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**Understanding parents' emotional experiences for neonatal education:  
A narrative, interpretive approach.**

Running (short) title: **Learning from parents' emotional experience**

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**Abstract:**

*Aims & objectives:* To explore the emotional experiences of parents who have had premature babies to inform and educate neonatal nurses and health professionals in this field.

*Background:* Parents find the neonatal unit a daunting and unfamiliar place leading to anxiety, uncertainty and fear about the future of their baby. Parents have significant emotional needs in relation to assisting them to cope with their neonatal experience. In line with a family-centred approach to neonatal education, it is essential to teach health professionals about the emotional impact of neonatal care based on an appreciation of the parent experience.

*Design:* A narrative-based, interpretive approach was undertaken in line with constructivist learning theory.

*Methods:* Twenty narrative interviews took place, with a total of twenty-three parents of premature babies. Following core story creation to create coherent stories from the raw transcripts, thematic analysis of the narrative constructs using the principles of Braun and Clarke's (2014) framework was undertaken. The study methods were compliant with the consolidated criteria for reporting qualitative research (COREQ).

*Findings:* Thematic analysis revealed key themes relating to: parents' emotions through the whole neonatal experience, feelings towards the baby, the environment, the staff and the transitions through the different phases of neonatal care. Both negative and positive experiences were reported.

*Conclusion:* Understanding the emotional experience from the parent's perspective, following birth of their premature baby, informs empathic, family-centred teaching and learning within the neonatal education arena.

*Relevance to clinical practice:* Students and health professionals alike can learn what is important in the delivery of care that addresses the emotional needs of parents and families.

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.

### **Impact statement**

#### **What does this paper contribute to the wider global clinical community?**

- Parents of premature babies describe compelling emotional narratives when relaying their stories that can be used to teach others wherever they work in the world.
- In line with the principle of emotions being a source of knowledge, understanding the emotional experience of having a premature baby from the parent's perspective should be an essential part of neonatal education worldwide.
- It is vital that students, staff and educators alike understand the importance of empathic, family-centred care where parents' emotional needs are central, to inform and educate those who care for them globally.

### **Key words**

Parent narratives, emotional experience, empathic learning, narrative, interpretive inquiry

### **Running title**

Learning from parents' emotional experience

### **Introduction**

Learning to care for neonates and their parents safely and competently is a fundamental principle of neonatal education that enables the multi-disciplinary team to acquire a level of knowledge and skill for the delivery of high-quality care (Department of Health, UK, 2009).

It has been acknowledged that within the neonatal speciality, nurses should receive

specialised education in relation to clinical skills (Turrill, 2014) and knowledge. Neonatal intensive care is a practice area where nurses worldwide attend to, and care for the complex needs of babies with a variety of conditions (Spence et al, 2016). Curricula for education 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 neonate and family is to address the psychoemotional needs of parents and close family members so that care is '*person-centred*'. Less is known about the integration of person-centred, emotion based education into programmes, particularly so within the neonatal field where the repertoire of clinical skills and knowledge to support practice is wide-ranging (Petty, 2014). Person-centred care is about focusing care on the person rather than the needs of the service. The individual's personal requirements, in this context, the neonate and family, are central to care (Draper and Tetley, 2013). While person-centeredness as a concept has been explored in certain nursing fields (Laird et al, 2014; Schwind et al, 2014) , within the field of neonatal care it is 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, 2015). It is therefore essential to ensure that those in our care anywhere in the world, the neonates and their families, lie at the heart of care delivery. It follows then, that a *family-centred* approach to education and learning must ideally also hold true this central principle.

Leading from this it is imperative to grasp an understanding and appreciation of parents' perspectives by exploring their experiences (Petty, 2017). In other words, before nurses and health professionals can look after parents' *emotional* needs and teach others to do so, they should ideally come to understand them. This paper discusses a narrative based study that aimed to explore parents' experiences of the neonatal unit and thereafter following birth of

their premature neonate. Stories were created from a re-configuration of the parents' raw narratives and analysis drew out themes based around the emotions expressed, that brought to light the experiences of these parents throughout their neonatal care trajectory.

## **Background**

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). 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 a neonate, 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 (Aftyka et al, 2017; Wigert et al, 2014; Williams et al., 2018).

Present across global boundaries are significant emotional needs in relation to the support required to improve parent's neonatal care experience, extrapolated from research undertaken, for example in England, Europe, Northern Ireland and the United States (U.S.) respectively (Howell and Graham, 2011; Picker Europe, 2015; Franck, et al., 2017; Williams et al., 2018). This was also found after discharge at home, as found in a large survey across the United Kingdom (UK) (The Smallest Things, 2017). This has led to key recommendations including the need for practical, financial and feeding support, facilitation of parent participation in care and information giving that is consistent and timely. This was highlighted for example in a Swedish, questionnaire-based study (Larsson et al, 2017) that explored parents' experiences and support needs relating to preparation for going home from neonatal care.

Moreover, the importance of care delivery relating to the *emotional* experiences of parents in line with a family-centred approach needs emphasising. Further research again undertaken in Sweden, 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 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). Giving birth prematurely is seen as an abrupt barrier to the transition towards becoming a mother, with feelings of disconnection, inadequacy, inability to fulfil a parental role and, what Spinelli et al (2016) described in an Italian study, as ‘temporal suspension’ (Spinelli et al., 2016). To concur, the words isolation, helplessness and powerlessness are often expressed by parents in the neonatal unit as cited by a UK author, Taylor (2016).

Certainly, mothers of premature neonates go through significant uncertainty in attempting to feel like a proper mother (Aagaard and Hall, 2008) and it is acknowledged that care given should be emotionally sensitive. In addition, to add to the above work undertaken in Scandinavia, more recent literature considers fathers’ needs and how they should receive personalised support specifically addressed to them, as they can be often missed or side-lined. A UK-based 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 along with anticipatory fatherhood, evolving identity and the difficulties of juggling paid work with visiting the neonatal unit. In addition, Harvey & Pattison (2013) also in the UK, focused on care of fathers during resuscitation, suggesting a requirement for more specific education in how to support their needs. One recent Italian study, found that fathers of premature neonates preferred not to touch their baby for fear of damaging them, compared

to those of healthy newborns. These fathers also identified that their baby's appearance and the technological nature of the environment including equipment were significant stressors as well as reporting significant fear about their baby dying (Stefana et al, 2018).

These studies highlight important issues relating to the emotional impact on admission to the neonatal unit 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. A recent study in Northern Ireland did explore experiences over this time span (Franck et al, 2017) using secondary, interview data. Parents described a variation in the quality of their experiences and highlighted inconsistencies in staff communication as well as limited practical and emotional support. In another U.S. prospective cohort study on health outcomes and cost of breast milk feeds, secondary analysis 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 emotional vulnerability, the mothers were found to develop emotional resilience by accessing sources of support that actively promoted their mental health including key individuals such as peer feeding counsellors or advisors and nurses working at the bedside, found to positively support them and help them cope with their psychological distress.

Both these studies explored parent's experience using secondary data. Key recommendations were put forward in relation to emotional support but not to specifically inform educational development. There is a gap in work that has used primary interview data from parent narratives directly, to inform curricula development in the field of family-centred neonatal education. This is particularly important when teaching nurses and health professionals new to this field. The specific and unique nuances of the neonatal speciality must include this

inherent emotional perspective; recognising vulnerability of parents and the 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.

## **Methods**

**Aims:** This aim of the study was to gain insight into parent experiences and use their stories to teach students, nurses and health professionals enhancing their understanding of the parent perspective. This study was one component of a larger study that comprised three phases. Firstly, parent narratives were gained from interviews; secondly, the narratives were used to create digital stories and thirdly, their contribution in relation to the enhancement of empathic learning was explored. *This* paper specifically focuses on the first completed phase regarding an appreciation of the parent's emotional experience of having a premature baby through the trajectory of neonatal care. Follow-on work will be the subject of future publication(s). Appreciation in the context of this paper involves gaining a full awareness or understanding of a situation. In an educational context, this is essential to truly learn about a phenomenon particularly important in this area that explores emotional learning.

**Design:** The study adopts an interpretive, narrative design. The foundation of narrative inquiry is based on the principle that people comprehend and attribute meaning to their lives through story (Andrews et al, 2008) and is one way to think about and study experience (Clandinin and Connelly, 2000). Indeed, the many approaches to, and definitions of narrative inquiry all involve "storytelling" in some way. Narrative is regarded as a written, spoken or visual story that can be presented in various formats, serves many purposes, approached in a variety of different interpretive ways (DePoy & Gitlin, 2016). Narrative inquiry is often used to illustrate individuals' perspectives and give them a voice. Analysis of stories can be a



unique and in-depth way to gain insight and see the world through the eyes of others (Riley & Hawe, 2005). This is suited within healthcare and nursing where gaining insight into the reality of patients, or in the context of this study, *parents*, is a valuable and comprehensive means of understanding their experience.

