

PARENTS' LIVED EXPERIENCE OF PROVIDING KANGAROO CARE TO THEIR PRETERM INFANTS

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ABSTRACT

Premature and low birthweight infants pose particular challenges to health services in South Africa. While there is good evidence to demonstrate the benefits of kangaroo care in low birthweight infants, limited research has been conducted locally on the experiences of parents who provide kangaroo care to their preterm infants. This phenomenological study explores the lived experience of parents who provided their preterm infants with kangaroo care at a tertiary-level maternity centre in the Western Cape. In-depth interviews were conducted with six parents: four mothers and two fathers. Data was analysed using an adaptation of the approaches described by Colaizzi (1978:48-71) and Hycner (1985:280-294). To ensure trustworthiness, the trustworthiness criteria described by Guba and Lincoln (1989:242-243) were applied. Kangaroo care is a phased process, each phase bringing a unique set of experiences. The eight themes that emerged are described: unforeseen, unprepared and uncertain - the experience of birth; anxiety and barriers; an intimate connection; adjustments, roles and responsibilities; measuring success; a network of encouragement and support; living-in challenges; and living with the infant outside of hospital. Challenges facing health care providers are described and recommendations for information about kangaroo care and support for parents are made.

OPSOMMING

Vroeggebore babas en babas met 'n lae geboortegewig stel besondere uitdagings vir Suid-Afrikaanse gesondheidsdienste. Daar bestaan goeie bewyse dat die kangaroosorgmetode voordelig is vir babas met 'n laegeboortegewig, dog is minimale plaaslike navorsing gedoen oor die ondervindinge van ouers wat hierdie metode gebruik om vir hul vroeggebore babas te sorg. Hierdie fenomenologiese studie verken die geleefde ervaringe van ouers wat vir hulle vroeggebore babas deur middel van die kangaroosorgmetode in 'n tersiêre kraamsentrum in die Weskaap gesorg het. Data is ingesamel deur in-diepte onderhoude met ses ouers te voer: vier moeders and twee vaders van vroeggebore babas. Data is ontleed volgens 'n verwerking van die metodes soos deur Colaizzi (1978:48-71) en Hycner (1985:280-294) beskryf. Om betroubaarheid te verseker, is die betroubaarheidskriteria van Guba en Lincoln (1989:242-243) toegepas. Kangaroosorg is 'n geleidelike proses; elke fase lei tot 'n unieke stel ondervindinge. Agt temas is uit die data geïdentifiseer: Onverwags, onvoorbereid en onseker - die geboorte-ervaring; angstigheid and hindernisse; 'n intieme verband; aanpassings, rolle en verantwoordelikhede; die meting van sukses; 'n netwerk van aanmoediging en ondersteuning; die uitdagings van binne die hospitaal leef; saamleef met die baba buite die hospital. Uitdagings wat gesondheidspersoneel te voorstaan kom en aanbevelings oor inligting met betrekking tot kangaroosorg en ondersteuning aan ouers word voorgestel.

INTRODUCTION AND BACKGROUND TO THE STUDY

The birth of a preterm infant is a crisis for the new parents. The mother is denied the last few weeks of pregnancy that help her to prepare psychologically for the birth and attachment process. Parents are in many ways as “premature” as their infants, and the birth of the preterm infant challenges previously held notions about birth and parenthood. Expecting to deliver a healthy full-term infant, they are faced instead with a small infant whose life is often supported by technological devices and who is cared for by highly skilled health professionals. The neonatal period is a particularly vulnerable one, and the wellbeing of a neonate can have lasting effects on subsequent quality of life (Nirmala, Rekha & Washington, 2006:178).

A premature infant is defined as an infant born at less than 37 weeks (259 days) of gestation, and a low birthweight (LBW) infant as weighing less than 2 500 g regardless of gestational age (WHO, 2003:iv). Spontaneous preterm labour is one of the most common causes of neonatal death (Pattinson, 2003:445). Premature infants require special care in well-managed facilities, and in poorly resourced settings there is a high rate of neonatal mortality (Ruiz-Peláez, Charpak & Cuervo, 2004:1179; WHO, 2003:1; Hann, Malan, Kronson, Bergman & Huskisson, 1999:37).

