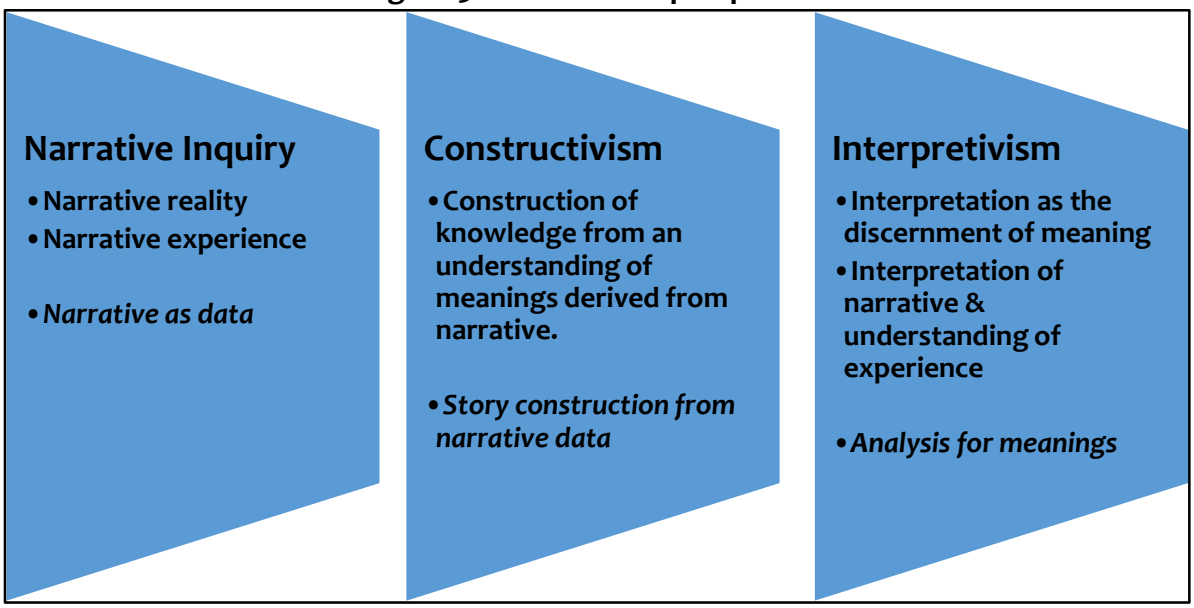
This chapter covers the theoretical framework underpinning the study's methodology. The overarching methodology is introduced in this chapter with further detail added in later chapters as relevant to that specific phase. Ethical considerations are also included.

3.1 Methodology

The methodological approach employed for this study was narrative inquiry. To reiterate from Chapter 2, this is research that focuses on personal experience through narrative and takes account of the relationship between individual experience and context (Allen, 2006; Kaplan-Myrth, 2007). As a result, it was considered appropriate for the study since such research seeks to discover an in-depth understanding of individuals' lived experiences and is valued as an approach in health research when we seek to explore and understand the patient, or indeed, the *parent* experience.

The three theoretical perspectives relevant to this study, narrative inquiry, interpretivism, and constructivism, all work together as one closely connected framework (Figure 3.1). *Narrative* is the starting point, by which we then *interpret* experience and by doing do *construct* meanings and knowledge, remembering always the parents at the centre. It is after all, their unique, personal experiences and narratives that form the basis of all subsequent analysis. It is important not to lose sight of the importance of a person-centred approach to care when researching people's experience.

Figure 3.1: Theoretical perspective



The interpretive approach required reflexivity to be applied throughout, introduced in chapter 1 in relation to how the personal background of the researcher influenced the decision to undertake this work and thereafter in chapter 2 where a reflection on the background literature was presented. Box 3.1 continues this reflexive thread, applied specifically to the design and methodological approach used in this study.

Box 3.1- Reflection: Design and theoretical approach

Being reflexive at this stage was about being thoughtful about my position and identity as a researcher and the theoretical predisposition that informed my methodological approach. Introspection of my own beliefs and theoretical stance was undertaken since, as Lambert et al (2010: 324) stated, ''One of the biggest issues a practitioner researcher faces is the way in which their knowledge and identity affects the collection of data''. The interpretive nature of qualitative research places researchers in a place where their own theoretical framework is a vital element in selecting the methodology (Carter et al, 2014).

Reflexivity in my study was a process that imparted transparency in relation to my methodology, a necessary element of quality (Finlay, 2002; Holloway and Freshwater, 2007). In Box 2.1 previously, a critique of this type of research was highlighted in relation to trustworthiness and authenticity, questioning validity (Holloway and Biley, 2011; Clancy, 2013) and the notion of truth (Walker et al, 2013). This is influenced by the social, political and cultural positioning of researchers (Thoresen and Öhlén, 2015). I recognised an emphasis on the interpretation of others' narratives to construct stories for learning. I was always mindful of how constructivists argue, that "to understand this world of meaning one must interpret it" (Schwandt, 1994, p. 118 cited by Johnson, 2009) and that reality is represented in the form of multiple constructions, based in social contexts and different experiences. Epistemologically, I was mindful of how knowledge was generated. As a qualitative researcher engaged in my own practice, I needed to accept that I not only influenced, but also actually actively constructed, the collection, selection and interpretation of data from the various participants gained through interviews and group discussions. Meanings were interpreted within a particular context of neonatal care. Within the narrative reality of constructivism, another researcher may well have unfolded a different story (Creswell, 2014), remembering that our own personal stance will influence how one constructs meanings (Collins and Cooper, 2014, Richardson, 2000, Streubert and Carpenter, 2011).

3.2 Specific methods

Methodologically, any approach can employ various methods to generate data that may reveal multiple perspectives. Narrative inquiry is no exception (Priest et al, 2002). This study employed a combination of methods through the different phases as follows:

- Initial study (Chapter 4): Semi-structured, individual interviews with six student nurses followed by core story creation and thematic analysis of narrative data.

- Phase 1 (Chapter 6): Twenty narrative, individual interviews with twenty-three parents of premature babies followed by core story creation, thematic and metaphor analysis of narrative data.
- Phase 2 (Chapter 7): Digital Story Creation applied to the reconfigured, 'storied' parent narratives using the ASPIRE model (Aims- Storyboarding-Population-Implementation-Release-Evaluation).
- Phase 3 (Chapter 8): Mixed methods approach including group, point-of-view (empathy exploration) exercises with sixty children's nursing students, individual interviews with seven children's nursing student nurses and an online questionnaire with a total of one-hundred and thirty-seven student nurses and practice staff combined.

Each phase is discussed and rationalised within the respective chapters, all carried out under an overarching narrative, interpretivist approach. Alignment between this narrative thread and all aspects of the research project was essential since in qualitative research, the entire project must be connected (Paradis et al, 2016) to ensure coherence.

3.3: Ethical considerations

An essential component of the initial, exploratory phases of the research was to ensure ethical approval was obtained. The study received ethical approval by the Social Sciences, Arts and Humanities Ethics Committee, University of Hertfordshire (Protocol number aEDU/PGR/UH/02074). The ethical considerations documented in the application included the following important areas:

- The emotional element: The issue of, what Boydell et al (2012: 10) refer to as, ''dangerous emotional terrain''. Interviewing both parents and student nurses about sensitive and challenging times or experiences had the potential to trigger difficult memories and emotions. This was addressed by ensuring all participants were aware of being able to stop interviews at any point and / or withdraw if they felt they needed to. The same applied to the questionnaire completion and the class exercises in phase 3 involving perspective-taking with student nurses.
- Risk assessment: In relation to the potential emotional effects, there was a need to document potential risks inherent in the study. This also included the need to ensure a safe venue for interview when travelling externally in an unknown area and that the lone researcher policy was followed.
- Support: The need for support service contact information on the participants' information sheets for them to seek further support and advice, if required.
- Information-giving: The need for clear and concise, easy-to -read participant information sheets that were free of jargon, to be given to all participants before any interview, questionnaire or exercise / interaction.
- The need for informed consent: This was an essential part of the approval process due to regulations requiring that sharing of research participant data was

undertaken with permission. Consent was obtained not only for the interview and audio recording of parent narratives but also to use components of their data in a future learning capacity to inform others about their experiences. Parents were made aware that certain common themes and points of interest from their narratives, when analysed as a collective whole, would be selected. They were informed that these themes would be reconfigured into final 'storied' formats to use for teaching nurses and health professionals. Again, assurances were clear relating to anonymity. The same assurances applied to the student nurse exercises, views and interview narratives in relation to what their data would be used for along with assurance of anonymity. For the online questionnaire, consent was implied for anyone who completed it, but they had information provided relating to the research overall, the aim of the survey and data management.

- Storage and management of personal information and data: The ethical application included assurances that all participant data would be stored securely and confidentially in line with current data protection regulations, with any interview and/or questionnaire data fully anonymised. Participants were reassured both in written and verbal formats about anonymity and confidentiality regarding their interview transcripts and the storage of their data. Tekiner (2017) also raised an issue with patient narratives and the danger of using data leading to a risk to confidentiality. This highlights the importance of the need for sound 'narrative ethics'.
- Power relationships: The need to assure that participants did not feel they had to take part and that no coercion or pressure would be applied. This was particularly

relevant in phase 3 with the student nurse participants due to the lecturer-student power relationship.

- Gatekeepers and permissions: An agreed gatekeeper was required for access to parent volunteers in phase 1 and for the student nurses, university lecturers and practice staff in phase 3, there was a need to obtain permission. This was obtained from the Dean of School for the students and lecturers and from the Research Governance leads from two Trusts. Gatekeepers were also identified in each of these two Trusts.
- The issue of trustworthiness: As highlighted earlier, 'truth' is one factor regarded as a potential ethical issue within qualitative, narrative research. Boydell et al (2012) and Lafrenière et al (2012) both highlighted this issue for consideration in relation to data interpretation honestly and accurately representing the experiences and words of the participants. If this is not achieved, then the interpretation can be deemed untruthful, hence unethical. Therefore, strategies were undertaken to ensure rigour and the assurance of ethical conduct from the outset (Appendix 1).
- Reflexivity: The need for a reflexive approach to ensure transparency of data analysis and reporting is an essential part of qualitative research such as this (Landy et al, 2016). At the beginning during the ethical approval application, the planned methodological strategies and the above potential issues / areas were documented in a transparent way and submitted to the ethics board. Reflexivity and ethical considerations are addressed in Box 3.2.
- Amendments: Throughout the course of the study, various amendments were required and so an ethical modification form was submitted when applicable:

Examples were, phase 3 modifications including addition / inclusion of practice staff and a change in title.

Box 3.2- Reflection: Ethical considerations

A reflexive approach was required during the ethical approval process for reasons stated above. A key example of this concerned recruitment of participants. Research suggests that recruiting participants to be interviewed about sensitive life events can be challenging (Kendall et al, 2007) due to the potential for distress. There was a vulnerability of parents who had premature babies and experience of emotional trauma from their protracted time in neonatal care. I knew the importance of being aware of my ethical responsibilities to avoid unnecessary upset and distress and to minimise 'risk' to my participants. By documenting a risk assessment, many potential issues came to my consciousness in relation to potential *emotional* risks to parents who would be reliving sensitive and poignant experiences or student nurses who may find the neonatal unit a daunting and unsettling place. Parents' welfare should always take priority and it was important that I had fully considered the need to build in offer of support if needed. Overall, a reflexive approach to qualitative research can help minimise the risk of harmful effects (Clarke, 2006) and was a vital consideration for ethical approval and a key dimension of myself as an ethical and socially responsible researcher (Hewitt, 2007).

Before turning to each of the three phases of the main study, it is necessary to report on a preliminary, small-scale study that was undertaken as part of the Doctorate in Education Programme. This initial study's methodology informed that of the main study and so warrants a separate chapter, which is now discussed.

Chapter 4: Working with narrative: an initial study

4.1 Introduction

This chapter as stated, provides an overview of an initial, small-scale research study that informed the methodology for the main study presented in Part 2. This initial study titled: 'Creating stories for learning about the neonatal care experience through the eyes of student nurses', serves as an example of a methodological approach that used interview narratives to construct stories using a process of 'Core Story Creation' (Emden, 1998). Participants for this study were student nurses studying for a degree in children's nursing who all underwent a placement in a neonatal unit, presenting to them a new and unfamiliar learning environment. The 'storied' constructs created from their narratives were used to create a digital storytelling resource focusing on the experience of working on neonatal unit for a given time.

4.2 Aims and research question

The research question posed for the initial study was: What can be learnt about the neonatal care experience from constructing stories using student nurses' narratives?

The study aimed;

- To develop stories from student nurse narratives working in neonatal care.
- To identify key themes from the stories with view to them being used to share perspectives and enhance learning in others about the care experience within this speciality by the development of a digital storytelling resource.
- To identify the strengths and limitations of this methodological approach in view of applying it to the main study.

4.3 Background

The neonatal speciality offers a wide range of learning opportunities relating to the physical and psycho-emotional care of vulnerable, sick and small babies and their families which are often challenging and complex. It follows that there is much to learn from those who have experienced being part of such a specialised environment such as parents, health professionals and learners themselves. In relation to the latter group, student nurses who work within specialised areas such as neonatal care for their practice placements are exposed to very new and challenging learning demands. The neonatal speciality is unfamiliar, learning needs may be poorly defined due to this. It was clear to the author who is an experienced neonatal educator, that students often voice uncertain expectations and anxiety around what they will face as a learner in this specialised environment. Student experiences and learning needs in the neonatal field have not been explored within the literature so little is known about this area. More importantly, in the context of nurse education, how their experience can be used to enhance teaching and learning for those new to working in this field is also unknown. This study focused therefore on the creation of stories from the narratives of student nurses and how they have informed subsequent resource development as a strategy to enhance understanding and learning in others, about the neonatal nursing field.

As the focus of this study was on the creation of stories for learning, it is pertinent at this point to refer again to the underpinning theoretical framework outlined in Chapters 2 and 3. To summarise as a reminder, stories and storytelling in a research context are part of narrative inquiry and interpretivism; research that captures personal and human

dimensions of experience and takes account of the relationship between individual experience and context (Clandinin and Connelly 2000; Lorem, 2008) when interpreting meanings. In this case, it was the student nurse's experience as a focal point. Again, the integral connection between people's experience, stories and narrative can be viewed within the theoretical perspective of constructivism; that is how people 'construct' their own meanings and understanding of the world by building on previous knowledge and experience through narrative. Bruner (1996) spoke of narrative 'structuring' whereby we create knowledge in 'storied' form arguing that story making is central to creating an understanding of the world. Polkinghorne also argued that narrative knowledge is maintained in emplotted stories (Polkinghorne, 1995). Story in the context of the present study was an account, or plot, of events constructed from the experience of student nurses within the neonatal context that could be interpreted to generate knowledge. By this, the aim was to make their narrative more understandable to clarify connections between events.

Referring to Figure 3.1 on page 75, the narrative of student nurses was the starting point; raw, unstructured whole accounts acquired from those who offered their version of the neonatal experience. The story created would be an interpretation and reconfiguration of their narrative, an account that relayed significant events and *constructed* with a beginning, middle and ending in the context of a plot. The latter was discussed by Emden (1998), who used Polkinghorne's term 'emplotment'. The process of emplotment can be used to create 'storied' constructs from raw data by reconfiguring it. In relation to the neonatal care context, the story in the form of a plot is akin to how we often view the neonatal 'journey', from the start of life (prenatal events), birth (first vital transition) and

through the varying dependency levels of neonatal care until the transition to the home environment and beyond. These transitions are a vital part of the neonate's emplotted journey.

A limited amount of research has used plot creation as a way to organise and make sense of narrative. Haidet et al (2006) undertook sixteen qualitative, in-depth interviews with primary care patients and using their illness narratives, developed a narrative framework for each one including characters, a start and endpoint with the events positioned in between, in the form of a plot. Findings revealed a level of complexity in patients' healthcare participation explained by thematic story elements that the authors felt were in dynamic interplay, throughout the 'storied' narratives.

Therapeutic emplotment has also been documented as being a narrative construction of lived time such as that used in the field of psychiatric medicine where the creation of story-like structures has emerged through therapist-patient interactions (Mattingly, 1994). Crossley (2003: 439) concurred and stated "therapeutic emplotment is implicitly incorporated by the patient, providing an underlying plot structure to his story". Tropea (2012) saw therapeutic emplotment as a way of improving connections with patients and that narratives can be constructed together. Such a definition places emplotment within the constructivist framework.

A study by Lapum et al (2010) on the analysis of stories from patients who had undergone open heart surgery placed a focus on what they termed, narrative form; i.e. how stories were put together and what structures storytellers drew upon. They

considered temporality, context, plot, scene and characters as essential shaping forces of a story and key elements of narrative emplotment, as a form of narrative analysis.

Emplotment has also been studied in relation to nurses' narratives. Kelly and Howie (2007) studied a 'storied' outcome focus in research undertaken to explore the use of nurses' stories to examine the effect of therapy on professional practice of psychiatric nurses. They described an eight-staged narrative analysis approach of emplotment taking principles from Polkinghorne's model. This comprised: connecting with someone's life story, scrutinising the life events, chronologically ordering events, core story creation, verification, plot examination and theme identification, examination of plot structure ending with the resultant emplotted whole narrative. The final product was a narrative construct that gave meaning and understanding to the data. They concluded that nurses' stories can be an effective means of exploring, comprehending and conveying nursing practice principles.

In neonatal care specifically, a descriptive study by Korhonen and Kangasniemi (2014) analysed nurses' interview narratives using Polkinghorne's model of narrative analysis and emplotment principle. They described the relationship between nurses and parents as a *plot* starting with formation, through the process of caring for the baby over time leading to when this relationship ended. A reconstructed narrative was formed as a result of the analysis. The aim of analysis was to find a plot that united the different parts of the material. A plot, they proposed, makes the narrative understandable and clarifies connections between events.

However, there is a gap in both the literature and practice development in terms of how stories are used to enhance learning and in the development of storytelling resources tailored to the needs of a speciality such as neonatal care. This initial study therefore addressed such a gap and strived to explore how storytelling could contribute to teaching and learning in this area. Furthermore, as little is known about how experiences and narratives of student nurses who have worked in such a specific area of care can be used to inform others, it was their stories that were of interest here.

4.4 Methods

This study adopted a narrative, interpretive design as discussed in Chapter 3. This is fitting with the theoretical perspective of constructivism where meaning-making is central, and an emphasis placed on co-construction and sharing of knowledge.

Interviews were chosen for this study as they were a suitable way to gather stories from students and gain access to, what Squire et al (2014) referred to as the narrative 'voice'. Interviews are used to gather information from individuals, usually by using a series of predetermined questions or a set of interest topics. Interviews are ideal when used to document participants' accounts, perceptions of, or stories (Mann, 2016) and therefore, for this study, they were the optimum choice of method. Interviews can be structured or unstructured; either following a set of questions that mimics a survey or be designed to enable interviewees to express themselves more freely. Interviewers need to actively listen and question, probe, and prompt further to collect rich narratives. Interviews generally yield richer, more in-depth data than closed surveys although they require

more time and resources to conduct and analyse. This time commitment however was deemed worth it, to produce the type of data required in a narrative study such as this.

4.4.1 Participants and recruitment

Six student nurses undertaking the children's pre-registration programme who had completed a placement in a neonatal unit within the previous four to six weeks were selected and interviewed. The group comprised five female and one male participant which was congruent with the usual gender balance in children's nursing. There were two first years, three second years and one first year student allowing stories to be collected across the whole breadth of training levels. However, all were completely new to neonatal care and had not been on a previous placement in this area. The sample was purposefully small due to the aim to pursue subsequent digital resource development and the need to avoid overload of content for both its creation and the eventual usability by the learner. Six selected stories were deemed to be sufficient for such a purpose since this was also a new idea for resource development.

Participants were selected by convenience sampling, a form of non-probability sampling where they were chosen due to being easily accessible; in this case, student nurses attending a neonatal placement during their pre-registration children's nursing programme over June-August 2015. They were approached within two weeks of completing their placement to ask if they would be interested in participating, an information sheet was given, followed up within an agreed time and a date was set. If agreement went ahead, consent forms were signed, followed by interview.

Regarding ethical considerations, approval was obtained from the author's Higher Education Institute (HEI) Ethics Committee. Consideration was given to areas highlighted in Chapter 3; namely, confidentiality and storage of interview data, potential emotional effects of recalling experiences, and the need for informed consent. The latter was obtained from the participants for both the interviews and subsequent use of their transcripts for story creation and resource development. Issues such as transparency of the student- researcher relationship and the potential emotive nature of interviewing is further discussed in relation to the main study in Part 2 in line with reflexivity which was undertaken throughout this initial study (see Box 4.1).

The methods used comprised the following stages:

- Semi-structured Interviews and transcription.
- Core story creation.
- Thematic analysis
- Verification of the stories.

Each of these components shall be now discussed in turn.

4.4.2 Interviews

Individual interviews with each of the participants were conducted to collect narratives. Interviews were carried out in a private, neutrally agreed venue negotiated between the researcher and participant. This was set apart from the neonatal unit itself.

The interviews were audio recorded. They were semi-structured starting with an open 'single question aimed inducing narrative' (SQUIN) as put forward by Wengraf (2009). The SQUIN was intentionally broad aiming to provide a means of eliciting data allowing participants to begin and construct their narrative on their own. The SQUIN was designed to enable the students to talk through their whole experience on the neonatal unit, and was: *Can you tell me about your placement on the neonatal unit, taking me through the events and experiences that were important for you, from the start to the finish of the placement?*

Questions were also prepared to elicit further information and to generate more rich data if required. It is acknowledged that interviewees may need further questioning if they do not know what further to say, necessitating further probing (Corbally and O'Neill, 2014) (See Appendix 2a for the interview schedule). Transcription was undertaken manually and yielded six raw transcripts of written narrative. Reissman (2008) suggested that transcription is not always necessary: however, the decision was made to transcribe from audio to written formats to make an 'end-product' that was tangible and to make the story creation more manageable.

4.5 Analysis

4.5.1 Story Creation and emplotment

Narrative analysis is one type of qualitative analysis that explores the data specifically looking for stories (Lichtman, 2012). Following transcription, the next stage was to work

with the raw narrative to create stories. Research detailed previously in the background section of this chapter (Haidet et al, 2006; Kelly and Howie, 2007; Lapum et al, 2010) has offered strategies for how stories can be constructed from narratives collected from the experiences of participants . Emden (1998) described more specifically, 'core story creation', a process to condense full length narratives or stories to briefer ones, to facilitate the narrative analysis process. Her work is based on both Polkinghorne's (1988, 1995) and Mishler's (1995) models which used similar methods to analyse narratives and to reconstruct events into a form of plot.

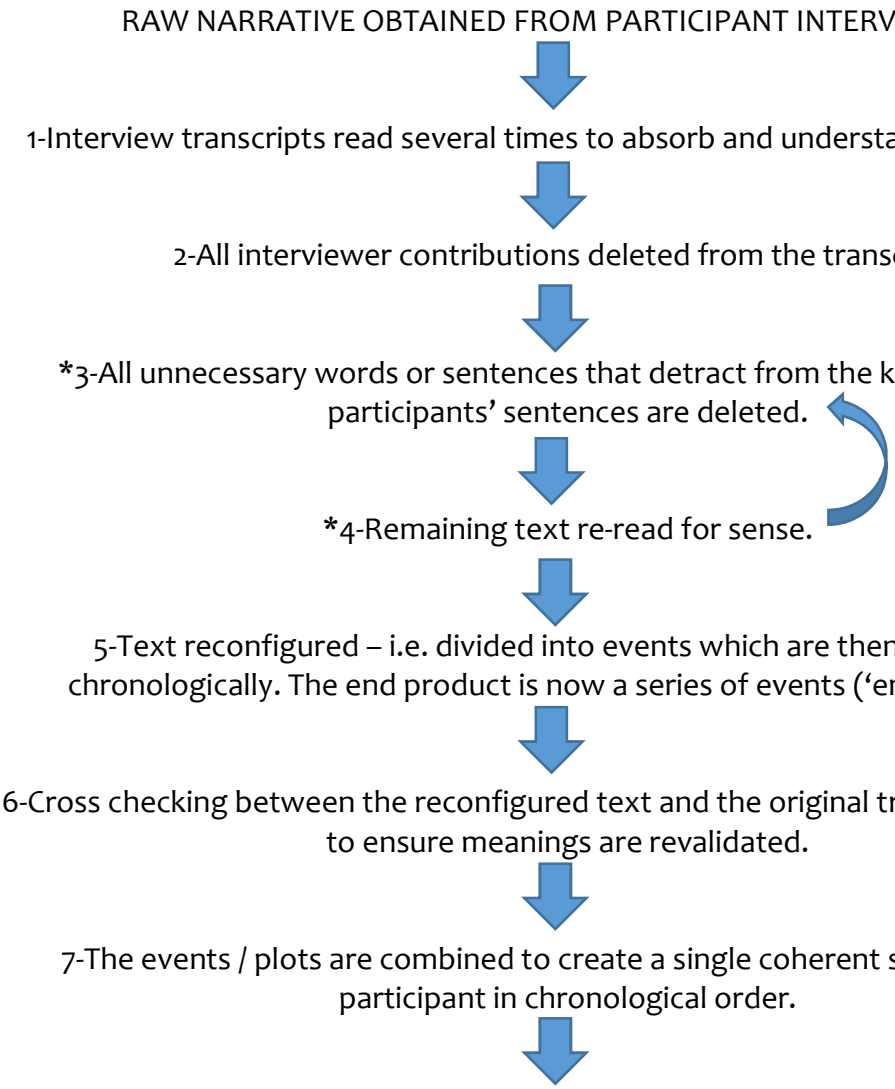
In this study, core story creation was used to create stories from the transcribed raw narratives within a constructivist approach. The process reconfigured and reordered the raw data into altered forms called 'storied constructs'. The process is outlined in Figure 4.1: Core Story Creation. This method of analysis was influenced by Bruner's (1991) narrative 'structuring' in which data collected consists of actions, events and happenings and the notion of emplotment therefore was akin to what Bruner (1991) termed 'story making' as referred to in an earlier section.

To illustrate this process, Appendix 2b and 1c contain examples from one participant, of a raw transcript and a story 'construct' following core story creation, respectively. Using this raw data, the process outlined in Figure 4.1 was applied (see pg. 93). Once the transcript was read and interviewer questions along with unnecessary text / words removed, the events spoken about (Appendix 2b) were sectioned, reordered and reorganised chronologically in the reconstructed story (Appendix 2c). For example, ''*When I first started my placem*ent'' formed the beginning of the story with ''*towards the*

end of the placement'' and ''I *saw this all at the end before I left''* with associated text, became the end of the story. The events that occurred in the middle made up the body of the story between start and finish, such as text starting with ''*As time went on''*, ''*there was one case in the second or third week''* and ''*by the first few weeks, I began to understand''*. These sections are shaded to illustrate them in both Appendix 2b and 1c.

The above account illustrates how a specific process can be used to construct stories from the reconfiguration of raw narratives of student nurses.

Figure 4.1: Core story creation
(Adapted from Emden, 1998; Kelly and Howie, 2007)



*Steps 3 and 4 repeated so only key ideas are retained.

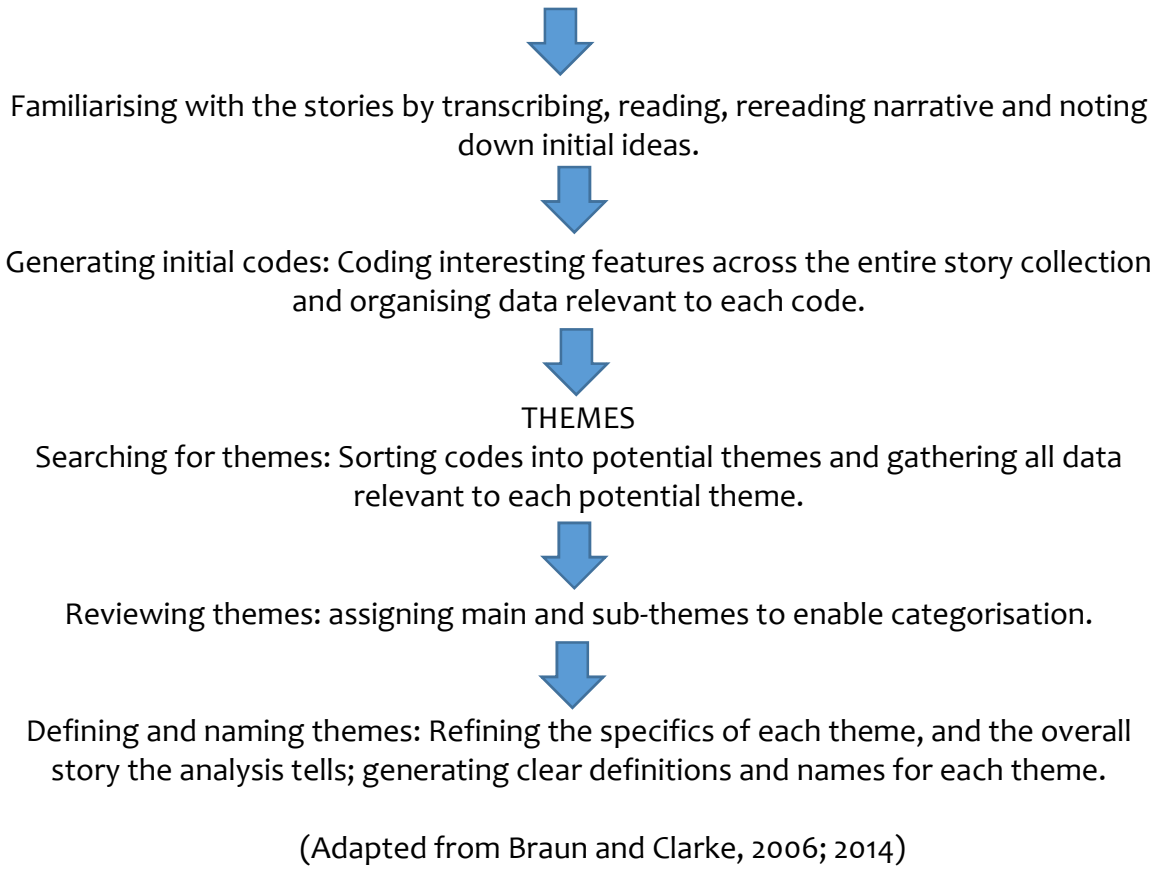
From this, final analysis of this narrative, already in 'storied' form, was then necessary to extract meanings and to generate themes from the data. This next stage was thematic analysis.

4.5.2 Thematic analysis

This was undertaken using Braun and Clarke's (2006, 2014) thematic analysis framework. Thematic analysis focuses on identifying and extracting common themes within raw data (Reissman, 2008). Themes are patterns across data sets that are used to identify important areas for further discussion and learning. Rationale for using the Braun and Clarke (2006; 2014) model for thematic analysis arose from its lucidity and clear, staged approach which also enabled main themes and sub-themes to emerge. While other frameworks do exist, this one served as a workable and feasible approach for the identification of a range of common themes.

The rationale for performing thematic analysis *after* the story creation stemmed from the fact that the created story became the unit of further analysis (Kim, 2016; Mishler, 1995). One may ask whether this process could have changed the meaning held and why was it necessary to change the raw data as that was what the participants said. However, rationale was proposed by Kim (2016) and Mishler (1995: 125) and their similar views of reconstructing the 'told from the telling' or, *reordering* a storyline to be chronologically organised. Participants may not tell their stories in an order that makes sense to the researcher and they may not be organised thematically or temporally. They may deviate or focus on a topic that is irrelevant or they may go backwards and forwards in time intermittently. Therefore, to reconstruct the order from the 'telling' makes the story more coherent, leading to the reconstructed storyline becoming the narrative for further analysis (Mishler, 1995). Hence, core story creation was followed by thematic analysis. Figure 4.2 outlines the thematic analysis process as it applied to the analysis of stories created from the preceding core story creation.

Figure 4.2: Thematic Analysis applied to Core Story Creation



(Adapted from Braun and Clarke, 2006; 2014)

After reading and familiarising with the stories, preliminary themes had emerged that were common across the six cases, in relation to what the participants spoke about, which then made it possible to categorise the data. This is often termed coding. This was done through an inductive process rather than being theory guided and deductive. With an inductive approach, the themes identified were linked to the data itself rather than to the specific questions that were asked. It is a process of coding the data without trying to fit it into a pre-existing coding frame or the researcher's analytic preconceptions (Nowell et al, 2017). Therefore, this form of thematic analysis was data-driven (Braun & Clarke, 2006).

Overall, a process of identifying common occurrences in the data to form initial codes (themes) and sub-codes (sub-themes) was undertaken. After initial codes had been identified in the data of two or three transcripts, codes were compared with each other to see any similarities and differences, and to determine which themes were consistently present throughout the whole dataset. For example, five main themes emerged in relation to what the participants spoke about: The nature of neonatal care, the neonate's experience, the parent's experience, the neonatal environment and the learning experience. These were colour coded within the text and each colour was linked to a number 1-5. Sub-codes a-g or as applicable depending on the quantity, were also given. For example, in Appendix 2d, the first theme: 'Nature of neonatal care' is theme 1, with the sub-themes a-d.; Appendix 2d also gives examples of quotes that illustrate all five main codes/ themes. The quotes were selected as they were deemed as representative of each theme and were commonly present within the whole interview dataset. For example, for theme 1: *''It's a completely different environment''*, *''The transition must be quite hard for some people''* and for theme 2, relating to the parent's experience; *''It must be so scary and stressful for them''*. It was also thought essential to ensure all participants had contributed to the data and that not all the quotes were drawn from only one or two (Anderson, 2010).

4.6 Trustworthiness and rigour

Verification of the narratives for credibility with the student nurses themselves was undertaken so that the genuine representations of what they had said could be validated against their own observations of that same episode. Participants were offered the opportunity to alter, add or remove anything from their stories. All participants verified both the transcripts and created stories and only minor changes were necessitated relating to inconsistencies from transcription. This process was based on principles outlined by Spalding and Phillips (2007) who sent selected vignettes from their participants raw data back to them so that they could see they were a genuine representation of their experience. This activity is synonymous with member checking, a process in which full transcripts and the final analysis are sent back to participants. In this case, both raw transcripts and the stories were sent so that the participants could verify that the narratives and the final, 'storied' product to be used for learning were true to their actual experience. This is said to authenticate credibility of data. This, as well as other strategies to address trustworthiness as applicable to this initial study are outlined in Appendix 1.

Relating to authenticity within this study, it was essential to address it in line with a reflexive approach. This, along with other reflective points, is discussed in Box 4.1 that follows.

Box 4.1- Reflection: Initial study

As I was a new researcher, reflective introspection was undertaken during my preparation for interviewing since I was inexperienced in this area. The initial study allowed me to reflect on the research process and imparted a degree of preparation for the main study. It also enabled me to 'try out' interviewing and test analysis strategies. The importance of piloting has been emphasised in the literature (Mitchell, 2015) in order to test and refine ideas and methods. As will be seen in Chapter 6, this was a useful process in so far as I was able to apply the same principles to story creation and narrative analysis in the main study.

Reflecting on the initial study also made me aware of my role and relationship with the students in line with an 'insider' relationship. Convenience sampling was appropriate to use in view of accessing the students as my participants. However, this meant that ensuring transparency regarding our relationship was vital; in other words, the fact that I was known to them as their lecturer but was now presenting as a researcher. It was important to be clear that taking part would in no way influence any future teaching interaction nor should the students feel that they were coerced into being involved. They needed to be reassured that they could opt out, decline to participate if they preferred. In phase 3 of my main study, my participants were also student nurses who were positioned 'internally'; i.e. within my own institution so considering the issue at this stage was useful preparation, returned to in Chapter 8.

Consideration of my relationship with my own students as participants was also warranted in relation to the notion of authenticity and truth. I needed to deliberate what was the potential influence of the questions asked on the rewriting of the student nurse narratives. It was possible that what was said, was done so in response to specific questions posed to the participants after the SQUIN. Therefore, this needed to be borne in mind in relation to these being 'true' accounts of experience given freely without some degree of direction. As above, reflecting on this issue was also useful in relation to preparing for the main study as interviews later became more unstructured and not as directed or guided by questions from the researcher. We shall return to the concept of authenticity later in Part 2 when we turn to parent narratives.

4.7 Findings

Thematic analysis of the created stories revealed key, common themes offering rich data that had the potential to be shared with peers as a way to learn about the neonatal specialty. Participants spoke at length about the nature of neonatal care and what it entailed and how it was different to other areas in children's nursing including the many transitions between dependency levels of care and the significant time period spent by families in neonatal care. Often the neonatal experience was described as a 'journey' and a process of 'transition' from birth of the baby until going home. For the neonate's experience, participants highlighted the importance of emotional and physical wellbeing of the baby recognising the emotional impact of separation from their parents along with the surrounding environment. There was an awareness of the parent experience in relation to the effect of neonatal admission on emotional wellbeing and the need to address this in vital ways through, for example, information-giving, ensuring empowerment and participation in care. The environment was seen to be a place with often intense noise and light that could disturb the babies, with barriers placed upon the family including, for example, incubator care. Important learning points were also articulated such as the value of developmental care and gentle handling of babies along with understanding the whole journey through neonatal care. A summary of the analysis outcomes with the key themes and sub-themes can be seen in Table 4.1.

Table 4.1: Results of thematic analysis (initial study)

Theme 1. The nature of neonatal care

Sub-themes

- Speciality different to other areas in children's nursing
- Structure of neonatal care: transitions between the dependency levels
- Neonates and families within neonatal care for a significant time period
- Neonatal experience as a 'journey' and a process of 'transition' between birth and home

Theme 2. The neonate's experience

Sub-themes

- The importance of emotional and physical wellbeing of the neonate
- The impact of separation from their parents
- The challenge of necessary life 'tasks'
- Awareness of their surroundings and the effects
-

Theme 3. The parent's experience

Sub-themes

- The effect of neonatal admission on emotional wellbeing
- The lack of, and need for parental control and empowerment
- The need for information and involvement in care
- Striving to get home
- Understanding and empathising with the parent's experience, needs and/or emotions
- The importance of developing relationships and communicating with parents

Theme 4. The neonatal environment

Sub-themes

- The effect of noise and light levels on the neonate and family
- Differences between the levels of dependency
- The experience of incubator care
- Environment as a barrier
- The importance of developmental care and gentle handling of neonates

Theme 5. The learning experience

Sub-themes

- The neonatal transition through the unit ('journey') akin to the 'learning journey'
- Support from mentors
- The need for consistency in communication and care
- Mentor willingness to teach students
- Emotions and needs of students
- The importance of teamwork
- Challenges to learning

4.8 Discussion

In relation to the findings, the discussion of this initial study addresses what can be learnt from the stories of student nurses in neonatal care for future practice in teaching and learning. This section also addresses what can be learnt about the process of core story creation for application to the main study.

4.8.1 Learning from student nurses' experiences

Concentrating on the neonatal care experience through the eyes of learners enables others to learn from those who had witnessed this specialised area for the first ever time in their training. Seeing and experiencing something new can reveal observances that may not be noticed by those experienced staff who can become over-familiar with the area. Certainly, studies that have focused on narratives and/or stories from student nurses have found there is much to be learnt from them, which in turn can inform future teaching and learning practice by educating others (Chesser-Smyth, 2005; DiVito-Thomas, 2005; Schwartz and Abbott; 2007; Bradbury-Jones et al, 2011; Melincavage, 2011; Edwards, 2013; Jonsen et al, 2013).

More recently, Edwards (2016) undertook a study that involved student nurses developing their own stories based on their clinical experiences. Following analysis of their interview data, the overall findings focused on: story content's revelatory role, which clarifies often hidden aspects of what is happening in the clinical setting; the exploratory role of stories, revealing what the priorities of nursing care are for this particular group and to identify what their main concerns might be; and story as a more

direct aid to learning. Edwards (2017) stated that stories can help develop understanding of nursing students' concerns, sensitivities and priorities, and can support mentors' important roles in students' learning. Another recent study by Urstad et al (2018) aimed to explore nursing students' experiences of creating digital stories as a tool for reflection for clinical placement experiences. The findings showed that the use of the student-created digital stories led to enhanced engagement and promoted feelings of ownership in their reflections resulting in deeper understanding of what they witnessed in practice.

Clearly, there is a role for the use of stories for learning about nursing practice. Urstad et al's work (2018) is particularly relevant to the current study as the stories were presented digitally. The current study used student nurse narratives to create a digital storytelling resource, which is outlined later in the chapter. The digital format was chosen for wider dissemination on the student's online learning platform and therefore, ease of accessibility.

So, what can be learnt from the student nurses in *this* study that focused on neonatal care? The reflections of the participant learners in this new and specialised field of care showed an unexpected high level of perceptiveness into the experiences of both neonates and parents as well as an ability to articulate their own development in a learning capacity. A strong onus was placed on emotional experience, particularly relating to parents. This should be acknowledged in relation to the researcher having a presumption that novice nurses, due to their level of training, would not perhaps be able to draw out such insightful observations and show such emotional awareness. Research has also suggested that novice nurses are not ready for complex critical thinking; for

example, OrlandBarak and Wilhelem (2005) analysed twenty-four stories of clinical practice written by student nurses about their perspectives towards learning to become a nurse. Findings suggested that student nurses focus on actions rather than on interactions; in other words, a focus on skill acquisition rather than a rich content of learning. This finding however was not upheld in the case of the current study, as the students clearly appeared to show a strong perception of emotion and empathic understanding along with an eagerness and commitment to support parents consistently throughout their stay.

The themes that emerged from the analysis of the stories really captured key elements of the neonatal speciality as a learning environment for students. What the students saw and how they verbalised parents' and neonates' experiences may serve to inform others who are learning about this field or those who may wish to prepare for a placement on the neonatal unit. The themes for learning that were consistently present in the narratives were indeed relevant and specific to this field bringing out the unique elements of what neonatal care involves. This was not however about skills learning specifically but more about the differences to expect between this field and other areas, the nature of the actual *baby*, the experiences of *parents* and the transitions through the many levels of care. This included both the physical and emotional journey of parents and learners and importantly, the humanistic side of neonatal care.

The aim for subsequent work was to use stories to inform others about the experience of neonatal care. Literature cited previously has shown the value of using personal narratives to teach health professionals about the more humanistic side of care

environments. In addition, stories illustrate the need to be critical in practice and it has been shown that students favour teaching using a more personal case study approach (DiVito-Thomas, 2005) as this encourages critical thinking and reflective practice. While the stories created in this study were not patient case studies, they were however personal learning encounters of *individual* students who had been involved in neonatal care. These illustrated the neonatal experience through a 'storied' approach rather than in the traditional, more fragmented way of teaching this speciality, for example, focusing on conditions, physiological systems or equipment used in this area.

These views concurred with the work of Edwards (2013) who analysed students nurses' written stories and illustrated the different ways in which stories could aid learning from practice, particularly by encouraging students to differentiate and structure clinical experiences that might otherwise remain untouched and not explicit for open discussion. She supported the notion of including student stories in the curriculum in relation to education around clinical practice contributing towards the transformation of nurse education.

4.8.2 Learning from the process of core story creation

The findings of the initial study along with the literature reviewed gave rationale to the value of creating stories. In view of the feasibility for continuing work at this point, what certainly worked well was the willingness of the student nurses to talk about their placement experiences and how they were able to capture not only the neonatal specific aspects of care but those relating to parents. In addition, the process of emplotment and

story creation described enabled the raw narratives collected from interviews to be managed effectively in that the finished, 'storied' product was clearer, shorter and more logical in how it read and flowed.

To develop a resource to use by others and one that made coherent sense, it was necessary to reconstruct the raw spoken narrative into a manageable form, as was done in this study using core story creation and subsequent thematic analysis. Reissman (2008: 61) in her book on narrative analysis supported the need to ''clean up spoken language to construct an unambiguous plot line", to make the textual stories shorter with clear beginnings, middle and ends. This was also necessary when transferring stories to a digital platform as long, unwieldy lengths of text do not suit such platforms or methods of teaching. Instead, key points through the experience of neonatal care needed to be extracted and presented, hence the importance of thematic analysis which identified key concepts for learning. The challenge was to achieve this without losing the significant notion of 'journey'. The parallel between telling a story and the student's, neonate's and / or family's journey through the neonatal care experience was an element to capture and needed to be preserved in any future resource development to avoid losing this unique concept. This is described after a consideration of the study limitations.

4.8.3 Limitations

Some limitations of this study were identified which were important to consider in relation to how this would inform the main study. Firstly, data generated in interpretivist studies cannot be generalised to the population, since it can be significantly influenced

by personal viewpoints, perceptions and values. Some may question if there is bias on the part of the researcher. Critics suggest that reliability and representativeness of data is undermined to a certain extent. However, data from qualitative work of this nature does not set out to generalise as it does for quantitative research. Instead, it is concerned with transferability. In other words, it is concerned with personal experience and understanding individual reality which may be transferable to other similar individuals and situations.

Further critique applies to the interview process. The SQUIN did not appear to elicit sufficient information in the first instance to achieve a full 'whole' account story. According to Wengraf (2009), a SQUIN used in the first part of an interview should be able to elicit a full 'history' and the interviewer should just support the informant as they attempt to answer it without any further questions, at least initially. However, more questioning was undertaken to really elicit desired information around appreciation of the neonatal experience as there was a concern that information obtained from the SQUIN would not yield sufficient data. However, Wengraf recommended following up after a certain point with questions about some of the topics raised by the actual interviewees. However, in this case questions were asked that had been prepared prior to interview. It may therefore have been preferable to be more fluid in questioning and, rather than prepare the subsequent questions, to ask the questions according to what the interviewees said. This would have allowed the narrative to be guided by them, rather than by predetermined themes.

Secondly, it was found that at times, students would stray from the focus on their experience of neonatal care as a student to raising negative comments about perceived poor support from their mentors or grievances about off-duty issues. Although these occurrences were not significant, it posed an unexpected issue and it was necessary to then encourage the student to get back to the story of experience rather than the interview being an opportunity to air negative issues. This may have been due to lack of clarity around the aim of the study. Even though a participant information sheet was given, and the aim of the interview was explained, students may have had their own preconceived idea of what the study's purpose was. Such an issue is important to be aware of, in line with interviewees going 'off-track' and planning for this prior to interviewing.

The third limitation was the small sample size on which to draw conclusions. However, the aim of the study was to collect individual stories as well as to explore methods to use in the subsequent inquiry; this was indeed achieved and so six participants sufficed. In addition, six stories were also adequate in view of the subsequent resource development which leads onto the implications for practice from these findings.

4.8.4 Implications for practice

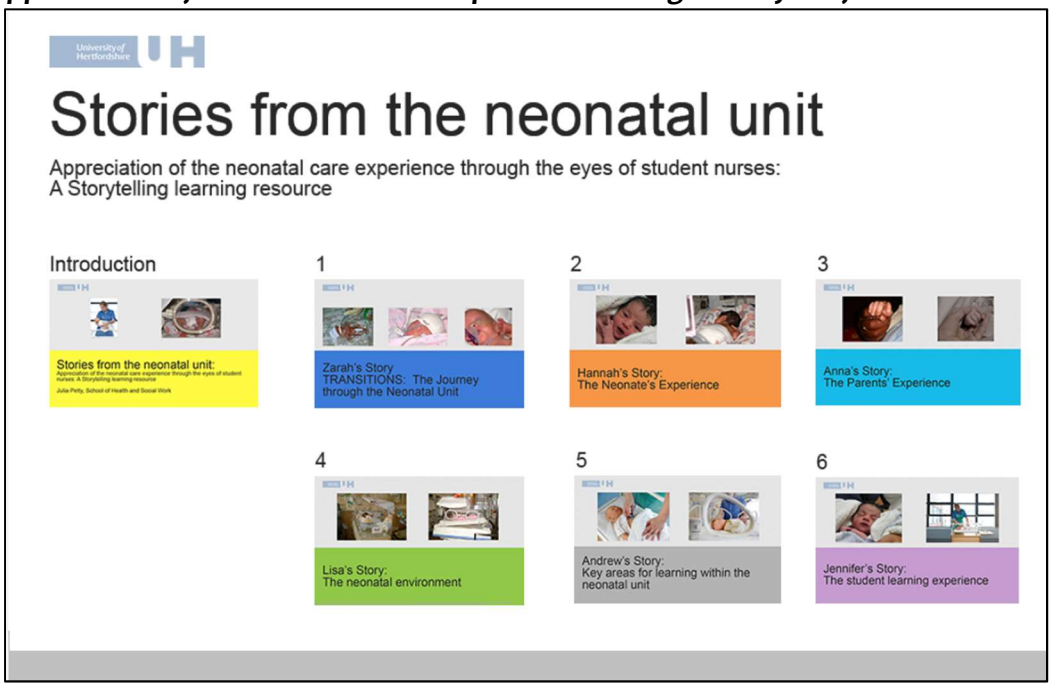
This study led to the production of a collection of stories from student nurses which conveyed key learning messages about the experience of neonatal care. For them to be of future value to other learners, they were developed into a digital storytelling resource using the six stories, each one highlighting a key learning theme revealed from the

analysis, tailored to neonatal care. The digital platform was chosen to represent the student stories. As stated earlier, this was deemed appropriate to ensure accessibility and ease of dissemination. Moreover, the use of online, multi-media resources is reported as having key benefits to both student engagement and interaction in relation to teaching key nursing subjects as illustrated in previous work by the author (Petty, 2013, 2014). The chapter now turns to how this resource was developed.

The previous analysis described how core story creation was undertaken using raw narratives referring to Appendix 2b and 1c respectively. Thematic analysis from coding the stories has also been described with an example seen in Appendix 2d. After the core stories were verified and agreed with the participants and any changes made from the feedback, the next stage involved condensing and transferring them to a digital platform. The six stories firstly needed to be condensed to enable them to be presented digitally. Appendix 2e shows the condensed version of the full story from Appendix 2c. It can be seen that the chronological order and key points remained but the length of each section was made much shorter. Next, six storyboards (sketch plans of what was to be included in the stories) were prepared using a template. These included extracts of 1st person text quotations from the participants' narratives, illustrative images and a 3rd person audio narrative of the participants stories in the author's voice. Appendix 2f gives an example of the storyboard for the first story developed, outlining the timing, placement of the chosen images and text quotes at stages throughout the voice narration. Reflective points were also included at intervals for the user to consider the learning from the stories. The resource was created using *Captivate* software that allowed the blending of the various multi-media elements.

The final resource comprising all six student stories is shown in Figure 4.3 [To access the resource, hold 'control' and click on the image]. This resource shows how student narratives have been used to create stories which have been condensed and represented digitally using multi-media combined with reflective learning points. The resource was then show-cased and evaluated.

Figure 4.3: Storytelling resource:
Appreciation of the neonatal care experience through the eyes of student nurses.



http://www.health.herts.ac.uk/elearning/petty/neonate/nav/
[Press control and click on the image or URL above to access the resource]

A group of thirty-two children's nursing students underwent an evaluation of the resource to appraise the perceived effectiveness and value of digital storytelling for learning. The evaluation was undertaken as a class group session using a brief questionnaire of three Likert-scale questions, delivered through an electronic voting system (EVS), as follows:

- Q1-To what extent do you think listening to these stories may be useful for learning?
- Q2-To what extent do you think listening to these stories may be useful in preparing you for a practice placement in the area?
- Q3-To what extent do you think this digital storytelling resource could enhance or support other learning (e.g. from practice or in the classroom)?

The Likert responses ranged from 1-5, representing 'no use at all', 'limited use', 'do not know', 'of some use' to 'very useful'. The students were also asked to write additional open answer comments in text form to qualify their responses. Two other open questions asked them about their opinions in relation to the field of children's nursing and the value of the storytelling resource from one's own peers.

- Q4-What aspects of caring for children do you think you may learn from this storytelling approach?
- Q5-What can you learn from your own peers' stories?

Questions 1-3 Likert scale responses are depicted graphically with a selection of open responses for questions 1-5 in Appendix 2g. Example quotes of student feedback that emerged from this evaluation are outlined in Appendix 2g. Quotes were selected based on how they captured the key, common elements from the student group as a whole.

Overall, it can be seen from this data that the evaluation results showed positive responses to the resource overall. Students expressed many benefits along with some constructive points for development. Positive feedback illustrated the potential benefits

of storytelling as a novel approach to learning for trainee nurses in this speciality, particularly helping them learn about the emotions involved. An example of feedback was: *''It gives you an insight into what to expect from practice and the different experiences you may encounter, some of which can be quite challenging emotionally''.* In addition, the resource appeared to give some of the benefits of peer-based learning (Boud et al, 2014; Ramm et al, 2015). Most students voiced that learning from one's own peers in this context was useful with an example here: *''It is helpful to listen to the views of other student nurse peers as we can relate to their experiences and listen to their reflections on practice''.*

Students also voiced the importance of preparation for practice in a new and specialised area of nursing and the role that such a resource could play in this. One respondent stated: *''It is very useful especially for those students who have not worked with neonates before and it is valuable to learn from other's experience''.* Being prepared for practice is an issue that commonly arises in the author's own place of work with many students raising the need to be adequately primed for different, unfamiliar clinical areas. Having a resource that can be viewed prior to a placement speciality could be used to raise familiarity and dispel some of the anxiety associated with going to a new and unknown area of practice.

Turning to consider the more negative feedback, while the technical platform was said to be user-friendly, some students stated that the stories were too long particularly as they were broken up into sections with reflective points to consider. One respondent felt that they wanted to listen to the story in it's entirely rather than it being interrupted

throughout with reflection points. In addition, three respondents felt that would prefer the actual voice of the student to tell the story in the 1st person rather than the 3rd person narration to enhance authenticity, questioning whether the digital outputs were stories in the true sense of the word. A few participants did not favour digital learning, and these may have been individuals who are more comfortable and familiar with traditional, text-based formats or do not have a learning style suited to digital learning. Student responses suggested that the resource needed to be integrated with other teaching techniques; both digital and text in combination. Other work has acknowledged that digital tools should not replace traditional methods but used alongside each other to enrich and optimise learning (Ileya et al, 2011). A flipped learning approach was suggested to support the literature (McDonald and Smith, 2013; Bergmann and Sams, 2014) that would see students using the resource as self-study prior to coming to class to discuss issues, with an emphasis on considering the emotions involved in neonatal practice.

Regarding the content development perspective, *Captivate* software was not accessible to the author and therefore a learning technologist assembled the actual resource. Such an approach could be improved in terms of ease of use and sustainability since *Captivate* was considered unsuitable for non-technical staff to use. This creates an issue should the learning technologist be unavailable in relation to the maintenance of the materials and the resource may become difficult to edit. Alternative software was considered that offered a more usable approach and therefore appropriate for academic staff to use.

Ongoing and future dissemination of the above digital resource is being undertaken with other student cohorts as part of the pre-registration curriculum in relation to the contribution of storytelling to enhancing teaching and learning in the challenging and specialist area of neonatal care. In addition, in clinical practice the resource is being used with new staff as preparation for working in the neonatal unit. Finally, the use of digital storytelling in this area of practice could also be applied to other specialisms of children's nursing opening discussions around further work in development of similar resources. Continued evaluation following dissemination to more student groups will be vital to gain wider opinion and gauge the need to make any adaptations to the resource, if applicable.

The findings of this preliminary study and evaluation paved the way for the main study. The pros and cons of the student resource revealed from the evaluation were factored into the development of the digital storytelling resource based on parent narratives (See Part 2, Chapter 7 – see Table 7.1, pg.215). Methodological principles of core story creation and emplotment as a means of narrative analysis was taken forward for the creation of stories informed by parents who also had the lived experience of being in a neonatal unit for a significant time period with their premature, sick and vulnerable baby at the start of life.

4.9 Summary

To summarise, a study and a teaching intervention has been described in which children's nurse students' stories about their experiences were converted into an electronic

resource. Important messages from the evaluation feedback included that the resource was especially successful at helping students prepare for the emotions involved in completing a placement in a neonatal unit and the stories appeared to enable students to relate to their peers and learn through them and their experiences.

Finally, following on from this initial study, three publications presented the work and findings (Petty, 2016b; 2017a; Petty and Treves, 2017) in various peer-reviewed journals. Firstly, the paper 'Creating stories for learning about the neonatal care experience through the eyes of student nurses: An interpretive, narrative study' (Petty, 2017a) provided an overview of the initial study concluding that the findings imparted real value to teaching and learning by enabling an appreciation of how narrative can be used to portray the experiences of learners. The paper also reported on how the findings supported an approach to analysing narrative to create stories for learning and inform subsequent digital resource development. A 'Thought-piece' in LINK journal (Petty, 2016b) outlined the background and development of the storytelling resource and reported on the evaluation of the resource in relation to the learning contribution for children's nursing students. Again, as with the previous paper, it highlighted how storytelling based on peer experiences was a useful and insightful approach to learning about a different speciality and preparing for practice in a new area. Finally, a paper 'Development of a digital storytelling resource to support children's nursing students in neonatal care' also provided an overview of the digital storytelling resource development and discussed the results of the evaluation in relation to its contribution to learning for students in a specialised area of practice. It revealed that storytelling based on peers' experiences is a valuable approach to learning and highlighted how important this is in a

specialty such as neonatal care where the unfamiliarity of the environment and patient group can cause anxiety and uncertainty among students. Overall, the resource was reported to be useful to children's nursing students who are preparing for a practice placement in an unfamiliar clinical area (Petty and Treves, 2017).

In summary, much has been revealed about the insight and observances of student nurses by listening to stories created from their narratives. These students entered a new field that offered different and specialised opportunities for learning. Others can learn from the journey that they have taken through this new learning experience. The anticipated contribution of this study to learning and teaching practice relates to how storytelling could be an alternative and innovative approach for understanding the neonatal care experience through the eyes of learners. This can now be applied to parents, the core focus of the main study. In addition, the process of 'core story creation' and thematic analysis to guide subsequent development of digital stories as applied to parents' narratives was found to be a feasible approach, supported both by other previous research as well as the outputs and evaluation from this initial study. Part 2 that now follows, moves to a focus on the main study turning firstly, to the experience of parents in neonatal care.

PART 2:

The main study: Creating stories from parents' premature birth experiences to engender empathy in nursing students

PART 2: The main study: Creating stories from parents' premature birth experiences to engender empathy in nursing students

Study timeline	Digital outputs and Publications
PART 1: Exploring narrative approaches and concepts (Chapters 1-4)	
• Chapter 1: Introduction • Chapter 2: Underpinning theory and concepts • Chapter 3: Design and methodology • Chapter 4: Working with Narrative: An Initial study	My Digital Story: Into the Light Petty (2016a) Publication Appreciation of the neonatal care experience through the eyes of student nurses. Storytelling resource Petty (2016b) Publication Petty (2017a) Publication Petty and Treves (2017) Publication
PART 2: The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students (Chapters 5-10)	
PHASE 1- 'Attention to narrative' – Exploring the parent's experience (Chapter 6)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	Petty (2017b) Publication Petty et al (2018a) Publication Petty et al (2019a) Publication Petty et al (2019b) Publication Petty et al (2019c) Publication
PHASE 2- 'Representation of narrative' – Creating the parent stories (Chapter 7)	
• Introduction • Aims and research question • Background • Methods • Analysis • Outputs • Discussion	Digital Stories Creating and telling Stories in Neonatal Care Another World On the Edge Connections Fighter Our Salvation The Long Haul Ahead Out of the Darkness Bittersweet
PHASE 3- 'Affiliation to narrative' – The impact of stories on empathic learning (Chapter 8)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	The Value of digital stories in neonatal care- Your views. – Evaluation Survey Neonatal Stories Website

Chapter 5: Introducing the main study

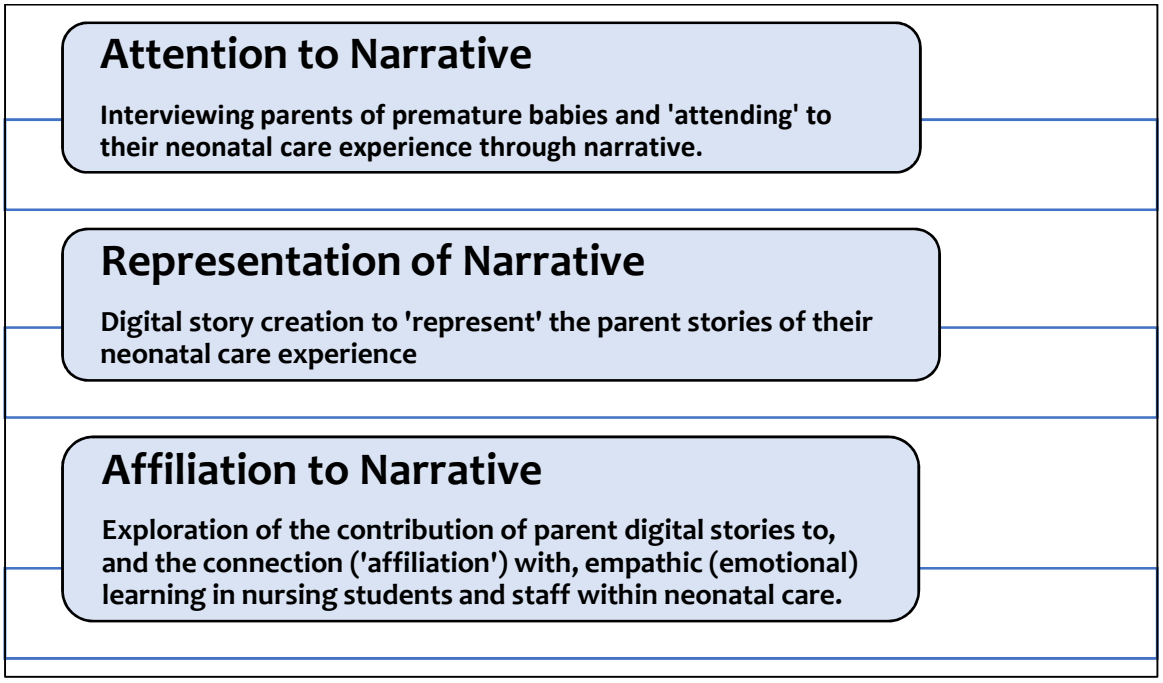
This chapter focuses on the main study starting with an overview of the conceptual framework upon which the study design was based. This then structures Part 2 of the dissertation. The main study is comprised of three main phases; all distinct but intricately linked, each phase with its own research question, methodology and findings.

5.1 Conceptual Framework

A conceptual framework was essential in the first instance to form an overall structure for the design of the study. Therefore, the three phases of the main study were organised within a conceptual framework derived and adapted from Charon's (2006; 2007) 'Narrative medicine' work that views narrative in terms of 'attention', 'representation' and 'affiliation'. Phase 1 was 'Attention' to narrative where parent stories were obtained and constructed from narrative interviews. Phase 2 was 'Representation' of narrative where said stories were developed into a digital platform to represent the created stories. Finally, phase 3 was 'Affiliation' to narrative where the 'connectedness' of narrative to person-centred, empathic understanding and learning was explored. Phases 2 and 3 were reliant on the initial phase 1, emphasising the importance of the raw experiences of parents and the story creation stage in order to produce a narrative 'product' to work with for the remainder of the study. The conceptual framework can be seen in Figure 5.1. This was adapted from Charon's three core terms described above using the author's own interpretation of each phase as relevant to this study.

Figure 5.1: Conceptual Framework

(Adapted by the author from Charon's (2006) 'Narrative Medicine' model)



5.2 Research questions

The overarching question for the main study was: *How do parent stories influence person-centred, empathic learning in neonatal nurse education?*

This first phase of the main study (*Attention to narrative*) addressed how parents in neonatal care described their care trajectory following premature birth and what can be learnt from their narratives about emotional experience. The question asked was: *How do parents describe their experience of neonatal care and what can be learnt by students and health professionals in this field?*

The second phase (*Representation of narrative*) referred to how can parents' emotional narratives could be used to create digital stories, to be presented and shared on an

online platform. The question asked was: *How can parents' experiences be represented as stories?*

Finally, the third phase (*Affiliation to narrative*) addressed the extent to which educational interventions in the form of digital stories could effectively foster empathic learning in students and health professionals in neonatal care, given the importance of recognising and learning about the emotional experience of others. The question asked was: *What is the contribution and value of parent stories to the empathic learning of nursing students and staff in the neonatal field*?

Each phase is now discussed in turn including aims and research question, background literature, methodology, analysis, findings and discussion.

Chapter 6: Phase 1: 'Attention' to narrative (exploring the parent's experience)

Study timeline	Digital outputs and Publications
PART 1: Exploring narrative approaches and concepts (Chapters 1-4)	
• Chapter 1: Introduction • Chapter 2: Underpinning theory and concepts • Chapter 3: Design and methodology • Chapter 4: Working with Narrative: An Initial study	My Digital Story: Into the Light Petty (2016a) Publication Appreciation of the neonatal care experience through the eyes of student nurses. Storytelling resource Petty (2016b) Publication Petty (2017a) Publication Petty and Treves (2017) Publication
PART 2: The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students (Chapters 5-10)	
PHASE 1- 'Attention to narrative' – Exploring the parent's experience (Chapter 6)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	Petty (2017b) Publication Petty et al (2018a) Publication Petty et al (2019a) Publication Petty et al (2019b) Publication Petty et al (2019c) Publication
PHASE 2- 'Representation of narrative' – Creating the parent stories (Chapter 7)	
• Introduction • Aims and research question • Background • Methods • Analysis • Outputs • Discussion	Digital Stories Creating and telling Stories in Neonatal Care Another World On the Edge Connections Fighter Our Salvation The Long Haul Ahead Out of the Darkness Bittersweet
PHASE 3- 'Affiliation to narrative' – The impact of stories on empathic learning (Chapter 8)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	The Value of digital stories in neonatal care- Your views. – Evaluation Survey Neonatal Stories Website

6.1 Introduction

This chapter reports on the first phase of the study that, in line with the conceptual framework, focuses on the '*attention*' to parent narratives in order to develop stories for learning. Set within a narrative, interpretivist theoretical approach, the background literature, methods and analysis within this first phase have three areas of focus. These are; firstly, how parents described their neonatal care experience, secondly the metaphors used in their accounts of experience and thirdly, the central role of parents in informing the learning of others. The chapter reports on the findings within each of the three areas of interest. It then discusses the application and relevance to practice as well as to the subsequent phase of the study that uses the parent stories to develop digital stories for learning.

6.2 Aims and research question

The research question for phase 1 was: 'How do parents describe their experience of neonatal care and what can be learnt by students and health professionals in this field?'

The aim of this phase of the study was to 'attend' to and explore how parents in neonatal care describe their care trajectory following premature birth and what can be learnt from their narratives about emotional experience. The aim was also, by the end of this phase, to have a set of key themes that would be used in the development of storytelling learning resources for phase 2.

6.3 Background

The literature on understanding and exploring parents' experiences in neonatal care is now discussed, in other words, studies that have 'attended' to narratives to explore experience.

6.3.1 How parents describe their experience of neonatal care

Experiencing the birth of a premature neonate and the subsequent admission to the neonatal unit presents parents with significant emotional challenges which are widely documented (Aagaard and Hall, 2008; Turner et al, 2014; Spinelli et al, 2016). Evidence highlights that parents find the neonatal unit a daunting and unfamiliar place (Gavey, 2007; Russell et al, 2014) full of anxiety provoking events, uncertainty and fear about the future of their baby (Al Maghaireh et al, 2016). In chapter 2, a selection of research studies highlighted the potential impact of having a premature baby and the subsequent care experience on various psychoemotional outcomes (Wigert et al, 2006; Fegran and Helseth, 2009; Uhl et al, 2013; Dellenmark-Blom and Wigert, 2014; Russell et al, 2014; Wigert et al, 2014; Blackburn and Harvey, 2018; 2019). Without doubt, the need for intensive care in the early days of life is not only arduous for the baby themselves but also, for the family. The behaviour and appearance of the baby, limited opportunities to accomplish parenting roles and the nature of the neonatal environment are significant stressors related to being a parent in a neonatal unit (Wigert et al, 2014; Aftyka et al, 2017; Williams et al, 2018) and lack of effective communication from health professionals is seen as a major cause of anxiety (Biasini et al, 2012).

Moreover, the importance of analysing the *emotional* experiences of parents in line with a family-centred approach needs emphasising. Further research has highlighted the intense emotions that parents encounter during their time in neonatal care. Dellenmark-Blom and Wigert (2014) termed this experience as an inner emotional journey in a descriptive study that explored parent experiences within one year of going home from the neonatal unit. In addition, literature strongly acknowledges a parental need to seek connections with others (Fenwick et al, 2008) with an importance placed on emotional closeness. This latter point was also illuminated by Flacking et al (2012) who recognised how giving birth prematurely is an abrupt barrier to the transition towards becoming a mother, with feelings of disconnection, inadequacy, inability to fulfil a parental role and, what has been described as 'temporal suspension' (Spinelli et al, 2016). To concur, Taylor (2016) highlighted how the words isolation, helplessness and powerlessness are often expressed by parents in the neonatal unit.

Certainly, mothers of premature neonates have been found to go through significant uncertainty in attempting to feel like a proper mother (Aagaard and Hall, 2008; Adama et al, 2016) and it is acknowledged that care given to them should be emotionally sensitive. In addition, more recent literature considers fathers' needs and how they should receive personalised support as they can be often missed or side-lined leading to high stress levels (Fisher et al, 2018; Noergaard et al, 2018). A qualitative researcher, Crathern (2011) explored the lived experience of first-time fathers and established that emotional challenges on the neonatal unit was a main finding within key themes of anticipatory fatherhood, evolving identity and the difficulties of juggling paid work with visiting the neonatal unit. In addition, Harvey and Pattison (2013), focused on care of fathers during

resuscitation, suggesting a requirement for more specific education in how to support their needs. One more recent study by Stefana et al (2018), found that fathers of premature neonates preferred not to touch their baby for fear of damaging them, compared to fathers of healthy newborns. They also identified that their baby's appearance and the technological nature of the environment including equipment were significant causes of stress as well as reporting significant fear about their baby dying.

These studies highlighted important issues relating to the emotional impact on admission to the neonatal unit and associated care, at key points of the neonatal journey. Less work however, has focused on the *whole* trajectory of the neonatal care experience from pregnancy through the neonatal unit and beyond into the community, from an emotional perspective. One study did explore experiences over this time span (Franck et al, 2017) using interview data from parents in neonatal care who described a variation in the quality of true family-centred experiences from pregnancy through to being at home. The parents also highlighted inconsistencies in how the staff team communicated with them and reported limited practical and emotional support. In another retrospective cohort study on health outcomes and cost of breast milk feeds, secondary analysis of interview data was carried out to explore the experiences of first-time mothers in neonatal care. Mothers were requested to tell their birth stories and how these had impacted on their lives since (Rossman et al, 2017). Recognising what the authors called 'emotional vulnerability', the mothers were found to develop emotional resilience by accessing sources of support that actively promoted their mental health. This included key individuals such as peer feeding counsellors or advisors and nurses working at the bedside who were found to positively support them through the neonatal care

experience and help them cope with their psychological distress. This study reinforced the need for emotional support based on an understanding of parents' experience.

Most recently, other research has explored parents' experiences of early care in relation to the impact on later psychoemotional outcomes following discharge (Petty et al, 2018b; Blackburn and Harvey, 2018; 2019; Fowler et al, 2019). Overall, parents described strong emotional narratives lucidly, highlighting the effect of having a premature baby and the subsequent neonatal care experience on their psychological well-being and coping mechanisms. This increases the need for tailored support in the neonatal unit and beyond, often for a significant period of time thereafter.

6.3.2 How parents use metaphor to describe their experience

Studies that have explored emotional experiences of patients have highlighted that one way to describe such experience is through the use of metaphor (Lananjeira, 2013; Kantrowitz-Gordon and Vandermause, 2016; Bleakley, 2017), particularly commonplace when articulating and recalling challenging events that are difficult to convey to others. Theorists have had differing views of metaphor and their value since the days of Aristotle who referred to them being alien names with 'transference' (cited in Southall, 2013). The central argument concerned whether metaphors were just an addition to existing thoughts or words, or whether they really had a deeper meaning. The former was proposed by philosopher Locke (1894), who saw metaphors as misuse of language and that this can portray inaccurate ideas. However, more recently Ricoeur regarded metaphor as fundamental to human expression (Ricoeur, 2003; 2013) allowing the

creation of meaning in language and recognising the power of this in constructing the world we perceive. Language, including metaphors, can represent how people understand the world and this has value in retrieving meaning in uncertain times, such as for parents in the neonatal unit who are faced with this uncertainty on an often-protracted basis. Lakoff and Johnson (2003) saw metaphors as being pervasive in peoples' lives, actions, thoughts and language, providing information about how they perceive and experience the world. Bruner agreed that metaphor is part of narrative (Bruner, 1992) allowing the creation of meaning and accepted the power of such language in constructing one's reality. In the context of the current study, this refers to the experience and reality of parents in neonatal care.

Metaphor is a common feature of stories (Llewellyn, 2017) often used to enrich language, express meaning and illustrate concepts in more compelling ways. Its use may enhance the ability to communicate particularly valuable in healthcare, even more so within *narrative* healthcare, which is based centrally on what people say to, and how they understand, each other. Arroligia et al (2002) said this is due to how metaphor can facilitate communication by rendering new concepts in familiar terms so that the patient can more easily explain and comprehend difficult concepts. Metaphor may have an ability to foster clarity regarding complex or elusive topics such as death (Periyakoil, 2008; Casarett et al, 2010), mental health issues and addiction (Shinebourne & Smith, 2010) and what it is like for patients who are sick during a prolonged stay in hospital (Beck, 2017), a situation many parents in neonatal care can resonate with.

