

ORIGINAL RESEARCH

Stoic survival: the journey of parenting a premature infant in the bush

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ABSTRACT

Introduction: The birth of a premature infant is a stressful and emotionally challenging time for parents. Families living in rural areas often have reduced access to the specialist services premature infants require, and different concerns from their metropolitan counterparts. Rural families may have to spend extended periods of time at a metropolitan centre while their child is in a neonatal intensive care unit (NICU). Regular return trips to hospital may be required for follow up. Parental experience of this unexpected event and the resultant intensive health service involvement requires further examination; most studies focus on the NICU experience. This exploratory study was undertaken from the rural paediatric allied health perspective. Because there are few accounts of rural families' experiences in the literature, this hermeneutic phenomenological qualitative study focused on the rural parent's experience of having a premature infant in a rural area during the first 12 months of the child's life.

Method: Participants were selectively recruited from the case lists of paediatricians in a rural/regional hospital. Seven parents (5 mothers and 2 fathers) of premature infants consented to participate in semi-structured interviews. Interviews were of 60-90 min duration per parent, and were audiotaped and transcribed verbatim. The transcripts were analysed thematically using a phenomenological approach. Process and reflection diaries were maintained in order to provide an audit trail.

Results: The participant group reflected a range of experiences. Parents described being initially shocked and then gradually adjusting to being the parent of a premature child. Three major themes emerged: (1) 'Coping through optimism' when parents consistently spoke positively about even stressful and difficult aspects of their experience; (2) 'Stoic survival' where parents did



not emotionally deal with their experience, often citing others' needs as having higher priority; and (3) 'Striving for normal' when parents focussed on the aspects of their child's medical care or development that was closer to that of a full term child. Parents described feeling devastated if they felt their infant regressed or was progressing too slowly, and elated whenever a new milestone was achieved.

Conclusion: Gaining insight into the experience of parents of premature infants can help health professionals ensure services more effectively meet the needs of these families. Rural families were pleased with their local services although they indicated that travelling to a metropolitan centre was extremely burdensome. While the families interviewed had access to some local specialist services, they expressed concern that if they resided in a more remote area there would be reduced access to services and greater personal strain. Further research is required to determine the experiences of Indigenous families, separated or divorced parents and families living in remote areas.

Key words: experience, infant, parents, premature, qualitative.

Introduction

The incidence of infants born at less than 36 weeks gestation is steadily increasing. Advances in medical intervention have resulted in improved survival rates for preterm infants¹. Australian data suggests that women residing rurally have poorer obstetric outcomes compared with their metropolitan counterparts, and are more at risk of having infants born prematurely². Infants born prematurely require extensive medical intervention and long-term follow up from a number of health disciplines. Health professionals are required to not only meet the needs of the child, but also to meet the needs of the parents and other family members during this difficult and stressful time³. In rural areas, these needs may be unique because families often have to travel great distances to access specialist care for their child, and are likely to have reduced access to support and services in their home town. Parents from rural areas are also less likely to be familiar with large metropolitan hospitals where specialist neonatal, paediatric and neonatal services are located. This study aimed to explore the experience of parents of premature infants living in a rural area during the first year of their child's life.

Existing research has been mainly nursing based and focussed on parents' experiences in the neonatal intensive care unit (NICU) in metropolitan areas. Not surprisingly,

parents have reported being in a state of shock when they initially arrive at the NICU⁴. Wigert interviewed such parents and they reported the need for time to inform and educate themselves regarding issues relating to their child⁴. Parents also reported wanting to be treated as an individual with recognition of their own circumstances. This may be especially true for families from rural areas because metropolitan staff may be less familiar with the support and services available in rural areas.

Heerman et al described the experiences of parents' from non-rural areas in NICUs⁵. The study revealed that parents shift from being a passive bystander to a more active advocate for their child's needs over time. Parents described being initially focussed on the NICU environment but gradually becoming more comfortable and being able to focus on parenting their child with greater ease⁵. Brinchmann et al described how parents wanted to be consulted about clinical decisions in the NICU; however, they did not want the final decision to be left entirely up to them, feeling too emotionally involved to make a rational choice⁶. The parents described a power struggle between themselves and health professionals regarding the day-to-day care of their child in the NICU.

