MOTHERS’ EXPERIENCES OF CARING FOR VERY LOW BIRTH WEIGHT PREMATURE INFANTS IN ONE PUBLIC HOSPITAL IN JOHANNESBURG, SOUTH AFRICA

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ABSTRACT

This study explored the experiences of mothers of very low birth weight premature infants in a neonatal unit of a public hospital in Johannesburg. The objectives were to determine difficulties faced by mothers, to evaluate coping strategies used by these mothers in dealing with the difficulties and to make recommendations regarding their care. In-depth individual interviews were conducted with a purposefully selected sample and the meaning of these mothers’ experiences was analysed by means of Tesch’s (1990) method of analysing qualitative data. Findings provided insight into emotions and challenges experienced by mothers during the hospitalisation of their infants. Shock and sadness were significant emotional reactions experienced after giving birth to very low birth weight premature infants; subjective suffering; various forms of support; maternal wishes and needs were some of the findings. Rooming-in facilities and information about their babies’ progress as well as psychotherapy and counselling services could enhance these mothers’ abilities to cope with their challenges.

KEYWORDS: low birth weight infants, paediatric intensive care, premature infants, premature infants’ mothers’ experiences

INTRODUCTION AND BACKGROUND INFORMATION

It is every expectant woman’s dream to have a healthy, uncomplicated pregnancy and a healthy, bouncy baby. For many women a fearful reality dawns with the onset of premature labour and delivery of a very low birth weight premature infant. The uterus is expected to carry the foetus to a gestational age of 40 weeks, in which time the foetal organs form and begin to function. A shorter gestation threatens the normal functioning of organs, especially the lungs. Difficulties arise when the very low birth weight premature infant must be taken away from the mother after birth and be put in a
neonatal intensive care unit (NICU), to gain weight and improve lung function (Evans & Madsen, 2005:188).

Many hospitals have recognised the importance of encouraging contact between infants and their mothers. Evans and Madsen (2005:189) note that some hospitals have areas in which parents can stay for prolonged periods, allowing mothers to interact with their very low birth weight, premature infants as much as possible. However, when the infant is too ill and even on a respirator, mothers find it difficult to maintain skin-to-skin contact. In other hospitals parents are encouraged to visit, taking precautions to minimise the risk of spreading infections. Lee et al. (2005:24) assert that identifying developmental and physiological needs of very low birth weight premature infants and their families has improved the survival rates of these infants.

Lee et al. (2005:22) observed that mothers who give birth to very low birth weight premature infants experience a certain degree of sorrow, anxiety, anger and depression. Evans and Madsen (2005:189) describe the hospitalisation of an infant as one of the most traumatic episodes of parenthood, especially the mother of the infant. Some mothers enjoy family and partner support during the infant’s hospitalisation while others have to walk the journey alone. Mothers might be rejected by their partners due to cultural beliefs, leading to frustration and isolation (Ntswane & Van Rhyn, 2007:86). The implementation of therapeutic programmes in the form of parent-infant interaction, maternal emotional, psychosocial and breastfeeding support can reduce maternal distress and increase confidence in caring for their infants (Lee at al., 2005:25).

PROBLEM STATEMENT

Caring for a very low birth weight premature infant in hospital can be emotionally draining, demanding in time and financial support to the mother. Most mothers are left to attend to the infant alone as partners work to sustain an income. Some partners abandon them and the infant for reasons such as beliefs that the infant was bewitched (Lee at al., 2005:26). Social behaviour adds more strain to new mothers of very low birth weight premature infants. Kwo and Shin conducted a similar investigation and found that in Korea, prematurity is stigmatised and people believe that all premature infants will be mentally disabled (Lee at al., 2005:25). The same study revealed that 30% of people expressed that it would be better to give a premature infant up for adoption than to seek medical treatment. The researchers in the current study observed that at the selected hospital in Johannesburg, mothers were discharged from hospital a few hours after delivery and instructed to come daily to extract milk for feeding their very low birth weight premature infants and to maintain mother-infant contact. Although much research has been conducted on very low birth weight premature infants and their care, little is known about the experiences of their mothers in the selected hospital. The study was therefore a realisation of the need to explore the experiences of these mothers and to discover their adaptation strategies and coping mechanisms to the challenges that they might face in caring for their hospitalised infants.
RESEARCH PURPOSE

