Experience of Parenting a Premature Infant - A Literature Review

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Aim: This poster presents a review of the qualitative literature examining parent’s experiences, thoughts and feelings about caring for a premature infant.

This review was conducted as part of an ongoing investigation using a phenomenological methodology to gain greater understanding of parents’ of premature infants lived experience during the first 12 months.

Background: A key aim of regional health services is to support families of premature infants and ensure that their infants are able to fulfill their developmental potential. Understanding the experiences of parents caring for premature infants will allow service delivery to reflect the needs of these families.

To date qualitative examinations of the experience of parents of premature infants have largely focussed on in the Neonatal Intensive Care Unit (NICU) in larger metropolitan centres. Little is known about parental experiences of caring for a premature infant post-discharge, particularly those living in rural areas.

Review Findings:
Parents NICU Experiences:
• Parents report a transition from passive bystanders to active advocates for their infants as the adjust to being parents of a premature infant [1].
• Initially parents report being focused on the NICU environment and obtaining information and gradually change to focusing on the infant [2].

Health Professionals Roles:
• Parents reported wanting to be involved with decisions regarding their infants care however do not want to be left with the final decision as they feel to emotionally involved to be objective [3].
• A power struggle between staff and parents was described by parents when making decisions regarding the day to day care of their infants [4, 5].

Provision of Information to Parents:
• Parents reported finding written information media such as videos or computer presentations was beneficial [6].
• Parents have expressed the importance for adequate time to inform and educate parents and wanted to be treated as an individual [3].

The Role of the Father:
• Fathers often return to work with renewed vigour and reported that this was due to feeling they need to provide for the family and while at work are the experts whereas as in the NICU environment feel more helpless [8].
• Fathers have also reported being stressed by trying to manage the demands of work, life outside the NICU and their family [9, 10].

Rural Issues:
• There is little research examining rural family’s experiences.
• A study from a non rural area reported fathers who lived further away from the hospital were more distressed [10].
• Parents have also reported travelling to see the infant, cost of child care for older children and loss of contact with friends were sources of stress [9].
• Difficulty accessing allied health services in rural areas has also been described in the literature [11].

Main Points:
• Majority of research has focussed on families experiences in the NICU [1, 2].
• Literature examining rural families experiences or allied health practices is sparse.
• Caring for a premature infant is complex, emotional and stressful [4].
• Families report wanting to be considered as unique individuals during this experience [3, 5].
• Health professionals are in a position to significantly influence the experience of families caring for a premature infant [5].

Future Directions: Ethical approval has been obtained to interview 6 – 8 parents using phenomenological methodology about their experiences parenting a premature infant in a rural area. Interviews will focus on the experience in general and more specifically coping strategies, the role of health professionals, how information is presented by health professionals, and rural issues.

References: