Maternal experiences of preterm birth

Hypothetical models of birthing rites of passage were used to examine maternal experiences of preterm birth. The isolation, helplessness and powerlessness experienced by the 'premature mothers' had a profoundly negative impact upon their well-being. The qualitative research study presented here offers insights into maternal needs at this difficult time.

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Key points

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1. The identity of the 'premature mother' should not be lost in caring for her premature infant.
2. Mothers should be given the opportunity to share their experiences with others in a similar situation. Rooms should be available on neonatal units for this purpose.
3. Transitional care visits should be available so that parents may room in with their infant prior to discharge.
4. Specialist neonatal nurses should be available in the community for mothers of preterm infants.

Much research has shown that preterm birth is a traumatic event although the nature of this traumatic event has not been fully explored.[1-8] There is very little qualitative research available, therefore an in-depth qualitative research project was established. This article utilises data accrued from the author's two comparative research studies that examined maternal experiences of premature birth, thereby offering insights into maternal needs at this poignant time.

The background to these studies

An initial study that compared the experiences of 22 women who provided 24 birth experiences was completed in 1992.[9-11] The key findings of this study were that:

1. Mothers of preterm infants need more support than was therein reported. Also there was a definite need for more professional training that would facilitate greater understanding of the problems and thereby offer more support.
2. The implications of preterm birth may be very far reaching, affecting the future mother/child relationship for at least the first 10 years.
3. Mothers of preterm infants, when compared to term mothers, suffer an increased risk of postnatal depression.[9]

A further article was published in 2008, which confirmed these findings and further defined the 'rites of passage' in terms of preterm birth.[11]

It was decided to establish a comparative study, which was completed in 2012. Within each of these sets of experiences were 12 of preterm birth, when the infant was taken immediately at birth to a neonatal unit. The mothers were matched according to the hospital of birth and the gestational age of the infant. The remaining 12 experiences in the initial study were full-term in nature, and the mothers experienced the expected type of scenario thus comprising a control group. Within each group was one experience where the infant died and one where the infant was born with a disability. All the women lived in the Midlands area and attended one of eight different hospitals.

Methodology

The methodology involved an initial telephone contact followed by a 38-question, postal questionnaire and concluded with a semi-structured interview carried out face-to-face in the mother's home, enabling the mother to feel as relaxed as possible. It is interesting that the study group interviews lasted approximately twice as long as those of the control group, particularly when it is recognised that the same interview schedule was used for all groups. It is noteworthy that the response to the questionnaire was 100%; this is unusual and may suggest a high level of commitment to the need for this type of research.

The theoretical framework

Human experiences of change tend to be organised via a tripartite structure at both the social and the individual level.[12-16] Van Gennep described these changes as 'rites of passage'.[12] According to Van Gennep there are three stages to the rites of passage: separation, transition and reincorporation (**TABLE 1**).

It has also been suggested that at these times of change society invokes certain rituals.[13,14,16,17] Funeral rites are implemented by most religions although it has been suggested that within Western societies their value has been greatly minimised.[16,18] It may therefore follow that other types of ritual, especially those around the time of birth, may likewise have been devalued.[9-11,19] It could be argued, however, that deeply entrenched psychological expectations that surround the rites of passage are

internalised as an accepted set pattern, which will be standard to all concerned within a particular group of people.

In his theory of attachment, Bowlby has suggested that certain events (eg engagements, marriages and funerals) trigger actual physiological changes, indicating that the sociological and physiological changes are very closely interrelated, or interdependent.[20,21] In the two comparative studies presented here, 100% of the mothers of preterm infants interviewed experienced postnatal depression, which may be attributed in some way to the hiatus of preterm birth.

In 1992, a model of hypothetical full-term birthing rites of passage was created regarding mothers' experiences of term birth within this framework (**TABLE 1**).

This model was appropriate to the analysis of the control group, however, as the appraisal continued it became necessary to also devise a hypothetical model of the preterm birthing rites of passage (**TABLE 1**).