Narrative is congruent with a constructivist theoretical approach to learning. As summarised by Jonassen et al (1999), learning is an engaging, active process in which the learner obtains and uses information to develop knowledge and meaning is then constructed from it. In other words, learning consists of individuals' constructed meanings. In the case of this study, narrative is the beginning; derived from parents' experiences which is then interpreted to assign meaning, for others to acquire knowledge. Here lies a close relationship between narrative, interpretivism and constructivism. Bruner summarises this in the "narrative construction of reality", the name given to his work (Bruner, 1991) in which he articulated how he believes that human beings organise experience and memories of events primarily in narrative form.

Participants and recruitment: Purposive sampling was employed. This is widely used in qualitative research and is a non-probability sampling method where participants are selected based on certain characteristics of a population and/or study objective. The study set out to recruit parents who had given birth to a premature baby (ies), who had spent a period greater than a week within the neonatal unit and had been discharged home, with the aim of gaining 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 37 weeks gestation and had spent less than a week in neonatal care.

In addition, participants were recruited on a volunteer basis through an identified gatekeeper linked to a well-known parent support charity, instrumental in bringing about initial contact between the parents and the researchers. This meant the researchers were not in control of the specific parent characteristics of those volunteering to tell their story, such as age or ethnicity, nor the number who would come forward. Each volunteer was interviewed for their story with the decision made to continue until the researchers agreed that saturation of data had been reached. For this reason, too, a strict time frame within which babies and parents had been discharged home was not set. Subsequently, the parents that volunteered for interview had all been discharged within the last ten years.

Overall, twenty-three participants were recruited comprising 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 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.

The twenty interviews 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. Originally, the interview schedule was semi-structured including prompts to follow the main, initial question that asked the parents to tell their story throughout pregnancy until the present day. However, it became clear during the initial

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interviews that prompts were not required and in fact, the interviews became narrative in nature. In the context of health, narrative interviewing is a way to collect participant stories about their health or illness experiences. 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 & Kirkpatrick, 2016). A ‘single question aimed at inducing narrative’ (SQUIN; Wengraf, 2009) was devised by the first author to elicit the parent’s story. This 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?*’

The interviews took place over a period of between sixty (minimum) and one hundred and five (maximum) minutes. They were recorded digitally and manually transcribed by the first author to enable her immersion in the data and familiarisation with emerging themes.

Transcripts were sent to and verified by the parents themselves.

Ethical approval was granted by the first author’s higher education institution (HEI) Social Sciences, Arts and Humanities Ethics Committee: Protocol number aEDU/PGR/UH/02074, which included assurances that all participant data would be stored securely and confidentially in line with current data protection laws, with any interview data fully anonymised. Informed consent to use interview narrative extracts for teaching purposes was also an essential part of the approval process due to the HIE regulations requiring that sharing of research participant data is undertaken with permission.

Analysis: There were various components to the analysis which was primarily carried out by the first author, with the second and third authors ensuring that they agreed with the methods,

reviewing data interpretation throughout the whole study. The researchers liaised regularly at each stage to ensure agreement and further verification of the emerging themes. Firstly, a process of core story creation was undertaken, otherwise known as emplotment. Each interview yielded raw narrative transcripts which were re-configured to create a coherent plot in storied, chronological form. The actual process of core story creation is the subject of a separate published paper (anonymous / blinded). Secondly, thematic analysis followed the story creation, congruent with the aforementioned work by Rossman et al (2017) where the actual stories from participants were used for the basis of analysis. Thematic analysis is appropriate in the context of the current paper, as the study focus at this stage was with the *content* of said stories; in other words, ‘what’ was spoken about in relation to experience, rather than ‘how’ it was told.

Thematic analysis of the text-based transcripts was undertaken using the principles of Braun and Clarke’s (2014) approach which involves: transcribing, familiarising, reading and re-reading the data, identifying initial points of importance and interest, coding them, and sorting codes into the identified themes. Finally, main and sub-themes are assigned and named (Braun & Clarke, 2014). Rationale for the use of this model arises from its clarity and staged approach which enables recurring themes and sub-themes to emerge from the participants’ stories. Once identified, NVivo (2012) was used to code the themes and organise the data in a manageable form. All original transcripts and the re-configured version (story) were sent to the parents to verify and confirm these were a true representation of events. The study is compliant with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al, 2007) (see Supplementary File 1).

