The lived experiences of fathers of a premature baby on a neonatal intensive care unit

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Available online 16 August 2010

**KEYWORDS**
Fathers; Neonatal intensive care unit; NICU; Preterm birth; Preterm baby; Preterm infant

**Abstract**

**Aim:** The aim of this study was to explore the lived experiences of fathers of a premature baby on a Neonatal Intensive Care Unit and also to raise awareness amongst healthcare professionals in relation to the needs of fathers whose infants are cared for in the NICU.

**Methods:** A qualitative phenomenological approach was chosen for the study and five fathers participated and were interviewed. Data analysis was based on the work of Van Manen (1990) who devised a six step approach to assist with analysis within phenomenological inquiry.

**Results:** The findings of the study indicate that the experiences of fathers of premature babies in the Neonatal Intensive Care Unit are diverse and complex. Having a premature baby in the NICU instigates a multitude of experiences for fathers.

**Conclusion:** In highlighting the experiences of fathers, this study raises awareness of the need for healthcare professionals to consider the unique perspective of fathers in the context of the NICU.

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doi:10.1016/j.jnn.2010.07.015

**Introduction**

The birth of a child into the world is a joyous occasion however; the premature birth of a child can evoke a variety of mixed emotions. Nothing
admission of their child to the NICU. Lundqvist and Jakobsson (2003) found that fathers experience a multitude of emotions during their infants stay in the NICU.

The study
Research question

“What are the lived experiences of fathers of a premature baby on a neonatal unit?”

Aim

✔️ To explore the experiences of fathers of a premature baby in the NICU setting.
✔️ To highlight the varying degree of experiences that fathers encounter while maneuvering through such a turbulent and intense experience.
✔️ To raise awareness amongst healthcare professionals in relation to the experiences of fathers whose infants are cared for in the NICU.

Method

A qualitative phenomenological approach was chosen for the study because the goal of phenomenological enquiry is for the researcher to understand the meaning of the experience as it is lived by the participant. The participants’ experience is the foci of the research and therefore the researchers felt that this approach would be most suitable to answer the research question.

Setting and sample

The setting for the study was a Neonatal Intensive Care Unit in Dublin, Republic of Ireland. Non-probability purposive sampling was used for the study. In qualitative research non-probability sampling is often used because the method of sampling can best provide the data required to understand the phenomena of interest (Parahoo, 2006). Purposive sampling helped to yield an accurate sample and face to face recruitment was used to recruit participants. The researchers set out specific criteria for participant inclusion in the study (see box 1).

All suitable participants were approached on one occasion and given a letter of invitation to participate in the study. Five fathers in total were interviewed for the study.

Box 1.

1. All participants must be fathers of a premature baby.
2. The premature baby must have been born between 24 and 30 weeks gestation.
3. The corrected gestational age of the fathers’ baby at the time of interview must be greater than 34 weeks but not more than 42 weeks.
4. The premature baby must be an inpatient of the Neonatal Intensive Care Unit at time of interview.

Ethical considerations

The study plan was presented to the Hospital Ethics Committee and ethical approval was granted. Access to the research site was granted by the Director of Nursing and Midwifery of the hospital.

Data collection

Five fathers were interviewed for the study. O’Callaghan (2002) suggest that interviews are an effective technique when exploring a person’s feelings and thoughts because such phenomena may not be obtained through surveys or questionnaires. Interviews were conducted at a time and place of convenience to the participants. Some participants were interviewed in their own homes and others were interviewed in a quiet private room within the hospital. All interviews were conducted by the same researcher.

Prior to the commencement of each interview the participant was informed of the purpose of the study and permission was sought to tape record the interview. The researcher assured all participants that they could withdraw from the study at any time without specification of reason. The researcher also engaged each participant in light conversation prior to the interview. This was important to make the participant feel at ease and comfortable in the researchers’ presence and also it allowed the researcher to ensure that it was a suitable time for the interview to take place. The nature of having a premature baby as an inpatient in the NICU can cause instability in one’s life (Kenner, 2007) and therefore the researcher felt that it was imperative to ensure that the timing of the interview would not cause further distress to the participant. Interviews lasted for between an hour and an hour and a half.
Data analysis

Data analysis was based on the work of Van Manen (1990) who devised a six step approach to assist with analysis within phenomenological inquiry. The six steps (see box 2) provided the researchers with methodical structure however also allowed the researchers the freedom to reflect upon and interpret emerging themes. O’Shea and Kelly (2007) suggest that an interpretive process is paramount in the process of analysis and reflection within phenomenology.