Themes were generated as a result of the data accrued from the postal questionnaire and the face-to-face interviews.

The thematic analysis

The hypothetical models of birthing rites of passage were used as a foundation for the thematic analysis and subsequent interpretation of the data arising from the semi-structured, personal interviews. From this analysis it was found that a surprising theme of loss characterised the responses given by the mothers of preterm infants. These responses in both studies were diverse in nature, ranging from loneliness, marginalisation, sadness and fear, through to isolation. It was found that these findings remained the same regardless of the age, social parity, education or occupation of the 'premature mother'.

Findings

The rites of separation: the term mothers' responses

There was considerable group similarity between the responses made by the term mothers, which was generally characterised by happiness. Commonly the control group reported the experience of birth as "a very happy time". The findings would appear to uphold the theory that mutual support from others in a similar situation is of vital importance to recovery.[14] All the mothers in this group were nursed alongside other mother and baby pairs. It would seem that being given a live, healthy baby is fundamental to the psychological well-being of the mother.

The rites of separation: the premature mothers' responses

The rites of separation for the premature mothers began, in the majority of cases (22 out of 24 mothers), unexpectedly. All of the women described with horror and disbelief the onset of labour. They likewise reported a professional denial and avoidance of the premature start to labour. Two of these women (3/1992 and 5/1992) subsequently experienced an emergency admission into hospital, where they encountered a similar professional denial from the hospital medical staff (**TABLE 2**).

> "She (the midwife) got her trolley out and straightened all the bits. I said, I'm going to have it. She said, oh no dear you're not ready yet. I said, I've had it. She was born on the bed. There wasn't a paediatrician, there wasn't an incubator." (7/1992)
>
> "I rang the hospital but nobody would listen to me. He was born by the door on the kitchen floor. We had to wait for an ambulance." (7/2012)

TABLE 2 Examples of the experiences of premature mothers and their professional care during labour.

The shock that these mothers experienced may have been further compounded by the rather larger divide encountered between the 'advertised baby' and the actual newborn. The difficulty in accommodating the real baby may be seen to have increased by the complete physical separation that ensued when the baby was immediately taken to the neonatal unit.

The rites of transition: the term mothers' responses

The control group mother and baby pairs were all taken immediately post-delivery to a postnatal ward where they stayed for between 24 hours and seven days. During this time the majority of the group perceived that they received adequate support from both the hospital staff and their family/social support networks:

"Very relieved that a long labour was over." (2/1992)
"Very confident in the professionals' skill." (4/1992)
"Very helpful and friendly staff." (8/1992)
"No worries." (10/1992)
"Happy." (16/1992)
"Needed a bit more support with baby care." (20/1992)

Although some of these women reported that they were very uncomfortable in hospital and dissatisfied with the care they received (18/1992 and 24/1992), all of the

Rite of passage	Typical term birth	Preterm birth
Separation The initial moving away from the antecedent lifestyle	Occurs at a given point in time, ie 38-42 weeks' gestation	Occurs at no particular time Taken into hospital
Transition A time of liminality, spent 'betwixt and between' the two states, often including seclusion from everyday life	Planning Pain Labour Safely delivered Upon and after delivery mother and baby are separate and yet together Bonding Social recognition Communitas, ie mutual support and sharing	Shock Pain No planning or planning incomplete Labour Unsafely delivered At delivery the baby is immediately taken away No bonding No social recognition No communitas
Reincorporation This signifies the beginning of life according to the new status quo. The acquisition of the new social role	Taking baby home after a short time post-delivery Reincorporation into society Party time – celebration of the new social position with cards and flowers	Do not take baby home for a long time Mother may initially go home alone Reincorporation flawed, as it is at the wrong time No or delayed celebration

TABLE 1 The rites of passage and their hypothetical role in term and preterm birth.

mothers stated the great benefit of being with their infant and being nursed alongside other women in similar situations. Many of them described the beginnings of long-lasting friendships that continued after their discharge, when they would attend mother and baby groups or meet socially together.