Kangaroo care (KC), also known as kangaroo mother care, comprises continuous skin-to-skin contact between mother and infant (dressed only in a nappy and hat), exclusive or nearly exclusive breast-feeding, and early discharge home with the infant in the kangaroo position once early adaptation problems to extra-uterine life have been resolved (Charpak, Ruiz, Zupan, Cattaneo, Figueroa, Tessier, Cristo, Anderson, Ludington, Mendoza, Mokhachane & Worku, 2005:514; Whitelaw, 1990:604; Ruiz-Peláez & Charpak, 1998:62). The practice was introduced in 1978 in Columbia (Charpak, Figueroa de Calume & Ruiz, 2000:1137; Dippenaar, Joubert & Brussow, 2006:16a) out of a necessity to provide a “natural incubator” in the face of shortages of incubators in Bogota, Columbia (Feldman, 2004:145). Originally an alternative to the usual minimal in-hospital care for stable LBW infants, it is the “most feasible, readily available, and preferred intervention for decreasing neonatal morbidity and mortality in

developing countries” (Charpak *et al.*, 2005:514), and has been endorsed by the World Health Organisation (WHO) as the best option for survival of LBW infants born in hospitals with inadequate resources (WHO, 2003:1-2).

KC has a number of advantages for both parent and infant: it is a natural, easy-to-implement and cost-effective intervention to improve breast-feeding and reduce morbidity and mortality in LBW babies (Henning, 2006:44; Charpak, Ruiz-Peláez, Figueroa de Calume & Charpak, 1997:687; Rodriguez, Nel, Dippenaar & Prinsloo, 2007:15b; Cattaneo, Davanzo, Uxa & Tamburlini, 1998:440) and earlier discharge (Hann *et al.*, 1999:39). It promotes nurturing behaviours that support growth and development (Dodd, 2005:236-237), including mental development (Tessier, Cristo, Velez, Giron, Nadeau, Figueroa de Calume, Ruiz-Peláez & Charpak, 2003:391-392). In South Africa KC has become an integral component of routine neonatal care (Heyns, Gie, Goussard, Beyers, Warren & Marais, 2006:535), and local guidelines have been published by Dippenaar *et al.* (2006:16c).

Role of parents in caring for their preterm infants

Parents, and in particular mothers, have to take on additional responsibility when they provide KC for their preterm infants. This is reported, however, as being a positive and empowering experience in respect of physiologically stable premature infants (Roller, 2005:215; Neu, 1999:163; Charpak *et al.*, 2005:520; Hann *et al.*, 1999:39). In a study investigating the psychological impact of KC on mother-infant bonding with preterm infants, Tallandini and Scalembra (2006:251) found that KC resulted in a better style of mother-infant interaction and a significant decrease in maternal emotional distress.

The needs and role of fathers in families with preterm infants has received limited attention until recently (Hynan, 2005:87-88). The birth of a preterm infant challenges father involvement in care-giving, perhaps because there is insufficient time for psychological, physical and emotional preparation (Lindberg, Axelsson & Ohrling, 2007:142) and the mother has such increased responsibilities. KC provides an opportunity for fathers to participate actively in the care of their preterm infants,

which is important for the fathers' fulfilment and beneficial to the family unit (Lindberg *et al.*, 2007:148-149; Neu, 1999:162; Lundqvist, Westas & Hallström, 2007:494-495).

In settings with a high incidence of premature/LBW infants, the most cost-effective and beneficial manner of caring for a stable preterm infant is KC. Limited research has been conducted on the lived experience of providing KC, particularly in South African settings.

RESEARCH DESIGN AND METHOD

The aim of this study was to explore parents' lived experience of providing KC to their preterm infants in a tertiary hospital setting in Cape Town. A qualitative, explorative and contextual study in the phenomenological tradition was undertaken. Phenomenology is appropriate for studies in which the research question aims to extract the "meaning or essence of an experience" (Morse, 1994:224) or "to describe a person's lived experience (phenomena)" (Van Manen, 1990:38).

The research question was formulated as follows: "*What is the lived experience of parents who provide kangaroo care to their preterm son/daughter?*"

Setting

The study was conducted in the neonatal nursery and KC ward at a tertiary maternity centre in Cape Town. This is the referral centre for two secondary hospitals and the midwife obstetric units in the Cape Peninsula. Accommodation was available for ten KC beds.

Population and sampling

The study population comprised all parents who were actively involved in providing KC to their preterm infants at a tertiary hospital in Cape Town. Both parents were included in the study, since fathers have historically been under-represented in research relating to their children (Lundqvist *et al.*, 2007:491).

Information-rich cases were selected for in-depth study, since this allowed the central issues of the phenomenon (providing KC) to be uncovered (Patton, 2002:242). Six parents - four mothers and two fathers - of preterm

infants who had experience of providing KC and had the capacity to provide full and sensitive descriptions of their experience were purposefully sampled. The participants met the following inclusion criteria: (1) a mother or father of a preterm infant receiving KC at the hospital at the time of the interview; (2) able to converse in English; and (3) infants were singleton births, more than seven days' old with weights above 1 000 g and not receiving critical care (intubation and/or life support). Participants whose experience of KC was considered typical by the nursing staff were initially interviewed, and thereafter people with particular knowledge of the KC experience or atypical, negative or in some way 'different' experiences. Three participants were not married but were living with their partners, two were married, and one was not in a relationship with the infant's father at the time of the study.