The purpose of this research was thus the need to explore the experiences of mothers of very low birth weight premature infants at the selected hospital in Johannesburg. The study intended to describe how these mothers coped with the difficulties and challenges they encountered.

Research objectives

The objectives of the investigation were to: explore the experiences of mothers of very low birth weight premature infants in a selected hospital in Johannesburg; to determine difficulties faced by mothers in caring for their infants and the coping strategies utilised in dealing with difficulties and to determine intervention methods; and to make recommendations regarding the care of the mothers and their infants to the clinical, research and nursing education departments.

DEFINITIONS OF KEY CONCEPTS

Very low birth weight infants, according to Fraser and Cooper (2003:782), are infants weighing below 1 500g at birth. For the purpose of this study a very low birth weight infant meant a single neonate born by normal vaginal delivery with a birth weight of 1 500g or less that was still hospitalised at the time of the data collection.

Mothers mean women who had given birth to very low birth weight premature infants, regardless of their age, parity or HIV/AIDS status.

A premature baby, according to Fraser and Cooper (2003:782), means a preterm infant born before the 37th week of gestation. For the purpose of this study, premature and very low birth weight baby were used concurrently, irrespective of the gestational age.

RESEARCH QUESTION

One research question was used to elicit the required information: “What are your experiences in caring for your very low birth weight premature infant and how do you cope?”

During the interviews the researchers observed the participants’ non-verbal communication and reported these observations in field notes (Ntswane & Van Rhyn, 2007:88; De Vos et al., 2002:286).

ETHICAL CONSIDERATIONS

Written permission to conduct the study was sought from the selected hospital authorities and ethical clearance was granted by the Faculty of Health Science Ethics
Committee of the University of the Witwatersrand prior to commencement of data collection. Informed consent was obtained from all participants by explaining the goals of the study, the possible advantages or disadvantages of participating, the credibility of the researchers, and to audio-tape the interviews. The participants were assured of confidentiality, anonymity and the freedom to opt out of the study at any stage without negative consequences.

MEASURES TO ENSURE TRUSTWORTHINESS

- Lincoln and Guba (1985) developed a model for qualitative inquiry parallel to the quantitative paradigm for reducing bias in research results:
  - Credibility (internal validity): The researchers in the study ensured truth of the experiences of mothers with very low birth weight premature infants, by dwelling for lengthy periods in the setting during data collection; each interview lasted between 60 and 90 minutes.
  - Transferability (external validity): The study results cannot be generalised. However, the researchers enhanced applicability by safeguarding all data transcripts, audio cassettes and the independent coder’s consensus discussion.
  - Dependability (reliability): One of the researchers conducted a pre-test with one participant prior to the main study to enhance consistency.
  - Confirmability (objectivity): To adhere to the criterion of objectivity, the researchers gave the completed study report to two of the participants to read and verify its truthfulness.

RESEARCH DESIGN AND METHOD

Since the purpose of this research was to explore and describe the experiences of mothers with very low birth weight premature infants and give these experiences meaning, the appropriate design was explorative, descriptive and contextual, within a qualitative paradigm (Burns & Grove, 2005:67).

Population and sample

The study population comprised mothers who had given birth to very low birth weight premature infants of less than 1 500g and whose babies were still hospitalised at the selected hospital’s neonatal unit during the data collection phase (Burns & Grove, 2005:366). A non-probability purposive sampling technique was implemented to identify participants (Burns & Grove, 2005:58). The criteria for inclusion were that each participating mother had a normal vaginal delivery and was able to speak English, Afrikaans, Setswana, Sesotho or IsiZulu, the languages in which the interviewers
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were proficient. The sample in the study comprised thirteen participants. The mothers’ demographic information is illustrated in Table 1.