The experiences of fathers in the NICU was explored by Pohlman who reported that fathers have different needs and perceptions in the NICU environment⁷. Fathers often worked



with renewed vigour due to the ongoing need to provide for their family. These men seemed to feel in control at work but they often felt helpless in the NICU. Fathers also reported being stressed by having to manage the demands of work and family outside the NICU, their partner and the premature infant.

There is a paucity of research examining the rural family's experiences. One study of families from a non-rural area reported that the geographical distance between home and hospital had a negative impact on the stress responses of fathers of premature infants⁸. Difficulty accessing rural paediatric health services, in particular allied health and early intervention services, has been described⁹; however, the impact on rural families has not been explored.

The present study used a hermeneutic phenomenological approach to examine parents' lived experiences of caring for a premature infant during the first 12 months of the child's life while living in a rural area. Providing access to families' lived experiences offers health professionals a deeper understanding of the needs of such families, and the ability then to ensure that services effectively reflect these needs.

Methods

Participants

A qualitative approach was determined to be best suited to addressing the research question. Gadamerian hermeneutic phenomenology underpinned this research because the aim was to elicit the essence of the lived experience of the participants. The researchers identified their pre-understandings of parenting premature infants. These were reflected on in conjunction with the data analysis in order to move beyond pre-understanding to understanding the phenomenon under investigation^{10,11}.

The setting was a regional town in New South Wales, Australia with a population of approximately 56 000, classified as an inner regional centre in the Australian

Standard of Geographical Classification (ARIA code: 2.2647)¹². The nearest NICU is 285 km away; however, if there are no available beds there, families are often transferred a NICU in other metropolitan centres a greater distance away. This regional centre has general paediatric medical and allied health services but no neonatal specialist services to provide follow up for premature infants. Premature infants and their families usually access local services, but must also travel back to the metropolitan location of their NICU for further developmental follow up.

Study participants were the parents of a child born at less than 34 weeks gestation who, at the time of the study was older than 12 months and under 7 years. Seven parents participated: 5 mothers and 2 fathers (Table 1), all of whom lived in the postcode area the regional town. The participants were recruited from the current case lists of paediatricians not directly involved in the study, who were provided with the projects aims and inclusion and exclusion criteria to assist in selection. Participants were excluded if their child had health problems unrelated to prematurity. After consultation with the local Indigenous community, Indigenous families were not included because it was determined that their unique experiences would be better investigated in a separate study.

Each participant was mailed an information package and informed that they were under no obligation to participate. When the invited parents returned completed consent forms they were contacted.

The seven parents who agreed to participate represented a diverse range of experiences and five individual families. Of these families three had been transferred to the closest NICU, one had not been transferred out of the regional hospital and, due to a shortage of available NICU beds, one infant had been transferred to a NICU approximately 700 km away. All families were being followed up by their regional or local child development team at the time of the data collection. One child had significant disability associated with prematurity but none of the other children had significant developmental issues at the time of the study.



Table 1: Participant information

Participant	Marital status	Twin birth	Birth weight (g)	Gestation (weeks)	Birth order
1. Mother	Married	Yes	1980 & 2098 [†]	33	1st Children
2. Father	Married	Yes	1980 & 2098 [†]	33	1st Children
3. Mother	Married	Yes	2490 & 2200 [†]	34	1st Children
4. Mother	De facto	No	758	26	1st Child
5. Father	Married	No	1814	32	2nd Child
6. Mother	Married	No	1814	32	2nd Child
7. Mother	Married	No	1190	30	2nd Child

[†]Birth weight of twins.

Data collection

The research team consisted of a physiotherapist working in paediatrics (LW), a postdoctoral academic with experience researching premature infants (KR) and a paediatric occupational therapy academic (RC). Semi-structured interviews were conducted with participants. Two sets of married couples were included; however, participants were interviewed separately in order to gain their individual perspectives. One author (LW) conducted all the interviews and the majority of the data analysis. Regular meeting with the other supervising members of the research team (KR and RC) were conducted to discuss the thematic analysis in order to gain different perspectives on emerging themes.