Ethical considerations

Written permission for the study was obtained from the Deputy Director of Nursing and the respective medical and nursing heads of the neonatal nursery and kangaroo care ward at the hospital. The study was approved by the Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town.

Written informed consent was obtained from participants. All transcripts remained confidential and anonymous. Participation was voluntary and parents were informed that there would be no direct benefit as a result of their participation. Since the nature of the interview may have been emotive for participants, arrangements were made for provision of emotional support after the interviews if necessary.

Data gathering

The raw data of a phenomenological study are participants' personal experiences. Data were gathered through interviewing, observing and writing (Munhall, 2007:187-192). The phenomenological interview seeks to "describe and understand the meaning of the phenomenon, by drawing from the participant a vivid picture of the experience, complete with the richness of detail and context" (Sorrell & Redmond, 1995:1120). Individual in-depth interviews of approximately 45-90 minutes each were conducted and audio-recorded in a quiet room adjacent to the neonatal nursery and KC

ward. Five interviews were conducted during the period of the infant's hospitalisation, and one after the infant had been discharged home but was still receiving KC. All the infants accompanied their parents to the interviews but caused minimal distractions. Interviews were conducted until the point of redundancy (Patton, 2002:246) or data saturation. Field notes and a research journal provided a detailed record of all interviews.

Data analysis

Interviews were transcribed verbatim. Data analysis was adapted from the stages recommended by Hycner (1985:280-294) and Colaizzi (1978:48-71). The interviews were listened to while reading and rereading the transcriptions. Phrases that pertained directly to the phenomenon and captured the essence of the participant's experience were extracted as units of general meaning, as described by Hycner (1985:282). Categories or "units of meaning that naturally clustered together" (Hycner, 1985:287) were then identified, and redundant ones were eliminated. Eight themes emerged.

Trustworthiness

Guba and Lincoln (1989:242-243) refer to the rigour of qualitative research as "trustworthiness", comprising credibility, transferability, dependability and confirmability. To achieve credibility the research was conducted in such a manner as to ensure that the phenomenon was identified accurately and described faithfully. Transferability involved presenting an accurate description of the interpretation of the lived experience of parents who provided KC, with the view that future parents of preterm infants and parents who have had a similar experience may recognise the description. Verbatim transcriptions, detailed field notes and a record of analytical decisions provided an audit trail that contributed to dependability (Guba & Lincoln, 1989:242; Speziale & Carpenter, 2007:98). To enhance confirmability, records of preconceived ideas about the study were noted in a research journal to minimise any bias during interviews and analysis.

FINDINGS AND DISCUSSION OF FINDINGS

KC is a phased process, each phase bringing with it a

unique set of experiences. It can be viewed as a journey beginning when the mother unexpectedly delivers a preterm infant. Immediately after birth, the preterm infant is taken to the neonatal intensive care unit (NICU) to be assessed and stabilised, and is cared for in an incubator. The mother is discharged from hospital once she no longer requires 24-hour nursing care, leaving her infant in hospital. This is the first of many hurdles that mother and infant will face. Once the infant is stable, the mother is invited to move into the 24-hour KC ward at the hospital, where she is taught how to manage her infant and is prepared for her infant's discharge home. Discharge home is dependent on the infant's progress and weight gain and the mother's confidence in handling her infant. Going home signals the beginning of a new family life, occurring weeks or months after birth, and brings a sense of normality to the birthing experience. Table 1 is an overview of the themes of parents' lived experience of providing KC for their preterm infants.

Theme 1: Unforeseen, unprepared and uncertain - the experience of birth

Preterm birth is a dramatic, life-threatening crisis that occurs with little or no warning, filling parents with intense disappointment and overwhelming fear. Every preconception of childbirth is shattered. Parents have to deal with loss and grief related to the early and abrupt termination of pregnancy, feelings of emptiness, uncertainty regarding the infant's prognosis, and fear related to touch. Parents feel cheated out of a full-term 'normal' birth. The labour occurs unexpectedly, "*too soon*", expressed by a participant as "*not his time*". Said one mother: "*I was 4 cm dilated already ... and I was seven months...*".

The anticipation of becoming a parent nine months after falling pregnant is replaced by the sudden reality of a preterm birth. The last few weeks of pregnancy, so important for psychological preparation, are lost. The preterm birth brings excitement tempered with a sense of loss of what might have been. "*The birth was the fifth of this month... August, and quite soon because the date would have been the end of September*". Parents feel rushed and shocked at the suddenness of it all, and are unprepared and disorganised: "*I was so busy working, and end of August would have been my finish*".

Table 1: Summary of themes: Parents' lived experience of providing kangaroo care to their preterm infants

- Unforeseen, unprepared and uncertain - the experience of birth
- Anxiety and barriers
- An intimate connection
- Adjustments, roles and responsibilities
- Measuring success
- A network of encouragement and support
- Living-in challenges
- Living with the infant outside of hospital

of working. So that weekend, it was, like chaos”.

Deprived of the special first few moments of getting to know their infant, the couple's introduction to their newborn is a strained quick glance before he/she is whisked away for medical attention. Mothers interviewed yearned to hold their infants but were prevented from doing so because of the infants' small size: *“I went into the nursery and saw ... this small baby and thought is it really my baby and ... I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her and then I couldn't touch her because she was too small”*. Roller (2005:214) found that one of the most distressing aspects of the immediate postbirth experience for mothers was that the mothers wanted to get to know their babies, but were prevented from doing so because of the medical support required. This disrupted relationship, which challenges the early attachment process, has been described by Fegran, Helseth and Fagermoen (2008:811), who report that mothers in their study felt powerless and experienced the premature birth as surreal and strange.

For certain participants there was the trauma of being told that the infant had died, only to hear later that he/she was indeed alive: *“Her birth was ... very traumatic for me, she was born at 24 weeks and declared dead at birth ... and then an hour later the sister came to the ward to tell me that my baby is alive and in the nursery”*. A father recalled his experience: *“She came out and the nurses looked at her, and they said ‘she is too small. She won't make it’. They said ‘Guys, do you*

want a footprint or anything?’ Then they gave her to us just to hold. We prayed for her soul and then they took her away ... the following morning ... the phone call came, ‘I am phoning from the hospital, here is your wife,’ she said the baby's alive”.

The parents found it difficult to trust the staff because they did not know what to believe as the truth, and needed to see for themselves that their infant was actually alive. *“In the beginning it was really difficult for me ... because I had to ask is it really my baby because of the fact that she was declared dead at birth ... when I saw her and I wanted to touch her and then I felt that I will sense whether this is my baby or not ...”*.

Theme 2: Anxiety and barriers

As the shock of the preterm birth subsides, parents realise that their infant is alive. Their anxieties surface and they need to create a protective emotional barrier. Participants felt incompetent when initially entering the NICU, an unfamiliar and intimidating environment with complex medical equipment and constant activity which focused on the infants' survival. High-tech equipment became a barrier: *“Unlike a ... term child ... that you take home and wash and handle immediately, with these little ones they are in incubators, you have to wash your hands, put on ... some disinfectant and then touch the baby and you can't touch the baby for too long ... you feel a bit deprived as a mother because you want to pick up your baby, you want to touch them maybe rub them [massage]”*.

Mothers who had previously had full-term infants were shocked at the “tiny” size of the preterm infant: “... you don’t know how to pick them up and how to handle them properly”. Participants feared bonding with their infant, so refused to establish an emotional connection: “I don’t want to get attached to someone who might not make it”. After the initial few days, parents felt they were “missing out”, and began to connect intimately with their infant. One father explained his conflicting feelings: “One then struggles to ... actually connect with your child because you, you are torn between ... becoming so attached to the child and the child dies the next day or the next minute for that matter and between not giving that child that warmth and affection for that short time that you might have with the child, for the child’s lifetime”.

Parents interviewed desperately wanted to hold their “delicate and precious” infants, but feared hurting them. They felt clumsy and anxious when they first held their infant in the KC position, but confidence increased as they spent time with them: “The first two days I didn’t want to touch him because I was afraid of hurting him ... but ... um I think that it [KC] provides you with that bonding experience”.

There is usually little if any preparation for a preterm birth, and the parents are unprepared to cope with an experience that might continue for several months. Participants had not heard about KC before the birth of their infant: “I mean you go to the clinic and even so I attended this hospital and okay there is posters and that but no one like told you about it [KC].” The fathers, intimidated by their lack of knowledge about even the simplest tasks (such as opening the incubator), felt scared: “I didn’t know what to expect. I didn’t know how I will react to baby, I definitely wanted a baby but, you know, I was scared of managing baby”.

