

Traversing the boundaries and borders of discharge from hospital following first stage surgery for complex CHD: The Parent Experience

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Little Hearts Matter
Half a heart, not half a life

Background: Empowering parents to take on the complex care of their infants at home is perhaps deemed as representing patient and family centred care. However, whilst children's nursing has historically been underpinned by a philosophy of family centred care [1], it could be argued that the process of monitoring a fragile infant at home has taken this philosophical perspective of holistic care, beyond the borders and boundaries originally expected of parents going home for the first time with their new baby. This neo transition of becoming a medical parent is superimposed upon the multiple transitions already being experienced by these families (new baby, new to parenthood, sick baby, cardiac surgery, ongoing and lifelong care needs).

Aim: The aim of this poster is to present the findings from a study exploring parents' experiences of the transition from hospital to home with their infant following first stage cardiac surgery for complex CHD (including functionally univentricular heart or systemic shunt dependent cardiac lesion).

Methodological approach: A mixed method approach, using a fully mixed concurrent dominant (QUALquant) status design [2] where a combination of methods were utilised to address the research objective during the data collection, analysis and inference stages [2,3]. Both constructivist and constructionist [4] approaches were incorporated within this study. **Theoretical Approach:** Middle range transition theory [5] **Design Frame:** Longitudinal prospective study **Sample:** 17 parents - 13 mothers, 4 fathers of 13 infants being discharged from a specialist cardiac centre in the UK were recruited into a feasibility study incorporating a home monitoring programme, which commenced in August 2013 and ended in February 2015 (reported elsewhere). **Data Collection Method:** Semi-structured interviews at 4 time points: T0 before discharge; T1 two weeks post discharge; T2 eight weeks post discharge and T3 following the second surgical intervention

Findings:

The experience of parents in this study revealed that their transition from hospital to home was complex and multi-faceted, with unanticipated physical and emotional transitions superimposed upon those that were expected such as parenthood and having a baby with a cardiac defect (for those prenatally diagnosed)

Postnatal diagnosis was an unexpected transition as well as the subsequent transitions during the hospital journey.

"...it feels like I'm still in a nightmare that I'll wake up any minute and I'll still be pregnant" (QH5 mother, T0).

In addition, numerous physical, emotional and social boundaries and borders were evident; classed as inhibitors within the middle range transition theory [5]:

Physical boundaries and associated emotionally traumatic events:

- Retrieval and transfer from the maternity unit, directly into the intensive care unit (ICU) or via the ward
- Cardiac theatre and then back to the ICU
- Transition back to the ward from ICU
- Crossing the threshold of the ward to the outside world with their infant at discharge

'It was awful, it was like I'd given birth to a baby and given her away' (RR8, T0)

Physical barriers:

- Environment
- Equipment in ICU
- Paralysed and sedated infant

'I was just focused on that one cot I wasn't even daring to look around me' (AZ7, T0)

Emotional barriers:

- Loss of parenting role in hospital
- Physical barriers created an emotional barrier impacting on bonding
- Anticipatory grief, dissociation, detachment

Boundaries:

- Fear of going home and uncertainty
- Fear of being alone at home, without monitors
- Fear of something happening and not knowing what to do
- Fear of loss