## Results

The analysis of the narratives from the twenty parent interviews revealed themes in six key areas; 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, parent's 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 actual or potential 'conflicts' or of them acting 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 (i.e. neither positive or 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 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 2a outlines the sources (interviews) in which the themes arose and the total occurrences across them all. Table 2b outlines a summary of the main themes. 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).

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.

*"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)

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, 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.

*"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)

Certain factors were found to influence the emotional experience of parents; for example, time factors, the health status or condition of the baby and previous experience of premature birth (Table 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 time-frame 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’ experiences. However, the study was not comparing this issue. Moreover, difficulties with recall was not 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 5 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, 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 parent's 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 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 the majority were white, Caucasian which shall be referred to again later.



## The Baby

Vulnerability of their baby was voiced by parents and this was often shocking and hard 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.

*"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)

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.

*‘‘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

Often the environment was found to be a source of distress, presenting a barrier to being a parent. Isolation and darkness were also apparent, commented on as if this was oppressive and stifling as a place to spend so much time in. Twelve parents made comments to this effect.

*‘‘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)

Conversely, providing an environment that encourages proximity and avoids 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 holds a valued and happy memory for them in relation to the early days of their baby's lives.

*‘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

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 this point cannot be underestimated and goes a significant way to reducing emotional distress. Conflicts were noted, commonly about communication issues between staff and parents, or across different units and professionals.

*‘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)

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.

*“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

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.

*“ 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)

Conversely again however, regressions are 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.

*“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)

### 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.

*“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)

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.

*“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)

## Discussion

It was clear from the volume of data from twenty rich, in-depth interviews all lasting over an hour, the sheer extent of an *emotional* narrative, both negative and positive that was threaded through. These findings concur with other work internationally, where emotional experiences are identified (Turner et al., 2014; Williams et al., 2018). The negative emotional experiences highlighted previously such as distress, worry, anxiety and turmoil, are terms consistent with the aforementioned work from the UK, Sweden and U.S respectively from Crathern (2011), Flacking et al (2012) and Williams et al (2018). However, more positive views around coping and emotional resilience also feature in the literature and cited by some parents in this study; Rossman et al (2017) states 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” (pg. 435).

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Parents thoughts about their own baby is congruent with Green et al (2015) who state 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' (pg. 82). In relation to staff, the perceived positive value of their role in the provision of parental support was purported by Turner et al (2014) and in Trajkovski et al's (2016) work on the necessity for collaborative family centred care. The parents views on the neonatal environment as having a significant impact on their experience were consistent with various authors (Cleveland, 2008; Hall & Brinchmann, 2009; Williams et al., 2018); 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 trajectory of neonatal care (Ballantyne et al., 2017) and regarding going home, persistent accounts of emotional stress has been reported in relation to both the very premature (Petty et al, 2018b) and the late premature baby (Premji et al., 2018).

What this study also adds, is a consideration of the different types of emotions that parents report. Classifying emotions according to whether they are positive or negative is congruent with traditional approach where emotions are categorised dichotomously, as unpleasant or pleasant, activated or deactivated, as explained by An et al (2017). Andries (2011) also outlines 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 through the whole parent data set of this study. However, Al et al (2017) point 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 arguing that each emotion contains some degree of *both* negativity and positivity. It was deemed fitting therefore, to follow this principle in the current study.

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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) say, emotions are central components of people's lives, both intrapersonally and interpersonally. Indeed, both positive and negative emotional experiences can have a powerful impact on people's functioning and this was the case in this study. All parents expressed negative emotions to some extent within their narratives, often suggesting 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 babies' outcomes were more favourable, difficult periods had passed or when speaking about the love for their baby or gratitude towards staff. Little is documented on *neutral* emotions since these seem to have lesser impact or certainly one that is less obvious within spoken narrative.

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



A key area in relation to the impact on practice arising from all six themes was that there is a 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 parent's 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 and propose that health professionals working in neonatal care can enable communication in an empathic way and work to reduce stress in parents in their care, 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 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: 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.