Training in KC was provided during the day for mothers and after hours for fathers, who expressed a preference for their partners or spouses to explain KC to them, “not somebody else”, as it was a private issue relating to their family unit. Fathers felt judged and criticised in their efforts to provide KC. “Another lady said, ‘I hope that you are not suffocating the child’, because her head was lying at the side...”. Fathers also had to make adjustments owing to their different anatomical build, which made it more challenging to offer KC: “It feels

like he is bunched up, because your chest goes inwards, you can let him lie at an angle ... but now with him lying on the one side it gives his body a chance to space out more ... with me being a bit of a slender person it just feels comfortable for both of us. It is better to get his chest as close to my chest as possible, so when I lie him sideways that has sorted that one out”.

Theme 3: An intimate connection

Despite the initial anxiety and environmental barriers, KC facilitated a special connection with the infant: “My first experience with kangaroo caring [for] her... when I took her out and put her against my skin, it was just ... a great sense of relief for the first time really I felt bonded with her, that it was my daughter. So I think that kangaroo care helps to bridge that initial ... gap that is between a mother and her preterm baby”.

Parents comfort and transfer strength, courage and hope to their infant through their touch, “like two bodies in one”. There is an intimacy between the parent and infant: “Your child gets to know you ... to feel you, to touch you, to smell you”. The physical closeness of their infant while in the KC position enhances the parents’ awareness of their infants’ cues and signals: “[I] feel her breathing.” One mother interviewed knew when her infant had a wind: “You can hear the breathing is different”.

This experience is a special time for parents; they have the unique opportunity to watch their infant develop as he/she would have in utero. Parents feel fulfilled and satisfied with the closeness of their infant: “I can touch her, hold her, stroke her”. Despite initial fear, the intimate connection between parents and their infants was reflected by one participant as follows: “It’s a nice feeling... it feels like I am bonded to my child”. “Getting to know” - a theme which emerged from Roller’s study (2005:214) in respect of the essential elements of the relationship between the mother and the new infant – is echoed in the current study as the theme of intimate connection.

One father said KC helped him to “be part of” his daughter’s life, while another said that it “helped me feel closer to him, we got used to each other much more quicker”. Although the fathers initially felt

overwhelmed by the preterm birth, once they were able to become involved in providing KC, their confidence increased: "*Kangaroo care has become so much part of me now. I am now owning this thing. I was thinking what was kangaroo care? It was nothing up in the sky, it was nothing other than what I was doing, all the other ideas, the breathing and the posture were part of it, and I developed it for myself so that it became more meaningful*". For fathers in particular the birth of a preterm infant is shocking, unexpected and difficult to understand, an experience which has been described in the literature (Lindberg *et al.*, 2007:144; Fegran *et al.*, 2008:813).

The overwhelming initial shock and surprise of delivering a preterm infant is contained once the parents are able to initiate KC; they become confident as they experience the intimate parent-child bond. This bond or attachment is a multifactorial, individualised process that requires physical contact and early interaction, which is severely impacted by a preterm birth and subsequent separation. Participants initially found it difficult to attach to their infant, a finding also reported by Jackson, Ternstedt and Schollin (2003:124), and Lundqvist and Jakobsson (2003:27).

Theme 4: Adjustments, roles and responsibilities

Provision of 24-hour KC created extra work, roles and responsibilities: "*Well obviously I've got a husband and another child at home, and obviously have to cook ... you have to clean and do a lot of other things, besides looking after yourself and the baby*".

The mother has two main roles, the first being the provision of breast milk through a nasogastric tube or cup. This reassured the mothers interviewed that this essential role benefits the infant's growth and development: "*About the third week there was less milk, the sisters encouraged me, by then she hadn't yet started breast-feeding ... but they encouraged me to keep putting her in the kangaroo care position and that really helped to stimulate the milk flow and when she eventually ...breast-fed I had more than enough milk*". Secondly, as a "*human incubator*" the warmth from the skin-to-skin contact with the mother provides comfort and promotes growth: "*It's your body temperature you give to the baby*".

Fathers initially felt useless and "*not really part of it*" as they could only watch as the mother cared for their infant. They physically distanced themselves from their preterm infant by returning to work and continuing their day-to-day activities. Unsure of their parenting skills in this setting, fathers felt intimidated in the neonatal nursery as their actions were under constant scrutiny from the nurses. They felt incompetent and not "*good enough*" to care for their infants: "*I was slightly nervous, but not as to say that I would crush her, but just that I would disturb her. I had this idea in my head that she still needed to be there ... with her mother. Though I am here, but maybe I might not be giving all that the mother does... the smells of the milk and everything, and me, I am just ... a man*". Lindberg *et al.* (2007:144-145) describe the sense of loss of control expressed by fathers of preterm infants. Similarly, Lundqvist and Jakobsson (2003:29) found that fathers who were not able to be active participants in their infant's care felt more stressed and alienated from the care-giving process. KC enabled fathers to feel that they had a parenting role – a role they thought was held exclusively by mothers: "*Kangaroo care made me feel I am doing the right thing, that's what I like about it*".