Examples of common metaphor used in relation to healthcare relate to war (fighting a battle), sports (winning or losing) and machines (referring to the body) (Periyakoil, 2008). Metaphors can help people make sense of both their own and others' emotional experience particularly as language can be an important mechanism for representing and/or explaining uncertainty (Appleton and Flynn, 2014). Other examples of metaphor in relation to uncertainly and fear are living on a knife-edge or life being like a ticking time-bomb or a 'simmering pot' (Beck, 2017: 60) ready to 'boil over' anytime. Beck also talked about a 'dagger to the heart' in relation to the sheer depth of emotion felt by parents. Nelson et al (2017) referred to families of patients with cancer experiencing a 'gripping at the heart'. Making sense of such metaphors in relation to how parents feel is key to the area of neonatal care where understanding parents' emotional experience during difficult and challenging times is important, to give sensitive care tailored to their needs (Obeidat et al, 2009; Fleck, 2016).

Metaphor as a powerful means of relaying emotional experience is linked to the concept of emotion within story. Since they are powerful way of making abstract concepts explicit, metaphors are frequently used to describe emotional states. The examples given above are potent metaphors which have the potential to move the listener. This in turn, resonates with them which may elicit affective empathy; that is an emotional response that connects them with the storyteller. The relationship between these concepts in how metaphor is linked to facilitating empathy in others has been documented in relation to the enhancement of emotional connections (Southall, 2013) and raised emotional awareness (Beck, 2016; 2017; Hardy and Sumner, 2018) between patients and health professionals. Many conditions are associated with strong emotional

connotations such as cancer, end-of-life and the uncertainty of life or death and so metaphor can be especially useful as a way of describing and explaining these areas (Woodgate and Busolo, 2017).

Within the neonatal field, a significant amount of research has explored parent perspectives in relation to experience. As discussed previously. emotional stress, anxiety and challenges such as uncertainty and fear of future outcomes are common themes that are well documented (Turner et al, 2014; Weis et al, 2015; Flacking et al, 2016; Banerjee et al, 2018a). However, in the neonatal field, metaphor specifically has been explored to a lesser degree compared to other fields of nursing and healthcare. A limited number of qualitative studies have provided commentary on how parents describe their experience in terms of the language used to relay what it was like for them emotionally. An early paper written by a parent of a premature baby described her experience using metaphors, such as ' roller-coaster' when referring to the difficulties of navigating through the neonatal trajectory (Layne, 1996). Similarly, in a study of factors affecting coping ability in the neonatal unit, parents referred to this 'roller coaster' in relation to their emotions (Stacey et al, 2015), highlighting the highs and lows of their experience; periods of hope followed by uncertainty and fear. Parents in Kantrowitz-Gordon and Vandermause's (2016) study used photographs from their children's photo history in a six month period since their premature birth to produce rich metaphors representing their distress as parents. The study concluded that metaphors can explain the gravity of distress in a way that is accessible to those who have never experienced premature birth. Examples of metaphors used to describe the emotional distress they experienced were, continually 'going through a tunnel' to depict the darkness they felt and 'feeling like

robot' to describe how they felt numb and lacking in emotion. Separation from their baby at birth for admission to the neonatal unit felt like being, 'cut from balloon strings' with a subsequent sense of having no grounding or certainty. This separation was also expressed metaphorically by Aagaard and Hall (2008). In their study exploring mothers' experiences of premature birth, metaphors were used to describe developing reciprocal relationships between themselves and their babies. This was seen as a 'journey' from 'their baby to my baby'. The maternal caregiving role was described as a moving process from silent vigilance to advocacy. Fenwick et al (2008) concluded that 'becoming connected' was a significant finding when mothers spoke about their ability to parent their baby in neonatal care. This was later supported by the writings of Fleck (2016) and Flacking et al (2016) regarding the parental distress exhibited when such connections and emotional closeness were not possible.

Such depth of emotion was also seen in the narratives of the parents in a study of post-traumatic stress disorder (PTSD) following traumatic birth. This study did not focus on premature birth per se, as did the others above. However, it revealed nine common metaphors that provided rich insights into the experience of PTSD due to childbirth; namely, feeling like a mechanical robot with the experience being like a ticking time bomb, an invisible wall, a video on constant replay, enveloping darkness, a dangerous ocean, a thief in the night, a bottomless abyss, and as suffocating layers of trauma. More recently, Beck (2017) explored the metaphors used by parents of babies born with obstetric brachial plexus injury. It was found that metaphors assisted mothers to express what they could not verbalise using medical terminology, providing useful insight for staff in understanding their perspectives. Again, while this study did not focus

on prematurity, the powerful 'dagger in the heart' metaphor summarised the depth and intensity of emotion expressed by these mothers caring for a baby with a specific physical condition. These studies revealed potent metaphors which impart insight into the emotions and experiences of parents for nurses and health professionals to learn from.

The impact on learning is important in the context of this study and there is a place for metaphor within education. Its use can be a valuable way to learn by explaining complex concepts (Kantrowitz-Gordon and Vandermause, 2016) and in the case of stories, they can make unfamiliar experiences more reachable for the learner. Sfard (2014) believed that metaphors enable learners to explore new topics and construct knowledge. Kittay also suggested that metaphor provides a means of learning something novel about the world and it is a tool for 'rearranging the furniture of the mind' (Kittay, 1990: 73). Relating to learning within healthcare, Ginn (2011) stated that metaphors have a hidden power that should be understood, being integral to how we understand things and that it is not possible to talk about disease without them. Masukume & Zumla (2012) discussed how medical signs and pathology have been communicated through metaphors historically, serving as teaching aids and enhancing memory retention for students.

As Jarvis (2005) proposed, telling stories can enable teachers to get closer to their students metaphorically, in that they may allow them to reveal parts of themselves on a personal level, again highlighting the connections that can be formed. Within story, educators may use metaphors to provide students with links to abstract concepts,

placing complex ideas into more simplistic forms. By this, they may have some transformational benefit in relation to a better understanding of the patient and so, potentially leading to more sensitive care. Milton (2017: 205) explained that metaphors represent concepts or structures of our understanding ''undergirded with transformational creativity'', emphasising their ubiquitous nature in how they are used to convey unique meaning messages within healthcare.

However, in a learning context, while describing experience using metaphors can contribute to a more vivid and deeper understanding in health professionals, there can also be misunderstandings (Jarvis, 2005). For example, if metaphor is used and is not understood in the way it was intended, this may cause confusion or disquiet in the learner. Box 2.1, in Chapter 2 (pg. 70) discussed the issue of how commentators raise issues with the concept of story in relation to how different people may interpret them as an expression of experience, leading to questions about 'truth' of parents' accounts. The same goes for metaphor. Metaphor may not be interpreted in the same way by different individuals leading to potential conflict in understanding, remembering the premise of people coming to different meanings depending on their own individual context, inherent within interpretivism. Therefore, caution should be applied when using metaphor. This point, as well as further critique of metaphor is discussed later in the chapter.

Nonetheless, given the evidence supporting the potential educational value of metaphors and how they are an integral part of narrative, their use within story creation is explored further in the next chapter.

6.3.3 How parents can inform our learning

Finally, this section turns to literature that supports the notion of parents having a central role in the learning of others by describing to us, their experiences. It is well documented how important family integrated care (FIC) is to enhance parental involvement, empowerment and confidence (Aloysius et al, 2018b; Banerjee et al, 2018b; D'Agata and McGrath, 2016) to decrease stress and go some way to ameliorating the psychological impact on families of having a premature baby on a neonatal unit (Jiang et al, 2014). From an education perspective, it is therefore essential that students and staff in this field learn from parents themselves about the emotional side of neonatal care to ensure they understand how to offer more sensitive and humanistic care to them. This person-centred approach acknowledges the notion of holistic care that incorporates a person's context and individual expression, preferences and beliefs, not limited to only the patient, but also including families and caregivers (Santana et al, 2018).

In line with a person-centred philosophy, the FIC model highlights how parents should be regarded as being equal members of the neonatal unit multidisciplinary team (Read and Rattenbury, 2018). It follows that parents are a source of valuable information for health professionals working in neonatal care. Such 'parent informed' teaching is congruent with the principles of FIC, that is education where both the health professional and parents are equitable partners and mutually learn from each other.

There is much to learn from the literature cited thus far in relation to understanding the parent experience extrapolated from parent accounts. However, in the main, the research does not always explicitly consider the views of parents in relation to asking specifically what health professionals can learn from them and their experiences. The study by Franck et al (2017) cited earlier discussed this issue in part. Forty sets of parents who had premature babies described their journey through the neonatal unit for a consultation on a neonatal care pathway. The secondary analysis of this data revealed important areas in relation to recommendations from the parent participants, for example: the need for information, provision of consistent practical and emotional support and the importance of ensuring parents are treated with empathy within a family-focused perspective. Findings from Blackburn and Harvey (2019) support the need for timely information and emotional support for parents in relation to both immediate and long-term care of their premature babies.

Certainly, much can be learnt here about what needs improving from the parent perspective. However, very little work has focused on this area as a *primary* analysis from parent narratives by asking parents first-hand about what they think health professionals could learn from them. Moreover, no research has addressed the development of tailored learning resources from the perspectives of the parents themselves in the neonatal field. Also absent is a parent-focused model for neonatal education, an issue that the current study takes forward, to develop a framework for learners in this specialised field. This is particularly important and relevant in the context of family integrated care, whereby the baby's family play a key, central role. Research

suggests that health professionals experience difficulties integrating family-centred care principles into their daily practice (Pineda et al, 2018; Trajkovski et al, 2016). Education is, therefore, absolutely vital to address and improve this situation.

In summary, the three areas of literature discussed in this chapter thus far have highlighted various gaps that are relevant to the current study. While research that explored parents' experiences has put forward key recommendations in relation to the need to give emotional support, recommendations do not exist to directly inform educational resource development specifically. In addition, there is sparsity of research in the *neonatal* field about using narratives and/or metaphors for education purposes. There is also limited work that has used primary interview data from the narratives of parents, to inform curricula development in the field of family-centred neonatal education and none that focuses on emotional experience. This is particularly important when teaching nurses and allied health professionals who are new to this field. The specific and unique nuances of the neonatal speciality must include the emotional perspective, recognising the vulnerability of parents and their sense of loss and turmoil at such a sensitive time when expectations suddenly change, and the unfamiliar world of the neonatal unit is imposed upon them.

The existing gaps identified here were addressed by the current study, with the aim to develop parent-centred, digital stories for learning, discussed in the next chapter.

6.4 Methods

Regarding the design of this phase of the study, the theoretical and conceptual frameworks have been discussed previously. The same theoretical approach is applied now. To reiterate, this phase seeks to explore *parents'* experiences of neonatal care using underpinning narrative inquiry theory, an interpretive approach used to explore and understand the *patient*, or the *parent* experience. Closely related is constructivism whereby people actively construct meanings from their own perceptions and interpretations to gain knowledge.

This phase employed interviews to acquire narratives. To add to the rationale for this chosen method from Chapter 4, Peters and Halcomb (2015) noted that the interview, or more importantly, the unstructured interview, is a method most often selected by researchers using a true narrative approach wishing to generate qualitative data. Indeed, in this phase of the study, narrative interviewing was employed. This is an unstructured form of interviewing which encourages and stimulates interviewees to tell a story about a significant event in their life.

The interview schedule (Appendix 3a) focused initially on one main question that asked the parents to tell their story throughout pregnancy until the present day. This more open, narrative type of interviewing was planned, following the initial study from Chapter 4 where it was thought that question prompts, required to elicit more information from the student nurses, may have influenced the authenticity of their stories; i.e. the questions asked may have led to specific topics of discussion rather than the participants really

'telling their story'. The desire was for the parents to talk freely and at length about their experience, for their stories to be forthcoming in a natural sense. Interviews in narrative inquiry on the whole should be 'conversations' according to Schneider et al (2017) who explained that an effective interview should seem to the participant to be an intimate yet focused dialogue. Questions should be broad with use of spontaneous follow-ups in response to what the participant says but beyond this, the researcher should allow the conversation to flow naturally rather than simply moving down a list of questions. A conversation allows the subject to feel comfortable expressing an opinion and provides opportunities for the subject to bring up ideas or experiences that may not have been previously considered by the researcher. This may also enhance the 'truth' of the stories told. In addition, told from lived experiences without being subjected to judgement, narratives from interviews can disclose essential meanings for individuals. Mann (2016) referred to the co-construction of meaning from qualitative interviews which Tamboukou et al (2013) agreed with, saying that stories are shaped by the listener. Meaning-making depends on the listener and how they respond. In this case, the author asked the parents to tell their own story and they did so with that specific purpose. The position of the listener also influences what is said which is an important part of reflexivity, to be considered later.

In the context of healthcare, narrative interviewing was deemed a suitable way to collect participant stories about their health or illness experience. They do not have a fixed agenda but let the person being interviewed have control over the pace, direction and content of the interview (Anderson and Kirkpatrick, 2016) without pressure or any element of formality. Narrative interviewing is also congruent with the overarching

narrative paradigm where the focus was to gain stories, rather than a prescriptive, structured form which would only seek closed responses. A narrative from an interview may therefore be any articulation of an experience or event in which one is telling a 'story' and this was asked of the participants. Congruent with underlying interpretivist constructivist principles, narratives are constructed in the context of the person speaking interacting with the listener (Lindseth and Norberg, 2004). After transcription, they become individual texts that can be read and re-read.

This above discussion supports the key assumptions of narrative interviews. To sum, stories are an important means through which we communicate with one another and so one way of eliciting stories is through interview. Moreover, the dynamic and 'messy' nature of qualitative data means that meanings extracted from interviews are contextual and constructed (Andrews, 2012). Finally, there is an importance of temporal framing within such a 'storied' approach, consistent with the principles of emplotment discussed earlier.

6.4.1 Participants and recruitment

Purposive sampling was used to recruit parents, a non-probability method widely used in qualitative research where participants are selected based on certain characteristics of a population and/or study objective (Etikan et al, 2016). The phase of the study set out to recruit parents who had given birth to a premature baby or babies, who had spent a period greater than a week within the neonatal unit and had been discharged home, with the aim of obtaining a variety of different experiences and unique stories for others to learn from. The inclusion criteria were intentionally broad since being too restrictive would have potentially prevented a varying range of experiences and stories. For the same reason, exclusion criteria were limited to parents whose babies were born after thirty-seven weeks gestation and had spent less than a week in neonatal care.

Overall, twenty-three participants were recruited via the above approach through an agreed gatekeeper provide by a well-known parent charity. The participants were comprised of sixteen mothers, one father and three mother-father pairs, who between them had a total of twenty-seven premature babies. Details of participants are outlined in Table 6.1 outlining gender, age and ethnicity of the parents along with gestation, birthweight of the baby and whether the pregnancies were singleton or multiple. Previous premature births, deaths and recurrent hospitalisations are also included. No restriction was imposed on who could tell their story between mothers and fathers, as again the aim was to gain *both* perspectives in the above-mentioned context of offering a variety of different experiences. In the mother-father pairs, both parents contributed to telling their stories.

In terms of rationale for the number of participants, Vasileiou et al (2018) acknowledged that there is no straightforward answer to the question of 'how many'. In this case, the initial plan was to aim for ten interviews but due to volunteers being so willing and forthcoming, it seemed unethical to then turn parents away. Those who came forward were keen to tell their story and really believed in the value of their voice being heard. In addition, although ten interviews would have been sufficient for story creation if they were created on an individual basis, the methodological approach chosen was to use composite themes as seen in Phase 2. To generate enough rich data to identify common and consistent themes, the decision was made to increase the number. Moreover, each experience and story were so unique, capturing a different element. Even by the time ten interviews had been completed, it was clear that diverse experiences were being reported that were detailed and compelling.

With twenty interviews, it was felt that saturation of data *had* been reached by determining when no new ideas were being gathered. van Rijnsoever (2017) argued that deciding on saturation should be at a researcher's discretion and judgment acknowledging that there are no rules for sample size in qualitative research; this allows flexibility. Guidelines therefore do not exist as such. This is fitting with interpretivism and having a more fluid and open approach than one would find with quantitative research.

Table 6.1: Participants (Part 2, Phase 1)

Participant details		Number and %
Parent(s) interviewed	Mother	16 interviews
	Father	1 interview
	Mother & father together	3 interviews
Age of parent	18-25 years	3 (11%)
	26-30 years	10 (37%)
	31-40 years	11 (41%)
	> 40 years	3 (11%)
Ethnicity of parents	Caucasian	23 (100%)
Age of child at interview	1-2 years	6 (22%)
	2-4 years	8 (30%)
	4-6 years	2 (7%)
	6-8 years	4 (14%)
	8-10 years	5 (20%)
	Died	2 (7%)
Gender of child	Male	14 (52%)
	Female	13 (48%)
Gestation born	24-26 weeks	13 (48%)
	26-28 weeks	3 (11%)
	28-30 weeks	6 (21%)
	30-32 weeks	5 (20%)
Birthweight	500-750 grammes	12 (44%)
	750 -1000 grammes	5 (20%)
	1000-1500 grammes	10 (36%)
Order of birth	1st child	18 (67%)
	2nd child	6 (21%)
	3rd child	2 (7%)
	4th child	1 (4%)
Singleton or multiple birth	Singleton	25 (93%)
	Twin	2 (7%)
Previous premature births	Yes	6 (21%)
	No	21(79%)
Previous neonatal death	Yes	2 (7%)
	No	25 (93%)
Recurrent hospitalisations after discharge (requiring re-admission)	Yes	14 (52%)
	No	13 (48%)

6.4.2 Parent interviews

The interviews started with an open 'single question aimed at inducing narrative' (SQUIN) as offered by Wengraf (2009). The SQUIN, as outlined in Chapter 4, was again kept deliberately broad aiming to provide a means of stimulating dialogue. This allowed participants to construct their narrative on their own, in this case to enable the parents to talk through their whole experience or 'journey' on the neonatal unit. The SQUIN asked for this phase of the study was: '*Can you tell me about your experience while you and your baby were on the neonatal unit, taking me through the events and experiences that were important for you, from admission to discharge?'*

One question that was asked of all parents at the end of their interview was, *'What can health professionals learn from you as parents, and your experiences in neonatal care*?' Since, the central aim of this study was related to education in line with a person-centred approach placing parents at the centre, this was deemed to be a key, additional question that would indicate parents' own views of what they felt was important for learners and staff to know, to ultimately improve person-centred practice.

The twenty interviews took place between February to July 2016 and were arranged at a convenient time with the twenty-three parents in their own home or an agreed, private location. Written information was given, and consent obtained prior to all the interviews. The interviews took place over a period of between fifty (minimum) and one hundred and forty-five (maximum) minutes. At the close of every interview, the parents were offered the chance to provide any additional information they considered relevant. This

allowed them to feel that their contribution was valued and confirmed the relevance of their experience to helping others in a similar or future situation.

All interviews were audio recorded using a voice recorder and the audio files were later transcribed manually. Verbatim transcription was undertaken by the author herself, due to the issues of confidentiality. The need for transcription has been discussed in the literature. Halcomb and Davidson (2006) raised the debate on the necessity for transcription of all verbatim audio recorded interview data and Reissman (2008) suggested that transcription is actually not always necessary. However, Stuckey (2014) saw that moving from raw interviews to valid interpretations requires preparing transcripts to enable this. Oliver et al (2005) regarded transcription as a powerful act of representation. For the present study, the decision was made to manually transcribe from audio to verbatim written formats to make an 'end-product' that was tangible and with which to work with. In other words, verbatim transcriptions provided the raw data in text form, necessary for later story creation. While it was time consuming, this also enabled an immersion and familiarisation with the content.

6.4.3 Emotion work of parent interviews

Due to the nature of the interviewing that involved reliving difficult and stressful times, the issue of managing and responding to emotions was necessary. Literature refers to this as the 'emotion work' involved in research of this nature (Darra 2008; Dickson-Swift et al, 2009) relating to emotions elicited in the participants when talking and reliving memories and sensitive topics. This is something that needs consideration when

researching sensitive and emotive topics such as the neonatal care experience (Ashton, 2014). This issue was an important part of reflexivity applied to this phase of the study and is discussed in Box 6.1.

Box 6.1- Reflection: Phase 1 Main study:
Dealing with the emotion work of interviewing parents

It was important to create a supportive environment, so the participants felt safe to discuss what they thought relevant and to demonstrate emotions. Once interviews began, asking parents to relate their story through the neonatal experience elicited certain emotions in many of them as they relived difficult events and memories, even those parents who were recalling their experience ten years previously. Writers have proposed strategies to deal with emotional responses during interviews on sensitive issues (Elmir et al, 2011; Baird and Mitchell, 2013) recognising that conducting interviews has the capability to emotionally distress people, especially when they are being asked to recall physical and/or emotional trauma. Researchers need to be constantly receptive to the body language and tones of participants' voices (Seidman, 2013). They should anticipate the likelihood of emotional responses and should adequately plan and prepare for them. Post-interview, I allowed time after each interview for feedback and discussion, important for them to compose themselves and to provide an opportunity to add or revise any information. Interestingly, the parents were often relieved that they had told their stories and hoped these would help others. Lowes and Paul (2006) suggested that study participants often experience qualitative interviews as cathartic and therapeutic.

Emotive work also involved managing my own emotions: It was difficult not to be moved at times by many of the experiences such as death of a twin baby, a baby dying after a lengthy and protracted time in intensive care, the separation and anxiety voiced by many of the parents. DeMarrais and Tisdale (2002) considered debriefing to be important, especially if a researcher is working alone, as I had, suggesting that researchers must plan strategies for dealing with their own emotional responses.

The sharing of experience between self and other has also been defined as "reflexive embodied empathy" (Finlay, 2005, p. 271), i.e. the researcher perceiving and feeling the felt experiences of the research participant during interviews (Doyle, 2013). According to Vazquez and Westcott (2014), this phenomenon can be experienced at both the cognitive and affective levels and develops from personal contact with the people being interviewed, involving being able to take and understand the positions, feelings and experiences of others. My own emotions therefore were a source of information to better understand the data collected from my parent participants.

The issue of emotion work of interviewing participants in research of this nature has been written up and published, with a focus on applying these strategies to parents in neonatal care (Petty, 2017b). The paper 'Emotion work in qualitative research: interviewing parents about neonatal care' defined 'emotion work' as a term used to describe the emotional responses that may arise in qualitative research exploring difficult experiences. It acknowledged at the outset that parents' experiences of neonatal care can raise sensitive issues during interviews. The aim of the paper was to reflect on the parent interviews to inform other researchers about the potential emotive issues that may arise. The discussion focused on issues relating to emotion work, the role of the researcher, emotional connections and empathic interviewing. It finally emphasised the importance of reflexivity for researchers and concluded that qualitative researchers undertaking narrative interviews should be prepared for emotive issues that arise while recognising the need for emotional intelligence. The challenge of achieving a balance between being an empathic, emotionally aware interviewer and remaining objective was highlighted. Strategies that researchers can use to address this balance and to manage the emotion work involved in research of this nature were provided.

6.5 Analysis

There were various components to the data analysis for this phase of the study. Firstly, core story creation was undertaken using the raw narratives followed by three occurrences of thematic analysis congruent with the three areas outlined in the background section for this chapter. The three areas were; (1) Parents' descriptions/ experience of neonatal care; (2) Parents' use of metaphors to describe their experience and (3) How parents can inform our learning. For these three areas of analysis, NVivo (2012) software was used to code the themes and organise the data in a manageable form.

6.5.1 Story creation and emplotment

Firstly, core story creation was undertaken, applying the principles of emplotment demonstrated and reported earlier in Chapter 4 in the initial study that informed the methodology for this phase. This process was based on the theories of Ricoeur (1984), Bruner (1991) and Polkinghorne (1995). To reiterate the process of core story creation, each parent interview yielded raw narrative transcripts which were reconfigured to create a coherent plot in 'storied', chronological form. To illustrate this process, Appendix 3b and 2c contain examples from one parent; of a raw transcript and a story 'construct' following core story creation, respectively. Using this raw data, the process of core story creation outlined in Figure 4.1 (in Chapter 4, pg. 93), was applied. As before, once the transcripts were read and unnecessary text / words removed, the events spoken about (Appendix 3b) were sectioned and reorganised chronologically in the

reconstructed story (Appendix 3c); for example, *''I was 29 weeks pregnant''* and *''the first night after I gave birth''* formed the beginning of the story with *''When Harry went home''* and *''Going home felt like another nightmare''* with associated text, became the end of the story. The events that occurred in between made up the middle of the story between start and finish, such as *''the whole period then was so stressful''*, and *''then it was just such a blur''* and *''when he went from intensive care, he did go to high dependency''*. These sections are shaded to illustrate them in both Appendix 3b and 3c. Further reconfiguration of the data and stories were undertaken later when the digital stories were developed, to be discussed in Chapter 7.

The process of core story creation has also been published in a peer-reviewed paper (Petty et al, 2018a); 'Core Story Creation: Analysing narratives to construct stories for learning'. The aim of this paper was to explain how core story creation is undertaken to construct stories from raw narratives obtained by interviewing the parents about their neonatal experiences and how the stories can be used to educate learners. It defined core story creation as a process that involves reconfiguration of raw narratives and 'emplotment', including reordering to form a constructed story. Thematic analysis was also explained in relation to drawing out learning themes informed by the participants. The paper concluded that core story creation using emplotment is a strategy of narrative reconfiguration that produces stories which can be used to develop resources relating to person-centred education about the patient experience. Implications for practice pointed to how stories constructed from raw narratives in the context of constructivism can provide a medium or an 'end product' for use in learning resource development contributing to educating students and health professionals about patients' experiences.

6.5.2 Analysis (1): Parents' experience of neonatal care

Thematic analysis followed the core story creation, congruent with the aforementioned work by Emden (1998), subsequently by Kelly and Howie (2007) and more recently, the study highlighted earlier by Rossman et al (2017) that used actual stories from parents as the basis of analysis. Thematic analysis was appropriate in the context of this phase, as the study focus at this stage was with the *content* of parent stories; in other words, *what* was spoken about in relation to the parent experience, rather than *how* it was told.

Thematic analysis of the text-based transcripts was undertaken using the principles of Braun and Clarke's approach (2014), again discussed in Chapter 4 (Figure 4.2, pg. 95). To reiterate, this approach involved: transcribing, familiarising, reading and re-reading the data, identifying initial points of importance and interest, coding, and sorting codes into the identified themes. Finally, main themes and sub-themes were assigned and named. Rationale for the use of this model again arose from its clarity and staged approach which enabled recurring themes and sub-themes to emerge from the parents' stories. Due to its flexibility and the fact that it can be modified for the needs of many studies, thematic analysis can offer provision of rich and detailed analysis of data (King, 2004 cited by Nowell et al (2017).

After reading and becoming familiar with the parent stories, preliminary themes emerged that were common across the dataset which then led to categorisation and coding of the data. This was a data-driven, inductive process due to there being no pre-existing coding frame or preconceptions (Braun and Clark, 2006; Nowell et al, 2017).

Overall, a process of identifying common occurrences in the data to form initial codes (themes) and sub-codes (sub-themes) was undertaken using the same process as for the initial study. After initial codes had been identified in the data of two or three transcripts, codes were compared to identify similarities and differences, and to determine which data were common throughout. These were coded within NVivo and then sub-coded (Appendix 3d). For example, the first theme on the parents' emotional experience was theme 1, with the sub-themes being both negative (*''I was so depressed'*) and positive (*''it felt so right''*) experiences. The same applied with the other themes, also coded for positive and negative; the baby, the environment, the staff, transitions and going home. Appendix 3e gives examples of parent quotes that illustrate all the codes/ themes with the negative and positive sub-themes for each. Rationale for the quote selection was given in Chapter 4 in relation to them being representative of the parents' commonly presenting themes within the whole interview dataset and to ensure they were all included in some way.

6.5.3 Analysis (2): Parents' use of metaphors

Metaphor analysis was also undertaken on the dataset. It was decided to perform this type of analysis after the interviews were completed and the core story creation had been undertaken due a realisation of how often *all* parents used metaphors to some degree. It was not originally anticipated that metaphors would be so prevalent; they arose from the parents' descriptive language related to their story. This added an extra layer of rich data in which to understand their experience particularly in line with emotions. In line with the open nature of narrative interviewing, the metaphors identified and used for analysis were

the parents' own words as they told their stories, spontaneously revealed rather than being elicited from specific interview questions, again congruent with experience told through narrative.

Different approaches are documented for analysis of metaphors specifically. For example, Lakoff and Johnson who have written seminal work on metaphor analysis, described a cognitive, linguistic model which they postulated, can reveal patterns of both thought and action. They have not though, developed an effective system to use when undertaking qualitative research (Schmitt, 2005). Cameron has analysed qualitative, interview based narratives and proposed in her book, *Discourse Dynamics Framework for Metaphor* that the distribution of metaphors showed clustering at certain points (Cameron, 2011; Cameron and Maslen, 2010). However, these above models are based on discourse analysis. The area of interest in this study was understanding experience and not the structure of language or discourse. Even Lakoff and Johnson acknowledged that metaphors are not just linguistic constructs but expressions of the structure of individuals' thoughts (Lakoff and Johnson, 2003).

Therefore, more relevant to the current study was a descriptive form of metaphor analysis. The analysis used was consistent with the work of Beck (2016; 2017) who used Pragglejaz Group's (2007) Metaphor Identification Procedure (MIP) acknowledged as a method for identifying metaphorically used words. In metaphorical analysis, the 'corpus' is text that come from natural language use (Charteris-Black, 2004); these were the interview narrative transcripts from parents. The corpus for this metaphor analysis

consisted of one-hundred-and-twenty-two pages of typed text yielded from the transcription process. The MIP included the following steps:

1. The text was read in full to ascertain an understanding of the content and meaning.

2. The lexical units were determined within the text, defined as is a single word, a part of a word, or a chain of words-see below.

3. (a) For each lexical unit, the context was considered, then; (b) whether it had a different meaning in other contexts and, (c) if the meanings in the different contexts contrasted but could be understood.

4. If yes to point 3, then this was deemed metaphorical.

An example of this approach is below:

"It/was/like/ being/in/a/long/dark/tunnel/It/was/suffocating/and/I/felt/trapped". The context here was a mother's account of the neonatal environment. The lexical units 'long', 'dark' and 'tunnel' combined had a different meaning to their real (usual) context when contrasted. However, this was understood as being how it made her feel. Feeling like she was suffocating and trapped continued this metaphorical explanation of the environment.

Another example was:

"He/was/next/to/me/but/so/far/away/almost/in/another/world/that/we/were/not/part/of/and/I/ couldn't/reach/him". The context in this example is a father speaking about the immense barrier between him and his baby. The lexical units 'far' and 'away' along with 'another' and 'world' as above, had different meanings to their usual context but understood in relation to the father's emotions at not being able, metaphorically speaking, to feel close to his son.

Overall, the lexical units in these sentences were regarded as being used metaphorically. This process was applied throughout all the transcripts. After all the lexical units were identified within the transcripts, they were categorised into the metaphor clusters most often used by the parents. Again, NVivo was used to code the metaphor clusters. Appendix 3f contains the raw coding from NVivo highlighting the metaphors and frequencies used throughout the dataset and Appendix 3g outlines a summary of quotes for analysis 2. Rationale for the quote selection has been given in Chapter 4 and in the preceding section.

6.5.4 Analysis (3): How parents can inform our learning

Overall, the same process of thematic analysis to identify common occurrences in the data to form initial codes (themes) and sub-codes (sub-themes) was undertaken. This was done as before, but this time with a specific focus on the final interview question responses; in other words, as applied to the specific part of the interview transcripts that answered the aforementioned key question: *'What can health professionals learn from you as parents, and your experiences in neonatal care?'* Key themes and sub themes were identified for this specific area of interest, although this was less inductive as the data was related to a specific question. Thematic analysis for this part was also applied to the raw transcripts. This data did not form part of the parent 'story' as it was an extra question posed at the end of the interviews. Appendix 3b displays an example of an interview transcript with the response to this specific question at the end. It can be seen that key themes were present that were common within the other parent narratives, for example: the importance of communication (*''giving important information was also*

needed'') being listened to (*''it's important that staff take the time to listen to us*''), the need to recognise when parents need support (*''I needed support and understanding at that point''*). Sub-themes were also identified, such as for the main theme 'Empathise', sub-themes related to how vital it was to give emotional and value led care to the whole family (*''attending to the emotional side was so vital*'' and *'' it's the way people acknowledge and talk to you with a more sensitive approach- that was so much appreciated''*). Appendix 3h contains the raw coding highlighting main and sub-themes used to address this part of the analysis within NVivo. Appendix 3i outlines a summary of quotes from analysis 3. Again, rationale for the quote selection in Appendix 3i has been outlined previously.

6.6 Trustworthiness and rigour

Data generated in interpretivist studies cannot be generalised since it can be significantly influenced by personal viewpoint and values. However, some may question if there is bias on the part of the researcher and critics suggest that reliability and representativeness of data is undermined to a certain extent. While qualitative work of this nature never sets out to generalise, the need to report and interpret findings in an unbiased way must be addressed. Referring to Shenton (2004) who provided a comprehensive summary of how to maximise trustworthiness and credibility of qualitative, narrative data, various specific strategies were employed which are outlined in Appendix 1 indicating which points were relevant to which phase. The strategies included the following:

- *Debriefing sessions with supervisors for peer scrutiny of the project, including discussion of the emerging findings*. Peer feedback was also obtained from various journals during the review process for the publications outlined in Chapter 1. Feedback came from a variety of expert reviewers which imparted rigorous and constructive critical feedback to improve the final articles for submission.
- *Use of "reflective commentary"* (Appendix 4). This was undertaken throughout the study.
- *Recognition of limitations in the study methods and their potential effects.* This included those within the recruitment process; for example, the aforementioned potential for bias in participant characteristics.
- *'Member checking' also known as participant or respondent validation*. This is a technique for exploring the credibility of results (Birt et al, 2016) by sending narrative transcripts back to the participants for verification. This reflects Denzin and Lincolns' (2017) views that researchers must always return to and reflect on the words people speak as they attempt to give meaning to their experiences. Before continuing with subsequent analysis, verification of the stories for credibility with participants themselves was the final stage of Emden's (1998) approach to core story creation. The transcripts along with the created stories were sent back to the parents in this study so that the authentic representations of what they had said could be substantiated against their own observations of the same episode, offering opportunities to alter, add or remove anything from their stories. This process is based on principles outlined by Spalding and Phillips (2007) to address trustworthiness of the data and interpretation, in line with optimising credibility of a study. As Wang and Geale (2015: 197) stated,

''researchers need to continually discuss the participant's stories with the participant…this process shapes how the researcher re-stories the account'' within the narrative framework. This 're-storying' could potentially impose a false order on the narrative creating misunderstandings. As acknowledged previously, with qualitative work such as this, one may ask, how can one guarantee that participants always get their facts right, remember events correctly and that the interpretation is the truth? Can their accounts ever really be authentic? However, it must be remembered that meaning-making is based on *perception*. The stories told by the parents were their own stories based on *their* perceptions. Indeed, the nurse may have said one thing, but the parent heard another. Therefore, the latter is their story and they act on it. From this, there was a need to recognise and embrace the subjective reality inherent in the study. It has already been emphasised how researchers are bound to acknowledge their subjectivity and permit a full examination of the effect of this on interpretation of stories told.

- *Admission of the researchers' beliefs and assumptions which could influence data interpretation.* The author for example, is an experienced neonatal nurse educator and so has significant prior knowledge and experience. This can place doubt on whether she had a true 'external' (outsider) perspective and could have limited objective views when interpreting parent narratives. Therefore, 'bracketing', the process of temporarily putting aside the researchers' own values and beliefs, was undertaken. However, there are potential problems with the ability to perform bracketing in relation to whether it is humanly possible to be truly objective (Chan et al, 2013). Various questions therefore arose regarding the suspension of values such as: is it really possible to be value neutral? Is it appropriate in this type of

research to distance ourselves from our own research? Can we always remove all our subconscious thoughts and / or unconscious biases that may affect the analysis and interpretation? Indeed, suspending one's values requires a deep level of self-awareness and self-consciousness and that it may be impossible to filter the inherent ways we experience events, no matter how aware and reflexive we try to be. As Grosz (1995: 13 cited by Mauthner and Doucet, 2003) pointed out, ''the author's intentions, emotions, psyche, and interiority are not only inaccessible to readers, they are likely to be inaccessible to the author herself''. As with limitations of any study and the need to be open about these, there may also be limits to the extent to which we can be aware of the influences on our research both at the time of conducting it and in the period that followed. Nonetheless, it was vital to engage in reflexivity to ensure transparency in relation to the issues raised above (Box 6.2).

- *Assurance of ethical considerations*. As outlined in Chapter 3, this was essential to ensure that trustworthiness and rigour in methods were documented as part of the approval process prior to the start of the study.
- *Ensuring compliance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al, 2007)* (see Appendix 5). This process was compulsory for article submission to a specific journal (Journal of Clinical Nursing), chosen as one of the journals in which to publish this phase of the study (Petty et al, 2019a).

Box 6.2- Reflection: Phase 1 Main study: Attention to narrative

An important issue to reflect on in this phase was the relationship between myself and my participants and how this may have affected the data analysis. Different relationships exist between researcher and participant in relation to where both are positioned within the research process; an insider / outsider perspective is often spoken of as 'positionality' (Ritchie et al, 2009; Moore, 2012). The concept of power was important to consider or rather, the extent to which the different power relationships can affect the meanings derived from qualitative data. This was pertinent particularly in line with a narrative, constructivist approach where the parent narratives used to 'construct' stories were also 'deconstructed' to derive meaning which of course may be interpreted differently by others. As stated earlier, meaning-making depends on the listener, who they are and what purpose the teller has in telling the story.

For phase 1, participants were parents who I did not know; it was necessary to account for potential power asymmetry, a feature of research with the balance generally considered to be in favour of the researcher who directs the process while the participant responds (Reid et al, 2018). Ari and Enosh (2012) argue that this power is co-constructed through the process, as participants exert power in shaping knowledge through choosing what to reveal. Taking the 'outsider' perspective, the parents were external to my own workplace and unknown to me. Although I had no relationship with the parents prior to this research, power dynamics needed careful consideration due to the potential for data collection to be influenced by power differences (Berry, 2016). It has been argued that there is an inevitable power imbalance in the research relationship. This is concisely summarised by Richards and Schwartz (2002) who said that when a researcher is also a health professional as in my case, this power imbalance could be exaggerated by the participant feeling pressurised to participate because of a sense of duty, or because they feel it is good will to do so.

However, the parent participants were not complete 'outsiders' as we were both placed within the neonatal speciality, as parents who has spent a significant period of time in a neonatal unit (s) or in my case as a professional with much experience in this area. By this,

parents had an insider element (inside the speciality). Ritchie et al (2009) suggested that this is a blurring of the apparent separation between 'insiderness' and 'outsiderness', highlighting a potential professional dilemma associated with a blurring of roles between the 'researcher' and 'nurse' role.

Blurring boundaries is commonplace when researchers immerse themselves in the settings that they are studying (Dickson-Swift et al, 2006), particularly when an emotional response is likely (Skene, 2012) as was the case here. Because of my previous experiences as a neonatal nurse, I believed myself to be experienced in dealing with people that are upset. However, I was also aware that I was there as a researcher and a professional. Collection of data should be unbiased, and my role should not have induced participants to give the answers that a researcher would prefer. Moreover, acting as a nurse and offering counselling should this be required, may have influenced the results (Dowling, 2006; Elmir et al, 2011).

At the same time, I felt it inappropriate to be too formal as this may have caused an unease in parents. Some connection was needed to enable the parents to talk freely. This was easier with some parents than others; some were obviously nervous while others were more relaxed and open. I felt this influenced their connectedness with me and vice versa and may well have affected what and how much information they imparted. In the narrative context, it is known that the narrator's connection with their 'audience' whether they are a researcher or anyone else, profoundly affects what is told and how (Almack, 2008; Hampshire et al, 2014).

6.7 Findings

Following the three different types of analysis, various important findings emerged which are now reported in relation to: (1) parents' descriptions/ experience of neonatal care; (2) parents use of metaphors to describe their experience and (3) how parents can inform our learning.

6.7.1 Findings: Parents' descriptions/ experience of neonatal care

The analysis of the narratives from the twenty parent interviews revealed themes in six key areas in relation to how they described their neonatal care experience; these were: the emotional experience, the baby, the environment, the staff and transitions through the different phases of neonatal care including going home and the period after discharge. Within these six areas, both negative and positive encounters were reported. In line with this, parents' emotional experience included both 'lows' and 'highs', the baby was described in terms of 'vulnerability' or 'strength', the environment in terms of 'distress' or 'comfort' and the staff discussed in relation to either acting in 'conflict' or as 'support pillars' to parents. Transitions between the different parts of the neonatal unit and/or between different hospitals were described as either 'regression' or 'progression' including the experience at home which was often thought to be a time of mixed and opposing experiences, with both 'challenges' and 'comforts' identified. In addition, some neutral feelings (neither positive nor negative) were also evident but these did not feature regularly. For example, in three out of the twenty interviews, one parent stated that they were "*not sure how they felt*", and another two said that they "*felt numb*". However, such expressions of 'numbness' were more associated with the early shock of experiencing

premature birth and were said in the context of subsequent negative emotion relating to fear and anxiety in the early adjustment period.

NVivo coding reflected the above-named categories, highlighting both positive and negative experiences for the main themes. Due to infrequency of occurrence, neutral feelings were not included. Table 6.2 outlines the sources (interviews) in which the themes arose and the total occurrences across them all, for the six areas of interest. Table 6.3 outlines a summary of the main themes including aspects of detail for each one. In the subsequent text, selected quotes were chosen to illustrate the emotional content threaded through the whole dataset. The numbers for each quote refer to the interview number (1-20).

Table 6.2: Frequency of themes (parent experience)

	Appearance in interviews (out of 20)	Total number of occurrences and %
How parents describe their emotional experience		Total 215
Challenging emotional experiences	19	157 (73%)
Positive emotional experiences	15	58 (27%)
How the baby is described		Total 68
Challenging experiences with their baby	15	45 (66%)
Positive experiences with their baby	10	23 (34%)
How the staff are described		Total 92
Challenging experiences with staff	10	23 (25%)
Positive experiences with staff	18	69 (75%)
How the environment is described		Total 33
Challenging experiences with the environment	10	17 (51%)
Positive experiences with the environment	10	16 (49%)
How transitions are described		Total 39
Challenging transition experiences	10	32 (95%)
Positive transition experiences	4	7 (5%)
How parents describe their experience at home		Total 152
Challenging ongoing experiences at home	18	122 (80%)
Positive ongoing experiences at home	16	30 (20%)

Table 6.3: Summary and explanation of themes (parent experience)

Theme	Negative experiences	Positive experiences
Parent's Emotional experience	**Lows**	**Highs**
	Feelings of anxiety and fear, uncertainty relating to outcome and survival. Challenging and difficult emotional experiences.	Feelings of elation, pride and being fortunate at being a parent. Feeling happy and hopeful particularly at key moments (e.g. during closeness with their baby)
The Baby	**Vulnerability**	**Strength**
	Fear of touching, harming or infecting their baby due to their size and fragility. Appearance of their baby- not looking like a 'real baby'	Feelings of pride, amazement and overwhelming sense of love and protection towards their baby. Baby being described as strong and being tough enough to survive very challenging circumstances
The Environment	**Distress**	**Comfort**
	The neonatal unit being dark and uncomfortable meaning an inability to relax. Feeling closed in and imprisoned, isolated	The neonatal unit being a 'second home' and a place in the hearts / memories of parents as a significant place in their lives
The Staff	**Conflicts**	**Pillars**
	Not being listened to and heard. Conflicting communications and levels of empathy between different staff and units	Staff being supportive and empathic, sensitive and caring towards practical and emotional needs. Staff being described as 'saviours' of both baby and parent
Transitions	**Regression**	**Progression**
	The feeling of disappointment and further uncertainty when baby is transferred back a level of dependency or to another hospital for surgery or tertiary treatment	The feeling of moving towards going home and being a normal family and living life together as a family. Feeling of relief and hope for the future as baby moves towards home
Going home	**Challenges**	**Hopes**
	The ongoing emotional challenges of being at home without the 24-hour support of the neonatal unit. The later, post-discharge emotional effects of the impact of giving birth prematurely and being in the neonatal unit with such a sick, vulnerable child	The sense of experiencing a miracle and the ultimate goal of going home. The feeling of achievement that their vulnerable baby has gone through so much distress and this garners hope for the future

6.7.1.1 Parents' emotional experiences

The well-used term 'emotional roller-coaster' featured commonly in the parents' narratives representing the highs and lows of the feelings reported during the neonatal trajectory. Nine parents used the term to describe mixed feelings associated with this often-tumultuous journey. Frequent words used to describe emotional 'low' points were, overwhelming, scared, terrifying, shock, anxious, difficult, horrendous, uncertainty, fear. The positive emotions or 'highs' were also reported particularly after a certain period of stability and assurance that their baby would be alright. Fourteen parents also reported the emotional benefits of certain strategies namely, psychosocial support from staff and being given information especially around the benefits of skin to skin care, expressing breast milk, feeding and being involved in the care of their own baby.

Certain factors could have influenced the reporting of emotional experience; for example, time factors, the health status or condition of the baby and previous experience of premature birth (Table 6.1). As stated in the discussion on recruitment, parent narratives were obtained from a variety of time frames, overall within a period of ten years. A long timeframe could have potentially influenced the ability to recall events and required consideration as a possible confounding factor. Indeed, practice in some areas has changed during this time and would have possibly impacted on the parents' recall of experiences. However, the study was not comparing time frames nor were difficulties with recall found to be the case. While the potential for recall bias needed considering, the parents in the study, even those whose children were now older than five years old, were able to recount their journey through neonatal care lucidly and freely, often stating that this was a valuable and cathartic process.

However, one striking difference between interviews that took place before five years and those undertaken at eight to ten years was the level of uncertainty expressed about the babies' futures. In the early days, parents expressed a greater level of uncertainty about the future, while after a longer period of time, more was known about the longer-term effects if any, of being born prematurely and receiving neonatal intensive care at an early age. Three parents in the former group, for example, expressed how this uncertainty caused them ongoing stress and anxiety, while two parents in the latter group, expressed a sense of relief that outcomes were more established, which reassured them greatly.

A factor that did appear to influence emotional experience was the health status of the babies. Those born more prematurely and/or had lower birthweights had more significant and recurring health problems continuing after discharge, including oxygen dependent chronic lung disease, feeding problems and gastro-oesophageal reflux often requiring repeated hospitalisations particularly in the first two years. This had occurred in fourteen out of the twenty-seven babies in total and these parents highlighted the emotional toll that this imposed adding to their existing stress of dealing with a vulnerable baby at home. Some parents spoke about their previous or other premature births and the difficulties of having to cope with more than one child with ongoing needs. Three mothers reported feelings of guilt, questioning their ability to have what they called a 'normal' pregnancy. However, two others as well as four of the parents who had other children before their premature birth, reported a development of emotional resilience, having been through the experience before, leading to better coping mechanisms. Hence, previous children whether premature or not, did have an influence

on parents' reports of their experience both negative and positive. Two parents had experienced the death of a twin; the mixed emotions of having to deal with bereavement and loss combined with the joy associated with a surviving twin going home was voiced very lucidly, highlighting how a combination of emotions is often present in accounts such as these.

No discernible differences were evident in the emotions experienced and reported according to age or gender of the parents or that of the child. It was not possible to make comment on different ethnicities of the parents as all were white, Caucasian which shall be referred to again later.

6.7.1.2 The Baby

Vulnerability of their baby was voiced by parents and this was often shocking and hard for them to assimilate emotionally. Four parents described the appearance of their baby as not looking like a 'real baby', referring to non-human terms such as 'ball', 'tiny little thing' or 'doll' for example. These and two other parents also made links with such feelings and an inability to bond initially. Well over half the parents also reported a fear of touching, harming or infecting their baby due to their size and fragility, again a factor influencing the ability to form emotional attachments. However, strengths that came from their babies were also appreciated by parents, particularly after some time on the neonatal unit, when they had seen them 'pull through' against the odds, expressing amazement at this. In addition, the sheer joy expressed by six parents was very evident;

while parents remembered such positive feelings towards their babies during interviews, clear in their facial expressions and often becoming emotional during memory recall.

6.7.1.3 The Environment

Often the environment was found to be a source of distress, presenting a barrier to being a parent. Isolation and darkness were also apparent, with comments that the unit could be oppressive and stifling as a place to spend so much time in. Twelve parents made comments to this effect. Conversely, providing an environment that encouraged proximity and avoided physical barriers was seen to be a source of comfort as reported by five of the participants. Seven of the parents also expressed how the neonatal unit held valued and happy memories for them in relation to the early days of their baby's life.

6.7.1.4 The staff

Over half of the parents reported an importance placed on the role of neonatal staff, in relation to the support they imparted throughout their hospital trajectory. One emphasised how the value of this support could not be underestimated and went a significant way to reducing emotional distress. Conflicts were noted, commonly about communication issues between staff and parents, or across different units and professionals. However, this was one theme where positive comments about staff far outweighed any negative views. Staff and the part they played in their baby's early life were remembered very fondly and were seen to be 'pillars' of support and strength for parents at difficult times. Great value was placed upon them and their role, particularly so if they worked closely with parents.

10.7.1.5 Transitions

Thirteen of the parents spoke about the transitions within neonatal care, so common within the whole trajectory. When babies were moved back to higher dependency levels requiring greater input of care, this led to further emotional turmoil and disappointment expressed on a par with regressing backwards, as expressed by seven parents. Conversely, regressions were balanced with progressions when babies improved and moved to areas where bonding and contact could be more readily facilitated and when feelings of hope could then be expressed.

6.7.1.6 Being at home

Finally, one significant transition is going home, and over half the parents expressed strong emotions about this significant event. Challenges often remained for significant lengths of time and for approximately half of the participants, there were reports of depression, panic attacks or post-traumatic stress disorder at some point during the neonatal trajectory after going home. Going home, for most of the parents was expressed as a time of moving forwards towards a future as a family, with hopes and plans to be made. There was a realisation in some of what they and their babies had lived through and where they were now, feeling thankful and thinking about the future ahead of them.

6.7.2 Findings: Parents' use of metaphors to describe their experience

Overall, the pervasive use of metaphors by parents was evident from the descriptive analysis, frequently and consistently present in all twenty interview narratives.

Metaphors appeared to generate interesting and revealing insights and served in some way as a key to understanding much more than just 'what happened'. Table 6.4 outlines the most common metaphor clusters (1-8) in order of frequency along with their occurrence within the twenty interviews. The eight most commonly used metaphor clusters were: journeying, altered reality, darkness, breaking, connections, fighting, salvation and being on the edge.

Table 6.4: Common metaphor clusters

Cluster number	Cluster title	Occurrence (in order of frequency)	Occurrence within interview sources (x20)
1	Travelling / journeying	87	16
2	Altered reality	59	12
3	Darkness and light	58	10
4	Breaking and crashing	57	11
5	Connection and belonging	51	12
6	Fighting and conflict	32	11
7	Salvation and strength	32	9
8	On the edge	20	9

6.7.2.1 Metaphors of journeying

By far the most common cluster found were journeying metaphors, used to express parents' circumstances through a course of time. This journey was often portrayed as a tumultuous and challenging ride or course through hurdles and barriers. The term 'long-haul' was used by three parents. Conversely, journeys for some gave opportunities for personal growth and hope and the move towards a final destination.

6.7.2.2 Metaphors of an altered reality

Entering the neonatal unit and being part of it for a considerable length of time often led to parents describing the experience as somehow not being real or being in another world. Frequent word counts were evident in the data for 'surreal', 'altered reality', a different or another 'world'. Parents also often described their baby in non-human terms; for example, animals and objects were commonly used such as 'little scrap', a 'ball with wires', a 'doll', 'tiny thing', a 'tiger'. Parents often linked this with difficulties or barriers to bonding. Such language may have been a way to protect themselves from the reality of seeing their baby in this way, which was often so unexpected and stressful particularly having to see their baby experience many unpleasant, but necessary procedures.

6.7.2.3 Metaphors of darkness

The neonatal unit was often regarded as a dark place where parents felt, in their words, trapped, imprisoned, institutionalised and isolated. The darkness portrayed here was often very profound and was revealed when parents spoke about the worst times during the neonatal care experience, for example, during periods when their baby was the sickest and may not have survived. However, hope and positive outcomes were conversely regarded as coming through the darkness and out the other side, 'into the light'.

6.7.2.4 Metaphors of breaking

Related to the above journeying metaphors, were those referring to crashing and breaking down in some way, often after discharge when realisation of the emotional

turmoil experienced in the neonatal unit came to fruition. This was a metaphor cluster that had solely negative meanings in relation to strong emotions and the toll that these emotions and experiences had on parents coping mechanisms. Eleven interviews had mention of either crashing or breaking in some way some significant periods after discharge in both mothers and fathers.

6.7.2.5 Metaphors of Connection

Parents voiced times when they were unable to bond or connect with their baby due to barriers but also the opposite, when they felt emotionally close. Metaphors of a bittersweet experience were articulated in relation to connecting with their babies. Mixed emotions were communicated too, for example, when babies moved to other units or parts of the unit or went home. Feelings of joy and elation were mixed with those of dread and fear.

6.7.2.6 Metaphors of fighting

The use of military metaphors by parents related to the perceived battle between the vulnerable baby 'fighting the odds' and coming through various conflicts or challenges along the way. Again, strength came out here in relation to that of their baby, battling through and 'winning' the fight. Generally, this cluster had very positive connotations rather than seeing 'fighting' as overly negative. Negative metaphors related to some conflicts encountered with staff in relation to differences of viewpoint or not being listened to, but these occurrences were not frequent.

6.7.2.7 Metaphors of salvation

Balancing the negative metaphors, were those that spoke positively about 'being saved' particularly in relation to how parents were treated by neonatal staff. 'Investment' in terms of time and emotional support by staff led to perceptions by parents of better outcomes in the future for their babies. In addition, while the baby may have been 'dehumanised' in many cases by the use of language, there was also the strength that parents saw within their baby. In other words, the baby themselves gave parents the strength to carry on.

6.7.2.8 Metaphors of being on the edge

With many parents, there was a consistent feeling of being 'on the edge' of something awful happening at any point when speaking about their baby particularly in relation to whether they would survive or not. Both mothers and fathers interviewed found this a very difficult subject to talk about. As for the breaking and crashing metaphors, this feeling of continual uncertainty continued for many parents, past discharge and into the community experience at home, highlighting both the short and long-term impact of the neonatal care experience.

6.7.3 Findings: How parents can inform our learning

The identified themes that emerged from the key question about what health professionals can learn from parents is now discussed. Overall, responses to this question revealed many areas in relation to how the parents wanted to be treated and what they felt was important for staff to be cognisant of, when caring for them and their

babies. The themes for learning identified by parents are outlined in Table 6.5. Five broad areas were identified regarding what parents saw as important in their care. These were, the importance of communication, listening to the parent voice, empathy and emotional care, acknowledgement of the parent role and the need for staff to realise and understand both parents' needs and what matters to them for a positive experience of neonatal care.

Table 6.5: Themes identified from parent narratives *'What can health professionals learn from you as parents, and your experiences in neonatal care?'* ***It is important for staff to……..…***
COMMUNICATE WITH US
<u>Communication includes:</u> How What When Who
LISTEN TO US
<u>Listening includes:</u> Being genuinely heard Parents having a voice Considering parents intuitive knowledge
EMPATHISE WITH US
<u>Empathising includes:</u> Delivering emotionally intelligent care Being sensitive care to the whole family Instilling humanistic values in care
ACKNOWLEDGE US AS PARENTS
<u>Acknowledging includes:</u> Including parents as part of the team Acknowledging the parenting role Facilitating parent involvement in care
REALISE OUR NEEDS AND WHAT IS IMPORTANT TO US
<u>Realising includes:</u> Understanding what is important to parents Enhancing the parent experience Delivering person-centred care

6.7.3.1 ''Communicate with us''

Parents identified the importance of full, open, honest information as early as possible which is consistent in the face of potential differences between neonatal units and staff members. The birth of a premature baby clearly put the parents under much emotional strain and effective communication was seen as a main factor contributing to making the parents' experience better. Communication is a frequently occurring area highlighted in other research that has explored parents' experiences in neonatal care. Whilst it is not always possible to prepare for the birth, effective communication is consistently highlighted as vital to reduce the impact of stress (Cockcroft, 2012).

6.7.3.2 ''Listen to us''

Being listened to in a genuine and consistent manner was also very important to many of the parents. They wanted to have a voice and be taken seriously when it came to identifying changes in their baby's condition and decisions about care included strong beliefs some parents held about how early care impacted on future outcomes of their babies. Literature has highlighted the need for neonatal nurses and other health professionals to take notice of the different needs of parents during their babies' stay in hospital (Mendizabal-Espinosa and Podsiadly, 2018).

6.7.3.3 ''Empathise with us''

Empathic, emotionally sensitive care was of significant value to parents during an often difficult and challenging period, as demonstrated in this study. The neonatal care experience poses many emotional challenges for families, parents and siblings that

require staff to be mindful of and for them to offer a compassionate approach to care while maintaining emotional intelligence. This concurs with a study that found empathic communication by staff as one of the main factors effective in reducing parental stress, providing evidence of the need to involve parents in an emotionally sensitive way from the beginning of their baby's stay in the neonatal unit (Enke et al, 2017).

6.7.3.4 ''Acknowledge us as parents''

Values-based care involving trust along with recognising and respecting parents as equal partners were regarded as important for them to feel their emotional needs were addressed properly. Parents also wanted to have acknowledgement and recognition of their role as a parent, to feel empowered and supported to engage in activities that made them feel like a parent and to be able to bond as a family. It has been shown that parents who partner with nurses and the healthcare team are better able to assume their roles as parents and overcome the stress associated with neonatal care. This is possible with creative partnerships that empower parents to build self-confidence and competence in their role (Fleck, 2016). Enabling the parenting role is vital and requires acknowledgement, careful support and nurturing (Vazquez and Cong, 2014).

6.7.3.5 ''Realise what is important to us''

Finally, parents wanted nurses and health professionals to realise and come to a genuine understanding of what is important for true person-centred, family focused care. Some parents verbalised the need for staff training in this area to ensure that parents' emotional needs were understood and considered throughout their neonatal journey.

Some referred to specific care practices that appeared to make their experience a more positive one such as facilitation of closeness by skin-to-skin, breast-feeding and developmentally supportive care along with being involved in the care of their babies. Again, the need for staff to realise how significant such practices were from the parents' perspective was seen as vital.

6.8 Discussion

The discussion addresses what can be learnt from these findings and how they can be used to inform the development of learning resources based on parents' stories. Again, there are three areas from which we can learn: Learning from Experience: Learning from Metaphors: Learning from Parents. The limitations of the study thus far are then discussed before moving to the next phase which focuses on the development of parent digital stories.

6.8.1 Learning from emotional experience

In relation to how parents described their experience of neonatal care, it was clear from the volume of data from the twenty rich, in-depth interviews, the sheer extent of an *emotional* narrative, both negative and positive that was threaded through. These findings further add to and concur with other work, where emotional experiences and intense feelings were identified (Turner et al, 2014; Williams et al, 2018). To give some examples; firstly, the emotional experiences voiced in negative ways such as distress, worry, anxiety and turmoil, are terms consistent with the aforementioned work of Crathern (2011), Flacking et al (2012) and Williams et al (2018). However, more positive views around coping

have also been referred to in the literature as emotional resilience, also cited by some parents in this study. Rossman et al (2017: 435) stated this as ''the ability to cope with and/or modify the effects of traumatic events by developing strategies to live a full and meaningful life''.

Parents' thoughts about their own baby were also congruent with Green et al (2015: 82) who stated a premature baby's appearance can challenge ''notions associated with the expectations of what a newborn infant should look like, feel like and behave like''. In relation to staff, the perceived value of the staff role in the provision of parental support (Turner et al, 2014) was seen in Trajkovski et al's (2016) work on collaborative family centred care. The parents' views on the neonatal unit environment as having a significant impact on their experience were consistent with various authors (Cleveland, 2008; Hall and Brinchmann, 2009; Williams et al, 2018) and certainly, providing an environment that encourages proximity and avoids physical barriers was seen to be a source of comfort, in line with the term 'emotional closeness' stated by Flacking et al (2016). For transitions within neonatal care, parents voiced mixed emotions commonplace through the whole trajectory of neonatal care (Ballantyne et al, 2017) including the often challenging experiences presented by these transitions or significant changes to care (Hutchinson et al, 2012). Regarding going home, accounts of emotional stress have been reported in recent literature in relation to parents' experiences after discharge following premature birth and the subsequent care (Blackburn and Harvey, 2018; 2019; Petty et al, 2018b; Premji et al, 2018).

The findings highlighted the different types of emotions that parents felt. Classifying emotions according to whether they were positive and negative is congruent with a traditional approach where emotions are categorised dichotomously, as unpleasant or pleasant, activated or deactivated, as explained by An et al (2017) who cited Plutchik (1980) and Russell (1980). Andries (2011), for example, outlined four main positive emotions (joy, happiness, gratitude and well-being) and four main negative emotions (anger, fear, envy and jealousy), all of which occurred to some degree within the whole parent data set of this study. However, An et al (2017) pointed to this mode of classification being difficult to reconcile with more current views on emotion that do not consider a single continuum from positive to negative and they argued that each emotion contains some degree of *both* negativity and positivity.

Whilst trying to make sense of emotions in the context of comprehending experience, what often makes them negative or positive is the context in which they occur, in this case the neonatal care trajectory. As Nezlek and Kuppens (2008) said, emotions are central components of people's lives, both interpersonally and intrapersonally. Indeed, both positive and negative emotional experiences can have a powerful impact on people's functioning as was the case in this study. All parents expressed negative emotions to some extent within their narratives, often explained in a way that suggested they found it hard to cope or that the experience was difficult for them. Conversely, positive emotion was expressed by parents more during periods of progression and hope, when their baby's outcome was more favourable and difficult periods had passed, when speaking about the love for their baby or gratitude towards staff.

Addressing the positive and negative emotions was deemed important in this study to bring out and balance the reports of experience, since very little literature exists on positive experiences to offset negative encounters that appear to be more commonplace. Indeed, some experience has a negative impact on parents, but much is also very positive. Indeed, in an educational context we can reap benefits from both sides by aiming to improve poor experiences of care or conversely, learning from good practice that is reported positively. This concurs with Janvier et al (2016: 3) who recommended to both clinicians and researchers that they should examine outcomes of neonatal care in relation to "both sides of the story". This study agrees and would extend Janvier's key point to educators too. Franck et al (2017) concurred and presented both positive and negative parent findings in their work on parent experience.

A key area in relation to the impact on practice was that there is an obvious and vital need to deliver emotional support to both mothers and father. Indeed, parents have identified that the support tailored towards the emotional aspects of their experience is essential (Toral-López et al, 2016). In view of the depth of emotion verbalised about their experience and their baby, the first two themes highlighted, it is clearly imperative to minimise parents' feelings of exclusion and increase participation supported by Wigert et al (2006) and to encourage bonding as early as possible. Enke et al (2017) would agree with this and propose that health professionals working in neonatal care can enable communication in an empathic way and work to reduce stress in parents, particularly those at greater risk of developing psychosocial issues. The neonatal team could consider creating an environment where parents' emotions are individually supported and their emotional

journeys recognised (Flacking et al, 2016). Staff can also be mindful of their valuable and unique role in assisting parents to cope with their emotional challenges.

In relation to the staff theme, neonatal units can ensure adequate staffing and education for healthcare staff including how to support emotional needs and how to facilitate sound communication with parents ensuring there is an optimal physical care environment for families (Wigert et al, 2014). Cleveland (2008) identified four key nursing interventions to help parents in addressing their psychological needs. These were provision of emotional support, enabling of parent empowerment, ensuring a conducive environment for parents to meet their needs and parent education including the encouragement of parents to practise new skills with guided participation. It is interesting however that since this paper, emotional care continues to be highlighted as an important need. This also provides rationale for integration of this area into staff education programmes and / or resources.

In addition, learners can be taught about how to provide an optimum environment for parents in relation to the fourth theme of this current paper (Hall and Brinchmann, 2009) that supports their practical and emotional needs. The physical environment can be thought through carefully with comfort and family inclusion in mind, in line with the delivery of safe, clinical care of the baby. This can happen in conjunction with staff education on the importance of communication and empathic care (Williams et al, 2018) emphasising how all these areas link together to facilitate ongoing emotional care.

The significance of transition experiences can also be included in any resource development, in relation to the fifth and sixth of the themes. Parents, as seen in this study,

go through many transitions following the birth and admission of their baby to neonatal care. These include the different aspects of hospitalisation, the various transfers between dependency levels and healthcare settings, all occurring during the period of transitioning to the parent role. Such transitions can clearly pose a challenge to parents who are already feeling vulnerable and stressed. Therefore, raising staff awareness of these significant moments in the parents' journey is required so that they can focus on opportunities to improve parents' early transition experiences. As Ballantyne et al (2017: 783) acknowledged, this includes ensuring staff-parent engagement, communication, information-sharing and decision-making that is shared between both parties, continuing through the whole ''illness-health trajectory''. In addition, these authors highlighted the importance of a focus on early transition strategies to nurture parent confidence, their competence in the parenting role and ongoing closeness to their babies.

6.8.2 Learning from metaphor

The findings from the descriptive analysis of metaphors can also inform us about the parent experience to further support other literature in nursing that has commented on how metaphor can be a powerful expression of emotion and experience (Jairath, 1999; Shinebourne and Smith, 2010; Warne and Stark, 2004; Laranjeira, 2013). The words and metaphors employed by patients often emphasises their emotional response to care and helps patients explain the depth of feeling about their experiences (Richardson and Grose, 2009), as seen in the current study.

In addition, the metaphors revealed in this study add to findings from limited neonatal research highlighted earlier. As well as commonalities, different metaphors have

emerged from this study such as being in an altered reality or another world, being on the edge and breaking or crashing further 'down the line', highlighting both immediate emotional challenges as well as the potential ongoing effects of their experience.
The findings within the reported evidence base as well as those of the current study have implications in relation to the role and usefulness of metaphors within neonatal care. Being able to express experience using metaphors can help both parents and those who care for them to make sense of this experience, enabling a poignant and evocative way to communicate. This is vital given the evidence on the emotional turmoil experienced by parents and the challenges in relation coping with the stress and certainty of having a sick, premature baby that is well recognised in the research (Blackburn and Harvey, 2018; 2019; Turner et al, 2014; Spinelli et al, 2016).

In addition, the need for effective communication as identified by parents (Obeidat et al, 2009; Weis et al, 2015; Fleck, 2016; Flacking et al, 2016) is an important area. Metaphors may serve to overcome communication barriers when parents are faced with difficult explanations particularly since this is regarded as a significant challenge (Biasini et al, 2012). In such cases, concrete language may not be enough for them. This was seen in the parents' narratives within the current study in that metaphors enabled parents to express how they felt at challenging moments during their neonatal experience and the 'nightmare' of having a sick, premature baby. Another element of metaphor in relation to verbalising difficult emotional issues was the way in which they bought distance to the parents' experiences. Avoiding the harsh language of possible death and the uncertainly of survival, metaphor allowed parents to speak about their feelings in a different way. Spall et al (2001) agreed that people use metaphors to avoid using difficult words like

death and so can express how they feel without using words which may upset them or others. However, one can also argue whether this avoidance of expression of emotion is to be welcomed and that this may lead to people not being truly open about their feelings.

Given the emotional needs highlighted, nurses, health professionals and indeed students learning about this area of practice can gain knowledge about the parent's experience to inform more empathic care. Indeed, studies show that metaphors can assist students to understand new, complex concepts in nursing education (Faulk and Morris, 2010). Nurse educators can use metaphors in planning learning activities to enable student and staff visualisation of ideas and concepts. This is applicable to the notion of metaphors and their contribution to learning, in line with what Clark and Rossiter (2008) and Gazarian (2010) call narrative pedagogy. Condon (2012) applauds the use of metaphors to enhance teaching and learning while at the same time warns of caution to guard against potential misunderstandings, a point raised earlier. This is considered later as a limitation.

However, there is still a case for the value of using metaphors when describing the emotional experience of parents in neonatal care. Metaphors provided a unique opportunity to learn about the parent experience. They can allow researchers, nurses and health professionals to view others' experiences with different viewpoints, by seeing what people experience and feel. They can create new meanings to enhance one's knowledge in line with the principles of constructivism and arts-based knowledge translation. Metaphor is one way of opening opportunities for creative and new possibilities (Sharoff, 2009; Malinski, 2009) in this context, for learning and teaching.

Southall (2013) saw metaphors as tools of creation with a potential for learning resource development based on narrative. They can capture and teach the complexities of the parents' emotional experience so that others can be taught to understand and empathise with them.

Nurses, health professionals and students in neonatal care require an understanding of parent experiences and feelings, so that emotional care is given in a person-centred, humanistic way responsive to their needs. Literature concurs, highlighting the need for neonatal staff education on empathy and other elements related to parental emotional experience (Turner et al, 2014; Weis et al, 2015). In line with narrative pedagogy, metaphors can play a key part in teaching and learning in that they can add clarity and depth to explanations, providing an opportunity to explore topics from creative and novel perspectives (Sharoff, 2013a). They can be perceived as being a window to one's inner awareness and insight (Sharoff, 2013b) and importantly to this context, the emotions of others.

Given the importance placed on emotional care of parents, the connection between narrative, metaphor and empathy needs emphasising due to the part that narrative and metaphors can play in the enhancement of empathic learning. Cameron (2011; 2012) linked metaphor closely with the connections between each other and believes that this can enhance empathy. If we can better understand parents' experience, we can then act to improve this if necessary. For example, by identifying the negative metaphors expressed in narratives, we can better understand such difficult moments and hopefully act to reduce these and make parents experience better. Overall, specific interventions

can be targeted based on metaphors expressed by parents, to help them emotionally (Beck, 2017).

6.8.3 Learning from parents

Parents in this study identified a range of issues that contributed to making their care experience both better and worse. It is clear that the benefits of integrating the family in care cannot be disputed (O'Brien et al, 2015) and has the potential to improve short and long-term infant and family outcomes such as reduction in parental stress. Other work concurs with these findings proposing that the implementation of interventions focused on reducing parental stress is crucial, to make the parent experience a more positive one. The study by Blackburn and Harvey (2019) commented on the timing and amount of information given to parents, vital for them to be prepared for the neonatal experience in relation to their immediate and ongoing care needs. The need to support parents on their emotional journey was emphasised in this study. Optimal information giving and ongoing, tailored support can then diminish negative consequences in family emotional health (Baía et al, 2016). Family integrated care (FIC) is an example of a strategy to ensure this occurs. It is vital to educate neonatal staff and students about such an approach to encourage active involvement of parents in the care of their baby on neonatal units (Skene et al, 2016; Patel et al, 2018).

The current study provides further support to add weight to any recommendations needed to improve the parent experience. In addition, what requires attention is how to educate about these key themes and integrate knowledge gained from the parents'

experience into the essential learning for all staff who work in this specialised and complex area. It is acknowledged that neonatal specific education must include care which promotes positive infant development along with family emotional stability aimed at enhancing parent–infant relationships (Picker Europe, 2015). Such core skills and knowledge must form the basis of a developmental and family-based approach to care which must be taught to those learning within this field (Turrill, 2014) .

Based on these findings, in conjunction with other key literature referred to, a parent-informed framework outlining what students and staff should know about the experience and needs of parents has been developed. This model was devised by the author using the key themes from this part of the analysis as a way to teach and capture core elements relating to what is important for parents. The model has been named as the mnemonic 'CLEAR': Communicate, Listen, Empathise, Acknowledge, Realise and is depicted in Figure 6.1. Moreover, specific examples of 'CLEAR' strategies informed by the parents themselves can be seen in Table 6.6. These align with research that has led to recommendations for supporting parental roles as caregivers of their babies in the neonatal unit, facilitating neonatal staff commitment to true family centred / integrated care and creating policies that support the emotional needs of parents (Craig et al, 2015; Franck et al, 2017).