Therefore, in relation to the first three themes in this study's findings, there is agreement with Al Maghaireh et al (2016). Certainly, as these authors found, work of this nature that explores parent experience is crucial for staff to develop care strategies that decrease parental stress and support parents when dealing with anxieties and challenges of admission to the neonatal unit. These strategies however can be taught to care providers incorporating the specific approaches known to be effective. Guidance can be offered to learners about how to facilitate family centred care; for example, taking the principles of summarised by Roué et al (2017). These include offering unrestricted parental access without the limits that may be set during shift changes or ward rounds and ensuring psychological support for parents that is directed towards parent education and facilitation of developmental care for the baby, an essential part of early and ongoing supportive intervention.

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 & 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 staff teaching, in relation to the fifth and sixth of the themes. Parents encounter many transitions following the birth and admission of their baby to neonatal care. These include different aspects of hospitalisation and 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. Raising staff

awareness of these significant moments in the parent's journey is required so that they can focus on opportunities to improve parents' early transition experiences. As Ballantyne et al (2017) acknowledge, this includes ensuring staff- parent engagement, communication, information-sharing and decision-making is shared between both parties, continuing through the whole "illness-health trajectory" (pg. 783). In addition, these authors highlight the importance of a focus on early transition strategies to nurture parent confidence, competence in the parenting role and ongoing closeness to their babies.

Finally to summarise, health professionals can learn from parents themselves in regard to what is needed to support them. Franck et al (2017) explain how parents felt that a family-centred approach was important at all phases of their healthcare journey, concurring with the findings of this study. Most parents felt that they would like to be actively included in both the decision making and the clinical care of their babies from an early stage. They also felt care is better if it is individualised and focused on the needs of the family rather than the health system, congruent with the person-centred philosophy outlined at the start. This family-centred principle can be applied globally; even with the vastly different resources and care facilities across the world, it can be argued that the impact of premature birth, resultant neonatal care and emotional needs of parents are of equal importance. A global definition of family care within the context of 'person-centeredness' is referred to by Stewart (2001) as care that *knows no boundaries* and can be applied to the care of neonates and parents anywhere in the world.

Before finally discussing the implications for practice of the findings, the limitations of the study need acknowledging. The study employed an interpretivist paradigm. Various disadvantages can be associated with this approach, relating to the subjective nature of the data collected and the meanings taken from it. Data generated in interpretivist can be

influenced by personal viewpoint and values. 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. However, referring the original interview transcripts back to the parents themselves was undertaken to verify the interpretations of their narratives and to contribute to strategies to ensure the 'trustworthiness' of the findings (Noble and Smith, 2015). Besides, 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, qualitative research of this nature is concerned with personal experience and understanding individual reality which *may* be transferable to other similar individuals and situations. Additionally, researcher reflexivity: a necessary process in qualitative research to ensure transparency in matters of recruitment and data analysis, was applied and reported in a previous paper (anonymous/ blinded).

Another issue to consider is the nature of recruitment; while this was not difficult in that parents were forthcoming, the ability to control who came forward was limited due to the sampling by volunteer basis. For example, most participants were mothers of 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 wider range of parents who have premature babies.

The broad time-frame at which interviews were undertaken could have potentially influenced the reported feelings associated with events. As rationalised earlier, the absence of strict inclusion and exclusion criteria was due to the volunteer nature of recruitment and the aim of

obtaining a variety of stories. If criteria were too narrow, this would have limited the opportunity to gain a range of different stories to learn from. Time span between events is discussed by Hutchinson et al (2012) who propose that this is an element of transition. Admittance to, discharge from the neonatal unit and age at the time of interview are examples of transitions over time. What occurs during this time is important as these experiences are unique to each parent. Whether or not this time period is one or ten years does not detract from each story having something to offer for learning in it's own right.

### **Conclusion**

This paper reported on a study highlighting the rich and compelling emotional experiences of parents. Understanding the emotional experience of having a premature baby from the parent's perspective can be used to educate health professionals in neonatal care, in turn aiming to contribute to enhanced empathic learning. Students and health professionals alike can learn what is important in the delivery of empathic, family-centred care placing parents and their needs as an integral component. Educators can use stories and key messages from parents as a core component of a narrative curricula on a global platform to contribute to enhanced empathic learning for anyone across the world caring for vulnerable neonates and their families.

