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Patterns of Transition Experience for Parents Going Home from Hospital with their Infant after First Stage Surgery for Complex Congenital Heart Disease

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ABSTRACT

Purpose: The purpose of this study was to explore parents' experiences of one specific timepoint in their infant's journey: the transition from hospital to home, following the first stage of their infant's cardiac surgery for complex congenital heart disease.

Design and Methods: A prospective longitudinal mixed methods study, underpinned with Middle Range Transition Theory (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). Face to face and telephone interviews were conducted and self-report forms completed by parents at four-time points: before discharge (T0), 2 weeks after discharge (T1), 8 weeks after discharge (T2) and after stage two surgery (T3). Interviews were transcribed verbatim before inductive thematic analysis.

Results: Parents were recruited over a 15-month period from 2013 to 2015. Twelve mothers and 4 fathers took part. The infants had functionally univentricular heart (left $n = 10$, right $n = 1$) and a systemic shunt dependent lesion, tetralogy of Fallot ($n = 1$). Dynamic constructivist and constructionist social processes occurred for all parents, involving physical, physiological, psychological and cognitive elements within four 'patterns of experience', two of which 'safety and security' and 'love and support' are presented in this paper.

Implications: Parental support is essential; parents need to be engaged in discharge planning process and given the opportunity to express their needs to ensure that discharge care is truly patient and family centered.

Conclusions: Transition from hospital to home was complex and multi-faceted, with unanticipated physical and emotional transitions superimposed upon those that were expected.

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Background

Parenting a fragile infant at home, in between the first and second stage of complex cardiac surgery for a functionally univentricular heart, takes the philosophical perspective of 'parenting' beyond the borders and boundaries expected of new parents, going home for the first time with their baby. The unanticipated neotransitions experienced during the birth, having a sick baby requiring cardiac surgery in the first few days of life and frequently an unstable post-operative recovery in hospital, is superimposed upon the expected transition of becoming a parent (Messias, Gilliss, Sparacino, Tong, & Foote, 1995; Svavarsdottir & McCubbin, 1996).

The transition from hospital to home timepoint and specifically parents' experiences of going home for the first time, with a fragile infant that has undergone complex cardiac surgery is minimally researched. A seminal study identified the extreme pressure experienced by parents of children with Hypoplastic Left Heart Syndrome (HLHS) as they

passed through a series of parenting phases during their child's multiple surgeries (Rempel & Harrison, 2007; Rempel, Harrison, & Williamson, 2009). Uncertainty and vulnerability were experienced, alongside the need for normalisation as parents passed through phases resulting in realisation, adjustment and accommodation (Lee & Rempel, 2011). The grounded theory study, was conducted during 2000–2001 at a time when mortality rates for HLHS were high at the study site (50%) probably relating to the implementation of a new Norwood surgical procedure four years earlier (Rempel et al., 2009; Rempel & Harrison, 2007). At the time, little was known about the long-term outcomes. Knowledge was being constructed whilst the parents, medical and nursing staff were learning with, from and about these children; parents would have had few examples upon which to build their parenting response and there was a lack of knowledge regarding parenting behaviour.

The parenting phases were conceptualized following a second grounded theory study as 'parenting under pressure' (Rempel, Ravindran, Rogers, & Magill-Evans, 2012). The phases overlapped and reoccurred throughout the patient's and parents' journeys from diagnosis, to first surgery, to discharge home, awaiting and experiencing

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further surgery. Furthermore, despite times of ease, parents remained uncertain about current and future outcomes (Rempel et al., 2012). It was recognized that the two sets of data had originated from distinct surgical series, where clinical outcomes for the infants differed and hence the treatment options and management strategies also varied. However, the researchers aimed to ascertain how family management changed over time from the initial diagnosis through the early period of home care. The main finding emerging was that 'parents demonstrated an intense, dynamic and transforming process of family management' throughout their child's journey (Rempel, Blythe, et al., 2012:54). Parents' experiences were multi-faceted and encompassed the need to safeguard, protect and maintain vigilance through monitoring to enhance survival (Meakins, Ray, Hegadoren, Rogers, & Rempel, 2015). A protective mechanism existed within parent-infant attachment, balancing nurturing for their child and protection for themselves against loss or harm. Subsequently, a five-facet model of parenting a child with HLHS was conceptualized to guide the development and evaluation of interventions for these parents, which included: survival parenting; 'hands off' parenting, expert parenting, uncertain parenting and supported parenting (Rempel, Rogers, Ravindran, & Magill-Evans, 2012).