Figure 6.1: The 'C L E A R' Approach to understanding what is important to parents

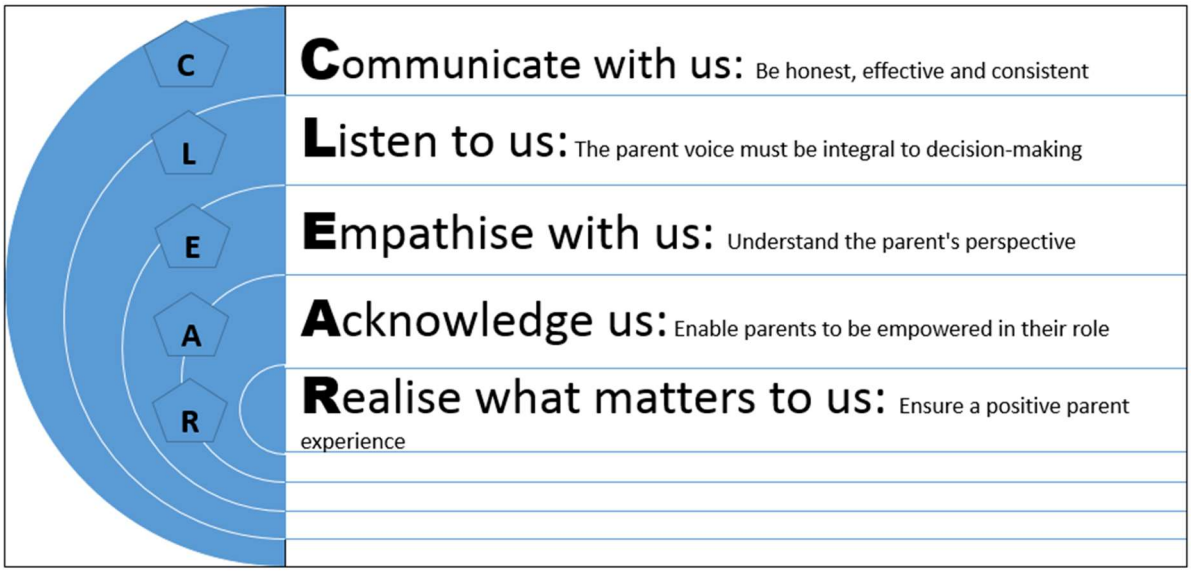


Table 6.6: 'CLEAR' Strategies for ensuring person-centred care of parents		
COMMUNICATE WITH US		
C	**What parents said** Give open and honest information consistently throughout the neonatal unit stay, starting as early as possible.	**Examples of strategies** • Tailor / individualise information needs for parents • Consistent and high-quality information as well as a supportive education programme • Train all staff in effective communication skills
LISTEN TO US		
L	**What parents said** Being properly listened to and having a voice enables parents to feel that they have a role in their baby's care. Parents feel that they have vital, intuitive knowledge that needs to be taken seriously.	**Examples of strategies** • Providing parents with the opportunity to participate in multidisciplinary rounds • Parents' opinions to be heard by regular discussions • Planned, scheduled meetings based on parent reflection (consider 'Guided Family centred care' – GFCC (Weis et al, 2015) • Involve parents in decision-making as part of the multi-disciplinary team

EMPATHISE WITH US		
E	**What parents said** It is essential to give parents emotionally intelligent care. This includes the instillation of values such as honesty and trust. The whole family including the father and siblings must be cared for emotionally and practically.	**Examples of strategies** • 'Psychosocial' strategies such as implementing staff-parent mentors, 24/7 parent presence and facilitation of parent peer support groups. • Provide psychological support for parents when required involving other professionals, charity links or volunteers in key parent support / pastoral care roles. Consider employing mental health practitioners / psychologists / counsellors. • Provide key support for discharge and follow up. • Screen for and normalise emotional distress. • Offer relaxation exercises (Fotiou et al, 2016)
	ACKNOWLEDGE US AS PARENTS	
A	**What parents said** Parents should be a vital part of the team. The importance of the parenting role must be acknowledged. The need to be involved in their baby's care contributes greatly to feeling empowered and having an essential role.	**Examples of strategies** • Family-Integrated Care (FIC) (Lee and O'Brien, 2018; Patel et al, 2018) • Parent involvement / participation in care (Ottosson and Lantz, 2017) • Include the whole family; fathers (Stefana et al, 2018; Noergaard et al, 2018), siblings (Morrison and Gullon-Rivera, 2017) and grandparents in care and visitation policies. • Educate parents and empower them to be "experts" in their baby's care and participate in the care team as equal partners (Platonos et al, 2018) • Provision of a 'coherent' environment (Thomson et al, 2013) conducive to FIC: e.g.: rooms for relaxation, peer contact and 'rooming in', kitchen and shower facilities, 24-hour parental access with no limitations during shift changes or rounds.
REALISE WHAT IS IMPORTANT TO US		
R	**What parents said** Staff must realise and understand what parents find important in making their neonatal experience a more positive one. Staff should be cognisant with not only the physical care of the baby but also the emotional and psychosocial needs of the parents / family to ensure care is truly person-centred.	**Examples of strategies** • Education and training for students and staff in the principles and importance of family centred care (Roué et al, 2017) and family-integrated care (see above). • Training is imperative for staff in the specific care interventions areas identified as having a positive impact by parents: e.g. effective pain and stress management, facilitation of breast-feeding and lactation support, skin-to-skin contact, developmental care and the more difficult ones relating to emotional care; e.g. breaking bad news (Macdonell et al, 2015)

6.8.4 Limitations

Before moving onto phase 2, the limitations of the current phase need discussing. The various criticisms associated with a narrative, interpretive approach relating to the subjective nature of the data collected and the meanings taken from it, have been discussed in chapter 4. Furthermore, as highlighted in chapter 2, possible misunderstandings may arise if narratives are interpreted or used differently to the original intended story, referred to as 're-storying', hence the need to ensure 'narrative vigilance' was applied to the data. It was important to address rigour in terms of the strategies employed to 'cleanse' the data and maximise authenticity and 'truth'. Authenticity was important in terms of truthfully depicting the parents' experience and to do them justice. It was important to establish the authenticity of what had been told, known as trustworthiness (Noble and Smith, 2015) and to adhere to key strategies documented to enhance this (Appendix 1). As seen in Chapter 4, an example of this was demonstrated by referring the original interview transcripts back to the participants themselves to verify the interpretations of their own narratives. This was done with the parents, remembering that these constituted their own stories, their own truth and even though others may have interpreted events differently, it was vital to stay true to the parent's version. If the parents themselves verified their own truth, then this was deemed authentic.

Another issue to consider was the nature of recruitment. While this was not difficult in that parents were forthcoming as volunteers, the ability to control who came forward was limited, due to sampling being on a volunteer basis. All parent participants in this study were mothers of white Caucasian ethnicity. This type of recruitment can limit the

spread and range of respondents required (Barbour, 2001) across gender and ethnic groups. Therefore, the participants were not representative of a range of different backgrounds. Further investigation of the perspectives of parents that incorporates more fathers and participants from a more diverse range of ethnic and cultural backgrounds would be useful to make the stories reflective of a much wider range of parents who have premature babies in the neonatal unit.

It was also necessary to consider the potential limitations of metaphor. As highlighted previously, there may be a concern that one can create over- simplified and even false representations of concepts being taught when using metaphor (Low, in Gibbs, 2008) leading to misunderstandings (Jarvis, 2005). In addition, misusing metaphors may undermine or act as a deterrent from an intended research question. Using metaphors that do not fit the data or are not appropriate to represent experience can lead to misrepresentation as Carpenter (2008: 274) stated, ''the choice to use metaphors should not become a self-serving attempt at creativity that supersedes subject and substance''. While metaphors can afford opportunities to pinpoint and explore unspoken or tacit behaviour and knowledge, Hagar (2008) regarded them as ''discursive constructs'' in that people use them to talk about subjects for longer than is necessary or appropriate. Bleakley embraced the use of metaphors and similes but conversely, he also stated that they can distort true meaning (Bleakley, 2017; 2019). While healthcare and medicine commonly use metaphors, for example, the body as a machine or object and /or treatment as war / conflict, he acknowledged that this type of language may conflict with person-centred values for care. Indeed, metaphors can sometimes be too negative, for

example ‘losing the battle’ can be seen as questioning whether the patient fought hard enough (Khullar, 2014). Elliott (2019) suggested that battling metaphors hold the suggestion that patients who then succumb, have failed. This view stemmed from Sample’s (2019) report of a yet to be published research study that found war metaphors can be more harmful than beneficial for cancer patients, for the above same reason. Battling against the odds was seen in the parents in this study. However, interestingly, this was more of a positive element of their journey through the different transitions of neonatal care. We must be mindful of the positive metaphors used to balance the negativity which many metaphors are associated with (Periyakoil, 2008). We should remember, among the challenges and emotional distress, the strength and resilience of many parents during their neonatal experience. In line with this, Sfard (2014) sees metaphor as a ‘double edged sword’.

However, while acknowledging the critique of metaphor, the cited above authors do agree that metaphors play some part in our construction of reality and that people use them so frequently, being often incapable of thinking about learning without using metaphors of some nature. This was certainly the case in the current study which came to light when analysing the lengthy, in-depth interview narratives of parents, hence the reason this aspect became a significant area of interest.

6.8.5 Implications for practice

It is clear from the findings of this first phase, that there are important implications for future practice relating to neonatal education. Education should include an

understanding of the parent experience informed by parents themselves to enable sensitive and effective communication required for partnership working (Aloysius et al, 2018b; Hall et al, 2016) and for the approach to care to be truly integrated and person-centred (Weis et al, 2015). Humanistic care should meaningfully align and be tailored to parents' needs to achieve and promote positive well-being and emotional health for them (Thomson et al, 2013). If learners and staff receive education on the psychoemotional needs of parents, as identified by the parents in this phase, knowledge relating to the variables associated with stress can then be used to provide better supportive emotional care for parents (Turner et al, 2014; Baía et al, 2016) and a more empathic workforce.

The findings of this phase of the study generated important insights into what parents needed, to feel emotionally close to their babies and supported adequately. This knowledge contributes to an increased awareness of how to support parents of premature babies to form positive relationships with their babies and to improve their experience. Students and healthcare staff should create a climate where parents' emotions and needs are individually supported (Flacking et al, 2016). One of the best ways we can create such empathic students and staff is to have them listen to the perspectives and stories of parents themselves. Learning from the parents in our care may enable a greater understanding of their experiences at difficult and challenging times. It is proposed in this study that having a deeper appreciation of parents' experiences can contribute to enhanced empathic learning. Designing learning resources that are informed by the parents themselves may ensure that we can better meet the emotional needs of parents so that neonatal education is truly person centred.

6.9 Summary: Phase 1

The study thus far has focused on the analysis of parent narratives, based on their experiences to be used for learning resource development and, in turn, for further exploration of empathic, person-centred understanding. The three aspects of analysis of parent narratives within this phase of the study has been published in three respective, peer-reviewed papers (Petty et al, 2019a, 2019b and 2019c). In order of publication date, firstly, 'Understanding parents' emotional experiences for neonatal education: A narrative, interpretive approach' (Petty et al, 2019a) aimed to report on the emotional experiences of the parents described in this chapter, with a specific focus on the first level of analysis (parent emotional experience). It concluded that understanding the emotional experience from the parent's perspective, following birth of their premature baby can inform empathic, family-centred teaching and learning within the neonatal education arena. Relevance to clinical practice was discussed in relation to how students and health professionals alike can learn what is important in the delivery of care that addresses the emotional needs of parents and families and how educators can use narratives and key messages from parents, both negative and positive, to teach family-centred principles to nurses and health professionals as a core component of a narrative curricula and potentially to enhance empathy. Secondly, 'Listening to the parent voice to inform person-centred neonatal care' (Petty et al, 2019b) focused on what students and staff can learn from parents about what they feel is important to make their experience better, the third level of analysis. The paper described the five key themes relating to the importance of: communicating; listening; empathising; acknowledging (the parent's role); realising (what matters to parents). It discussed the development of the 'CLEAR'

framework and explained that this highlights what parents want staff to be cognisant of when caring for them and their babies. Again, the paper concluded that learning from the parents in our care enables a greater understanding of their experiences at difficult and challenging times and that having a deeper understanding of parents' experiences can contribute to enhanced empathic learning. Thirdly, 'Using parent metaphors for learning about the neonatal care experience: an interpretive perspective' related to the second level of analysis; how metaphors were used by parents to describe their neonatal care experience and how these can contribute to empathic learning of health professionals. It discussed the common metaphors used to describe experience and concluded that parents widely used compelling and emotive metaphors to describe and express both difficult and challenging times as well as progression forward. The relevance to practice was highlighted in how metaphors serve as a powerful way for health professionals to learn about the emotional experiences of parents and potentially enhance their empathic understanding.

Chapter 7: Phase 2: 'Representation' of narrative (creating the parent stories)

Study timeline	Digital outputs and Publications
PART 1: Exploring narrative approaches and concepts (Chapters 1-4)	
• Chapter 1: Introduction • Chapter 2: Underpinning theory and concepts • Chapter 3: Design and methodology • Chapter 4: Working with Narrative: An Initial study	My Digital Story: Into the Light Petty (2016a) Publication Appreciation of the neonatal care experience through the eyes of student nurses. Storytelling resource Petty (2016b) Publication Petty (2017a) Publication Petty and Treves (2017) Publication
PART 2: The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students (Chapters 5-10)	
PHASE 1- 'Attention to narrative' – Exploring the parent's experience (Chapter 6)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	Petty (2017b) Publication Petty et al (2018a) Publication Petty et al (2019a) Publication Petty et al (2019b) Publication Petty et al (2019c) Publication
PHASE 2- 'Representation of narrative' – Creating the parent stories (Chapter 7)	
• Introduction • Aims and research question • Background • Methods • Analysis • Outputs • Discussion	Digital Stories Creating and telling Stories in Neonatal Care Another World On the Edge Connections Fighter Our Salvation The Long Haul Ahead Out of the Darkness Bittersweet
PHASE 3- 'Affiliation to narrative' – The impact of stories on empathic learning (Chapter 8)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	The Value of digital stories in neonatal care- Your views. – Evaluation Survey Neonatal Stories Website

7.1 Introduction

Phase 1 highlighted that there is a need to teach students and staff about the emotional care of parents that includes an awareness of person-centred, empathic understanding. Clear, potent emotional themes came through from parents congruent with the term 'narrative messages' outlined by Frank et al (2015) that communicate needs and feelings. The question now, in line with the study's conceptual framework for phase 2, is how to '*represent*' the parent narratives so that these powerful messages can be relayed to the learner. The focus turns now to the development of digital stories based on parents' emotional experiences.

This chapter discusses background evidence relating to digital storytelling. It also provides an overview of digital storytelling development used in this study with links to three of the final digital story outputs. The discussion section sets the scene for the final phase which evaluated the digital stories with student and staff participants and explored further, the connection or 'affiliation' between digital storytelling and empathy.

7.2 Aims and research question

The research question for this phase was: 'How can parents' experiences be represented as stories?' The aim was to develop a collection of stories informed by parent narratives represented on a digital platform to use for learning and teaching of student nurses and health professionals working in the neonatal field of healthcare.

7.3 Background

The background evidence focuses on story format and the nature of digital storytelling specifically. Rationale for the choice of using a digital approach is offered before discussing the different ways that digital stories can be created within the context of constructivism.

7.3.1 The advent and nature of digital storytelling

As Barber (2016) said, to consider digital storytelling, we should first discuss traditional approaches. Chapter 2 discussed the use and potential value of stories and storytelling generally in education and healthcare, drawing on distinctions between fact / true-life stories verses fiction. Indeed, stories take many forms in which people's experience can be *represented*, each one with its own benefits and weaknesses. Learners may be more suited to one over another, due to their preferred style of learning, important for educators to consider when constructing resources and planning curricula.

Moon and Fowler (2008) remind us that stories can be imaginary or real accounts of one's own or others' personal experience, highlighting a distinction between fiction and non-fiction. Stories may be oral or written, or depicted in drama, dance, music, film, television, drawing, cartoons although mostly it is the written word that traditionally has received most interest. When 'story' is used in an educational context, we must assume the material will be shared with others or communicated for learning. This is not to ignore the fact that, according to narrative theorists, we spend much of our thinking time

as individuals and living our lives through stories. This connects us back to the ontological perspective of narrative theory.

As highlighted earlier, it is important to reiterate how story has the power to depict a strong affective content and move people emotionally. The Health Foundation (2016) website encapsulated this well, stating: ''Stories take many forms, but they usually have some elements in common. Rather than a list of dry facts, stories have a narrative or sequence and they introduce people or characters. We respond to stories, particularly when there is emotional detail, and remember information given in story form much more vividly''.

This leads onto the notion of story in digital format specifically. It is the abovementioned communicative and emotive aspects of stories in an educational context that makes digital storytelling so attractive for this study. Robin (2008) believes that digital stories have the power to communicate compelling narratives particularly of an emotional nature in creative ways, due to the varied types of media available that can be blended together imaginatively.

Digital storytelling, by combining narrative with a variety of digital content, typically has a strong emotional component (Price et al, 2015). The practice was originally developed by Joe Lambert and colleagues in San Francisco in the early nineties in line with the move to more affordable and user-friendly personal computer technology and digital editing software that came into being at this time. Lambert regarded it as a creative arts process used to capture personal stories with images and sound in a three to five-minute digital

clip (Lambert 2010). The variety of multi-media, visual appeal and timing are important aspects to capture the user's interest and keep their attention. Lambert (2010, 2018) also emphasised the inclusion of emotional content for dramatic effect in depicting the point of view of another's experience. Since its advent, digital storytelling has been used in many contexts including education, business, political arenas and, relevant to this study and the current chapter, healthcare.

Robin (2016) categorises digital storytelling into three categories: *personal narratives*; stories that contain accounts of significant incidents in one's life; *historical documentaries*; stories that examine dramatic events that help us understand the past, and *stories that inform or* instruct the viewer on a concept or practice. There is an element of each of these three categories within the stories of parents who have been through the neonatal experience. Firstly, this is certainly a significant event for all of them, secondly their personal narratives often include particular dramatic events and thirdly, they serve to inform learners about the practice of caring for the emotional elements of neonatal practice. Literature concurs, reporting that the presentation of stories on a digital platform enhances engagement and reflection (Boase, 2008; Renda, 2013), key elements of learning which in turn, enhances their emotional effect (Educause, 2007, Matthews, 2014). Digital stories have been described as ''short, personal multimedia tales told from the heart'' by Meadows (2019; cited by Robin, 2019) again, emphasising their emotive nature. If people are moved emotionally, this engages their mind at an affective level, and we can learn about others' experiences. Barrett (2006) and Schwartz (2012) refer to the potential of digital storytelling as a 'deep learning tool', consistent with the notion of enhancing engagement.

Within healthcare, both Grendell (2011) and Gazarian (2010) have explained how digital stories are a form of narrative pedagogy that can help transform learning by supporting a more holistic approach to patient-centred care and enabling nurses and health professionals to understand patients, their emotions and experiences. Digital storytelling has also been defined as an arts-based research method that has the potential to meaningfully capture peoples' experiences and share research findings in an engaging manner (de Vecchi et al, 2016, Gubrium et al, 2014). There are strong links therefore between emotion, engagement and learning.

7.3.2 Rationale for digital storytelling

The strong emotional element of digital storytelling was a significant factor in the decision to use it as the platform on which to represent the parent experience in this study. An important conclusion was identified from a recent literature review that examined the findings of sixteen studies within healthcare on the use of digital storytelling (Moreau et al, 2018). This was that, interestingly and perhaps contrary to what would be expected, patient only / 'talking head' type digital stories were not found to have an obvious positive effect on learning. Conversely, stories that were co-constructed, usually between the creator and the patient, were of greater benefit to learning. This served as one aspect of rationale for the approach used in this study.

In addition, previous research by the author on teaching neonatal-specific biology to students that compared a digital approach to a more 'traditional' text-based resource, found that the former was more effective for learning (Petty, 2014). This was reported to be due to increased student interaction and engagement, supporting an earlier literature

review that concluded how technology- enabled teaching was beneficial due to its enhanced ability to capture the user's attention and engage them in learning (Petty, 2013). Research in other fields have also reported benefits to learning which may be attributed to students becoming engaged and motivated when using digital storytelling for knowledge creation (Niemi and Multisilta, 2016). Finding an alternative to text-based stories was congruent with the current digital era where students use online and technology-based resources as a major part of their programmes of study. Therefore, it was fitting to develop resources that harnessed new and innovative technologies.

Further rationale for the use of digital storytelling related to a gap in research that has explored the effectiveness of digital stories based on the narratives of research participants. There is also a dearth of digital resources in neonatal care specifically leading to a desire and determination to address this limited availability and find an alternative approach to current traditional teaching methods, to enhance understanding of the neonatal care experience. Another strong influencing factor was the aspiration to share the stories with learners widely on a readily accessible, open-access online platform.

7.3.3 Digital story creation

Having answered why digital stories were chosen, the next question was how to develop them within a constructivist approach, cognisant with the underpinning theoretical framework of narrative, interpretive inquiry. Many studies that have explored the effectiveness of digital storytelling in healthcare have been undertaken within

undergraduate nursing (Moreau et al, 2018). This finding may reflect the emphasis that nursing places on lived experiences, the use of constructive frameworks and collaborative learning in educational practices. Peters (2000) explained this clearly; constructivist epistemology offers an alternative to traditional pedagogy in that it is student focused and considers previous learning by the students as a foundation upon which to modify, build and expand on new knowledge. Constructivism also appears to be congruent with adult education theory and therefore offers great potential for the enhancement of self-directed learning. It enhances empowered learning due to the consideration of prior knowledge and the ownership of learning by the students. In the context of this study, Daskolia et al (2015) proposed that constructivism has established itself as an epistemological paradigm, a learning theory and a design framework, in conjunction with the advent of digital media.

The link between constructivism, knowledge acquisition and learning about experience of others was summarised by Jonassen et al (1999). They regarded learning as an active, engaging process in which the learner uses sensory input, obtains knowledge and constructs meaning out of it. This reminds us that learning is contextual and is a social activity: in other words, it is intimately associated with our connection with other human beings. In relation to the neonatal field, this concerns learning about the experiences of parents. How digital resources are designed for constructive learning (Duffy et al, 2012) applying this perspective to learning with technology (Jonassen et al, 1999) is now discussed in relation to digital story development.

The process of constructing a story requires numerous cognitive strategies to come into play, such as selecting, inferring, arranging and revising information. The process leads to the construction of a new story or narrative based on existing information, reflection and evaluation (Boase, 2008). This view is very relevant to the present study. Making and telling a story transforms it from its raw form and makes it more real. Storytelling requires the active use of prior knowledge and experience, thus enriching the cognitive resources which are available for future narrative thought and analysis (McDrury and Alterio, 2016).

A key writer on constructivist approaches to digital storytelling is Smeda who acknowledged that according to constructivism, teaching is a co-construction of knowledge between learner and teacher with further transformation of that knowledge into individual student knowledge (Verenikina 2008; Dakich, 2008 cited by Smeda et al, 2014). Digital storytelling can thus facilitate a constructivist approach by providing a vehicle for combining digital media with experience from practice. It encourages learners' motivation and helps educators in building learning environments that facilitates them to construct knowledge based on the reading of real stories and the influences of these (Smeda, 2014; Smeda et al, 2010). By enhancing emotional awareness and empathy which lie at the heart of this study, digital storytelling can be used to engage learners in higher order thinking and deep learning (Dakich, 2014). Consequently, it is a powerful model for creating constructivist e-learning environments (Smeda et al, 2014).

There are many papers that have focused on the development of digital resources. An example is seen in a study that designed and implemented a case study approach in a digital format guided by a constructivist perspective on support for learning. Bacigalupo

et al (2003) facilitated active individual and collaborative learning, through engagement in a series of linked problem-solving tasks, and offered a means of integrating theoretical and experiential perspectives. However, this work was a case study approach of change management rather than having a patient story *per se*, at the centre.

Looking at work on patient-focused storytelling within health, there are examples available that have been implemented and evaluated. For example, Moon and Fowler (2008) discuss a story telling project by Greenhalgh that taught health professionals about patients' experiences of diabetes. This had positive results on the insights and understandings of participants, although was not a digital resource. One can argue whether storytelling resources need to be digital. However, in view of the dissemination opportunities and the current importance and usage of online platforms as discussed earlier, it is more fitting to have a technology enabled resource. Examples of digital resources in health include a narrative film focusing on human papilloma virus (Frank et al, 2015), a five-minute narrated digital story on palliative care (Price et al, 2015), a genetic resource comprising numerous stories from those with varying conditions (Kirk et al, 2013) and a range of other illnesses and conditions told by the patients themselves on a multi-media platform (Christiansen, 2011; Fenton, 2014; Fix et al, 2012; Gidman, 2013). Overall, from methods used in such work, valuable insights are generated about the pedagogic principles likely to encourage ''transformational learning and patient centred practice" (Christiansen, 2011: 292).

It is clear that many exemplars of digital story development exist in varying forms while sharing commonalities in the methods used such as the use of patient stories of

experience, multi-media presentation and the encouragement of user engagement, shown to be essential with technology enabled learning tools (Petty, 2013, 2014). The importance of looking at others' examples of digital resources was to guide the methodology for this phase regarding how to build them and what to include. This was challenging given the multitude of different examples that exist and the actual detail of how they were developed is generally not available. To make sense and in some way consolidate the differing models, it was necessary to base the approach on work that fitted with a humanistic, storytelling approach but also gave a structured way to work and develop a resource. Specific examples have been selected therefore with these aims in mind.

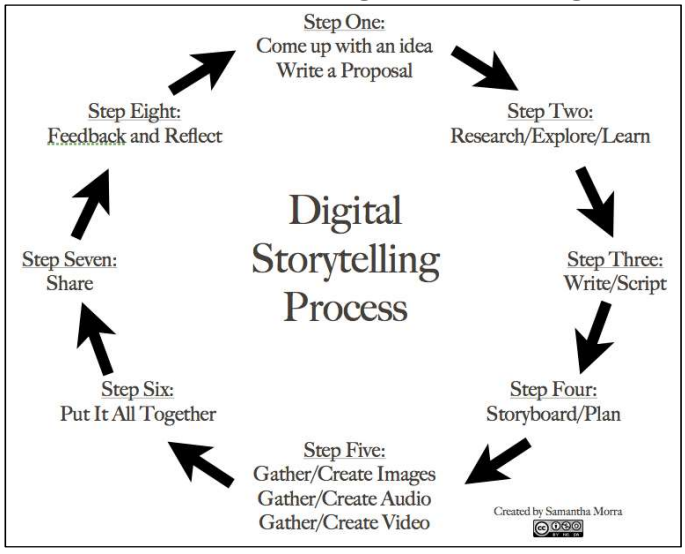
Firstly, Lambert's (2018) seven-part framework for the conception and development of digital stories was grounded in seven elements of constructing a multimedia story with an emphasis on the storytelling process. The seven elements of digital storytelling included point of view, emphasis on the dramatic question, emotional content, the gift of the storyteller's voice, soundtrack, economy (relating to time) and pacing. Each element built upon the next to create a dynamic and meaningful story. These principles of good practice are part of ensuring sound pedagogy.

D'Alessandro et al, (2004) proposed similar elements to be built into digital storytelling development including: the telling of individual, memorable stories based on real patients and their own words, emphasising the holistic problems faced by the patient and family and de-emphasising the disease the patient has. The authors stated that any resource should also be written at the appropriate level, used for independent study by health

professionals locally and nationally and take a limited amount of time for students to work through and author. This last point is debatable due to previous experience with developing digital resources and realisation of how much time this takes. The task of reducing full length stories down to a manageable length and format for a digital platform presents a challenge requiring adequate preparation.

Overall, there is an emphasis by these authors on memorable, patient stories. The digital template developed by the above authors includes the patient's story at the centre, or in this study context, it is the parent's story that would be the focal starting point. The clinical course would be told through either the patient's voice or a narrator (D'Alessandro et al, 2004). Another model is Morra's the '8 Steps to Great Digital Stories'. Figure 7.1a depicts this approach (2016). Morra writes on her website that digital stories must be personal and their development based on narrative in the form of a story which should be made concise to capture and retain attention. This should include universal story elements involving collaboration at a variety of levels; in the case of this study, there was both collaboration and co-production with various others in the production of the stories.

Figure 7.1a: Morra's Model for Digital Storytelling development



http://edtechteacher.org/8-steps-to-great-digital-storytelling-from-samantha-on-edudemic/

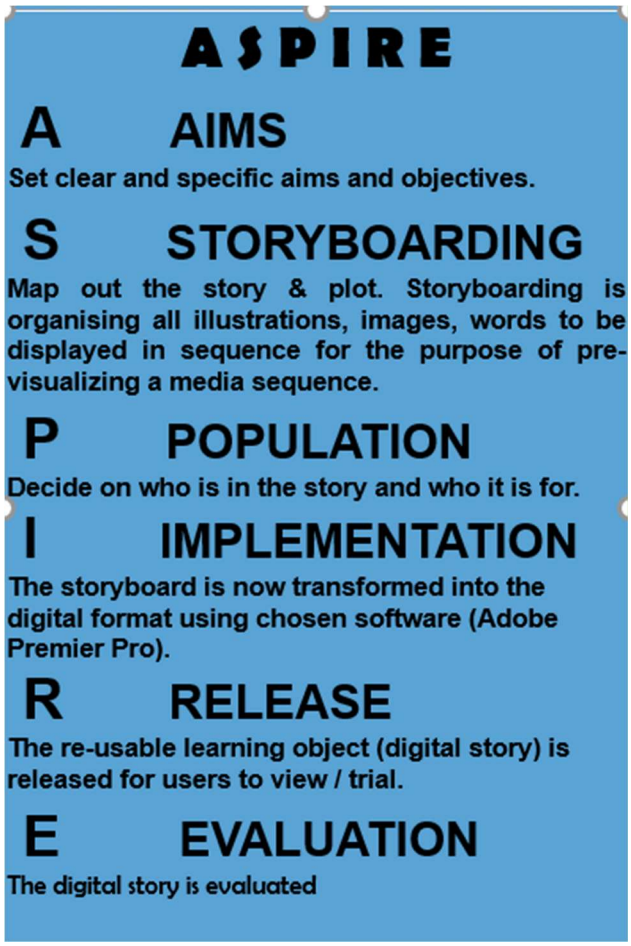
The Morra approach was particularly relevant to the present study as research to collate narratives is integrated into the model at the very outset. It also fits with the principles of constructivism due to the structured element comprising Morra's key terms: 'explore, write, create, plan' and 'putting it all together' to 'share'. Evaluation in the form of feedback and reflection is the final step, a vital element of resource creation.

Another point that needed addressing was how visually appealing digital resources should be, to draw people and engage them to use them. This concerns visual design that Syke's book referred to as *Stories that move mountains* pertaining to how an audience can be 'moved' by the visual elements of a story and emphasising the power of stories to communicate key emotive messages (Sykes et al, 2013). Sandars et al (2008) also emphasised the importance of story writing, using a variety of visually appealing multi-media and the continued use of reflection and evaluation.

The final model discussed is one that the author received training in, as part of her own learning process for this study; namely, the ASPIRE model (Figure 7.1b) (FutureLearn, 2016): See https://www.futurelearn.com/courses/e-learning-health/0/steps/17130. ASPIRE (Aims-Storyboarding-Population-Implementation-Release-Evaluate) uses a stepwise, structured approach and includes elements of the above approaches already discussed. This variety of approaches and their commonalities fit with the essence of this current study particularly in view of placing narrative and story at the heart of resource development. However, ASPIRE had an extra benefit. It was used to develop some exemplars within healthcare: See https://www.nottingham.ac.uk/helmopen/ The course strapline (https://www.futurelearn.com/courses/e-learning-health) is around the design of

effective e-learning that tells powerful, real-life stories, in health and other sectors. Although Morra's model looked appealing and applicable, no research could be found on the effectiveness of this approach and those used by D'Alessandro (2004) and Sandars et al (2008) were somewhat outdated. In addition, due to ASPIRE being a 'tried and tested' method and having completed the course, *E-Learning for Health* using this approach, it was therefore chosen to develop the digital stories for this study.

Figure 7.1b: The ASPIRE approach



(FutureLearn.com, 2016)

7.4 Methods

The specific approach used to develop the digital stories is now discussed. While this was based on common principles of sound pedagogical practice for digital story creation, the approach used was novel in view of the lack of such work in the field of neonatal education. Firstly, it is important to refer back to the initial study (chapter 4) which as stated, was in part instrumental in informing the methodology for the main study. Some aspects of the digital storytelling resource developed as a result of this initial study, were used in the resource development in this phase, for example, core story creation and thematic analysis. In addition, areas that required improvement following the evaluation were also considered and factored in. Table 7.1 outlines the similarities and differences between the first and second digital storytelling resource.

Table 7.1:
Similarities and differences between the 2 digital storytelling resources (Parts 1 and 2)

Part 1: Initial study	**Part 2: Main study**
Similarities	
• Raw narratives were obtained from interviews • Core study creation was used to reconstruct and condense long raw narratives into 'storied' constructs • Reconstructed stories sent to participants for verification of representation of their experience • Thematic analysis identified key themes to guide content of the stories for the resource itself	
Differences	
• Participants: student nurses	• Participants: parents
• Stories told in 3rd person	• Stories told in 1st person
• Length 10-12 minutes	• Length maximum 4-5 minutes
• Story interspersed with reflection points	• Story told without interruption with reflection points
• Software: Articulate	• Software: Adobe Premier Pro

Leading on from the above comparison of the two approaches to digital resource development, the following features (Table 7.2) made the approach used in the main study distinct from others used elsewhere and were therefore unique.

Table 7.2: Unique features of the digital story development used in the main study

- The starting point was a collection of narratives from parent experience in neonatal care.
- Stories were told by a narrator, not the actual parent but someone telling the story of the parent in the 1st person (i.e. acted)
- Digital stories were based on composite narratives and themes and not individual stories
- The process used metaphor themes within the core stories to provide the central focus for the story main theme and title.
- Co-construction was undertaken between creator, parents (at the point of core story creation in phase 1), illustrators / animators and voice actors (in phase 2).

Firstly, it is important to highlight that the stories were not based on individual accounts but were written based on common themes through the whole dataset. This approach was taken to align again with a constructivist approach. Stories were constructed from the composite themes taken from analysis of a data set of narratives. The themes were grouped and in accordance with the narrative method by Polkinghorne (1995). The material was read through as a whole so that the narratives formed emerged from the material by combining the descriptions of all participants taking part in the study, meaning that they did not represent an individual story. Instead, they were types of narrative generated as a result of analysis consistent with the approach used by Korhonen and Kangasniemi (2014) who combined and reconstructed interview narratives from nurses relating to their relationships with parents in neonatal care, the aim of which was to find a plot that united the different parts of the total material or complete dataset. Haydon et al (2018) referred to emplotment as a merger of multiple dialogues /

conversations into one narrative that encompasses the events conversed, though presented in a sequence that creates a narrative plot (Tropea, 2012).

Stories developed in this way were in part fiction, *based on* themes from real life narratives. This is documented as being a valid and influential style of developing a story as highlighted earlier by Moreau et al (2018). As Fairbairn (2005: 32) stated**,** ''We all have experiences of relating to and living vicariously inside the stories that are told by others – whether those are real stories that have happened to them, or stories that they have created, using elements of their experience''. Lindseth and Norberg (2004) would agree and believed that stories told from lived experiences may not be subject to factual judgement but as narratives, they are still capable of disclosing essential meanings.
In addition, the literature analysed found that co-constructed stories had a more positive influence on learning. In learning, co-construction is a distinctive approach where the emphasis is on collaborative or partnership working (Pratt et al, 2019). Hence, co-construction continues the alignment with constructivist theory at yet another level.

Overall, stories in phase 1 have been developed in conjunction with parents who provided the narratives. In this phase, the digital stories were further co-constructed using a collaborative approach with various individuals who took on specific elements; namely, a creator (the author), an illustrator, an animator and a voice artist, for each story. As well as constructing a product with others, the aim was that the learner would then construct knowledge from the digital stories.

Overall, constructing the digital stories used a combination of illustrations, images, voice narration and text, blended to make a series of short videos. While the narration of the stories used the 1st person, these were spoken by voice actors and not the actual parents. The reasons for this were firstly due to the actual participants not being available for voice recording but also secondly due to the stories being written from composite data from all participants. Also, importantly, was the need to address an ethical issue inherent in this type of work concerning confidentiality and consent to having the parent speak for open-access viewing. A reluctance and hesitancy were noted from many in post-interview discussions about dissemination of the stories. Regarding imagery too, illustrations were used in the main (rather than photographs) for similar reasons due to parents often feeling uncomfortable with the thought of their own baby's images being used on an open platform and not wanting to consent to this. In addition, using photographs is fraught with complexities and barriers around copyright for use and so having illustrators working for the sole purpose of the stories meant that no breach would occur. These issues which influenced such choices in the planning and making of the digital stories are discussed further within a later section on trustworthiness and rigour.

In relation to the story titles, it was vitally important to choose ones that could capture the initial attention of learners. The eight most frequent metaphor clusters from phase 1 were therefore used to provide a focal point for the story titles. Imagery was added within the story to further highlight these metaphors. The rationale for this lies in the value of metaphor for learning, discussed in phase 1. It has been shown how analysing metaphors can be used to understand emotions. In other words, and to reiterate, metaphor themes

found in the parent data integrated into composite digital stories has potential for learning.

Phase 1 highlighted strong affective content around the significant emotional themes relating to 'struggling' and other challenges within the parent narratives. Examples were, the challenging journey or long haul through the neonatal trajectory, feeling disconnected and / or becoming connected with their babies, being in darkness but then coming through into the light eventually when going home. These were pivotal metaphors that emerged from phase 1 of the study and used for the digital stories.

7.4.1 Digital story development

The approach to the actual process in the development of the digital stories was chosen that incorporated the underlying principles of the ASPIRE model. The rationale for using it has been discussed in the preceding section. Mainly, a current, tested and reputable approach was required which had an element of familiarity but that also captured the essential requirements of others' work such as Morra's and Lambert's. The starting point for digital story creation was the story 'constructs' developed from core story creation of the raw interview narratives in phase 1 (Appendix 3c) and the merging of metaphor clusters to form the composite themes (Appendix 6a).

Overall the process involved the following stages in order, through the ASPIRE stages:

- AIM: To develop a digital storytelling resource using the stories from phase 1.
- STORYBOARD: Digital resources required firstly the development of storyboards which are plans divided into panels, each panel representing a part of the plot with

corresponding pictures and parts of the script (Table 7.3). Script writing should be kept brief in line with the timing of a digital story, to a very condensed version of the full one. These were written to be no more than 200 words (Appendix 6b). Then, was the vital process of representing the structured parts of the story on the storyboard template in conjunction with a combination of media (Appendix 6c). Renda (2013) drew on the theories of Paivio and Baddeley to explain multi-media learning. Paivio's dual-coding theory articulated that the two ways to expand on learned material are by both verbal associations and visual imagery. Baddeley's working memory theory assumed that people have separate channels for processing verbal and visual information; the former processes sequential organisation of language, while the nonverbal system is involved in the analysis and generation of visual, auditory and affective mental images and the latter explaining the emotional effect that digital media can have. Mayor (2014: 5) also explained the principles of cognitive theory of multimedia learning and maintained that "in the process of trying to build connections between words and pictures, learners are able to create a deeper understanding than from words or pictures alone". Combining systems for processing and viewing of digital stories allows for an ability to engage in different cognitive activity which has the potential for generation of a deeper understanding and meaning from an experience. Schwartz (2012) agreed with this and that engaging in digital stories enables students to achieve higher level learning objectives. The soundtrack of the voice also needed to correspond appropriately in line with the pictures / illustrations and key text quotes at appropriate moments in the story. Spoken narrative is often said to be at the heart of digital storytelling (Renda, 2013). In a 'storied' setting, images and quotes by

themselves do not necessarily narrate (Banks and Zeitlyn, 2015), but they do provide opportunity to attend to key points in the story, reflect and engage in thought which may depict or enhance the story's messages (Machin, 2007). The scripts had been sent to voice actors and illustrators for them to produce both elements in preparation for the storyboards in full.

Table 7.3: Storyboard Template

Stage of story PLOT	Time	Script	Voice (audio-track)	Images	Text (Quotes)
TITLE SLIDE					
START	TIME FRAME IN SECONDS /MINUTES	ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	START AUDIO TRACK OF VOICE	INDICATE IMAGE NUMBER	TEXT (QUOTES) APPEAR ON THE SCREEN
MAIN STORY					
MAIN STORY					
MAIN STORY					
MAIN STORY		ADD MORE ROWS AS REQUIRED			
END					
FINAL CREDITS					

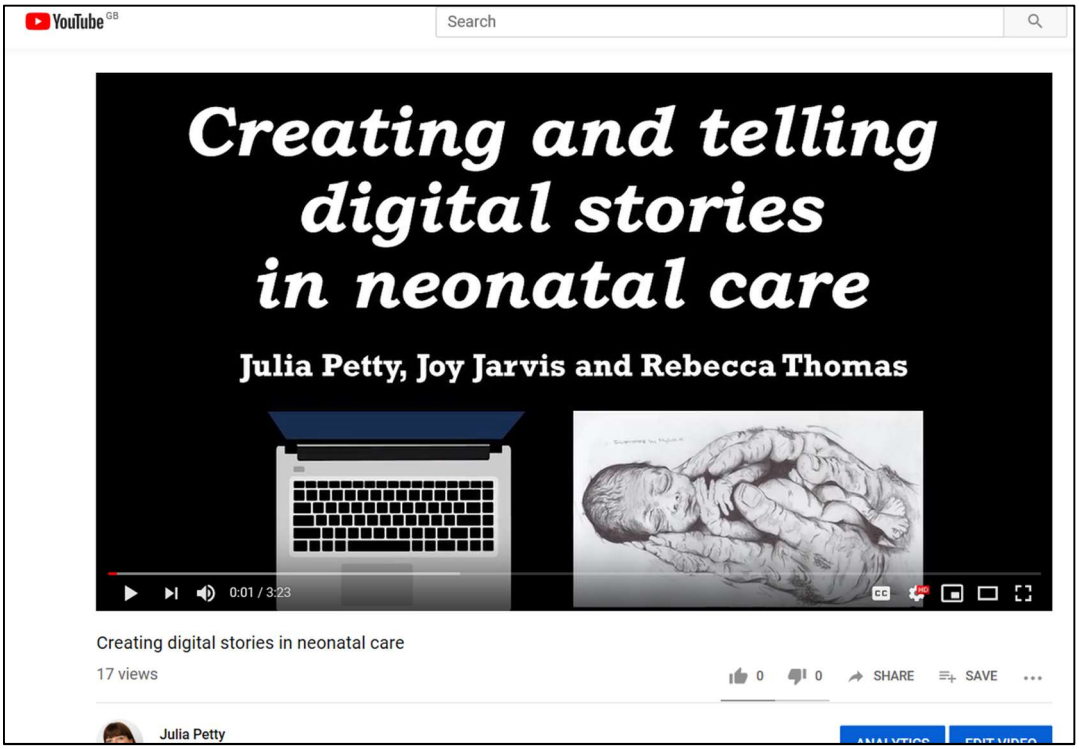
- POPULATION: This concerned who was involved. The digital stories were created in collaboration with others so that the final product was co-constructed. It was also important to be mindful of the audience in relation to how the script was written, the language used and what the viewer would be seeing and hearing when the story was put together. For this reason, 'P' also referred to peer review. Before

final publishing of the videos, they were shown to an external peer for review, so clarity and coherence of the stories could be verified, as 'previews.

- IMPLEMENTATION: This involved producing the actual videos using *Adobe Premier Pro*, a timeline-based video editing application that uses a combination of media including audio, images and text. These were added to the timeline in a 'storied' manner and edited to produce a brief video in MP4 format, compatible with a range of platforms including YouTube and the University online learning environment. The final 'product' was then ready to be released / show-cased.
- RELEASE: The video was released on a suitable platform in this case, YouTube.
- EVALUATION: Evaluation was an essential final part of the process to ascertain the effectiveness of the digital stories for the final phase. Without feedback from the participants it would have been impossible to gauge whether the process of making the stories was in itself useful or even transformative. It was clear however, according to De Vecchi et al (2017) that, while studies often contain superficial descriptions of the digital storytelling participation process, there is limited research where the process is formally evaluated. The evaluation strategy used is discussed in Chapter 8.

To explain the ASPIRE process used, a video was developed to explain the process of creating the digital stories which can be accessed in Figure 7.2. The storyboard process for the creation of this video can be seen in Appendix 6d and 3e; the script and storyboard template respectively.

Figure 7.2: Creating and Telling digital stories in neonatal care



https://www.youtube.com/watch?v=cjiVYYDqhyQandfeature=youtu.be
[Press control and click on the image or URL above to access the resource]

7.5 Trustworthiness and rigour

Trustworthiness in this phase concerned the notion of 'truth' in relation to whether the digital stories were a true representation of the parents' experiences. This was congruent with the current 'representation' phase of the conceptual framework for the study. At this point, the original narratives had been sent back to the parents for verification to ensure, as Frank (2002) said, plausibility and respect for those telling their stories. However, stories were constructed from a merging of collective themes which could have potentially un-validated the extent to which they were a real reflection of individual experience. In addition, the characters and the plot being part-fiction were based on composite themes written by the author plus spoken by voice actors rather than the actual parent themselves which could have further lessened the truth element

of representation. The question of whether telling the story of 'another' can lessen authenticity has been a common theme through this study thus far, requiring consideration at each phase. Rationale for the method in this phase arose firstly, from the literature supporting third party storytelling as discussed previously. Secondly, many of the parents did not welcome their own voices nor their babies' pictures being made so accessible to others on an open, online platform and preferred someone else to give voice to their stories. It would also have been challenging to revisit the parents for voice recording in their own homes due to distances involved, time constraints, potential environmental and practical interruptions and the need for appropriate equipment.

The importance of maintaining participant confidentiality when using digital stories in online media also needed to be acknowledged, as supported by Rieger et al (2018). The anonymity promised at the point of consent potentially acted as a safety net for the parents and therefore, they potentially felt more comfortable to speak openly during the interview with this assurance. If they were then to speak out and tell their story on an open platform, anonymity may have been at risk. There are ethical questions about removing a participant's right to choose to have their story, voice, and digital story shared in a public forum, who decides this and who 'owns' the story. Researchers should give such issues careful consideration which was done in this study.

de Jager et al (2018) discussed ethical issues and acknowledged that there are also several challenges in using creative activities for research purposes relating to judging the quality of the artefacts produced. Boydell et al (2012) also raised ethical aspects of representing experience when digital storytelling is used in a research context. They

cited Lundy's (2007) consideration of voice, audience, space and influence arguing that simply allowing participants an opportunity to express their views is insufficient. In a digital storytelling context, researchers should question what degree of control participants have of the display of their work after the research project is completed. For example, do participants have the opportunity to decide where their voice is heard, to what audience, in what space, in what contexts, or for whom to have influence?

It was felt that creating stories based on composite themes rather than individual stories mitigated against some of these ethical risks. Moreover, it is also important to reiterate that there were twenty *interviews* but not twenty stories developed for this study. Therefore, merging themes to develop stories ensured that aspects of experience from *all* participants were included, meaning that every parent contribution was valued, honoured and certainly to some degree, *represented*. This was felt to be ethically right. For all these above issues as for phase 1, transparency about how the stories were constructed was needed in line with a reflexive approach (Box 7.1).

Box 7.1- Reflection: Phase 2 Main study: Representation of narrative

The main issue for a reflexive approach in this phase of the main study was whether the created stories were a true representation of the parent experience. Baker et al (2016) stated that a vital question to ask is: How will you represent participants authentically while remaining true to the research question? 'Representation' as a term was particularly pertinent to my study, so this was an important question. Baker also said that usually, researchers consider representation in terms of how to protect participant identity; for example, by assigning pseudonyms to ensure anonymity. However, it is more complex than this as sample sizes are often small and so anonymity can be reduced. Moreover, reporting findings includes interview extracts and so participants may remain identifiable despite attempts to anonymise. I was aware about the need to give voice to the unique experiences of my participants but at the same time, preserving their anonymity and privacy. Overall, there was a need to ensure a balance between staying true to the parent's own story and ensuring confidentiality.

The other issue relating to the issue of true representation was that pertained to earlier in Chapter 4, Box 4.1, where the kinds of questions asked during interview may have influenced the final narrative and story, hence reducing the extent of true authenticity. The interviews were narrative (rather than structured) as much as was possible to prevent specific questions influencing the narrative. In true narrative interviewing, input from the interviewer should be absent or minimal. However, at times, prompts were still required if parents found it hard to know what to say or hesitated in their storytelling for whatever reason. Therefore, I needed to accept that certain influences had an impact on the final narratives from the parents, not only relating to prompts and questions during interview but also regarding the position and power relationship with myself and the parents, addressed in the previous chapter. This required a critical, reflexive approach in how I reported the representation of others' personal experience, accepting that authenticity was not completely possible in the true sense. I needed to ask, that while addressing authenticity may suggest attempts at accuracy and honesty, does it guarantee these values?

7. 6 Outputs

Eight digital stories were developed in total. Three of these stories were used to evaluate and explore the impact on learning: Another World, On the Edge and Fighter [press control and click on each hyperlink above to access the stories]. These three stories were developed first and were used for phase 3 to explore empathic learning, as seen in Chapter 8. All eight digital stories can be accessed through a website which is showcased in Chapter 9.

7.7 Discussion

Using qualitative interview data to create stories based on parent experiences as this study has done, offers a valuable opportunity to generate new knowledge from digital storytelling. This aimed to engage students and staff in higher order thinking and deeper learning (Dakich, 2014) by enhancing emotional awareness. Using the underlying principles of constructivist learning environments (Smeda et al, 2014), the development of resources proceeded with these in mind. Constructivism helps educators build learning environments that encourage learners to construct knowledge (Smeda, 2014; Smeda et al, 2010), in this case from stories. Narrative teaching strategies typically use small numbers of participants to highlight underpinning meanings of experience (DePoy and Gitlin, 2016). Because of the nature of narrative data, these rich descriptions and meanings are rooted, not only in the story content but also in the words and metaphors used to tell the story.

Digital storytelling also shows how to communicate compelling narratives in creative ways (Robin, 2016) which has great potential for education. This fits with the concept of arts-based pedagogy which encompasses digital storytelling within healthcare (Perry et

al, 2011), an approach that uses art as a medium to support knowledge development (Nguyen et al, 2016) and shown to foster self and cultural awareness (McIntosh, 2013). Using narratives and, indeed metaphors as an integral part of parent stories can be used to educate others in line with an arts-based knowledge translation (ABKT) approach. ABKT is defined by Archibald et al (2018: 2) as, "the use of any art form to communicate knowledge (e.g., research from various sources), represent and reconstruct data, and promote empathic understanding". This in turn, influences knowledge and/or changes in behaviour. Using the arts to disseminate knowledge can take many forms as alternative forms of representation to text or the spoken word such as visual (e.g. video, photography), performative (e.g. drama) or literary (e.g. stories, poetry or fiction). It is the latter example that is relevant here in the sharing of stories to evoke emotional responses. Stories enable a human connection to be gained using techniques such as plot, characters, and specific language; for example, metaphor to evoke emotion and connections. ABKT strategies have a powerful and unique emotional component and disseminate knowledge by engaging the learner with the context (Parsons and Boydell, 2012; Rieger and Schultz, 2014), in this case with parents in neonatal care.

It is beyond the scope of the study to explore the specific nuances of art-based research as the onus here is on story and digital storytelling. Nonetheless, digital representation of story in this context did include the use of arts and it was interesting to see if any of the features used within the stories emerged as important for learners within the next phase that evaluated the impact on learning about the emotional experiences of parents.

7.7.1 Limitations

The potential limitations and disadvantages of digital storytelling generally have been discussed, as well as issues relating to truth and representation of experience for this phase of the study. Ethical implications posed by digital storytelling have also been considered in view of what Boydell calls 'dangerous emotional terrain' (Boydell et al, 2012: 10) of relaying sensitive topics and issues, issues around confidentiality, consent and ownership of participants' stories. Limitations in relation to the stories that were developed within this phase also require acknowledging. The first limitation relates to the term 'representation' in relation to the nature of the participants. Diversity in relation to ethnicity, gender and the age of the participants was not diverse. Therefore, the characters in the plots only really 'represented' a specific demographic.

In addition, there was a need to be aware of not over-simplifying complex emotional challenges experienced by parents by reducing their experiences to a short digital artefact. This paves the way for a key question: what learning does occur from a short digital learning object? For true person-centred care, do nursing students require sustained or longer educational encounters with patients to augment what is learnt during an episodic or short three-to-five-minute digital story compilation? Some studies have commented on the educational benefits of reflection activities, peer support, or additional guided learning following the use of patients' digital stories (Christiansen, 2011; Taylor and Hutchings, 2012; Snelgrove et al, 2016) concluding that other supporting learning strategies were required in conjunction with the stories.

Passive nature of watching and / or listening to the stories also requires recognising given that there was no interactive element. Interaction is known to engage learners. One can argue though that the emotive element of the stories was sufficient to engage the learner's attention and interest, held by the compelling, affective element of such stories. The issue of engagement of the stories is a factor that is explored in the next phase in Chapter 8, remembering of course that at this point, the digital stories had not yet been evaluated. In addition, also to be explored was the comparative value of digital verses text-based means to deliver emotive messages. One must consider that not all students have digital preferences and regard a combination of formats as a better way to enhance their learning. Students also have a strong preference for learning from practice directly combined with digital resources (Petty and Treves, 2017).

Finally, the risks to authenticity as addressed earlier need reiterating, due to the stories not being the actual parent voices. However, literature has stated that digital stories from patients alone had no measurable effect of learning with limited benefits whereas, co-construction between the person developing the digital story and the patient had a more positive effect. The stories in this study were developed using co-construction and collaboration between various people. While this may question the part that parents truly played as a co-constructor of the stories, it was however appropriate due to the approach used; i.e. the stories were developed from composite narratives / themes rather than individual stories. In addition, the stories could not have been developed without the parent narratives in the first instance; they were borne out of their experience. The term ''voices from the heart'' as termed by Matthews (2014) is apt in this case. Parent voices were at 'the heart' of digital storytelling creation. Leaving this section

with such a metaphor seems very fitting as it captures the emotional element in digital stories. Emotions have come through consistently from the literature and discussion within this chapter, worthy of further study and is what the next phase now sets out to explore.

7.8 Summary: Phase 2

This chapter has discussed and analysed the concepts of story, specifically digital storytelling as the chosen platform on which to 'represent' parent narratives. Such an approach has been discussed within the constructivist paradigm of learning, which gives creators a designer role and emphasises the importance of social participation and collaboration in designing digital artefacts that are of relevance to a particular audience (Daskolia et al, 2015), in this case learners in neonatal care. Constructivism in this phase of the study places an overt emphasis on development of digital media and stories as tools that can be used by learners to construct knowledge based on experience.

Literature has highlighted how students learn from digital stories, either their own or those from or about others to, gain subject- specific knowledge. It is now appropriate to turn to the area of neonatal care specifically that has not been studied in relation to this topic. For learning to take place, digital stories must firstly be developed. This phase has demonstrated one approach, culminating in a collection of digital stories. The next stage is to now explore and evaluate the potential impact of them on empathy, learning and practice within the neonatal nursing education arena.

Chapter 8: Phase 3: 'Affiliation' to narrative (exploring the impact of stories on empathy)

Study timeline	Digital outputs and Publications
PART 1: Exploring narrative approaches and concepts (Chapters 1-4)	
• Chapter 1: Introduction • Chapter 2: Underpinning theory and concepts • Chapter 3: Design and methodology • Chapter 4: Working with Narrative: An Initial study	My Digital Story: Into the Light Petty (2016a) Publication Appreciation of the neonatal care experience through the eyes of student nurses. Storytelling resource Petty (2016b) Publication Petty (2017a) Publication Petty and Treves (2017) Publication
PART 2: The Main Study: Creating stories from parents' premature birth experiences to engender empathy in nursing students (Chapters 5-10)	
PHASE 1- 'Attention to narrative' – Exploring the parent's experience (Chapter 6)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	Petty (2017b) Publication Petty et al (2018a) Publication Petty et al (2019a) Publication Petty et al (2019b) Publication Petty et al (2019c) Publication
PHASE 2- 'Representation of narrative' – Creating the parent stories (Chapter 7)	
• Introduction • Aims and research question • Background • Methods • Analysis • Outputs • Discussion	Digital Stories Creating and telling Stories in Neonatal Care Another World On the Edge Connections Fighter Our Salvation The Long Haul Ahead Out of the Darkness Bittersweet
PHASE 3- 'Affiliation to narrative' – The impact of stories on empathic learning (Chapter 8)	
• Introduction • Aims and research question • Background • Methods • Analysis • Findings • Discussion	The Value of digital stories in neonatal care- Your views. – Evaluation Survey Neonatal Stories Website

8.1 Introduction

This chapter focuses on the third phase of the study which involved the '*affiliation*', or the connectedness between stories and person-centred, empathic learning. This phase explored the extent to which storytelling, in this case using a digital platform, enhanced empathic learning in student nurse participants and practice staff working in neonatal care. Empathy and empathic learning as concepts are defined and explained followed by an analysis of the literature that has explored empathy within healthcare and nursing, including the links with storytelling. A critique of empathy explores, among other issues, whether empathy can be taught and measured, leading to a rationale for the methods used in this phase. A mixed methods approach comprising 'point-of-view', reflective exercises, interviews and a questionnaire distributed to students and practice staff are explained, followed by the findings and a discussion that presents a model of empathic learning informed by this phase.

8.2 Aims and research question

The research question for this phase was: 'What is the contribution and value of parent stories to the empathic learning of nursing students and staff in the neonatal field?' Through the digital stories developed as an educational intervention discussed in phase 2, the aim was to explore their perceived value and contribution to empathic learning in nursing students and practice staff. By doing this, whether there was an 'affiliation' or, in this context, a connection between stories, empathic learning and practice was also explored.

8.3 Background

This section outlines what is meant by empathy, the links between storytelling and empathy along with a critique of this concept within the learning and teaching context.

8.3.1 The nature of empathy

There are numerous definitions of empathy within the literature. In keeping with the study aims and underlying theoretical framework, definitions that best fit are found within health literature containing elements inherent within interpretivist epistemology. In medicine, empathy is appreciated as the ability to perceive the *meaning* and feelings of another and to communicate those feelings to the other person (Stein-Parbury 2005 cited by Brunero et al, 2010). In a nursing context, it has been described as a capacity to supportively communicate a sensitive awareness and assertion of another's feelings and unique meanings that are attached to them (Mearns and Thorne, 2007, cited by Williams and Stickley, 2010). The key word *meaning* is core to these definitions as it is to interpretivism and indeed narrative, where we seek to understand others (in this case, their emotions) through narrative. In the context of this study, meaning-making is the *understanding* of a phenomena, hence the focus on this specific aspect.

From a historical perspective, empathy was first described by Adam Smith more than a century ago as a way of communicating affect and emotional contagion (Agnosta. n.d). More recently, it is a term articulated widely by psychologists such as Rogers (1975) who explained it as a state of perceiving the internal frame of reference of someone else and the associated emotional components and meanings. Hoffman (cited by Schaffer, 1996)

also referred to the emotional responsiveness someone shows to the feelings experienced by another person, an ability to identify with another's emotions and understand what they are feeling. Similarly, Goleman (cited by McGregor, 2012) stated, "the emotional notes and chords that weave through people's words and actions – the telling tone of voice or shift in posture, the eloquent silence or tell-tale tremble – go by unnoted". To notice them, one must have empathy. Being 'responsive' is an important part of this definition. In recent years, Baron-Cohen, a prolific writer on this subject believed that it involves imagining others' experiences, appreciating that different people have different perspectives and responding to their feelings with an appropriate emotion (Baron-Cohen, 2019).

Within healthcare, the notion of being responsive to others is key, as is the concept of empathic 'understanding', central to Katz's (1963) views of empathy. Katz stated that health professionals should have an openness and respect for others' feelings and as Levasseur and Vance (1993) proposed, should display a mode of caring. Ehmann (1971) believed that when we empathise, we achieve a close communication with another person and a fuller understanding of them as an individual. All such definitions are person-centred views concurring with Wlodarski who described empathy as an intellectual understanding and recognition of another's emotional mental state; "I understand what you feel" (Wlodarski, 2015: 232), consistent with Ancel (2006: 251) from a nursing paper, who voiced empathy as, "I understand what you are thinking and feeling".

Whether it is possible to achieve a true understanding of another person can be questioned, as it requires getting in complete synchrony with others' feelings which some may not be able to truly accomplish. One may ask, if we have not experienced something as intense as, for example, the birth of a premature baby, can we really truly understand those who have? Further critique of empathy is discussed later.

In the specific context of this study, a core component of the definition of empathy is understanding the other. Empathy means to understand how another person is feeling, because we experience our own feelings clearly, resonate with them and respond to them. This perspective is intricately linked to the narrative-based, interpretive theoretical framework of the study. Shapiro (2008; 6) stated that bio- medical knowledge cannot produce empathy due to its emphasis on reductionism, positivism and objectivity stating that, ''just as we have logico-scientific premises from which the scientific paradigm emerges, so we need a narrative paradigm grounded in certain philosophical premises about the proper relationship between people, to produce empathy and compassion''. Charon (2001; 2006), whose narrative medicine model has framed the conceptual framework of this study, spoke of the 'narrative road to empathy', placing what people say as a fundamental component of the concept. Although not within health, 'narrative empathy' is a term also articulated by Keen (2006) relating to the sharing of feelings and perspective-taking induced by reading, hearing, or imagining narratives of another's situation and condition.

There is also a key role of imagination with this study's definition of empathy, a word often used in discussions about empathy. One needs to imagine certain things to be able to respond to them. McKinnon (2018) spoke about empathy in nursing saying that it is a process involving engagement, an active process which fits well with Constructivism in a learning context, comprised of listening, echoing and imagining in the construction of knowledge. The concept of imagination also emphasises the role of fiction in harnessing empathy. Keen declared that there would probably be no fiction if we did not have the ability to imagine how it feels to be another or to be in another's situation.

As well as imagination, the words imitation (in the sense of taking another's perspective), and identification (relating to someone) are also often used. They are associated functions that we engage in actively as part of perspective-taking. The distinction is that empathy involves understanding and meaning-making. Another term used often synonymously with empathy, is sympathy. Marsden (2017) explained this distinction as follows; feeling concern or compassion for someone, is not empathy, it is sympathy, but, if someone feels (and understands) what someone else is feeling, that *is* empathy. In short; sympathy = "feeling for" and empathy = "feeling with" (e.g. 'I feel your pain'). Sympathy is also more uncontrolled and visceral as a reactive response whereas empathy is more of an active construct, a skilled response that can be learnt (Jeffrey, 2016). Pity is another reactive feeling, a term commonly used to describe an uncontrolled response like sympathy.

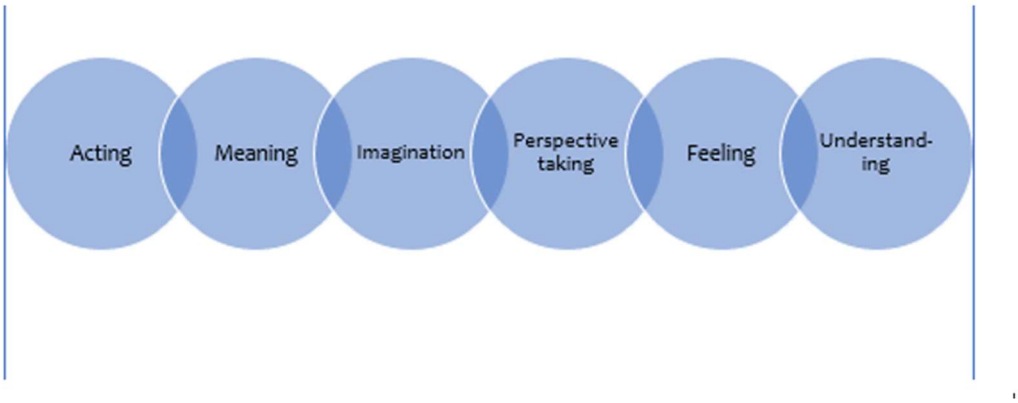
As well as different definitions and related terms, there are also various components to empathy, to further add to its complexity. Tamayo et al (2016) discussed three aspects. Affective or emotive empathy involves experiencing and internalising the feelings experienced by others, cognitive empathy describes the capacity to understand another person's perspective and behavioural empathy is related to action, involving the outward expression of internally experienced (cognitive and emotive) processes within practice. These authors stated that affective empathy is the strongest within health professionals and that educational interventions need to address increasing cognitive empathy. In nursing, if this can be achieved and one can be taught to understand their patient's perspective, then behavioural empathy may be augmented with the potential for improving person-centred care in line with transformative learning.

Williams and Stickley (2010) however argued that it is not helpful in a nursing context to split empathy up in a reductionist way and that we should think holistically, accepting it is a multi-faceted concept. McKinnon (2018) proposed the most important part of empathy in relation to nursing is the behavioural aspect as that is what impacts on practice. Ideally if empathy is increased, then care will be more compassionate. Here lies another important distinction; between empathy and compassion. These are closely related, person-centred terms. However, empathy is the understanding of another's feelings while compassion, a willingness to care for and alleviate the suffering of others, comes about because of empathy (Charlton, 2016). One can argue that nurses need empathy to be compassionate, although this is not necessarily agreed by some who say that compassion is another reactive response to seeing others suffer (Maxwell, 2008) and empathic understanding is not wholly necessary. Nonetheless, it is another fundamental

aspect of nursing care (Bramley and Matiti, 2014) and the difference between the two terms may not matter. After all, both can contribute to more person-centred, humanistic nursing care in the patient's best interest.

Overall, it is clear that defining empathy is complex due to the multifaceted nature and lack of agreement about what it includes. To attempt to bring together a coherent model that is relevant to the core of the study around learning and understanding, a model of empathic learning is presented in Figure 8.1.

Figure 8.1: A Model of empathic learning (adapted from Keskin, 2014)



To explain this model, when a person tries to understand someone else, they understand that person, they then act to give meaning to their experiences. They may imagine themselves as that person, evaluate events from that person's perspective and share their feelings. As a result, they develop an understanding by anticipating the feelings and thoughts of that person (Keskin, 2007; cited in Keskin, 2014).

What is missing from this model however is the *learning* that occurs and acting on this to influence practice. It is presumed that Keskin equates understanding with learning as the final stage of this model, but this needs to be more explicit; an understanding of what? Is this understanding related to knowledge and if so, what knowledge? The chapter returns to this model again later where it is reviewed in the light of the findings of this final phase. Overall, the concept of empathic learning in the context of this study, is to understand and learn about the emotional experiences of others, to give better care, hence, to include the effect on behaviour and practice is essential.

8.3.2 Links between storytelling and empathy

The link between narrative and the effect on empathy within healthcare has been highlighted earlier in Chapter 2 by referring to the work of Charon (2001; 2006, 2007), Shapiro et al (2006a), DasGupta (2007) and Greenhalgh (1999), all key champions in the link between the two concepts who believe in the 'power' of narrative to 'move' people and how it can impart a type of knowledge that pure science cannot teach. The assumption is therefore that increasing empathy, an inherent part of emotional intelligence (Hurley, 2008) results in better understanding of our patients.

But what about storytelling specifically? The Empathy Museum's Clare Patey (cited by The Health Foundation website, 2016) said, ''Stories have a transformative power to allow us to see the world in a different way than we do if we just encounter it on our own. Stories are an entry point to understanding a different experience of the world''. This aspect of storytelling, presenting a different perspective of the world, is important

when it comes to connecting with each other. It gives us an opportunity to learn from another person's experience and it can shape, strengthen or challenge our opinions and values. When a story catches our attention and engages people, they are more likely to absorb the message and meaning within it than if the same message was presented simply by factual information and figures. When someone tells us their own personal story, we catch some insight into a view of the world that may be different from our own. When we see the world as they see it, or walk in their shoes, the experience can inspire empathy within them. This is consistent with Divinsky (2007) who stated that stories offer insight and new understanding into the perspectives of others. Fairbairn (2005: 53) also described the imagination needed to tell stories and summarised the connection very well, ''by sharing in and identifying with stories told by others, we learn to understand and empathise with their experiences''.

Empathy is also seen in terms of a 'connection' metaphor, linked to how it is formed from and within personal, deep-rooted emotional stories, congruent with the 'affiliation' element of the study's overarching conceptual framework. Cameron's (2011) study provided a prime example of this. Her interest was how people use metaphor and what they do with it in conversation, focusing in her study on reconciliation between two people, one whose father had been killed during the conflict in Northern Ireland, and another who was responsible for the murder. She analysed the metaphors within the conversations between them and this led her to identify strong connections between narrative, metaphor and empathy. Certainly, there are times when metaphors are powerful in revealing the impact of the events within stories (Hall and Power, 2011). As has been discussed in chapter 6, metaphors can serve as a compelling expression of

oneself through narrative, in this case, parents in neonatal care who used them eloquently and frequently. The analysis of these metaphors raised awareness of emotions within their narratives, representing compelling emotional messages that could evoke empathy.

The link between stories and empathy has also been illustrated by storytelling projects such as *Patient Voices* and *Health Talk* online. The intention behind *Patient Voices* (https://www.patientvoices.org.uk/stories-htm) was, in their words, to "touch the hearts" of those watching the stories to understand the storytellers experience. *Healthtalk* online (http://www.healthtalk.org/peoples-experiences/pregnancy-children) drew upon databases of patient experiences gathered by qualitative research interviews into over forty different illnesses and health conditions that were captured in text and through video. The benefits of digital storytelling have been reported (Healthtalk, 2017). For example, Harland (2018) wrote about his experience of digital storytelling and how this enhanced empathy within his field of physiotherapy. Snow et al (2016) found that undergraduate medical students' learning and confidence improved after viewing patient stories about a specific procedure. One group saw clips from *Healthtalk.org* of women talking about their experiences of a particular procedure and demonstrated a better knowledge base in an assessment about this topic than those who had not experienced the stories. The former group also reported to be more confident about discussing the procedure with the patients themselves.

Overall stories, or as illustrated above, *digital stories* can bring to life the patient voice.

Hall and Powell (2011) summarised this well in relation to mental health nursing in that when people tell their stories, these elicit more information and understanding about a person than just asking 'how are you?' Instead they suggested that one should ask; what is your story? Then the 'storied' plot, with the beginning, middle and end is *told*, capturing experiences of those within it so that those listening can come to understand them.

Can then, student empathy be enriched by methods that use illness narratives and the involvement of patients and relatives, to bring their reality to life in the classroom? Indeed, another area of evidence relates to how empathy can be taught by educational interventions or resources such as stories.

8.3.3 Teaching empathy

Research suggests that exposing students to educational strategies including personal narratives via a variety of delivery modes can enhance empathy. Stepien and Baernstein (2006) reviewed several studies that explored the effectiveness of interventions to enhance empathy. They concluded that empathy may be amenable to positive change with a range of interventional strategies, for example using communication skill workshops that address the behavioural dimension of empathy demonstrating a greater impact on participants; in other words, communicating more empathically had a positive influence on patient experience. Later, a narrative review of twenty-nine articles (Lam et al, 2011) pertaining to multi-professional empathy training were identified. Such training included: experiential training (e.g. simulation, games, live experiences in placement),

exposure to videos about patients, communication skills training and writing exercises. All except two studies reported positive findings in relation to enhanced empathy for all these methods, as measured by pre and post empathy scores using various scales. The findings suggest that, contrary to the earlier views of Tamayo et al (2016) and regardless of training method, individuals *can* learn about the concept of cognitive empathy. However, the review also concluded that the effects of training on the ability to take the perspective of others and then demonstrate it in clinical practice was less clear and not possible to ascertain from the literature. In addition, both the above reviews pointed out the potential issues with the research reviewed, in relation to varying and wide definitions of empathy, small sample sizes, lack of adequate control groups, and variation among existing empathy measurement instruments. Moreover, it seems that little is known about the teaching of affective (emotional) empathy involving eliciting emotional responses as well as any changes in behaviour, both difficult factors to measure.

Another literature review by Batt-Rawden et al (2013) also suggested that educational interventions can be effective with respect to enhancing empathy in medical students. They analysed eighteen articles and fifteen reported a significant increase in empathy following interventions that included exposure to patient narratives and creative art strategies such as the use of theatre, drama and film, problem-based learning, patient interviews, experiential learning, role-play and reflective writing, all showing positive benefits to some degree.

In nurse education, empathy is often associated with experiential learning and acquiring knowledge from the lessons of life experiences as well as those of patients. Brunero et al

(2010) performed a literature review of seventeen studies that focused on empathy education programmes in nurse education. Eleven reported significant improvements in empathy scores versus six studies that did not. The interventions that were reported to be effective comprised experiential (practice-based) courses of various lengths and specific empathy skills training in communication and listening with one study using a visual arts programme.

Since then, other work in nurse education has explored empathy in relation to various interventions. Cunico et al (2012) undertook a longitudinal study to determine whether a specific training course would enhance empathy in student nurses during their training. One-hundred-and-three participants completed the study, which was found to be effective, especially for women. Results regarding men were less clear. Petrucci et al (2016) supported this gender specific difference in empathy in a study that measured levels in both, finding that female students showed higher empathy levels than males. Moreover, nursing students scored higher on empathy scores than other professionals. Levett-Jones et al (2017) examined the impact of a point-of-view simulation exercise in three-hundred-and-ninety students caring for people with brain Injury with the use of a device that mimicked hemiparesis. Participants reported significantly higher empathy scores following the exercise. Similarly, Bas-Sarminto et al (2017) used a combination of role-playing followed by behaviour analysis and de-brief with forty-eight second-year nursing students and post intervention empathy scores improved with the students who also evaluated this learning positively.

Although positive outcomes were shown, these studies did not use stories *per se*, although narrative-based interventions have been documented. Shapiro et al (2004) has shown positive increases in perceived empathy from using an elective literature and poetry course for medical students. Pre and post intervention scores on an empathy scale plus interview data found a significant improvement in empathy for patients and each other. This author has also documented the benefits of personal reflective writing to enhance empathy within medical training (Shapiro, 2008, 2012) stating a belief in storytelling as being a critical factor within medical training to enhance understanding of the patient. Leonard et al (2018) however, did focus more on story as an intervention and explored the impact of a learning experience using real 'patient voices' with nurse students. Panel members of patients who had experienced acute and chronic illness from either the perspective of the patient or caregiver, took part in a session and presented their narrative to students, engaging them in a conversation about their nursing care experience. Both the patients and students fed back that the experience highlighted the importance of empathy particularly beneficial for students transitioning into their first clinical experience. One quote really summarised the value; ''Real life stories inspired me to give the best nursing care I know how to give… It made me realize we have been missing this piece so far in our education" (Leonard et al, 2018: 65).

Heidke *et al* (2018) aimed to determine whether the integration of interviews based on experiences of patients into a first-year nursing course influenced empathy in thirty-two students. Results showed overall that nursing students demonstrated moderate levels of empathy but after the intervention, there was a significant increase in students' empathy

towards vulnerable and disadvantaged people. The authors concluded that the patient voice can strengthen teaching practices that promote caring behaviours.

A limited amount of work has also emerged from art-based research within nursing. The abovementioned study cited in Brunero et al's (2010) review by Wikstrom (2001) used a visual art method to facilitate students' discovery of personal knowledge of empathy involving a visual-verbal-writing process in which a reproduction of Edvard Munch's the Sick Child was studied and interpreted. Four-hundred-and-forty-eight student nurses worked alone on written reports and in small-groups and discussed whether the picture facilitated the discovery of a personal knowledge of empathy. The results showed that visual art stimulated the students to discuss and write about empathy (Wikstrom, 2001) highlighting a valuable strategy that facilitated students to make personal connections with the picture by their own free reflective documentation and open commentary.