Participants were asked a series of open-ended questions about their experience of being a parent of a premature infant during the first 12 months of their child's life. Questions were derived from research team consensus and based on clinical experience. The question were grouped according to a number of predetermined areas, including general lived experience, services received, the effect of the experience on relationships, and how experience may have been affected by living in rural area. The interviews of 60-90 min duration each were audiotaped and transcribed verbatim. Transcripts were analysed thematically. Once themes were identified, transcripts were searched for information contradicting the researchers' interpretations. Process and reflection diaries were maintained by the researchers to provide an audit trail

and to allow written reflection of pre-understanding and emerging understanding of the topic.

Ethics approval

Ethical approval was obtained from Hunter New England Area Health Human Research Ethics Committee (approval no. 07/09/19/4.03).

Results and Discussion

The participants described a 'journey' which they revealed was emotionally traumatic, stressful but 'character building'. They frequently reported gaining a different perspective on life, and that the hardship made relationships stronger - especially with their partner.

...it bought us closer together because it was the most stressful thing we've ever been through and we really relied on each other. Participant 1 Mother

When asked about how the experience had affected their personal relationships, without exception all stated that it had brought them closer to their partner. All parents also reported that others, such as friends and relatives, often had little understanding of what they were experiencing which made it difficult to ask them for support. All parents were still together at the time of the interviews.



All parents reported initial shock and confusion over what was happening with their infant. This led to a gradual understanding and acceptance as their child made developmental and medical gains. This is consistent with Heerman et al's findings that parents struggled initially with acceptance of their situation⁵.

Five of the seven parents had infants who were transferred to a metropolitan hospital. These parents reported feeling burdened by having to travel and relocate to a metropolitan hospital, often in an unfamiliar city.

There was a lot of crying and wondering and just wanting to come home and you know. The family ringing, we rang each other like 50 times a day – the biggest phone bill. 'Cause they would ring me and I would ring them on the mobiles it didn't matter what it was, so it was very traumatic. Especially when [husband] left when he came back to come home that was pretty yeah... Participant 7 Mother

it's quite a strain though being away from home and leaving [older sibling] behind as well, cause she was too young to understand what was going on, umm at the end of the day if that's what you have to do its what you have to do, it doesn't come into it, you don't think about it actually, but that was the experience, it was an inconvenience for the health of your baby. Participant 6 Mother

While four parents said the burden was financial, all reported that the being away from home was an emotional burden. Five participants who used accommodation subsidies during their hospital stay, such a (charitable foundation) Ronald McDonald House were extremely grateful for these facilities; however, they said that the opportunity to stay at home would have been preferred.

The parents who had other children often had to leave them in the care of relatives, such as grandparents. Not being able to care for older children was a source of stress for parents during a disruptive and stressful time. Additionally they felt they were burdening the relative who was caring for the

child. Parents felt that the siblings of the premature child missed out on parental attention again later due to the demands of caring for a premature infant, which were accentuated by having to travel to access specialist services.

...the two older ones, well they probably suffered, they probably suffered because I wasn't there for them enough in those first, I mean they still needed me, but in that first 12 months I guess I really wasn't there for them, it was all about [the premature child]. Participant 7 Mother

Three of the participants lived on rural properties on which they worked as well as having other employment. The travelling was particularly difficult for these families because they were unable to take leave and needed to tend to the livestock and perform properties duties.

...especially when you're running your own property as well and working. It was lucky it happened in winter time so there wasn't any hay to make. Participant 2 Father

These three parents described being unable to leave their properties for extended periods. They reported that one or both parents were working on the property at night after returning home from hospital during the day.

As parents became more familiar with the NICU they came to feel more comfortable in that environment, with the care of familiar health professionals and with a high level of specialist care. Parents described the subsequent anxiety of returning to their local hospital where they perceived the level of care to be less specialised and not individualised.

That was the biggest shock coming from that high level hospital ...in hindsight I probably wouldn't come back as early if I could do it just 'cause you don't have that connection...and they were really busy. Participant 3 Mother



Five parents felt that more preparation for the return home would be beneficial, allowing them to anticipate issues. Further orientation to the rural hospital or to available local services was described as essential for adjusting to the change. Two parents, including one father, felt that they had adequate orientation to local services.

All parents expressed relief at getting home from hospital, yet trepidation at having to be the primary carers for their child without medical staff on hand if something went wrong.