Findings & discussion of findings

Following Van Manen’s six step approach sub themes were filtered down into five central themes. The five themes identified permeated throughout all of the interviews (see box 3).

Effects of hospitalization

The effects of hospitalization are wide ranging and consequently a number of sub themes were derived from analysis. The sub themes that were identified were anxiety, feelings of helplessness and fear of the unknown.

Anxiety

On examination of the findings the phenomena of anxiety was intrinsically linked with the effects of hospitalization. The anxiety experienced by the fathers of the premature babies in the NICU was immense.

One participant discussed the anxiety he experienced when he and his wife went to see their twins for the first time:

"And then we went and seen them in the NICU and that’s when we got a bit scared. Nobody, the Lord himself could have prepared us to walk into that room. We were prepared for worst case scenario and what could go wrong."

This particular father was describing the first occasion when he and his wife went to see their twins in the NICU. This is an emotional experience and is well documented within the literature. Hynan (2005) suggests that having a baby hospitalized in a NICU elicits emotional distress and anxiety for the parent. Lindberg et al. (2007) alludes to this by suggesting that parents and fathers in particular are not ready for the rollercoaster ride that results from the premature birth of their child. Jackson et al. (2003a) has also found that fathers were unprepared for the preterm birth of their babies.

The anxiety experienced by fathers was directly linked to their experience of becoming a father to a premature baby and being in the NICU. Anxiety which occurs following preterm birth of a baby is a very natural response for both mothers and fathers (Franck et al., 2005). Prematurity can result in death depending on the severity of prematurity and the high risk of acquiring an infection (Kenner, 2007). The findings show that fathers were acutely aware of the volatile nature of having a premature baby in the NICU. One father described how he feared to touch his baby in case of giving him an infection:

"Well, I generally was always very dubious about lifting them or touching them. As much as I wanted to, I generally would not want to disturb them, if they were asleep for example or especially when they are that bit younger or smaller. I would be quite nervous of taking them out and

Box 2.

1. Turning to the nature of the lived experience.
2. Investigating experience as we live it rather than as we conceptualize it.
3. Reflecting on the essential themes which characterize the phenomena.
4. Describing the phenomena through the art of writing and rewriting.
5. Maintaining a strong and orientated relation to the phenomenon.
6. Balancing the research context by considering parts and wholes.

(Van Manen, 1990)
handling them. More so because I don’t want to disturb them or put them at risk of infection.”

Another father discussed the anxiety he experienced the moment following the birth of his baby and his baby being whisked away:

“None of this we knew anything about. My wife didn’t even get to see him when he was born. He was just whisked away. I got a chance to look at him for a bit and he opened his eyes and he was gone. It was such an anxious time.”

This finding that immense anxiety is experienced by fathers of preterm babies in the NICU concurs with similar findings pertaining to fathers in the literature (Lindberg et al., 2007; Arockiasamy et al., 2008; Sloan et al., 2008) mothers (Holditch-Davis et al., 2003; Preyde and Ardal, 2003; Heermann et al., 2005; Aagaard and Hall, 2008) and both parents (Jackson et al., 2003; Carter et al., 2005; Franck et al., 2005; Gavey, 2007; Turan et al., 2008).

Feelings of helplessness
The feeling of helplessness permeated throughout the interviews. One father reflected on the helplessness he felt when he saw his babies for the first time:

"It was initially the most scariest thing I had ever seen. When we walked in and saw them my legs were weak. I felt so helpless as I could do nothing for them.”

This feeling of helplessness transcends the literature. Lindberg et al. (2007) identified the feeling of helplessness as an inherent emotion for the parents of a premature baby in a NICU setting. The inability to participate in the care of the premature baby is a fundamental cause of this helplessness (Lindberg et al., 2007).

Another father reflected upon how helpless he felt when he saw his babies in the incubator:

“I felt a bit helpless because they were in the glass incubator and I couldn’t really do anything for them, couldn’t even touch them in the initial stages.”

The involvement of parents in participation of care and decision making in relation to their child’s care is a predominant factor in alleviating feelings of helplessness (Lindberg et al., 2007).

Fear of the unknown
The ‘fear of the unknown’ for the future outcome of their child was a predominant finding amongst all fathers in the study. One father reflected on the fear that he felt while waiting outside of the Theatre to be taken in to see his twins who were about to be born via emergency cesarean section:

"I remember standing outside the Theatre in my scrubs. Eh, didn’t really know what to expect. I was been brought in at one time and em there was too many between doctors and nurses. There was too many in there. I remember standing outside and saying prayers to every dead relative that I’ve got, begging them to do something for them. I didn’t really know what to expect.”