More recently, Adamson et al (2018) undertook a study using pre and post interview design relating to an art-based intervention. Eight trained nurses attended six ninety-minute group narrative training sessions that included story writing using written and visual narratives that were shared and discussed. The findings confirmed that storytelling through narrative teaching may be a promising intervention that enhanced nursing empathy relating to patients, families and the nursing team. This appeared to humanise the clinical environment and permitted nurses to grasp the meaning of complex care experiences enabling a more supportive environment. This study was in the field of

children's rehabilitation. Other work relating specifically to educational interventions for staff to enhance empathy is sparse in the child health field. Some research has focused on art-based knowledge translation to create interventions for dissemination of information for parents and children in the field of croup, chronic pain and asthma (Hartling et al, 2010; Reid et al, 2017; Archibald et al, 2018) but these studies did not explore the effect on empathy.

One paper has been found in the neonatal field that reports on an evaluation of using a medical memoir within a nursing programme with a group of students (Low and LaScala, 2015). The book *Small Wonder: The story of a child born too soon* (LaScala, 2009), describes the premature birth of this author's baby and her experience during the first year of life providing a view through the lens of a mother. It was used to augment classroom and practice-based experience. An end-of-course evaluation of the memoir gave positive results in view of the student feedback. The book widened students' views of the patient experience, engaged them and gave them an opportunity to expand their empathy capacity. This paper did not report a research study *per se,* nor did it use a tool to measure empathy so there were no formal findings reported nor any discussion of factors may have that influenced the positive reports of such an intervention. However, it did use a *story* as a specific educational strategy. No other work appears to exist in the neonatal field in education regarding enhancement of empathy and no research has been found linking empathy with the use of digital stories within the child or neonatal speciality.

8.3.4 Critique of empathy

From the literature thus far, it appears there is a consensus within health that empathy can be taught. As Ancel (2006) proposed, empathy is a teachable skill, which many others have concurred with. But, is it really that simple? Is it really possible to teach empathy? Williams and Stickley (2010) spoke of nurses' innate capacities for empathy but also referred to them learning through experience, the value of an emotional kind of understanding for practice. Here, it appears that both inherent and taught aspects are present and important. Certainly, in nursing, it would be expected that nurses are empathic in their nature, this being an inherent part of being 'caring' towards others. Moreover, while it is well documented that empathy can indeed be enhanced by educational strategies, some literature has also cited a decline or an erosion of empathy over time during one's training, particularly within the medical profession (Mahoney et al, 2016). In nursing, this is synonymous with the notion of compassion fatigue that occurs when nurses develop declining empathic ability from repeated exposure to others' suffering. (Peters, 2018). This may be due to external factors such as workload, short staffing, lack of time, stress and burn-out whereby people can lose these caring qualities. Adamson et al (2018) referred to the many elements in healthcare that 'assault' empathy such as the factors cited above, along with poor job satisfaction, a relentlessly busy workplace and patient demand. Dean (2017) also asked: Are our busy doctors and nurses losing empathy for patients? If this is indeed the case, it is vital to act to ensure empathy is restored.

Also cited, is a deficit of empathy in some, the reasons for which are complex. Krznaric (2014) saw a global empathy deficit in current times, demonstrating for example, in the

public narrative around refugees and immigration. Baron-Cohen (2012) spoke at length about certain people having no empathy in his *Zero degrees of empathy* text. In healthcare, Harland (2018) has observed that health professionals may be unwilling, unable or not used to using empathy in practice (Harland, 2018) – this has a negative impact on the patient. In part, lack of empathy in neonatal settings led to this very research in relation to a perceived lack of awareness of parents' emotional challenges within the intensely stressful time experienced by parents (See Preface). The literature that supports the ability to teach empathy highlights that, while it may decline over time, thankfully it is something that can be developed or enhanced by tailored interventions.

Certainly, empathy is a complex phenomenon influenced by many factors. It is hard to define simply, and it is also difficult to know the optimum strategy for both teaching or measuring it. The question of how to 'measure' it is addressed in the Methods section. However, perhaps more fitting with the interpretive approach of this study, it is more apt to refer to 'evaluate' or 'appraise', rather than to 'measure' empathy and to consider an evaluation of one's perception of how empathy may be enhanced.

Furthermore, to add to the complexity, empathy is not always a positive concept. There is an assumption often documented in the nursing literature, that it is a desirable attribute without question. But there is a more negative side to empathy; it has been documented that 'too much empathy' for example, can cloud decision-making especially in healthcare as one can become too 'emotional' and easily influenced over and above a more rational process of logical thought. Bloom (2016), in his critique of empathy (*Against Empathy*), would agree saying that it can be exploited and therefore used to

incite an emotional rather than a rational response. He also believed that seeing and feeling the world from the perspective and feelings of one person will be biased, selective and partial, based on a person's own perspective (Marsden, 2017). Others have agreed and stated that those we chose to feel empathy for tend to reflect our own biases and prejudices so that we can easily feel empathy for people we identify with (Molenberghs, 2017). Bloom also regarded empathy as having a selfish dimension in that when we feel pain or frustration, we act to reduce our own discomfort vicariously, rather than through concern for who he calls the 'consumer'. As Marsden (2017) summarised in his blog, it is by ''removing our emotional involvement with consumers can we make rational decisions about how to best meet their needs".

However, this is not appropriate in the healthcare sense as to remove emotional involvement goes against the very essence of nursing. As Goleman (cited by McGregor's, 2012 website) stated, a ''failure to register another's feelings is a major deficit in emotional intelligence, and a tragic failing in what it means to be human…… the root of caring, stems from emotional attunement, from the capacity for empathy." Therefore, rather than being detached, Halpern (2001 cited by Jeffrey, 2016) said that it is preferable to 'decentre' and imagine the situation from the patient viewpoint while putting aside one's own emotional perspective. This requires emotional intelligence in maintaining a sense of boundary with the other person. By this, one can come to understand what the other person is feeling and be able to then care for them appropriately in a person-centred way. Empathic learning has occurred in this context about the person being cared for. This is the essence of empathy in the context of this study.

Further critique follows in the Methods section which discusses the methods used to explore the effect of the digital stories created in phase 2, on empathic learning.

8.4 Methods

Narrative inquiry within the interpretivist approach has been articulated through the study so far and continues in the current phase. The onus now turns to the perspectives of student nurses and neonatal staff, in relation to their views of the digital stories and their contribution to empathic learning. It is *their* narratives that are of interest now and the exploration of key themes.

Student nurses along with a group of educators and neonatal staff were presented with selected stories from phases 1 and 2. Then using a combination of a 'point-of-view' / reflective exercises (named 'empathy exploration exercise'), interviews and a questionnaire, their views were explored to appraise how they identified and empathised with parents, what person-centred learning they took from the stories and whether they felt the stories enhanced their empathic understanding and learning within the neonatal care context. Evaluative views on the format of digital stories verses other forms of story were also included in the questionnaire.

The rationale for this combination of methods is now outlined. Firstly, in relation to measurement of empathy. The question of whether empathy can be taught has been addressed in the previous section, due to its complex nature. The same question applies to whether empathy can be measured. This is a really important issue to explore in relation to the methodology for this phase of the study. Overall positive outcomes from

educational interventions have been reported in the previously cited research measured by validated tools or self- assessment qualitative evaluations. Empathy has been measured quantitatively by rating scales based on numerous criteria yielding empathy 'scores' (Hojat et al, 2002; Rosenthal et al, 2011; Tavakol et al, 2012; Batt-Rawden et al, 2013; Williams et al, 2015). However, this does not fit with the narrative agenda nor does it correspond to the interpretive paradigm that underpins this study. It is difficult to marry the notions of evaluating a deep, emotional concept such as empathy with a checklist type 'tool' that assigns a score. *Narrative empathy* as put forward by Keen would say this is not appropriate. It is perhaps more appropriate to use self-reporting as congruent with a narrative approach where one can openly express one's views. Therefore, qualitative ways of measuring empathy have been explored and while there are a more limited number of studies, nonetheless, the methods stay true to the essence of this current study.

Earlier in the background section, the two studies by Wikstrom (2001) and Adamson et al (2018) demonstrated positive benefits of educational interventions on empathy using art-based approaches. Other research included reflective, narrative and 'point-of- view' writing (Shapiro, 2012). The latter is a method that entails asking students to write from another's point of view or perspective to enhance empathy. This method was used in two studies (Dasgupta and Charon, 2004; Shapiro et al, 2006b) that evaluated training for medical students where participants were asked to write about their personal illness, a relative's or asked to write from a patient's perspective. The findings by Gupta and Charon indicated that the training was well-received by medical students following a qualitative evaluation of the perceived value of the exercise. Shapiro (2012) performed a

linguistic analysis according to the presence or absence of certain themes and students demonstrated significantly greater awareness of the emotional aspects in their point-of-view writing compared to another clinical reasoning exercise about the same patients. Shapiro in other work spoke of this as understanding 'othering' of the sick person (Shapiro, 2008) and how reflective writing allowed multiple interpretations to emerge with the purpose of a better appreciation of emotions of self and 'other.' One study involved medical students rewriting stories taken from several perspectives. Students discussed these rewrites, which helped them feel more emphatic and connected with others in their class. (Dhurandhar, 2009). Emergent principles of point-of-view methods were partly incorporated into this phase of the study.

As well as exploring the extent to which the digital stories may enhance empathy or empathic learning, it was also important to gauge views of the stories themselves. Therefore, another element added to this phase was that of feedback evaluation. Evaluation is an essential part of any resource development for teaching and learning (Barrett, 2006; Boase, 2008; Renda, 2013; Rieger et al, 2018). Methods used to evaluate resources comprise questionnaire / survey measurement of degrees of satisfaction based on Likert scale or similar, other rating scales, open written and / or verbal responses and feedback. Clearly, a mixture of both quantitative and qualitative data is often collected. It is preferable to use a combination in order to more fully gauge the effectiveness of any learning resource (Vivekananda-Schmidt at al, 2004) which can provide a more robust understanding of results by triangulating them, a strategy undertaken to enhance trustworthiness of a study (Appendix 1).

In addition, the use of a qualitative methodology does not rule out quantitative methods (Hesse-Biber, 2010). While recognising that qualitative data allows for the experiences of participants to be voiced very aptly, there may be other ways for quantitative data to be incorporated to add further information. This was recognised as far back as 1985 by Lincoln and Guba (1985), further supported more recently by Guetterman et al (2015) who discussed the benefits of integrating methods. Tariq and Woodman (2013) acknowledged that a key challenge is the successful integration of quantitative and qualitative data during analysis and interpretation but that using different types of data can generate varying insights into a research question. This can result in a more enriched understanding of the phenomena in question, as was the intention behind this phase's methodological approach.

To sum, using a combination of methods was deemed appropriate in line with a mixed-methods approach for this phase, defined as using a blend of methods along with both quantitative and qualitative analysis in a single study (Creswell and Plano Clark, 2007) and is commonly used by health researchers. It has the potential to utilise the strengths and counterbalance the weaknesses of both types of analysis, especially powerful when addressing complex issues, in this case, empathic learning.

Regarding the strengths and weaknesses for each method of data collection, both interview and questionnaire for example are intended to explore participant perceptions. Interviews are classically conducted in person, but this style of data gathering also includes open-ended surveys. While quantitative questionnaires and qualitative interviews can ask the same questions, the interview provides deeper, more detailed

answers and allows for further development of thoughts and responses. The drawback of conducting interviews is that they are more time consuming and expensive than a fixed survey-based study. An interview, however, is perhaps the most direct way for a researcher to understand outlier cases (Paradis et al, 2016; Schneider et al, 2017).

8.4.1 Participants, recruitment and methods

The participants, mode of recruitment and associated methods used for specific sub-groups for this phase of the study are outlined below. A summary is provided of the participants in Table 8.1, including the specific roles held and length of time spent working in neonatal care, if applicable. Overall, there were three main participant groups; children's nursing students, adult/mental health nursing students and practice staff making a total of one-hundred-and-thirty-seven participants in total. The details are as follows:

GROUP 1- CHILDRENS NURSING STUDENTS: 60 children's nursing students made up of two cohorts, one a first-year group and the other was a third-year group (n=29 and 31 respectively) plus 7 second year children's nursing students

These two cohorts completed the point-of-view / reflective exercises and the questionnaire. These students were recruited by convenience sampling due to the timing of these two groups being present in the University for timetabled sessions. Convenience sampling is where participants meet certain practical criteria, such as easy access, distance/ proximity, availability at a given time or the willingness to participate (Etikan et

al, 2016). This method can be criticised due to the potential for bias in selection and in this case, for any element of coercion in relation to the student-lecturer relationship. This is addressed later.

Appendix 7a includes the student class 'point-of-view'/ reflective tasks (empathy exploration exercises), and questionnaire. To give more detail, the point-of-view / reflective exercises involved firstly, asking the students to watch the three videos ('Another World', 'On the Edge' and 'Fighter') and then asking them to answer four questions taking the perspective of a parent, using single adjectives or short descriptive terms (for example; 'worried', 'out of control'). In other words, they were asked to imagine they were the parent of the babies and write down the words / terms on different post-it notes for each question. These were:

Imagine you are a parent of one of the babies, describe how you think you would have felt……

- when your baby was admitted to the NNU?
- when you first saw your baby?
- during the long length of stay in the NNU?
- when your baby was discharged home?

Secondly, the students were asked to reflect on the videos and write down in spaces provided, what both enhanced and hindered their learning. Thirdly, they were given a questionnaire to explore views of the stories on a range of issues relating to emotion, learning and the format of digital stories. Regarding questionnaire development, Burns and Kho (2015) stated that a systematic approach should be used to develop the

questions ensuring that that key points are not missed. Careful phrasing is necessary to limit the chance of misunderstanding. To assist with the questions on format, the students were given the written scripts of the stories, so they could see the words that they had previously listened to and watched on the screen and so they were able to make comparisons. Two students with study needs agreements relating to their speed of reading requested to answer the questionnaire after the session, via the online version. The online version of the questionnaire can be accessed by clicking here [Press control].

As well as the above first and third year children's nursing students, seven second years were interviewed on a one-to-one basis. These students volunteered to be interviewed following an invitation sent via email. They were also recruited by convenience sampling due to them being in placement at a local Trust close to the University where facilities were available for interviewing. The decision to interview selected students was to gather further, more individual-based information, to enrich those views collected by the other methods. In addition, this ensured that all three years of student nurses across the whole programme were included and represented, felt to be important to identify any potential differences between their views and feedback. The interviews involved firstly, showing the students the three videos. Secondly, they were then asked the questions from the questionnaire given to the first and third year students, in a structured form. However, the latter part of the interview became less structured and the questions were followed up asking them to expand on their responses, to give reasons for them and to ask them what enhanced or hindered their learning. Appendix 7b outlines the interview schedule.

GROUP 2: OTHER FIELD NURSING STUDENTS. 31 first year adult and mental health nursing students (n=22 and 9 respectively)

This group of students was also shown the three videos and then asked to complete either a paper or an online version of the questionnaire according to their preference, in class. As above, in relation to convenience sampling, this cohort were in the University during a scheduled module. The decision to include student nurses who were on another programme to children's nursing was to see if any variations were evident between the different fields. This group also represented a more diverse demographic in relation to gender, age and ethnicity than the children's nursing students.

GROUP 3: EDUCATORS AND NEONATAL STAFF. 39 practice staff comprising University educators (n=12) and practice staff working within a range of roles within neonatal care (n= 27) (Table 8.1)

This group of staff completed the anonymous questionnaire sent online via identified gatekeepers in two Trusts, who gave permission for the survey URL to be sent to neonatal staff as well as to a group of lecturers within the University of Hertfordshire, School of Health and Social Work. The decision to include educators and practice staff was due to the desire to explore views of those who teach student nurses, to gain the perspective from the teaching side, both University and clinical based. The aim was to recruit no more than ten to twenty from each area. Appendix 7c outlines the full questionnaire or it can be accessed online here [press control].

Additional participant information: The numbers of participants for the two student nurse groups (Children's nursing and Adult/Mental health nursing) were controlled by the cohort numbers in these groups. Ninety-eight in total across all students ensured an adequate number to gather a range of different views and this was felt to be sufficient to inform this phase adequately. As discussed in Chapter 6, qualitative sample sizes needed to be large enough to allow new information to emerge of the phenomenon under study, but small enough so that the depth of key cases was not prohibited (Vasileiou et al, 2018). Morse (2000) identified that as richer data are collected from each person, fewer participants are needed. As there was a significant opportunity for respondents to give detailed open responses, this yielded many rich, detailed and lengthy written comments to work with and analyse. Also, of importance along with the quality and volume of the qualitative data that emerged, was to consider the limits within the scope of the study. This all gave rationale for not continuing for any longer than was necessary with the online part of the questionnaire, stopping at 39 for practice staff to add to the student nurse groups, making the total number of participants as 137.

To sum, for the practice staff, 39 respondents completed the questionnaire within a given time frame (over a six-week period). Recruitment ceased therefore once the numbers aimed for had been achieved and it was clear following regular review of the questionnaire data on the Bristol Online Survey link, that the open responses from the respondents were comprehensive, detailed and explanatory.

In relation to participant gender, age and ethnicity, the following information was collected:

- Children's nursing students (n=67) were all female except for one male; forty-five (67%) were age 18-25 years, sixteen (24%) were age 26-35 years and six (9%) were > 35 years of age; forty-seven (70%) were white Caucasian and twenty (30%) were in the Black, Asian and minority ethnic (BAME) group.
- Adult / mental health nursing student group (n=31), nineteen (61%) were female, twelve (39%) male; thirteen (42%) were age 18-25 years, ten (32%) were age 26-35 years and eight (26%) were > 35 years of age; fifteen (48%) were white Caucasian and sixteen (52%) were in the BAME group.
- Educator / staff group – this information was not collected.

Table 8.1: Participants (Part 2, Phase 3)

Role	Used digital stories before for learning or teaching?		Length of time working in neonatal care					
	YES	NO	None	Place-ment only	Less than 1 year	1-5 years	5-10 years	>10 years
ALL participants (n=137)	**30 (22%)**	**107 (78%)**	**56 (40.9%)**	**49 (35.8%)**	**3 (2.2%)**	**2 (1.5%)**	**2 (1.5%)**	**25 (18.2%)**
Breakdown of participants below:								
Children's Nursing Students (n=67)	8	59	19	48				
Adult and mental health nursing students (n=31)	11	20	31					
Practice staff (n=39)	11	28	6	1	3	2	2	25
Breakdown of practice staff below:								
Nurse in clinical practice (n=11)	1	10			1	2	2	6
Clinical support worker (n=1)	1		1					
Educator (clinical) (n=4)	1	3						4
Educator (University) (n=12)	6	6	5	1	2			4
Doctor (n=1)		1						1
Nurse Manager (n=2)	0	2						2
Advanced neonatal nurse practitioner (n=7)	0	7						7
Network lead (n=1)	1							1

The data in this table relates to questionnaire Q1a (role), Q1c (number of years working in neonatal care) and Q1d (previous use of digital stories). NB- For Q1b – all participants were UK based.

8.5 Analysis

Each component of the analysis is now discussed in turn.

8.5.1 'Point-of-view' exercise & reflective exercise

Word frequencies were ascertained from the first exercise where the children's nursing students assigned words to how they would have felt, for the four perspective-taking questions. Figures 8.2 -8.5 represent this word frequency using Word Clouds, a simple mode of descriptive analysis useful for visual representation, a method said to reinforce common word occurrences highlighting their importance (Bletzer et al, 2015).

For the reflective writing exercise on identifying what both enhanced and hindered learning from the digital stories, all comments were collated, entered into NVivo and coded according content on illustrations, animation, voice, text and timing (Table 8.2). Appendix 7d contains extracts of the raw data from the point-of-view and reflective exercises. It can be seen what words were commonly used to describe emotions relating to the stories viewed; *scared, helpless, shocked, anxious*, to give some examples. In addition, various comments are outlined about what enhanced student learning such as images, animation and voice, or what hindered it, such as distraction or lack of animation.

8.5.2 Questionnaire and student interviews

Descriptive analysis of the questionnaire quantitative responses was undertaken. As *all* participants completed the questionnaire, a combined analysis was undertaken. Justification must be given for the use of descriptive, rather than statistical analysis

relating to the Likert scale choice questions. Descriptive analysis is undertaken to present patterns of data within a selected dataset only. It is used to give a general summary using frequency and /or percentages and it summarises and presents data in the form of visual summaries such as graphs. As the data was not going to be generalised to the population as a whole, where inferential statistics would be used, descriptive analysis was deemed appropriate

Descriptive analysis of all questions was performed. All response frequencies along with the percentages are outlined in Appendix 7e for each question. In addition, Figures 8.6 - 8.21 illustrate graphically, the responses to individual questions for the whole dataset (all participants) and broken down into the three groups (Children's Nursing students, Adult / Mental health nursing students and Practice staff).

Rationale for analysing the whole participant group as well as breaking this down into the three separate groups was to ascertain if and where any differences arose relating to views of the digital stories. Other potential variations were addressed but not reported due to lack of any discernible difference or emerging points of interest; for example, differences across variations in gender, age and ethnicity were not found, nor were any evident according to stage of training of the student nurses (between first, second and third years).

The qualitative analysis of the open responses / comments was combined for all participants along with the responses from the student interviews. This data was entered into NVivo and coded according to the four main areas of interest: Emotion/Empathy,

Learning, Impact and Format. These main themes were congruent with the questions from the questionnaire itself and so analysis was not as data-driven as for phase 1. Coding was therefore undertaken under these four broad themes to identify sub-themes (sub-codes) using the principles of thematic analysis outlined in these previous chapters (Figure 4.2: Chapter 4, pg. 95). Appendix 7f contains extracts from the interview raw data following transcription and Appendix 7g, contains the questionnaire qualitative raw data extracts (open responses). These quotes were chosen to present key examples of each theme that captured the essence of what was felt about the stories across several different participants. Selected questionnaire participant responses can be seen in Appendix 7h. In the Findings section shortly. Table 8.3 outlines the main themes (Emotion/Empathy, Learning, Impact and Format) and sub-themes identified under each theme. Key quotes for each are in Tables 8.4, 8.5, 8.6 and 8.7, all representing each of the sub-themes.

8.6 Trustworthiness and rigour

As for the other two preceding phases, strategies to address trustworthiness were applied, highlighted in Appendix 1. Firstly, the mixed-methods approach contributed to ensuring triangulation, undertaken to increase confidence in the findings (Heale and Forbes, 2013). As before, ensuring a reflexive approach to ensure transparency of data analysis and reporting was vital which included, in this instance, ensuring that the 'insider' role was considered (Landy et al, 2016) due to interviewing students and the familiarity between them and the researcher. This included declaring the relationship with the participants and the potential influence this may have had, not only on them

agreeing to take part but to the openness and willingness to impart honest views. Reflexivity is discussed in Box 8.1. Again, as for phase 1, there was compliance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al, 2007) (see Appendix 5). Limitations are discussed later in the chapter.

Box 8.1- Reflection: Phase 3: Affiliation to narrative

In phase 3 with the student nurse participants, I presumed there would be less of an emotive element than with the parents as the purpose of the interviews and the class exercises was not to gain their stories or personal experiences. Instead, it was to explore the perceived value of the digital stories. Overall, this presumption was indeed the reality as these encounters were more congruent with a teacher-student transaction as I was presenting to them teaching resources and finding out their views. However, I still found there was an element of the students during interview, opening up about what they felt about the babies and parents they had cared for in the neonatal unit, much like the findings in the initial study in Chapter 4. I was unprepared, as an example, for one student nurse revealing that she had had a premature baby some years ago before starting her nursing degree. Seeing the stories had reminded her about this difficult time and she stated she felt, in her words *''quite emotional''*. This was unexpected, and I learnt that although I knew the student well, this only extended to my lecturer – student relationship. Again, there was a need once again to find a balance between staying objective as a researcher and keeping focused on the task in hand (i.e. the interview) and ensuring that the student felt able to talk this through if she needed to.

I asked students that they should be honest in their views and that any opinions about the digital stories would be respected, honoured and seen as constructive. This was to guide further development and improvement but at the same time, they needed to be advised to not air negative views about staff or workplaces. However, another specific dilemma arose during an interview when I asked a question from the schedule about

what hindered their learning, in relation to the digital stories. Rather than respond to this, the student started to air grievances about lack of time in her placement to learn. My sense of control of the dialogue was challenged by the participant deviating from the schedule. I was unsure of how to react, feeling it inappropriate as a researcher to challenge or make a direct response. To avoid distractions and regain control, I steered the conversation back to the interview schedule. This raised an interesting question for me as to how to manage other information that is revealed, also found in the initial study when students at times spoke negatively about the mentoring they had received Parents too, at times would remember people in neonatal care that they disagreed with.

In relation to student nurse interviews, it was also important to maintain boundaries as I was their lecturer, as well as a researcher. I needed to be clear about this from the outset of the class exercises and interviews to reassure the students that they should not feel coerced into participating in any way and that their involvement was a separate research interaction to any learning and teaching delivered. In relation to the balance of power, not only the interviews but also the classroom exercises needed consideration in the third phase of the study in relation to the 'insider' perspective. Insider- researchers who examine those within their own organisation can offer a unique perspective because of their knowledge of the people involved (Asselin, 2003; Berry, 2016). However, the potential problem and challenges of researcher credibility (Arber, 2006; Darra, 2008), both within the organisation and at the point of reporting research findings (Dearnley, 2011) needed acknowledging. As an 'insider-researcher' I needed to maintain my commitment to the transparency of the research process, the philosophy of openness and collaboration, and to 'giving voice' to the student nurse participants.

8.7 Findings

The findings within each area of analysis are now discussed in turn.

8.7.1 Point-of-view' exercise & reflective exercise

Figures 8.2 – 8.5 highlight the most frequently used words used by students to describe how they would have felt in the parent's position. Collectively, the word 'scared' was used by most participants for all four questions. Also, very prominent adjectives were; worried, overwhelmed, sad, consumed, upset, tired and alone, all negative emotions to depict experience. These words resonated with the data collected from parent interviews in phase 1. Interestingly, the same adjectives were used in similar frequencies. Positive descriptions such as happy, love and hope were used much less commonly but were evident in relation to seeing the actual baby and going home. While there was consistency between students and parents in describing the baby, this was not the case for how parents felt when their baby was discharged home. 'Happy' was not a commonly used word by parents highlighting a misconception in that students assumed this was always a positive event whereas in reality, the transition home poses a significant emotional and anxiety-provoking challenge.

This type of analysis was a simplistic and somewhat crude way of making sense of data and caution should be and was applied to linking this with empathy in its whole, complex form. However, it did serve as a useful and stark reminder of commonly expressed emotions relating to parent experience. In addition, it was reassuring that students could identify and express parallel emotions to those articulated by parents, that they were

aware of these feelings and could potentially consider them in their nursing care of families. In relation to the inconsistency of words used to describe going home, this served as a useful learning point for students in relation to making them aware of how challenging this time can be for parents and the presence of mixed emotions at this stressful time of transition.

Figures 8.2-8.5: Words used in perspective-taking by student nurses

Figure 8.2: Describe how you think you would have felt when your baby was admitted to the NNU

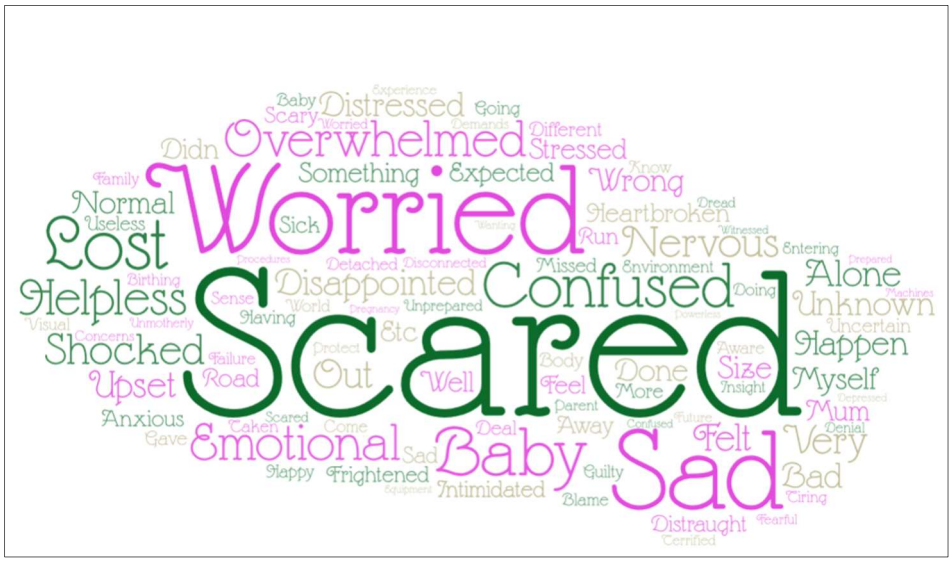


Figure 8.3: Describe how you think you would have felt when you first saw your baby

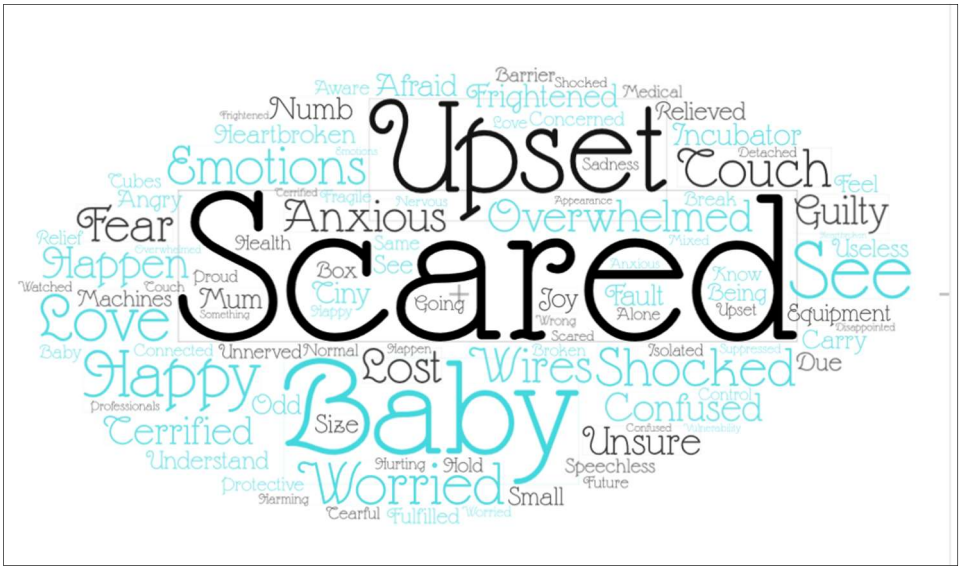


Figure 8.4: Describe how you think you would have felt during the long length of stay in the NNU

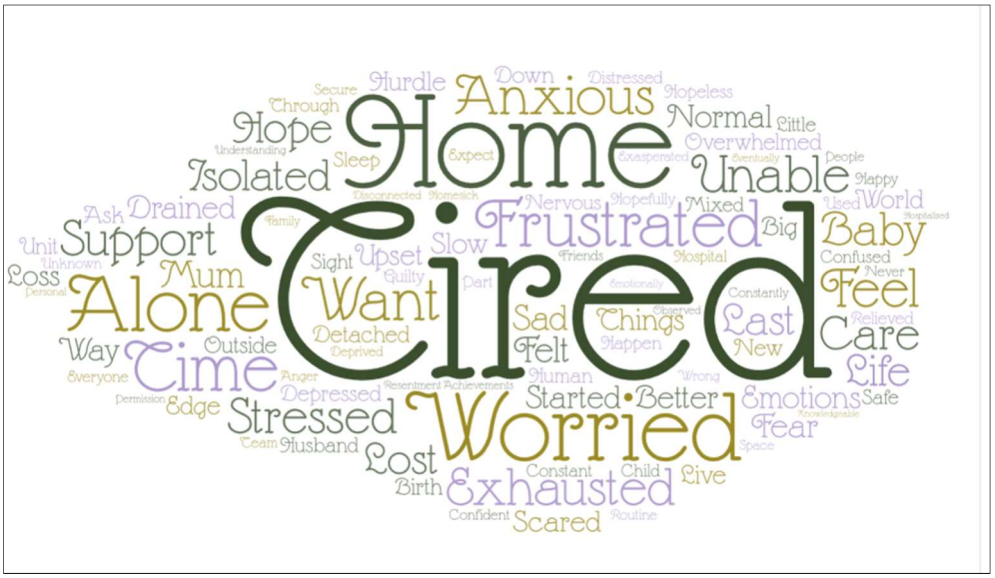


Figure 8.5: Describe how you think you would have felt when your baby was discharged home

Relating to what enhanced and hindered learning, Table 8.2 outlines selected written quotes from the student nurses about what they thought about this question, in relation to the digital stories. Views were most prevalent regarding the multi-media aspects of the illustrations, animation, voice, text and timing.

Table 8.2: What helped and hindered learning? Summary of key quotes

<u>What helped learning</u>

Illustrations

- *"The images explained the story and stood out"*
- *"The visuals were helpful', they were eye catching"*
- *''Pictures showing the emotions and how overwhelming it all is"*

Animations

- *''Animations and sub-titles of key words worked well, they kept my interest"*
- *"I liked how the pictures moved and changed at appropriate times"*

Voice

- *''The emotions in the voices"*
- *"The narrators were taken from the parents' perspective's"*
- *"Hearing words from parents helps to emphasise"*

Text

- *''The writing emphasised key parts"*
- *"Having the animation but also with some other words/phrases coming out was intriguing"*
- *''Certain quotes stood out- such as…." she was like a little red ball being whisked away in a funnel''*

Timing

- *"Short timings have real impact as they send key messages in a nutshell"*
- *''Short and sweet- helps you remember"*

What was particularly appealing?

- *''The mixture of the colours, quotes, pictures, size of font"*
- *"The first story was more captivating because the audio and visual help to get the emotions felt"*
- *''Pictures along with words allow you to visualise the neonatal intensive care unit environment"*
- *''The titles of the episodes really stuck in my mind as they will powerful messages"*
- *''The feeling of powerlessness as parents"*
- *''The intensity of the care and how much reassurance that parents will need was good"*
- *''How parents feel when they first see the machines"*
- *"How the mother felt"*
- *"The dad's view"*
- *"It takes so long to recover, how long the parents are affected after"*
- *"The real-life thoughts and feelings of the parents that had to go through this"*
- *"Ensuring parents know and are supported to hold their baby and also to get emotional support including the dad"*
- *"It is useful to have a visual eight for information about the procedures which is useful"*
- *"Understanding emotions from the parents' point of view"*

- *''One part that stood out for me was the emphasis put on the barriers which prevents parents feeling that they can look after their own baby''*
- *''Having knowledge to explain what was happening and supportive identifying issues parents may have, the support that they needed''*
- *''Identifying the length of time of the admission and the amount of procedures/monitoring was required''*
- *''Good to show how small the baby was, and visualisation of the huge number of monitors''*
- *''Preparing parents about the neonate environment, it is OK to express feelings''*
- *''I enjoyed the scene where there were pictures of the individuals involved in the care of the baby''*
- *''The depiction of the neonatal unit with all the machines flashing in the dark and looming over the neonate was useful in relation to enhancing learning about parents' feelings''*

<u>What hindered learning</u>

Illustrations

- *''Quality of the illustrations was less engaging in the third video'' ('Fighter')*
- *''Lack of colour in third video''*

Animations

- *''Animations can be quite distracting at times…* (in the first video, 'Another World')- *sometimes animation is distracting rather than helping''*
- *''The second video ('On the Edge') had fewer visuals / animations – this was not so engaging''*

Voice

- *''The voices were clear and easy to listen to although it did appear a little rushed at times, I guess to fit the story in within a short time span''*

Text

- *''The text only appears for a short time which made the videos hard to follow at times when trying to read the text as well as look at the pictures and listen – this is not good for students with dyslexia''*

Timing

- *''The first two videos were a bit long-winded''*
- *''They are perhaps too short – I wanted to hear more about care''*

What was particularly lacking?

- *''Lack of music – music could be added to enhance emotional effect''*
- *''More animation on the second video would make it more interesting to watch''*
- *''Some explanations would have been helpful, for example, about procedures''*
- *''It would be interesting to know more about certain things, such as the long-term side effects- she turned blue and stopped breathing…. Why?''*

Overall, comments on what enhanced learning compared to those relating to what hindered it, were four times more prevalent. It was clear that the blending of the multi-media aspects of the digital stories was well-received, a factor that aided learning and had an emotional impact in relation to the ability to evoke an affective element, feeling or message. Particularly positive was the effect of the narrator's voice and the benefits of *listening* to the story. The subjectivity of views was also clear; for example, as seen in Table 8.2, two students thought the brevity of the stories aided memory and impacted learning while another thought that the short timing was inhibitive. Conversely, one person even said that the videos were too long. Such differences of opinion probably reflected individual preferences for learning. Further discussion of these elements relating to learning are discussed for theme 4; Format of stories, as similar themes were evident from the questionnaire and interview responses on this topic.

8.7.2 Questionnaire and interviews

To reiterate, the open responses for interview and questionnaire data for all questions were collated and analysed as a collective whole in relation to the broad themes highlighted in Table 8.3, along with the sub-themes that emerged. The findings are now discussed under each of these four broad themes: Emotion, learning, Impact and Format. Appendix 7e outlines all quantitative analysis for each question that corresponds to each question depicted in the graphs: Figures 8.6 – 8.21.

Table 8.3: Summary of qualitative data analysis from interviews and questionnaire (Phase 3): Themes and sub-themes

Theme	Sub-themes
EMOTION **The effect of digital stories on emotion and empathy**	o Realising what parents feel o Emotional awareness o Being moved o Enhancing empathy
LEARNING **The perceived value of digital stories for learning and knowledge acquisition**	o Insight into the parent's perspective o Leaning about others' emotions o Learning about the whole neonatal journey o Learning about the need for compassionate, empathic care
IMPACT **The potential impact of digital stories on practice**	o Raising awareness of parents' needs in practice o Increasing parent emotional support o Using digital stories for practice preparation o Using digital stories to teach others
FORMAT **The format of digital stories for representing emotion and evoking empathy**	o Engagement o Authenticity o Learning via the senses o Making connections

Theme 1: EMOTION- The effect of digital stories on emotion and empathy

As seen in Figures 8.6 and 8.7, the majority of responses for the questions of whether the digital stories increased understanding of parents' feelings and secondly, enhanced empathy were 'Completely agree' (62% / 50.4%) or 'Agree' (35% / 39.4%) for the whole group collectively. Only a few responses were unsure (2.1%/7.3%) about these questions and this was due to participants not being able to identify with this possibility, having never worked on a neonatal unit as they were children's students who were yet to be placed there or students in other nursing fields. For those who answered 'Disagree' or 'Completely disagree' (<2%), these were mainly trained staff who thought they were already empathic due to their experience. However, there were certainly others who still felt a reminder was needed for staff even those who were experienced.

Some of the specific open responses for this theme can be seen in Table 8.4 regarding the realisation of what parents feel, a raised emotional awareness, being moved emotionally and enhancement of empathy. These were common sub-themes documented in the open responses freely and often with much detail. Appendix 7e-h highlights the detail within the written responses and the prevalence of these themes showing overall, the value placed on the stories with regards to emotion and empathy. Bringing in critique here too, for comments supporting 'Disagree' / 'Completely disagree', one respondent obviously felt no emotion, saying the stories left them 'cold', and others questioned whether empathy can really be present unless one has been through the experience themselves.

Figure 8.6 **Helpfulness of digital stories in understanding parent's experience and feelings**

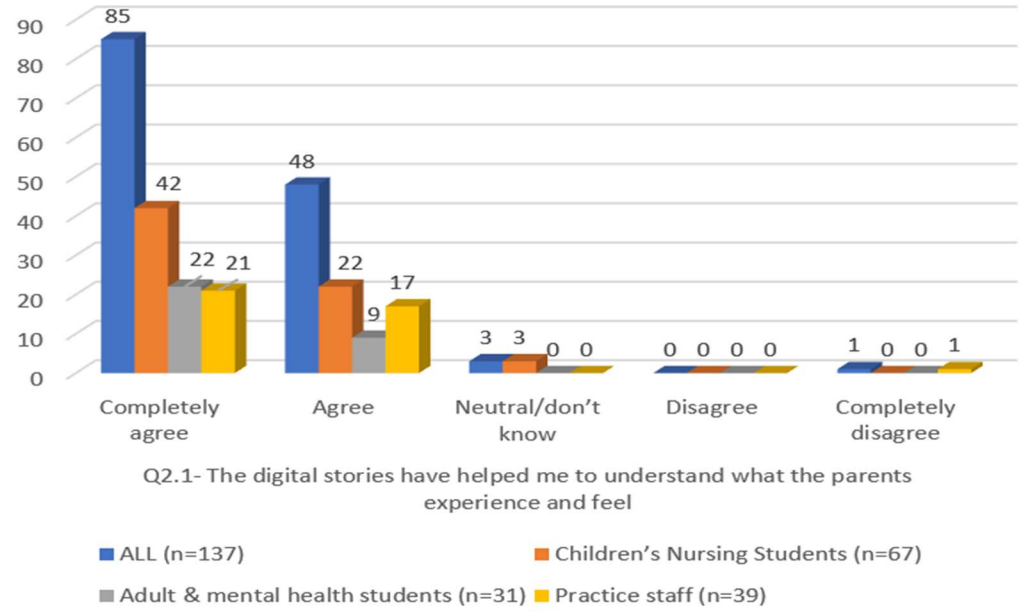


Figure 8.7 **The extent to which digital stories increase empathy towards babies and parents**

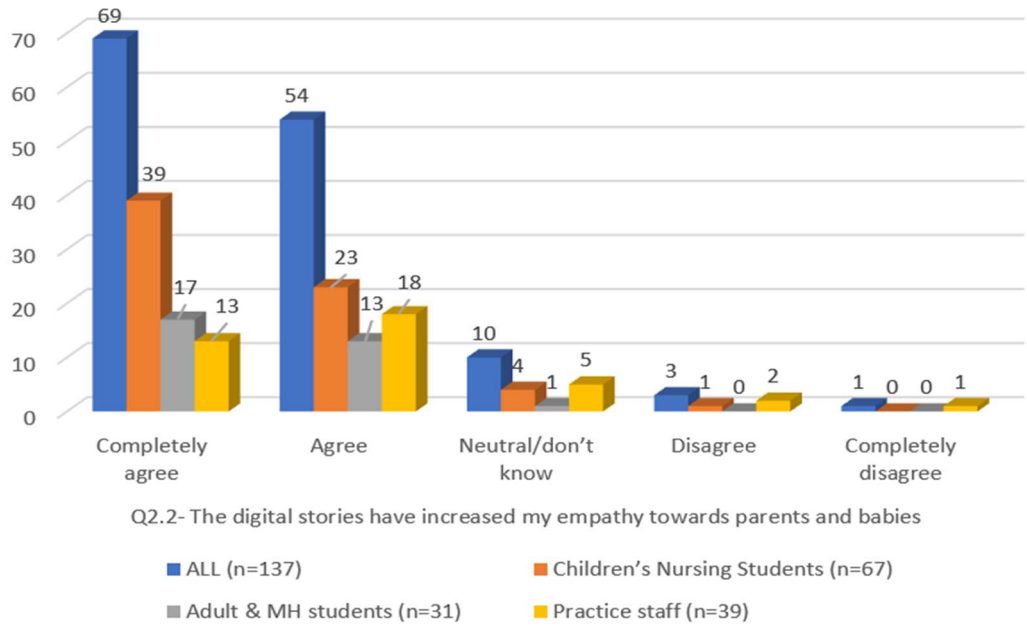


Table 8.4: Selected quotes for theme 1
EMOTION: The effect of digital stories on emotion and empathy

Realising what parents feel

''I never realised how out of place some parents feel'' (Children's nursing student- third year)

''I realised how parents must feel when their babies go to the neonatal unit''
(Children's nursing student- second year)

''Any student going to the neonatal unit should watch the videos as they will realise what emotions the parents have- this is not always known or realised'' (Neonatal nurse)

''Even though I have worked for many years in neonatal care, we can become immune to the parents' feelings – a reminder is needed so that we don't get complacent and don't forgot the trauma that they go through'' (Neonatal clinical educator)

Emotional awareness

''It gives you a real sense of emotion and I feel that will make you more empathic and compassionate'' (Adult student nurse)

''It would make me more aware of patients' feelings and experience they went through''
(Mental health student)

''Every experience is different, no story will ever be the same, …. Staff will be more understanding of the individual's emotion'' (Neonatal clinical educator)

Being moved

''Seeing images even if drawn bring up emotions in me''
(Children's nursing student- first year)

''Watching the videos and hearing what the parents experience and the emotional roller-coaster…… you can feel their emotions''
(Children's nursing student – second year)

''Can hear the sadness in the voices within the animations gives a better emotional response- you can really feel for them'' (Advanced neonatal nurse practitioner)

Enhancing empathy

''The videos helped me empathise the pain they were feeling''
(Children's nursing student- first year)

''It was very emotive thus highlighting the need to be empathic and supportive to families in desperate situations'' (Mental health student)

''It's important to hear from real-life patient experiences to gauge how appropriate the care given is, also to try and create empathy prior to experience for us as student nurses to know how to act upon difficult situations''
(Children's nursing student- third year)

''Evokes a sense of empathy for the parents and makes you realise just how important empathy actually is- we all need reminding of it in practice'' (Neonatal educator)

Critique

''They left me feeling cold'' (Neonatal nurse)

''I wonder if we can really put ourselves in the parent's place…. The stories only go so far'' (Neonatal sister)

''Unless you have been there, I don't think you can properly put yourself in their position – but you can imagine'' (University Lecturer)

''I am already empathic due to years of working in this area'' (Neonatal nurse)

Theme 2: LEARNING- The perceived value of digital stories for learning and knowledge acquisition

As seen in Figures 8.8 and 8.9, most responses for the questions of whether the digital stories enhanced, firstly learning about neonatal care and secondly, about the patient experience were 'Completely agree' (49% / 42.3%) or 'Agree' (58.4% / 33.6%) for the whole group collectively. For the responses that were unsure (7.3%/6.6%) about these questions, this was due to participants wanting more information about certain aspects of neonatal care such as clinical skills, the use of technology and equipment. For those who answered 'Disagree' or 'Completely disagree' (only one for each response), again these were trained staff who did not feel the stories added any further information to their existing knowledge base due to their experience. However, for those who were unsure

or did not agree about the role of digital stories for learning, some did comment that they would be useful and/or essential for students and junior staff new to the area.

Some of the specific open responses for this theme can be seen in Table 8.5 highlighting various selected responses regarding the role of the digital stories in enabling insight into parents' experiences, the value of learning about emotions, the usefulness of learning about the whole parent 'journey' and the awareness of the need for person-centred, compassionate care following viewing of the stories. Again, common sub-themes were documented. Appendix 7e-h collectively further highlight the value placed on the stories with regards to learning and knowledge gain. Regarding critique, there were some comments stating that more information would have been beneficial on, for example, the different levels of care, the more 'medical' / clinical type of care and about the healthcare team. This suggested that some participants may have felt a focus on emotional learning was limited leaving them with a need for more information. However, they did still feel the emotional element was valuable for learning overall.

Figure 8.8 **Usefulness of digital stories for learning about neonatal care**

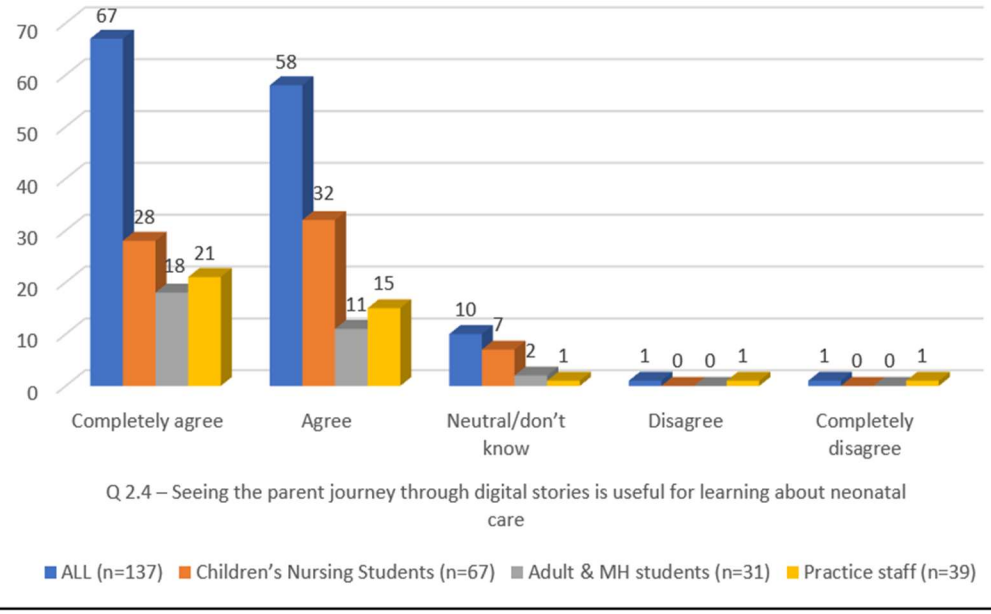


Figure 8.9 **Effectiveness of digital stories for learning about patient experience**

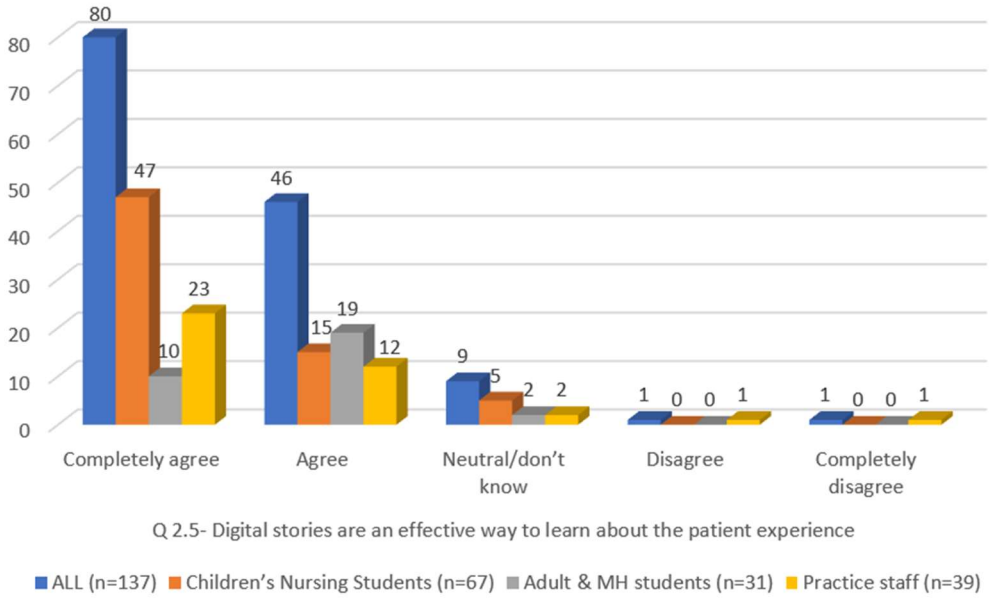


Table 8.5: Selected quotes for theme 2
LEARNING: The perceived value of digital stories for learning and knowledge acquisition

Insight into the parent's perspective

''The use of real testimonies and the visual work allowed an insight into the world of the parents' perspective'' (Nurse educator)

''The point of view from parents gave me an insight into neonatal care'' (Children's nursing student- second year)

''What goes through the mind of a parent, and how they feel once they have left the care of the doctors and nurses'' (Healthcare assistant)

Learning about others' emotions

''I learnt that both having a premature baby and being in the neonatal unit can be daunting and anxiety provoking for parents'' (Children's nursing student- third year)

''…demonstrates visually the struggles the parents and babies go through'' (Children's nursing student- first year)

''More emotional as pictures show how many wires are used. Shows how scary it can be'' (Children's nursing student- second year)

''the stories show parents are overwhelmed emotionally – we can express and identify their emotions easier'' (neonatal nurse)

''You see how parents feel through expressions and the daunting environment is illustrated'' (Nurse manager)

Learning about the whole 'journey'

''The fact the stories included progression of journeys through the various stages of neonatal care was very valuable'' (Network Lead)

''felt like you were going through the journey… with the family''(Doctor)

''The whole story, from birth, stay…home… experiencing the whole story really brings the story / experience to life'' (University Lecturer)

Learning about the need for compassionate, empathic care

''I could see clearly the emphasis on isolation that parents feel, particularly mothers who feel left out not having their babies – this is often forgotten during care'' (Neonatal nurse)

''It was so good to see the effect on fathers too and that also need compassionate care'' (Advanced neonatal nurse practitioner)

''Neonatal care can be a hard time for parents. It is important to understand each individual and continually support them, providing sufficient person-centred care'' (Children's nursing student- third year)

Critique

''I would have liked more about the different journeys; e.g. through intensive care, special care, transition and home… as well as procedures'' (Children's nursing student- second year)

''good emotional awareness but medical learning limited'' (neonatal nurse)

''not much about nursing or personal, hands-on care stood out in the clips'' (Children's nursing student- first year)

''not a lot of information regarding the healthcare team'' (Children's nursing student- third year)

Theme 3: IMPACT- The potential impact of digital stories on practice

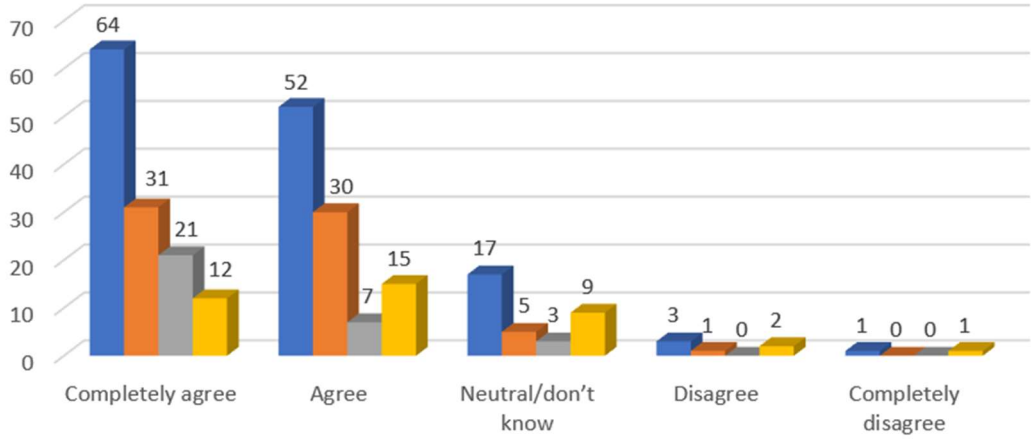
Figures 8.10 – 8.16 represent the questions relating to impact of the digital stories. Firstly, a similar pattern is seen for Themes 1 and 2 relating to the question about the impact of the stories, on giving more effective, empathic, person-centred care (Figure 8.10). Most responses were 'Completely agree' or 'Agree', with > 75% found for these two responses combined. Secondly, when asked whether the stories would have an impact on their practice, the majority of responses were 'Yes' for the group as a whole, although for the children's nursing students, almost half of this group answered, 'Don't know' (Figure 8.11). Thirdly, for the questions about affective, cognitive and behavioural empathy (Figures 8.12, 8.13 and 8.14) and the impact on understanding (Figures 8.15 and 8.16), >75% of the overall responses were' significant' and 'moderate'.

To give more detail on these findings, a different pattern of results was found within this theme relating to the increased number of responses for 'Unsure / Don't know' (Figure 8.11). Taking this question of the potential impact of stories on practice, 27.7% of the whole group answered with the unsure response. This showed that the ability to ascertain impact on practice is difficult to gauge or that other factors may hinder or confound impact being possible. Most of these responses were from the children's nursing students; 44.8% of this group compared to 12.7% and 9.8% for the other student groups and practice staff respectively. It was unclear as to why this might be the case. For the seven responses (17.9% of the whole group) that answered 'No' to any potential impact in practice, these were trained staff who commented that they were experienced and so felt it was unnecessary to make any changes. Interestingly, none of the students responded 'No' to this question highlighting that there is a potential for stories to have impact on one's practice even if there was a considerable degree level of uncertainty as to what and how this may manifest. This appeared to be based on acquiring new knowledge to inform practice in line with transformative learning, which was encouraging.

There were also more responses for 'Unsure/ Don't know' for the impact on affective, cognitive and behavioural empathy (7.1%, 8.6% and 10% respectively) which may have due to questioning the perceived ability to truly take a parent's perspective and doubt relating to the capacity for the digital stories to have a long-term influence on one's practice. It is interesting and again, encouraging to note that there were no responses for 'None' in relation to impact.

Some of the specific open responses for this theme can be seen in Table 8.6. Impact on one's practice was commonly identified in relation to having an increase awareness of parents' needs, an increase in likelihood of giving parents more emotional support, future use of digital stories for practice preparation and staff wishing to use them for future teaching. Critique in relation to impact related to, once again, staff already being experienced and so impact would be more limited for them. In addition, some felt the length of the stories and the limited content would lessen their longer-term impact.

Figure 8.10 **The part digital stories play in enabling more effective, empathic, person-centred care to babies and families**



Q 2.6- Seeing the neonatal journey through storytelling will enable me to give more effective, empathic person-centred care to neonates / families

ALL (n=137)
Children's Nursing Students (n=67)
Adult & MH students (n=31)
Practice staff (n=39)

Figure 8.11 **The potential impact of digital stories on practice**

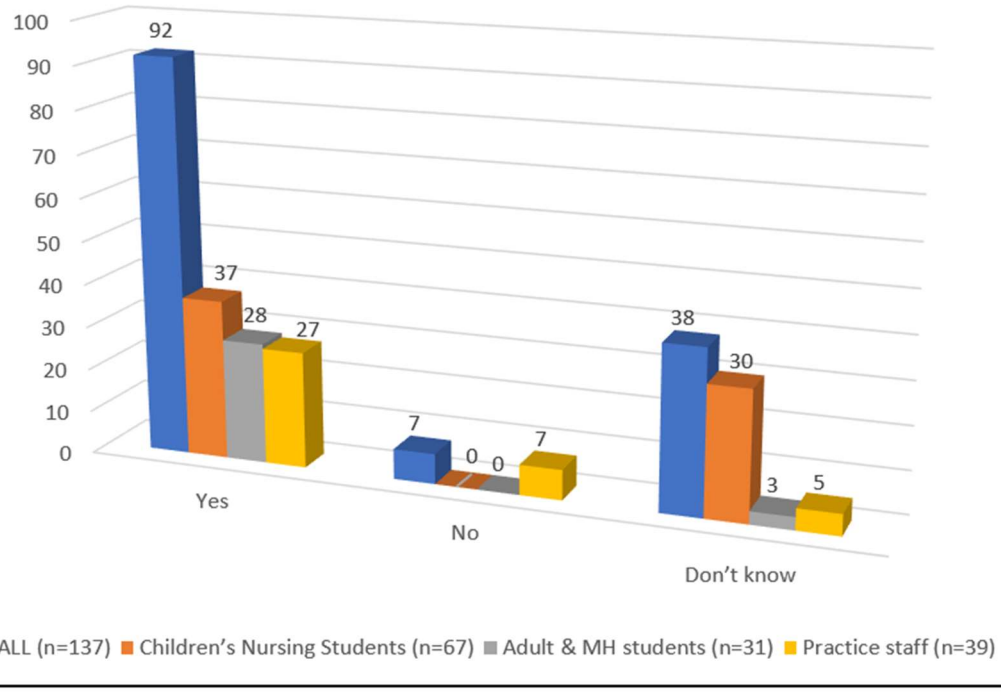


Figure 8.12 **The potential impact of digital stories on affective empathy**

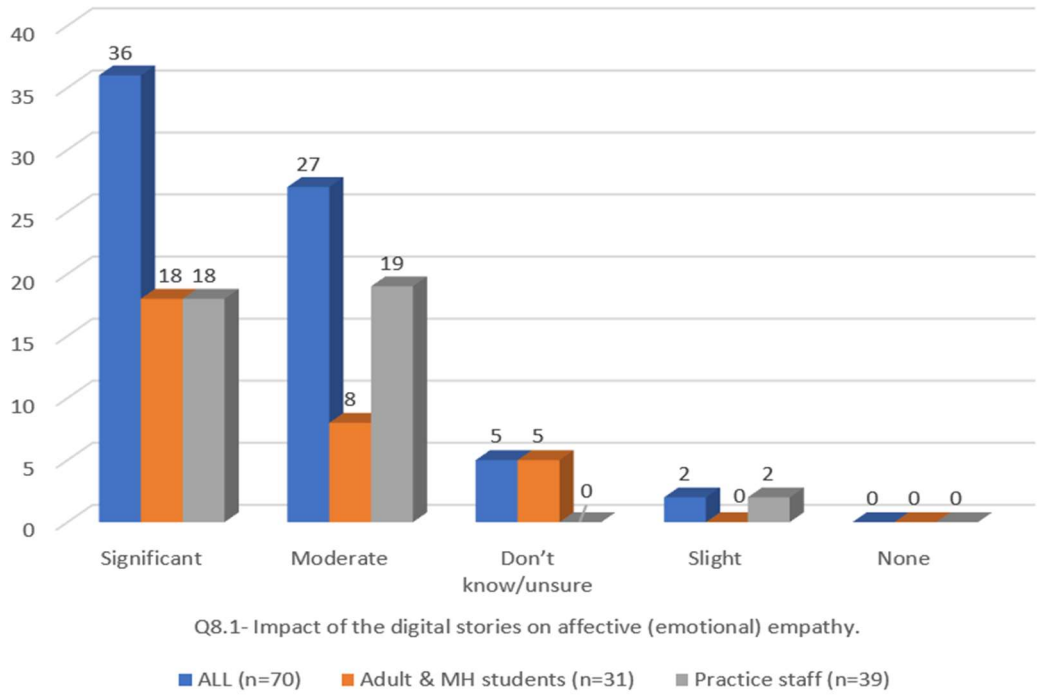
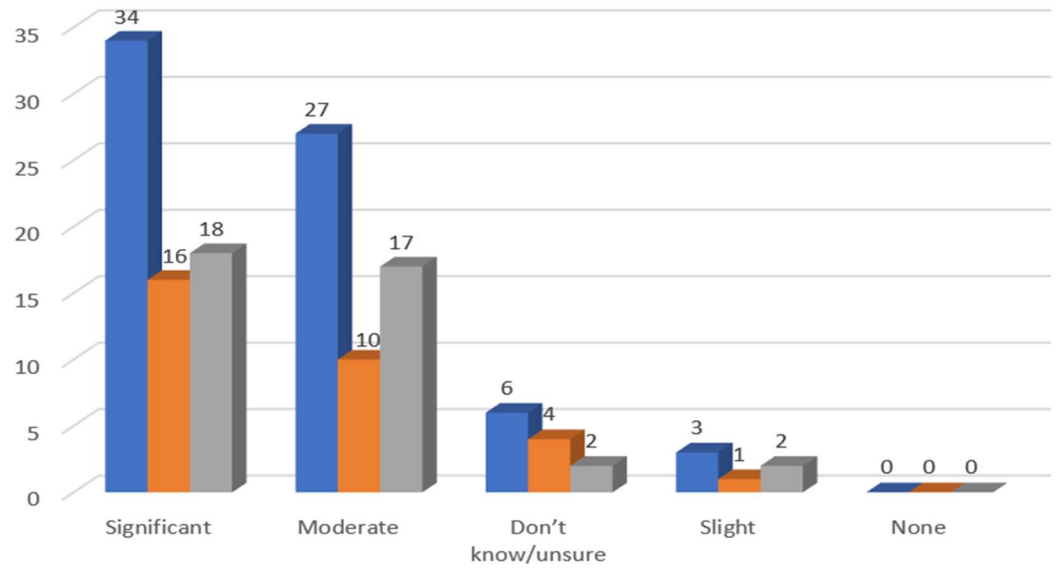


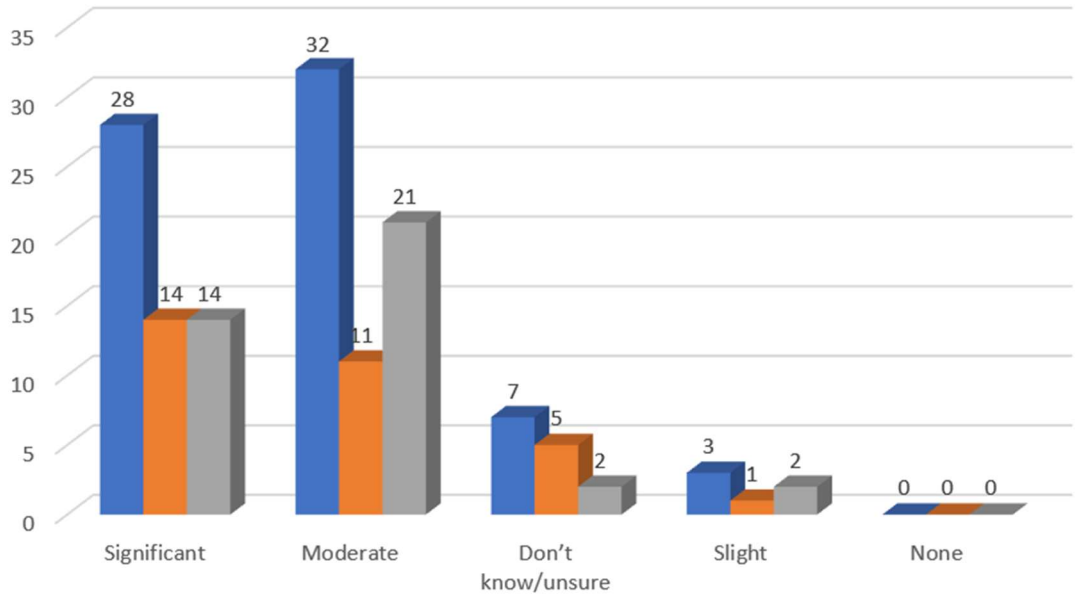
Figure 8.13 **The potential impact of digital stories on cognitive empathy**



Q8.2- Impact of the digital stories on cognitive empathy.

ALL (n=70) Adult & MH students (n=31) Practice staff (n=39)

Figure 8.14 **The potential impact of digital stories on behavioural empathy**



Q8.3- Impact of the digital stories on behavioural (compassionate) empathy.

ALL (n=70) Adult & MH students (n=31) Practice staff (n=39)

Figure 8.15 **The potential impact of digital stories in understanding the emotions of parents**

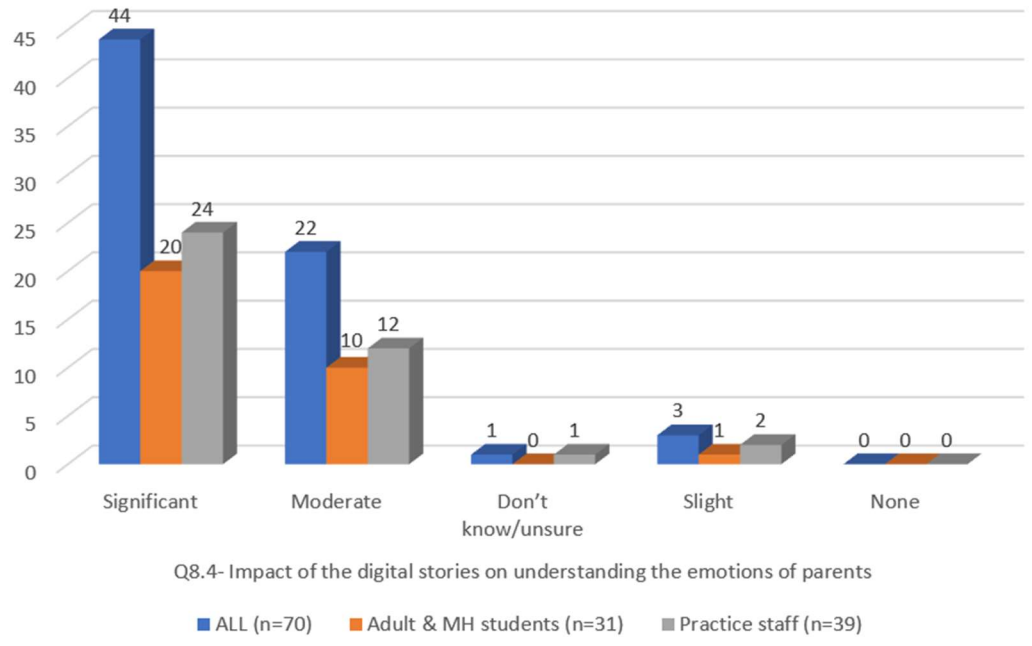


Figure 8.16 **The potential impact of digital stories on understanding what parents need to make their experience better**

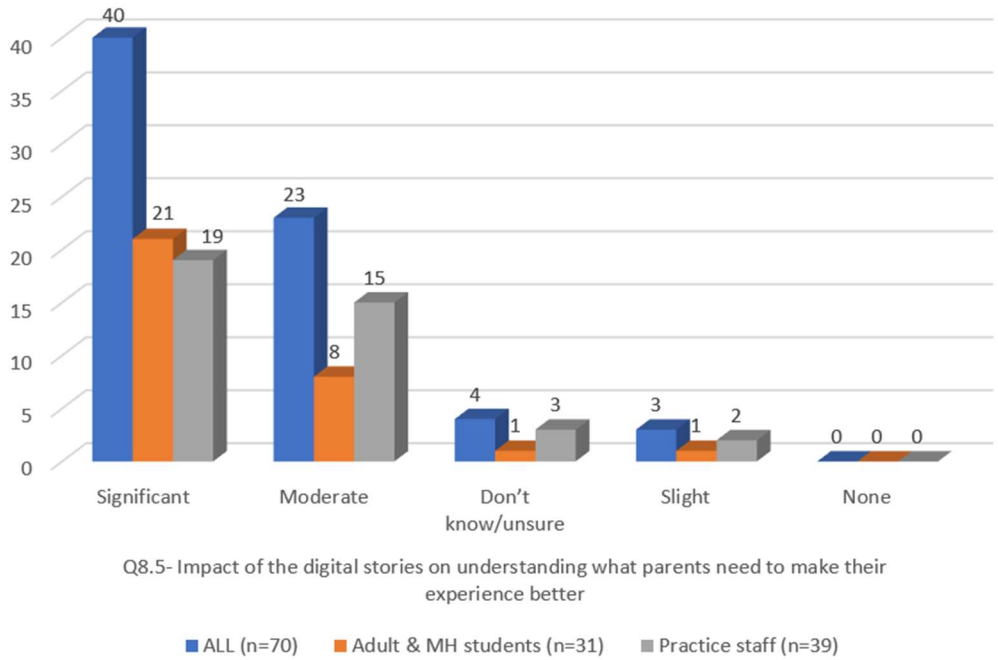


Table 8.6: Selected quotes for theme 3
IMPACT: The potential impact of digital stories on practice

Raising awareness of parents' needs in practice

''Gives an increase in awareness so attitudes and approaches can be adjusted'' (Neonatal clinical educator)

''Making us more aware of what parents need is good as sometimes we don't know, they may be afraid to say or ask… but now I know that they need' (Children's nursing student- third year)

Increasing parent emotional support

''I will become more empathic towards the parents and make sure they are supported. I will remember the person-centred care is key to understanding the parents better'' (Neonatal nurse)

''I would be more empathic and find more ways to support parents and patients'' (Mental health student)

Using digital stories for practice preparation

''I think this would be useful for students to see before placement on the neonatal unit as it's an excellent way to think about how families may feel and the many barriers they face'' (Children's nursing student- second year)

''I feel that when I do my neonatal placement, I will be more aware and sensitive as to how the parents may be feeling, I can empathise with the journey they are going through and help make them cope with changes in their child's care'' (Children's nursing student- first year)

Using digital stories to teach others

''I will use them for future teaching'' (Neonatal clinical educator)

''The stories will be an excellent resource to use for learners and new staff'' (Nurse manager)

''it is definitely something that needs to be incorporated into the BSc Hons UG curriculum'' (University Lecturer)

Critique

''Having worked for many years in neonates, it will probably not change my practice as I hope I already understand parents' feelings but would recommend definitely to newer staff'' (Neonatal nurse)

''The impact would be limited due to the act they are so short, only a few minutes- maybe short-term impact only but not longer term'' (Advanced neonatal nurse practitioner)

I need to see the text too to remember key points – for example, certain quotes – ''she was like a little red ball being whisked away in a funnel'' (Adult student nurse)

Theme 4: FORMAT- The preferred format of story to represent and teach about emotion and evoke empathy

Figures 8.17 – 8.21 represent the questions relating to presentation aspects of the digital stories. For the questions on clarity, visual appeal and how engaging the stories were, a similar pattern is seen for Themes 1, 2 and 3 in that the majority of responses were 'Completely agree' or 'Agree', with > 75% obtained for these responses combined, for these questions. Some answered 'Unsure/ Don't know' (12.4% of the whole group) and this was due to different preferences for some stories over others and whether the participants preferred the multi-media presentation compared to more standard text-based stories. However, there was an overwhelmingly positive response to digital stories as a format with only one person in total answering 'Completely disagree' for all these questions; this person clearly did not enjoy the stories although did not expand on why.

In relation to which format evoked more emotion and empathy, it was clear that the digital format was preferred for the group as a whole and the individual groups. However, a combination of formats also received a positive response suggesting that the integration of a digital format with other forms of learning would perhaps be more desirable. Individual preferences came through for mode of learning; a few participants did prefer reading stories rather that a digital format for example.

Some of the specific open responses for this theme can be seen in Table 8.7. The common themes in relation to format and how this contributed to emotion and empathy were: engagement, authenticity, learning with the senses and making connections.

Overall, the use of multi-media was found to be engaging, held interest, captured the senses and participants often commented on how this helped them connect with the emotional side of the story and presentation. Voice in particular, was found to be a strongly emotive feature. Critique centred on limited authenticity due to the voices not being the real parents, a preference for reading words to have more of an effect with one participant finding the voices to be 'cold' and 'harsh'. As for the other three themes however, negative comments were much less frequent with the majority being very constructive in relation to suggestions for future development and improvement of the stories.

