

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?**

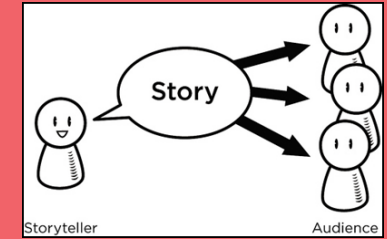
Participants

- 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.



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

4

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

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 most 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.
- Thankyou to UH / UTS for funding support
- *Contact: Julia Petty* [*j.petty@herts.ac.uk*](mailto:j.petty@herts.ac.uk)

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