The rites of transition: the premature mothers' responses

The descriptions given by the study group mothers may be said to highlight a bleak contrast with those made by the control group. Invariably they depicted a situation in which they were severely disorientated and quite understandably extremely anxious, their graphic descriptions tended to fully describe the traumatic birth experiences in terms of disbelief, confusion and loss. It would appear that these feelings were emphasised because the infant was removed upon delivery (**TABLE 3**). From the data accrued it would seem that these groups of premature mothers felt that they did not truly belong anywhere, that they were held in limbo.

"I was scared because I wanted it all over and done with; whatever was going to happen. I felt like I wasn't really there." (11/1992)

"I was frightened, I thought the baby was going to have only one arm or something. My vision was tunnelled, I did not know what to think." (19/1992)

"I'd think about all my faux pas and I used to freak out, I couldn't just walk on the ward normally like any other mother." (1/2012)

"They have to warn you about everything that might happen and so by that stage I was very worried. Very worried." (5/2012)

TABLE 3 Examples of the feelings of premature mothers regarding the birth.

"They're the people that know, they're the experts, it's marvellous what they can do." (1/1992)

"I just felt like a spare part. You may as well have not been there." (5/1992)

"The nurses were always too busy to ask anything, too busy for me." (9/1992)

"It was horrible, it was the beeping and it got to the point that every time I got near the unit I was physically sick." (1/2012)

"I do understand why they have to tell you everything but I'd just rather they hadn't done it to me. I'd rather not have known any of that, it just made me more stressed." (19/2012)

TABLE 4 Examples of the feelings expressed by premature mothers regarding neonatal care.

The specialist neonatal care that the infants received was often highly praised and valued. However, many of these mothers regarded themselves as inept and clumsy in comparison to the highly skilled healthcare professionals (**TABLE 4**).

Most of these mothers also reported a very negative response from the staff on the postnatal ward. Once again many described a professional denial of their trauma, alongside feelings of isolation, loneliness and sorrow because they were nursed with term mother-infant pairs.

It may have been that the postnatal staff believed that maternal care was being tendered by the neonatal unit staff, however most of the mothers felt unable to take the time of the neonatal unit staff, who they felt were better employed in the care of their babies. Many of them described strong feelings of guilt concerning the flawed birth. This scenario engendered a lack of support from other premature mothers because there was generally no opportunity for the development of mutual support, ie communitas. In fact, several of these mothers found their situation so intolerable that they requested an early discharge (**TABLE 5**).

From these findings it is reasonable to surmise that most of these mothers found their rites of transition traumatic.

The rites of reincorporation: the term mothers' responses

The rites of reincorporation for the term mothers all occurred at the expected time and the group generally reported a positive response both from and towards, the healthcare professionals. Although many reported an initial period of anxiety, this was usually short lived:

"I was scared a bit... first baby but then you know he was always alright and everything just fell into place." (10/1992)

"My health visitor was really nice. A nice lady – she'd got plenty of time for you." (16/1992)

"The midwife came everyday, she was good. Then the health visitor came after day 10 and she was very good." (20/1992)

In the main, this group expressed pride in their babies who they located in terms of family position and expectations. All the women reported a wealth of information that was readily available ranging from television programmes through to childcare manuals.

"I think at the end of it I'd have discharged myself." (5/1992)

"They never offered to take me to see her. Nobody sat and talked it through with me. I discharged myself the next day." (7/1992)

"I was in a side room. I did not want to stay in that place. I needed to get home." (13/2012)

"I did not want to be there, I could hear the other babies crying, it was torture on toast." (3/2012)

TABLE 5 Examples of the feelings expressed by premature mothers regarding care on the postnatal ward.

Overall there was a general feeling of satisfaction with the outcome of their birthing experiences. The two mothers who expressed most dissatisfaction with their rites of passage were unsurprisingly the mother of the baby who died (12/1992) and the mother of the baby with a disability (24/1992). It was found that the responses of the mother of the disabled baby were similar to responses generally given by the mothers of preterm infants. This would appear to indicate a need for further research into the rites of passage for mothers who suffer the death of a baby and/or the birth of a disabled baby.