Yeah we were just walking around on eggshells for the first couple of weeks. Yeah you don't know what you're doing, you're just flying by the seat of your pants with them, you haven't got the midwives there to show you what to do or if there's a problem you just can't spin around and ask them. . Participant 2
Father

Surprisingly, six of the seven parents reported that living in a rural area may have given them improved access to existing services. They felt they could easily contact clinicians to discuss concerns, and said that living in a smaller community may have allowed clinicians to get to know them on a more personal level. Conversely, four parents expressed concern that the outcome for their child and the support they received may not have been as good had they resided in a more remote setting.

Major themes

Three major themes were identified from the interviews: coping through optimism, stoic survival and striving for normal.

Coping through optimism: 'Coping through optimism' was a particularly strong theme across all interviews. Participants often related to very negative parts of their experience in a positive way. For example seeing their child being intubated, a father driving to a metropolitan hospital

knowing he was going to miss the birth or having to temporarily leave the child in hospital.

It just really, really shook us. But in saying that it was also an experience I look back on with fondness too because it did open my eyes and just show me what it was all about and what could happen and what we were up against. Participant 7
Mother

Parents generally looked back at the experience in an optimistic way as being difficult but 'character building' and life changing. The parents for whom the premature infant was their first child often said they came through the experience because they didn't know any different.

Well I guess being my first kids I don't know any different than having a premature [infant]... I've only ever had a preemie baby um yeah so I can't really I don't know, I don't know what a full term would be like. Participant 3
Mother

The following extract of a mother meeting her infant for the first time and seeing him being intubated still emphasises the positive aspect of being able to see and spend time with her infant, rather than dwelling on the distress of witnessing the intubation.

....what's happened is you know he's stopped breathing, he's had respiratory failure and all that kind of stuff and all I could see is his little arms kind of getting thrown everywhere cause the doctors are rolling him over... so I think that was a bit full-on but still nice at the same time cause you could just, like once he's settled down and everything I could just sit there and just stare at him and that's all I did for hours, I couldn't touch him cause he was so fragile but um yeah like we could sit and stare. Participant 4
Mother

Parents indicated that thinking optimistically was a way of coping with the situation because focussing on the negative



aspects would make the experience more difficult or impossible.

Stoic survival: The theme 'stoic survival' that emerged from the data described families not thinking about the experience in depth at the time or afterwards. Participants stated that they had never discussed the impact of caring for a premature infant with other people.

...there was no need to talk about it cause it just brings it up again doesn't it, it brings emotions up and yeah 'cause it was just being normal and not worrying about it, get on with it. Participant 5 Father

All parents reported that while the experience was emotionally difficult and stressful, they felt they simply had to do what was needed for the sake of the child or their partner. Five of the seven parents reported having to ignore their own emotional needs in order to be strong for the premature child and the rest of their family.

I was eventually wheeled into where he was, and I just broke down and broke down in tears. I just couldn't believe that was my baby, he was just a pathetic sight, I just thought he was pathetic. He just had tubes, machines beeping and going off everywhere and just the tiniest baby that I've ever seen in my entire life and I just, it was too much for me. But I rose above that and overcame the emotion and got on with it. I thought well here I am and they told me what I had to do. Participant 7 Mother

This was a strong theme for the fathers who were interviewed. They tended to see their role as being carer for the mother first and the infant second. When asked what he saw as his role in caring for the family one father stated:

Oh just for [his wife], to look after her and tell her everything's fine. Participant 5 Father

The fathers stated that they were keen to be involved in the care of their infant; however, this was often done by the nursing staff and the mother. The fathers also stated that it was difficult to continue their role as breadwinner, being a husband, spending time at the hospital, attending appointments at later stages, and caring for any siblings, but that it was just something that needed to be done.

...we didn't sort of get time to sit down and have a good cry about it or anything like that about it either, we just dealt with it, we were strong for [the older sibling] and everyone else and we just dealt with it and just got through it. Participant 6 Mother

Yet there was evidence of this being an extremely emotionally difficult time for fathers who had little chance to reflect on it emotionally.