Figure 8.17 **The extent to which digital stories are clearly presented**

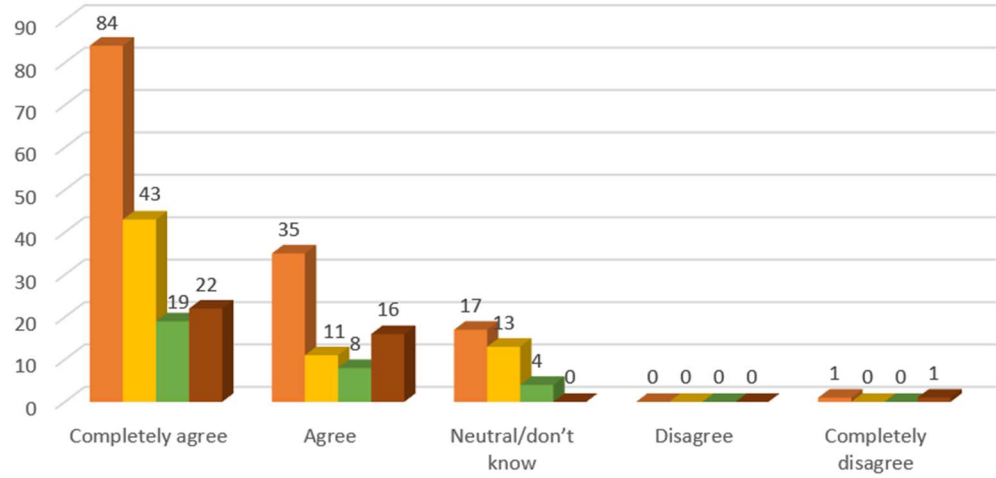


Figure 8.18 **The extent to which the digital stories have visual appeal**

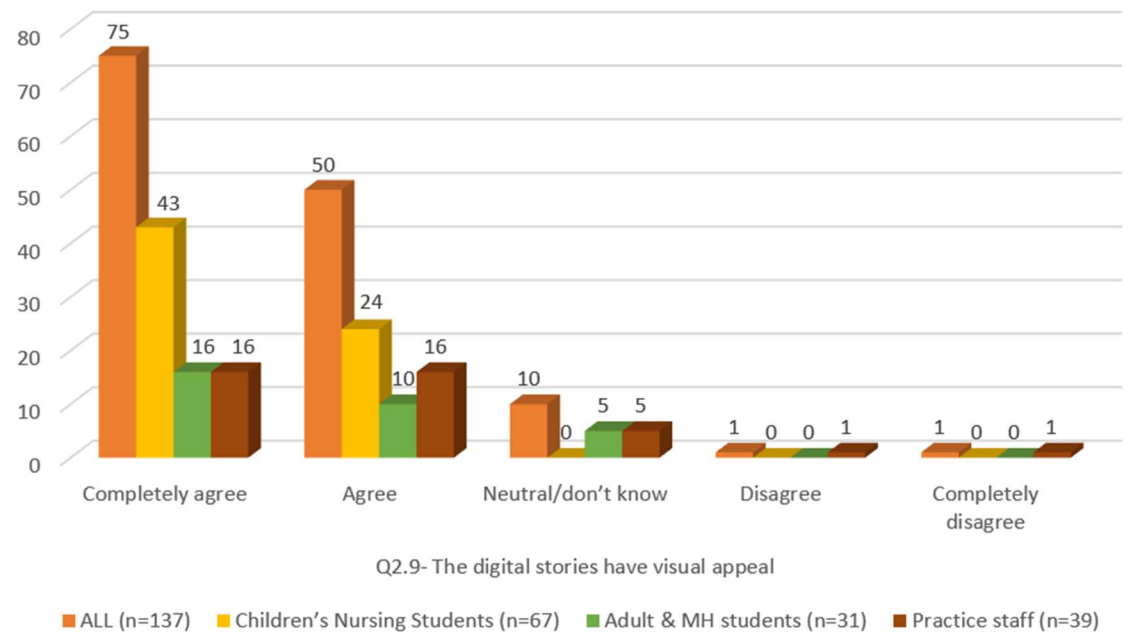


Figure 8.19 **The extent to which the digital stories have an engaging presentation**

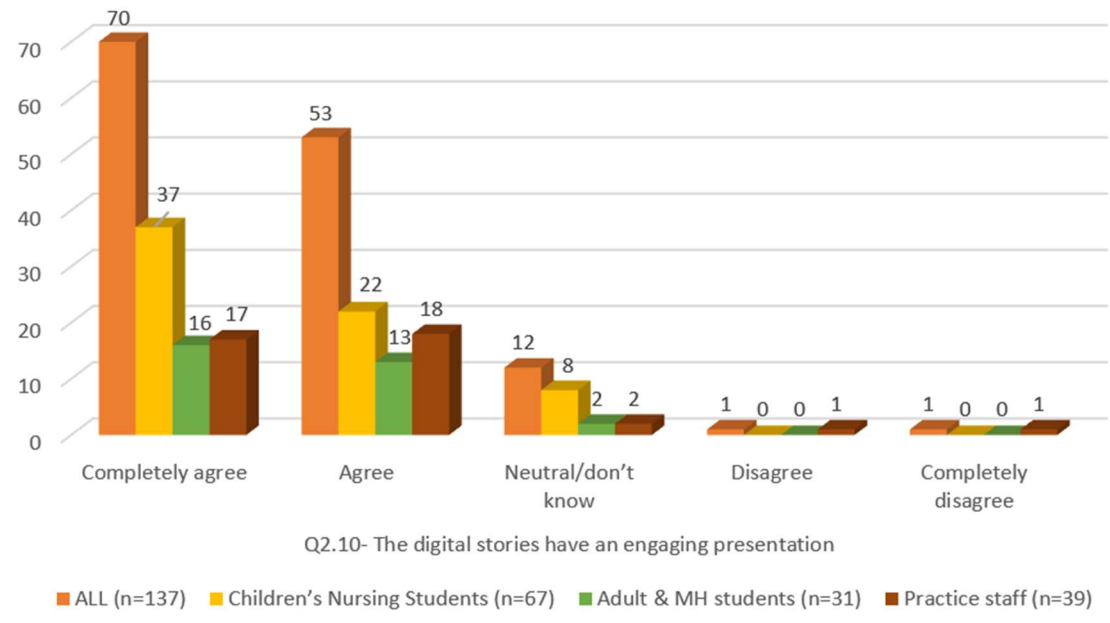


Figure 8.20 **The most effective format to learn about the emotions of parents**

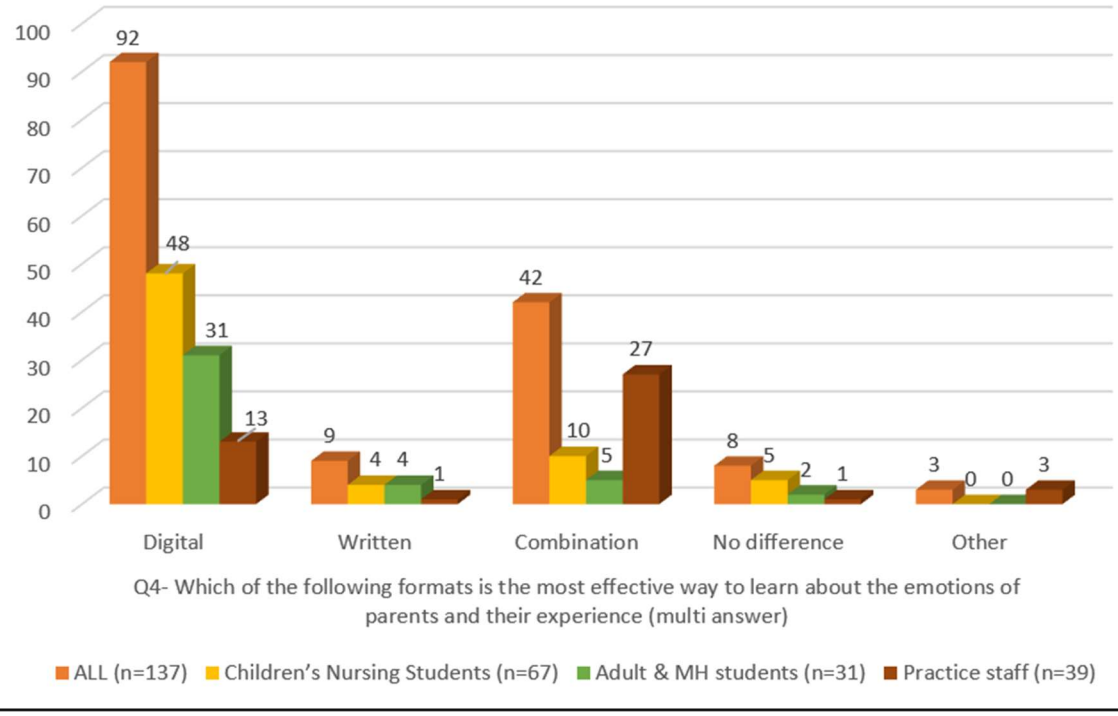


Figure 8.21 **The most effective format to evoke empathy**

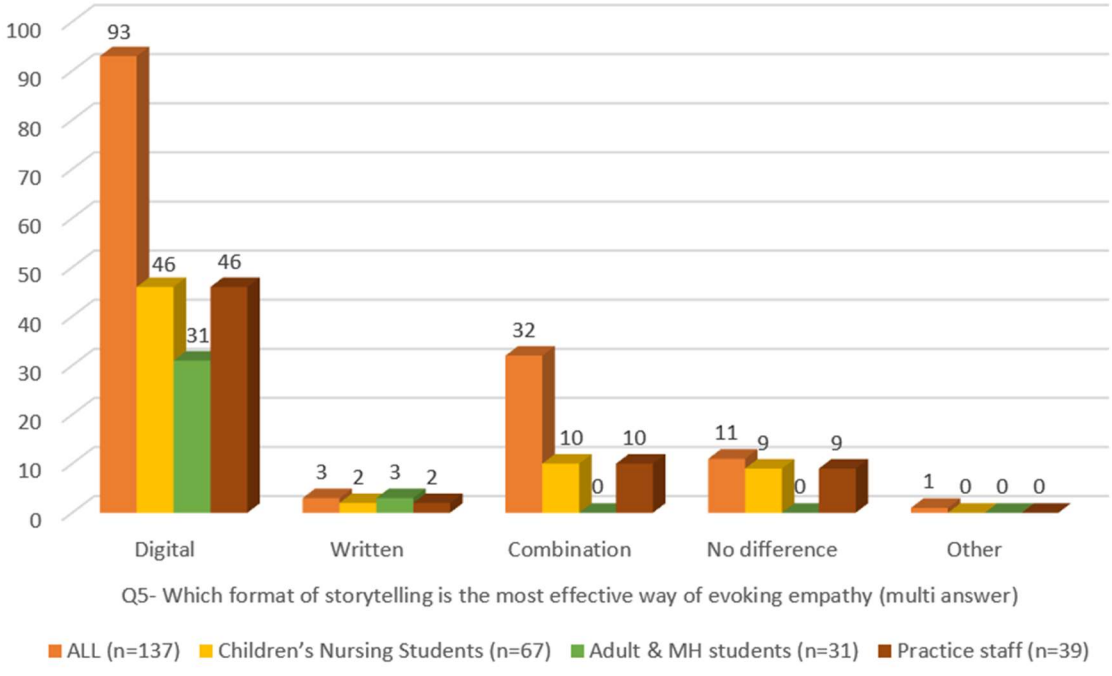


Table 8.7: Selected quotes for theme 4
FORMAT: The format of digital stories for representing emotion and evoking empathy

Engagement

''Hearing and watching what the parents and babies go through sums it up and keeps people engaged'' (Children's nursing student- third year)

''Having the visuals engaged me more'' (Neonatal nurse)

''There is more engagement and listening to parents / people gives you more of an insight into their thoughts and feelings'' (Children's nursing student- first year)

Authenticity

''The cartoons gave her speech and writing context. The actor reading the script gave the words a voice and someone to focus on. This makes it feel more real'' (Adult nursing student)

''The videos feel real, shows it can really happen and how emotions are high for parents'' (Mental health nursing student)

''You hear someone telling it, so it seems more real'' (Children's nursing student- first year)

''This is because when I watched the digital videos, I was able to link it to reality and I understood the various experiences in the video clip'' (Neonatal nurse)

''Made the script felt real. The scripts used good, simple language but were very detailed in demonstrating care and gave realistic expectations'' (University Lecturer)

'' I felt the videos were clear representation of what it is like in the unit. I related to what the parents said about apprehension towards holding the babies and the noises but from a student perspective'' (Children's nursing student- second year)

Learning via the senses

''Very informative by using a mixture of words, pictures and illustration'' (Network Lead)

''Easy to visualise and hearing the voices and physically seeing the story makes it stick in my heard more and understand more'' (Clinical support worker)

''Hearing a person speak about their personal experience makes it easier to understand their emotions and hear how they feel'' (Children's nursing student- second year)

''The sound of the parents resonates in your mind and it almost repeats their thoughts and feelings inside your head, so you can empathise with them more clearly'' (Neonatal clinical educator)

''You can understand better how they are feeling when you hear parent's voice'' (Neonatal nurse)

''The feelings are given a voice'' (Children's nursing student- second year)

Making connections

''With digital stories, the emotions and tone of the story can really be felt, whereas with written, you hear in your mind what you want to hear, and the meaning can be misinterpreted'' (Advanced neonatal nurse practitioner)

''Being able to see the parents' emotions as well as hearing it does help to create a bond of how they feel'' (Children's nursing student- second year)

''Emotion expressed invoice with a visual illustration touches the heart'' (Adult nursing student)

''More of a connection to the family. Listening to a story is good and useful to understand emotions. Digital allows more of an opportunity to connect with the story of each parent and hear the emotions of the voice'' (University Lecturer)

Critique

''The voice did make me feel the experience but not so much with the video'' (Children's nursing student- first year)

''It would have been even more effective if real parents talking'' (Children's nursing student- second year)

''No difference between digital and written – the same messages are conveyed'' (Children's nursing student- third year)

'I prefer reading a story rather than watching abstract pictures- this holds my attention more especially with phrase like 'On the edge'- the text quotes however did help this during the videos'' (Mental Health nursing student)

''The images appear rather cold to my personal taste and the voices are also quite harsh. I Liked the father's voice, but I strongly disliked the voices for the first two videos'' (Advanced neonatal nurse practitioner)

8.8 Discussion

The analysis and findings of Phase 3 are now discussed to illuminate key messages and areas of interest that can be applied to future practice. There are some key points that have emerged from this phase. Firstly, digital stories based on parent narratives strongly raised emotional awareness in the viewer, be they student or staff, about the parent experience. This suggested that digital stories may enhance affective empathy, which was defined as the ability to recognise or internalise the emotions of others (Tamayo et al, 2016). A question posed here is whether it was affective empathy that was enhanced or a raised emotional awareness about others' feelings. There is a distinction between the two as the former is *feeling* the same as someone else, while the latter is *being aware of* others' feelings. One may ask however, does this distinction matter? Most important was that those viewing the stories could come to a clearer understanding of parents' emotions in order to impact on and/or transform practice.

Participants commonly expressed they could clearly see and/or hear the emotions of parents through the stories. This raised their understanding of what parents experienced emotionally and contributed to positive views about what can be learnt from parents in these situations. This is empathic learning as defined in the context of this study, rather than actual empathy in its fullest sense. There was still an overwhelming response particularly in relation to emotions being articulated and an acute raising of awareness about the parents' feelings. The themes 'emotion' and 'learning' were an integral part of all the open response narratives, threaded throughout. Overall, the findings of this phase of the study showed that students may be facilitated to become aware of, and to

some degree understand what the parents felt and experienced during their neonatal care trajectory.

In relation to cognitive empathy, the ability to put oneself into another's situation and feel with them or the same as them was more questionable. Even though most participants agreed that stories *would* impact their cognitive empathy on a Likert scale, the *extent* to which digital stories would do so was less clear and there was more doubt expressed by participants. This concurs with Tamayo et al (2016) who, to reiterate, stated that education strategies were needed aimed at increasing cognitive empathy. One can ask, can we completely and truthfully step into another person's shoes unless we have actually been there? As cited by a participant in Table 8.4, *''I wonder if we can really put ourselves in the parent's place…. The stories only go so far''.* Some other quotes reinforce this opinion, for example, this statement from a student nurse; *''I try to put myself in their shoes but not experiencing what they go through every day does not even compare''*, and, *''I do wonder if we can ever truly understand the emotions felt by families on a neonatal unit unless we have personal experience of the day to day reality of 'living' on the unit''.* In addition, the next two quotes are from a student nurse participant and someone from practice, both who had given birth previously to premature babies, *''Reading about and seeing another perilous journey, bravely fought and won, when your own baby is facing his darkest hour, is only something another parent who has been there can relate to''*, and, *''The experiences reawaken my own fears and anxieties from having a prem son myself. My own experiences have always underpinned my neonatal nursing practice and ability to empathise with parents on many aspects of their journey that I can relate to''.*

Fairbairn (2005: 50) however, stated that it *is* possible to empathise with others whose lives are very different from our own. He believes this can be done by simply exercising our imaginations and drawing on aspects of our own experience. Because empathy involves imagination, ‘’we can even empathise with people in experiences that we are unlikely ever to have, or perhaps that we will never be able to have”. But is imagination enough to really see oneself in the same position as a parent who has had a premature baby on the verge of not surviving or who must undergo significant lengths of time in hospital seeing their baby undergo a succession of invasive procedures, never being sure that they will go home? The starkness and seriousness of this situation is not often known.

The third aspect of empathy is behavioural empathy; in this context, the effect on one’s behaviour as a result of the digital stories. Again, as for cognitive empathy, most participants agreed that this would be impacted following viewing of the digital stories and when asked would their practice be changed, while most did say yes, some respondents said they did not know or were unsure. Amongst the student nurses, the main reason for this latter response was due to not knowing what the neonatal unit experience entailed. Neonatal care was new to them and so they would not know if and how their practice would change or be impacted. For staff, the ‘unsure’ response was due to them already being knowledgeable and experienced enough to know about parents’ experiences and being aware of these. However, that said, many participants did also express that they would be reminded to give more compassionate and person-centred care. As Bramley and Matiti (2014) pointed out, this is so essential within an outcome-focused and data driven healthcare system and that nurse education should

play a major role in developing nursing knowledge and awareness of compassionate care.

This leads to another key message from this phase in how the findings link to the CLEAR model proposed in the Discussion for phase 1 (Figure 6.1, pg. 192). To reiterate, this model developed by the author, captured what parents said health professionals must be cognisant of, when caring for them in the neonatal unit (**C**ommunicate with us / **L**isten to us / **E**mpathise with us / **A**cknowledge our role / **R**ealise what we go through). The same 'CLEAR' elements were evident in the learning that can be gained from the digital stories; for example:

- **C**ommunicating with parents is vital (*''I find the digital stories keep my attention to learn about the subject being taught, showing empathy and compassion and effective communication''* / *''Because to understand how the parents feel, always communicate these feelings at the time. It enhances care and compassion skills''*).
- **L**istening to parents is also important (*'' These stories will allow me to continue to listen to the needs of the parents and ensure they feel that they are in a safe environment. They will also allow me to ensure they understand everything that is happening and learn from things that didn't go well for them''*)
- **E**mpathic care is needed (*''I will be more empathic and find more ways to support parents and patients''* /*'' I will become more empathic towards the parents and make sure they are continuously supported. I will remember the person-centred care is key to delivering affective care and understanding the parents better''*).
- **A**cknowledgement / Awareness of needs and the parenting role (*'' I particularly liked the Dad's story as it acknowledges the need for emotional support''* / *''I am*

aware of how parents feel when they can't see or touch their baby- they can't be a proper parent and that must be so hard").

- **R**ealisation / Recognition / Reinforcement of what parents go through (*''I learnt that parents have compassionate care needs for additional support when they leave hospital to cope with the emotional, psychological and physical stress they encounter" / ''makes you realise just how important empathy actually is" / ''I have realised how much they are dealing with …… we need to be most compassionate to make them be at a better place. Our caring attitude matters").*

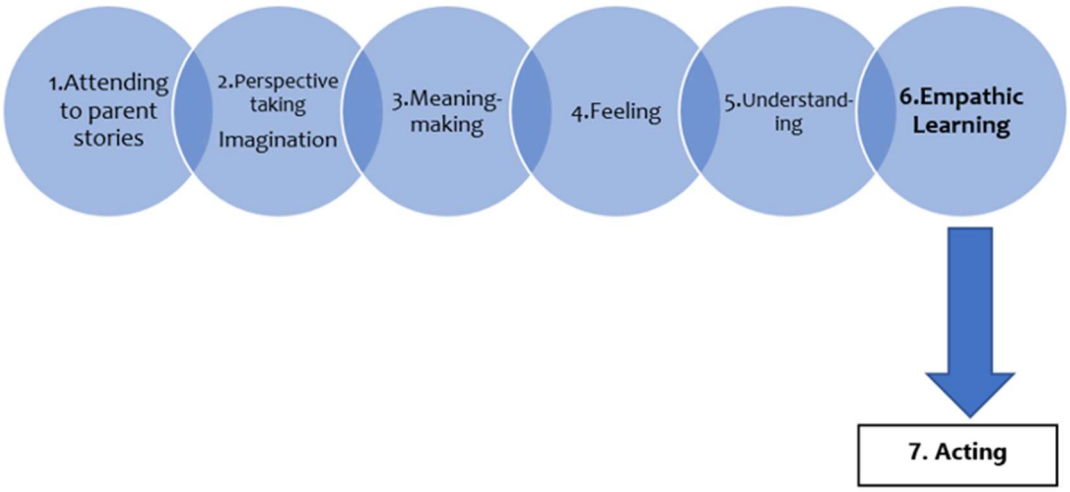
Certainly, there was a compelling narrative here that showed how both students and staff were aware of the needs of parents and how to potentially make things better. This has great potential for the future development of similar resources that can be used to integrate into what Conle (2003) referred to as a 'narrative curricula'. This is discussed in the main Discussion chapter 9.

The other area that was explored in this phase related to the multi-media elements of digital stories and the part they play in evoking emotion, empathy and raising awareness and understanding of emotional experience. Generally, and in the main, multi-media learning was seen to be beneficial and enhanced learning, engaging more than one sense to augment the experience which appeared to evoke emotion and empathy. The main feature of this was the power of the voice and how listening to a narrated story really enhanced the emotional impact experienced by parents. The potential use of this for future resource development is discussed in Chapter 9.

8.8.1 Enriching an understanding of empathic learning

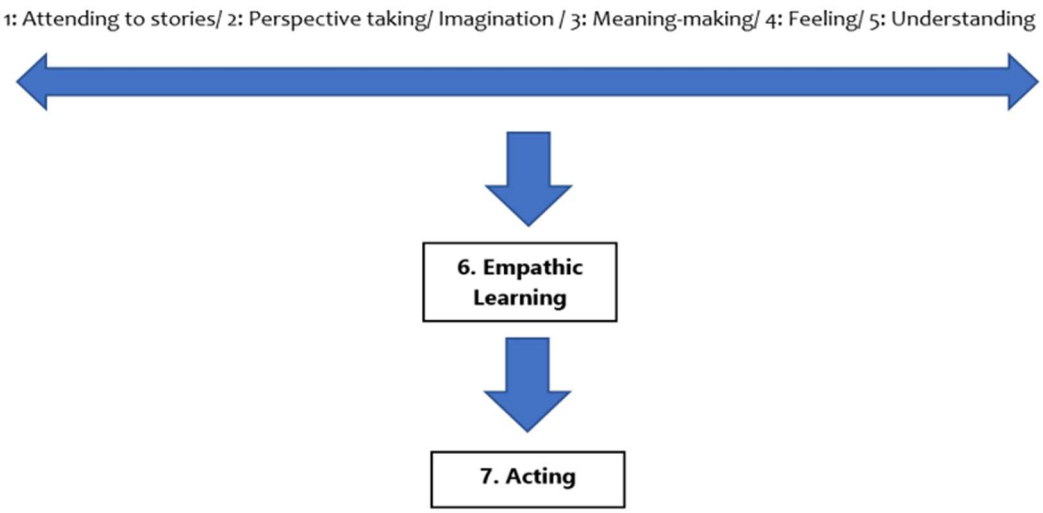
Finally, in the light of the emphasis on *understanding* as a vital component of empathic learning, rather than 'empathy' *per se*, the discussion now presents an enriched model. Adapted from Keskin's (2014) approach from earlier (Figure 8.1; pg. 240), this updated model (Figure 8.22) is informed by the study findings. It is presented below in three different formats: as a comprised model, as a process and as a cycle with the final cyclical model including the parent in the middle, to incorporate the 'person-centred' element of neonatal care. A difference between the format below and the original Keskin model is that the starting point is now the parent experience and their unique stories. The learning that ensues all stems from the parents. Most importantly however, 'acting' on the learning has been added as the main essential difference in relation to the potential impact on practice, congruent with transformative learning.

Figure 8.22: An enriched model of empathic learning
8.22a: A comprised model

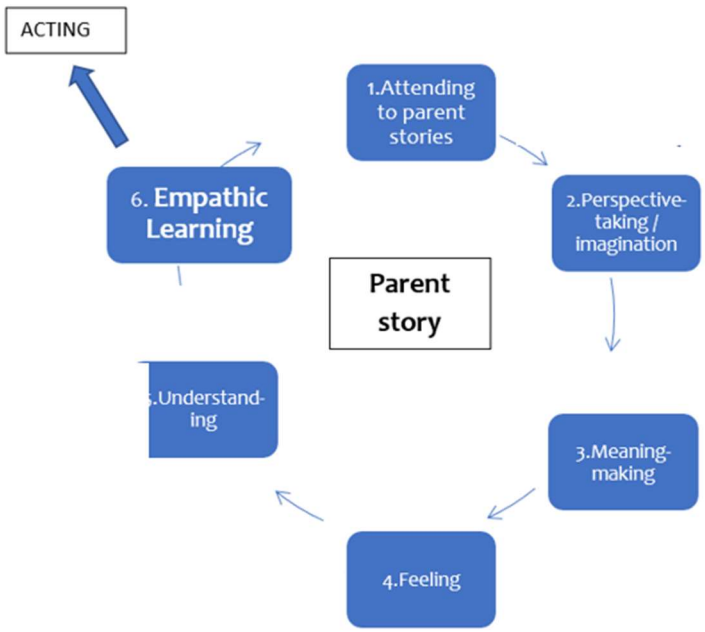


To explain, when someone attends to a parent story (1), they imagine the parent perspective (2) and construct meaning about their experience. This meaning-making (3) includes the feelings (4) of the parents and in turn, a further understanding (5) is developed of the parent emotional experience. Learning (6) results from this, to gain new knowledge to act upon (7) in practice.

8.22b: Empathic learning as a process



8.22c. Empathic learning as a cycle



(Figures 8.22 a-c are adaptations of Figure 8.1: original source Keskin, 2014)

The addition of the parent story to this current model may enrich understanding about emotional experience of this important group and, in turn, potentially impact one's practice in caring for them. There is much to apply to education practice in view of using parent stories to help students engage in perspective-taking, meaning-making and the understanding of others' feelings in order to give better, more empathic care.

Clearly, the digital stories created and used in this study have received an overwhelming positive reception and evaluation supported by a very comprehensive and detailed collation of rich open, verbal and written responses to questions posed. Again, the limitations of this phase require discussion to ensure adequate rigour has been applied to the reporting of these findings.

8.8.2 Limitations

As highlighted in Chapter 6, recruiting through convenience sampling can lead to bias as there is less control about selecting the demographics of those who are within the sample. As for the parents, there was limited diversity in relation to gender for the children's nursing students although more of a range existed for age and ethnicity. In the adult / mental health students, there was also a wider range of genders, ages and ethnicities, in fact there were more students from a BAME background than white Caucasian, so a different demographic existed compared to the children's nursing students. Gender, age or ethnicity was not collected as part of the questionnaire and on reflection, this should have been included. That said, while differences across these groups may have revealed interesting differences, in this study no discernible differences

in views were found when comparing the breakdown of these attributes through the student groups.

Convenience sampling of student nurses can also be associated with a potential for coercion. Therefore, it was vital to ensure that participants knew they could opt out if they wished to. An important part of reflexivity was acknowledging the student-lecturer research relationship with respect to power and the influence on the participant; this was addressed in Box 8.1.

Another limitation to consider is to revisit the point that empathy is very complex, as is teaching it. Williams and Stickley (2010) stated that by describing affective, cognitive and behavioural components of empathy as a series of responses, leads to a detraction from the overall meaning. These authors warned of caution to be taken when using a reductionist approach to empathy rather than a holistic approach. In addition, can short video exposure really uncover or evoke a concept like empathy? Some of the participants did question the true ability to empathise with parents particularly in line with taking their perspective and some doubted whether there would be a longer-term impact. One may ask if empathy has been truly explored or is it more about raising awareness of emotions and increasing understanding of them in parents. The model developed is not one of empathy *per se*; it is about coming to some understanding in relation to learning and then applying this learning to practice in order to be potentially transformative. However, this is the most important issue in relation to the impact on practice since being transformative in healthcare is about making a difference, improving and enhancing person-centred care, at least to some degree.

Areas of critique relating to the multi-media aspects of the digital stories were also raised by the participants themselves. These needed to be considered for a balanced, critical view of the stories and to factor in such feedback for future improvement and further development. Examples of negative points were; limited content for learning, reduced authenticity due to voice narration not being the parents and as above, questions about the ability for the stories to have a longer-term influence or to be able to enhance cognitive empathy (perspective-taking) unless someone has been through the experience themselves. One participant said that the short length was impactful while others commented this would reduce the impact. This highlights the subjectivity of opinions and the different styles and preferences for learning. Participants themselves self-reported their own individual learning styles- *''I am a visual learner'', ''I learn better by actually hearing an experience'' and ''seeing the written word has more of an impact''.*

It must be remembered that the digital stories are, and should be, brief providing a snapshot only of complex experiences. They did not intend to replace real-life practice and interaction with parents in the clinical area. Moreover, they are not intended to be used alone. Ideally, they need to be integrated and used alongside other forms of learning and teaching such as classroom discussions, online learning and practice-based learning, in a blended and/ or a flipped classroom approach. This, and other issues raised, are discussed further in Chapter 9.

8.9 Summary: Phase 3

This third and final phase of the study has explored the views of a sample of student nurses and staff relating to three selected digital stories to ascertain their contribution to

empathic learning about the parent experience. The stories were received positively overall, reported to be a valuable and interesting way to learn about parents' emotional experiences, congruent with enhanced affective empathy. While the effect on cognitive empathy, impact on future practice and transformative learning was not so certain, the participants still agreed that watching the digital stories would influence their practice by raising awareness of both parents' emotional experiences and importantly, the need for more compassionate, empathic care.

Chapter 9. Discussion

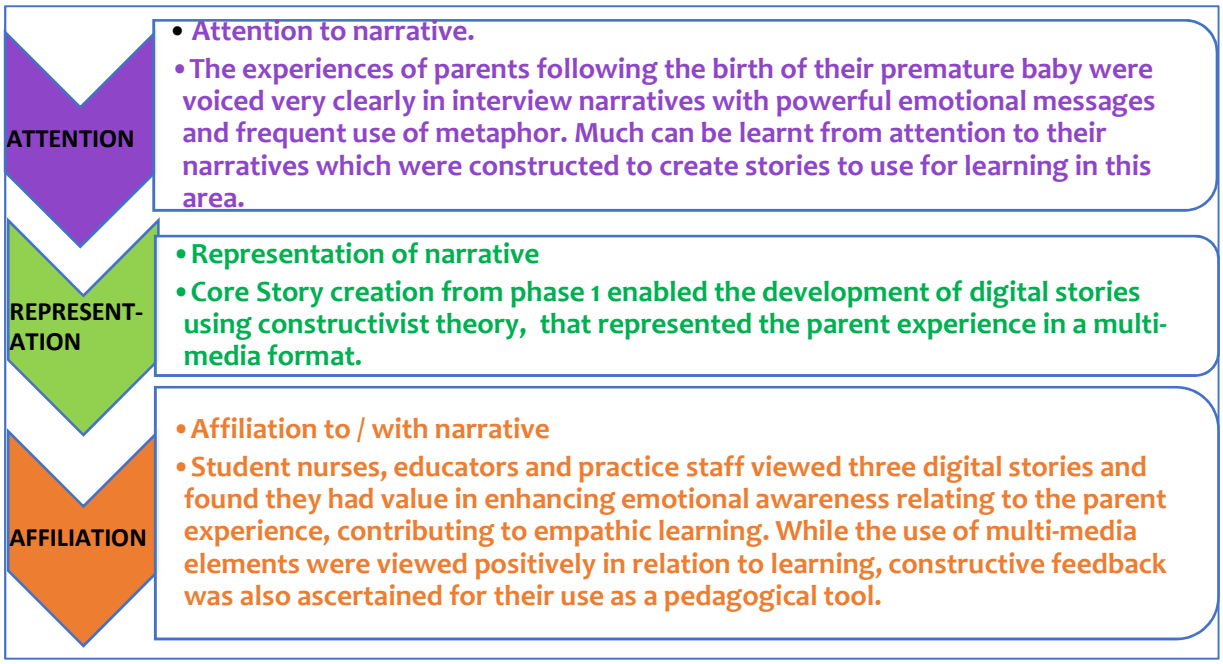
9.1 Introduction

This chapter brings all three phases of the main study together. A discussion section for each phase has already been presented. The focus now is on a synopsis and amalgamation of the various areas of discussion and what this means for pedagogy and practice. A focus on storytelling as a pedagogical tool is presented in line with the model of empathic learning highlighted in chapter 8 (Figure 8.22a-c, pg. 301-2). Limitations, implications for practice, future research and dissemination of the findings are also covered.

9.2 Summary of three main phases (Attention, Representation, Affiliation)

A summary is depicted in Figure 9.1 which outlines the main findings of each phase of the study.

Figure 9.1: A summary of the study findings: Attention-Representation-Affiliation



Some key issues arising out of the study findings are now discussed, remembering always to place the parent and their story at the centre, in line with a person-centred philosophy.

9.3 The pedagogical value of story creation

What this study has explored is the creation of stories for learning to answer the overarching question: *How do parent stories influence person-centred, empathic learning in neonatal nurse education?* It showed how narrative has the potential to educate and transform thought and used to explore and understand experience. Narrative inquiry, in a pedagogical context, focuses on how individuals make sense of their world, the self, but importantly for this study, of the parent experience from which we can learn (Riley and Hawe, 2005; Price, 2011). The study was interested in how learners and health professionals made sense of what parents experienced to learn about person-centred neonatal care and potentially enhance empathic learning.

From an ontological perspective in the context of health education, stories of illness can provide a medium for the education of both patients and health professionals who are learning, providing a way of connecting the different worlds of both. From an epistemological viewpoint, enhancing narrative knowledge from creating stories leads to deeper understanding about a situation or person who is vulnerable, ill, under the care of professionals or, in this case, the family or carers of the patient. As a result, the outcome of a narrative approach to producing stories in this study was not the generalisation of objective, scientific data but a more profound understanding of experiences from the

perspectives of patients and, in the case of research methodology, the participants (parents) that were selected for the study (Johnson, 2009). Again, this was congruent with a humanistic, person-centred healthcare system that places human experience at the heart of care (Charon, 2001; Charon, 2007; DasGupta, 2007; Divinsky, 2007; Hall and Powell, 2011).

The theoretical underpinning of interpretive, narrative inquiry in the context of learning and teaching has also been termed 'narrative pedagogy' by some authors (Gazarian, 2010; Grendell, 2011). However, narrative is very broad and in view of now considering implications for practice, it is perhaps preferable to think more specifically about storytelling as pedagogy.

9.4 Storytelling as pedagogy

Storytelling can be said to have true pedagogical value in this context, within the narrative paradigm. In Chapter 2, the literature reviewed clearly highlighted how narrative and stories can be used to construct identity (Squire et al , 2014), contribute to sense-making (Missel and Birkelund, 2011; Andrews et al, 2013), serve as a source of implicit communication and facilitate reflection (Moon, 2013; Haidet et al, 2006) and aid transformative learning (Hoggan and Cranton, 2015; McDrury and Alterio, 2016).

The potential pedagogical value of story creation is vast. Literature also supports this and again, Chapter 2 illustrated how stories can enable us to gain insight into the lived experiences of patients and families (Christiansen, 2011; Rashotte, 2005), with which this

study's findings concur and support. Engaging with stories enables an understanding to be developed of the healthcare experience (Fenton, 2014). In addition, ''there is a growing realization that patients and service users are a rich source of healthcare-related stories that can affect, change and benefit clinical practice'' (Haigh and Hardy, 2011: 411).

Themes have emerged in this study that are vitally important for learners and health professionals caring for neonates and their families to take note of, to better understand patient / parent experiences and therefore ultimately, offer more person-centred care (Petty, 2016b). Moreover, 'storied' constructs as we have seen in this study provided an end-product that was packaged to create a resource, digital in format, that can now be disseminated for learning purposes in relation to enhancing understanding through narrative. Again, research that has evaluated the effect of digital storytelling has highlighted its value in providing an effective medium used to capture and share knowledge, enhance reflective learning and promote a better understanding of the patient (Price et al, 2015). Digital storytelling therefore has integrated the strengths of narrative and technology.

Grendell (2011) would agree in her paper that links narrative pedagogy, technology and curriculum transformation, citing storytelling as a significant pedagogy relevant to nursing. She believes that using a combination of story and technology, nurse educators can transform the curriculum to improve the effectiveness of learning. She went on to say how storytelling as a strategy can support a more holistic approach to patient centred care that can help nurses to understand the person rather than purely the disease. This is an important implication for future practice in how digital storytelling can

be used to teach students about giving care that encompasses a more holistic approach to be included within any curriculum planning, particularly important at the current time when core nursing standards in nurse education are being reformed and revalidated (Nursing and Midwifery Council, 2018).

Conle (2003), although placed within the education sector and not health, spoke of the potential for a narrative curriculum. She stated, as narrative practices become more widely established, a clear understanding of their nature and function should accompany their use, again necessary for any new curriculum development. Storytelling is one such narrative practice. To support Conle's view, Goodson et al (2010) proposed that narrative learning as a concept seeks to shift the focus of learning from a strongly prescriptive and defined curriculum to accommodate personal narrative styles, thereby aiming to encourage engagement and motivation in learners. This was very evident in the students and staff's views of the digital stories regarding engagement with the stories themselves and motivation to use the knowledge to apply to practice. Hence narrative learning as a concept, if embraced, has significant implications for neonatal nurse education.

The study findings contribute towards an understanding of storytelling as a pedagogical approach that facilitates student learning in a specialised field, neonatal nurse education, another area that is currently being reviewed nationally (RCN, 2015; NHS, 2017). It is hoped the results of this research may improve understanding of the ways in which storytelling pedagogy can contribute to the learning and professional practice of neonatal nursing students. This is especially important since integration of the parent voice is becoming increasingly prominent in line with family-integrated care discussed in

Chapter 6. This study does not advocate storytelling as the only teaching approach to be used but would propose it should augment and enrich other methods, be they practice, or classroom based. The intention is also to provide new and important evidence relating to storytelling that is based on research. This research provides new insights regarding the value of storytelling as a key teaching strategy to enhance the knowledge of children's and neonatal nursing students and staff, an area not explored to any significant extent in health education research.

Within neonatal nursing too, it is not only the scientific domain that requires teaching; the affective domain is just as valuable. However, it is more difficult to teach and assess this aspect because of the nature of it being a subjective, nebulous concept (e.g. being empathic) rather than having objective student outcomes (e.g. performing a drug calculation). It must be remembered that nursing practice is more than just the acquisition of technical skills. Affective learning deals with attitudes, feelings and emotions which are essential to nursing practice. It is also often difficult to teach students how to give person-centred, compassionate care but through integration of storytelling pedagogy as reported by the participants in this study, students may develop increased emotional awareness, sensitivity and an enhanced sense of empathy.

A question that arises however is, at what level does this occur? The findings of this research indicate that storytelling may prepare students with both knowledge and emotional awareness encompassing the affective domain of learning for their future nursing profession. Also, in the cognitive domain, it seems it can contribute to knowledge gain, enhanced comprehension and potential application to practice. But

nurses face many diverse issues within the healthcare environment and must be able to make appropriate, immediate decisions in complex situations, particularly vital in a specialised area such as neonatal care. They are required not just to recall information but apply previously learned information to new situations and be able to engage in critical thinking as part of the intellectual domain. The extent to which digital storytelling can contribute to this is unknown. Future research on whether it leads to learning at a deeper intellectual level would be interesting, for example, more developed critical thinking, improved problem solving and better communication skills. Gazarian (2010) in a study that used principles of 'narrative pedagogy' for development of digital stories in nurses found that they enhanced critical thinking strategies including the ability to problem solve from a range of perspectives. In the context of this study, one of these perspectives should be that of the parents.

9.5 Empathic learning from parents in neonatal care

In Chapter 8, another question raised in the discussion was whether empathy in its true holistic sense was engendered? In other words, can the increase in awareness of emotional experience of parents equate to enhancement of empathy? This was discussed in the light of study limitations. However, what *was* clear was that most respondents in phase 3 commented on some increase and/or effect on their learning and enhanced understanding of what parents experienced. On this basis, to follow with the concept of empathic learning introduced previously in Figure 8.1, an enriched, adapted model of empathic learning emerged informed by the findings of this research (Figure 8.22; pg. 301). An integral component of this model is emotion ('feelings') which the

discussion shall now turn to, within the context of 'empathic learning', an important emotional, person-centred concept.

9.5.1 The role of emotion in learning

Digital stories appear to be an effective and evocative way of telling the stories of others and depicting their emotional experience from which we can learn. Emotion has been a strong theme threaded through each phase of this study and it is clear that it has a role in learning, particularly within the aforementioned model of empathic learning. Goldie (2005, cited in Evans and Cruse, 2005) refers to the relationship between emotions and epistemological rationality observing that emotions can both help and hinder the capacity to gain knowledge of the world. On the one hand emotions can offer insights that would not be available in their absence but, at other times emotions predispose us to adopt certain beliefs and may distort our ability to see things as they are. However, from the findings of this study within an interpretive, constructivist approach, it seems that emotion does play *some* part in construction of knowledge within the neonatal field, in seeking to assign meaning to the experiences of parents.

9.5.2 Emotion as knowledge

Emotions elicited through storytelling have a part to play, not only in the development of personal resilience (East et al, 2010) but in how they provide opportunities to honour the experiences of participants who contribute to knowledge by recounting their stories of difficulty and adversity. In other words, the emotional responses of parents impart knowledge about an *affective* type of experience, so vitally important to this study that explored the effect of narratives on empathic learning. Epistemologically, our emotional

responses to others and what they say about their experience can be useful in the creation of knowledge (Camacho, 2016) or as Mauthner and Doucet (2003: 419) states, "our emotional responses to other people constitute sources of knowledge". In other words, the principle of 'emotion as knowledge' is how emotional experience can sometimes teach us things about the world that ''reason alone'' may miss (Goldie, 2005, cited in, Evans and Cruse, 2005). This may also contribute to engendering or enhancing empathy in those who care for our vulnerable babies and their families.

In this study, feeling moved and affected by what parents said within the stories showed that narratives do have an influence on empathic understanding and above all, have the power to teach us about the experience of those within neonatal care. Emotions elicited through stories can provide opportunities for parents to contribute to knowledge by recounting their experiences of difficult times as shown in a paper by the author described earlier (Petty, 2017b). As an important part of this, emotional intelligence, needs to be present, which is about identifying, using, managing, and understanding emotions not only in oneself but also in others (Beauvais et al, 2011; Szeles, 2015). In nursing, this is necessary to be able to provide sensitive and compassionate care, balancing an ability to manage ones' own emotions but still being able to feel moved by others' difficult experiences. It is something that is difficult to teach in a classroom but must be developed through active listening, engagement and participation (Brackett and Katalak, 2007) so it could be argued that any educational intervention that seeks to educate about emotional experience and care requires a level of emotional intelligence for learners to be able to apply what they learn to their care of others. In relation to stories, Brackett and Katalak (2007) cited Mayer et al's (2004: 3) skills-based model

including the perception of emotion, i.e. the ability to perceive emotions in oneself and others, ''as well as in other stimuli, including objects, art, stories, and music''. They also described the skill of using emotion to facilitate thinking, to focus attention, communicate feelings, engage in problem solving and decision making, all essential elements of learning in nurse education.

As seen in Chapter 6, Collins and Cooper (2014) stated that researchers need to stay in touch with their own emotions. On the above premise then, this should also apply to those who are viewing the digital stories so that true connections may be made between feelings and knowledge. As Divinsky (2007) believes, health professionals can only fulfil the promise of a person-centred approach to care if they let down their defences, but at the same time ensuring the above balance is maintained.

This level of emotional intelligence may not however be present in more junior student nurses as it is after all, in Mayer's view, an attribute made up of skills which require development over time. These students may not yet have reached a stage in their training and development where they are fully able to assimilate the emotional challenges associated with challenging healthcare settings due to lack of knowledge, autonomy and confidence but also the resilience that needs to be developed through emotional intelligence (Aradilla-Herrero et al, 2013; cited by Cleary et al, 2018). This may influence the capacity to see the relevance of the emotional messages from digital stories and could have been the reason that many junior student nurses in this study were not clear about the potential impact on their practice. This is another reason why storytelling should be integrated into the curricula *throughout* a programme and not just

presented on an ad-hoc, occasional basis. In this study, one can argue that the impact of the digital stories given as a 'one-off' would limit the extent of any impact for the participants particularly those who had never seen a digital story previously in their learning. This raises a point to consider for future development of digital storytelling within neonatal nurse education, but it also presents a potential limitation of the study in relation to the contribution to behavioural empathy and the effect on the participants' practice for more junior students compared to experienced students and staff. This along with the other limitations of the study shall now be discussed.

9.6 Limitations

Limitations for each phase of the study have been covered in Chapters 6, 7 and 8 but a summary of the main points are provided here for the study as a *whole*.

Firstly, the interpretive nature of the data in view of the 'trustworthiness' issue has been addressed throughout the study, within each phase. Strategies have been articulated and a reflexive approach has been used and explained. Secondly, it has been acknowledged that the nature of the participants did not represent a wide demographic in relation to gender and ethnicity in particular (mostly white, Caucasian, females). The lack of diversity was seen especially in the parent and the children's nursing student groups. It must also be remembered that the narrow demographic is reflected in the stories although the limited number of fathers' views were included, and a male voice / story was represented within phase 3. Diversity in culture however was not possible in relation to the parent characters in the stories although it was factored into the illustrations of the workforce within stories 1 and 2.

Thirdly, considering the complexity of empathy as a concept and its many components, the methods for phase 3 (for example, the perspective-taking exercise) may have been a rather simplistic way to appraise it. In other words, a question is whether more robust methods of 'measuring' empathy could have led to more valid conclusions to be drawn in relation to concepts as complex as empathic learning. One can ask, is self-reporting from participants sufficient? However, this was rationalised by wishing to stay faithful to the underpinning narrative approach and focus on what the participants freely said, analysing their rich, written, open responses.

Fourthly, there is the question of measuring the impact of digital stories on practice. This is an important one particularly in nurse education, where linking and applying knowledge to practice is absolutely essential. Can this question of impact on practice really be answered especially since, as raised previously, some of the participants had not been exposed to digital storytelling before and so in essence, this was a new experience presented to them as a one-off, short exposure? Moreover, most of the first-year student nurses and some from the other years had not yet been exposed to the neonatal environment questioning whether they would be able to answer how their practice would change. As acknowledged when critiquing the methods, using self-reporting to address the question of *how one might change their practice* is not the same as *seeing changes implemented*, if this indeed would be feasible. One can argue that digital stories may have an immediate and short-term impact, but may question the potential *longer-*term one, an issue that was raised by some of the participants themselves. Nonetheless, this would be an interesting research topic to address further in future work.

Finally, although the overwhelming response to the digital stories was positive in relation to learning, it is necessary to consider digital storytelling in the context of other forms of learning within nursing practice, particularly practice-based learning and that delivered within the classroom. Some respondents felt that the stories were limited due to lack of certain content relating to aspects of care and the actual neonatal environment and equipment, highlighting the need for more information. This may be from students who often are very skills focused and feel they must learn about *clinical*-based care, perhaps not always seeing the relevance of learning about emotions. There is much more potential with the development and further improvement of digital stories which considers the constructive feedback from the participants in this study. This point leads appropriately to the penultimate discussion point relating to the implications for future practice.

9.7 Implications for future practice and research

Many of the respondents in this study indicated that the digital stories were likely to influence their practice in relation to them having a better understanding of the emotions and needs of parents. This has key implications for practice in terms of the potential for behavioural empathy, in other words the 'practice of empathy' and the part that stories may play in influencing future person-centred, emotion-led care of parents of premature babies who go through protracted and stressful periods of uncertainty. The potential limitations relating to validating the link between digital storytelling and future impact have been raised and discussed. It remains however, that the influence on practice is an essential issue to explore further given the perceived benefits of digital storytelling revealed by the study participants. If such work is going to be developed

further in neonatal nurse education, then it is important to consider what needs to be done to maximise the potential of digital stories for improved person-centred practice. McKinnon (2018) in his paper on the ontology of empathy referred to the power of empathy to enhance practice. His discussion is congruent with what has been said in this work about constructivist theory, stating that exploration of stories both fiction and nonfiction together with the sharing of personal narratives between learners can aid empathic skill construction. He also believes that an insight into the ontology of empathy provides a basis for the construction of learning and teaching tools and resources, relating to skills development for practice. From this, he followed with the notion that empathy is not an emotion *per se*, but a tool for identifying and comprehending the emotional state of another; a means and not an end. This fits with the model of empathic learning put forward earlier with an onus on *understanding* and that digital stories can be seen as a pedagogical tool in which to enhance and nurture this understanding. Nurse educators who are teaching students about this highly emotive area of care, as indeed *any* area of nursing care, must be mindful of the theory-practice connection. We must consider whether empathic understanding and learning, achieved from an educational tool such as a digital story translates into practice. Various key recommendations now follow to address this question, bringing back some of the earlier discussion points to apply to neonatal nurse education.

Develop a narrative-based neonatal curriculum

If one can learn from narratives to really understand what patients or parents experience, then it follows that students / staff would give more empathic, person centred care as distinct from the care that focuses mainly on clinical skills. Neonatal care

is a distinct area of children's nursing and one that offers the learner a wide variety of diverse skills and knowledge areas including one very important topic, that of preterm birth and it many facets. The implications of preterm birth and the subsequent neonatal care along with the often-protracted 'journey' through the neonatal unit, is one that offers huge opportunities for learning. Traditionally, education has focused and often still does, on technological advances and clinical skills necessary to care for these very vulnerable patients and their families. However, less attention has always been centred on assessing *person-centred* care as a distinct area to technological care. What therefore is needed, is to incorporate parents' experiences into curriculum development; for example, involve parents within new module creation, simulation teaching and assessment planning using stories as a focal point. Bramley and Matiti (2014) proposed, following an interview study with patients about compassion, a concept closely linked with empathy, that staff need to understand the impact of care and for them to understand, in the patients' and authors' words: 'how it feels in my shoes'. They recommended the introduction of vignettes of real-life cases from the patient 'lens' to engage practitioners in collaborative learning. This could also be used with nursing students, as a legitimate and valuable way of incorporating the parent voice into learning and assessment strategies.

Instil a person-centred agenda into programme learning outcomes

A key message from this study is that storytelling, as a learning and teaching strategy, may enhance empathic learning contributing to a person-centred approach to learning. The need for empathy is a strong 'emotional message' and a person-centred concept that was prevalent in the narratives of both parents, students and staff in this study. In

relation to healthcare, empathy is an essential nursing attribute involving understanding inner experiences and perspectives of individuals (Cooper, 2011) combined with an inherent ability to communicate this back to patients. Understanding what parents go through during their time within a neonatal unit while they live with their babies' uncertain journey should not be under-estimated. Learners need to be aware of this so that they can be prepared for such a key learning objective when they care for parents in practice.

Therefore, since empathic care is seen as essential within the concept of person-centeredness, learning outcomes for any neonatal nursing student or other student working in a neonatal placement should articulate this. Feo and Kitson (2016: 2296) refer to a fundamental care definition where care ''involves actions on the part of the nurse that respect and focus on a person's essential needs'' to make sure both physical and emotional health needs are attended to (Feo et al, 2018). Education therefore must also do the same. Empathy is an essential part of this care as identified in this study, important as it is *person*-focused not condition-focused, (Jeffrey, 2016); it relates to human understanding and is so closely connected to narrative. Again, this ultimately highlights the potential value of a narrative approach to pedagogy that enhances a person-centred approach to learning. This requires clarity for the student who is learning about this field of nursing.

Encourage exploration of parent-focused literature and research

An underpinning theme from this study is how narratives can reveal insights into the *experience* of parents. There must be a genuine inclusion within any curriculum of the

relevant evidence that is parent-focused. Previously, literature reviewed for this study has explored how the neonatal care experience has a profound impact on how parents feel and function as a 'parent', including feeling excluded, isolated and overwhelmed (Williams et al, 2018; Noergaard et al, 2018), along with having a strong but often unachievable need to participate in their baby's care (Aloysious et al, 2018b; Pineda et al, 2018). Literature has also highlighted the importance of family integrated care (Patel et al, 2018), the need for effective communication (Biasini et al, 2012) and positive human interaction and dialogue between themselves, their babies and staff (Wigert et al, 2014). In this study, parents reflected on the significance of their 'journey' through neonatal care and what it meant to them. Taking learners through the parent journey could be one approach that guides them through the different transitions including the actual care but also the associated emotional ramifications of this challenging time. The journey metaphor equates to a 'storied' approach to learning where a student can be steered through the different stages of the parent trajectory.

Emphasise the value of qualitative research to inform knowledge

Using stories as a teaching strategy may encourage learners to consider a qualitative approach to healthcare education in conjunction with the traditional, quantitative and objective, audit-based data that is collected on a vast range of care practices within healthcare. If we want to improve the patient experience, then the former approach that focuses on humans rather than numbers needs to be embraced and considered to be worthy evidence. Lambert (2010) concurred with this. As a reminder, he asserted that while statistics inform how systems experience individuals, stories tell us how individuals experience systems. In neonatal care, vitally important data is collected to analyse

outcomes, admission data and audit practice which can assist service provision planning (Royal College of Paediatrics and Child Health, 2018) but there is also a need to 'humanise' care in this field and remember the neonate and family at the heart of care.

Incorporate parent experience into assessment strategies

Analysing experience can be an influential strategy for opening up professional practice for discussion and providing an effective vehicle for students to critically challenge areas of practice. Stories can be used for his, presented in the classroom or online. In addition, assessment can be centred around them or indeed, students can develop their own digital story based on parent narratives as an assessment strategy. This is another avenue of inquiry worthy of future research.

Develop and use storytelling as a pedagogical tool

The development of teaching and learning strategies and/or resources that can be used to educate students and staff about patient perspective is vital, in this case, parents in their care. The creation of learning resources based on narratives and storytelling is an alternative and innovative approach to current traditional teaching methods, to enhance understanding of the neonatal care experience. There needs to be a commitment to the development of well-designed learning materials that integrates narrative in the form of storytelling, if this approach to teaching and learning is really to be properly embraced in the neonatal nurse education arena. In neonatal care, if assurance is given to developing such materials that capture the neonate's and parent's experience and tell their story, this can be used to support teaching and learning as part of the vast spectrum of knowledge and skills required to deliver holistic, empathic, person-centred nursing care.

Given the emerging interest in how stories can used for health professionals to learn how best to care for their patients and understand their experiences along with the findings of this study, the current higher education environment means that educators cannot remain stagnant in the ways that they teach. Innovative methods need to be developed in line with the changing demands on resources and curriculum delivery. HEIs that deliver nurse education should work towards developing programmes of blended learning including those that include narrative methods in the form of storytelling, particularly in specialisms such as neonatal care that have specific person-centred needs and that not been explored in this way within educational research.

Future research

Research within the medical field in particular has explored the use of stories or narratives to enhance empathic care in various ways (Rosenthal et al, 2011; Shapiro et al, 2006a and b; Tavakol et al, 2012). However, there is less research within nursing especially in specialisms such as neonatal care. Prior to the current study, no studies have explored the use of digital stories based on parent narratives in the neonatal field and their contribution for learning and teaching nor has there been a focus on the contribution to empathic learning specifically. Therefore, there is a need for further research in this field in how narrative and especially storytelling can contribute to enhancing empathy and more specifically into how this can be incorporated into future teaching, learning and assessment strategies for neonatal nurse education. The current study is a starting point that can now lead to future research.

One other potential theme to explore further would be to gauge the views of students over a course of time and follow them through to their practice at intervals at different stages. One could then ask, how *did* stories impact on your practice rather than how *would* it? Work in other fields has explored how storytelling can impact on professional learning for students in practice. Gidman (2013) for example, explored students' perceptions of patient stories during practice placements which revealed the value of engaging with service users as a resource for learning. It follows that educators should recognise and value this form of teaching to enhance practice-based learning. However, providing the space and opportunity for students to listen to stories during their placements and actively facilitate reflection on these learning experiences is an ongoing challenge in the real world of healthcare practice and the question therefore remains on how to address this, particularly challenging in a specialist area such as neonatal care due to the unique nature of the patient and the specific needs they present.

In addition, the concept of art-based research and knowledge translation is one that has only received relatively brief coverage in this study as it was beyond its scope. Studies have been referred to that have used art-based methods such as video and story-based methods to disseminate research findings (Hartling et al, 2010; Fix et al, 2012; Rieger and Schultz, 2014; Reid et al, 2017). This study, in part, found that participants identified specific elements of the digital stories that enhanced or hindered learning and much of this analysis focused on the effect of illustration, voice and multi-media. Using different arts-based approaches such as types of visual imagery and the various ways that they can be presented in story form would be an interesting and illuminating area to explore in future research recognising that storytelling itself, is an art-form. In addition, further exploration

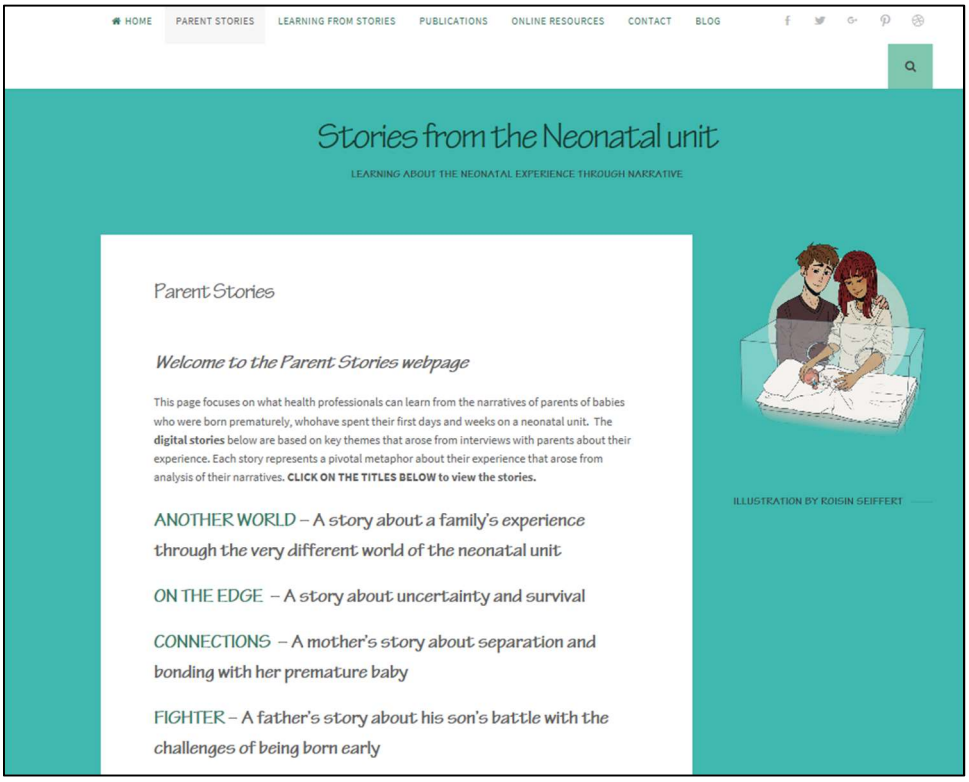
of the different ways to tell a story in relation to voice narration would be of interest since this was found to be a very impactful feature of the digital stories. Many possibilities have been opened up for discussion, in relation to future narrative-based inquiry to further explore the power and value of stories in the teaching of emotional experience and potential enhancement of empathy.

9.8 Dissemination

To fully appreciate the learning potential of digital storytelling, stories must be shared among learners, and individuals need opportunities to use and reflect on them. Literature supports how digital technologies can be embraced to facilitate student and staff education, using creative ideas (Banerjee et al, 2018b). In this study, as an example of a 'creative idea', metaphors based within narratives were used to co-construct digital stories using a variety of different illustrations, voices and text quotes blended together, in line with the principles of narrative and constructivist pedagogy. The stories constructed in the present study are now part of an online website used to share the stories, to be disseminated to students, staff and educators for them to learn or teach others about the neonatal experience from the perspectives of parents. The website has been disseminated nationally and is already being shared within certain Operational Delivery Networks (ODNs) as well as with neonatal educators and practice staff across the UK. Further dissemination will involve submission of phase 2 and 3 findings for publication and a follow-up evaluation of the website will be written and shared with a charity who assisted with essential funding for the site development. Plans are also underway to show-case the stories at a national neonatal education special interest group meeting and neonatal nursing conference.

Figure 9.2 features the website *Stories from the Neonatal unit* that has been created to host the digital story collection (www.neonatalstories.com).

Figure 9.2: Digital storytelling website: 'Stories from the Neonatal Unit'



https://neonatalstories.com/parent-stories/
[Press control and click on the image or URL above to access the stories and website]

Disseminating the parent voice on this online platform will hopefully contribute in some way to sharing what is important to care for parents emotionally. This will in turn may enhance knowledge acquisition that can be applied to clinical neonatal practice. Having an online platform enables dissemination on a global level offering far-reaching opportunities to share the stories on an open-access basis to benefit a wide audience. Dissemination of the outputs and findings of each phase have been published and presented at various national and international conferences during the whole programme. These are outlined in Appendix 8.

9.9 Becoming a researcher

Finally, the Discussion ends where the whole dissertation started; with reflexivity. As discussed earlier, reflexivity involves both epistemological and personal elements. How my own background and experience as a nurse and educator influenced the interpretation of others' narratives has been considered. This final discussion of reflexivity concerns another personal element which involved thinking about how the research has benefited me personally and professionally and what I have learnt. Box 9.1 below outlines the learning and development that has taken place during throughout the research study.

Box 9.1- Reflection: My learning journey

To start, I engaged in professional learning during this research as a novice researcher grasping a new role which imparted an essential benefit; that of the facilitation of personal and professional learning and transformation through the research process (Bailey, 2007). This is in line with what Shaw (2013) referred to as a transformative journey into reflexivity which involves, as a key element, reflection on one's self. I have learnt a considerable amount from reflection on my work at each stage and I saw reflexivity and reflective engagement as an essential component in my journey in learning to be a researcher. Reflection on practice and oneself is a process of making sense of events, situations and actions in order to learn from them. However, reflexivity goes further, as Noble and McIlveen (2012) proposed, it goes beyond self-observation to reflexivity being a process of critical consciousness, learning, transformation and of course action.

As a nurse, it was a natural process for me to engage in introspective reflection on my actions which I believe is a fundamental part of the reflexive process. Introspection of my own role(s) was particularly relevant for me since I was a novice researcher. I started the research process as a nurse and an educator, rather than as a researcher. This new and extra role and the merging of such with my existing professional roles

has meant an evaluation of my own research identity. Dualism between being an experienced 'practitioner' and a novice 'researcher' was an issue I addressed during my research. Reflexivity also meant an analysis of the personal dimensions of my joint roles and how they interrelated. I needed to have self-awareness to reconcile these differing roles in relation to my doctorate journey. Self-awareness is seen by Holloway and Freshwater as being one of the essential skills required to be a good narrative researcher (Holloway and Freshwater, 2007). Herland (2017) referred to affective and reflective responses being present during research of this nature, important because there is still a need to highlight the unspoken inner 'self-dialogue'

I believe one's own learning is another factor to ensure research is undertaken with the appropriate skills to ensure good practice. For example, benefits have been reported in how training individuals in the creation of digital stories positively impacted the creator's own learning. For example, research has found that attending training workshops ranging from 3–5 days long that covered the processes of creating effective digital stories was very beneficial for personal learning and growth (Walsh et al, 2010; Hewson et al, 2015). I concur with this as I was fortunate to attend such a workshop to create my own story (Figure 1.1) and learn the fundamental skills of digital storytelling. The detail of this and other formal learning undertaken during the course of the doctorate programme is outlined in Appendix 8 along with all outputs, publications and conference presentations.

In summary, a significant amount of personal and professional learning has occurred during the whole doctoral process which will continue thereafter, beyond this study. To continue a common and previously cited metaphor from parents in this study, such a learning 'journey' has been an integral component of my personal reflexivity, development and growth to becoming a researcher.

Chapter 10: Conclusion

Within a narrative, interpretive theoretical framework using principles of constructivist learning theory, this study explored the narratives of parents in the neonatal unit to develop stories to enhance person-centred, empathic learning. Understanding the rich and compelling emotional experiences of parents following the birth of their premature baby informed digital storytelling creation to use as a pedagogical tool in the field of neonatal nurse education. An evaluation and exploration of the value of digital stories based on the parent narratives found that powerful emotional messages, often expressed through metaphor, enhanced awareness, understanding and insight into the parent experience. This highlighted what is important in the delivery of empathic, person-centred care placing parents and their emotional needs as a core component. Educators can use stories and key messages from parents to enhance empathic learning, as an integral part of a narrative curricula for anyone caring for vulnerable babies and their families.

10.1 Key messages

The key messages from this study are outlined as follows:

- Parents described their neonatal care experience using a strong emotional narrative, both positive and negative, during their neonatal care trajectory from the labour ward through to being at home after discharge.
- Parent narratives revealed important learning points for those caring for them in relation to communication, being listened to, having empathy, acknowledging

their role as parents and realising what is important to them to make their experience better (**C**ommunicate-**L**isten-**E**mpathise-**A**cknowledge-**R**ealise =CLEAR).

- Stories can be constructed from parents' raw narratives using a process of emplotment known as 'core story creation'.
- The use of metaphors was a common and consistent way to express emotion, particularly relating to challenging times that were difficult to express.
- Common metaphor clusters can be used as pivotal themes for the creation of a collection of digital stories, in this case that represented the parents' experiences.
- Student nurses within varying levels of their training and nursing fields along with practice staff and educators evaluated the digital stories positively overall and it was clear they were an effective and innovative way to learn about emotional experiences of parents.
- In relation to impact, by evoking emotion in the learner as well as learning about parents' emotions throughout their challenging neonatal care journey, this contributed to enhancing *affective* empathy. However, the impact on *cognitive* empathy was not so clear-cut or agreed, due to doubt about one's ability to really be able to take a parent's perspective in such a challenging situation.
- *Behavioural* empathy was more difficult to ascertain since this would only be observable in practice. Nonetheless, participants *did* articulate that watching the digital stories would influence their practice by raising awareness of parents' experiences and the need to give more compassionate, empathic care. This was important in line with the potential for transformative learning relating to improving person-centred, emotion-led care in practice.

- Participants revealed both positive and negative features of digital storytelling that influenced how effectively emotion was portrayed. A positive feature was how animation, narration and key quotes presented together impacted on learner engagement and authenticity. In addition, the power of voice was a particularly favoured feature of the digital stories to evoke emotion and influence empathic learning. However, brevity of the stories and lack of content around other aspects of nursing care meant the stories had more limited value for some participants.
- It is essential for staff caring for babies and their families to learn to understand their emotional experience and support parents in a sensitive and responsive way. Digital stories can be one way of teaching this essential aspect of care that is often difficult to teach in the classroom setting within the context of narrative healthcare.
- Finally, and importantly in the context of neonatal nurse education, students and health professionals can learn from the emotional experience of others, in this case parents. The emotions of parents in this study imparted knowledge about an affective type of experience, so vitally important to this study that sought to ultimately explore the effect of stories on empathic learning.

Finally, a selection of quotes from some of the study participants ends the discussion, which summarise the essence of the parent's story and its value for learning about the neonatal care experience.

- *''It's so important to listen to us and hear what we go through- I don't think people can really comprehend the depth of how we feel about the fact we may lose our baby at any point and how emotionally difficult that is'' (parent).*

- *''Telling their stories and animating them, allows for a deeper understanding of what they [parents] have experienced. The fact there is a focus on the story rather than the medical narrative allows me as a professional to 'check in' emotionally to the lived experience rather than the clinical care and this has been very thought provoking. This is also vital for students learning'' (Neonatal nurse educator).*

- *''Watching these digital stories gave an incredible insight to people's real-life experiences, on an emotional level'' (2nd year children's nursing student).*

- *''It's important to hear from real-life patient experiences in order to gauge the appropriate care and also to try and create empathy prior to our experience … this is for us as student nurses to know how to act in such difficult situations'' (1st year children's nursing student).*

- *''The stories evoked a sense of empathy for the parents …. It makes you realise just how important empathy is as a student'' (3rd year children's student nurse).*

Within the context of narrative-based neonatal nurse education, there is a place for digital storytelling informed by parent narratives to teach students and staff about the emotional impact of the neonatal experience so that they can potentially give more empathic, person-centred care.

Bibliography

Aagaard, H and Hall, E. (2008). Mothers' Experiences of Having a Preterm Infant in the Neonatal Care Unit: A Meta-Synthesis. *Journal of Pediatric Nursing*, *23*(3), 26–36.

Abolafia, M. Y. (2010). Narrative construction as sensemaking: How a central bank thinks. *Organization studies*, 31(3), 349-367.

Adama, E. A, Bayes, S, Sundin D (2016). Parents' experiences of caring for preterm infants after discharge from neonatal intensive care unit: a meta-synthesis of the literature. *Journal of Neonatal Nursing*, 22(1), 27-51.

Adamson, K, Sengsavang, S, Charise, A, Wall, S, Kinross, L, and Balkaran, M. (2018). Narrative Training as a Method to Promote Nursing Empathy Within a Pediatric Rehabilitation Setting. *Journal of Pediatric Nursing*, 42, e2-e9.

Aftyka, A, Rybojad, B, Rosa, W, Wróbel, A, and Karakuła-Juchnowicz, H. (2017). Risk factors for the development of post-traumatic stress disorder and coping strategies in mothers and fathers following infant hospitalisation in the neonatal intensive care unit. *Journal of Clinical Nursing,* 26(23–24), 4436–4445.

Agosta, L. (n.d.). Empathy and Sympathy in Ethics. The Internet Encyclopaedia of Philosophy. Retrieved August 29th2019 from, https://www.iep.utm.edu/emp-symp/

Allen, C. (2006). Narrative Research. *Nurse Researcher*, *13*(3), 4–6.

Al Maghaireh, D. F, Abdullah, K. L, Chan, C. M, Piaw, C. Y, and Al Kawafha, M. M. (2016). Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit. *Journal of Clinical Nursing*, 25, 2745–2756.

Almack, K. (2008). Women Parenting Together: A reflexive account of the ways in which the researcher's identity and experiences may impact on the processes of doing research. *Sociological Research Online*, *13*(1).

Aloysius, A, Platonos, K, Deierl, A, and Banerjee, J. (2018a). The neonatal parent experience: How IFDC can help. *Journal of Neonatal Nursing*, *24*(1), 66–73.

Aloysius, A, Platonos, K, Theakstone-Owen, A, Deierl, A, and Banerjee, J. (2018b). Integrated family delivered care: Development of a staff education programme. *Journal of Neonatal Nursing*, *24*(1), 35–38.

Alvesson, M. and Skolberg, K. (2017). *Reflexive Methodology* (3rd edition). London: Sage.

An, S, Ji, L. J, Marks, M, and Zhang, Z. (2017). Two Sides of Emotion: Exploring Positivity and Negativity in Six Basic Emotions across Cultures. *Frontiers in Psychology*, 8, 610. doi:10.3389/fpsyg.2017.00610

Ancel, G. (2006). Developing Empathy in Nurses: An Inservice Training Program. *Archives of Psychiatric Nursing,* 20(6), 249-257.

Anderson, C. (2010). Presenting and evaluating qualitative research. *American Journal of Pharmaceutical Education*, 74(8), 41. doi:10.5688/aj7408141

Anderson, L, Kinnair, D, Hardy, P and Sumner, T. (2012). They just don't get it: using digital stories to promote meaningful undergraduate reflection. *Medical Teacher*, 34(7), 597-8.

Anderson, C. and Kirkpatrick, S. (2016). Narrative interviewing. *International Journal of Clinical Pharmacology*, *38*(361).

Andrews, M. (2012). What is Narrative Interviewing? Retrieved August 29th, 2019 from, http://eprints.ncrm.ac.uk/2968/1/What_is_narrative_interviewing.pdf

Andrews, M, Squire, C, and Tamboukou, M. (Eds.). (2013). *Doing Narrative Research*.