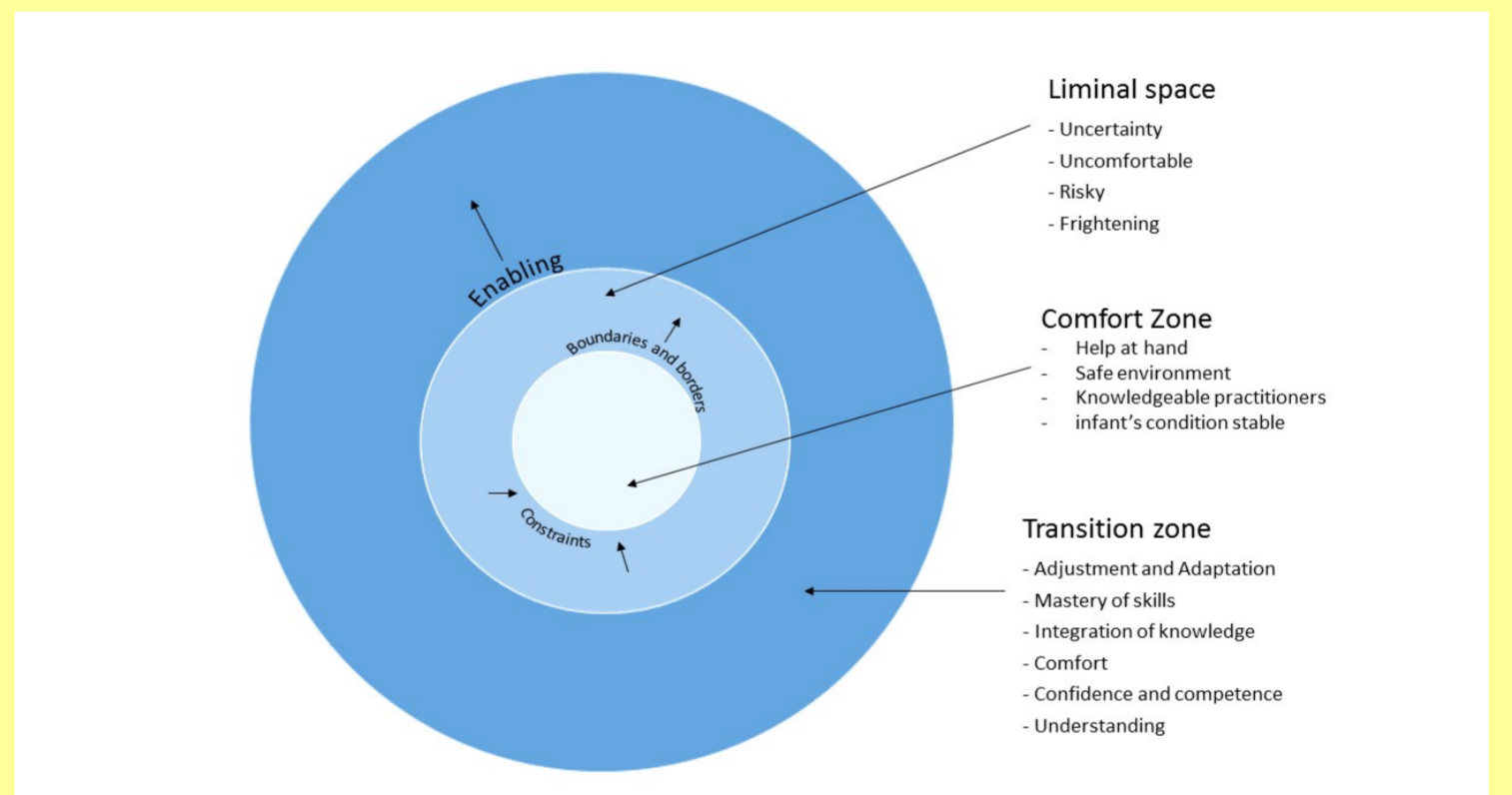
Discussion:

Development of a Conceptual Framework

The transition from hospital to home and traversing the physical boundary of leaving the hospital for the first time with their infant, was loaded with emotionally traumatic experiences that could not be separated from the specific physical transition that was being explored within this study (hospital to home).

At T0 parents were in an uncertain place (betwixt and between), where they could not visualise what was ahead and how it would feel and this created anxiety and fear, at the same time as excitement. What the middle range transition theory [5] did not take account of was the liminality that occurred for parents at the point of being told that they could go home with their baby. For some parents the transition from hospital to home was a crossing point from a place of safety and security, which had become a comfort zone into the unknown, uncertain place (see figure 1).

Fig. 1 Borders, boundaries and liminality during the transition from hospital to home



The parents in this study were also bounded by a common ground, the social community that they had developed whilst in the ward environment of being a parent, but more importantly the boundary of being a parent of an infant with CHD. Exiting into a world where those boundaries were different, where other parents did not have the same experiences as them was frightening, irritating and isolating.

A conceptual framework emerged which related to the rite of passage for parents transitioning from hospital to home (Fig. 2)

Conclusion:

Whilst processes of parents moving 'from one place to another' has previously been identified [6,7] in the models 'Parenting Under Pressure' and 'Facets of Parenting' and perhaps as motivational categories [8]; none of the extant evidence identified liminality as a concept or as a means of contextualising the transitional parenting experience for parents of infants with complex CHD.

In this study transition across the liminal space was a constraint for some, but it was also enabling. Parents were also bounded by the physical, emotional and social constraints in terms of their preparedness to go home, the fragility of their infant, the distance between the hospital and home, their home environment and the availability of support. Those parents that did not want to go home, were not ready or comfortable enough to cross the physical boundary into the liminal space.