Every night was hard to leave the hospital. Especially everyone you love sitting in the hospital and you go home to an empty house. Participant 2 Father

Clinical services supporting these families must recognise that families can have difficulty reflecting on the true emotional nature of their experience because to do so is 'just too difficult'. This may be especially true for fathers, because services tend to support the mother and the baby more.

Striving for normal: 'Striving for normal' was another strong theme emerging from the interviews and describes parents focussing on any aspect of the child's care or development that made the premature infant more like those who are full term. Parents described happiness when a child achieved a new goal, such as coming home from hospital, first steps or gaining weight. Parents also described frustration and devastation if the child regressed or progressed at a slower than anticipated rate.

You tend to push them, you know what I mean. I was getting frustrated with them when they weren't



feeding and the paediatricians kept saying look it's not going to come for weeks yet, basically you want to get home you want to get back to normal... the more normal they are treated, it's that step closer to getting home. Participant 1 Mother

Parents reported that regular developmental monitoring through their child's first year helped them to set new developmental goals as well as giving them reassurance that their child was making progress.

It was great... that there was a lot of follow up cause then I just knew there was continually an eye on her, an unbiased eye going over what she was doing. Participant 6 Mother

Parents reported receiving information from a variety of sources regarding their child's progress. They reported valuing the opinion of an expert who was not emotionally involved with the family the way a grandparent or family friend might be, saying that this assisted them to set realistic goals and expectations for their child.

Limitations of the study

While the parents interviewed provided a vivid account of a wide range of experiences, there were only seven participants. The majority of participant felt satisfied with follow up; however, these responses may vary if participant families had lived in more remote areas with fewer local paediatric services. Parents who were separated or divorced may have different accounts of the way a premature child affected their relationships. Only one of the families had a child with significant long-term health issues. The information provided by this family was surprisingly consistent with those parents whose children had had better outcomes. However, this sample is too small to offer reliable conclusions. Finally, participants' positive responses may have been influenced by the fact that the interviewer (LW) was a clinician in the local child development service clinic at the time of the study.

Conclusions

Participants described an extremely emotional, stressful and life-changing experience. Satisfaction was expressed with the services they received in the rural health service, claiming good access to services and reporting that they were able to come to know their clinicians personally. However, the rural town of the study has follow-up services for premature infants with medical and allied health services, and parental experiences may be different where such services are not available, as is the case in many rural areas.

Parents reported that the travelling and living away from home while the child was in hospital was an additional stressor; however, they felt that their child had been transferred to get the best possible care in a tertiary facility. Most participants reported that living in a rural area created a financial burden on families at a time of illness, and that families were thankful for services that assisted with this, such as the Isolated Patients Travel and Accommodation Assistance Scheme and Ronald McDonald House.

Clinicians working with premature infants and their families should recognise that parents may describe their experience in an overly positive manner and may be avoiding dealing with the experience emotionally as a coping mechanism. This is likely to be the case not only in the initial period in the NICU, but also for many months afterwards. Indeed Holditch-Davis found symptoms of post-traumatic stress disorder in mothers when their child was at a 6 month adjusted age¹³.

Health workers should also recognise the unique experiences of the fathers of premature infants and ensure that their needs are met. Educating fathers about how to interact with their child, and discussing how to manage the time demands of work, leisure and family may assist fathers to settle into their new life role. This is consistent with the reported experiences of Swedish fathers of premature infants described by Lundquist and Jakobsson⁸ and American fathers, described by Pohlman⁷.



Clinicians can assist families to set realistic goals and expectations for their child. This is particularly important for rural families, whose unique situation may need to be managed differently from that of urban families. The bonding process may be assisted by reducing parental frustration from being unsure how to help their child or cope with a child who does not seem to be responding to their efforts. For instance, clinicians trained in child development may notice subtle developmental progress that is not evident to the parents.

Further research is needed into the experiences of families where the parents are separated or divorced, and also into the experience of Indigenous families of premature infants, who are likely to represent a largely underserved group, particularly in rural areas.

This research has highlighted the unique experience of rural-dwelling families of premature infants. It begins to illuminate the way families adjust to the shock of the arrival of a premature infant and offers some insight into their coping mechanisms. By being aware of the unique issues confronting families from rural areas, clinicians can be better prepared to meet the needs of rural families in the future.

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