Parents’ experiences of caring for an extremely premature infant at home

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THE STUDY

• **Parents’ experiences of caring for an extremely premature infant at home**

• Collaborative, jointly funded study - University of Hertfordshire and University of Technology, Sydney.

• A study aiming to explore parent experiences following discharge from neonatal care... Narrative, interpretive design

• Links between understanding human experience through peoples narratives, and interpreting them to understand this experience and ultimately to influence practice.
Aim & objectives

- **AIM:** To gain insight into the post-discharge experiences of parents in relation to the adequacy of preparation for caring for their extremely premature infant at home.

- **Objectives:** To gain parent narratives through interviews to facilitate insight into neonatal community experiences following discharge of their premature infant (1-6 years post discharge, <30 weeks gestation)

- To enhance understanding of parental views to how they were prepared for the transition home and their experiences at home, in order to inform nursing practice and resource development.
Background

• Survival has increased of extremely premature babies.
• Morbidity continues including developmental & behavioural problems (Galeano & Carvajal, 2016; Whittingham, 2014).
• Parenting at home is challenging, socially disruptive (Boykova, 2016) requiring increased professional and ongoing, community support (Ingram et al, 2016; Staniszewska et al, 2012)
• Question... How to best prepare and support parents after discharge from NNU?
Participants

• 14 parent(s) of preterm neonates interviewed: 7 parents from a local Trust parent group and 7 from previous interview data (UK).
• 10 parents (Australia)
• Mothers / fathers / or both
• Recruitment – volunteer basis through identified gatekeepers
Ethical considerations

• NHS Ethics (HRA) process
• Consent
• Voice recording
• Transcription
• Confidentiality and data protection
• Risk... Potential emotional upset / relived emotions from prior experience
The interview process

• Location: participant’s home or an agreed venue
• Semi-structured interviews – for example, how did it feel to go home?, what has it been like at home?, challenges?
• Final key question: If you could tell another mother/father leaving hospital with his/her extremely premature baby 3 things that were important/really useful to you – what would they be?
Analysis

- Making sense of narratives and experience
- What is it like for them and what can we learn?
Thematic analysis

- 14 transcripts
- Broad themes identified as well as sub-themes
- Constant comparative analysis
- Themes coded using NVivo
Themes

• Parents described the following…..
  - Emotional and mental health of parents
  - The need for health professional education about prematurity
  - The need for parental support and preparation
  - The continuing health needs of the baby.
  - Uncertain outcome – life versus death
• Commonalities across all cases
Theme 1- Emotional & mental health

It was terrifying - after so long, the support pillars of the neonatal unit were removed.. We felt on our own.

Mixed feelings of joy and fear. .....it was like stepping into the unknown

We didn’t sleep properly for at least 18 months after going home.... We took turns to watch him through the night

It was much later on that the emotional stress started to take its toll – I was diagnosed with depression...
Theme 2- The need for education

The neonatal staff and outreach were fantastic—Much can be learn from them about care of premature babies.

There is a real need for education of GPS, practice nurses and health visitors in the different need of premature babies.

At home, after outreach had stopped, no-one seemed to understand the specific needs of the premature baby.
Theme 3 - Support needs

The support from other parents who have gone through the same thing is so valuable.

Support is needed in all aspects - emotional, practical and financial.

Support is needed for a long-time – later than is sometimes offered from outreach.

No-one prepared us for the emotional challenges that we faced – support in this area is vital…
Theme 4- Continuing health needs

Endless appointment with many professionals

We were back in A&E at least three times in the 1st year.

No-one could visit or come close to him in case of infection

We have finally stopped going back into hospital with breathing problems at age 4

Feeding problems and reflux were a continuing problem and had us exhausted.
Three things to help other parents

• Get to know other parents for support.
• Don’t be afraid to ask questions when you go home and get advice at any time.
• Be confident in your own knowledge as a parent
• Make the lost of the support offered
• Consider counselling if you need to and support for you as a parent – be open about this with people, family and health professionals
• Be prepared for the emotional stress and remember you will get through it
Conclusion

• Having an extremely premature baby has a potential significant impact on parents in the community setting
• Adequate preparation and ongoing support by both peers and health professionals is essential
• Emotional support is a particular need requiring tailored interventions.
Implications for practice...

• Learning from the parents’ experiences to inform future care
• Highlight pointers for education
• The need to raise awareness in the community about the specific needs of prematurity
• Tailored advice and education for parents at home
The next steps......

• Write up for publication – in progress
• Further dissemination and collaboration
• Further exploratory work into the education needs of health professionals about the specific support needs of parents of premature babies.
• Tailored resources to optimise preparation and support for community based care
Acknowledgements

• Thank you to the neonatal parent group for their involvement and to the neonatal staff for acting as gatekeepers.

• Thank you to UH / UTS for funding support

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References