Theme 5: Measuring success

Successful care of a stable preterm infant is determined primarily by weight gain. Parents perceive weight gain as a measure of success, progress and development. A setback, especially related to the infant's weight, is extremely disappointing since this is yet another hurdle to overcome before the infant can be discharged. Failure to gain weight when the measure of success is weight gain impacts on the mother mentally and emotionally. All she can do is hold and feed her infant. There is a sense of helplessness; they can only do so much and they want to do more. They cannot force their infants to grow any faster: "*Weight gain for them is crucial ... that is the only way really, that one can see whether they are ... developing. Especially as a parent ... the doctors might be able to see through other things, but as a parent your only measure of how your child is doing is the influence of weight gain*".

Parents interviewed were able to recollect the exact weight that their infants had gained or lost each day: "*Once he picked up 50 grams and one day he picked up 10 [g] and 20 [g]*". Although unpredictable, weight

gain symbolises a step closer to discharge and to life as a family outside the hospital. One participant just hoped that her infant would pick up *"another 40 [g] today"*, which would enable her infant to be discharged. There is a sense of accomplishment as the infant responds contentedly to the physical closeness and warmth of the skin-to-skin contact: *"She gained 50 grams. I think it was because I was here. I noticed every time when I am with her and doing kangaroo she gains weight"*.

As the infant's condition improved, the connection between parents and infant became stronger. KC helped to *"overcome that fear"* of handling their *"tiny"* infants. The dream of a perfect birth was gone, but once parents began to experience the pleasure of their preterm infant, they recognised that life was no longer only a series of hurdles but an incredible journey – *"... but as you can see it is a challenge"*.

Theme 6: A network of encouragement and support

Support is important during this emotional and anxious period. Supportive partners/fathers are vital, particularly in the stressful postbirth period when mothers fear losing their infants. One father interviewed suppressed his own emotions and fears in order to support his partner: *"I needed to be strong for her, because I knew that she was going through a hell of a lot. I was too ... but ... I think to balance all ... the emotions ... that I had to suppress it"*.

The maternity ward staff become companions to the parents, sharing their journey from inadequacy and fear to confidence, providing support and information and including them in their infants' care: *"They do inform you every day ... they keep you up to date. ... inform you of the progress of the infant, if there is something wrong with him or things like that, the sisters are quite clued up so they keep you clued up as well"*. Mok and Leung (2006:731), in a study which explored the supportive behaviour of nurses as experienced by mothers of premature infants, identified four types of support that nurses and midwives can offer: communication and information support, emotional support, esteem support and quality care management (which includes linking mothers with other mothers of premature infants).

Participants said that other mothers in the ward provided encouragement and became trusted listeners who understood their bad days: *"when I felt that I can't survive this day"*. Support came from being able to share feelings, fears and emotions with other mothers: *"Often we would meet either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could enquire about each other's children and that ... has also helped strengthen us as mothers"*.

The traumatic experience became a growth point which they were able to share with others, as one mother exclaimed: *"It made my life richer. I always share it with other moms; they can take out what they want to. It might help them in some way"*. Fathers also wanted to share: *"We came here for a developmental [assessment] here in the hospital, and then I just felt that I just had to approach this other woman and say 'Ladies, don't worry, you see this little one – she was just like your babies and she is doing well'"*.

Parents constantly feared that something unpredictable might happen to their infant while they were not at the hospital, yet they were not encouraged by the nurses to stay with their infants: *"If she doesn't make it ... we want to be there ... so we were always there"*. Parents are isolated after the birth of their preterm infant. Although nothing can eliminate fear, loss of control and hopelessness, the support that parents receive from their families, the staff within the institution and their children enables them to cope with the experience rather than be overwhelmed by it.

Theme 7: Living-in challenges

Mothers return to the hospital environment to 'live in' with their infant, but miss the support of family, who are restricted to visiting hours. The KC ward confines the mother's world to a bed permanently raised at a 45° angle in a room shared with seven other mother-infant couples. Her days are filled with caring for her infant and conversing only with staff and her roommates. With her infant securely attached to her for 24 hours a day, she can no longer move about freely and sacrifices her own needs, placing her infant's wellbeing and safety above her own. Backache, boredom, loneliness, tiredness and anxiety become an integral part of the living-in experience.