From this excerpt it is clear that the father was fearful of what would be. He turned to prayer and begged for his babies’ safe arrival.

Another father described the fear that he felt for his premature babies’ future:

"I was building up for the worst. Nobody wants to have a child. (pause) I mean everybody wants to have a normal child. I’m not being selfish it’s just being human. If you have a child with any disabilities, as my mother used to say; ‘if you have a child with a disability it’s because God feels you can take care of it’. This is her way of looking at it.”

Clearly from this excerpt the father is fearful of how his baby will be physically and developmentally in the future. He describes his wish to have a ‘normal child’ as being a natural human desire. Arockiasamy et al. (2008) alludes to the advancing incidences of premature survival rates within their study and highlight the fear and anxieties fathers experienced due to the nature of the premature babies early lives. Not knowing about the present and future can be of great concern to fathers of premature babies (Arockiasamy et al., 2008).

Realisation of becoming a father to a premature baby
The thought of becoming a parent is an emotional experience. Joseph et al. (2007) suggests that parents primarily look forward to the impending birth of their child and the varying new roles that parenthood encompasses. However, the majority of parents are not ready for the premature births of their babies (Hynan, 2005; Pohlman, 2005; Joseph et al., 2007). The realisation of becoming a father to a premature baby is daunting in itself. The findings within the study alluded to this concept of realisation. One father described how he realised the seriousness of his babies prematurity after he took a good look at them:

"And when I saw the babies and had a good look at them. I really realised how serious it was.”
Another father described how he became aware of the serious nature of having a premature baby after talking to a nurse:

"And when I went over to see him a nurse came over and said 'God he really is so small'. You know, it kind of starts hitting home. Oh my god, he is in serious trouble. He has a long, long way to go ...................... you kind of think how is he going to manage?"

Lundqvist and Jakobsson (2003) found that the realisation of becoming a father to a premature baby was marked by a state of unreality for fathers. The prematurity of one’s baby and the lack of personal contact as a result of incubator care and the size of the baby hindered the realisation of becoming a father for some of the participants of their study (Lundqvist et al., 2007). This concept of 'unreality' permeated throughout this study and concurs with current literature. Lundqvist and Jakobsson (2003) also found that the lack of personal contact and the tiny size of the baby hindered the realisation of becoming a father for some fathers.

Information sharing: the double edged sword

The ability to inform parents of their baby’s condition is paramount in relieving parental anxiety. Not knowing the world around oneself can intensify the heightened level of negative emotions experienced by fathers and mothers within the NICU setting (Joseph et al., 2007; Lundqvist et al., 2007). Ahmann (1998) suggests that the sharing of information can be extremely beneficial to the parents of a sick hospitalized child. Information sharing, the consequential negotiation between healthcare professionals and parents ensures the development of a relationship built upon trust. This relationship is essential if anxieties are to be alleviated for the parents and fathers in particular. One of the fathers highlighted the importance of this relationship:

"I mean I found the doctors and nurses, I mean if you asked them a question they would just stop what they were doing and they would just sit down and talk to you. For half an hour if needed. So, I found that nobody was ever too busy to give us time. And often just to give us explanations. That is what we needed. Cos as a stranger, a Joe-soap and coming in. They don’t understand anything of what’s going on in there."

This excerpt outlines the importance of information sharing and the positive effect that the caring nature of the doctors and nurses had on him. Information sharing with the medical and nursing staff can put the parents of a premature baby at ease and alleviate certain fears. Information sharing is considered a gold standard within family-centered care however findings from the study also indicate that disadvantages can also arise from information sharing. Information sharing was found to be somewhat of a ‘double edged sword’ meaning that it had both positive and negative effects on fathers in the study.

One father highlighted the importance of information sharing but specified that it had to be in 'lay mans' terms to ensure understanding and alleviate fear:

"When you go in there first, you’re kind of wondering is the baby going to die in the next minute......... explanation is good and the more explanation that could be given the better for me. In Lay Mans terms. You don’t really need to know the exact science behind it. They just need to know it in Lay Mans terms."

Another father noted that information sharing was not always consistent:

"One problem may be with the whole thing is that I found that often we were told different things by different people. Quite often. Nothing serious now, but I found if you asked the same question six different times to six different people you would get six different answers."

This finding concurs with a finding from Sloan et al. (2008) who also found that different nurses gave different answers when asked the same questions by fathers in relation to their premature baby.