### **Relevance to clinical practice**

Importantly in the context of education, students, nurses and health professionals can learn from the emotional experience of others, in this case parents. Emotions elicited through stories can provide opportunities for parents to contribute to knowledge by recounting their experiences of difficult times (Petty, 2017). The emotional responses of parents in this study imparted knowledge about an affective type of experience, so vitally important to this study

that seeks to ultimately explore the effect of narratives on empathy, an essential person-centred concept. Epistemologically, our emotional responses to others and what they say about their experience can be useful in the creation of knowledge (Camacho, 2016).

Emotions can be seen here as a source of knowledge. Indeed, emotional experience can sometimes teach us things about the world that ‘reason alone’ may miss (Goldie, 2005).

This principle of ‘emotions as knowledge’ may also contribute to engendering or enhancing empathy in those who care for our vulnerable babies and their families. Empathic care is seen as essential, again in line with an international definition of person-centredness highlighted previously. Feo et al (2018) 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’ (pg. 2296) to make sure both physical and emotional health needs are attended to. In the neonatal context, this relates to family-centred care for education. Empathy is an essential part of this definition as identified by patients or parents themselves.

It follows that there is a need to teach students, nurses and other health professionals about the emotional needs of parents that includes awareness of family and person-centred needs along with the importance of communication, empathy and other behaviours and / or strategies that might improve parent’s experience. The question now, is how to do this, which leads to the next phase of the main study which will focus on the development of parent digital stories to be reported separately. Few studies have explored the use of stories based on parent narratives in the neonatal field and the part that these can play in healthcare education on a global level to potentially contribute to empathic learning. The power and value of stories in the teaching of emotional experience and potential enhancement of empathy is now being explored by the authors. A key message is that educators in nursing and healthcare can use effective teaching strategies if they wish to promote empathy (Stepien & Baernstein,

2006). Empathy after all is person-focused not condition-focused, (Jeffrey, 2016) and crucially, relates to human understanding.

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**Table 1: Participant details**

Participant details		Number and %
Parent(s) interviewed	Mother	16 interviews (80%)
	Father	1 interview (2%)
	Mother & father together	3 interviews (6%)
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	22 (95%)
	French	1 (5%)
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 (19%)
	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	1 <sup>st</sup> child	18 (67%)
	2 <sup>nd</sup> child	6 (21%)
	3 <sup>rd</sup> child	2 (7%)
	4 <sup>th</sup> 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%)

**Table 2a: Frequency of themes**

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



**Table 2b: Summary & explanation of themes**

<b>Theme</b>	<b>Negative experiences</b>	<b>Positive experiences</b>
	<b>Lows</b>	<b>Highs</b>
<b>Parent's Emotional experience</b>	Feelings of anxiety and fear, uncertainty relating to outcome and survival.	Feelings of elation, pride and being fortunate at being a parent.
	Challenging and difficult emotional experiences.	Feeling happy and hopeful particularly at key moments (e.g. during closeness with their baby)
	<b>Vulnerability</b>	<b>Strength</b>
<b>The Baby</b>	Fear of touching, harming or infecting their baby due to their size and fragility.	Feelings of pride, amazement and overwhelming sense of love and protection towards their baby.
	Appearance of their baby- not looking like a 'real baby'	Baby being described as strong and being tough enough to survive very challenging circumstances
	<b>Distress</b>	<b>Comfort</b>
<b>The Environment</b>	The neonatal unit being dark and uncomfortable meaning an inability to relax.	The neonatal unit being a 'second home' and a place in the hearts / memories of parents as a significant place in their lives
	Feeling closed in and imprisoned, isolated	
	<b>Conflicts</b>	<b>Pillars</b>
<b>The Staff</b>	Not being listened to and heard.	Staff being supportive and empathic, sensitive and caring towards practical and emotional needs.
	Conflicting communications and levels of empathy between different staff and units	Staff being described as 'saviours' of both baby and parent

	<b>Regression</b>	<b>Progression</b>
<b>Transitions</b>	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	<p>The feeling of moving towards going home and being a normal family and living life together as a family.</p> <p>Feeling of relief and hope for the future as baby moves down the dependency levels of care towards home</p>
	<b>Challenges</b>	<b>Hopes</b>
<b>Going home</b>	<p>The ongoing emotional challenges of being at home without the 24-hour support of the neonatal unit.</p> <p>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</p>	<p>The sense of experiencing a miracle and the ultimate goal of going home.</p> <p>The feeling of achievement that their vulnerable baby has gone through so much distress and this garners hope for the future</p>