The living-in dominated the mothers' lives: "*All the time you have your baby with you ... sleep with you, eat with you, walk with you*". It impacted on their relationships with their partners or spouses, family, friends and social support, their employment and leisure. They were confined to the hospital until their infant was ready for discharge. There was tension between the mother's desire to stay in and care for her infant and her desire to be at home. In hospital they felt close to their infants but isolated from family support. The adjustments were compensated for by the joys, as illustrated by this mother: "*When she eventually came over to be with me ... 24 hours in the kangaroo care unit, I was very excited about that ... I just didn't expect that I would be that elated to have her with me*".

Fathers, excluded by KC ward rules from the living-in experience, felt frustrated and helpless at being unable to interact with their infants. One father witnessed a fellow father's exclusion from the KC ward: "*I was inside sitting there and there was another father, he had his daughter and he was kangaroo caring. I felt 'yes', it's happening, but what was so very disturbing was just at that point in time the nurse said 'No, men are not allowed' and they had to ask him to go out. I understood it at one point but I also felt that the approach was rather harsh*". The participant felt that the nurses had unfairly judged the father, assuming that he had ulterior motives because he was a man.

Theme 8: Living with the infant outside of hospital

The final phase of the cycle occurs when parents take their preterm infants home to begin a 'normal/regular' life outside the hospital. All mothers surveyed looked forward to going home. Parents had to incorporate the principles/skills that they had learnt from KC into their daily lives. One father had felt uncomfortable in the hospital setting and had not provided KC, but started it after his infant's discharge home. "*At home I didn't have spectators ... I felt at peace and I could hold her and put her on me and it was beautiful*." Another participant postponed his return to work: "*I am at the point where I am only starting much later at work now, I work part-time. Why is this parenting thing taking a hold of me? Because I just feel I am spending a lot of time with them ... getting to know them*".

KC makes it possible for parents to work alongside health professionals in the care of their preterm infants. They become more acutely aware of the vulnerability of their infants owing to their size and gestational age. This awareness increases their desire to go beyond the boundaries of the preterm infant's needs, not only to provide for their survival but also to enable them to prosper. Moving through these phases is both positive and negative, since parents are eager to spend time with their infants yet are prevented from doing so because of their small size and instability. Conversely, when mothers have the opportunity to spend 24 hours with their infants in the KC ward, they are sometimes unable to cope with the additional demands required.

In a phenomenological study conducted over an 18-month period, Jackson *et al.* (2003:124) conceptualised the internalisation of parenthood of a preterm infant as a time-dependent process with four syntheses of experiences – alienation, responsibility, confidence and familiarity. These themes resonate with those which emerged in the current study.

LIMITATIONS OF THE STUDY

The study findings are limited in that purposive sampling was done of a naturally occurring group from only one hospital. The findings of this contextual qualitative study, though not generalisable, may provide further understanding regarding the potential of KC as a tool to promote parental involvement in the care of preterm infants in the context of the current health care environment.

Since interviews were conducted in English there is a risk that, despite being fluent in the language, participants whose home language was not English may have had difficulty in expressing their thoughts and feelings. Parents with preterm infants who depend on staff to support them and care for their infants in either the NICU or the KC ward may have been reluctant to express negative feelings.

CHALLENGES AND RECOMMENDATIONS

Perinatal mortality and morbidity in South Africa continue to be a major concern (Pattinson, Woods, Greenfield & Velaphi, 2005:1), and the challenge is to improve the

survival rates for LBW babies. KC has been shown to make a difference (Rodriguez *et al.*, 2007:15b), but implementation requires effective facilitation (Pattinson, Arsallo, Bergh, Malan, Patrick & Phillips, 2005:927). The high numbers of perinatal deaths and the infant mortality rate reflect the inadequacy of the current health services to meet the needs of the expanding South African population. The health facilities are challenged by increasing demands for treatment and care which place economic and physical strain on hospital resources. The implementation of KC can reduce costs of specialised equipment and the time that preterm infants spend in hospital.

Individual hospitals and midwife obstetric units encourage women to attend antenatal sessions to promote safe pregnancy and delivery. A broader awareness of prematurity/low birthweight and information about its causes and the option of providing KC should be encouraged, particularly for women in high-risk groups. Parents who have provided KC successfully could be invited to support new parents of preterm infants.

Cultural differences may affect responses to KC and this aspect needs further exploration in the South African context. A Ugandan study on skin-to-skin contact in full-term newborns found that acceptability of health practices is influenced by knowledge and sensitisation, and pregnant women's choices are dependent on social, cultural and economic factors (Byaruhanga, Bergstrom, Tibemanya, Nakitto & Okong, 2008:185). Jackson *et al.* (2003:128) postulate that the differences in mothers' and fathers' experiences may be related to cultural beliefs and gender-based expectations of parenthood.