TABLE 1: Demographic information of participating mothers (n=13)

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>5</td>
<td>38%</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>8</td>
<td>62%</td>
</tr>
<tr>
<td>Age</td>
<td>15 – 20</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>21 – 25</td>
<td>4</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>26 – 30</td>
<td>4</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>31 and above</td>
<td>4</td>
<td>31%</td>
</tr>
<tr>
<td>Occupation</td>
<td>Student</td>
<td>2</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>5</td>
<td>39%</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>6</td>
<td>46%</td>
</tr>
<tr>
<td>Postpartum period in days</td>
<td>1 – 10</td>
<td>5</td>
<td>39%</td>
</tr>
<tr>
<td></td>
<td>11 – 20</td>
<td>7</td>
<td>53%</td>
</tr>
<tr>
<td></td>
<td>21 – 30</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>31 and more</td>
<td>1</td>
<td>8%</td>
</tr>
</tbody>
</table>

Data collection

Data were collected over a 3-month period between June and August, 2008. Data were gathered by means of individual in-depth interviews with mothers of infants who were still in hospital without restrictions and they had control of the interviews (Mayan, 2001:14). All interviews were recorded on audiotape, with the permission of the participants then translated into English and transcribed verbatim, for analysis purposes (Burns & Grove, 2005:335). The researchers used communication techniques such as empathy, reflecting, probing, and clarifying during data gathering (Uys & Middleton, 2004:139).

Data analysis

The researchers assumed data analysis by performing bracketing, removing all preconceived expectations about the phenomenon under study (Burns & Grove, 2005:532). They used Tesch’s method (Creswell, 2008:186) of analysing qualitative data to transform the data into research results (LeCompte, 2000:46). Topics that emerged were given codes, which were written next to each topic to allow for easy retrieval. Topics were then turned into categories, which allowed the grouping together of similar data (LeCompte, 2000:148). Subcategories emerged under each category. After completing the above steps, important verbatim quotations were identified for inclusion in the report. A co-coder was engaged to analyse the data independently. The
researchers and the co-coder reached consensus regarding the identified categories, subcategories and themes.

RESULTS AND DISCUSSION

Five major categories emerged from the interviews: emotions, subjective suffering, support, desperate wishes and expressed needs.

**TABLE 2: Major categories, subcategories and themes arising from the interviews**

<table>
<thead>
<tr>
<th><strong>MAJOR CATEGORIES</strong></th>
<th><strong>SUBCATEGORIES</strong></th>
<th><strong>THEMES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Emotions</td>
<td>Mother of the infant</td>
<td>Shock and sadness, Grief/depression, Fear and worries</td>
</tr>
<tr>
<td></td>
<td>Father of the infants</td>
<td>Indifference</td>
</tr>
<tr>
<td>2: Subjective suffering</td>
<td>Mother of the infant</td>
<td>Experiences of loss and ignorance</td>
</tr>
<tr>
<td>3: Support</td>
<td>Spiritual, physical and emotional support</td>
<td>Spiritual – God’s providence, Physical – financial concerns, Emotional – empathy or lack of empathy</td>
</tr>
<tr>
<td>4: Desperate wishes</td>
<td>Mother of the infant</td>
<td>Speedy growth of the infant</td>
</tr>
<tr>
<td>5: Expressed needs</td>
<td>Rooming-in facilities, Nurses’ attitudes, Maternal information</td>
<td>Bonding with the infant, Positive or less positive, Good to know about baby’s treatment and progress</td>
</tr>
</tbody>
</table>

Subcategories were developed as the analysis proceeded: within the framework of the major categories comprehensive themes were developed to support the subcategories. The discussion is highlighted by direct quotations from the participants and accompanying literature control. Table 2 portrays a schematic condensation of the data analysis.
Emotions

Shock and sadness

Shock is a sudden and disturbing physical or mental impression in response to terrifying unexpected events (Uys & Middleton, 2004:236). Most mothers in this study described how their despondency was preceded by a state of shock when they first saw the baby. “I was not ready to have him; it was a shock to me.”