The rites of reincorporation: the premature mothers' responses

The rites of reincorporation of the premature mothers once again portrayed a stark contrast with those of the full-term mothers. These mothers reported little support from the community healthcare professionals. It may have been that the professionals assumed that the mothers were receiving the necessary support from the neonatal unit. It would be fair to say that in the early stages, when 18 of the infants remained on the unit when the mother was discharged, it would have been very difficult for the professionals to make contact.

This type of scenario may be better defined as an extended liminal stage of transition, rather than a rite of reincorporation. Such a delay in the rites of passage falls well outside of the normal/stereotypical expectations.

Many of these mothers reported little specialist help together with another denial of the trauma they had suffered and an

underlying presumption of a normal birth (**TABLE 6**).

Some of these mothers described a social denial enacted by friends and relatives, who avoided visiting or even discussing the infant who remained in hospital.

Powerlessness

The concept of the 'locus of control'[22] may be significant to our understanding of the preterm birth rites of passage, wherein all control is wrested from the mother by the medical professionals. It is necessary that she should accept the medical control of not only herself but also her baby. Kitzinger (1992)[23] suggested that such a situation often results in a 'birth crisis' that may have far reaching psychological effects upon the woman.

It may be recognised that an emergency hospital admission and/or delivery may act as such a stressor. According to Seligman (1975),[24] a common outcome of this type of event is depression. It was found in this study that all of the premature mothers reported subjective feelings of cognitive disturbance, describing depression as the outcome to their preterm rite (**TABLE 7**).

Only two of the women in the 1992 study experienced transitional care (17/1992 and 21/1992); their comments were really positive. They and one other (9/1992) reported much greater support once they returned home as they received specialist follow-up care from a family care sister who acted as a link with the neonatal unit (**TABLE 8**). Nevertheless, the majority of the group perceived that they received inadequate care.

"Everything stopped, went dead. I was crawling the wall – neurotic about germs and things; sterilise, sterilise. I got dermatitis sterilising my hands." (5/1992)
"My doctor patted me on the head and said that I was too worried. Very patronising." (7/1992)
"Every professional person you met was someone who was absolutely used to dealing with term babies. When you mention premature it suddenly becomes very vague." (13/1992)
"Just want you to do what is best and you have to make a decision about the best thing for my baby." (5/2012)
"Frightened, very frightened." (19/2012)

TABLE 6 Examples of feelings of premature mothers regarding life at home with their infant.

Discussion

Support needs for premature mothers

The findings from these studies depicted significant differences between the two experiences of the birthing rites of passage. It was found that mothers of preterm infants were all affected by this experience, which they felt had a negative effect upon their parenting. Unfortunately, there was not enough data to say what interventions had helped these mothers to cope with their feelings and emotions but some mothers were able to talk about those services that helped them:

- being heard, especially in labour, where separation was not accepted nor understood. A highly skilled midwife was found to be the ideal solution to this issue.

FIGURE 1 The parents' room on the neonatal unit at Leicester Royal Infirmary. The comfortable seating and pleasant decor allow parents to get together for the benefit of communitas.

"I was not normal." (3/1992)
"A lot of the first three years are a bit of a blur. Most of the time, certainly the first couple of years, I was a total zombie." (13/1992)
"I know this is horrible but he was sort of doing my head in." (19/1992)
"...panic attack and I was having violent diarrhoea because my stomach was always knotted." (1/2012)
"I felt quite useless and I think I felt guilty about the whole thing... I can't even hold on to the baby for the full length of time you're meant to!" (19/2012)

TABLE 7 Examples of feelings of premature mothers about their 'inner selves'.