Another father described how information sharing was conveyed in differing ways by different people and this affected how he felt about his baby’s progress:

"To put it into perspective, you meet Dr. X and I mean you’re coming out singing. Dr. X gives you so much hope and so much to live for. Dr. X is so upbeat about things, but yet realistic ......... realistic in a way that you think that there is life at the end of the tunnel. Whereas Dr. Y, well I know, God Dr. Y is a great Doctor, but you well feel like slashing your wrists sometimes after talking to Dr. Y."

The differences of information sharing and the styles utilized by various members of the healthcare team were made apparent on examination of the findings. Arockiasamy et al. (2008) suggest that the ability of a healthcare professional to communicate effectively with a father in relation to their child empowers the father. Also the
consistency of the information received from the healthcare professional is vital (Arockiasamy et al., 2008). Griffin and Abraham (2006) suggest that information sharing and the implementation of a family centered approach to care can significantly decrease anxieties of the parents prior to discharge of their baby home. An increased level of competence can be achieved by parents of a preterm baby if the information sharing has been positive and fruitful (Griffin and Abraham, 2006). Dunn et al. (2006) intensify this argument by suggesting that the unbiased and complete communication between healthcare providers and families can positively affect the quality and long term outcomes of the premature baby. Consequently, to withhold information or to give unclear information to the parents in relation to their child can have poor implications for the parents and the child. The provision of information sharing to parents of premature babies on the neonatal unit can improve parents’ mental health outcomes and reduce the baby’s length of stay on the neonatal unit (Melnyk et al., 2006).

Arockiasamy et al. (2008) and Lindberg et al. (2007) both found that information sharing can increase the level of perceived control fathers have upon the situation in relation to their care. Arockiasamy et al. (2008) does however; acknowledge that sometimes too much information sharing can exacerbate fears that fathers may have. The finding that information can be a ‘double edge sword’ concurs with these various other findings within the literature relating to information sharing.

Paternal role Vs maternal role

To date the focus within published research has been the experiences of parents of premature infants in the NICU (Jackson et al., 2003a; Carter et al., 2005; Gavey, 2007) or more predominately the experiences of mothers of preterm infants in the NICU (Holditch-Davis et al., 2003; Preyde and Ardal, 2003; Heermann et al., 2005; Pohlman, 2005; Aagaard and Hall, 2008). The differences that fathers and mothers experience during their time within the NICU are vast. Following examination of the literature it appears that the mother is more often seen as the preterm baby’s primary carer. The findings of this study concur with this same concept within the literature. Many of the fathers interviewed reported that they experienced many differences between their paternal role and the maternal role whilst in the NICU.

One father described the differences he encountered in relation to the maternal and paternal divide following the birth of his premature baby:

"I think when the nurse came to my wife and said "kiss your baby you mightn’t see him again". Why didn’t she say it to me, as well? I just felt that this was the normal mother to baby and that father was in the background. I just felt that. I was a bit disappointed I have to say because I did think if she meant that, I would never get to see him and kiss him alive again. To be honest I just said to myself, typical. Kiss baby and he is gone. Typical, it wasn’t a big issue then but I probably would have asked to kiss him”.

On analysis of this interview it became very clear that this particular father was deeply upset about this incident. He made reference to the incident on two separate occasions during the hour and a half long interview. He also made particular reference to the inequality he experienced in relation to the incident was that:

"It didn’t bother me, but the one thing I would say that I wasn’t treated equally.”

Another father described the build up to the birth of his baby and how as a father he felt quiet helpless in the situation:

"The lead up to the delivery, you really are a spare wheel in the room. As a man, there is really little you can do. You can be just very supportive to your wife and stay out of the way as much as possible.

It is clear from this excerpt that this father felt more of a hindrance rather than a help at the birth of his child. His reference to ‘staying out of the way’ indicates that he did not believe that he had a valued role within the situation.

Another father described how the emphasis was always on the mother:

"There is more of an emphasis on the mothers. If the two of us were sitting there and someone came up to us, it would always start with; "Ok Mom, now it’s time to change the nappy". There was never really; "Ok Dad, now it’s your turn". The emphasis is always on the mother.

The same father also reported how the emphasis always remained with the mother even when it came to updates of care:

"I mean any time we ever got a phone call they would always ring my wife. They would have both numbers but they would always ring my wife. So generally the emphasis was on the mother.”
Constraints of work

Findings from the study show that work is a primary factor in relation to the level of involvement and participation in the care of their child, experienced by the fathers. The impact of having their child as an inpatient in a NICU was a major distraction and cause of concern for the fathers. One father who was self-employed discussed the difficulties he experienced while his baby was in the NICU:

"Yeah, I found that hard yeah. I run my own business so I often said to my wife "I wish I worked for someone so I could tell them I'm taking a month or two months off. You don't have to pay me it doesn't matter". Yeah, that was a big problem for me. Trying to concentrate on running a business when you got something as serious going on is so hard. Every little problem that comes up during the day is a huge problem because your real problem is constantly at the back of your mind."