Adjusting to the new situation, developing confidence over time, and becoming comfortable as they mastered new skills demonstrated that some of these parents could pass through that liminal space; it was their rite of passage and their threshold concept [9] to mastery of a new normal, which encompassed competence, integration and comfort (see fig. 2). Implications for practice include the need to assess parents' psychosocial functioning prior to discharge so that appropriate support can be provided during the transitional period.

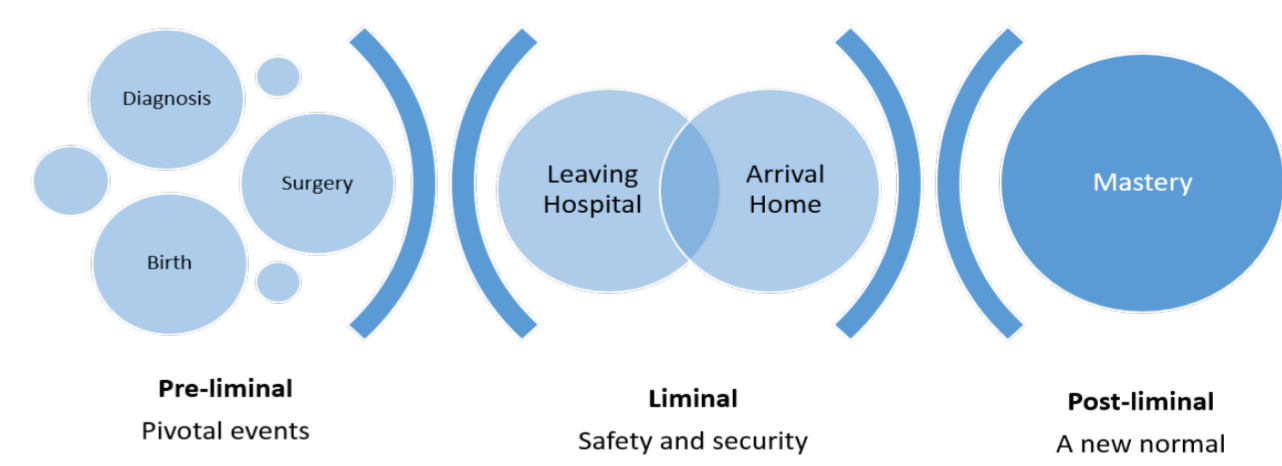


Fig. 2 The rite of passage of transition from hospital to home

References:

1. Glasper, E.A. (2015) Editorial: Sick Children are Greater than the Sum of Their Parts: Does Family-Centred Care Promote Holistic Practice? *Iss in Comp Ped Nurs* 38(2):71-76
2. Leech NL, Onwuegbuzie AJ (2009) A typology of mixed methods research designs. *Qual Quant*. 43: 265-275
3. Clarke PN, Yaros PS. (1988) Transitions to New Methodologies in Nursing Science. *Nurs Sci Q*:147
4. Crotty M. (1988) The Foundations of Social Research. Meaning and Perspective in the Research Process. London. Sage.
5. Meleis, A.I., Sawyer, L.M., Im, E.O., Hilfinger Messias, A.K., and Schumacher, K. (2000) Experiencing Transitions: An Emerging Middle-Range Theory. *Adv in Nurs Sci* 23(1):12-28
6. Rempel GR, Rogers LG, Ravindran V, Magill-Evans J. (2012a) Facets of Parenting a Child with Hypoplastic Left Heart Syndrome. *Nursing Research and Practice*. available at: <http://www.hindawi.com/journals/nrp/2012/714178/>, accessed 08/01/15
7. Rempel GR, Ravindran V, Rogers LG, Magill-Evans J. (2012b) Parenting under Pressure: a grounded theory of parenting young children with life-threatening congenital heart disease. *J Adv Nurs*. 69(3), 619-630
8. Pridham, K., Harrison, T., Krolikowski, M., Bathum, M.E., Ayres, L., and Winters, J. (2010) Internal Working Models of Parenting. Motivations of Parents of Infants with a Congenital Heart Defect. *Adv in Nurs Sci* 33(4): E1-E16
9. Myers, J.H.F. & Land, R. (Eds) (2006) *Overcoming Barriers to Student Understanding. Threshold concepts and Troublesome Knowledge*. Oxford. Routledge.

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