"The family sister was like an umbilical cord with the unit; she really helped." (9/1992)
"The family sister was marvellous." (17/1992)
"It was really good to sit and talk things over with another mum in the same situation." (21/1992)
"I really liked her coming to see me, she was my life line." (1/2012)

TABLE 8 Examples of feelings expressed by the mothers who experienced transitional care.

- service design: the availability of family rooms where mothers could get together to gain the benefit of communitas. It was found that the premature mothers felt a great sense of loss due to the physical separation from their baby. It was apparent that accommodation for mothers adjacent to neonatal care units would offer respite from this distress. This could be transitional and precede eventual rooming in with the baby.
- neonatal nurse care within the community: both groups highlighted the importance of this.

From this research it would appear that there might be a need for transitional care for all premature mothers. Medical research has indicated the positive nature of this type of nursing.[3,4,7,25-28] This type of regime encourages the mother to carry out care for the baby and, as the infant's health improves, offers rooming in as a transitional phase to discharge. This study indicates that the mothers of preterm infants were better able to negotiate the missing steps of their rite of passage. These findings might suggest that good transitional care should be seen as a

priority for mothers of preterm infants.

In light of the above findings, it may be beneficial if such mothers could experience contact with other premature mothers. There was little difference in the two data sets in terms of the experience of the mothers of preterm infants. The only difference was the availability of the parents' rooms in the second data set. A specialist postnatal ward had been created alongside the neonatal unit with a sitting room equipped with comfortable seating and pleasant decor (**FIGURE 1**).

Conclusion

The isolation, helplessness and powerlessness experienced by premature mothers had a profoundly negative impact upon their well-being. Progress in neonatal care, in terms of the survival of many more babies born at earlier gestational ages, must be applauded; however, the experiences of the mothers who continue to undergo dissatisfaction with their rites of passage must have a negative impact upon the future well-being of the family.

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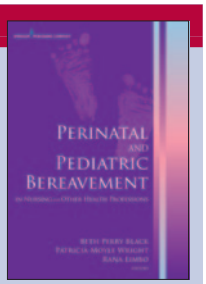
Book review

Perinatal and Pediatric Bereavement: In Nursing and Other Health Professions



Beth Perry Black, Patricia Moyle Wright and Rana Limbo (Editors)
Springer Publishing Company, ISBN: 978-0-826-12926-0
$85, paperback, 420 pages

It is always welcome when a body of work is published that adds greatly to our knowledge and stimulates thought and debate around a particular discipline. *Perinatal and Pediatric Bereavement* is one such book, containing a wide range of perspectives that address the complexities of human experience relating to perinatal, neonatal and paediatric deaths.

Contributions span a uniquely north American perspective drawing in content from academics and healthcare professionals across the USA and Canada. At Sands, given our focus on stillbirth and neonatal deaths, the perinatal bereavement section is highly relevant, yet the paediatric bereavement chapters also offer valuable and in-depth insight to help professionals understand the broad spectrum and profound nature of parental, child and sibling grief. Unusually, little-covered specialist areas are also included, such as the effect on siblings of suicide victims and the particular bereavement experiences of lesbian couples that lose a baby.

This book expands our knowledge about the range of evidence-based research that does exist and much supports Sands' own principles of good practice published in *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. This new volume also confirms for the reader how unique an experience baby bereavement is.

It is good to see such a high level book validate the devastating effect on parents and families that such an awful tragedy has on their lives. This is in evidence right from the onset in the very moving foreword written by Betty Ferrell PhD, a palliative care nurse whose own son Andrew died at just three months of age in a neonatal intensive care unit. "This is a story of love, hope and healing," she writes after describing how caring and professional the healthcare workers that tended for her son were, but how little they knew about supporting a parent or siblings when a child dies.

The 18 contributors probe all aspects of bereavement care and the book should enhance the work of any healthcare professional involved in caring for bereaved parents and families. The publication of *Perinatal and Pediatric Bereavement* will hopefully help bring forward the day when all bereaved parents are given the help and support they need by professionals, both in the immediate aftermath of a death and in the longer term.

Erica Stewart
Sands' Bereavement Support Services Manager