It is clear from this excerpt that the impact of being self employed was the source of great difficulty to this father. Taking unpaid leave from work to concentrate on his preterm baby was not even an option for him. Also it is clear from this excerpt that trying to run a business while his baby was in the NICU became particularly difficult as his mind was always concerned with the greater worry for his baby. Another father commented on how he only got to see his baby for short periods in the evenings due to the constraints of his work:

"I'm working during the day. I work 9 to 5 and I don't get to spend that much time in the ward itself. I do see other fathers there and we do chat but it is mainly basic chit chat. I only get to see him for an hour or so a day, depending on what time I get out of work, you know?"

This father linked the constraints of work with how he received information regarding his baby’s progress:

".........the fact that she [his wife] is here longer than I am. I am only here 30—45 min in the evening time, so and it seems to be quieter at that time of the day. And I am not sure, I may be wrong in saying this but it appears to me that the doctors are more around in the mornings and afternoons, than the evening times. So my wife would pick up the information during the day so, you know, I would obviously get that information second hand from the wife. It was always difficult to get a hold of the on call doc. They're very busy!"

Pohlman (2005) suggests that work is a necessity. The provision of income for the family is vital and fathers were seen as the providers within society (Pohlman, 2005). This stereotypical viewpoint that society places upon the father is mirrored within Hynan’s (2005) study. The ‘Men are from Mars; Women are from Venus’ analogy that Hynan (2005) depicts is evident within this theme.

However, the findings from this study also suggest that solace and modes of coping can be achieved by working. One of the participants alluded to this concept:

"People would say "You’re up there every night. You go to work, you shower you eat. You go up to the hospital and you come home and watch TV, you go to bed". It becomes a routine. People don’t understand that, it just comes natural. It’s not like Oh god I have to go up here again. You do it. So I think working helps. I think if I wasn’t working I would have gone stir crazy. You would be worried about everything. You definitely need to keep occupied. It’s therapy."

This finding concurs with Pohlman’s (2005) study and Arockiasamy et al. (2008) study. Fathers attributed work as a mechanism to cope (Pohlman, 2005) and as a mechanism for distraction (Arockiasamy et al., 2008). Although work served as both a coping mechanism and a distraction for some fathers findings from the study also indicated that for some work was made even more difficulty by the fact that they had a sick baby in the NICU:

"Trying to concentrate on running a business when you got something as serious going on is so hard".

The constraints of work and the effects they have upon the father and his involvement in care is apparent within the findings of the study. The provision of income that work provides is a common theme within the little research that is known about this topic and concurs with the findings.

Strengths and limitations of the study

There are strengths and limitations evident in all research studies. The strengths of examining the lived experiences of fathers of a premature baby on a NICU include the acknowledgement of fathers within society and the role of the father during such a turbulent time. No Irish studies have been published to date detailing the experiences of this group of people within the Irish healthcare system.
One of the primary limitations of this study included the difficulty in recruitment of participants. Premature births in essence are unplanned and occur sporadically. In consequence, the ability to foresee the births of such babies is frequently impossible creating recruitment difficulties. In addition, many of those who might have been eligible to participate were not English speaking and therefore could not be interviewed for the purpose of this study. However, this limitation indicates the need for future research specifically designed to enable the participation of such fathers so that their lived experiences may be elucidated.

Conclusion

The purpose of this study was to explore the lived experiences of fathers of a premature baby in the NICU setting and also to raise awareness amongst healthcare professionals of the experiences and needs of this group within the NICU context. The findings of the study indicate that the experiences of fathers of premature babies in the NICU are diverse and complex.

Having a premature baby in the NICU instigates many effects of hospitalization for fathers. They experience anxiety, feelings of helplessness and also fear of the unknown. Fathers often feel like they are considered a second parent by members of the healthcare team as the primary focus is on the mother and infant. Findings from the study also indicate that information sharing is a double edged sword having both positive and negative effects upon fathers. Constraints of work were found to be an extra difficulty that fathers have to deal with while they had a sick infant in the NICU. However, for some fathers work became a therapeutic tool which enabled them to cope more effectively with the stressful situation that they were propelled into.

Current published literature detailing parental experiences of having a preterm baby in the NICU is predominately based on the experiences of mothers or parents collectively. In highlighting the experiences of fathers, this study raises awareness of the need for healthcare professionals to consider the unique perspective of fathers in the context of the NICU.

References