London: Sage.
Andries, A. M. (2011). Positive and negative emotions within the organizational context. *Global Journal of Human-Social Science Research*, 11(9). Retrieved August 29th, 2019 from, https://globaljournals.org/GJHSS_Volume11/4-Positive-And-Negative-Emotions-Within-The-Organizational-Context.pdf
Appleton, L, and Flynn, M. (2014). Searching for the new normal: Exploring the role of language and metaphors in becoming a cancer survivor. *European Journal of Oncology Nursing*, *18*(4), 378–384.
Arber, A. (2006). Reflexivity: A challenge for the researcher as practitioner? *Journal of Research in Nursing*, *11*(2), 147–157.
Archibald, M. M, Hartling, L, Ali, S, Caine, V, and Scott, S. D. (2018). Developing "My Asthma Diary": a process exemplar of a patient-driven arts-based knowledge translation tool. *BMC Pediatrics*, 18(1), 186.
Ari B. A and Enosh G. (2012). Power relations and reciprocity: dialectics of knowledge construction. *Qualitative Health Research*. 23, 422–429.
Arroliga, A. C, Newman, S, Longworth, D. L, and Stoller, J. K. (2002). Metaphorical medicine: Using metaphors to enhance communication with patients who have pulmonary disease. *Annals of Internal Medicine*, 137(5), 376.
Ashton, S. (2014). Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse Researcher*, *22*(1), 27–31.
Asselin, M. E. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Professional Development*, *19*(2), 99–103.
Bacigalupo, R, Bath, P. A, Booth, A, Eaglestone, B, Levy, P, and Procter, P. (2003). Studying health information from a distance: the impact of a multimedia case study. *Health Informatics Journal*, 9(5), 5–15.
Baía, I, Amorim, M, Silva, S, Kelly-Irving, M, de Freitas, C, and Alves, E. (2016). Parenting very preterm infants and stress in Neonatal Intensive Care Units. *Early Human Development*, *101*, 3–9.
Bailey, C. J. (2007). Practitioner to researcher: reflections on the journey. *Nurse Researcher*, *14*(4), 18–26.
Baird, K and Mitchell, T. (2013). Issues for consideration by researchers conducting sensitive research with women who have endured domestic violence during pregnancy. *Evidence Based Midwifery*, 11(1), 21.
Baker, L, Plelan S, Snelgrove, R, Varpio, L, Maggi J, and Ng S. (2016). Recognising and responding to ethically important moments in qualitative research. *Journal of Graduate Medical Education,* 8(4), 607–608.
Baldwin, C. (2007). *Storycatcher: Making Sense of Our Lives Through the Power and Practice of Story.* Novato: New World Books.
Ballantyne, M, Orava, T, Bernardo, S, McPherson, A. C, Church, P, and Fehlings, D. (2017). Parents' early healthcare transition experiences with preterm and acutely ill infants: a scoping review. *Child: Care, Health and Development*, *43*(6), 783–796.
Banerjee, J, Aloysius, A, Platonos, K, and Deierl, A. (2018a). Family centred care and family delivered care – What are we talking about? *Journal of Neonatal Nursing*, 24(1), 8–12.
Banerjee, J, Aloysius, A, Platonos, K, and Deierl, A. (2018b). Innovations: Supporting family integrated care. *Journal of Neonatal Nursing*, 24(1), 48–54.
Banks, M, and Zeitlyn. D. (2015). *Visual Methods in Social Research (2nd Edition).* London: Sage.

Barber, J. F. (2016). Digital storytelling: New opportunities for humanities scholarship and pedagogy. *Cogent Arts and Humanities*, 3(1), 1181037.
Barbour, R, S. (2001). Checklists for improving rigour in qualitative research. *BMJ*, 322, 1115–1117.brauncameron
Baron-Cohen, S. (2012). *Zero Degrees of Empathy.* London: Penguin.
Baron-Cohen, S. (2019). Center for building a culture of empathy. Retrieved August 29th 2019 from, http://cultureofempathy.com/References/Experts/Simon-Baron-Cohen.htm
Barrett, H. (2006). Researching and Evaluating Digital Storytelling as a Deep Learning Tool. Proceedings of Society for Information Technology and Teacher Education International Conference. Retrieved August 1st 2019 from, https://electronicportfolios.com/portfolios/SITEStorytelling2006.pdf
Bas-Sarmiento, P, Fernández-Gutiérrez, M, Baena-Baños, M, and Romero-Sánchez, J. M. (2017). Efficacy of empathy training in nursing students: A quasi-experimental study. *Nurse Education Today*, 59, 59-65.
Bateson, G. (2000). *Steps to an Ecology of Mind*. Chicago and London: University of Chicago Press.
Batt-Rawden, S. a, Chisolm, M. S, Anton, B, and Flickinger, T. E. (2013). Teaching Empathy to Medical Students. *Academic Medicine*, *88*(8), 1171–1177.
Beauvais, A. M, Brady, N, O'Shea, E. R, and Griffin, M. T. Q. (2011). Emotional intelligence and nursing performance among nursing students. *Nurse Education Today*. 31(4), 396-401.
Beck, C.T. (2016) Posttraumatic stress disorder after birth: A metaphor analysis. *MCN: The American Journal of Maternal Child Nursing* 41: 76–83.
Beck, C. T. (2017). Caring for a Child With an Obstetric Brachial Plexus Injury: A Metaphor Analysis. *Journal of Pediatric Nursing*, *36*, 57–63.
Berger, PL, and Luckman, T (1991). *The Social Construction of Reality*. London and New York: Penguin.
Bergmann, J, and Sams, A. (2014). *Flipped learning: Gateway to student engagement*. International Society for Technology in Education.
Berry, L. (2016). The research relationship in narrative enquiry. *Nurse Researcher*, 24(1), 10–14.
Biasini, A, Fantini, F, Neri, E, Stella, M, and Arcangeli, T. (2012). Communication in the neonatal intensive care unit: a continuous challenge. *The Journal of Maternal-Fetal and Neonatal Medicine.* 25(10), 2126-2129.
Birt, L, Scott, S, Cavers, D, Campbell, C, and Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, 26(13), 1802–1811.
Bishop, E. C, and Shepherd, M. L. (2011). Ethical reflections: examining reflexivity through the narrative paradigm. *Qualitative Health Research*, *21*(9), 1283–1294.
Blackburn, C. and Harvey, M. (2018) 'A different kind of normal': parents' experiences of early care and education for young children born prematurely. *Early Child Development and Care.* 1-14. DOI: 10.1080/03004430.2018.1471074
Blackburn, C. and Harvey, M. (2019) 'We weren't prepared for this': Parents experiences of information and support following the premature birth of their infant. *Infants and Young Children.* 32(3), 172 – 175.
Bleakley, A. (2017). *Thinking with Metaphors in Medicine: The State of the Art.* Taylor and

Francis.
Bleakley, A. (2019). War on words- Cancer is a disease, not a battle. Letter. *The Guardian*, 12th August
Bletzer, K. V. (2015). Visualizing the qualitative: making sense of written comments from an evaluative satisfaction survey. *Journal of Educational Evaluation for Health Professions*, 12(12), doi:10.3352/jeehp.2015.12.12
Bloom, P. (2016). *Against Empathy: The Case for Rational Compassion*. London: Vintage
Boase, C. (2008). *Digital Storytelling for Reflection and Engagement: a study of the uses and potential of digital storytelling. HEA*. Retrieved August 29th, 2019 from, http://resources.glos.ac.uk/tli/lets/projects/pathfinder/index.cfm
Boud, D, Cohen, R, and Sampson, J. (Eds.). (2014). *Peer learning in higher education: Learning from and with each other*. Routledge. London.
Boydell, K. M, Volpe, T, Cox, S, Katz, A, Dow, R, Brunger, F, ... and Cook, S. (2012). Ethical challenges in arts-based health research. *International Journal of the Creative Arts in Interprofessional Practice*, 11, 1-17.
Brackett, MA, and Katulak. NA. (2007).Emotional intelligence in the classroom: Skill-based training for teachers and students. *Applying emotional intelligence: A practitioner's guide*. 1-27. Retrieved July 19th 2019 from, https://pdfs.semanticscholar.org/39c6/caf945679ceb8f6dbab8b1eee4127360e73b.pdf
Bradbury-Jones, C, Sambrook, S, and Irvine, F. (2011). Empowerment and being valued: a phenomenological study of nursing students' experiences of clinical practice. *Nurse Education Today*, 31(4), 368-372.
Bramley, L, and Matiti, M. (2014). How does it really feel to be in my shoes? Patients' experiences of compassion within nursing care and their perceptions of developing compassionate nurses. *Journal of Clinical Nursing*. 23(19-20), 2790-2799.
Braun, V, and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
Braun, V, and Clarke, V. (2014). What can thematic analysis offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9, 1–2.
Brown, B. (2015). *Daring Greatly: How the Courage to Be Vulnerable Transforms the Way We Live, Love, Parent, and Lead*. New York: Penguin Random House.
Bruner, J. (1991). The Narrative Construction of Reality. *Critical Inquiry*, *18*(1), 1–21.
Bruner, J. (1992). *Acts of Meaning*. Harvard University Press.
Bruner, J. (1996). *The Culture of Education*. Cambridge: Harvard University Press.
Bruner, J. (2014). *Making Stories: Law, Literature, Life.* Cambridge, Massachussets, London: Harvard Publishers.
Brunero, S, Lamont, S, and Coates, M. (2010). A review of empathy education in nursing. *Nursing Inquiry*, *17*(1), 65–74.
Burns, K, and Kho, M. E. (2015). How to assess a survey report: a guide for readers and peer reviewers. *CMAJ : Canadian Medical Association Journal.* 187(6), E198–E205. doi:10.1503/cmaj.140545
Caldwell, K. (2012). Storytelling as a Pedagogical Tool. Retrieved August 29th 2019 from, http://teachingthroughthearts.blogspot.com/2012/07/storytelling-as-pedagogical-tool.html
Camacho, D. (2016). Blurring boundaries: An emotionally aware caregiver, social worker,

and researcher. *Qualitative Social Work, in press*.
Cameron, L. (2011). *Metaphor and Reconciliation: The Discourse Dynamics of Empathy in Post-Conflict Conversations*. New York and London: Routledge.
Cameron, L. J. (2012). *Metaphor and reconciliation: The discourse dynamics of empathy in post-conflict conversations.* Routledge.
Cameron, L and Maslen, R. (2010). *Metaphor Analysis: Research Practice in Applied Linguistics, Social Sciences and the Humanities*. London: Equinox.
Carpenter, J. (2008). Metaphors in qualitative research: Shedding light or casting shadows? *Research in Nursing and Health*, *31*(3), 274–282.
Carter, C, Lapum, JL, Lavellee, LF Martin, LS. (2014). Explicating Positionality: A Journey of Dialogical and Reflexive Storytelling. *International Journal of Qualitative Methods*, *13*(1), 362–376.
Casarett, D, Pickard, A, Fishman, J. M, Alexander, S. C, Arnold, R. M, Pollak, K. I., and Tulsky, J. A. (2010). Can metaphors and analogies improve communication with seriously ill patients?. Journal of Palliative Medicine, 13(3), 255-260.
Chan, Z. C, Fung, Y. L, and Chien, W. T. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process. *The Qualitative Report.* 18(30), 1-9.
Charalambous, A, and Beadsmoore, A. (2009). Towards a theory of quality nursing care for patients with cancer through hermeneutic phenomenology. *European Journal of Oncology Nursing*, 13(5), 350-360.
Charlton R. (2016). *Compassion, Continuity and Caring in the NHS.* London: RCGP.
Charon, R. (2001). Narrative Medicine A Model for Empathy, Reflection, Profession, and Trust. *JAMA*, *286*(15), 1897–1902.
Charon, R. (2006). *Narrative Medicine: Honoring the Stories of Illness*. Oxford and New York: Oxford University Press.
Charon, R. (2007). What to do with stories. *Canadian Family Physician*, *53*(8), 1265–1267.
Charteris-Black, J. (2004). *Corpus approaches to critical metaphor analysis.* New York: Palgrave MacMillan.
ChesserSmyth, PA. (2005). The lived experiences of general student nurses on their first clinical placement: A phenomenological study. *Nurse Education in Practice*. 5, 320–327.
Christiansen, A. (2011). Storytelling and professional learning: A phenomenographic study of students' experience of patient digital stories in nurse education. *Nurse Education Today*, *31*(3), 289–293.
Clancy, M. (2013). Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher, 20*(6), 12–16.
Clandinin, FM. and Connelly, J. (2000). *Narrative Inquiry; experience and story in qualitative research.* San Francisco: Jossey-Bass.
Clark, M. C, and Rossiter, M. (2008). Narrative learning in adulthood. *New directions for adult and continuing education*, (119), 61-70.
Clarke, A. (2006). Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher*, *13*(4), 19–29.
Cleary, M, Visentin, D, West, S, Lopez, V, and Kornhaber, R. (2018). Promoting emotional intelligence and resilience in undergraduate nursing students: An integrative review. Nurse Education Today. 68, 112-120. doi:10.1016/j.nedt.2018.05.018
Cleveland, L. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric,*

Gynecologic, and Neonatal Nursing, *37*(6), 666–691.
Cockcroft, S. (2012). How can family centred care be improved to meet the needs of parents with a premature baby in neonatal intensive care? *Journal of Neonatal Nursing*, *18*(3), 105–110.
Cole, M. (2009). Storytelling: its place in infection control education. *Journal of Infection Prevention*, *10*(5), 154-158 5p.
Coles, R. (1989). *The Call of Stories: Teaching and the Moral Imagination.* Houghton Mifflin. Boston.
Collins, C. S, and Cooper, J. . (2014). Emotional intelligence and the qualitative researcher. *International Journal of Qualitative Methods*, *13*, 88–103.
Condon, B. B. (2012). Metaphorically Speaking . . . *Nursing Science Quarterly*, *25*(4), 316–317.
Conle (2003). An anatomy of narrative curricula. *Educational Researcher*. 32(3), 3-15.
Connelly, F. M, and Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14
Cooper, B. (2011). *Empathy in Education; Engagement, Values and Achievement*. London: Bloomsbury Press.
Corbally, M. and ONeill, C. (2014). An introduction to the biographical narrative interpretive method. *Nurse Researcher*. 21 (3), 34-39.
Craig, J. W, Glick, C, Phillips, R, Hall, S. L, Smith, J, and Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology*, *35*(S1), S5–S8.
Crathern, E. (2011). *Disrupted biographies : the lived experiences of first time fathers with a preterm infant in a neonatal intensive care unit*. Retreived on 3rd September 2019 from, https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.555719
Creswell JW and Plano Clark VL. (2007). *Designing and Conducting Mixed Methods Research*, London: Sage Publications Ltd.
Creswell, J. (2014). *Research Design: Qualitative, quantitative and mixed method approaches* (4th editio). Los Angeles and London: Sage publishers.
Crossley, M. L. (2003). 'Let me explain': narrative emplotment and one patient's experience of oral cancer. *Social Science and Medicine*, 56, 3, 439-448.
Cunico, L, Sartori, R, Marognolli, O, and Meneghini, A. M. (2012). Developing empathy in nursing students: a cohort longitudinal study. *Journal of Clinical Nursing*. 21(13-14), 2016-2025.
Czarniawska, B. (1998). *A Narrative Approach to Organization Studies*. London: Sage
D'Agata, A. L, and McGrath, J. M. (2016). A framework of complex adaptive systems. *Advances in Nursing Science*, *39*(3), 244–256.
Dakich, E. (2014). Theoretical and Epistemological Foundations of Integrating Digital Technologies in Education in the Second Half of the 20th Century. In: *Reflections on the History of Computers in Education.* Berlin: Springer.
D'Alessandro, D. M, Lewis, T. E, and D'Alessandro, M. P. (2004). A pediatric digital storytelling system for third year medical students: the virtual pediatric patients. *BMC Medical Education*, *4*(10), 1–6. https://doi.org/10.1186/1472-6920-4-10
Darra, S. (2008). Review: Emotion work and the ethics of novice insider research. *Journal of Research in Nursing*, *13*(3), 262–263.
DasGupta, S. (2007). Between stillness and story: lessons of children's illness narratives. *Pediatrics*, *119*(6), e1384-91.

DasGupta, S, and Charon, R. (2004). Personal Illness Narratives: Using Reflective Writing to Teach Empathy. *Academic Medicine*, *79*(4), 351–356.
Daskolia, M, Kynigos, C, and Makri, K. (2015). Learning about urban sustainability with digital stories. *Constructivist Foundations*, 10(3), 388-396.
Dean, S. (2017). Are our busy doctors and nurses losing empathy for patients? Retrieved August 29th 2019 from, https://theconversation.com/are-our-busy-doctors-and-nurses-losing-empathy-for-patients-68228
Dearnley, C. (2011). A Reflection on the Use of semi-structured interviews. *Nurse Researcher, 13*(1), 19–28.
de Jager, A, Fogarty, A, Tewson, A, Lenette, C, and Boydell, K. M. (2018). Digital Storytelling in Research: A Systematic Review.*The Qualitative Report*, 22(10), 2548-2582.
Delaney, L. J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian*, 25(1), 119-123.
Dellenmark-Blom M. and Wigert, H. (2014) Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: a phenomenological hermeneutical interview study. *Journal of Advanced Nursing*, 70(3), 575–586.
deMarrais, K, and Tisdale, K. (2002). What Happens When Researchers Inquire Into Difficult Emotions?: Reflections on Studying Women's Anger Through Qualitative Interviews. *Educational Psychologist*, *37*(2), 115–123.
Denning, S. (2000). *The Springboard: How Storytelling Ignites Action in Knowledge-Era Organizations*. Boston and London: Butterworth Heinemann.
Denzin, NK and Lincoln, YS. (Eds.), (2017). *Handbook of Qualitative Research* (5th Edition). Thousand Oaks, CA: Sage.
Department of Health, UK (2009). *Toolkit for High-Quality Neonatal Services.* Retrieved August 2nd 2019 from, http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/Toolkit-2009.pdf
DePoy, E and Gitlin, L. (2016). Naturalistic Designs. In *Introduction to Research* (5th ed.). Missouri: Mosby, Inc.
De Vecchi, N, Kenny, A, Dickson-Swift, V, and Kidd, S. (2016). How digital storytelling is used in mental health: A scoping review. *International Journal of Mental Health Nursing*, *25*(3), 183–193.
De Vecchi, N, Kenny, A, Dickson-Swift, V, and Kidd, S. (2017). Exploring the process of digital storytelling in mental health research: A process evaluation of consumer and clinician experiences. *International Journal of Qualitative Methods*, 16(1), 1609406917729291.
Dewey, J. (1938). *Experience and education*. New York: Touchstone.
Dewey, J and McDermott, JJ. (1981). *The Philosophy of John Dewey: Volume 1. The Structure of Experience. Volume 2: The Lived Experience*. Chicago and London: University of Chicago Press.
Dhurandhar, A. (2009). Writing the Other: An Exercise in Empathy. *Journal for Learning through the Arts*. 5, 1-19. https://doi.org/10.5811/westjem.2011.5.6700
Dickson-Swift V, James EL, Kippen S, L. P. (2006). Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, *16*(6), 853–871.
Dickson-Swift, V, James, E, Kippen, S, and Liamputtong, P. (2009). Researching sensitive topics: Qualitative research as emotion work. *Qualitative Research*, *9*(1), 61–79.
Dirkx, J. M. (1998). Transformative learning theory in the practice of adult education: An

overview. *PAACE Journal of Lifelong Learning*, 7, 1-14.
Divinsky, M. (2007). Stories for life: introduction to narrative medicine. *Canadian Family Physician*, *53*(2), 203–205.
Di Vito-Thomas, P. (2005). Nursing student stories on learning how to think like a nurse. *Nurse Educator,* 30(3), 133-136.
Dodgson, J. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*. 35(2), 220-222.
Dow, JW. (2006). *The Evolution of Knowledge Systems: Narrative Knowledge versus Scientific Knowledge.* Retrieved August 29th, 2019 from, https://www.academia.edu/2654516/The_Evolution_of_Knowledge_Systems_Narrative_Knowledge_versus_Scientific_Knowledge
Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher, 13*(3), 7–21. https://doi.org/10.7748/nr2006.04.13.3.7.c5975
Doyle, S. (2013). Reflexivity and the capacity to think. *Qualitative Health Research*, *23*(2), 248–255
Draper, J and Tetley, J. (2013). The importance of person-centred approaches to nursing care. Retrieved August 29th, 2019 from, http://www.open.edu/openlearn/body-mind/health/nursing/the-importance-person-centred-approaches-nursing-care
Duffy,TM, Lowyck, J and Jonassen, D. (2012). *Designing environments for constructive learning*. New York: Springer.
East, L, Jackson, D, O'Brien, L, and Peters, K. (2010). Storytelling: an approach that can help to develop resilience: Relating personal experiences can help participants to cope with their conditions and improve research. *Nurse Researcher*, *17*(3), 17–25.
Educause. (2007). 7 Things you should know about Digital Storytelling. Retrieved August 29th, 2019 from, https://net.educause.edu/ir/library/pdf/ELI7021.pdf
Edwards, S. L. (2013). *Learning from practice: the value of story in nurse education.* Doctorate in Education Thesis. Retrieved August 29th, 2019 from, https://uhra.herts.ac.uk/handle/2299/10351
Edwards, S. L. (2016). Narrative analysis: how students learn from stories of practice. *Nurse Researcher*, 23(3), 18-25.
Edwards, S. L. (2017). What nursing students reveal about and learn from mentors when using stories of clinical practice. *Nursing Management*, 23(10), 32-39.
Ehmann, VE. (1971). Empathy. Its Origin, Characteristic and Process. *Perspectives in Psychiatric Care*. 9(2), 72-81.
Elliott, J. (2019). War on words- Cancer is a disease, not a battle. Letter. *The Guardian*, 12th August
Ellis, C, and Bochner, A. (2000). Autoethnography, personal narrative, reflexivity: Researcher as subject. In Denzin, NK and Lincoln, YS. (Eds.), (2000). *Handbook of Qualitative Research* (2nd Edition). Thousand Oaks, CA: Sage.
Elmir, R, Schmied, V, Jackson, D, and Wilkes, L. (2011). Interviewing people about potentially sensitive topics. *Nurse Researcher*, *19*(1), 12–16.
Emden, C. (1998). Conducting a narrative analysis. *Collegian.* 5(3), 34–39.
Enke, C, Oliva y Hausmann, A, Miedaner, F, Roth, B, and Woopen, C. (2017). Communicating with parents in neonatal intensive care units: The impact on parental stress. *Patient Education and Counseling*, *100*(4), 710–719.
Etikan, I, Musa, S. A, and Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1-4.

Evans, D, and Cruse, P. (Eds.) (2005). In: *Emotion, Evolution And Rationality.* Oxford and New York: Oxford University Press.
Fairbairn, G. (2005). Storytelling, ethics and empathy. *The International Journal of Communication Studies*. 2(3), 48-55.
Faulk, D and Morris, A. H. (2010). The Perspective Transformation Journey Using a Metaphor to Stimulate Student Engagement and Self-reflection. *Nurse Educator*, *35*(3), 103–104.
Fegran, L and Helseth, S (2009). The parent-nurse relationship in the neonatal intensive care unit context--closeness and emotional involvement. *Scand J Caring Sci*. 23(4), 667-73
Fenton, G. (2014). Involving a young person in the development of a digital resource in nurse education. *Nurse Education in Practice*, *14*(1), 49–54.
Fenwick, J, Barclay, L, and Schmied, V. (2008). Craving closeness: A grounded theory analysis of women's experiences of mothering in the Special Care Nursery. *Women and Birth*, *21*(2), 71–85.
Feo, R, and Kitson, A. (2016). Promoting patient-centred fundamental care in acute healthcare systems. *International Journal of Nursing Studies. 57*, 1-11.
Feo, R, Conroy, T, Jangland, E, Muntlin Athlin, Å, Brovall, M, Parr, J, ... and Kitson, A. (2018). Towards a standardised definition for fundamental care: A modified Delphi study. *Journal of Clinical Nursing*, *27*(11–12), 2285-2299.
Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*(2), 209–230.
Finlay, L. (2005). "Reflexive embodied empathy": A phenomenology of participant-researcher subjectivity. *Humanistic Psychology*, *33*(4), 271–292.
Fisher, W. (1985). The Narrative Paradigm: In the Beginning. *Journal of Communication*. 35, 74-89.
Fisher, D, Khashu, M, Adama, E. A, Feeley, N, Garfield, C. F, Ireland, J, and Thomson-Salo, F. (2018). Fathers in neonatal units: Improving infant health by supporting the baby-father bond and mother-father coparenting. *Journal of Neonatal Nursing*. 24(6), 306-312.
Fix, G. M, Houston, T. K, Barker, A. M, Wexler, L, Cook, N, Volkman, J. E, and Bokhour, B. G. (2012). A novel process for integrating patient stories into patient education interventions: incorporating lessons from theater arts. ,. *Patient Education and Counseling*, *88*(3), 455–459.
Flacking, R, Lehtonen, L, Thomson, G, Axelin, A, Ahlqvist, S, Moran, V, and Dykes, F. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatrica, 101*(10), 1032–1037.
Flacking, R, Thomson, G, and Axelin, A. (2016). Pathways to emotional closeness in neonatal units - a cross-national qualitative study. *BMC Pregnancy and Childbirth*, *16*(1), 1–8.
Fleck, P. (2016). Connecting Mothers and Infants in the Neonatal Intensive Care Unit. *Newborn and Infant Nursing Reviews*, *16*(2), 92–96.
Fotiou, C, Vlastarakos, P. V, Bakoula, C, Papagaroufalis, K, Bakoyannis, G, Darviri, C, and Chrousos, G. (2016). Parental stress management using relaxation techniques in a neonatal intensive care unit: A randomised controlled trial. *Intensive and Critical Care Nursing*, *32*, 20–28.
Fowler, C, Green, J, Elliott, D, Petty, J, and Whiting, L. (2019). The forgotten mothers of

extremely preterm babies: A qualitative study. *Journal of Clinical Nursing*, 1–11. https://doi.org/10.1111/jocn.14820
Franck, L, McNulty, A, and Alderdice, F. (2017). The Perinatal-Neonatal Care Journey for Parents of Preterm Infants. *The Journal of Perinatal and Neonatal Nursing*, *31*(3), 244–255.
Frank, A. (2002). Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods*, *1*(1), 109–117.
Frank, A. (2013). *The Wounded Storyteller (2nd Edition).* Chicago and London: Chicoago University Press.
Frank, L. B, Murphy, S. T, Chatterjee, J. S, Moran, M. B, and Baezconde-Garbanati, L. (2015). Telling stories, saving lives: Creating narrative health messages. *Health Communication*, *30*(2), 154–163. https://doi.org/10.1080/10410236.2014.974126
FutureLearn. (2016). The ASPIRE Framework. The University of Nottingham. Retrieved August 29th, 2019 from, https://www.futurelearn.com/courses/e-learning-health/0/steps/17130
Gavey, J. (2007). Parental perceptions of neonatal care. *Journal of Neonatal Nursing*, *13*(5), 199–206.
Gazarian, P. K. (2010). Digital stories: incorporating narrative pedagogy. *The Journal of Nursing Education*, *49*(5), 287–290.
Geertz, C. (1973). Thick Description: Toward an Interpretive Theory of Culture.In: *Interpretation of Cultures*. New York: Basic Books.
Gerrig, R. (1993). *Experiencing Narrative Worlds: On the Psychological Activities of Reading*. Yale. New Haven.
Gibbs, R. (2008). *The Cambridge Handbook of Metaphor and Thought.* Cambridge: Cambridge University Press.
Gidman, J. (2013). Listening to stories: Valuing knowledge from patient experience. *Nurse Education in Practice*, *13*(3), 192–196.
Ginn, S. (2011). Metaphors in Medicine. Retrieved September 1st, 2019 from https://blogs.bmj.com/bmj/2011/08/23/stephen-ginn-metaphors-in-medicine/
Good B (1994). Illness representations in medical anthropology; a reading of the field. Chapter 2; In *Medicine, Rationality and Experience; An Anthropological perspective*. Cambridge: Cambridge University Publishers.
Goodson, I. F, Biesta, G, Tedder, M, and Adair, N. (2010). *Narrative Learning*. London and New York: Routledge.
Gordon, O. (2019). *The First Breath- How Modern Medicine Saves the Most Fragile Lives*. London: Bluebird.
Green, J, Darbyshire, P, Adams, A, and Jackson, D. (2015). Looking like a proper baby: Nurses' experiences of caring for extremely premature infants. *Journal of Clinical Nursing*, *24*(1–2), 81–89.
Greenhalgh, T, and Hurwitz, B. (1998). *Narrative based medicine*. London: BMJ books.
Greenhalgh, T, and Hurwitz, B. (1999). Narrative based medicine- Why study narrative? *British Medical Journal*, *318*, 48–50.
Grendell, R. N. (2011). Narrative pedagogy, technology, and curriculum transformation in nursing education. *Journal of Leadership Studies*, 4(4), 65-67.
Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal*, 29(2), 75-91.
Gubrium, A. C, Krause, E. L, and Jernigan, K. (2014). Strategic authenticity and voice: New

ways of seeing and being seen as young mothers through digital storytelling. *Sexuality Research and Social Policy*. 11(4), 337-347.
Guetterman, T. C, Fetters, M. D, and Creswell, J. W. (2015). Integrating Quantitative and Qualitative Results in Health Science Mixed Methods Research Through Joint Displays. *Annals of Family Medicine*. 13(6), 554–561. doi:10.1370/afm.1865
Hager, P. (2008). Learning and Metaphors. *Medical Teacher*. 30(7), 679-86.
Haidet, P, Kroll, T. L, and Sharf, B. F. (2006). The complexity of patient participation: lessons learned from patients' illness narratives. *Patient Education and Counseling*, 62(3), 323-329.
Haigh, C, and Hardy, P. (2011). Tell me a story - a conceptual exploration of storytelling in healthcare education. *Nurse Education Today*, *31*(4), 408–411.
Halcomb, E. J, and Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, 19(1), 38-42.
Hall, E. O. C, and Brinchmann, B. S. (2009). Mothers of preterm infants: Experiences of space, tone and transfer in the neonatal care unit. *Journal of Neonatal Nursing*, *15*(4), 129–136.
Hall, J. M, and Powell, J. (2011). Understanding the Person through Narrative. *Nursing Research and Practice*, *doi:10.115*, 1–10.
Hall, S. L, Phillips, R, and Hynan, M. T. (2016). Transforming NICU Care to Provide Comprehensive Family Support. *Newborn and Infant Nursing Reviews,* 16(2), 69–73.
Hampshire, K. and Blell, M. and Iqbal, N. and Simpson, B. (2014). The interview as narrative ethnography: seeking and shaping connections in qualitative research. *International Journal of Social Research Methodology*, *17*(3), 215–231.
Hardy, P. (2007). An investigation into the application of the Patient Voices Digital Stories in Healthcare Education: quality of learning, policy impact and practice-based value. Retrieved August 29th, 2019 from, http://www.pilgrim.myzen.co.uk/papers/phardymsc.pdf
Hardy, P. (2017). DNA of Care: one year on- sharing the learning. Retrieved July 29th 2019 from, https://www.patientvoices.org.uk/pdf/presentations/20171207%20DNA%20of%20Care%20shared%20learning%20event.pdf
Hardy, P, and Sumner, T. (2018). *Cultivating Compassion How Digital Storytelling is Transforming Healthcare* ((2nd Edition). London: Palgrave MacMillan.
Harland, N. (2018), Increasing Empathy. Digital Storytelling in Professional Development; Chapter 18, in: Hardy, P, and Sumner, T. (2018). *Cultivating Compassion How Digital Storytelling is Transforming Healthcare* ((2nd Edition). London: Palgrave MacMillan.
Hartling, L, Scott, S, Pandya, R, Johnson, D, Bishop, T, and Klassen, T. P. (2010). Storytelling as a communication tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information. *BMC Pediatrics*, 10(1), 64.
Harvey, M. E, and Pattison, H. M. (2013). The impact of a father's presence during newborn resuscitation: A qualitative interview study with healthcare professionals. *BMJ Open*, *3*(3), 1–8.
Haydon, G, Browne, G, and van der Riet, P. (2018). Narrative inquiry as a research methodology exploring person centred care in nursing. *Collegian*, 25(1), 125-129.
Heale, R, and Forbes, D. (2013). Understanding triangulation in research. *Evidence-Based Nursing.* ebnurs-2013. https://ebn.bmj.com/content/16/4/98

Health Foundation. (2016). *The Power of Storytelling*. Retrieved August 29th 2019 from, https://www.health.org.uk/newsletter-feature/power-of-storytelling
Healthtalk online. (2017). *Impact Report*. Retrieved July 16th, 2019 from, http://www.healthtalk.org//files/upload/latestimpactreport.pdf
Heidke, P, Howie, V, and Ferdous, T. (2018). Use of healthcare consumer voices to increase empathy in nursing students. *Nurse Education in Practice*, 29, 30-34.
Herland, M. (2017). Reflexive research: Investigating the process of growth in recognition of self-awareness and affect. *Qualitative Social Work*. 16(4), 566-580.
Hesse-Biber, S. (2010). Qualitative approaches to mixed methods practice. *Qualitative Inquiry. 16*(6), 455-468.
Hewitt, J. (2007). Ethical components of researcher-researched relationships in qualitative interviewing. *Qualitative Health Research*, *17*(8), 1149–1159.
Hewson J, Danbrook C, Sieppert J. (2015). Engaging post-secondary students and older adults in an intergenerational digital storytelling course. Comtemporary Issues in Educational Research. 8, 135–42.
Hoggan, C, and Cranton, P. (2015). Promoting Transformative Learning Through Reading Fiction. *Journal of Transformative Education*, 13(1), 6-25.
Hojat, M, Gonnella, J. S, Nasca, T. J, Mangione, S, Veloksi, J. J, and Magee, M. (2002). The Jefferson Scale of Physician Empathy: further psychometric data and differences by gender and specialty at item level. *Academic Medicine*, *77*(10), S58–S60.
Holloway I. and Biley, F. (2011). Being a qualitative researcher. *Qualitative Health Research*, *21*, 968–975.
Holloway, I, and Freshwater, D. (2007). *Narrative Research in Nursing*. Chichester: Blackwell.
Hughes, R and Huby, M. (2002). The application of vignettes in social and nursing research. *Journal of Advanced Nursing*. 37 (4), 382-386.
Hurley, J. (2008). The necessity, barriers and ways forward to meet user-based needs for emotionally intelligent nurses. *Journal of Psychiatric and Mental Health Nursing*. *15*(5), 379-385.
Hutchinson, S. W, Spillett, M. A, and Cronin, M. (2012). Parents' Experiences during their Infant's Transition from Neonatal Intensive Care Unit to Home: A Qualitative Study . *The Qualitative Report.* 17(12), 1-20.
Ileya, K, McInulty, L, Jones, I, York, J and Johnson, M. (2011) Developing competence in cardiac care through the use of blended learning: Course members' and mentors' accounts. *Nurse Education Today,* 31, (4), 323-327
Jairath, N. (1999). Myocardial infarction patients' use of metaphors to share meaning and communicate underlying frames of experience. *Journal of Advanced Nursing*, *29*(2), 283–289.
Janvier, A, Lantos, J, Aschner, J, Barrington, K, Batton, B, Batton, D, … Spitzer, A. R. (2016). Stronger and More Vulnerable: A Balanced View of the Impacts of the NICU Experience on Parents. *Pediatrics*, *138*(3), e20160655–e20160655.
Jarvis, J. (2005). Telling Stories in Class: an exploration of aspects of the use of narrative in a higher education context. *Journal for the Enhancement of Learning and Teaching*. 2(1), 6-13.
Jarvis, J, Dyson, J, Thomas, K, Graham, S, Iantaffi, A and Burchell, H. (2004). Learning through creating stories: developing student teachers understanding of the experiences of pupils with special educational needs in mainstream classrooms.

Retrieved September 2nd, 2019 from, http://www.leeds.ac.uk/educol/documents/00003733.htm
Jeffrey, D. (2016). Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter? *Essay Journal of the Royal Society of Medicine*, *109*(12), 446–452.
Jiang, S, Warre, R, Qiu, X, O'Brien, K, and Lee, S. K. (2014). Parents as practitioners in preterm care. *Early Human Development*, *90*(11), 781–785.
Johnson, N. (2009). The role of self and emotion within qualitative sensitive research : a reflective account. *Enquire*, *2*(2), 191–214.
Jonassen, D. H, Peck, K. L, and Wilson, B. G. (1999). *Learning with technology: A constructivist perspective.* New York: Pearson.
Jonsén, E, Melender, H. L, and Hilli, Y. (2013). Finnish and Swedish nursing students' experiences of their first clinical practice placement—A qualitative study. *Nurse Education Today*, 33(3), 297-302.
Kalitzkus, V, and Matthiessen, P. F. (2009). Narrative-based medicine: potential, pitfalls, and practice. *The Permanente Journal*, 13(1), 80–86.
Kantrowitz-Gordon, I, and Vandermause, R. (2016). Metaphors of Distress. *Qualitative Health Research*, *26*(8), 1031–1043.
Kaplan-Myrth, N. (2007). Interpreting people as they interpret themselves: Narrative in medical anthropology and family medicine. *Canadian Family Physician*, *53*(8), 1268–1269.
Katz, RL. (1963). *Empathy: Its Nature and Uses*. New York: Free Press.
Keen, S. (2006). A Theory of Narrative Empathy. *Narrative*. 14(3), 207-236.
Kelly, T and Howie, L. (2007). Working with stories in nursing research: Procedures used in narrative analysis. *International Journal of Mental Health Nursing*, 16, 136-144.
Kendall, M, Harris, F, Boyd, K, Sheikh, A, Murray, S. A, Brown, D, … Worth, A. (2007). Key challenges and ways forward in researching the "good death": qualitative in-depth interview and focus group study. *BMJ (Clinical Research Ed.)*, 1–6. https://doi.org/10.1136/bmj.39097.582639.55
Keskin, S. C. (2014). From what isn't empathy to empathic learning process. *Procedia-Social and Behavioral Sciences*. 116, 4932-4938.
Khullar, D. (2014). The Trouble with Medicine's Metaphors. *TheAtlantic.Com*. Retrieved August 29th, 2019 from, https://www.theatlantic.com/health/archive/2014/08/the-trouble-with-medicines-metaphors/374982/
Kim, J. (2016). Narrative Data Analysis and Interpretation: Flirting with Data. In *Understanding Narrative Inquiry: The crafting and analysis of stories as research*. Singapore: Sage.
Kingdon, C. (2005). Reflexivity: not just a qualitative methodological research tool. *British Journal of Midwifery*, *13*(10), 622–625. https://doi.org/10.12968/bjom.2005.13.10.19835
Kirk, M, Tonkin, E, Skirton, H, McDonald, K, Cope, B, and Morgan, R. (2013). Storytellers as partners in developing a genetics education resource for health professionals. *Nurse Education Today*, *33*(5), 518–524.
Kittay, E. F. (1990). *Metaphor: Its cognitive force and linguistic structure.* Oxford and New York: Oxford University Press.
Kleinman, A. (1989). *The Illness Narratives : suffering, healing, and the human condition*. New York: Basic Books.
Korhonen, A, and Kangasniemi, M. (2014). Nurses' narratives on termination of primary

nursing relationship with parents in neonatal intensive care. *Scandinavian Journal of Caring Sciences*, 28(4), 716-723.
Kroth, M. and Cranton, P. (2014). *Stories of Transformative Learning. International Issues in Adult Education.* Rotterdam; Boston; Taipei: Sense Publishers.
Krznaric, R. (2014). *Empathy: Why it Matters, and How to get it*. London: Ebury Publishing.
Lafrenière, D, Hurlimann, T, Menuz, V, and Godard, B. (2012). Health research: Ethics and the use of arts-based methods in knowledge translation processes. International *Journal of the Creative Arts in Interdisciplinary Practice*, 11(1). Retrieved July 19th, 2019 from, http://www.ijcaip.com/archives/IJCAIP-11-paper3.html
Laird, E. A, McCance, T, McCormack, B, and Gribben, B. (2015). Patients' experiences of in-hospital care when nursing staffwere engaged in a practice development programme to promote person-centredness: A narrative analysis study. *International Journal of Nursing Studies*, 52(9), 1454–1462.
Lakoff, G and Johnson, M. (2003). *Metaphors we live by*. Chicago: Chicago University Press.
Lam, T. C. M, Kolomitro, K, and Alamparambil, F. C. (2011). Empathy Training: Methods, Evaluation Practices, and Validity. *Journal of MultiDisciplinary Evaluation*, *7*(16), 162–200. Retrieved August 29th, 2019 from, http://www.eric.ed.gov/ERICWebPortal/detail?accno=EJ941841
Lambert J. (2010). *Cookbook for digital storytelling.* New York: Digital Diner Press.
Lambert, J. (2018). *Digital Storytelling: Capturing Lives, Creating Community (5th Edition).* New York and Oxford: Routledge.
Lambert, C, Jomeen, J, and McSherry, W. (2010). Reflexivity: a review of the literature in the context of midwifery research. *British Journal of Midwifery*, *18*(5), 321–326.
Laranjeira, C. (2013). The role of narrative and metaphor in the cancer life story: A theoretical analysis. *Medicine, Health Care and Philosophy*, *16*(3), 469–481.
Landy, R, Cameron, C, Au, A, Cameron, D, O'Brien, K, Robrigado, K, ... and Nixon, S. (2016). Educational strategies to enhance reflexivity among clinicians and health professional students: a scoping study. *Forum: Qualitative Social Research*. 17(3), http://www.qualitative-research.net/index.php/fqs/article/view/2573
Lapum, J, Angus, J. E, Peter, E, and Watt-Watson, J. (2010). Patients' narrative accounts of open-heart surgery and recovery: Authorial voice of technology. *Social Science and Medicine*, 70(5), 754-762.
Laranjeira, C. (2013). The role of narrative and metaphor in the cancer life story: A theoretical analysis. *Medicine, Health Care and Philosophy*, *16*(3), 469–481.
LaScala, S. (2009). *Small Wonder: The story of a child born too soon.* Gill, MA: Barton Cove Publishers.
Layne, L. (1996). "Hows the baby doing?" Struggling with Narratives of Progress in a Neonatal Intensive Care Unit. *Medical Anthropology Quarterly*, *10*(4), 624–656.
Lee, S. K, and O'Brien, K. (2018). Family integrated care: Changing the NICU culture to improve whole-family health. *Journal of Neonatal Nursing*, 24(1), 1–3.
Leonard, C. R, Zomorodi, M, and Foster, B. B. (2018). The impact of caring: teaching students' empathy through the patient voice. *Creative Nursing.* 24(1), 62-66.
Levasseur, J. and Vance, DR. (1993). Doctors, Nurses and Empathy. In, Spiro, H, McCrea Curnen, MG, Peschel, E, and St. James, D, (1993). *Empathy and the Practice of Medicine*. New Haven and London: Yale Publishers.
Levers, M. J. D. (2013). Philosophical paradigms, grounded theory, and perspectives on

emergence. *Sage Open*, 3(4), 2158244013517243.
Levett-Jones, T, Lapkin, S, Govind, N, Pich, J, Hoffman, K, Jeong, S. Y. S, ... and Everson, N. (2017). Measuring the impact of a 'point of view'disability simulation on nursing students' empathy using the Comprehensive State Empathy Scale. *Nurse Education Today.* 59, 75-81.
Lichtman, M. V. (2012). *Making Meaning from your data. In Qualitative Research in Education: A User's Guide*. London: Sage.
Lincoln, YS, and Guba, EG (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
Lindsay, GM, and Schwind, JK. (2016). Narrative inquiry: Experience matters. *Canadian Journal of Nursing Research*, 48(1), 14-20.
Lindseth, A, and Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145-153.
Llewellyn, R, Jaye, C., Egan, R, Cunningham, W, Young, J, and Radue, P. (2017). Employing imaginative rationality: using metaphor when discussing death. *Medical Humanities*, 43(1), 71-72.
Lorem, G.F. (2008). Making sense of stories: the use of patient narratives within mental health care research. *Nursing Philosophy*, 9, 62-71.
Locke J. (1894). *An essay concerning human understanding. 2 Vols.* Oxford: Clarendon.
Low, M, and LaScala, S. (2015). Medical memoir: A tool to teach empathy to nursing students. *Nurse Education Today*, 35(1), 1–3. https://doi.org/10.1016/j.nedt.2014.10.001
Lowes, L, and Paul, G. (2006). Participants' experiences of being interviewed about an emotive topic. *Journal of Advanced Nursing*, 55(5), 587-595.
Lundy, L. (2007). Voice is not enough: Conceptualising article 12 of the United Nations convention on the rights of the child. *British Educational Research Journal*, 33(6), 927-942.
Macdonell, K, Omrin, D, Pytlik, K, Pezzullo, S, Bracht, M, and Diambomba, Y. (2015). An effective communication initiative: using parents' experiences to improve the delivery of difficult news in the NICU. *Journal of Neonatal Nursing*, 21(4), 142-149.
Machin, D. (2007). *Introduction to multimodal analysis*. London: Hodder Education.
Macintyre, M. (2001). Taking care of culture: Consultancy, anthropology and gender issues. Social Analysis: *The International Journal of Social and Cultural Practice*, 45(2), 108-119.
Mahoney, S, Sladek, R. M, and Neild, T. (2016). A longitudinal study of empathy in pre-clinical and clinical medical students and clinical supervisors. *BMC Medical Education,* 16(1), 270. doi:10.1186/s12909-016-0777-z
Malinski, V. M. (2009). Metaphor: Creative Energy Informing Nursing Research. *Nursing Science Quarterly*, 22(630), 310–311.
Mann, S. (2016). *The Research Interview. Reflective Practice and Reflexivity in Research Processes*. Basingstoke: Palgrave MacMillan.
Marsden, P (2017). Speed Summary: Against Empathy – The Case for Rational Compassion. Retrieved August 29th 2019 from, https://brandgenetics.com/speed-summary-against-empathy-the-case-for-rational-compassion/
Masukume, G, and Zumla, A. (2012). Analogies and metaphors in clinical medicine. Clinical Medicine, *Journal of the Royal College of Physicians of London*, 12(1), 55–56.
Matthews J. (2014). Voices from the heart: the use of digital storytelling in education. *Community Practitioner.* 87, 28–30.
Mattingly, C. (1994). The concept of therapeutic "emplotment". Special issue; narrative

representation of illness and healing. *Social Science and Medicine*, 38, 6, 811–822.
Mauthner, N. S, and Doucet, A. (2003). Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology*, *37*(3), 413–431.
Maxwell B. (2008). Professional Ethics Education Studies in Compassionate Empathy. New York: Springer.
Mayer, J. D, Salovey, P, and Caruso, D. (2004). Emotional intelligence: Theory, findings, and implications. *Psychological Inquiry*, 15, 197–215.
Mayor, R. E. (2014). *Multimedia learning (2nd Edition)*. New York and Cambridge: Cambridge University Press.
McAdams, D. P. (2006). The problem of narrative coherence. *Journal of Constructivist Psychology*, 19(2), 109-125.
McDonald, K, and Smith, C. M. (2013). The flipped classroom for professional development: part I. Benefits and strategies. *The Journal of Continuing Education in Nursing*, *44*(10), 437-438.
McDrury, J and Alterio, M. (2016). *Learning through storytelling in higher education: using reflection and experience to improve learning*. London and Sterling, VA: Routledge.
McGregor, T. (2012). Empathy and Life. Retrieved August 29th, 2019 from, https://hubpages.com/politics/Empathy-and-life
McIntosh P. (2013). The current educational climate: why the creative arts and humanities are important to creativity and learning in the classroom. In: McIntosh P, Warren D (Eds.) *Creativity in the classroom: case studies in using the arts in teaching and learning in higher education*. Chicago: Intellect Ltd.
McKinnon, J. (2018). In their shoes: An ontological perspective on empathy in nursing practice. *Journal of Clinical Nursing*. 27(21-22), 3882-3893.
Melincavage, S. M. (2011). Student nurses' experiences of anxiety in the clinical setting. *Nurse Education Today*. 31(8), 785-789.
Mendizabal-Espinosa, R. M, and Podsiadly, E. (2018). Encouraging parents to care for babies in the neonatal unit. *British Journal of Nursing*, *27*(8), 424.
Mezirow, J. (2000). *Learning as Transformation: Critical Perspectives on a Theory in Progress. The Jossey-Bass Higher and Adult Education Series.* San Francisco. Jossey-Bass Publishers.
Millard. C (2010). Illness Narratives and Idioms of Meaning in Two Tibetan Medical Clinics. In *Medicine, Health, and Modernity: Proceedings from the XIth International Association of Tibetan Studies Meetings*. Schrempf, M. (ed.) Bonn: International Institute for Tibetan and Buddhist Studies.
Milton, C. L. (2017). Ethics and Discovering New Meanings With Metaphors. *Nursing Science Quarterly*, *30*(3), 205-206.
Mishler, E. (1995). Models of Narrative Analysis: A Typology. *Journal of Narrative and Life History*, *5*(2), 87–123.
Missel, M, and Birkelund, R. (2011). Living with incurable oesophageal cancer. A phenomenological hermeneutical interpretation of patient stories. European *Journal of Oncology Nursing*, 15 (4), 296-301.
Mitchell, G. (2015). Use of interviews in nursing research. *Nursing Standard*, 29(43), 44–48.
Molenberghs, P. (2017). Understanding others' feelings: what is empathy and why do we need it? *The Conversation.* Retrieved August 29th 2019 from, https://theconversation.com/understanding-others-feelings-what-is-empathy-and-

why-do-we-need-it-68494
Moon, J. (2013). *A Handbook of Reflective and Experiential Learning Theory and Practice*. London: Routledge.
Moon, J, and Fowler, J. (2008). "There is a story to be told..."; A framework for the conception of story in higher education and professional development. *Nurse Education Today*, *28*(2), 232–239.
Moore, J. (2012). A personal insight into researcher positionality. *Nurse Researcher*, *19*(4), 11–14.
Moreau, K. A, Eady, K, Sikora, L, and Horsley, T. (2018). Digital storytelling in health professions education: a systematic review. *BMC Medical Education*, 18(1), 208.
Morra, S. (2016). 8 Steps to great digital storytelling. Retrieved August 3rd, 2019 from, http://edtechteacher.org/8-steps-to-great-digital-storytelling-from-samantha-on-edudemic/
Morrison, A, and Gullon-Rivera, A. L. (2017). Supporting Siblings of Neonatal Intensive Care Unit Patients: A NICU Social Story as an Innovative Approach. *Journal of Pediatric Nursing*, *33*, 91–93.
Morse JM. (2000). Determining sample size. *Qualitative Health Re*search. 10(1), 3–5.
Mullan, F, Ficklen, E and Rubin, K. (2006). *Narrative Matters: The Power of the Personal Essay in Health Policy.* Baltimore John Hopkins University Press.
Murphy, J. W, Franz, B. A, and Schlaerth, C. (2018). The Role of Reflection in Narrative Medicine. *Journal of Medical Education and Curricular Developmen*t, *5*, 2382120518785301. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6055100/
National Health Service. (2017). *Exploring New Ways of Working in the Neonatal Unit.* Retrieved August 29th 2019 from, http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/11/Exploring-New-Ways-of-Working-in-the-Neonatal-Unit-LODN.pdf
National Health Service England (NHS England) (2019). *The NHS Long-term plan.* Retrieved August 29th 2019 from, https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf
Nelson, M, Kelly, D, McAndrew, R, and Smith, P. (2017). 'Just gripping my heart and squeezing': Naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting. *Patient Education and Counselling*, 100(9), 1751 1757.
Nezlek, J. B, and Kuppens, P. (2008). Regulating positive and negative emotions in daily life. *Journal of Personality*, 76(3), 561-580.
Nguyen M, Miranda J, Lapum J, and Donald F. (2016). Arts-based learning: a new approach to nursing education using andragogy. *Journal of Nurse Education.* 55, 407–10.
Newbury, J. (2011). Reflexivity in a study of family carers in home palliative care: A personal account. *Nurse Researcher*, *19*(1), 30–36.
Niemi, H, and Multisilta, J. (2016). Digital storytelling promoting twenty-first century skills and student engagement. *Technology, Pedagogy and Education*, 25(4), 451-468.
Noble, K, and McIlveen, P. (2012). Being, knowing, and doing: A model for reflexivity in social constructionist practices. In *Social constructionism in vocational psychology and career developmen*t. Rotterdam: Sense Publishers.
Noble, H, and Smith, J. (2015) Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18, (2), 34-35

Noergaard, B, Ammentorp, J, Garne, E, Fenger-Gron, J, and Kofoed, P. E. (2018). Fathers' Stress in a Neonatal Intensive Care Unit. *Advances in Neonatal Care*. 18(5), 413–422.
Nolan, S. (2018). Fact, fiction and something in between: narratives on authenticity. Retrieved August 29th 2019 from, https://www.uos.ac.uk/content/fact-fiction-and-something-between-narratives-authenticity
Nowell, L. S, Norris, J. M, White, D. E, and Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*. 16, 1-13.
Nursing and Midwifery Council (NMC) (2018). *Standards for Nursing*. Retrieved August 29th, 2019 from, https://www.nmc.org.uk/standards/standards-for-nurses/
Obeidat, H. M, Bond, E. A, and Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of Perinatal Education*, 18(3), 23–29.
O'Brien, K, Bracht, M, Robson, K, Ye, X. Y, Mirea, L, Cruz, M, … Lee, S. K. (2015). Evaluation of the Family Integrated Care model of neonatal intensive care: A cluster randomized controlled trial in Canada and Australia. *BMC Pediatrics*, *15*(1), 1–9.
Oliver, DG, Serovich, JM and Mason, T. (2005). Constraints and Opportunities with Interview Transcription : Towards Reflection in Qualitative Research. *Social Forces*, *84*(2), 1273–1289.
OrlandBarak, L and Wilhelem, D. (2005). Novices in clinical practice settings: Student nurses stories of learning the practice of nursing. *Nurse Education Today*, 25, 455–464.
Ottosson, C, and Lantz, B. (2017). Parental participation in neonatal care. *Journal of Neonatal Nursing*, *23*(3), 112–118.
Paddam, A, Barnes, D. and Langdon, D. (2010). Constructing vignettes to investigate anger in multiple sclerosis. *Nursing Research*, 17 (2), 60-73.
Paley, J. and Eva, G. (2005). Narrative vigilance: the analysis of stories in health care. *Nursing Philosophy*, 6, 83-97.
Pallai, E, and Tran, K. (2019). Narrative Health: Using Story to Explore Definitions of Health and Address Bias in Health Care. *The Permanente journal*, *23*, 18-052.
Paradis, E, O'Brien, B, Nimmon, L, Bandiera, G, and Martimianakis, M. A. (2016). Design: Selection of Data Collection Methods. *Journal of Graduate Medical Education*, 8(2), 263–264.
Parsons, J. A, and Boydell, K. M. (2012). Arts-based research and knowledge translation: Some key concerns for health-care professionals. *Journal of Interprofessional Care*, 26(3), 170-172.
Patel, N, Ballantyne A, and Bowker G for the Helping Us Grow Group (HUGG), *et al (2018).* Family Integrated Care: changing the culture in the neonatal unit *Archives of Disease in Childhood.*103:415-419.
Patey, C. (2016). *The Power of Storytelling*. The Health Foundation. Retrieved August 29th 2019 from, https://www.health.org.uk/newsletter-feature/power-of-storytelling
Periyakoil, V. S. (2008). Using metaphors in medicine. *Journal of Palliative Medicine*, *11*(6), 842–844.
Perry M, Maffulli N, Willson S, and Morrissey D. (2011). The effectiveness of arts-based interventions in medical education: a literature review. *Medical Education*. 45, 141–8.
Peters M. (2000). Does constructivist epistemology have a place in nurse education? *Journal of Nurse Education*. 39, 166–72.

Peters, E. (2018). Compassion fatigue in nursing: A concept analysis. *Nursing Forum*, 53(4), 466-480.
Peters K, and Halcomb E (2015) Interviews in qualitative research. *Nurse Researcher.* 22, 4, 6-7.
Petrucci, C, La Cerra, C, Aloisio, F, Montanari, P, and Lancia, L. (2016). Empathy in health professional students: A comparative cross-sectional study. *Nurse Education Today.* 41, 1-5.
Petty, J. (2013). Interactive, technology-enhanced self-regulated learning tools in healthcare education: A literature review. *Nurse Education Today*, *33*(1), 53–59.
Petty, J. (2014). Exploring the effectiveness of an interactive, technology enabled learning tool to enhance student knowledge in neonatal practice. *Journal of Neonatal, Paediatric and Child Health Nursing*, *17*(1), 2–10.
Petty, J. (2016a). Learning from narrative to understand the person-centred experience in neonatal nursing: A literature review. *Journal of Neonatal Nursing*, 22(6), 297–308. 5
Petty, J. (2016b). Appreciation of the neonatal care experience through the eyes of student nurses: The Development of a Storytelling learning resource. *LINK.* Retrieved August 29th 2019 from, https://www.herts.ac.uk/link/volume-2,-issue-2/appreciation-of-the-neonatal-care-experience-through-the-eyes-of-student-nurses
Petty, J. (2017a). Creating stories for learning about the neonatal care experience through the eyes of student nurses: An interpretive, narrative study. *Nurse Education Today*. 48: 25-32.
Petty, J. (2017b). Emotion work in qualitative research: interviewing parents about neonatal care. *Nurse Researcher*, *25*(3), 26–30.
Petty, J and Treves, R (2017). Development of a digital storytelling resource to support children's nursing students in neonatal care. *Nursing Children and Young People.* 29(2), 32-37.
Petty, J, Jarvis, J and Thomas, R. (2018a). Core Story Creation: Analysing narratives to construct stories for learning. *Nurse Researcher*. 24(4), 46-50.
Petty, J, Whiting, L, Green, J, and Fowler, C. (2018b). Parents' views on preparation to care for extremely premature infants at home. *Nursing Children and Young People*, *30*(4), 22–27. https://doi.org/10.7748/ncyp.2018.e1084
Petty J, Jarvis J, Thomas R. (2019a). Understanding parents' emotional experiences for neonatal education: A narrative, interpretive approach. *Journal of Clinical Nursing.* 28(9-10), 911-1924.
Petty J, Jarvis J, Thomas R. (2019b). Listening to the parent voice to inform person-centred neonatal care. *Journal of Neonatal Nursing*. 25(3), 121-126.
Petty J, Jarvis J, Thomas R. (2019c). Using parent metaphors for learning about the neonatal care experience: an interpretive perspective. *Journal of Child Health Care.* doi: 10.1177/1367493519875853. E-pub ahead of print.
Phillipi, J. (2010). Transformative Learning in Healthcare. *PAACE Journal of Lifelong Learning.* 19, 39-54.
Picker Europe. (2015). *Parents ' experiences of neonatal care : Findings from Neonatal Survey 2014*. Retrieved August 29th 2019 from, https://www.picker.org/wp-content/uploads/2014/12/P2725_Neonatal-Survey-2014_-Online-Version_Final.pdf
Pineda, R, Bender, J, Hall, B, Shabosky, L, Annecca, A, and Smith, J. (2018). Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes. *Early Human Development. 117*, 32–38.

Pink, D. (2008). *A Whole New Mind: Why Right-Brainers will rule the future*. New York: Marshall Cavendish.
Pithouse-Morgan, K, Khau, M, Masinga, L, and van de Ruit, C. (2012). Letters to those who dare feel: Using reflective letter-writing to explore the emotionality of research. *International Journal of Qualitative Methods*, *11*(1), 40–56.
Platonos, K, Aloysius, A, Banerjee, J, and Deierl, A. (2018). Integrated family delivered care project: Parent education programme. *Journal of Neonatal Nursing*, *24*(1), 29–34.
Polkinghorne, D. (1988). *Narrative Knowing and the Human Sciences*. Albany: University of New York Press, Albany.
Polkinghorne, D. (1995). Narrative configuration in qualitative analysis. In R. Hatch, R and Wisniewski (Ed.), *Life History and Narrative*. London and Washington: Falmer Press.
Pragglejaz Group (2007). MIP: A method for identifying metaphorically used words in discourse. *Metaphor and Symbol*, 22, 1–39.
Pratt, H, Mackay, M, Green, C, Woodhouse, G, Marriott-Statham, K, and University of Wollongong, New South Wales, Australia. (2019). Courageous collaboration in co-constructing learning and teaching resources. *International Practice Development Journal,* 9(1), 1-6.
Premji, S. S, Pana, G, Currie, G, Dosani, A, Reilly, S, Young, M, … Lodha, A. K. (2018). Mother's level of confidence in caring for her late preterm infant: A mixed methods study. *Journal of Clinical Nursing*, *27*(5–6), e1120–e1133.
Price, B. (2011). Improving clinical reasoning in children's nursing through narrative analysis. *Nursing Children and Young People*, *23*(6), 28–34.
Price, D. M, Strodtman, L, Brough, E, Lonn, S, and Luo, A. (2015). Digital Storytelling: An Innovative Technological Approach to Nursing Education. *Nurse Educator*, *40*(2), 66–70.
Priest, H, Roberts, P, and Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data. Part 1: Theoretical issues. *Nurse Researcher.* 10, 1, 30-42
Råheim, M, Magnussen, L. H, Sekse, R. J. T, Lunde, Å, Jacobsen, T, and Blystad, A. (2016). Researcher–researched relationship in qualitative research: Shifts in positions and researcher vulnerability. *International Journal of Qualitative Studies on Health and Well-Being*, 11. http://www.ijqhw.net/index.php/qhw/article/view/30996
Ramm, D, Thomson, A, and Jackson, A. (2015). Learning clinical skills in the simulation suite: The lived experiences of student nurses involved in peer teaching and peer assessment. *Nurse Education Today*, *35*(6), 823-827.
Rapport, N. (2004). The narrative as fieldwork technique: processual ethnography for a world in motion. Chapter 5 in: Amit, V (ed). *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* New York and London: Taylor and Francis.
Rashotte, J. (2005). Dwelling with stories that haunt us: Building a meaningful nursing practice. *Nursing Inquiry*, *12*(1), 34–42.
Read, K, and Rattenbury, L. (2018). Parents as partners in care: Lessons from the Baby Friendly Initiative in Exeter. *Journal of Neonatal Nursing*, *24*(1), 17–20.
Reid, K, Hartling, L, Ali, S, Le, A, Norris, A, and Scott, S. D. (2017). Development and Usability Evaluation of an Art and Narrative-Based Knowledge Translation Tool for Parents With a Child With Pediatric Chronic Pain: Multi-Method Study. *Journal of Medical Internet research*, 19(12), e412.
Reid, A. M, Brown, J. M, Smith, J. M, Cope, A. C, and Jamieson, S. (2018). Ethical dilemmas

and reflexivity in qualitative research. *Perspectives on Medical Education*, 7(2), 69–75.
Reissman. (2008). Thematic analysis. In *Narrative Methods for the Human Sciences* (pp. 53–76).
Renda, C. (2013). Evaluating Digital Stories as Multi-Modal Reflections on Experiences. In R. McBride and M. Searson (Eds.), *Proceedings of SITE 2013--Society for Information Technology and Teacher Education International Conference.* New Orleans: Association for the Advancement of Computing in Education (AACE). Retrieved August 10th, 2019 from, https://www.learntechlib.org/primary/p/48351/.
Richards, H M. and Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice*, *19*(2), 135–139.
Richardson, L. (2000). Writing: A method of inquiry. In Y. Denzin, N and Lincoln (Eds.), *Handbook of qualitative research* (2nd Edition). Thousand Oaks, CA: Sage publishers.
Richardson, J, and Grose, J. (2009). The use of descriptive words and metaphor in patient and carer experience of palliative day care: secondary analysis of a qualitative study. *The Open Nursing Journal*, *3*, 18–24.
Ricoeur, P. (1984). *Time and Narrative, Volume 1.* Chicago: University of Chicago Press.
Ricoeur, P. (1992). *Oneself as Another*. Chicago: The University of Chicago Press.
Ricoeur, P. (2003). *The Rule of Metaphor: The Creation of Meaning in Language*. London: Routledge.
Ricoeur, P. (2013). *Hermeneutics*. Cambridge: Polity Press.
Rieger, K, and Schultz, A. S. (2014). Exploring Arts-Based Knowledge Translation: Sharing Research Findings Through Performing the Patterns, Rehearsing the Results, Staging the Synthesis. *Worldviews on Evidence-Based Nursing*, 11(2), 133-139.
Rieger, K. L, West, C. H, Kenny, A, Chooniedass, R, Demczuk, L, Mitchell, K. M, ... and Scott, S. D. (2018). Digital storytelling as a method in health research: A systematic review protocol. *Systematic reviews,* 7(1), 41.
Riley, T, and Hawe, P. (2005). Researching practice: The methodological case for narrative inquiry. *Health Education Research*, *20*(2), 226–236.
Ritchie, J, Zwi, A. B, Blignault, I, Bunde-Birouste, A, and Silove, D. (2009). Insider–outsider positions in health-development research: reflections for practice. *Development in Practice,* 19(1), 109–112.
Robert, D, and Shenhav, S. (2014). Fundamental Assumptions in Narrative Analysis: Mapping the Field. *The Qualitative Report*, 19(38), 1-17. Retrieved August 12th, 2019 from, https://nsuworks.nova.edu/tqr/vol19/iss38/3
Robin, BR. (2008). Digital storytelling: A powerful technology tool for the 21st century classroom. *Theory into practice*, 47(3), 220-228.
Robin, BR. (2016). The power of digital storytelling to support teaching and learning. *Digital Education Review.* 30, 17-29.
Robin, BR. (2019). Educational Uses of Digital Storytelling. Retrieved August 29th, 2019 from, https://digitalstorytelling.coe.uh.edu/page.cfm?id=27andcid=27
Roddy, E and Dewar, B. (2016). A reflective account on becoming reflexive : the 7 Cs of caring conversations as a framework for reflexive questioning. *International Practice Development.* 6(1), 1–8.
Rogers, C. R. (1975). Empathic: An Unappreciated Way of Being. *The Counselling Psychologist*, 5(2), 2–10.
Rogers, CR. (1980). *Congruence, Unconditional Positive Regard and Empathy.* Boston: Houghton Mifflin.

Rosenthal, S, Howard, B, Schlussel, Y. R, Herrigel, D, Smolarz, B. G, Gable, B, … Kaufman, M. (2011). Humanism at heart: preserving empathy in third-year medical students. *Academic Medicine*, *86*(3), 350–358.

Rossman, B, Greene, M, Kratovil, A, and Meier, P. (2017). Resilience in Mothers of Very-Low-Birth-Weight Infants Hospitalized in the NICU. *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *46*(3), 434–445.

Roué, J, Kuhn, P, Lopez Maestro, M, Maastrup, R, Mitanchez, D, Westrup, B, and Sizun, J. (2017). Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit. *Archives of Disease in Childhood: Fetal and Neonatal Edition*, *102*(4), F364–F368.

Royal College of Nursing. (2015). Career, education and competence framework for neonatal nursing in the UK. Retrieved August 29th 2019 from, https://www.rcn.org.uk/professional-development/publications/pub-004641

Royal College of Nursing. (2016). What-person-centred-care-means. https://rcni.com/hosted-content/rcn/first-steps/what-person-centred-care-means

Royal College of Paediatric and Child Health (RCPCH) (2018). *National Neonatal Audit Programme Annual Report 2018 - on 2017 data.* Retrieved August 29th, 2019 from, https://www.rcpch.ac.uk/resources/national-neonatal-audit-programme-annual-report-20182017-data

Russell, G, Sawyer, A, Rabe, H, Abbott, J, Gyte, G, Duley, L, and Ayers, S. (2014). Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study. *BMC Pediatrics*, *14*(230), 1–7.

Ryan GS (2018) Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*. 25, 4, 14-20.

Sample, I. (2019). 'War on Cancer' metaphor is harmful, research shows. *The Guardian*, Aug 10th.

Sandars, J, Murray, C, and Pellow, A. (2008). Twelve tips for using digital storytelling to promote reflective learning by medical students. *Medical Teacher*, *30*(8), 774–777.

Sanders J. (2009). The use of reflection in medical education. *Medical Education.* 31, 408–415

Santana, M. J, Manalili, K, Jolley, R. J, Zelinsky, S, Quan, H, and Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations*, *21*(2), 429–440.

Schaffer, HR. (1996). *Social Development*. Oxford: Blackwell.

Schmitt, R. (2005). Systematic Metaphor Analysis as a Method of Qualitative Research. *The Qualitative Report Volume*, *10*(2), 358–394.

Schneider, N. C, Coates, W. C, and Yarris, L. M. (2017). Taking Your Qualitative Research to the Next Level: A Guide for the Medical Educator. *AEM Education and Training*, 1(4), 368–378.

Schon, D. (1991). *The Reflective Practitioner: How Professionals Think in Action*. London and New York: Routledge.

Schwartz MR. (2012). Storytelling in the digital world: achieving higher-level learning objectives. *Nurse Educator*, 37, 248–51.

Schwartz, M, and Abbott, A. (2007). Storytelling: A clinical application for undergraduate nursing students. *Nurse Education in Practice*, 7(3), 181-186.

Schwind, J. K., Lindsay, G. M., Coffey, S., Morrison, D., & Mildon, B. (2014). Opening the black-box of person-centred care: An arts-informed narrative inquiry into mental

health education and practice. *Nurse Education Today*, *34*(8), 1167-1171.
Segal, F. (2019). *Mother Ship*. London: Vintage
Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences.* New York: Teachers College Press.
Sfard, A. (2014). Metaphors in Education. Retrieved August 5th, 2019 from, http://link.springer.com/10.1007/978-94-007-6165-0
Shapiro, J. (2008). Walking a mile in their patients' shoes: empathy and othering in medical students' education. *Philosophy, Ethics, and Humanities in Medicine :*, *3*(10), 1–11. https://doi.org/10.1186/1747-5341-3-10
Shapiro, J. (2012). Narrative medicine and narrative writing. *Family Medicine*, *44*(5), 309–311. https://doi.org/10.1056/NEJMp038249
Shapiro, J, Boker, J. R, Shapiro, J, and Morrison, E. H. (2004). Teaching empathy to first year medical students: evaluation of an elective literature and medicine course. *Education for Health. 17*(1), 73-84.
Shapiro, J, Kasman, D and Shafer, A. (2006a). Words and wards: a model of reflective writing and its uses in medical education. *The Journal of Medical Humanities, 27*(4), 231–244.
Shapiro, J, Rucker, L, Boker, J and Lie, D. (2006b). Point-of-view writing: a method for increasing medical students' empathy, identification and expression of emotion, and insight. Educ Health, 19, 96-105.
Sharoff, L. (2009). Expressiveness and Creativeness: Metaphotical Images of Nursing. *Nursing Science Quarterly*, *22*(4), 312–317.
Sharoff, L. (2013a). The Beauty of Metaphors. *Holistic Nursing Practice*, *27*(2), 63–73.
Sharoff, L. (2013b). Creative Power of Metaphorical Expression. *Journal of Holistic Nursing,* 31(1), 6–18. https://doi.org/10.1177/0898010112461948
Shaw, R. (2013). A model of the transformative journey into reflexivity: an exploration into students' experiences of critical reflection. *Reflective Practice*, *14*(3), 319–335. https://doi.org/10.1080/14623943.2013.767229
Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*, 63–75. https://doi.org/10.1111/j.1744-618X.2000.tb00391.x
Shinebourne, P, and Smith, J. A. (2010). The communicative power of metaphors: An analysis and interpretation of metaphors in accounts of the experience of addiction. *Psychology and Psychotherapy: Theory, Research and Practice*, *83*(1), 59–73.
Simsek A. (2012). Transformational Learning. In: Seel N.M. (eds) *Encyclopedia of the Sciences of Learning*. Boston, MA: Springer.
Skene, C. (2012). Parental involvement in neonatal pain management: reflecting on the researcher-practitioner role. *Nurse Researcher*, *19*(4), 27–30.
Skene, C, Gerrish, K, Price, F, Pilling, E, and Bayliss, P. (2016). Developing family-centred care in a neonatal intensive care unit: An action research study protocol. *Journal of Advanced Nursing*, *72*(3), 658–668.
Smeda, N. (2014). *Creating Constructivist Learning Environments with Digital Storytelling*. Retrieved Sept 4th, 2019 from, http://vuir.vu.edu.au/25833/1/Najat%20Smeda.pdf
Smeda, N, Dakich, E, and Sharda, N. (2010). Developing A Framework for Advancing E-Learning through Digital Storytelling. *Engineering and Science*, (July 2010), 169–176. Retrieved July 20th, 2019 from, http://vu.academia.edu/NalinSharda/Papers/625888/Developing_a_framework_for_

advancing_e-learning_through_digital_storytelling
Smeda, N, Dakich, E, and Sharda, N. (2014). The effectiveness of digital storytelling in the classrooms: A comprehensive study. *Smart Learning Environments*, *1*(6), 1–21.
Snelgrove S, Tait DJR, Tait M. (2016). Teaching psychology to student nurses: the use of 'talking head' videos. *Research in Learning Technology*. 24, 30891
Snow, R, Crocker, J, Talbot, K, Moore, J, and Salisbury, H. (2016). Does hearing the patient perspective improve consultation skills in examinations? An exploratory randomized controlled trial in medical undergraduate education. *Medical Teacher.* 38(12), 1229-1235.
Song, H. (2017). James Clifford and the Ethical Turn in Anthropology. *Cultural Critique*. 97, 176-200. Retrieved August 29th, 2019 from, https://muse.jhu.edu/article/674302/pdf
Sontag. S. (1979). *Illness as Metaphor*. New York: Vintage.
Southall, D. (2013). The patient's use of metaphor within a palliative care setting: theory, function and efficacy. *Palliative Medicine*, *27*(4), 304–313.
Spalding, N. J, and Phillips, T. (2007). Exploring the Use of Vignettes: From Validity to Trustworthiness. *Qualitative Health Research*, *17*(7), 954–962. https://doi.org/10.1177/1049732307306187
Spall, B, Read, S, and Chantry, D. (2001). Metaphor: Exploring its origins and therapeutic use in death, dying and bereavement. *International Journal of Palliative Nursing*, *7*, 345–353.
Spence, K, Sinclair, L, Morritt, M. Lou, and Laing, S. (2016). Knowledge and learning in speciality practice. *Journal of Neonatal Nursing*, *22*(6), 263–276.
Spinelli, M, Frigerio, A, Montali, L, Fasolo, M, Spada, M, and Mangili, G. (2016). 'I still have difficulties feeling like a mother': The transition to motherhood of preterm infants mothers. *Psychology and Health*, *31*(2), 184–204.
Spiro, H, McCrea Curnen, MG, Peschel, E and St. James, D. (1993). *Empathy and the Practice of Medicine.* New Haven and London: Yale University Press.
Squire, C, Davis, M, Esin, C, Andrews, M, Harrison, B, Hyden, LC and Hyden, M. (2014). *What is Narrative Research*? London and New York: Bloomsbury Publishing.
Stacey, G and Hardy, P. (2011). Challenging the shock of reality through digital storytelling. *Nurse Education in Practice*, 11 (2), 159-64.
Stacey, S, Osborn, M, and Salkovskis, P. (2015). Life is a rollercoaster. . .What helps parents cope with the Neonatal Intensive Care Unit (NICU)? *Journal of Neonatal Nursing*, *21*(4), 136–141.
Stefana, A, Padovani, E. M, Biban, P, and Lavelli, M. (2018). Fathers' experiences with their preterm babies admitted to neonatal intensive care unit: A multi-method study. *Journal of Advanced Nursing*, *74*(5), 1090-1098.
Stepien, K. A, and Baernstein, A. (2006). Educating for Empathy: A Review. *Journal of General Internal Medicine*, *21*(5), 524–530.
Strawson, G. (2004). *Tales of the unexpected.* Retrieved August 29th 2019 from, https://www.theguardian.com/books/2004/jan/10/society.philosophy
Streubert, H. J, and Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th editio). Philadelphia: Lippincott, Williams and Wilkins.
Stuckey HL. (2014). The first step in Data Analysis: Transcribing and managing qualitative research data. *J Soc Health Diabetes*. 2, 6-8
Sykes,M, Malik, AN and West, M. (2013). *Stoies that Move Mountains: Storytelling and Visual Design for Persuasive Presentations*. Chichester: Wiley.