The aim of this feasibility study was to explore parents' experiences of one specific timepoint in their infant's journey: transition from hospital to home, following the first stage of their infant's cardiac surgery for a functionally univentricular heart (right and left) or a systemic shunt dependent lesion. This broadened the group of parents from previous studies, to include those with infants who might also be clinically fragile in between surgical stages, to identify contemporaneous factors that might have implications for current nursing practice. Infants with complex CHD are recognized as being particularly fragile and significant mortality occurs within the first year (Townsend et al., 2013). Although most deaths occur in hospital, around 20% of post-operative deaths may occur after these infants have been discharged from hospital (Hindocha, 2010). Hence, the decision to focus this research on an exploration of the experience of parents of these infants.

Conceptual Methods

Different theoretical perspectives were explored, including family resilience, adaptation and adjustment (McCubbin & McCubbin, 1993) and transition theory (Chick & Meleis, 1986; Meleis et al., 2000) to identify an appropriate theory to underpin the study. As transition was the key concept being explored in line with the research question and aims, the middle range transition theory (Meleis et al., 2000) was chosen as the underpinning theoretical concept for the study, and because it explored the nature of transitions within a nursing context.

Purpose

The purpose of this feasibility study was to explore parents' experiences of one specific timepoint in their infant's journey: the transition from hospital to home, following the first stage of their infant's cardiac surgery for complex congenital heart disease (CHD). Complex CHD referred to functionally univentricular hearts and defects that are dependent upon a shunt between the systemic and pulmonary circulations.

Design

A fully mixed concurrent dominant status (QUALquant) approach was employed, where integration of the different methods occurred in addressing the research objective and during the data analysis and inference stages of the research process (Clarke & Yaros, 1988; Leech & Onwuegbuzie, 2009). A prospective longitudinal design was chosen to explore a cohort of parents over time who shared the same experience of being discharged from hospital to home with their infant following cardiac surgery for complex CHD (Thomas, 2013). This paper presents

part of a feasibility study of parental home monitoring and assessment of babies with complex congenital heart disease. The study tested the feasibility of using a Congenital Heart Assessment Tool (CHAT) as part of a home monitoring programme (HMP) for infants with functionally univentricular hearts or those with systemic shunt dependent heart conditions. At the commencement of the study (2013) only two children's cardiac centers in the UK had a home monitoring programme for infants with HLHS; however, the efficiency of their programmes had not been evaluated or published.

Methods

Recruitment

Ethical approval was obtained from the University Research Ethics Committee, the National Research Ethics Committee and the Local NHS Research and Development approval (at the study site). Recruitment to the study took place over a 15-month period [August 2013–end of November 2013 (4 months); April 2014 until end of February 2015 (11 months)], with the aim of recruiting 60 families. However, the feasibility study was suspended due to staff changes at short notice.

A convenience sample was recruited from the ward of a tertiary children's cardiac surgery center, within a children's hospital in the United Kingdom. The research nurse communicated daily (Monday – Friday) with the ward team to screen infants ($n = 80$) and identify potential participants, who were parents of infants who had returned to the ward following first stage cardiac surgery and were being prepared for discharge home. Parents whose infants were unexpectedly discharged at the weekend were missed. The research nurse checked inclusion and exclusion criteria (Table 1) before eligible parents were given a letter from the consultant cardiologist inviting them to consider taking part in the study, plus a copy of the Participant Information Sheet. Potential participants were given at least 24 h to consider participation in the study. Although both parents were invited to participate, only four couples chose to participate together. The research nurse explained the study further, answered questions and provided all relevant information. Participants were allocated a unique identifier number for anonymity. Following written consent participants provided demographic information about the infant and family, with the infant's medical details being completed by the research nurse from the infant's medical notes.

Data Collection

The MRT Theory (Meleis et al., 2000) was used to design the choice of data collection strategies to enable exploration of the type, patterns and properties of the parents' transitions (Creswell & Plano-Clarke, 2011). Specific descriptive demographic data were collected to explore the inhibitors or facilitators such as: parity or parenting experience; demographics – gender, age, educational level, employment, ethnicity, language, home environment. The study also explored parents' patterns of response to the transition, by identifying processes that moved them either in the direction of health or toward vulnerability and risk. Quantitative data (reported elsewhere) were collected around psychosocial functioning to identify parents' confidence in caring for their infant at

Table 1
Inclusion and Exclusion Criteria.

Inclusion criteria	Exclusion criteria
1. All parents of infants that have recently undergone stage 1 treatment for complex congenital heart disease at the study site, before discharge planning commences	1. Parents of Infants that have already been discharged
2. Able to read written English	2. Currently involved in any other research study
3. Able to comprehend spoken English	
4. Able and willing to give informed consent.	

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