“Seeing her, I just crushed with shock, she is so small.”

The feeling of sadness followed as the mothers patiently waited for the discharge from hospital of their infants, evident in quotations like: “It’s painful because I can’t spend time with my baby.”

Some mothers related how the sadness worsened every time they had to leave the neonate in hospital and when people at home enquire about the baby. “I feel sad like I am abandoning him … The questions people ask about my baby hurt me.”

Eriksson and Pehrsson (2005:128) investigated the emotional reactions of parents after the birth of an infant with extremely low birth weight, and report that the state of shock was the most appropriate immediate reaction that any woman experienced and sadness was the distinctive type of mental state expressed by most mothers in taking care of their very low birth weight premature infants.

Grief and depression

Feelings of depression and grief were universal to mothers during the early stages after the babies were born, as explained by some participating mothers: “In the beginning I cried a lot and I could not sleep at night, thinking if he would survive or not.”

One participant in this study had lost a very low birth weight, premature neonate the previous year; feelings of depression, helplessness and loss of interest were still evident weeks after the birth of the new baby: “... I lost another baby in this ward, now it’s the same story; I don’t feel well.”

Yam and Au (2004:118) conducted a similar study in Hong Kong where mothers reported similar feelings and admitted that crying seemed to relieve their emotions, especially when there was no obvious improvement in the child. Carter et al. (2008:110) investigated parental responses when their infants were in neonatal intensive care units and confirmed that physical and emotional isolation from the baby was the main cause of grief, anxiety and depression. The fact that their babies are of low birth weight is a source of enormous anxiety and distress to mothers in particular. This is confirmed in a quantitative study by Rondo et al. (2003:266) who found that maternal distress was significantly associated with low birth weight (RR=1.91, p=0.019) and anxiety (RR=2.32, p=0.015).
Fear and worries

Fear is the response to emotional threat, danger and anxiety due to psychological and social situations. Mothers verbalised experiencing fear for the neonates’ lives during the first few days, but as the babies improved in weight and health the fear and worry changed to joy and affection. The following quotations highlight this feeling: “I am scared to hold her; she is very small.” “My love for him gives me hope.” “When the nurse inserted the tube in his tiny nose, I felt the pain with him.”

Partridge et al. (2005: 265) conducted an international comparative study to investigate very low birth weight infants’ parents’ perceptions of counselling. They reported that the unfamiliar hospital situation aggravated their fears. A similar study in rural India by Mohan et al. (2004:5) revealed that parents, especially the mothers, worried a lot; however, the love for their sick children gave them hope. Love for their children in neonatal and pediatric intensive care was a universal theme in parents of all cultures (Evans & Madsen, 2005:189).

In the current study mothers had misconceptions about the cause of premature labour and the very low birth weights of their babies. They seemed to feel guilty about what happened, as demonstrated by the following quotation: “I blame myself for this situation; I should not have stressed about my boyfriend’s behaviour.”

For some mothers guilt feelings were caused by leaving the baby in hospital: “When I am at home, I feel very guilty as if I am abandoning my baby.” Guilt and blame were also feelings expressed by parents in the study by Eriksson and Pehrsson (2005: 131) with regard to the cause of extreme low birth weight of their children. However, Yam and Au (2004:118) reported that Chinese mothers admitted that distancing and avoiding coming to their babies’ neonatal care units gave them temporary relief.