Szeles H. M. (2015). Developing emotional intelligence in student nurse leaders: a mixed methodology study. Asia-Pacific Journal of Oncology Nursing. 2(2), 89–98.
Tamayo CA, Rizkalla MN, Henderson KK. (2016). Cognitive, Behavioral and Emotional Empathy in Pharmacy Students: Targeting Programs for Curriculum Modification. *Frontiers in Pharmacology*. 7(96). doi:10.3389/fphar.2016.00096
Tamboukou, M, Andrews, M and Squire, C. (2013). Introduction: What is Narrative Research? In Andrews, M, Squire, C and Tamboukou, M (eds.) (2013). *Doing Narrative Research (2nd Edition).* London: Sage.
Tariq, S, and Woodman, J. (2013). Using mixed methods in health research. *JRSM short reports.* 4(6), 2042533313479197.
Tavakol, S, Dennick, R, and Tavakol, M. (2012). Medical students' understanding of empathy: A phenomenological study. *Medical Education*, *46*(3), 306–316.
Taylor, L. S. (2016). Maternal experiences of preterm birth. *Infant*, *12*(2), 57–61.
Taylor AM, and Hutchings M. (2012). Using video narratives of women's lived experience of breastfeeding in midwifery education: exploring its impact on midwives' attitudes to breastfeeding. *Maternal and Child Nutrition*. 8, 88–102.
Teh, YY, and Lek, E. (2018). Culture and Reflexivity: Systemic journeys with a British Chinese family. *Journal of Family Therapy*. 40, 520-536.
Tekiner, H. (2017). Ethical Considerations Related to Narrative Medicine. InTech Open. Retrieved August 29th 2019 from, https://www.intechopen.com/books/patient-centered-medicine/ethical-considerations-related-to-narrative-medicine
Thomas, C, Reeve, J, Bingley, A, Brown, J, Payne, S, and Lynch, T. (2009). Narrative research methods in palliative care contexts: two case studies. *Journal of Pain and Symptom Management,* 37(5), 788-796
Thomson, G, Moran, V. H, Axelin, A, Dykes, F, and Flacking, R. (2013). Integrating a sense of coherence into the neonatal environment. *BMC Pediatrics*, *13*(84), 1–8.
Thoresen, L, and Öhlén, J. (2015). Lived Observations: Linking the Researcher's Personal Experiences to Knowledge Development. *Qualitative Health Research*, *25*(11), 1589–1598.
Tong A, Sainsbury P, Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal of Qualitative Health Care.* 19(6), 349-357.
Toral-López, I, Fernández-Alcántara, M, González-Carrión, P, Cruz-Quintana, F, Rivas-Campos, A, and Pérez-Marfil, N. (2016). Needs Perceived by Parents of Preterm Infants: Integrating Care Into the Early Discharge Process. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, *31*(2), e99–e108.
Trajkovski, S, Schmied, V, Vickers, M. H, and Jackson, D. (2016). Experiences of neonatal nurses and parents working collaboratively to enhance family centred care: The destiny phase of an appreciative inquiry project. *Collegian*, *23*(3), 265–273.
Tropea, S. (2012). "Therapeutic emplotment": A new paradigm to explore the interaction between nurses and patients with a long-term illness. *Journal of Advanced Nursing*, *68*(4), 939–947.
Turner, M, Chur-Hansen, A, and Winefield, H. (2014). The neonatal nurses' view of their role in emotional support of parents and its complexities. *Journal of Clinical Nursing*, *23*(21–22), 3156–3165.
Turrill, S. (2014). The education of UK specialised neonatal nurses: Reviewing the rationale for creating a standard competency framework. *Nurse Education in*

Practice, *14*(5), 504–511.
Uhl, T, Fisher, K, Docherty, SL and Brandon. DH. (2013). Insights into Patient and Family-Centered Care Through the Hospital Experiences of Parents. *Journal of Obstetric, Gynecological and Neonatal Nursing*, 42, 121-131.
Urstad, K. H, Ulfsby, K. J, Brandeggen, T. K, Bodsberg, K. G, Jensen, T. L, and Tjoflåt, I. (2018). Digital storytelling in clinical replacement studies: Nursing students' experiences. *Nurse Education Today*, 71, 91-96.
van Rijnsoever F. J. (2017). (I Can't Get No) Saturation: A simulation and guidelines for sample sizes in qualitative research. *PloS One. 12*(7), e0181689.
Vasileiou, K, Barnett, J, Thorpe, S, and Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*. *18*(1), 148.
Vazquez, MM, and Westcott, H. (2014). Researchers' reflections of empathy following interviews with migrants. *Qualitative Research Journal*, *14*(3), 214–227.
Vazquez, V, and Cong, X. (2014). Parenting the NICU infant: A meta-ethnographic synthesis. *International Journal of Nursing Sciences*, *1*(3), 281–290.
Verenikina, I. (2008). Scaffolding and learning: Its role in nurturing new learners, In, Kell, P, Vialle, W, Konza, D and Vogl, G, (Eds.), *Learning and the learner: exploring learning for new times.* Wollongong: University of Wollongong.
Vivekananda-Schmidt, P, Hassell, A. B, and McLean, M. (2004). The evaluation of multimedia learning packages in the education of health professionals: experience of a musculoskeletal examination package. *Nurse Researcher*, *11*(3), 43–55.
Walker, S, Read, S, and Priest, H. (2013). Use of reflexivity in a mixed-methods study. *Nurse Researcher*, *20*(3), 38–43.
Walsh, C. A, Shier, M. L, Sitter, K. C, and Sieppert, J. D. (2010). Applied methods of teaching about oppression and diversity to graduate social work students: a case example of digital stories. *The Canadian Journal for the Scholarship of Teaching and Learning*, 1(2), 3.
Wang, C. C, and Geale, S. K. (2015). The power of story: Narrative inquiry as a methodology in nursing research. *International Journal of Nursing Sciences*, 2(2), 195-198.
Warne, T, and Stark, S. (2004). Service users, metaphors and teamworking in mental health. *Journal of Psychiatric and Mental Health Nursing*, *11*(6), 654–661.
Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, *53*(4), 459-469.
Weis, J, Zoffmann, V, and Egerod, I. (2015). Enhancing person-centred communication in NICU: A comparative thematic analysis. *Nursing in Critical Care*, *20*(6), 287–298.
Welford, C, Murphy, K, and Casey, D. (2011). Demystifying nursing research terminology. Part 1. *Nurse Researcher*, 18(4), 38-43.
Wengraf, T. (2009). *Qualitative Research Interviewing- Biographic Narrative and Semi structured Methods.* London: Sage publishers.
Wigert, H, Johansson, R, Berg, M and Helstrom, A. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences*, *20*(1), 35–41.
Wigert, H, Dellenmark Blom, M, and Bry, K. (2014). Parents experiences of communication with neonatal intensive-care unit staff: an interview study. *BMC Pediatrics*, *14*(304), 1–8.

Wikstrom, B. (2001). Work of art dialogues: An educational technique by which students discover personal knowledge of empathy. *International Journal of Nursing Practice*, *7*(1), 24–29.
Williams, B, Boyle, M, Brightwell, R, Devenish, S, Hartley, P, McCall, M, … Weber, A. (2015). Undergraduate paramedic students' empathy levels: A two-year longitudinal study. *Journal of Nursing Education and Practice*, *5*(1), 58–64.
Williams, J, and Stickley, T. (2010). Empathy and nurse education. *Nurse Education Today*, *30*(8), 752–755.
Williams, K, Patel, K, Stausmire, J, Bridges, C, Mathis, M, and Barkin, J. (2018). The Neonatal Intensive Care Unit: Environmental Stressors and Supports. *International Journal of Environmental Research and Public Health*, *15*(1), 1–13.
Wlodarski, R. (2015). The Relationship Between Cognitive and Affective Empathy and Human Mating Strategies. *Evolutionary Psychological Science*, *1*(4), 232–240.
Woodgate, R. L., and Busolo, D. S. (2017). Healthy Canadian adolescents' perspectives of cancer using metaphors: a qualitative study. *BMJ Open*, *7*(1), e013958.
Woods, A. (2015). The Limits of Narrative : Provocations for the Medical Humanities.*Medical Humanities*, *37*(2), 73–78.
Wright JM, Heathcote K, Wibberley C (2014) Fact or fiction: exploring the use of real stories in place of vignettes in interviews with informal carers. *Nurse Researcher,* 21(4), 39-43.
Young A. (1976). Some implications of medical beliefs and practices for social anthropology. *American Anthropology.*78(1), 5–24.

Appendix

Page

APPENDIX 1

Appendix 1: Strategies to optimise trustworthiness

Based on Guba's (1981) Four Criteria for Trustworthiness (adapted from Shenton, 2004)

Credibility

- *Ethical application ensures transparency, recognition of researcher- participant roles and detail of recruitment to achieve approval (see Chapter 3) *(for all phases)*
- *Adoption of appropriate, well recognised research methods **(for all phases)*
- Development of early familiarity with culture of participating organisations
- Random sampling of individuals serving as informants
- Triangulation via use of different methods * (phase 3)
- Tactics to help ensure honesty in informants
- Iterative questioning in data collection dialogues
- Negative case analysis
- *Debriefing sessions between researcher and superiors (supervisors) **(for all phases)*
- Peer scrutiny of project by supervisors and peer reviewers from publishers prior to publication* (phases 1 and 2- conferences and peer reviewed journals)
- *Use of reflective commentary/ diary *(See Appendix 4) (for all phases)*
- *Description of background, qualifications and experience of the researcher **(for all phases)*
- *Member checks of data collected, and interpretations/theories formed * (phases 1 and 3)*
- *Thick description of phenomenon under scrutiny (qualitative data) * (phases 1 and 3)*
- *Examination of previous research to frame findings **(phases 1 and 3)*

Transferability

- *Provision of background data to establish context of study and detailed description of phenomenon in question to allow comparisons to be made **(for all phases)*

Dependability

- Employment of "overlapping methods"
- *In-depth methodological description to allow study to be repeated **(for all phases)*

Confirmability

- *Triangulation to reduce effect of investigator bias * (phase 3)*
- *Admission of researcher's beliefs and assumptions * (Boxes 2.1 – 9.1)*
- *Bracketing of own values **(for all phases)*
- *Recognition of limitations in study's methods and their potential effects **(for all phases and Discussion chapter 10)*
- *In-depth methodological description to allow scrutiny of research **(for all phases)*
- *Use of diagrams to demonstrate "audit trail" * (for all phases)*
- *Employ reflexivity throughout the study starting with ethical application *-(See Boxes 2.1 – 9.1).*
- *Use of an approved checklist for reporting qualitative data (COREQ) (See Appendix 5).*

APPENDIX 2

Appendix 2a) Initial study: Interview schedule

Start with opening brief:

Thank you for agreeing to participate in this study and to be interviewed. As you know, I am researching what can be learnt about the neonatal care experience from the perspectives of student nurses. I am interested in finding out about your experiences during your time on the neonatal unit; for example, how you felt, what you saw, learnt and appreciated, what you understood about the experiences of neonates and families / parents. Using what you tell me about your experience, I would like to firstly, create a story about this experience and secondly identify key learning themes that emerge, with the view that both may be useful to other learners in this field of nursing.

SQUIN ('single question aimed at inducing narrative' (Wengraf, 2009)

- **Can you tell me about your placement on the neonatal unit, taking me through the events and experiences that were important for you, from the start to finish of the placement?**

Prompts that may to follow:

- How did you feel when you first started on the neonatal unit?
- What specific areas did you want to learn about?
- When you finished the placement, how did you feel?
- What did you learn during your time working on the neonatal unit?
- Were there any events that stood out in relation to it being a positive experience for you?
- Were there any particular challenges?
- How would you describe the neonates' experiences?
- How would you describe the parents' experiences?
- How would you describe the neonatal environment?
- Is there anything else you felt you have learnt or appreciated during your time working on the neonatal unit?

Appendix 2b) Initial study
Raw Interview transcript example

Can you tell me about your placement on the neonatal unit, taking me through the events and experiences that were important for you, from the start to finish of the placement?

When I first started my placement, I was just observing everything. A lot of teamwork goes on – We were there for 10 weeks so we got to know the day to day running of the place well. It was intensive, but you have to make sure that it doesn't get to you too much- just go at your own pace and not rush yourself. It was all really really good.
One thing I did notice was that as a student, I thought when I went in, that the neonatal nurses and the midwives would work together but it wasn't like that. But the midwives tell us about mums and when they are due in and so on, but they don't really understand, that when the babies are sick- like I know they want the baby to stay with mum but…we had some issues like that with mums like we are not allowing them to bond with their babies. There was one time when a complaint form was put in as it was like the midwives didn't tell us anything- …… *(This incident was about lack of communication between nnu and the maternity unit)*

To see how they should work together and it is important to work as a team and there is no harm in asking. I would say that was my best placement ever. At the end of the placement, I saw that you get to see the journey from when the baby comes in and then the rest and when the baby goes home. You get to see the difference

And I also went out with the outreach- a baby in hdu, then to itu, then she went to sc and then rooming in and then in the home. It's amazing how it really helped the parents and how it makes such a big difference to them.

It's great and interesting to see how the mum and family coped and how the nurses are working with them and supporting them and so that when the outreach has finished, they have the support of their GPs. So, the support is there. The whole journey is seen by going to the home

How did you feel when you first started on the neonatal unit?
I was absolutely- so so scared. I didn't know how I was going to touch the babies, ….it's like being a first time parent because on the general wards they can speak for themselves but like these babies, you just feel like they can't tell us isn't it, you feel that you can't touch as they are fragile, when I was left to do it on my own, I felt a bit more confident so it was good to get more practice.
The first week I was really scared and nervous, but the team were there, and they were so supportive, and helped if there was anything big – helping us get involved – it was excellent

What specific areas did you want to learn about?
When I first started I didn't have a clue- I thought that NICU was just one ward area, with itu patients and sc and tc. I was really interested in the sc and tc not so much the hdu and itu as I was a bit more scared, because they are so fragile. I like to see the babies when

they are stronger, and you can be a bit more hands on with them. I would say that sc and tc was what I liked the most. I like to do everything so on tc, I could do everything for them and then hand over to the parent and other nurses and it makes you feel like you can do things and feel part of the team. I felt that while I was in sc, you actually get to know the parents a bit more- you can teach them something as well and this is a nice thing- they didn't look at you as student- they look at you to help them. I saw this all at the end before I left.

When you finished the placement, how did you feel?
I achieved all- it was a brilliant placement as were there so long. We learnt loads of things. At first, I was scared to even look at the baby but as time went on, I saw it's not so scary- you feel at first that you can't touch them, but some are big and strong esp. term babies.

Were there any events that stood out in relation to it being a positive experience for you?
Stood out- I saw that the nurse that were there and had been there for longer than the newly qualified nurses, I wouldn't say they had forgotten but … like there was nurses who didn't know how to do a particular test. They have been there are a long time and things change. But there wasn't anything really that stood out in negative way except some of the nurses didn't act as if they cared. But you have to treat them how you would want your baby to be treated. I saw that medication had been left there and not given - it was on the top of the incubator.

You have to give individualised care…. Why… it's a really busy ward and too many babies, staff get very frustrated and they then don't work as a team. They want to keep on top of everything so that everything is done at a certain time, and parents are coming in as well and... For example, the feed was at 12.00- we waited about 15 minutes and they say oh, you shouldn't wait that long but the outreach nurses say you have to wait that long as you have to empower the parents. All levels – differences? Still preferred the sc. In itu, when I was there, you just observe and that's it. You don't get the chance to do anything. All the nurses were really good but sc is really hands-on compared to the others.

Were there any particular challenges?
Other than issues of communication between depts. and nurses and how they are with the babies. Anything else- handover was given, parents were not allowed to stay in the room and have to go out. And if the child needs feeding, the round takes ages. Sometimes more than half an hour and you are not giving the parents a chance to take over everything. Sometimes the parents they were getting frustrated, a bit they felt like they can be with their baby and it's hard as student nurse as you can't really say anything to them. We have to stick together in sc and they get to know each other anyway. I know there was an issue about that and letting the grandparents visit – that was being looked into.

How would you describe the neonates' experiences?
By the first few weeks, I began to understand that they do have awareness of what is going and their environment- sometimes I think some nurses forgot this. Things are done

to them and you still need to be there to calm then down and reassure them, where they are with all the tubes etc. but in sc, you can see them looking around and they do feel everything. You just need to be very aware of this.

How would you describe the parents" experiences?
For a first-time baby, you have a perception of having a baby- that it's going to perfect but here it's a shock and everything happens at once- they need support and they are not always given that support. An example is when the ward is so busy – they need to spend time with their baby and in itu some parents didn't come in for the whole day – but you can do things, you can sing to them, talk to them, hold them and sometimes parents were literally there for the whole day. There was one parent that I saw in outreach- she was literally there the whole day from 8 until 9 at night. She would bring clothes and hold her and in sc, she did everything, and I know it's hard when you have kids at home but if you are willing to spend that time here, its best

Support? – The unit had the family support worker and the volunteer from BLISS. She started one day a week as obviously she has been in the unit, she was there to ask how they were doing and how they were coping with it and tell them whatever they are feeling, that its ok. These parents, if they have never been in that situation of have never heard of something, then they may say why is it happening to me. She would come in and speak to them in person and ask them how they have been. Sometimes when mums have babies the, nurses and doctors and everyone are worried about the baby and forgot about mum as an individual - but what about mum- you need to care about her as well, you need to ask her how she is and things like that. I noticed that some of the mums if they were a bit emotional, then it completely normal but imagine how you would be- it must be very scary, we must understand that … as a student nurse it shouldn't be oh good, that baby has a ng tube, its normal thing for me but for parents to see that tube, then it must be really scary for them and they wonder what it is.

There was one case in the second or third week, when there was one mum who was a bit challenging to talk to, but no-one actually sat her down and spoke to her – she made comments like is my baby going to come back again and is she going to stay alive and things like that and it was really upsetting, I noticed that the nurse was allocated to the baby downstairs and hadn't explained anything to her, (in tc)… Things need explaining – for sure.

And they have needs for sure. As a nurse you know that baby is fine that they had a temperature- so *you* know that baby is fine, but you don't know if mum thinks the baby is fine – she doesn't know why the baby has to have an injection and things like that
One thing I also noticed that if there is a planned C section the mum was allowed to come into the unit and look around hdu, itu and sc- everything explained, and mums were would familiarise themselves. If the mum hadn't a C section, then it would be unplanned, and she wouldn't know anything and would get really scared. Nurses don't always give them a clear answer sometimes. It's what makes them a bit scared and questioning- if the answer is given to them, then they would not feel like that
Fathers? There was one particular dad who came in in the evening and he did everything for the baby – like some guys literally come in and don't so anything; like one dad came in

and fell asleep in the chair- they come in after work and then are so tired. And it's hard for the dads - Dad has been through a long journey as well and we sometimes forget about them. It is a bit hard. It's good if dad can also come in. I know when you come onto the unit there is a board, just before you go in, and it says how dad is feeling so like if mum is breast feeding then the dad can change them and give them to the mum so there are things they can do.

It's not just team work between the professionals, its teamwork with the mum and dad as well. That's really important. Just before we left in the last week, mum would do some things and dad would do the other so that mum could have a rest – it was really nice to see. She didn't have any other family members and no other support at home, so this was the ideal set up especially to prepare for going home….Other cases of course I saw when mum would do everything- you know, and dad comes in just for a cuddle and that's it….

How would you describe the neonatal environment?
Really calm – itu, hdu. The nurses know how to deal with a situation. They know how to deal with it appropriately before it gets escalated– they all work together as a team - good teamwork. It's important because you need your support. As a nurse it is really hard to be in an environment like this with all the pressure. The babies are so small with even the slightest mistake – you don't know what could happen. I think it's really hard place to work in.

It was busy, but it was calm. Nurses could about 4 babies, but they would work together. I went to delivery suite- for a crash call, the baby was already delivered. The neonatal nurses and doctors were all worried about the baby and stabilising the airway and so on, the midwives were dealing with the mum- they are more mum centred I would say. Before I went to placement – I thought neonatal nurses and midwives would work together but it is completely different, and the role are not the same. It's easier if the baby is with the mum but when the baby needs observations or if the blood sugars are low, then that's the issue I have …… they have to go to the unit

One case I saw was in recovery- the baby's blood sugar was low, and it needed to be 2.6 and up------- so the woman was getting confused and so I was getting confused. Different things being said. It was so unprofessional how they managed it- she came, and she didn't have to take her to the side and say that. It makes the parents think that we aren't working together. But it's not how it is….

Again, with that mum explanation was needed – what is the blood sugar – what should it be and what happened if the baby doesn't breast feed. Once the baby came and explained everything then the mum said she understood everything. She wanted to establish breast feeding but the baby needed to have a normal blood sugar so needed explaining- the midwife needed to explain and then she did understand after all was explained. Lack of close relationship between the neonatal unit and midwives again

Relevance to children's nursing ……

I would say making sure that you are aware of the family- we are all aware of the neonate, but you need to make sure that you can communicate with them- they can't speak but they can cry and tell you things that way, so you need to look at this. You know how you are feeling with the baby- even if they are in the incubator- you have to give them the care that you would give to a child or one that can talk or who can express how they are feeling- just because a baby is so small and can't express things, they haven't got the energy

Making sure you are aware they are an individual and give individualised care – it is good to have routine going but you need to look at the baby and work with the family. You just have to consider the parents and ask them things – ask them how they were and how they are feeling and what effect it is having on them….
It's nice for them to know that you can care for them too

Is there anything else you felt you have learnt or appreciated during your time working on the neonatal unit?

I would say I learnt how to handle a neonate and how to comfort. How to work as part of a team and you have to understand they're your team support, need to be clear what they say to each other, so we can understand each other. Don't be scared to tackle a problem and ask anything- I did ask – there was this one baby who was 38 weeks who came in after a heel prick for a SBR, took them upstairs and it came up as really high. Parents were asking about everything- they had been told the baby's sbr was really high and she was really crying – I wondered if I should have said that and the parents were told to go and get coffee. Miscommunication occurred and literally after that day the mum did not leave the baby- some people get so scared and they think it will be bad- somebody spotted it and that was lucky- the mum thought the baby was getting a transfusion and so hearing that, it must have been very scary. It wasn't as bad as that though and so these things must be bought up- I was the one writing everything down and I wondered if I should have said something- she didn't say anything, but once when we were at University and the NMC came and said that we shouldn't change anything and stick to what we know is right.

I really felt like the nurse was being rushed and she was going to correct it when the mum had left. We are taught different things from different nurses and if one nurse does one thing and one says something different – I should just say it, but she told me not to. For example- at the end a ngt feed was given and she gave it one way and then another nurse did it differently- you have to question. Every time I did an observation for the baby I thought was it right. But overall it was a really good experience and I really enjoyed it. I thought it would be really scary, but it was a really nice experience and we were taught loads. Dementia conference- Again, they elaborated on things and how they were passionate about the job …. Explained what she saw at the conference and you can relate it our area. We cried so much, and it made us cry- it was so sad.

Also, it was great how the nurses said they really learnt from the students – one nurse said how parents don't know all the jargon and as student nurses we really noticed that. The simple terms were needed to explain things- parents need that and so do we…

Appendix 2c) Initial study
Story construct following core story creation
(from raw interview transcript in Appendix 2b)

THE BEGINNING

When I first started my placement, I started to observe everything. I was really scared. I didn't know how I was going to touch the babies as they were so fragile and can't speak for themselves like on the children's ward. It must be like being a first-time parent. When I was left to do the care on my own though, I started to feel more confident, so it was good to get practice. In the first week, although I was scared and nervous, the team were there and were so supportive, they helped if this was needed and also helped us to get involved – it was excellent.

Also, when I first started I didn't have a clue- I thought that the neonatal unit was just one ward area, but it has an intensive care, special care, transitional care and high dependency area. I was really interested in the special and transitional care, not so much the higher dependency areas as the babies in these areas were so much more fragile and again I felt quite scared to handle them. In intensive care, you just observe and that's it. You don't get the chance to do anything. I like to care for the babies when they are stronger, and you can be more 'hands on' with them in special or transitional care compared to the other areas. For example, on transitional care I could do everything for the babies and then hand over to the parent and other nurses; this makes you feel like you are capable of doing things and you feel part of the team. I also felt that while I was in special care, you actually got to know the parents more- you can teach them, and this is nice; - they didn't look at you as a student- they looked at you to help them.

THROUGH THE NEONATAL UNIT LEARNING JOURNEY

We were there for 10 weeks and as time went on, we got to know the day to day running of the place very well. It was intensive, but you have to make sure that it doesn't get to you too much- you need to make sure you just go at your own pace and not rush yourself. It was all really good. You get to see the journey from when the baby comes in and then throughout their stay until when the baby goes home. You get to see the difference. The complete journey is seen by going into the home. I did have the opportunity to go out with the outreach team; this was for a baby who had been in intensive care and then high dependency. Then she went to special care followed by rooming in and then got discharged home. It's amazing how visiting the home after this whole journey really helped the parents and how it makes such a big difference to them. It is so interesting to see how the mum and family coped and how the nurses work with them and support them and so that when the outreach has finished, they then have the support of their GP services.

So, there were many positive experiences. There were also some challenges during the time on the unit. One thing I did notice was some degree of a lack of communication between the neonatal unit and the maternity unit. I thought that the neonatal nurses and the midwives would work together more but it wasn't like that. The midwives tell us on the unit about potential deliveries and when they are due which is good but when that baby gets sick, it is hard for the mum, as they possibly cannot bond with their baby. The

midwives however seemed to want to keep the mum and baby together all the time which I understood why, but it is not possible when the baby is admitted to the neonatal unit. We need to be saying the same thing. Overall, it is the lack of close relationship between the neonatal unit and midwives that I observed that meant the information was not consistent at times.

By the first few weeks, I began to understand that the baby's experience is important as they do have awareness of what is going and their environment. Things are done to them and you need to be there to calm then down and reassure them, especially as they have all the tubes etc. Even in special care, you can see them looking around and they do feel everything. You just need to be very aware of this.

As for parents, you would have a perception of having a baby- that it's going to perfect but being admitted to the neonatal unit is a shock. Everything happens at once- so they need support and they are not always given that support. An example is when the ward is so busy – they need to spend time with their baby and in intensive care, some parents didn't come in for the whole day. But as a nurse, you can do things, you can sing to them, talk to them, and hold them. On the other hand, parents were literally there for the whole day. There was one parent that I saw in outreach- she was literally there the whole day from 8 until 9 at night. She would bring clothes and hold her baby and in special care, she did everything. I know it's hard when you have kids at home too but if you are willing to spend that time here, it's best for the baby.

They also need support. Sometimes when mums have babies the nurses, doctors and everyone are worried about the baby and often forgot about mum as an individual - but what about mum? - you need to care about her as well, you need to ask her how she is. I noticed that some of the mums were emotional, which is completely normal and imagine how you would be- it must be very scary, we must understand that … as a student nurse it shouldn't be 'oh good, that baby has a nasogastric tube', its normal thing for us but for parents to see that tube, it must be really scary for them and they must wonder what it is.

There was one case in the second or third week, with a mum who was a bit 'challenging' to talk to but no-one had actually sat her down and spoke to her – she made comments like 'is my baby going to come back again' and 'is she going to stay alive' and things like that and it was really upsetting. She just needed things explaining. Parents have needs and as a nurse you know that baby is fine if they had a temperature for example- but you don't know if mum thinks the baby is fine – she doesn't know why the baby has to have an injection or other tests. Nurses don't always give them a clear answer. It's what makes them a bit scared and questioning- if the answer is given to them, then they would not feel like that.

Dad has been through a long journey as well and we sometimes forget about them. Just before we left in the last week, there was a couple where mum would do some things and dad would do the other so that mum could have a rest – it was really nice to see. She didn't have any other family members and no other support at home, so this was the ideal set up especially to prepare for going home…. Other cases of course I saw when

mum would do everything- you know, and dad comes in just for a cuddle and that's it…... It's not just team work between the professionals, its teamwork with the mum and dad as well. That's really important. I saw this all at the end before I left.

Overall, I also noticed that the environment was really calm – especially in intensive care and high dependency. The nurses know how to deal with a situation appropriately before it gets escalated– they all work together as a team and there is good teamwork. This is so important because you need your support. As a nurse it is really hard to be in an environment like this with all the pressure. The babies are so small with even the slightest mistake – you don't know what could happen. I think it's really hard place to work in.

THE END

At the end of the placement, I felt I had achieved so much. At first, I was scared to even look at the baby and now I know, it's not so scary- you feel at first that you can't touch them, but some are big and strong especially term babies. I would say I learnt how to handle a neonate and how to comfort them. I also learnt how to work as part of a team and to understand the staff are your team support. A lot of teamwork goes on. To see how the staff should work together and how important it is to work as a team is really good. I would say that was my best placement ever.

My final message on leaving, in relation to children's nursing, is that I would say making sure that you are aware of the family is so important- we are all aware of the neonate, but you need to make sure that you can communicate with the family. Also, the babies can't speak but they can cry and tell you things that way, so you need to look at this. You know how you are feeling with the baby- even if they are in the incubator- you have to give them the care that you would give to a child or one that can talk or who can express how they are feeling- just because a baby is so small and can't express things, they haven't got the energy, so remember this. You need to look at the baby and work with the family. You just have to consider the parents and ask them things – ask them how they are, how they are feeling and what effect it is all having on them…. It's nice for them to know that you can care for them too. The simple terms were needed to explain things- parents need that and so do we.

Appendix 2d) Summary of themes and quotes (Initial study)

Theme 1. The nature of neonatal care

Sub-themes

- Speciality different to other areas in children's nursing
- Structure of neonatal care: transitions between the dependency levels
- Neonates and families within neonatal care for a significant time period
- Neonatal experience as a 'journey' and a process of 'transition' between birth and home.

''It's a completely different environment. The transition must be quite hard for some people especially when the babies have been here for such a long time''

''You get to see the journey from when the baby comes in and then throughout their stay until when the baby goes home. You get to see the difference. The complete journey is seen by going into the home''

Theme 2. The neonate's experience

Sub-themes

- The importance of emotional and physical wellbeing of the neonate
- The impact of separation from their parents
- The challenge of necessary life 'tasks'
- Awareness of their surroundings and the effects.

''I was able to see how the neonate experiences everything. It must be so scary and stressful''

''We also need to remember to watch the baby's' cues and to not disturb them if they do not like something- sounds small, but these little things matter''

Theme 3. The parent's experience

Sub-themes

- The effect of neonatal admission on emotional wellbeing
- The lack of, and need for parental control and empowerment
- The need for information and involvement in care
- Striving to get home
- Understanding and empathising with the parent's experience, needs and/or emotions
- The importance of developing relationships with and communicating with parents.

''I think parents can feel very helpless especially again in intensive care where they can't touch their baby or hold them or do any of the things they expected to do''

''It can be quite isolating and if parents are not involved in care, there must be a feeling of utter powerlessness. They may feel they have no control and so it is essential to involve them as much as possible so that they understand the care and grasp everything better''

Theme 4. The neonatal environment

Sub-themes

- The effect of noise and light levels on the neonate and family
- Differences between the levels of dependency
- The experience of incubator care
- Environment as a barrier
- The importance of developmental care and gentle handling of neonates

''Understanding the baby's experience is important as they do have awareness of what is going and their environment''

''I think the environment, even for the parents, is overwhelming''

Theme 5. The learning experience

Sub-themes

- The neonatal transition through the unit (neonatal 'journey') as akin to the 'learning journey'
- Support from mentors
- The need for consistency in communication and care
- Mentor willingness to teach students
- Emotions and needs of students
- The importance of teamwork
- Challenges to learning

''They (baby and family) 'had the whole range of care really. It was the week I was leaving that she went home so it was so nice to see her for the whole admission from the start to going home. She was there for 9 weeks, and I was only there a week longer than her- a lot can happen in that time, between the different levels of neonatal care''

''I was a bit daunted really with all the different apparatuses, all the different noises and showing the parents what was what- so I found I could empathise with them when they were new into the unit. I didn't know how I was going to touch the babies as they were so fragile and can't speak for themselves like on the children's ward. It must be like being a first-time parent''

Appendix 2e) Initial study
Condensed story / script example

ZARA'S STORY
Title: Transitions -the journey through the neonatal unit

(1) Introduction- This is an account of the Zara's experience on the neonatal unit during her time spent there for a clinical placement as a student nurse. The main thing to consider in this story is the journey through the neonatal unit in the form of transitions through the different dependency levels as experienced by the neonate, the family and the student herself. He is her story……

(2) On arrival to the neonatal unit. When the Zara first started on a placement, she started to observe everything, but she fell really scared, she didn't know how she was going to touch the babies because they look so fragile and can speak for themselves. Zara remember thinking, it must be like being a first-time parent. When she was left to do care on her own however, she started to feel a bit more confident and it was good to get more practice with the babies so in the first week although she felt scared and nervous, the staff were there for her but also helped her to get involved.

(3) The first few days. Also, when Zara first started, neonatal unit, she thought it was just one ward area, but she soon found out it was split into many different levels of dependency, including intensive care, high dependency and special care and transitional care when the babies are moving towards going home. She felt after working in all of them in the first few days, but she wanted to work more in the special and transitional parts of the unit because she felt she could care for the babies when they were much stronger and that she could be more hands-on. She could do everything for the babies in special and transitional care and she could help parents. She felt this made her capable of doing things and feel part of the team. She also felt that you could get to know the parents more, she felt that you can teach them, and this was very valuable experience. They didn't look to her as a student, she felt they looked to her to help them. Reflection point: Zara has likened her feelings to those of a parent, why do you this she said this and what are the parallels between the feelings of a student nurse and those of a parent?

(4) Reflection point- Answer guide- In relation this question, you may have considered about emotions that may be similar, being in an unfamiliar unit, feeling scared especially at first. You may also have thought about how unsure they feel at handling the babies and being unacquainted with the environment and the equipment. It seems that both parents and student nurses go through the transitions between the different dependency levels through their time on the NN and also as time goes on, they do say they start to feel more confident in handling the babies and being more involved in the baby's care.

(5) Thinking about the parents. As time went on, Zara was able to learn more about the parents and what they were going through. She imagined that they would have a perception of their baby and it's all going to be perfect but then they are admitted to the

NNU which must be such a shock, and everything happens at once. She realised that they need support, and that this can be difficult particularly when the ward is so busy and if the family cannot come in due to other commitments at home. However, by the second or third week, she realised that there are things as a nurse that you can do if the parents aren't there; you can talk to the babies, you can touch them, you can sing to them and hold them. It is hard for parents if they have other children at home to care for too, but if they can come in and spend time with the baby, it's much better for that baby.

(6) The parent's journey. During the 10 weeks on the NNU, Zara realised that parents really need a lot of support particularly of they haven't been in this situation before- for example, they may never have heard of something or they may ask 'why is it happening to me?' We must not forget about mum for example, many of the mums are very emotional which is completely normal but is also hard for dads too. Dad has also been through a long journey as well. Let's take a moment to now think about a second reflection point….How should we attend to the emotional needs of parents during their time on the neonatal unit?

(7) Reflection point- Answer guide- You may have thought about the following points…. it's important that we understand and try and empathise with what the parents may be feeling on admission and through the difference transitions. We must listen and spend time with the parents as much as possible, realising that sometimes this is hard when the unit is busy. We need to be able to empower parents and be involved in the case, involving both mum and dad. We need to support them to attend to all the babys' needs. It's important to think about other sources of support- other roles, charities, many sources, parent support groups.

(8) Communication. As the placement continued, by the first few weeks, she began to understand Zara realised how important communication with the family was... but also she thought about the actual babies, that they can't speak but they can cry and tell you things and even if they are in the incubator, you have to give them the same care that you would give to any child in your care and just because they are so small, and can't express things in the same way because they haven't got the energy, you still treat them the same.

(9) The environment. As time went on, Zara noticed that the environment was also really calm especially in intensive care and high dependency. The nurses there really knew how to deal with the situation appropriately before it escalated and they a worked together as a team. This was really important especially when you are learning in such an environment with all the pressure. Because the babies are so small, even the slightest mistake can make a huge difference and it can be a really hard place to work in.

(10) The end of the placement. Towards the end of the placement on the neonatal unit, Zara realised that understanding the experiences of the babies and the different parts for the unit was very important for learning. She saw this all at the end before she left. She thought how amazing it was that visiting the home after this whole journey really helped the parents and how it made such a big difference. She thought how interesting is was

how mum coped and how important it was for nurses to support hem so that when outreach had finished, they then have the support of the primary care services to continue the journey, Overall, the complete journey was seen by going into the home.

(11) The journey through the unit. Overall, through the ten-week placement, Zara felt that she had got to know the running of the neonatal unit very well and had an understanding of the different levels of dependency and the transitions from each one. She had seen babies admitted and had seen babies and families come in and then had cared for them throughout their stay, through itu, high dependency and special care and then transitional care until the baby is discharged home. You really get to see the difference… At this point, let's think about a final reflection point...Think about the different transitions that the neonatal and family make through the NNU from birth until going home... what are the differences between the levels of care?

(12) Reflection point- Answer guide- Levels of care refer to the physical dependency and care required to maintain normal physiological function, for example this might be ventilation to support their breathing, blood pressure and other vital signs, nutrition and fluid management to give some examples. The smaller sicker babies who are less mature may require more physical support and they are often admitted to itu in the first instance depending of course on their gestation and condition. As their condition improves, they then progress to being in hdu and then on from there into special care and sometimes transitional care before being discharged home. This is the time that parents are taking over the care in order to prepare for discharge home. So, these changes or transitions can pose challenges for the neonate and parents because they both need to be able to cope with the environment and new challenges but also, they provide opportunities to strive towards going home and this is where the journey continues.

(13) Conclusion. To summarise, Zara's story has highlighted the importance of understanding the different transitions through the NNU and how parents and student nurses both experience these over time. These transitions have been spoken about in terms of a journey starting with admission to the neonatal unit and then working through the different dependency levels and striving towards going home as the ultimate goal. It has also realised awareness of attending to the parents' emotional needs during their time spent on the unit and how this is an essential part of the care for the neonate and family whatever level of care they are nursed in throughout the whole of their journey through the neonatal unit and beyond.

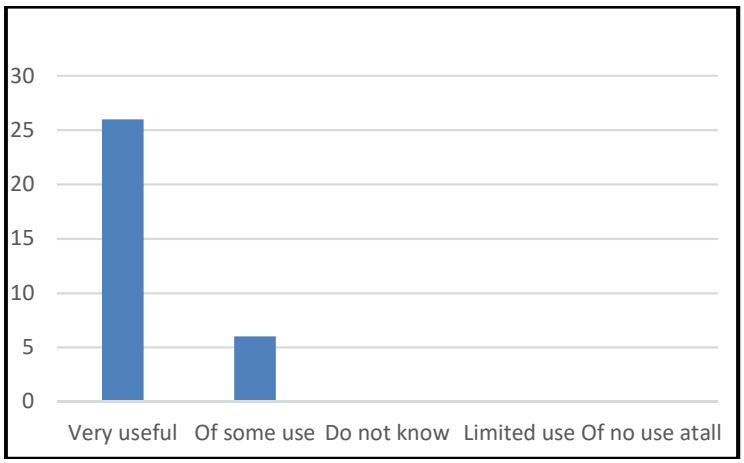
Appendix 2f) Initial study
Storyboard Example- Zara's story

PLOT	TIME FRAME IN MINUTES: SECONDS	SCRIPT: ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	START AUDIO TRACK OF VOICE	IMAGES	TEXT TO APPEAR ON THE SCREEN
1-TITLE SLIDE		1- Introduction		-Baby in plastic bag -Baby on CPAP -Baby with pacifier	Zara's Story: TRANSITIONS- The Journey through the Neonatal Unit
2- THE START	00.34	2- On arrival to the neonatal unit		-Baby in plastic bag	*''I was really scared''* *''I didn't know how I was going to touch the babies; they were so fragile''* *''It must be like being a first-time parent''*
3- MAIN STORY	01.11	3- The first few days		-Neonatal unit	*''I thought the neonatal unit was just one area but there is intensive care, high dependency, special and transitional care''*
4- MAIN STORY	00.50	4- Reflection point. What are the parallels between the feelings of a student nurse at the start their placement and those of the parents when their baby is admitted to the unit?			Answer guide- Similar *emotions* (for different reasons) *Unfamiliarity* Changes occur over *time* *Transitions* between different dependency levels
5- MAIN STORY (middle part)	00.49	5- Thinking about the parents		Hand-baby and parent	*''I came to realise you can do things for them, you can talk to them and hold them, especially in special care''.*
6- MAIN STORY (middle part)	00.36	6- The parent's journey		Baby on CPAP	*''Its normal for mum to be emotional''* *''We must not forget that Dad has been through a long journey too''*
7- MAIN STORY	01.15	7- Reflection point. How should we attend to the emotional needs of parents during their time on the neonatal unit?			Answer guide- Understand and empathise Listen. Enable and empower them to be involved. *Support* them to attend to all the baby's needs. Provide other *sources of support*.

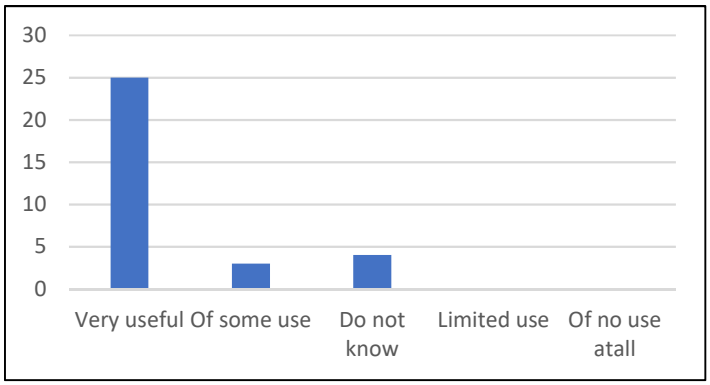
PLOT	TIME FRAME IN SECONDS /MINUTES	SCRIPT: ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	START AUDIO TRACK OF VOICE	IMAGES	TEXT TO APPEAR ON THE SCREEN
8-MAIN STORY (as time went on)	00.27	8- Communication		Small baby in hands	*''A baby is so small; they can't speak but they can cry and tell you things''*
9-MAIN STORY (as time went on)	00.51	9- The environment		Baby with pacifier	*''The environment was really calm, even in the intensive and high dependency areas''*
10- TOWARDS THE END	00.37	10- The end of the placement		Baby being bathed	*''It's amazing how visiting the home after the whole journey really helped the parents''*
11-END OF THE STORY	00.45	11- The journey through the unit		Baby feeding	*''You get to see the journey from when the baby comes in and then throughout their stay until when the baby goes home. You get to see the difference. The complete journey is seen by going into the home''*
12- FINAL THOUGHTS	01.13	12- Reflection point. Think about the different transitions that the neonate and family make through the neonatal unit from birth until going home. What are the differences between the different levels of care?			Answer guide- The physical *dependency* levels of the baby. Sicker, smaller babies are often admitted to itu. As condition improves, they '*progress*' to HDU and SC. These transitions pose *challenges* but also represent the move towards home, where *the journey continues……*
13- CONCLUSION	00.44	13- Conclusion			Key learning points: Transitions through the neonatal experience The neonatal journey and the strive towards home The emotional needs of parents The importance of understanding these areas in relation to key knowledge for nursing care of neonates and families
14-FINAL CREDITS					

Appendix 2g) Initial study
Resource evaluation questions and selected responses

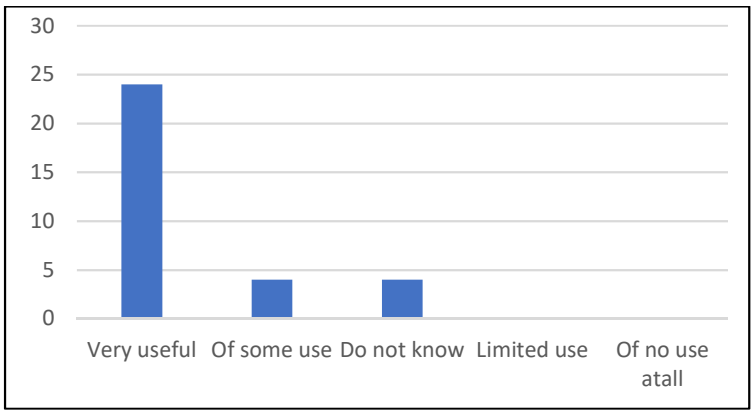
Q1-To what extent do you think listening to these stories may be useful for learning?



Q2-To what extent do you think listening to these stories may be useful in preparing you for a practice placement in the area?



Q3-To what extent do you think this digital storytelling resource could enhance or support other learning (e.g. from practice or in the classroom)?



Appendix 2g) continued
Selected open responses

1-To what extent do you think listening to these stories may be useful for learning?

''Learning from other's experiences is more memorable''
''To gain a true and real- life perspective into the neonate's and families experiences''

2-To what extent do you think listening to these stories may be useful in preparing you for a practice placement in the area?

''Having this type and the right information can prepare you for a new area''
''Giving examples of things to expect allows you to feel at ease when entering a new environment''

3-To what extent do you think this digital storytelling resource could enhance or support other learning (e.g. from practice or in the classroom)?

''It is engaging to listen to personal experiences''...''easy to use and navigate, points for reflection - these are really useful to get you thinking''
''Blended learning is brilliant for helping to reinforce learning in class and practice''
''It would be useful for some but not others- we all learn in different ways''

4-What aspects of caring for children do you think you may learn from this storytelling approach?

''The emotional aspects of caring such as forming a professional relationship / therapeutic relationship with families''
''Being able to empathise with parents and families''
''Valuing feelings and perspectives of neonate and families; real life understanding''

5-What can you learn from your own peers' stories?

''It gives you an idea / insight of what to expect in practise looking at the different perspectives of student nurses''
''Only some experiences are transferable- not everyone's experiences are going to be similar''
''It gives another students point of view which you can relate to more''
''Listening to other students may make you more comfortable going into the unit.''

APPENDIX 3

Appendix 3a) Phase 1- Main Study
Interview schedule

Start with opening brief:

Thank you for agreeing to participate in this study and to be interviewed. As you know from the Information sheet, I am researching what can be learnt about the neonatal care experience from your perspective. I am interested in finding out about your experiences during your time on the neonatal unit and through your baby's journey; for example, how you felt, what you saw and what you experienced at the different stages through this journey. Using what you tell me about your experience, I would like to firstly, create a story about this experience and secondly identify key learning themes that emerge, with the view that both may be useful for health professionals learning about the care of babies in this field of nursing and healthcare.

SQUIN ('single question aimed at inducing narrative'- (Wengraf, 2001)

- *Can you tell me about your experience while you and your baby were on the neonatal unit, taking me through the events and experiences that were important for you, from admission to discharge?*

Directed questions to follow (these may be addressed from asking the above question but if not, then these questions will be useful to elicit more information):

- Can you tell me (a bit more) about your pregnancy?
- Can you tell me (a bit more) about your baby?
- *How did you feel when you and your baby were first admitted to the neonatal unit?*
- *Tell me about what it like to see your baby in intensive care (if applicable)*
- *What was it like for you when you baby was transferred from intensive care to high dependency / from high dependency to special care / from special care to transitional care (as applicable- this may be all stages / level or just one or two)*
- *When you and your baby were discharged home, how did you feel?*
- *What has it been like for you and your baby now that you are at home?*
- *Were there any events that stood out in relation to it being a positive experience for you?*

- *Were there any particular challenges for you and your baby?*
- *How would you describe your baby's experience?*
- *How would you describe the neonatal environment?*
- *Is there anything else you felt you have learnt or appreciated during your journey through the neonatal unit?*
- *Is there anything in particular that you think health professional caring for babies like yours should know / learn?*

Appendix 3b) Phase 1- Main Study
Raw interview transcript example

(N.B. All names and hospitals have been anonymised by the use of pseudonyms)

J - Can you start by telling me about your neonatal experience starting at the beginning and talk me through from the start until the current day?

O - So…. To cut a long story short I was 29 weeks pregnant after what seemed to be quite a normal pregnancy with just a few red flags every now and again. We were basically told to go away and enjoy the pregnancy and then suddenly I found I had a strange sensation in my stomach area and I called the midwife and they couldn't see anything but said go home and have a scan the next day. They found that he (Harry) had Hydrops Fetalis and he had pleural effusions both sides. I had too much amniotic fluid which was why I was feeling so strange. And then they referred us to a fetal medicine unit …… Hospital A (anon) where they did a surgical procedure to try and insert a drain into his thorax to drain out the fluid from what he had collected in the womb. But that didn't work at first because the drain was half in and half out- however, it did drain out some of the fluid that was pressing on his lungs. So, it saved his life and I was told at that point that he would be premature as the procedure was quite a risky one anyway plus due to the polyhydramnios which had built up and was building up again. They monitored me every few days, but it did build up again over the weekend and then I went into labour at 32 weeks exactly. I was actually in hospital when I went into labour at hospital A because I'd just gone for an antenatal appointment. I started bleeding and they kept me in and then in the morning and then my waters broke, and Harry was born four hours later. He was taken to intensive care and then basically stayed in the unit for about five months with a whole range of different things. We spent the first three months in xx (anon) in intensive care and high dependency and then back into intensive care again. The whole period then was so stressful. Then he went to hospital B (anon) for surgery and then he came back to Hospital A and went into special care and then they discharged him for the last month to the Whittington for his fifth month where he was able to go home.
J-Why did he have surgery? - O- He had a Nissan's fundoplication because he had such severe reflux and because he was at risk of aspirating and he did aspirate once. So, they felt that he couldn't be fed safely and was being tube fed through a nasogastric tube and through a jejunal tube and he had all sorts of issues with his digestion not working. Things didn't seem to work properly so he had his operation at around three months old at Hospital B.

J- Was that back in intensive care? O- No, he wasn't in the intensive care, he was on a ward which was quite a shock for us because we were so used to him being on a neonatal unit and he was suddenly put on a ward with all these older children and it wasn't at all the same level of attention that we were used to. At Hospital B, we were able to pick him up and hold him and walk around with him which we weren't used to. We had never seen him not attached to loads of stuff, so it was a real shock and all very disconcerting. It was a very different hospital at the time to what it is now and it's all changed a lot. When he was there, we were in the old Southwood wing which is older

and since then it's become a lot more modern and sparkly and the environment is much nicer. We also went back for cardiac surgery and its much newer and the environment is much better, much more like Hospital A which is all nice and new.

J-Did he have the cardiac surgery more recently then? O- Yes, he had a fenestrated ASD and he had to have open heart surgery as they didn't think it would be successful as a keyhole, but he's made a full recovery from that. That was the last operation. He probably had one surgery every year because after the gastrostomy it didn't heal well at all so he had to have two operations to close it so that was a long-drawn-out process. J-So that's ok and all closed now? O- Yes, it's all fine and he eats really well now…. And I also should have mentioned that he had a diagnosis of X (anon) syndrome which I don't know if I mentioned that before, but we found out when he was two months old when he was at Hospital A.

J-Was that due to thinking there was more going on? O- Yes, we knew he had Hydrops in the womb and then when he was born. When he was in my womb they tested him at that point …. for the chromosomal abnormalities such as cystic fibrosis, toxoplasmosis and everything came back clear and when he was born they did every other possible test …. they did everything, and everything came back normal and then they tested him for X (anon) syndrome and it took two months to get the result. That explains a bit why he was born early, the hydrops was part of the X (anon) syndrome but also perhaps was why he was born prematurely. Thinking back though, then it was just such a blur.

J-Thank you for that. I was going to ask you more about pregnancy, but you have answered most of what I was going to ask for that bit. So, can I ask you then…how you felt when Harry was admitted to the neonatal unit?

O-It was really awful, all that whole time was a real nightmare ……that first night after I gave birth it was fine and so… I was kind of up and about. But, Harry been taken immediately… I only saw really just a glimpse of him, so you just see your baby just for a moment and then they get whisked away. I was bought a photograph of him before they put the ventilator onto him, so I just had a photograph of him and I remember they came in to do my temperature and so on, once I had given birth because they said I had a fever, but I was so scared because …. Well too scared to even go and see him because I was frightened of infecting him or something, so I think that night I was just in an awful state where I hadn't actually seen him. I didn't really know as well that I could go and just see him at any time in the night, I kind of wish …..because I know the midwives are very busy on the postnatal unit but nobody sort of said to me, look you know what, it will be fine for you to go and hold his hand, you can wash your hands and you can go at four (o'clock) in the morning if you want to because it was just on the floor nearby … but it felt much much further away. And I could see the little…. is it a resuscitaire? the little box, cot thing where they put healthy babies … a bassinette type thing and there was an empty one next to my bed as I had a room on my own and it was just really strange and really surreal. And the next day I went to see him, and I was just really paranoid that was going to infect him, you know…. was I going to make him ill?

When he went from intensive care, he did go to high dependency… but I remember, in intensive care, he was in the incubator, he was on the ventilator and yes just I was trying to think back to everything…. Yes, he had wires and tubes and we, we didn't know if he was going to survive …. Sorry I am just trying to remember what they were saying to us, they didn't give out numbers or anything. They were sort of saying this is quite a critical time and that the next 24 to 48 hours were really critical especially due to the hydrops and they didn't really know. We didn't know what was going to happen, they were sort of saying we don't deal with this very often so that was really scary and yes that I remember being very afraid to touch him because he just seemed so tiny and vulnerable and I don't think I actually got to hold him for about a week or so.

When Harry went home though, things changed a bit…. On the one hand, going home felt like another nightmare but also it was really amazing and wonderful. It's been so long five months he had been born in the January and it was now the June so two seasons had passed, and it was warm we went out to the park and it was just a miracle to have fresh air. There was a point at the Hospital B where we could take him outside …. there was an area outside, where we could walk across the bridge with him in a pushchair but that was pretty much as much as we done. Apart from that he hadn't had fresh air. So, it was wonderful to be home. He still being tube fed by then. It was just the tube feeding, and I had done that at the Hospital A…. been able to stay in to get used to doing it, in one of the rooming in rooms which was really good, to be close to him.

Before going home though, going back to what I was saying… did he go to high dependency and then back to itu. But then, he was just in the incubator and we were just you know using our fingers really to hold onto him and his, his own hands and fingers. And he was so beautiful, and we just fell in love with him you know, very beautiful and his eyes were open and very blue. It was lovely to see him, and we always felt that he was a person and he was a really strong character right from the beginning. So really, it was very well…. it was terrifying really terrifying. That was also such a blur…. Trying to express milk and all of the other things you have to do and that becomes a huge part of your day … it was just exhausting. The first night after I gave birth, until knowing we were going home was exhausting and a complete nightmare.

WHAT CAN HEALTH PROFESSIONALS CAN LEARN FROM YOU……

EXPLAINING THINGS IN THE RIGHT WAY:

Back to expressing milk for example……, again some nurses were really good at explaining and saying it's alright you don't have to express all the time, some could have said to me you don't have to express every three hours exactly, go to 2 and half hours. Another person would say you're doing your best so that's all you can do. It's the way people acknowledge and talk to you with a more sensitive approach- that was so much appreciated. I think a mother in a new environment who hasn't been a mother before will take everything literally plus in the crazy experience of the neonatal unit, everything that is said to them is taken very seriously. So, if somebody said you must make sure you mustn't pass your germs onto your baby, then that's how I took it.

Another example: If somebody is responding to things in a very 'OCD' way like I was, then you can explain that you can be more flexible, and you don't have to take everything literally just use common sense. And there are so many protocols and procedures and that was also something that drove me mad…. Yes, there was one time when I did get really upset with a nurse one time, is just the way that somebody says something to you, Harry was in high dependency and she said right, it's time that we started me doing more of his care, but I was very anxious. He had all these wires on him I was just so scared of pulling something or doing something terrible. Also I just felt so overwhelmed and to the point that I felt I couldn't cope with being told that I got to do X, Y, and Z ..I had already done that with all the expressing and everything and then she said, something like when ''he's your baby and is your responsibility"……, and I just got really really upset. I remember this because I was overwhelmed by responsibility for him. I needed support and understanding at that point. Maybe some parents are ready to be like that and I knew at some point I would be. I was there doing everything, and it wasn't like I wasn't there to take care of him but it's just that I needed support and understanding at that point. It just really knocks your confidence. And I think that also one of the things that stressed me out about expressing were all the rules, about the hygiene of the milk and everything … Again, I began to feel obsessed about it and I remember throwing milk away. I think I remember feeling I might have touched a bit of it, but I just remember feeling so terrified and I wish someone had kind of noticed that, because it was really sad that I was throwing things away

We had been there about three or four days, there was a sort of in-house therapist who was like a really irritating Blue Peter presenter…with lots of enthusiasm. I think it was probably the most depressing hour, she just laid it on really thick saying we must feel it's like the end of our lives, and that we may not ever work again and that it's the worse time of our lives and that he may not make it.

DISCUSSING PLANS WITH PARENTS

Especially with all the different problems, there was always a sense that there was a plan a b and a plan c, if needed.

Giving important information was also needed and to talk to parents when they have to do something difficult, like they have to put a line in or do something painful. They need to explain to you whether or not you need to be there or what it's like, how to actually handle the baby of course. I remember that with some of the other parents and they might have been really upset if they thought that one of the nurses was being rough with their child. I remember one day the nurse was putting a feeding tube down Harry, down his nose and my mum got so upset about it, because it's unpleasant to watch and we were not used to that, watching the tube go down. And also, the feeling the parent has the anxiety about whether they should be there. Is it better for them to be there to hold their child afterwards or not there for the procedure? At the time the ethos on the unit was that parents had to leave and go out when they were doing something like that. I think looking back that was probably the right thing, but I've heard that more recently

from one of the consultants who we stay in touch with, that they now encourage parents to be there. I think if you give the parents' choice they will feel that they have to be there and that can be really difficult for them but then again that may be the right thing for them ... It is difficult…….

THE IMPORTANCE OF TALKING TO PARENTS

I think it's important when the staff really take time to talk to us as parents and that makes such a difference. One or two of the consultants were really amazing at doing that, they did find the time to do that. Or they would say we can't talk to you right now but say at 3 o'clock you've got half an hour with us and they would come back. *We would* have a weekly update which was good, and the consultant was really always around. it's important that staff take the time to listen to us too.

CALLING PARENTS BY THEIR NAMES

The other thing that could have made a difference is for the nurses to call us by our names rather than just 'mummy'. When you've been there for some time and you start read the notes, I think nurses should be aware of what has been written and so be able to answer questions about it. I remember thinking again it was like 'mummy did this' and 'mummy came in' 'mummy did that'- would have been nicer if it was 'Fatima did that' or 'Fatima came in'….

It just makes quite a difference and I know they have a lot of names to learn but I think with a normal healthy baby it's different, but I think in the neonatal unit it would be really nice to have a name rather than just be called mummy all the time like everybody else. To be fair many of them did know our names at the end and the doctors certainly did call us by our names but you know you feel as a mother that you're not really you any more, it's hard to explain. It's important to humanise us really and attending to the emotional side was so vital.

Appendix 3c) Phase 1- Main Study
Story construct following core story creation
(from raw interview transcript in Appendix 3b)

(N.B. All names and hospitals have been anonymised by the use of pseudonyms)

HARRY'S STORY – As told by Olive.

THE START

To cut a long story short I was 29 weeks pregnant after what seemed to be quite a normal pregnancy with just a few red flags every now and again. We were basically told to go away and enjoy the pregnancy and then suddenly I found I had a strange sensation in my stomach area and I called the midwife and they couldn't see anything but said go home and have a scan the next day. They found that Harry had Hydrops Fetalis and he had pleural effusions both sides. I had too much amniotic fluid which was why I was feeling so strange. And then they referred us to a fetal medicine unit (Hospital A- anon) where they did a surgical procedure to try and insert a drain into his thorax to drain out the fluid from what he had collected in the womb. But that didn't work at first because the drain was half in and half out- however, it did drain out some of the fluid that was pressing on his lungs. So, it saved his life and I was told at that point that he would be premature as the procedure was quite a risky one anyway plus due to the polyhydramnios which had built up and was building up again. They monitored me every few days, but it did build up again over the weekend and then I went into labour at 32 weeks exactly. I was actually in hospital when I went into labour at Hospital A because I'd just gone for an antenatal appointment. I started bleeding and they kept me in and then in the morning and then my waters broke, and Harry was born four hours later.

The first night after I gave birth, it was really awful, all that whole time was a real nightmare …… that first night after I gave birth it was fine and so I was kind of up and about. But, Harry been taken immediately… I only saw really just a glimpse of him, so you just see your baby just for a moment and then they get whisked away. I was bought a photograph of him before they put the ventilator onto him, so I just had a photograph of him and I remember they came in to do my temperature and so on, once I had given birth because they said I had a fever. But I was so scared because …. Well too scared to even go and see him because I was frightened of infecting him or something, so I think that night I was just in an awful state where I hadn't actually seen him. I didn't really know as well that I could go and just see him at any time in the night, I kind of wish …..because I know the midwives are very busy on the postnatal unit but nobody sort of said to me, look you know what, it will be fine for you to go and hold his hand, you can wash your hands and you can go at four (o'clock) in the morning if you want to because it was just on the floor nearby … but it felt much much further away. And I could see the little…. is it a resuscitaire? the little box, cot thing where they put healthy babies … a bassinette type thing and there was an empty one next to my bed as I had a room on my own and it was just really strange and really surreal. And the next day I went to see him, and I was just really paranoid that was going to infect him, you know…... Was I going to make him ill?

THE MIDDLE

ADMISSION TO THE NEONATAL UNIT

In intensive care, he was in the incubator, he was on the ventilator and he had wires and tubes and we didn't know if he was going to survive …. They didn't give out numbers or anything. They were sort of saying this is quite a critical time and that the next 24 to 48 hours were really critical especially due to the hydrops and they didn't really know. We didn't know what was going to happen, they were saying we don't deal with this very often so that was really scary and yes that I remember being very afraid to touch him because he just seemed so tiny and vulnerable and I don't think I actually got to hold him for about a week or so. He was just in the incubator and we were just you know using our fingers really to hold onto him and his, his own hands and fingers. And he was so beautiful, and we just fell in love with him you know, very beautiful and his eyes were open and very blue. It was lovely to see him, and we always felt that he was a person and he was a really strong character right from the beginning. So really, it was terrifying…. really terrifying. And then it was just such a blur…. Trying to express milk and all of the other things you have to do and that becomes a huge part of your day … it was just exhausting.

THROUGH THE NEONATAL UNIT

He was taken to intensive care and then basically stayed in the unit for about five months with a whole range of different things. This whole period then was so stressful. We spent the first three months in Hospital A in intensive care and high dependency and then back into intensive care again. Then he went to Hospital B (anon) for surgery and then he came back to Hospital A and went into special care and then they discharged him for the last month to the hospital C (anon) for his fifth month where he was able to go home.

OTHER EVENTS DURING THE NEONATAL JOURNEY

Harry had a Nissan's fundoplication because he had such severe reflux and because he was at risk of aspirating and he did aspirate once. So, they felt that he couldn't be fed safely and was being tube fed through a nasogastric tube and through a jejunal tube and he had all sorts of issues with his digestion not working. Things didn't seem to work properly so he had his operation at around three months old at Hospital B. He was on a ward which was quite a shock for us because we were so used to him being on a neonatal unit. He was suddenly put on a ward with all these older children and it wasn't at all the same level of attention that we were used to. At Hospital B we were able to pick him up and hold him and walk around with him which we weren't used to. We had never seen him not attached to loads of stuff, so it was a real shock and all very disconcerting. It was a very different hospital at the time to what it is now and it's all changed a lot.

THE STAFF

The neonatal staff were amazing. I think with the postnatal midwives though, I think there was a disconnect there. I would have liked a lot more support because well... for example not knowing that I could have gone to see him, it just wasn't made obvious and

like I remember going out the middle of that first night because I was really cold and I was asking for a blanket and the midwife was just really grumpy, looking back I was thinking ….gosh look what I've just been through you know and I was all on my own and I just think, when thinking back of that lack of compassion, looking back at it all. The neonatal staff were really lovely though- they gave me all the information I needed as soon as I started talking to them and they were incredibly supportive because as a parent, a huge amount of your contact is with the staff and I have really good memories of the first few days when they were there looking after us. We really appreciated how incredible they were and how sensitively they gave us information because I was discharged after one night in hospital and then we had to go home then we would be calling them every day and also sometimes at night. They were always really balanced so they wouldn't lie, they wouldn't be overly positive but at the same time they were very careful not to frighten us.

TRANSITIONS

When Harry went from intensive care, did he go to high dependency and then back to itu. I remember one of the nurses said to me early on that it would be a bit like a rollercoaster and it would be up and down backwards and forwards and that's exactly what it was like. His Hydrops did get better quite soon, they gave him a diuretic and he just' weed out the extra fluid and that got sorted. Then he started to have problems with the reflux, and then he had an SVT and that's when he went back into intensive care, so he was having abnormal heart rhythms as well. Then came the diagnosis of the genetic condition and the geneticists came so all these different things kept happening.

The difficulty of moving back to itu was interesting. It was quite difficult and there was always that feeling when you walk into the unit in the morning, you go into the nursery where he was the day before and they go…. he has been moved and you think, oh my God what's happened. Sometimes they would be moved around with different cots for no real reason. It was like …. we've taken him into the other room to have a look at him or something and then in the night you might get a phone call and you didn't know. It was just this constant feeling. And I think it was very frightening at that time …..for example, when he had the SVT and went back into intensive care because we just wanted him to get out of the incubator into one of those open bassinette type things and it was such an amazing feeling when that actually happened, when he could wear his own clothes as he had not worn his own clothes at all. But it all took a very long time with Harry and his breathing was terrible and his breathing well you know he was on CPAP for what seemed like forever, I remember them saying that he may come home on CPAP you know ….we just wanted him to breathe normally and of course eventually he did but we wanted that to happen sooner- he had the CPAP by the nasal prongs and he hated it. He also had suspected NEC, constant infections and it was just a nightmare in terms of his ongoing problems.

Special care, -I think that was a lot more relaxed and I suppose there wasn't a huge difference for us between the special care and high dependency in terms of what was going on because a lot of it, the scary stuff that was going on happened when he was in high dependency, the NEC and the SVT and so on, but special care we were a lot more

relaxed and at that point he was coming out into the baby bouncer and he was a bigger baby. Then we went to hospital C…. and again, when he was in a much more relaxed environment than we were used to really. When he went from intensive care, he did go to high dependency area where I think there was one nurse for every two babies but yes then once we realised they weren't so worried about him, no one was watching him all the time like a hawk, you could then really forget that….

THE DIFFERENT UNITS

With one hospital, the experience we had was really disappointing, later on we went back there we had really positive experiences especially last year with the cardiac surgery was really brilliant really amazing but that first experience was really, was not good really …..For example, I'm not sure whether this is really relevant but a lot of the experience we had, the equipment was….. The equipment was not so good, and we have many issues with them. I suppose it was the lack of continuity that wasn't good. I would just be put into a room with him and it was the first night out ever spent with him where I could stay all night…. although that was probably good it was the first time I'd done that, and it was terrifying, you know I wasn't used to it at all. I remember me and my mum, we were sitting on the bed and we had Harry next to us and really did not know what to do…. we never been in that situation before because he was always attached to something before. The only time I got close to that was when I put my head inside the bassinette close to him. And I had held him with kangaroo care but that was with lots of help. It was really shocking but I suppose on the other hand it was quite reassuring as well because we knew it was all okay, but there were differences with the machines they used as well and there was all so much to get used to. Hospital B … they were all really nice there and it was very breezy with lots of fresh air.

I suppose at that point there weren't any major medical issues, it was just a case of getting used to feeding him with the gastrostomy and making sure he was stable I suppose. There I suppose it was more the feeling of lack of privacy because we were in a big room with lots of other families.

GOING HOME

When Harry went home, on the one hand, it felt like another nightmare but on the other hand, it was really amazing and wonderful. It's been so long five months he had been born in the January and it was now the June so two seasons had passed, and it was warm we went out to the park and it was just a miracle to have fresh air. There was a point at the *Hospital B* where we could take him outside …. there was an area outside, where we could walk across the bridge with him in a pushchair but that was pretty much as much as we done. Apart from that he hadn't had fresh air. So, it was wonderful to be home. He still being tube fed by then. It was just the tube feeding, and I had done that at the H*ospital B*…. been able to stay in to get used to doing it, in one of the rooming in rooms which was really good, to be close to him.

Outreach services also came to us. The community nurse I think came practically every day when we first went home. We did have a neonatal follow-up nurse as well and then we went back into the hospital to see a paediatrician to follow him up and he had speech and language then about his feeding. We saw the dietician too for his tube feeding as well. The community nurse and the neonatal nurse came to us at home but the others we went to the hospital for the follow-up. And later he was referred to physiotherapy which was at home as well

THE END - CONTINUING CARE

He does have quite a lot of follow-up still. He still has physiotherapy now and he has been referred for occupational therapy. He's got a dietician if he needs one and he has still few doctors following him up. Endocrinology, cardiology, paediatricians so there are quite a few.

Ongoing problems include developmental delay and whether that's due to his prematurity or again the genetic condition, it's hard to say. But it could be due to his prematurity and the fact he spent months in hospital. I know that 32 weeks these days is nothing to worry about, but he was much iller than the average baby at that age so yes, it's his motor skills fine and gross that are delayed so…… For example, my daughter who is half his age can already do things that he finds difficult such as getting dressed and undressed, eating and feeding himself with a spoon and holding a pen, things like that, climbing things, following instructions, he may have dyspraxia as well we think. I think he's got sensory issues and he seems to touch things a lot. I think he might have sensory processing disorder, but this is all due to the fact he gets very overwhelmed by noise. He finds school really difficult. He's at a local school but it is really difficult. We are trying to move him actually because they haven't been very supportive of his needs sadly…… It's just not a very nurturing school. They don't seem to care very much at all but is only part-time at the moment because…. I don't know, they think he finds it difficult. His focus and attention are a bit delayed as well so he gets very tired very easily, can't sit and listen for too long but is very bright and very articulate. He is very sensitive and very sweet ……

I think he could have had the occupational therapy much sooner, that would have been good in terms of the sensory issues. It would have been good to know about that earlier. But I only really kind of heard about it quite recently and found out about it, and I thought gosh that sounds exactly like Harry. So, I think if he had had follow-up for that from the start something that may have helped. But I do think we had loads of support, so I think that's been very a positive experience in terms of the medical care. The experience with school is the first time we were not well supported. But up until now we've had a great team of doctors, nurses, therapists and childcare and everyone has been supportive.

Appendix 3d) Phase 1- NVivo Raw data nodes
Summary table Analysis 1 (parent experience)

THEMES AND SUB-THEMES (NODES)	Sources	References
1 How parents describe their emotions	17	97
1a Challenging experiences as a parent	19	157
1b Positive experiences as a parent	15	58
2 How the baby is described by the parent	13	25
2a Challenging experiences with their baby	15	45
2b Positive experiences with their baby	10	23
3 How the staff are described by parents	2	3
3a Challenging experiences with staff	10	23
3b Positive experiences with staff	18	69
4 How the environment is described	13	21
4a Challenging experiences with the environment	9	17
4b Positive experiences with the environment	10	16
5 How transitions are described	11	17
5a Challenging transition experiences	10	32
5b Positive transition experiences	4	7
6 How parents describe their experience at home	7	22
6a Challenging ongoing experiences at home	18	122
6b Positive ongoing experiences at home	16	30

Appendix 3e) Summary of quotes from analysis 1 (parent experience)

<u>Parent's emotional experiences</u>

Negative

''It was just the uncertainty of it all that was so overwhelming'' (4: mother)

''I was too scared to even go and see him'' (3: mother)

''Emotionally, we both found it so difficult'' (2: father)

''It was terrifying… I just thought this was normal. I was too emotional to be of any help…'' (5: father)

''I was so depressed ...it was due to being separated from my baby'' (1: mother)

Positive

''You just hold your child, there is a chemical reaction that feels like your hearts are sort of close together….it feels so right, it felt just like that'' (1: mother)

''Developmental care was done there, and this helped me to connect properly with him … that made you feel confident'' (5: mother)

''Skin to skin contact made us feel so much better and more bonded with them'' (11: mother)

<u>The Baby</u>

Negative

''And it was terrifying... I just had to hope that he would still be alive the next day'' (5: father).