KC is considered the norm for the care of preterm infants no longer requiring active intervention. However, information regarding KC among the public is limited, and in this study parents' first introduction to KC was at an overwhelmingly emotional time. Further information and support are essential to assist parents of preterm infants in their transition to parenthood. The preterm infant is not an isolated individual but is part of a family, and the family therefore has to be considered in the course of care of this infant. Lundqvist *et al.* (2007:496) advocate that professionals need to be especially sensitive to the father's role in the family, to

establish communication with both parents, and encourage their feelings of becoming a family. Sensitive provision of relevant information to parents requires that nurses and midwives themselves feel confident and competent regarding the benefits and challenges of effective kangaroo care. Engler, Ludington-Hoe, Cusson, Adams, Bahnsen, Brumbaugh, Coates, Grieb, McHargue, Ryan, Settle and Williams (2002:152), reporting on a national United States survey of KC, recommend that education about KC and ways to overcome barriers to its practice are needed to enhance implementation of this effective intervention.

Nurses and midwives control access to the mother and infant (e.g. through visiting rules), and may allow personal/practical preferences to interfere with best practice regarding infant care. Health professionals are in a position to make a difference as they are present in the interaction between parent and infant (Roller, 2005:216). KC requires committed parental involvement to be successful, and parents become members of the infants' health care team. It promotes parent-infant attachment in the hospital setting, and continues after the infants' discharge home. Tessier *et al.* (2003:387) found that parental involvement strengthened the connection between infant and 'carrier', which has been confirmed in this study.

The study demonstrates that support of parents in both the NICU and KC ward is essential and needs to be effective and multifaceted. The parents surveyed in this study were resourceful and sought out support from staff, partners and other mothers where necessary. The introduction of a counsellor working exclusively in the NICU and KC ward may provide the additional support that health personnel are unable to provide owing to time constraints and excessive workloads. Parent support groups and individual parent-to-parent support may be another option to consider. Gender-sensitive support and information is an aspect of KC which needs to be developed. Jackson *et al.* (2003:128) suggest that studies on parenthood from a gender perspective are needed.

It is evident that KC is an essential tool that enhances parent-infant attachment through the positive relationships that are formed between parents and their preterm infants. Although KC is a structured method of providing care, it is not a rigid set of step-by-step rules

or exact guidelines to be followed; it is an evolving way of allowing parents to regain confidence in their own abilities to care for their preterm infant at a pace at which they feel comfortable. Roller (2005:216) states that KC "affords the mother and infant an opportunity to get to know one another in a profound and synergistic way". Her study did not include fathers; however, the fathers in the current study described similar experiences.

CONCLUSION

An understanding of parents' lived experience as they grappled to adapt to a preterm birth and cope with unfamiliar KC has been described in this study. The themes have explicated parents' joys, fears, frustrations and needs while coping with their infants' preterm birth and adjusting to providing KC. Parents of preterm infants in this study were shocked at their infants' early arrival, and faced particular challenges in forming a relationship with and feeling attached to their infants. There are many factors which influence parents' adaptation to the events that unfold after the birth of their preterm infant and during his/her hospitalisation in the NICU. The parents' support structures, including the staff in the hospital, can make this transition into parenthood either a struggle or a success. Acknowledgement of parents' fears, struggles and successes can assist the nurses in providing family-centred care while the infant is cared for in the NICU.

Parents who participated in this study shared their joys and frustrations about KC as well as their experiences of fear, loneliness and lack of support. Parents of preterm babies need to know that there is hope for their infants, since they feel that they struggle to form an attachment for fear that their infant may not survive. Information plays a role in easing the parents' anxiety. The 24-hour continuous provision of KC empowers parents and improves communication. Parents gain an awareness of the infants' condition and provide relevant health information on a daily basis to the health care personnel.

In the unfamiliar NICU, KC offers a glimmer of hope for parents; it gives them a sense of purpose and returns to them the role of primary care-giver, equipping them to confidently celebrate their infants' discharge home. Through their involvement in their infants' care, the parents find meaning in their lives. Although parents

(especially fathers) in this study were initially overwhelmed by the preterm birth, once involved in KC their fears lessened and their confidence increased. KC became their lifeline, facilitating a strong connection to their preterm infants.

The parents who participated in the study were unanimous that, despite having to cope with what appeared at times to be insurmountable obstacles, they had enjoyed the experience. They shared how they had 'grown' from insecure intruders in the NICU to competent care-givers of tiny preterm infants. Parents of preterm infants have an important role to play through providing KC. Health professionals need to acknowledge this contribution and partner with parents in caring for these very precious preterm infants.

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