Indifference of the fathers

Most fathers of the very low birth weight premature neonates showed indifference towards the mothers and babies. They were described by the mothers as showing apathy, lacking emotion and motivation. Some partners and spouses refused to visit their babies because they were afraid of the babies’ small size: “My boyfriend has lost hope in our baby and this hurts me so much.” “He says the baby is too small and he feels uncomfortable.” “My husband becomes irritable when I ask for transport money to come to see the baby.”

In the reviewed literature fathers reportedly showed caring and supportive attitudes towards the mothers and the babies (Evan & Madsen, 2005:188; Partridge et al., 2005:270).
Subjective suffering

Experiences of loss and ignorance

The results of this study indicated that inadequate information was given to mothers which did not help them to deal with their losses. Hastings and Lloyd (2007:344) emphasised the need for parents of premature neonates to be emotionally, physically and socially supported by health care providers to enable them to care for their infants. The mothers in the current study showed naïve concern over the wellbeing of their infants. The theme of ignorance is demonstrated by quotations like: “My baby was on oxygen but they said nothing and for the whole week I was sick worried.” “I think a lot about whether my baby is comfortable, well fed and whether nappies are changed.”

Mohan et al. (2004:5) identified ignorance among the rural Indian mothers regarding hospitalisation of their children. However, in their study the ignorance was motivated by traditional and cultural beliefs.

Support

God’s providence

The trust these mothers had in God gave them courage that they and their babies would go through whatever situation. The trust in God was expressed as: “I ask myself what happened, but I put everything to God’s hands.”

Partridge et al. (2005:265) reported that the mothers in their research expressed having adequate religious discussions with their physicians about the care of their children and about decision making. Mothers were informed about what the medical team could do for the infants and that God would provide for them all. Some participants in the current study expressed faith in the nurses’ abilities: “God is there and I have faith that the nurses are trained and know what to do.”

A few participants enjoyed spiritual support from their families and friends: “My boyfriend’s family is praying for him.”

Auslander, Netzer and Arad (2003:30) investigated parents’ satisfaction with care in the neonatal intensive care unit and they reported that ultra-orthodox Jewish parents relied on their religion for coping and that the rabbi was trusted for decision making and support. In the study by Yam and Au (2003:118) all mothers used social support and positive appraisal as their coping strategies.

Financial support

Even though the mothers in this study did not have to worry about hospital bills like other mothers in the reviewed literature, they experienced financial burdens as they were unemployed and had to pay for public transport to commute daily to and from the hospital. This theme is evidenced by quotations like: “He is supporting me because he
gives me the little he can to come here.” “He can hardly pay for the rent for us to live in a safe place; he does not give me money to come see the baby.”

Payne and Carpenter (2007:89) studied barriers of compliance with effective hand hygiene practices by neonatal health care workers. The results of their study showed how prolonged hospitalisations, as a consequence of neonatal infections, generated significant economic burdens on the families. Families might experience economic burdens as a result of lost wages, and transport costs, incurred by long hospitalisations of very low birth weight infants.

Empathy

The theme of empathy is significant to those mothers who enjoyed the support of their partners or parents and the lack of empathy is significant to those who have poor support from significant others. This was expressed in the following quotation: “Without my mother and my husband’s support I wouldn’t have been able to handle this.” “He becomes angry when he has to stay with the older child.” “My husband is cold towards me these days.”

Similar studies (Hastings & Lloyd 2007:342; Yam & Au 2004:118) reported that mothers received less social support and confessed that the tension in the relationships with their husbands and in-laws aggravated their stress levels. Different results were reported by Auslander et al. (2003:18) where fathers were more positive than mothers in assessing the care and wellbeing of their premature babies.

Desperate wishes

Infants’ speedy growth

In this study the mothers seemed to understand that the weight gain of their infants was the most important outcome of care. Most mothers expressed desperate wishes for their babies to gain weight: “My only need and wish is for my baby to grow bigger.” “I envy mothers whose babies are big. I wish to hold mine too.”