''It felt very strange -; you don't feel that the baby belongs to you and she didn't even look like a real baby'' (7: mother)

''I had this almost constant feeling of terror that I would somehow damage him''(10: mother)

''he was so fragile, and I was so terrified- I didn't want to get too close'' (6: mother)

''when he was ventilated that was heart-breaking because it didn't look like him…. I couldn't bond with him'' (8: mother)

''They're so fragile that you feel you don't want to hold them but really, they're so robust that you should do this… …I was gently stroking his arm and it felt terrific'' (1: mother)

''And what I find fascinating is that they are so small and vulnerable and then they grow into this…. He is amazing and so strong'' (10: father)

''we were just using our fingers to hold onto him and his own hands and fingers… he was so beautiful, and we just fell in love with him'' (9: mother)

The Environment

Negative

''that was the hardest bit and I remember them pulling the curtain round, but I just remember hearing the babies cry and then I was trying to express, and I just wanted to see my baby'' (12: mother)

''I think there is this thing about feeling institutionalised and sometimes a feeling of isolation and feeling quite trapped'' (7: mother)

Positive

''They put the incubator alongside me and showed me, so I got to see her ….so immediately, I was more bonded with her. Right at the start'' (13: mother)

…''a place where they felt safe and happy and he wrote about the hospital, but I said it was the most wonderful thing I had read, to know that they are his memories, was wonderful'. (15: mother)

The Staff

Negative

''I really got to the point when I thought you really have got to listen to parents I just think if someone had explained to us a bit more, we could have been more prepared'' (2: father)

''Staff said different things to us – this was very confusing and unsettling'' (14: mother)

''The neonatal staff gave me all the information I needed, and they were incredibly supportive. We really appreciated how sensitively they gave us information'' (16: mother)

''You saw the depths of compassion and the human side of people…. you must get to a raw point to see that'' (19: mother)

''I came out mentally unscathed I think, due to how we were cared for by the staff... '' (17: mother)

''They really saw us as part of his care team and that made an enormous difference to our experience to his outcome as well'' (10: father)

Transitions

Negative

'' I was quite emotional when we were moved -it was so different to where we were used to... She struggled a bit and her oxygen when up…. that was hard as she was doing well until then'' (18: mother)

''after 12 weeks of this amazing wonderful support system, we were transferred to another unit. We had to make an appointment to discuss notes, … that freedom; it was all taken away. We had sort of gone backwards'' (6: father)

Positive

''We felt like celebrating when he went to special care... our hope returned'' (18: mother)

''And then he went into a hot cot and then into a normal one. And that made a lot of difference because you could touch him. It felt more like our baby'' (20: mother)

<u>Going home</u>

Negative

''When he came home I just wanted him to be back in hospital; I couldn't cope'' (8: mother)

''It was a difficult time for so long''... I had panic attacks'' (8: mother)

''We never left him unattended, if one of us had to leave then we would take it in turns to stay awake and to make sure he was breathing'' (10: father)

''None of the other parents understood what we had experienced… mentally heart-breaking and very difficult'' (17: mother)

''My husband needed to have counselling, sometime after discharge … it all caught up with him'' (19: mother)

Positive

''Going home was terrifying, but going out into the wider world was our future'' (1: mother)

''It felt amazing. I wasn't scared at all as I so wanted to be a parent and was the first time I've held him without everybody staring at me'' (11: mother)

''Each step was a milestone, a miracle almost; we could look to a future''
''I think that gave us a bit of hope and we were able to carry on'' (5: father)

Appendix 3f) Phase 1- NVivo raw data nodes
Summary table from Analysis 2 (metaphor analysis)

THEMES and SUB-THEMES (NODES)	Sources	References
1a How parents describe their emotions		
1a (i) A different world	6	13
1a (ii) Altered reality	10	12
1a (iii) Darkness	9	12
1a (iv) Breaking	7	12
1a (v) Punishment	5	7
1a (vi) Nightmares	4	8
1b Challenging experiences as a parent		
1b (i) Struggling	9	19
1b (ii) Directional movement	12	28
1b (iii) Dehumanisation	3	3
1c Positive experiences as a parent		
1c (i) Being part of a system	5	8
1c (ii) Moving forward	2	3
1c (iii) Giving strength and salvation	0	0
2a How the baby is described by the parent		
2a (i) Animals	4	4
2a (ii) Objects	10	21
2a (iii) Differences	6	9
2b Challenging experiences with their baby		
2b (i) On the edge of death	6	11
2b (ii) Loss	6	9
2b (iii) Hurdles and barriers	10	21
2c Positive experiences with their baby		
2c (i) Connections	4	5
2c (ii) Investment	1	1
2c (iii) Strength	3	8
3a How the staff are described by parents		
3a (i) Saviours	4	13
3a (ii) Life in their hands	4	4
3b Challenging experiences with staff		
3b (i) Battles	11	23
3b (ii) Barriers	6	9
3c Positive experiences with staff		
3c (i) Hearts and minds	4	6
3c (ii) Within memories forever	0	0
4a How the environment is described		
4a (i) Darkness and light	1	1
4a (ii) Temporary home	1	3
4b Challenging experiences with the environment		
4b (i) Prison	4	6
4b (ii) Institutionalisation	2	4

THEME / NODE	Sources	References
4c Positive experiences with the environment		
4c (i) Brightness	1	1
4c (ii) Breath of fresh air	0	0
5a How transitions are described		
5a (i) Rollercoaster	9	14
5a (ii) Journey	6	10
5c (iii) Bittersweet	1	3
5b Challenging transition experiences		
5b (i) Removal of support pillars	1	1
5b (ii) Being moved	0	0
5c Positive transition experiences		
5c (i) Seeing the light	1	2
5c (ii) Moving forward	2	2
6a How parents describe their ongoing experience at home		
6a (i) Unreachable	0	0
6a (ii) Goal	0	0
6b Challenging ongoing experiences at home		
6b (i) Crashing	5	11
6b (ii) Breaking down	7	15
6c Positive ongoing experiences at home		
6c (i) Release	0	0
6c (ii) Miracle	1	1

Cluster number	**Cluster title**	**Occurrence (in order of frequency)**	**Number of interviews**
1	Travelling / journeying	87	16
2	Altered reality	59	12
3	Darkness and light	58	10
4	Breaking and crashing	57	11
5	Connection and belonging	51	12
6	Fighting and conflict	32	11
7	Salvation and strength	32	9
8	On the edge	20	9

Appendix 3g) Summary of quotes from analysis 2 (metaphor analysis)

Metaphors of journeying
''We knew it would be a long haul…… we realised what was ahead… the long and rocky road'' (17, mother)
''There were so many ups and downs, bumps along the way as it were…… sounds a cliché, but just like a roller-coaster''. It's such an apt term to describe what it was like'' (11, mother)
''We were on a long road towards going home and being together as one unit'' (12, mother)
Metaphors of an altered reality
''We entered the very different world of the neonatal unit…. nothing seemed real'' (2, father)
''It was like being in another reality…. it was surreal…. a parallel universe'' (Interview 3, mother)
''He didn't look real…… Looked like a bright red shiny ball in a plastic box…… being whisked away from me…. not a baby'' (4, mother)
''She was in there somewhere, a shiny little doll covered in wires and tubes, like she was in an oven…… …… But I couldn't get to her'' (10, father)
Metaphors of darkness
''The neonatal unit was like a dark tunnel, at times we felt imprisoned and trapped'' (14, mother)
''They wanted to put him in a side room… but I couldn't. Why would they isolate us? Hadn't we been punished enough? It was like being on death row'' (20, mother)
''Finally, as if a miracle had happened, we came home… like the light at the end of such a period of darkness and dread…… it felt fantastic'' (10, father)
Metaphors of breaking
''My husband crashed and burned about 18 months after we came home'' (16, mother)
''It broke us…. we never expected this. We were planning to be a family but to see him like this…… We felt broken'' (7, mother)
Metaphors of Connection
''There was my baby... in a closed box…… Separated and torn away. And I felt like I was a million miles away'' (6, father)
''The bond was broken…… I couldn't connect and there were so many barriers…'' (15, mother)

''The feeling was wonderful when I held him finally…. our hearts meshed together as one'' (1, mother) *''Coming home was such a bittersweet experience…… the support pillars came tumbling down round us but at the same time, we felt desperation to be home, to bond properly and be a family''* (19, mother) *''Feelings of happiness at my boy getting better were tinged with sadness at leaving this wonderful support system and moving to another unit''* (2, father)
Metaphors of fighting *''He was such a fighter…… so small and weak and yet he fought hard and came through all the hard times…. So strong''* (5, father) *''I called him my warrior…… he came back from the brink so many times''* (18, mother)
Metaphors of salvation *''The neonatal staff were our saviours…… they saved us all, emotionally this was so important for then and for our future''* (16, mother) *''The unit and staff were our support pillars, we were part of a strong system… they all have a special place in our hearts……''* (13, mother) *''when we go back, it is like painting by numbers…… it was all black and white at first but then I could colour it in with different colours each time… it became brighter''* (9, mother)
Metaphors of being on the edge *''We didn't know if he would survive from one hour or day to the next. All the time, we felt like he, and we, were on the edge of a cliff, almost falling but clinging on''* (7, mother) *''When I thought about her, I felt like I was at the edge of a large, black hole, looking down at nothing''* (8, mother)

Appendix 3h) Phase 1- NVivo Raw data nodes
Summary table Analysis 3 (learning from parents)

Name	Sources	References
a COMMUNICATE	4	10
How	13	26
What	15	39
When	10	16
Who	3	3
b LISTEN		
Being properly listened to	6	11
Having a voice	1	2
Parents intuitive knowledge	8	14
c EMPATHISE		
Emotionally intelligent care	15	24
The importance of values	10	16
The whole family	11	23
d ACKNOWLEDGE		
Parents as a vital part of the team	2	4
The importance of the parenting role	6	14
The need to be involved	8	11
REALISE		
What makes experience worse		
e1 Transitions	2	4
e2 Discharge home	10	22
e3 Uncertain outcome	5	8
e4 Expecting death	5	6
e5 Feeding and expressing milk	15	18
e6 The environment	6	17
What makes experience better		
e10 Involvement in care and decision making	7	11
e11 Peer support and helping each other	13	20
e12 Memories and keepsakes	8	11
e7 Skin to skin contact or Kangaroo care	13	18
e8 Developmental care	4	5
e9 Feeding and expressing	9	15

Appendix 3i) Summary of quotes from analysis 3 (learning from parents)

Communicate with us *''You need to be able to communicate properly with us, you must be careful how you say things…… be honest and accurate but sensitive''* *''I would say to any health professional, think about what you say and how you say it''* *''Consistency is so important so that we don't get confused''*
Listen to us *''We must be listened to''* *''Our voice is so important… our views must be taken on board''*
Empathise with us *''Staff should try and have empathy and understand, the emotional side of it all''* *''These small things make such a difference''* *''Consider our emotional health ... I was depressed, and no-one noticed''.* *''As a dad, I felt I didn't have a role and I was emotional too''*
Acknowledge us as parents *''After that, I felt empowered and I felt I could voice what I wanted''* *''You must include us from the start''* *''We are the parents; we are, or should be part of the team''*
Realise what is important to us *''Try and give us more support at difficult times''* *''It is so important for staff to realise and understand what we need at such difficult times''* *''These things (skin-to-skin, developmental care) are so important and help us all''*

APPENDIX 4

Appendix 4: Reflective commentary extract
Reflective commentary extracts

5a: Consent was an area that was not as straightforward as I expected- for example, when was it best to get this? – at the point of first contact, after a certain time period, at the first meeting? I had not thought about these questions previously and so consent forms were signed at the interview meeting – however, I wondered if parents with such busy and often hectic lives had really read the information sheet thoroughly enough to be truly informed and whether they really knew the specific aims of the study, due to some of the questions they asked me after the interview. I needed to take their word on that however as all did say they had read the information and fully understood. Above all, I knew they had consented to me gaining, recording and using their narratives for educational purposes.

5b: On arrival to the parents' house or agreed venue, as a novice researcher, I was at first unsure as to how to start the interview meeting. Feelings of nervousness surprised me, and I wondered if parents felt the same. However, after an introductory preamble, confirming receipt of information sheets, signing of consent forms and explaining confidentiality reinforced the purpose of the study and provided an opening conversation before the interview serving also to set the scene. I felt more comfortable with this over the course of the six-month interview period – familiarity and 'practice' set in after time. A small digital audio recorder was my means of recording the interviews and I hoped that the participants would pay it no particular attention after the first minute or so; however, this was not to be so, in many cases. I had of course not considered that for many families, the children themselves would be present at the interview. These included either the child themselves who had been born preterm and/or their siblings at varying ages; the voice recorder therefore provided an exciting device in which generated much interest for them. I remember one of the children grabbing and running off with it to play with it as a 'pretend' phone necessitating an altercation between said child and mother to get it back. At one interview, I resorted to placing the recorder up on a high shelf to keep it from inquisitive hands. While perhaps meaning the interview process was not as smooth as I would like, such occasions did provide a light relief, ended up being very amusing and a reminder of the joys and reality of children exploring and learning in the presence of a new person.

5c: Another unexpected issue related to that of the actual interview questions. In true 'semi-structured' style, I had a list of questions which I planned to ask in a set order eliciting open responses for each one. However, the reality was different in that my initial opening question which in essence asked for their story, actually gave me all the information I required. In other words, the reality of asking a parent who has undergone such an intensive and lengthy time on a neonatal unit to tell me their story meant they did just that, often taking up to an hour if not longer to relate it. My specific subsequent questions were then often not necessary in these cases. I came to realise after the first four interviews that I was actually engaging in 'narrative' interviewing rather than anything that was in any way even semi 'structured'. This was a key example of how reflexivity and examining the interview on an ongoing basis enabled me to be flexible and to not concern myself if all my pre-prepared questions had already been answered.

5d: An additional example of reflexivity and learning from the interview process was by playing the audios back straight to myself soon after the interviews and documenting notes in a reflective commentary. I felt shocked at how audible my voice was that I could hear too much of my voice and at times appeared to speak my own views perhaps too readily. - For example, I heard myself agreeing with a mother who stated the need for better family support on neonatal units. While this can at times be a natural reaction to being asked something, I realised I needed to be stay objective and not to say too much. I also remembered that I also found a similar issue in my pilot study interviews with student nurses and that I had not put this into practice here. I then realised how difficult it was to stay *neutra*l in a conversation with another. I had also possibly slipped into my clinical nursing role that replies on a natural two-way conversation between nurse and 'patient' or in this case 'parent' to elicit and exchange information.

5e: An example of what I learnt about myself as a researcher and where I put changes into place was in relation to transcription issues. Very little appears to be written about the transcription stage, but one writer discusses issues relating to confidentiality. This indeed came up in my study when I was asked by two of the parents who would be transcribing and listening to the interviews. One mother was concerned when she became angry about an incident that happened in one neonatal unit that someone else would hear her language used in response to a time when she was not happy. The fact she was worried made me in turn feel uncomfortable and to revisit my plans for getting the interviews transcribed by someone else, who would be a stranger to us. Therefore, the decision was made to transcribe the interviews myself, an onerous but yet now essential process. The other issue that also concerned me in relation to confidentiality was the naming by many parents of the neonatal units their babies had been admitted to, in some cases many different units. Transcribing the narratives myself would avoid anyone else hearing those units named along with certain named nursing and medical staff.
The above few examples show reflexivity worked to change my views during the research process.

APPENDIX 5

Appendix 5: Checklist / consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Source https://academic.oup.com/intqhc/article/19/6/349/1791966

Domain1: Personal Characteristics

1. Interviewer/facilitator Which author/s conducted the interview or focus group? **J. Petty**

2. Credentials What were the researcher's credentials? **MSc, MA Academic Practice**

3. Occupation What was their occupation at the time of the study? **Senior Lecturer in children's nursing**

4. Gender Was the researcher male or female? **Female**

5. Experience and training What experience or training did the researcher have? **Undertaking the Doctorate in Education programme**

Relationship with participants

6. Relationship established Was a relationship established prior to study commencement? **Parents- no Student nurses - yes**

7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research **The study, aims and reasons for the study were explained verbally before any research / interview interaction to support information from the participant information sheets in each phase of the study.**

8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic **Yes, this has been addressed in relation to both reflexivity and limitations which were covered for each phase of the study and in the discussion.**

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis **Narrative, interpretive inquiry**

Participant selection

10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball **Purposive (phase 1) Convenience (phase 3 and initial study)**

11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email **Email via gate-keeper (parents) / Face-to-face (students) / via email (survey)**

12. Sample size How many participants were in the study? **6 (initial study) 23 (phase 1 parents) 137 (phase 3)**

13. Non-participation How many people refused to participate or dropped out? Reasons? **Phase 1- not known. Recruitment was via volunteer basis so all those that came forward were interviewed until required number of interviews obtained. Phase 3- no-one refused to participate, nor did anyone drop out**

Setting

14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace **Phase 1- Home or other venue as agreed between researcher and participant. Phase 3- classroom or in a private, prearranged room in a University setting.**

15. Presence of non-participants Was anyone else present besides the participants and researchers? **No**

16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date **Phase 1- volunteer basis, parents who have had a premature baby. Phase 3- student nurses at various years in the nursing programme and a selection of health professionals working in neonatal care**

Data collection

17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested? **Narrative interviewing for Phase 1 so prompts were not necessary for most participants. Phase 2 did require a more structured interview schedule with direct questions.**

18. Repeat interviews Were repeat interviews carried out? If yes, how many? **No**

19. Audio/visual recording Did the research use audio or visual recording to collect the data? **Audio**

20. Field notes Were field notes made during and/or after the interview or focus group? **Yes – own notes were taken.**

21. Duration What was the duration of the interviews or focus group**? One to two hours.**

22. Data saturation Was data saturation discussed? **Yes; this was addressed and discussed.**

23. Transcripts returned Were transcripts returned to participants for comment and/or correction? **Yes in all phases.**

Data analysis

24. Number of data coders How many data coders coded the data? **One**

25. Description of the coding tree Did authors provide a description of the coding tree? **All codings and raw data are presented within the Appendix and summaries / explanations within the text.**

26. Derivation of themes Were themes identified in advance or derived from the data? **From the data (Phase 1) and from the questions posed (Phase 3)**

27. Software What software, if applicable, was used to manage the data? **NVIVO for Phase 1 and 3**

28. Participant checking Did participants provide feedback on the findings? **Yes, for all phases.**

Reporting

29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number **Yes**

30. Data and findings consistent Was there consistency between the data presented and the findings? **Yes**

31. Clarity of major themes Were major themes clearly presented in the findings? **Yes**

32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes? **Sub-themes yes**

APPENDIX 6

Appendix 6a) Phase 2- Main Study
Composite themes – to use for digital story creation

THE START
''We entered the very different world of the neonatal unit…. nothing seemed real'' (2, father)
''It was like being in another reality…. it was surreal…. a parallel universe'' (3, mother)
''At the start, it was all so strange... like being in another world'' (1, mother)
''We didn't know where to turn, what to do and how to connect…. we could not adjust'' (7, mother)
''We felt like we had entered the unknown… this was just the beginning'' (5, father)
MIDDLE
''He went through ups and downs, twists and turns…. No day was the same…'' (9, mother)
''The journey after that was a roller-coaster'' (7, mother)
''One step forward and two backwards…. It was a rocky road through the unit… the different transitions'' (10, father)
''Never knowing at each point of the journey, what would be at the end'' (18, mother)
''Each day was filled with uncertainty'' *(5, father)*
THE END
''We moved towards the final destination''(12, mother)
''We had finally arrived ... our family all together… there had been many barriers and hurdles along the way'' (16, mother)
''We had come through the dark times and out the other side'' *(5, father)*
''Finally, being at home was like a miracle'' (12, mother)
''Coming home was such a bittersweet experience…. … the support pillars came tumbling down round us but at the same time, we felt desperation to be home, to bond properly and be a family'' (19, mother)

Appendix 6b) Phase 1- Main Study
Condensed story / script example

'ANOTHER WORLD'

Josh was born at 25 weeks after I had discovered I was bleeding and had gone into the maternity unit to be monitored. I was already high-risk; my blood pressure was high, and I had protein in my urine; my placenta was being scanned and it looked like Josh had stopped growing inside me. I didn't know why... I thought I had done something wrong, maybe I should have stopped work earlier… I remember asking; ''What have I done to him?'' My partner and I were both there. At the delivery I was numb with fright, it was so overwhelming. From that point, nothing seemed real anymore. I was no longer pregnant, but my baby was not with me. I cried; I needed to be there with him. All I had was a photograph. After what seemed like hours, I managed to get up to the neonatal unit to see him. Through the mist of the incubator, I saw him, so so tiny, a shiny little doll covered in tubes with a breathing machine attached to him. I looked at my partner and we both realised we had entered the very different world of the neonatal unit. We didn't even know that the world of neonates even existed before then; it was new, a different place, surreal…. It was almost like a strange dream. We could hear beeps, bleeps, alarms… I will never forget those noises, all the time they were there… and the dimmed light…. It was like being in a dark, underground subway sometimes with little light or chance to look out to the outside world. And it was hot too…… stifling...However, above all, above all of that was the love we felt for this tiny little thing… we touched him, held his hand, through those walls…

So, this was our new reality for the next 4 months. We got used to the environment, incubators, machines, the busy days, babies in and out all the time, the comings and goings of life on the neonatal unit. We lived, between us, on the unit at any one time. We couldn't leave him alone. He had so many procedures…… drips, IVs, chest drains, breathing and feeling tubes... and more…. He had to know in the future that we were there with him through all of that. He is our baby and we are a family.
We wanted to get to know him… but there were so many barriers. It was so important for us to live this life together and be part of his care. Slowly we were shown how to hold him, soothe him, clean him, change his nappy, wet his lips. This was so scary at first… I thought; I can't do it…. I am going to break him, hurt him or infect him in some way…These fears and worries have only just gone away after 18 months.

So, time passed… He went through the different rooms. Each change was filled with fear and I was terrified that he would not cope in yet another new world around him. At times, you feel isolated in that world and you don't know what's really going on around you, but you are saved in a way by people that help you through it… caring staff, helping us, telling us that we could do it, that we were his parents…
Going home, the support pillars are all removed, and you almost have to start all over again. But after a while, we began to do OK with the support of outreach and my GP. Our tiny, wonderful baby grew into a beautiful boy. He has many ongoing issues that we will deal with together. That world within the neonatal unit is fixed in our memories ready to tell him about later on… his life began there, and the foundations laid down. A place in our hearts.

Appendix 6c) Phase 1- Main Study
Storyboard example- 'Another World'

Stage of story PLOT	Time	Script ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	Voice (audio-track)	Images	Text (Quotes)
THE START	0.08	Josh was born at 25 weeks after I had discovered I was bleeding and had gone into the maternity unit to be monitored. I was already high-risk; my blood pressure was high, and I had protein in my urine; my placenta was being scanned and it looked like Josh had stopped growing inside me.		Pregnant mum	
MAIN STORY	1.23	I didn't know why... I thought I had done something wrong, maybe I should have stopped work earlier… I remember asking; ''What have I done to him?''		Baby in womb	*''What have I done to him?''*
MAIN STORY	0.37	My partner and I were both there. At the delivery I was numb with fright, it was so overwhelming. From that point, nothing seemed real anymore. I was no longer pregnant, but my baby was not with me. I cried; I needed to be there with him. All I had was a photograph.		Parents by cot	
MAIN STORY	1.01	After what seemed like hours, I managed to get up to the neonatal unit to see him. Through the mist of the incubator, I saw him, so so tiny, a shiny little doll covered in tubes with a breathing machine attached to him. I looked at my partner and we both realised we had entered the very different world of the neonatal unit.		Baby and wires and lights	*''It was new…. A different place''*
MAIN STORY	1.34	We didn't even know that the world of neonates even existed before then; it was new, a different place, surreal…. It was almost like a strange dream.		Parents looking on	*''It was almost like a strange dream''*
MAIN STORY	1.39	We could hear beeps, bleeps, alarms… I will never forget those noises, all the time they were there… and the dimmed light…. It was like being in a dark, underground subway sometimes with little light or chance to look out to the outside world. And it was hot too…… stifling...		Equip-ment flashing	
MAIN STORY	2.01	However, above all, above all of that was the love we felt for this tiny little thing… we touched him, held his hand, through those walls… So, this was our new reality for the next 4 months. We got used to the environment, incubators, machines, the busy days, babies in and out all the time, the comings and goings of life on the neonatal unit. We lived, between us, on the unit at any one time. We couldn't leave him alone. He had so many procedures…… drips, IVs, chest drains, breathing and feeling tubes... and more…. He had to know in the future that we were there with him through all of that. He is our baby and we are a family. (continued overleaf)		Baby and hand	*''The love we felt for this tiny little thing… we touched him, held his hand, through those walls…''*

Stage of story PLOT	Time	Script ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	Voice (audio-track)	Images	Text (Quotes)
MAIN STORY	2.20	We wanted to get to know him… but there were so many barriers. It was so important for us to live this life together and be part of his care. Slowly we were shown how to hold him, soothe him, clean him, change his nappy, wet his lips.		Parents looking in	*''We wanted to get to know him… but there were so many barriers''.*
MAIN STORY	2.52	This was so scary at first… I thought; I can't do it…. I am going to break him, hurt him or infect him in some way… These fears and worries have only just gone away after 18 months.		Baby and barrier	
MAIN STORY	3.06	So, time passed… He went through the different rooms. Each change was filled with fear and I was terrified that he would not cope in yet another new world around him. At times, you feel isolated in that world and you don't know what's really going on around you, but you are saved in a way by people that help you through it… caring staff, helping us, telling us that we could do it, that we were his parents…		Mum holding baby Corridors and doors Mum and team	
MAIN STORY		Going home, the support pillars are all removed, and you almost have to start all over again. But after a while, we began to do OK with the support of outreach and my GP.		Going home	
MAIN STORY		Our tiny, wonderful baby grew into a beautiful boy. He has many ongoing issues that we will deal with together.		Little boy	
THE END		That world within the neonatal unit is fixed in our memories ready to tell him about later on… his life began there, and the foundations laid down…. A place in our hearts.		Hospital and heart	*''His life began there, the foundations laid down. A place in our hearts''.*
FINAL CREDITS					

Appendix 6d) Phase 2- Main Study
'Creating and telling digital stories in neonatal care'- Script

Digital storytelling has the potential to meaningfully capture participants' experiences and share them in a highly engaging manner. It combines the art of telling stories with a mixture of digital media, including text, pictures and audio narration, all blended together to tell a story that revolves around a specific theme…. In this case, the theme is that of the parent experience within one speciality of children's nurse education; neonatal care.

(Robin, 2016; De Vecchi et al, 2016; Rieger et al, 2018)

In line with what Gazarian calls narrative pedagogy, listening to digital stories from parents in our care enables us to learn from their experiences. Stories can not only engage and motivate the learner but also can lead to greater understanding, compassion and empathy towards patients, carers and parents. The question therefore is whether they have the power to enhance empathic learning.

(Jarvis et al 2004; Gazarian, 2010; Shellenbarger and Robb, 2015; Hardy and Sumner, 2018)

Many frameworks exist for digital story creation- here the ASPIRE model is applied to the creation of digital stories based on parent experience from the neonatal unit.

A… – the AIM was to educate learners in this field about the emotional experiences of parents…….. this empathic learning is essential in order to give more person-centred care.
S … for STORYBOARDING, parent interview narratives were reconfigured using core story creation to form a plot, known as narrative emplotment which brings the elements of a story into an imaginative order and a meaningful whole. After condensing into short scripts, key metaphors were extracted to form the basis of the stories, each lasting 3-4 minutes.

(Petty et al, 2018a; Ricoeur, 2013)

P… the POPULATION is student nurses and health professionals within neonatal care, all such individuals who emotionally support parents as part of their role and practice

I … IMPLEMENTATION involves the storyboard template including the script, voice narration, selected text quotes and pictures being constructed into a digital format to create a video as the final product.

R … RELEASE of the videos enables them to be showcased within the classroom, on a one-to one or small group basis or online.

E … EVALUATION from those viewing the stories allows feedback to inform future digital story development and enable adjustments and improvements to the materials.

E …. ENGAGEMENT – By engaging with the narratives of parents, these can inform the content of digital stories. And, by engaging with these digital stories, learners can in turn come to understand the emotional experiences of parents which can impact on the care that they give. In other words, knowledge about emotional experience learnt through digital media can be translated from the classroom and into practice.

Digital stories can be created and used to engage and teach us about the parents' experience in neonatal care with the aim of influencing a more person-centred, empathic understanding and approach to practice. "You can only understand people if you feel them in yourself." – John Steinbeck. And you can only give empathic care if you understand others and feel in yourself something of what they have been through. Digital stories can play an integral part in this person-centred understanding.

Appendix 6e) Phase 2- Main Study:
'Creating and telling digital stories in neonatal care'- Storyboard for video

Stage of story PLOT	**Time** IN SECONDS /MINUTES	**Script** ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	**Voice (audio-track)**	**Images**	**Text (Quotes)**
TITLE SLIDE					
MAIN STORY 1	0.06	*Digital storytelling has the potential to meaningfully capture participants' experiences and share them in a highly engaging manner.*		Person watching screen	*Empathy*
2	00.17	*It combines the art of telling stories with a mixture of digital media, including text, pictures ….*		Screen with words	*Text Pictures*
3	00.24	*…and audio narration, all blended together to tell a story that revolves around a specific theme….*		Loud speaker	*Audio*
4	00.27	*In this case, the theme is that of the parent experience within one speciality of children's nurse education; neonatal care.*		Sad parents	*References*
5	00.30	*In line with what Gazarian calls narrative pedagogy, listening to digital stories from parents in our care …*		Baby feeding and incubator	*Narrative Pedagogy*
6	00.35	*…enables us to learn from their experiences.*		Desk and laptop	
7	00.43	*Stories can not only engage and motivate the learner but also can lead to greater understanding,*		Baby and parents looking in	
8	00.48	*…compassion and empathy towards patients, carers and parents.*		Head and learning	*Empathy Compassion*
9	00.56	*The question therefore is whether they have the power to enhance empathic learning.*		Parents	*References*
10	1 min	*Many frameworks exist for digital story creation- here the ASPIRE model is applied to the creation of digital stories based on parent experience from the neonatal unit.*		Laptop and head phones	*ASPIRE*
11	1.11	*A… – the AIM was to educate learners in this field about the emotional experiences of parents…. ……. this empathic learning is essential in order to give more person-centred care.*		A + IMAGE	*A*
12	1.21	*S …for STORYBOARDING, parent interview narratives were reconfigured using core story creation to form a plot , known as narrative emplotment which brings the elements of a story into an imaginative order and a meaningful whole. After condensing into short scripts, key metaphors were extracted to form the basis of the stories, each lasting 3-4 minutes.*		S + IMAGE	*AS* *References*
13	1.43	*P… the POPULATION is student nurses and health professionals within neonatal care, all such individuals who emotionally support parents as part of their role and practice.*		P + IMAGE	*ASP*

Stage of story PLOT	Time IN SECONDS /MINUTES	Script ADD SECTIONS OF THE SCRIPT IN STAGES BELOW	Voice (audio-track)	Images	Text (Quotes)
14	2 mins	*I … IMPLEMENTATION involves the storyboard template including the script, voice narration, selected text quotes and pictures being constructed into a digital format to create a video as the final product.*		I + IMAGE	*ASPI*
15	2.11	*R … RELEASE of the videos enables them to be showcased within the classroom, on a one-to one or small group basis or online.*		R + IMAGE	*ASPIR*
16	2.21	*E … EVALUATION from those viewing the stories allows feedback to inform future digital story development ….*		E +IMAGE	*ASPIRE*
17	2.28	*….and enable adjustments and improvements to the materials.*		Class and teacher	
18	2.30	*E ….ENGAGEMENT – By engaging with the narratives of parents, these can inform the content of digital stories.*		E + ENGAGE	*Engage*
19	2.37	*And, by engaging with these digital stories, learners can in turn come to understand the emotional experiences of parents which can impact on the care that they give.*		Baby and hand	
20	2.40	*In other words, knowledge about emotional experience learnt through digital media can be translated from the classroom and into practice.*		Laptop	
21	2.44	*Digital stories can be created and used to engage and teach us about the parent's experience in neonatal care….*		Parents on screen	
22	2.49	*….with the aim of influencing a more person-centred, empathic understanding and approach to practice.*		Baby in hands	
23	2.56	*And you can only give empathic care if you understand others and….*		Parents and incubator	
24	2.58	*… feel in yourself something of what they have been through.*		Empathy	
25	3 mins	***"You can only understand people if you feel them in yourself." – John Steinbeck.*		Quote	*See left**
END	3.11	*Digital stories can play an integral part in this person-centred understanding.*		Parents	
FINAL CREDITS and REFS	3.14				

APPENDIX 7

Appendix 7a) Phase 3- Main Study
Point-of-view exercises for class sessions

Using digital stories to explore empathic learning: Brief

At the start of the session, a verbal explanation will be given the exercises with a brief background about the study and how the digital resources have been created (see Introductory script to participants). The participants will therefore know that they will listen to the parent stories and that they will be asked some key questions afterwards relating to how they would feel as parents and about aspects of learning. The digital stories will then be played to the group.

PART A POINT-OF-VIEW (POV) EXERCISE

The aim of this exercise is…

- To explore how students consider the parent's perspective

Brief for participants:

Having listened to the parent story, can you answer these questions as if you were the parent in the story…? Write your brief answers on the provided post-it notes in just one or a few words / one sentence maximum….

- Describe how you think you would have felt when the baby was admitted to the neonatal unit.
- Describe how you think you would have felt when you first saw your baby.
- Describe how you think you would have felt when your baby was transferred to another hospital / area of the unit / ward.
- Describe how you think you would have felt when the baby was discharged home.

PART B IDENTIFICATION OF LEARNING POINTS

The aim of this exercise is…

- To ascertain what enhanced and hindered learning?

Questions for the group:

Can you identify below, any part of the digital story that stood out for you in relation to enhancing your learning?

Was there anything that hindered learning?

Please write your comments down on other different coloured post-it notes

PART C THE VALUE OF DIGITAL STORIES TO ENHANCE EMPATHY

The aim of this part is to ascertain the extent to which the participants feel that digital stories contribute to empathic, person-centred learning. The participant will be given a questionnaire with Likert scale responses and a space for open answers at the end.

Brief for participants:

On a scale of 1 to 5, please rate the following statements which ask you about your thoughts on the stories you have seen:

(1=completely disagree; 2=disagree; 3=neutral; 4=agree; 5=completely agree)

You may also wish to write down the reason for your answers and there is space underneath for further comments

The digital stories have helped me to understand what the parents experience and feel.

1 2 3 4 5

The digital stories have increased my empathy towards parents and babies.

1 2 3 4 5

Digital stories would increase empathy in others who work in neonatal care

1 2 3 4 5

Seeing the parent journey through digital stories is useful for learning about neonatal care.

1 2 3 4 5

Digital stories are an effective way to learn about the patient experience

1 2 3 4 5

Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.

1 2 3 4 5

Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.

1 2 3 4 5

The information in the digital stories is clearly presented.

1 2 3 4 5

The digital stories have visual appeal.

1 2 3 4 5

The digital stories have an engaging presentation.

1 2 3 4 5

Out of the digital or the written format, which is the most effective way of learning about the emotions of parents and their experience?

Digital Written Combination No difference Other

Give your reason(s)

Out of the digital or the written format, which is the most effective way of evoking empathy?

Digital Written Combination No difference Other

Give your reason(s)

Did you prefer story 1, 2 or 3 in relation to learning, or was there no difference?

1 2 3 No difference

Give your reason(s)

Appendix 7b) Phase 3- Main Study
Interview schedule – for student nurse interviews

THE VALUE OF DIGITAL STORIES TO ENHANCE EMPATHY

The aim to ascertain the extent to which the participants feel that digital stories contribute to empathic, person-centred learning. The participants will be shown three digital stories and then asked a series of Likert scale item questions, followed by open questions asking them to expand on reasons for their answers.

Brief for participants:

On a scale of 1 to 5, please rate the following statements which ask you about your thoughts on the stories you have seen:

(1=completely disagree; 2=disagree; 3=neutral; 4=agree; 5=completely agree)

The digital stories have helped me to understand what the parents experience and feel.

1 2 3 4 5

What is the reason for your answer?

The digital stories have increased my empathy towards parents and babies.

1 2 3 4 5

What is the reason for your answer?

Digital stories would increase empathy in others who work in neonatal care

1 2 3 4 5

What is the reason for your answer?

Seeing the parent journey through digital stories is useful for learning about neonatal care.

1 2 3 4 5

What is the reason for your answer?

Digital stories are an effective way to learn about the patient experience

1 2 3 4 5

What is the reason for your answer?

Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.

1 2 3 4 5

What is the reason for your answer?

Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.

1 2 3 4 5

What is the reason for your answer?

The information in the digital stories is clearly presented.

1 2 3 4 5

The digital stories have visual appeal.

1 2 3 4 5

The digital stories have an engaging presentation.

1 2 3 4 5

What are the reasons for your answers?

Out of the digital or the written format, which is the most effective way of learning about the emotions of parents and their experience?

Digital Written Combination No difference Other

Out of the digital or the written format, which is the most effective way of evoking empathy?

Digital Written Combination No difference Other

What are the reasons for your answers?

Did you prefer story 1, 2 or 3 in relation to learning, or was there no difference?

1 2 3 No difference

Give your reason(s)

What did you learn from the digital stories you watched / listened to above ('Another World', 'On the Edge' and / or 'Fighter')....

Do you think that watching and/or listening to digital stories will influence or change your practice in any way? If so, please explain.

Appendix 7c) Phase 3- Main Study
Questionnaire

The value of digital stories in neonatal care: your views

https://herts.onlinesurveys.ac.uk/the-value-of-digital-stories-in-neonatal-care-your-views

Introduction - view the digital stories

Thank you for taking part in this evaluation survey. I would welcome your views about the value and use of digital stories from the neonatal unit. A digital story is a brief video that uses text, pictures and voice to tell a story about someone's experience.

An information sheet has been sent separately to this link. Taking part in the survey means that you have given your consent to participate but you can stop the survey at any point if you change your mind.

The stories here are based on parent narratives about experiences of their neonatal stay and beyond. For links to three stories, see below. Each one lasts 2.5 - 4.5 minutes and they will each open in a separate window, so you can easily navigate between them and back to the survey. Please turn your sound on, then watch and listen to the stories and answer the questions that follow.

- Another World
- On the Edge
- Fighter

Many thanks for participating. Your views are valued and will contribute to making improvements and refinements to this material.

Your role and use of digital stories

1. What is your current job title / role?

a. If you selected Other, please specify:

b. Which country (s) do you work in?

c. How many years have you worked in neonatal care?

d. Have you used digital stories when studying or teaching? Yes / No

i. If Yes, please explain

Your views

2. Please can you rate the following statements about the 3 digital stories you have watched (links above). Please don't select more than 1 answer(s) per row.

Completely disagree Disagree Unsure / neutral Agree Completely agree

- The digital stories have helped me to understand what the parents experience and feel.
- The digital stories have increased my empathy towards parents and babies.
- Digital stories would increase empathy in others who work in neonatal care
- Seeing the parent journey through digital stories is useful for learning about neonatal care.
- Digital stories are an effective way to learn about the patient experience
- Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.
- Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.
- The information in the digital stories is clearly presented.
- The digital stories have visual appeal.
- The digital stories have an engaging presentation.

3. Please add any further comments to explain your answers.

4. Which of the following formats is the most effective way to learn about the emotions of parents and their experience?

Digital Written Combination No difference Other

a. Please give reasons for your answer to this question in the box below.

5. Which format of storytelling is the most effective way of evoking empathy?

Digital Written Combination No difference Other

a. Please give reasons for your answer to this question in the box below.

6. Please identify what you learnt from the digital stories you watched / listened to above ('Another World', 'On the Edge' and / or 'Fighter')....

7. Do you think that watching and/or listening to digital stories will influence or change your practice in any way?

Yes No Don't know

a. Please give reasons for your answer to this question in the box below.

8.Empathy can be seen in terms of three different levels: Affective (emotional) empathy- feeling an emotional response to another. Cognitive empathy – being able to take the perspective of another. Behavioural empathy- the behavioural expression of empathy towards another (this is sometimes called compassionate empathy; i.e. behaving more compassionately towards another). Having watched / listened to three examples of digital stories of parent experiences, how might these and others like them, have an impact on the following? Please rate them on a scale of 1-5

Please don't select more than 1 answer(s) per row.

No impact/ Slight impact /Don't know / unsure /Moderate impact / Significant impact

- Affective (emotional empathy)
- Cognitive empathy
- Behavioural (compassionate) empathy
- Understanding the emotions of parents
- Understanding what parents need to make their experience better

a. Please add any further comments to explain your answers.

Thank you for participating

Once, again thank you for taking the time to participate in this survey. Your views will inform future digital storytelling resource development.

Appendix 7d) Phase 3- Main Study
Raw data extracts- Point-of-view exercise

1: Describe how you think you would have felt when your baby was admitted to the NNU

Sad scared worried helpless
Nervous emotional
Shocked sad
Lost
Scared worried distraught
Distressed heartbroken
Disappointed in myself, heartbroken
Sad scared nervous
Heartbroken worried
Very scary different to what's expected when having a baby
Scared confused
Sad stressed worried
Entering the unknown
Scared uncertain for our future
Scared overwhelmed as a parent
Distressed upset overwhelmed
Confused lost alone scared disappointed terrified
Frightened intimidated by unknown equipment and procedures
Scared Fearful wanting to run away and not deal with it sad and I have lost out on my pregnancy
Scared worried emotional

2: Describe how you think you would have felt when you first saw your baby

Shocked emotional numb
Speechless
Frightened, in love
Upset
Scared relieved
Shocked scared
In love protective
Terrifying to see how tiny they are, and all the machines
Scared
Overwhelmed
Heartbroken
Worried shocked
Anxious happy worried
Scared
Upset guilty that I didn't carry them correctly
Heartbroken Upset angry as if it was my fault this happened
Small fragile can break can't touch them due to the barrier of incubator
Why is this happening to me or us I don't feel connected to my baby Is this really my baby

3: Describe how you think you would have felt during the long length of stay in the NNU
Fed-up frustrated anxious hopeful
Exhausted anxious
Alone lost
Exhausted
Worried on edge
Hopeless
Drained hopeful
Time going so slow and nervous for every day to come
Distressed worried loss of hope
Like it will last for ever
Tired
Overwhelmed
Confused constant up and down of emotions
Fear of the unknown
Upset about not being able to go home with the baby
Disconnected from the outside world and family and friends

4: Describe how you think you would have felt when your baby was discharged home
Elated scared watching baby constantly nervous
Happy but also frightened
Happily, and relieved, nervous, on edge
Elated
Relief
So happy
Relieved happy but scared I will damage him
Relieved nervous
Happy hopefulness
Relief but fear that you will no longer have the support of the nurses
Worried happy
Happy anxious
Thrilled relieved
Scared happy overwhelmed
Relieved scared
Excited but also really scared and panicky as well as alone
Relieved scared
Happy concerned that something would go wrong
Relieved unsure
Scared happy ready unprepared at the same time potentially alone
The new journey to begin full of emotions
Happy nervous
Excited nervous support system gone not knowing what to do next now that the baby is finally home going through the what ifs
Unprotected when discharged home
Happy to go home nervous about doing everything myself
Am I on my own now? What do I do? Is my baby okay?

Happy that you are not in hospital but anxious for the unknown. What will happen next?
Worried scared relieved happy
Very happy not alone with support gone
Relieved alone how am I going to do this for?
Relieved scared worried that something would go wrong

What enhanced learning?
The writing emphasised some parts
The images to explain the story show realism and stand out
The colours, quotes, pictures, size of font
Animation and subtitles of keywords, using different voices
The titles of the episodes really stuck in my mind as they were powerful messages
Emotions in the patient voice
The visuals
The feel of powerlessness as parents
Having the animation but also with some of the words/ phrases coming out was intriguing
Intensity of the care and how much reassurance the parents will need
How the parents feel when first seeing the machines
Pictures showing the emotions and how overwhelming it all is
The dads view
The narrators were taken from the parents' perspective
I find it useful to have a visual aid, the information about procedures is also useful
Understanding emotions from the parents' point of view
monitoring required
Parents and words helps to empathise

What hindered learning?
Bit long winded
Animations that don't move
Nothing hindered learning for of x21 - all was very good
How grateful they were for their support
I found the and other world illustrations distracting rather than helping
The second video clip had fewer visuals
Maybe explaining terminology?
The changing of colour and the people in consistency within the connection film
Connections – images merged together, making it harder to identify what's happening
The first clip connections, the animation didn't hold my interest as much, but I liked the use of key phrases of text on the screen as quotations. However, the words did not always fit with what was being spoken on the audio and for someone with dyslexia (me), this made it hard to follow in places.
The last video was a bit funny engaging in terms of animation and the storytellers tone of voice
Didn't really like the third pictures as it was like a child drawing

Appendix 7e) Raw data extracts- Questionnaire quantitative analysis summary

Questionnaire item		ALL (n=137)	Children's Nursing Students (n=67)	Adult and MH students (n=31)	Practice staff (n=39)
Q2.1- The digital stories have helped me to understand what parents experience and feel **(Figure 8.6)**	Completely agree	**85 (62.1%)**	**42 (63%)**	**22 (71%)**	**21 (54%)**
	Agree	**48 (35.1%)**	**22 (33%)**	**9 (29%)**	**17 (43.5%)**
	Neutral/don't know	**3 (2.1%)**	**3 (4%)**	**0**	**0**
	Disagree	**0**	**0**	**0**	**0**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q2.2- The digital stories have increased my empathy towards parents and babies **(Figure 8.7)**	Completely agree	**69 (50.4%)**	**39 (58.3%)**	**17 (54.8%)**	**13 (33.3%)**
	Agree	**54 (39.4%)**	**23 (34.3%)**	**13 (42%)**	**18 (46.2%)**
	Neutral/don't know	**10 (7.3%)**	**4 (5.9%)**	**1 (3.2%)**	**5 (13%)**
	Disagree	**3 (2.2%)**	**1 (1.5%)**	**0**	**2 (5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q 2.3 - Digital stories would increase empathy and others who work in neonatal care	Completely agree	**80 (58.4%)**	**21 (31.3%)**	**25 (80.6%)**	**34 (87.3%)**
	Agree	**40 (29.2%)**	**32 (47.7%)**	**5 (16.2%)**	**3 (7.7%)**
	Neutral/don't know	**16 (11.7%)**	**14 (21%)**	**1 (3.2%)**	**1 (2.5%)**
	Disagree	**0**	**0**	**0**	**0**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q 2.4 – Seeing the parent journey through digital stories is useful for learning about neonatal care **(Figure 8.8)**	Completely agree	**67 (49%)**	**28 (41.8%)**	**18 (58.1%)**	**21 (54%)**
	Agree	**58 (42.3%)**	**32 (47.8%)**	**11 (35.6%)**	**15 (38.5%)**
	Neutral/don't know	**10 (7.3%)**	**7 (10.4%)**	**2 (6.5%)**	**1 (2.5%)**
	Disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q 2.5- Digital stories are an effective way to learn about the patient experience **(Figure 8.9)**	Completely agree	**80 (58.4%)**	**47 (70.2%)**	**10 (32.3%)**	**23 (59%)**
	Agree	**46 (33.6%)**	**15 (22.4%)**	**19 (61.2%)**	**12 (31%)**
	Neutral/don't know	**9 (6.6%)**	**5 (7.4%)**	**2 (6.5%)**	**2 (5%)**
	Disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q 2.6- Seeing the neonatal journey through storytelling will enable me to give more effective, empathic person-centred care **(Figure 8.10)**	Completely agree	**64 (46.7%)**	**31 (46.3%)**	**21 (67.8%)**	**12 (30.8%)**
	Agree	**52 (38%)**	**30 (44.8%)**	**7 (22.6%)**	**15 (38.5%)**
	Neutral/don't know	**17 (12.4%)**	**5 (7.4%)**	**3 (9.6%)**	**9**
	Disagree	**3 (2.2%)**	**1 (1.5%)**	**0**	**2**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1**
Q2.7- The digital stories have helped me to understand the needs of parents as service users more effectively in the field of neonatal care	Completely agree	**77 (56.2%)**	**46 (68.8%)**	**17 (54.9%)**	**14 (35.9%)**
	Agree	**41 (30%)**	**18 (27.2%)**	**8 (25.8%)**	**15 (38.5%)**
	Neutral/don't know	**16 (11.7%)**	**3 (4%)**	**6 (19.3%)**	**7 (18.1%)**
	Disagree	**2 (1.4%)**	**0**	**0**	**2 (5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**

Questionnaire item		ALL (n=137)	Children's Nursing Students (n=67)	Adult and MH students (n=31)	Practice staff (n=39)
Q2.8- The information in the digital stories is clearly presented **(Figure 8.17)**	Completely agree	**84 (61.3%)**	**43 (64.2%)**	**19 (61.3%)**	**22 (56.4%)**
	Agree	**35 (25.6%)**	**11 (16.4%)**	**8 (25.8%)**	**16 (41.1%)**
	Neutral/don't know	**17 (12.4%)**	**13 (19.4%)**	**4 (12.9%)**	**0**
	Disagree	**0**	**0**	**0**	**0**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q2.9- The digital stories have visual appeal **(Figure 8.18)**	Completely agree	**75 (54.8%)**	**43 (64.2%)**	**16 (51.6%)**	**16 (41%)**
	Agree	**50 (36.5%)**	**24 (35.8%)**	**10 (32.2%)**	**16 (41%)**
	Neutral/don't know	**10 (7.3%)**	**0**	**5 (16.2%)**	**5 (12.8%)**
	Disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q2.10- The digital stories have an engaging presentation **(Figure 8.19)**	Completely agree	**70 (51.1%)**	**37 (55.2%)**	**16 (51.6%)**	**17 (43.8%)**
	Agree	**53 (38.7%)**	**22 (32.8%)**	**13 (41.9%)**	**18 (46.2%)**
	Neutral/don't know	**12 (8.8%)**	**8 (12%)**	**2 (6.5%)**	**2 (5%)**
	Disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
	Completely disagree	**1 (0.7%)**	**0**	**0**	**1 (2.5%)**
Q4- Which of the following formats is the most effective way to learn about the emotions of parents and their experience (multi answer*) **(Figure 8.20)**	Digital	**92 ***	**48**	**31**	**13**
	Written	**9**	**4**	**4**	**1**
	Combination	**42**	**10**	**5**	**27**
	No difference	**8**	**5**	**2**	**1**
	Other	**3**	**0**	**0**	**3**
	***NB: no percentages provided as this was a multi-answer question				
Q5- Which format of storytelling is the most effective way of evoking empathy (multi answer*) **(Figure 8.21)**	Digital	**93 ***	**46**	**31**	**46**
	Written	**3**	**2**	**3**	**2**
	Combination	**32**	**10**	**0**	**10**
	No difference	**11**	**9**	**0**	**9**
	Other	**1**	**0**	**0**	**0**
	***NB: no percentages provided as this was a multi-answer question				
Q7- Will watching/listening to digital stories influence or change your practice? **(Figure 8.11)**	Yes	**92 (67.1%)**	**37 (55.2%)**	**28 (90.3%)**	**27 (69.3%)**
	No	**7 (5.2%)**	**0**	**0**	**7 (17.9%)**
	Don't know	**38 (27.7%)**	**30 (44.8%)**	**3 (9.7%)**	**5 (12.8%)**
***NB- The questions below were asked of those completing the online version of the questionnaire only so for ALL, n=70					
		*n=70		n=31	n=39
Q8.1- Impact of the digital stories on affective (emotional) empathy **(Figure 8.12)**	Significant	**36 (51.4%)**	**N/A**	**18 (58%)**	**18 (46.2%)**
	Moderate	**27 (38.5%)**		**8 (25.8%)**	**19 (48.8%)**
	Don't know/unsure	**5 (7.1%)**		**5 (16.2%)**	**0**
	Slight	**2 (14.2%)**		**0**	**2 (5%)**
	None	**0**		**0**	**0**

Questionnaire item		ALL (n=70)	Children's Nursing Students	Adult and MH students (n=31)	Practice staff (n=39)
Q8.2- Impact of the digital stories on cognitive empathy **(Figure 8.13)**	Significant	**34 (48.6%)**	**N/A**	**16 (51.6%)**	**18 (46.2%)**
	Moderate	**27 (38.6%)**		**10 (32.2%)**	**17 (43.8%)**
	Don't know/unsure	**6 (8.6%)**		**4 (12.9%)**	**2 (5%)**
	Slight	**3 (4.2%)**		**1 (3.2%)**	**2 (5%)**
	None	**0**		**0**	**0**
Q8.3- Impact of the digital stories on behavioural (compassionate) empathy **(Figure 8.14)**	Significant	**28 (40%)**	**N/A**	**14 (45.1%)**	**14 (36%)**
	Moderate	**32 (45.7%)**		**11 (35.6%)**	**21 (54%)**
	Don't know/unsure	**7 (10%)**		**5 (16.1%)**	**2 (5%)**
	Slight	**3 (4.3%)**		**1 (3.2%)**	**2 (5%)**
	None	**0**		**0**	**0**
Q8.4- Impact of the digital stories on understanding the emotions of parents **(Figure 8.15)**	Significant	**44 (62.8%)**	**N/A**	**20 (64.5%)**	**24 (61.5%)**
	Moderate	**22 (31.4%)**		**10 (32.3%)**	**12 (31%)**
	Don't know/unsure	**1 (1.4%)**		**0**	**1 (2.5%)**
	Slight	**3 (4.4%)**		**1 (3.2%)**	**2 (5%)**
	None	**0**		**0**	**0**
Q8.5- Impact of the digital stories on understanding what parents need to make their experience better **(Figure 8.16)**	Significant	**40 (57.1%)**	**N/A**	**21 (67.8%)**	**19 (48.8%)**
	Moderate	**23 (32.8%)**		**8 (25.8%)**	**15 (38.5%)**
	Don't know/unsure	**4 (5.7%)**		**1 (3.2%)**	**3 (7.7%)**
	Slight	**3 (4.4%)**		**1 (3.2%)**	**2 (5%)**
	None	**0**		**0**	**0**

For open comments in response to Qs 3, 4a, 6, 7a and 8a: See Table 8.3 for themes

Appendix 7f) Phase 3- Main Study
Raw data extracts- Interview transcript

What did you learn from the digital stories you watched / listened to?

I learnt that both having a premature baby and being in the neonatal unit can be daunting and anxiety provoking for parents. I felt the videos were clear representation of what it is like in the unit. I related to what the parents said about apprehension towards holding the babies and the noises but from a student perspective. I could see clearly likes the emphasis on isolation that parents feel, particularly mothers who feel left out not having their babies.

Neonatal care can be a hard time for parents. It is important to understand each individual on their own and continually support them, providing sufficient person-centred care. It was clear to me that each family felt very overwhelmed and frightened when pushed into the world of neonatal care. However, each story portrayed that despite the hurdles along the way, the parents learn to cope and become stronger.

The whole story, from birth, stay… home… experiencing the whole story really brings the story / experience to life.

Do you think that watching / listening to digital stories will change your practice in any way?

It stresses the importance of patient and family welfare within the neonatal unit. Ensuring the parents often be supported and encouraged to participate in their baby's care. The videos stress the importance of informing and repairing parents with what to expect within the unit and with their child's care

I will become more empathic towards the parents and make sure they are continuously supported. I will remember the person-centred care is key to delivering affective care and understanding the parents better.

I think the stories will help me to see the neonatal journey from a parent's view which will assist me to support them through that journey with both the physical care of the baby and also the emotional support for mum and dad

Being able to see how it feels in the parent's perspective and also attaches the feeling of seeing it every day (being immune) and taking each parent as an individual of their own experience

Gives an increase in awareness so attitudes and approaches can be adjusted

I feel that when I do my neonatal placement, I will be more aware and sensitive as to how the parents may be feeling, I can empathise with the journey they are going through and help make them cope with changes in their child's care

Appendix 7g) Phase 3- Main Study
Raw data extracts- Questionnaire open responses

What did you learn from the digital stories you watched / listened to?

The parents are completely unfamiliar with the neonatal unit and this isn't always recognised by nursing staff

I learnt that the parents go through a lot during their time on neonates with their babies. At times, it is a rollercoaster of emotions and that they need supporting as well as the baby.

That parents may have to stay on the neonatal units for prolonged periods and this affects their emotions. Basic support is crucial. Parents feel they may hurt their child and so building up their confidence is important.

I learnt about how the parents were identifying the support they received from different professionals like the GP surgery, neonatal units and children's nurse. This reflected on how compassionate they were and extending care to both the baby and the parents, giving them reassurance.

How parents must feel when their babies got to the neonatal unit.

That pregnancy / delivery is different for all parents and for various different reasons. It is unexpected and is hard to prepare for difficult situations.

Neonatal care is crucial in ensuring premature children grow and this affects parents severely

The parents' perspective

How parents feel whilst babies are in the neonatal units and how it continues to affect them afterwards, parents need a lot of support

How the parent feels which means that it could offer more specific support

How parents feel when their child is in neonatal unit, understanding the possible complications the child might have growing up.

How emotionally tiring it is on the parents and families

How scary it is for the parents when having a neonate baby. It is a sensitive time and parents need support

Do you think that watching / listening to digital stories will change your practice in any way?

I will be able to support and care for a child in a holistic way by putting the family centred care into practice. It has made me see it from the parent's perspective and what they were going through

Don't know- have to have more experience to determine this

I have gained an understanding of how parents feel and what they go through

Understand how it affects parents – how scared I feel, and I learnt about some of the staff the babies and parents come through for

I would be more empathic and find more ways to support parents and patients

I have no previous experience with neonate's, so they gave me some insight

As it shows what babies and families go through in neonate's. I would be more sensitive in these circumstances

Allows me to better understand their feelings which in turn allows me to empathise with them.

Because you understand how the parents feel of it, always communicate these feelings at the time. It enhances care and compassion skills

I will have more understanding for the parents and what they are going through

I don't know -I feel that I was always quite engaging and empathic towards patients and caregivers, but I know there's always room for improvement

Because you have more of an understanding of the impact you have. I will be aware that parents are fearful and to keep encouraging

Yes, it always this will help me to think about how parents feel and will also, to an extent prepare me so that I am able to know the resilience I need

It helps us understand more about what they had to go through and how they needed the support

I will be able to empathise more clearly with parents about how the different areas of the hospital can make them feel

Digital stories allow you to recognise how scary the neonatal unit can be for parents

Hearing parent experiences aids my understanding thus making me more empathic. So, I can adapt my practice in response to this.

Appendix 7h) Phase 3- Main Study
Examples of survey responses – selected participants

Student nurse

Jisc Online surveys

The value of digital Stories in neonatal care: your views

Response ID	Start date	Completion date	
361134-361125-35604846	23 May 2018, 19:48 (BST)	23 May 2018, 19:57 (BST)	

Introduction - view the digital stories

Your role and use of digital stories

1	What is your current job title / role?	Student nurse
1.a	If you selected Other, please specify:	
1.b	Which country (s) do you work in?	UK
1.c	How many years have you worked in neonatal care?	For a student placement only
1.d	Have you used digital stories when studying or teaching?	No
1.d.i	If Yes, please explain	

Your views

2	Please can you rate the following statements about the 3 digital stories you have watched (links above).	
2.1	The digital stories have helped me to understand what the parents experience and feel.	Agree
2.2	The digital stories have increased my empathy towards parents and babies.	Completely agree
2.3	Digital stories would increase empathy in others who work in neonatal care	Completely agree
2.4	Seeing the parent journey through digital stories is useful for learning about neonatal care.	Completely agree
2.5	Digital stories are an effective way to learn about the patient experience.	Completely agree
2.6	Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.	Completely agree

2.7	Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.	Completely agree
2.8	The information in the digital stories is clearly presented.	Agree
2.9	The digital stories have visual appeal.	Agree
2.10	The digital stories have an engaging presentation.	Agree

3	Please add any further comments to explain your answers.	

4	Which of the following formats is the most effective way to learn about the emotions of parents and their experience?	Combination
4.a	Please give reasons for your answer to this question in the box below.	

5	Which format of storytelling is the most effective way of evoking empathy?	Digital
5.a	Please give reasons for your answer to this question in the box below.	

6	Please identify what you learnt from the digital stories you watched / listened to above ('Another World', 'On the Edge' and / or 'Fighter')….	The family are presented with a terrifying situation which they have no preparation for. They do not know how to react to this and some blame themselves but regardless they want to be there for their babies.

7	Do you think that watching and/or listening to digital stories will influence or change your practice in any way?	Yes
7.a	Please give reasons for your answer to this question in the box below.	Hearing parent experiences aids my understanding thus making me more empathetic. So I can adapt my practice in response to this.

8	Empathy can be seen in terms of three different levels: Affective (emotional) empathy- feeling an emotional response to another. Cognitive empathy – being able to take the perspective of another. Behavioural empathy- the behavioural expression of empathy towards another (this is sometimes called compassionate empathy; i.e. behaving more compassionately towards another). Having watched / listened to three examples of digital stories of parent experiences, how might these and others like them, have an impact on the following? Please rate them on a scale of 1-5	
8.1	Affective (emotional empathy)	Moderate impact
8.2	Cognitive empathy	Slight impact
8.3	Behavioural (compassionate) empathy	Significant impact
8.4	Understanding the emotions of parents	Moderate impact

8.5	Understanding what parents need to make their experience better	Significant impact
8.a	Please add any further comments to explain your answers.	

Nurse in clinical practice

Jisc Online surveys

The value of digital Stories in neonatal care: your views

Response ID	Start date	Completion date	
361134-361125-35630295	24 May 2018, 12:57 (BST)	24 May 2018, 13:12 (BST)	

Introduction - view the digital stories

Your role and use of digital stories

1	What is your current job title / role?	Nurse (in clinical practice)
1.a	If you selected Other, please specify:	
1.b	Which country (s) do you work in?	Uk
1.c	How many years have you worked in neonatal care?	1 - 5 years
1.d	Have you used digital stories when studying or teaching?	No
1.d.i	If Yes, please explain	

2	Please can you rate the following statements about the 3 digital stories you have watched (links above).	
2.1	The digital stories have helped me to understand what the parents experience and feel.	Completely agree
2.2	The digital stories have increased my empathy towards parents and babies.	Agree
2.3	Digital stories would increase empathy in others who work in neonatal care	Completely agree
2.4	Seeing the parent journey through digital stories is useful for learning about neonatal care.	Completely agree
2.5	Digital stories are an effective way to learn about the patient experience.	Completely agree
2.6	Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.	Unsure / neutral

2.7	Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.	Unsure / neutral
2.8	The information in the digital stories is clearly presented.	Completely agree
2.9	The digital stories have visual appeal.	Completely agree
2.10	The digital stories have an engaging presentation.	Completely agree

3	Please add any further comments to explain your answers.	

4	Which of the following formats is the most effective way to learn about the emotions of parents and their experience?	Digital
4.a	Please give reasons for your answer to this question in the box below.	

5	Which format of storytelling is the most effective way of evoking empathy?	Digital
5.a	Please give reasons for your answer to this question in the box below.	

6	Please identify what you learnt from the digital stories you watched / listened to above ('Another World', 'On the Edge' and / or 'Fighter')….	There is a lot of parents that dont know about the neontal unit. As this is not explained while they are pregant. But yet all three story have gone through similar feelings and worries

7	Do you think that watching and/or listening to digital stories will influence or change your practice in any way?	Yes
7.a	Please give reasons for your answer to this question in the box below.	As we some times get caught up with caring for the baby that we forget get what parents must be feeling. By watching the video it brings back that even though we work there for parents this can be a scare day everyday and the not knowing can be scary.

8	Empathy can be seen in terms of three different levels: Affective (emotional) empathy- feeling an emotional response to another. Cognitive empathy – being able to take the perspective of another. Behavioural empathy- the behavioural expression of empathy towards another (this is sometimes called compassionate empathy; i.e. behaving more compassionately towards another). Having watched / listened to three examples of digital stories of parent experiences, how might these and others like them, have an impact on the following? Please rate them on a scale of 1-5	
8.1	Affective (emotional empathy)	Significant impact

8.2	Cognitive empathy	Moderate impact
8.3	Behavioural (compassionate) empathy	Moderate impact
8.4	Understanding the emotions of parents	Significant impact
8.5	Understanding what parents need to make their experience better	Moderate impact
8.a	Please add any further comments to explain your answers.	

Clinical nurse educator

Jisc Online surveys

The value of digital Stories in neonatal care: your views

Response ID	Start date	Completion date	
361134-361125-35618287	24 May 2018, 08:53 (BST)	24 May 2018, 09:17 (BST)	

Introduction - view the digital stories

Your role and use of digital stories

1	What is your current job title / role?	Educator (clinical)
1.a	If you selected Other, please specify:	
1.b	Which country (s) do you work in?	UK
1.c	How many years have you worked in neonatal care?	More than 10 years
1.d	Have you used digital stories when studying or teaching?	No
1.d.i	If Yes, please explain	

Your views

2	Please can you rate the following statements about the 3 digital stories you have watched (links above).	
2.1	The digital stories have helped me to understand what the parents experience and feel.	Agree
2.2	The digital stories have increased my empathy towards parents and babies.	Unsure / neutral
2.3	Digital stories would increase empathy in others who work in neonatal care	Completely agree
2.4	Seeing the parent journey through digital stories is useful for learning about neonatal care.	Completely agree
2.5	Digital stories are an effective way to learn about the patient experience.	Completely agree
2.6	Seeing the neonatal journey through storytelling will enable me to give more effective empathic, person-centred care to neonates and families.	Agree
2.7	Thinking about the digital stories has helped me to understand the needs of parents as service users more effectively, in the field of neonatal care.	Unsure / neutral
2.8	The information in the digital stories is clearly presented.	Agree
2.9	The digital stories have visual appeal.	Completely agree
2.10	The digital stories have an engaging presentation.	Completely agree

3	Please add any further comments to explain your answers.	Very easy to watch, yet thought provoking - very useful to novice learners

4	Which of the following formats is the most effective way to learn about the emotions of parents and their experience?	Digital
4.a	Please give reasons for your answer to this question in the box below.	

5	Which format of storytelling is the most effective way of evoking empathy?	Combination
5.a	Please give reasons for your answer to this question in the box below.	

6	Please identify what you learnt from the digital stories you watched / listened to above ('Another World', 'On the Edge' and / or 'Fighter')….	That despite the electronic world we are now exposed to, the technology in the ITU is still alien to parents

7	Do you think that watching and/or listening to digital stories will influence or change your practice in any way?	Don't know
7.a	Please give reasons for your answer to this question in the box below.	Having worked for many years in neonates, will probably not change my practice as I hope I already have an understanding of parents' feelings but would definitely recommend to newer staff

8	Empathy can be seen in terms of three different levels: Affective (emotional) empathy- feeling an emotional response to another. Cognitive empathy – being able to take the perspective of another. Behavioural empathy- the behavioural expression of empathy towards another (this is sometimes called compassionate empathy; i.e. behaving more compassionately towards another). Having watched / listened to three examples of digital stories of parent experiences, how might these and others like them, have an impact on the following? Please rate them on a scale of 1-5	
8.1	Affective (emotional empathy)	Moderate impact
8.2	Cognitive empathy	Significant impact
8.3	Behavioural (compassionate) empathy	Moderate impact

8.4	Understanding the emotions of parents	Moderate impact
8.5	Understanding what parents need to make their experience better	Significant impact
8.a	Please add any further comments to explain your answers.	

APPENDIX 8

Appendix 8: Summary of training and dissemination outputs

Training (2013-2019)

Digital literacy skills acquired and used:

- *Dragon Naturally Speaking*- for interview transcription
- *NVivo* – qualitative data analysis management software
- *Mendeley*- Citation management system
- *Adobe Premier Pro* – Video creation software
- *WordArt* – word cloud creations
- *WordPress*- web-site creation and web-design
- *Bristol Online Surveys* (BOS)– for online survey creation and analysis

Training courses completed

- E-learning course with 'Future Learn': 6 weeks, online: *Designing E-learning for health* (https://www.futurelearn.com/courses/e-learning-health)
- Digital storytelling work-shop with *Patient Voices*: 3-days (https://www.patientvoices.org.uk/uohreflection-htm)
- Qualitative data analysis Masterclass with David Silverman: one-day course at University of Southampton

- University of Hertfordshire: Research Development programme sessions
  - Qualitative Analysis
  - Interviewing
  - How to build a web-site in 3 hours
  - Disseminating your research online
  - NVivo training
  - Literature searching
  - Excel

Publications

- Petty, J. (2016a). Learning from narrative to understand person-centred experience: a literature review. *Journal of Neonatal Nursing*. 22(6), 297-308.
- Petty, J. (2016b). Appreciation of the neonatal care experience through the eyes of student nurses: The Development of a Storytelling learning resource. *LINK* (UH online journal). https://www.herts.ac.uk/link/volume-2,-issue-2/appreciation-of-the-neonatal-care-experience-through-the-eyes-of-student-nurses
- Petty, J. (2017a). Creating stories for learning about the neonatal care experience through the eyes of student nurses: An interpretive, narrative study. *Nurse Education Today*. 48: 25-32.
- Petty, J. (2017b). Emotion work in qualitative research: interviewing parents about neonatal care. *Nurse Researcher*, 25(3), 26–30.
- Petty, J and Treves, R (2017). Development of a digital storytelling resource to support children's nursing students in neonatal care. *Nursing Children and Young People*. 29(2), 32-37.

- Petty, J, Jarvis, J and Thomas, R. (2018a). Core Story Creation: Analysing narratives to construct stories for learning. *Nurse Researcher*. 24(4), 46-50.
- Petty J, Jarvis J, Thomas R. (2019a). Understanding parents' emotional experiences for neonatal education: A narrative, interpretive approach. *Journal of Clinical Nursing*. 28(9-10), 911-1924.
- Petty J, Jarvis J, Thomas R. (2019b). Listening to the parent voice to inform person-centred neonatal care. *Journal of Neonatal Nursing*. 25(3), 121-126.
- Petty J, Jarvis J, Thomas R. (2019c). Using parent metaphors for learning about the neonatal care experience: an interpretive perspective. *Journal of Child Health Care* (online, advanced publication)

Conference presentations

- May 2019. Petty, J, Whiting, L, Fowler, C and Green, G. *Nursing knowledge in supporting parents of premature babies at home.* Oral presentation for the Council of International Neonatal Nurses (COINN) conference, Auckland, New Zealand.
- May 2019. Petty, J. *Understanding and teaching the parent's emotional experience through digital storytelling.* Poster presentation for the Council of International Neonatal Nurses (COINN) conference, Auckland, New Zealand.
- May 2019. Petty, J and Whiting, L. *Parent perspectives of premature infant discharge from hospital & health professional knowledge.* Oral presentation. University of Hertfordshire (UH), School of Health and Social Work (HSK) Research Seminar series.
- March 2019. *Empathic learning: teaching the parent's emotional experience through digital storytelling*. Oral presentation. Royal College of Nursing Education Forum, Bristol.
- October 2018. Petty, J. *Innovations in Education and Training*. Oral presentation. United European Neonatal and Paediatric Society. (UENPS). Bucharest, Romania.
- July 2018. Petty, J. *Metaphor analysis for learning: an example from educational research in children's nursing.* Oral presentation. UH HSK Research conference
- June 2018. Petty, J, Jarvis, J and Thomas, R. *Digital Storytelling in nurse education: Creating & telling stories to engage learners in the classroom.* Video presentation. UH Learning and Teaching conference.
- June 2018. Petty, J, Darby, V, Fearns, D, Goode, K and Nagalingam, K. *The value of digital storytelling for nurse education: Our experience and reflections*. Oral presentation. UH HSK Learning and Teaching conference
- May 2018. Petty, J. *Core Story Creation: Analysing narratives for learning*. Poster presentation. University of Cambridge School of Education, Kaleidoscope conference.
- April 2018. Petty, J and Whiting, L. *Parents' experiences of caring for an extremely premature infant at home.* Oral concurrent session. Royal College Nursing International Research Conference, Birmingham University.
- January 2018. Petty, J and Whiting, L. Caring for an extremely premature infant at home after neonatal intensive care: Parents' experiences. Oral presentation. Beds and Herts Education Network meeting, East and North Herts NHS Trust.
- November 2017, Petty, J. *A global view of nurse education- exploring parental and nurses' perspectives.* Joint European Neonatal Society Congress, Venice, Italy.

- September 2017. Petty, J. *Exploring the parent's experience through narrative.* Oral presentation. Australian Council of Neonatal Nurses (ACNN) Seminar, Sydney, Australia.
- June 2017. Petty, J. *Digital representation of the patient journey using the ASPIRE framework: developing reusable learning objects to tell stories*. Oral Poster presentation. UH, HSK, Learning & Teaching conference.
- June 2017. Petty, J. '*Narrative Inquiry- working with stories to understand experience in a learning and teaching context'.* Oral presentation. UH HSK Research Seminar series.
- April 2017. Petty, J, Whiting, L, Roberts. S & Meager, G. *Evaluation of the NHS England Youth Forum: How service user involvement of young people in healthcare can contribute to research informed teaching*. 3-minute oral poster presentation. UH Learning and Teaching conference.
- August 2016: Petty, J. '*Storytelling as a strategy to improve the learning experience of nursing students in neonatal care' and 'Appreciation of the neonatal care experience through the eyes of student nurses: creating stories for learning'.* Oral and poster presentations. COINN conference, Vancouver, Canada.
- July 2016: Petty, J. '*Narratives from preterm birth and beyond: phase 1. Collecting stories from parents of premature neonates to teach nursing students about the lived experience of person-centred neonatal care'.* Oral presentation. UH HSK, Research conference.
- March 2016: Petty, J. '*An evaluation of storytelling as a strategy to improve the learning experience of children's nursing students in neonatal care'.* Poster and Oral presentations. HSK, Learning and Teaching conference.
- March 2016: Petty, J. '*Appreciation of neonatal care through the eyes of learners: Using children's nurses' stories to enhance the learning experience for others.'* Oral presentation. RCN Education Forum, Telford.