Evans and Madsen (2005:191) reported that mothers mentioned that the most traumatic episode of parenthood was when they were unable to hold their sick babies in their arms. Another complication of prematurity is an immature sucking reflex, which, according to Pillitteri (2009:711), contributes to feeding difficulties. This often leads to mothers exploring feeding alternatives. Mothers in the current study expressed their wish to breastfeed the babies in statements like: “I wish I could feed him on the breast and not by express milk.” “If I can put him on my breast, it will soothe me.”

All mothers wished to take their infants home: “I just wish to take my baby home and then the many questions will stop.” Evans and Madsen (2005:189) reported that in their research parents were encouraged to provide direct care for the infant as a way to get to know the infant and to prepare for taking the infant home.
Needs

Bonding

For any mother, her maternal instinct is to be continuously with her newborn infant, to care and nurture. This is not possible for mothers of very low birth weight premature infants, whose infants require hospitalisation. The need to bond with their infants was expressed in statements like: “It would be better to be around my baby all the time.” “We could be given a room to stay in order to check our babies day and night.”

Evans and Madsen (2005:190) report that some hospitals in their study had unlimited visiting hours for parents, and others had areas in which parents could stay for prolonged periods to be near their infants.

Nurses’ attitudes

Positive experiences with the nurses were reported by some mothers saying that the nurses gave them hope, evidenced in statements like: “The nurses have been kind and gave me hope.” “I find strength and hope from nurses.”

Auslander et al. (2003:21) reported that the quality of medical care and attitudes of staff members arose as important issues in parents’ satisfaction with care in the neonatal intensive care unit. They added that emotional support and information are important basic tenets of family-centred care in neonatal units (Auslander et al., 2003:32). However, not all the mothers’ experiences were positive in the current study, because some mothers reported being confused and fearful of the nurses: “I’m confused by the different reports about his progress.” “Some nurses are not approachable; I’m scared to ask questions.”

Auslander et al. (2003:29), as well as Evans and Madsen (2005:190), also reported that in their respective studies nurses were more frequently criticised for a lack of professionalism. In this study there was lack of information given to mothers regarding their infants’ care and conditions. This is evident from comments such as: “My baby was sick and no one said anything to me.”

With a lack of information came worries and fears of the unknown. Supporting this theme on a deeper level was a mother’s statement: “They put my baby in a bottle [incubator] and pushed a tube into her nose and I did not sleep that night with worry.” Evans and Madsen (2005:190) reported similar results in their study about information to parents regarding their infants. When parents were not informed about the conditions of their infants, they imagined the condition to be much worse than the reality. Auslander et al. (2003:28) argued that providing information was a helpful attribute of any neonatal intensive care nurse.
CONCLUSIONS

The results of this study showed that for many women, a fearful reality dawns with the delivery of a very low birth weight premature infant. This study showed that these mothers went through a turmoil of emotions and other difficulties when taking care of their infants. The study revealed that mothers used various coping strategies like prayers and trusting God. The mothers reported that receiving emotional support and information was important to them.

RECOMMENDATIONS

A rooming-in facility that allows the mothers to stay in the hospital for the duration of the infants’ hospital stay should be introduced. This would enable constant bonding and cut down on travelling costs.

Education of mothers regarding the care and progress of their infants; the observation of mothers for psychological symptoms and referrals for psychotherapy and counselling, could enhance the mothers’ capabilities to cope with their challenges.

The nursing education curriculum should emphasise the psychosocial care of mothers with very low birth weight infants.

LIMITATIONS OF THE STUDY

The ability to reach conclusions based on these findings is limited by some methodological problems. The study was qualitative and thus its findings cannot be generalised. The translation of the tape recorded interviews from the different vernacular languages into English might have resulted in the loss of valid information regarding the experiences of mothers in caring for their very low birth weight premature infants. Hence the researchers recommend that further research be conducted in other settings.

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