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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

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 neo-transitions 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 et al 1995; Svavarsdottir and McCubbin 1996).

The transition from hospital to home timepoint and specifically parents' experiences of going home the 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 and Harrison 2007; Rempel, Harrison and Williamson 2009). Uncertainty and vulnerability were experienced, alongside the need for normalization as parents passed through phases resulting in realisation, adjustment and accommodation (Lee and 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 and Harrison 2007, Rempel et al 2009). 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 et al 2012a). The phases overlapped

and reoccurred throughout the patient's and parents' journeys from diagnosis, to first surgery, to discharge home, awaiting and experiencing further surgery. Furthermore, despite times of ease, parents remained uncertain about current and future outcomes (Rempel et al 2012a). 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 et al 2012c:54). Parents' experiences were multi-faceted and encompassed the need to safeguard, protect and maintain vigilance through monitoring to enhance survival (Meakins et al 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 et al 2012b).

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 and 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 and Yaros 1988, Leech and 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 hours 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 and 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 home (Maternal Confidence Questionnaire, Zahr 1991), signs of General Anxiety Disorder (GAD7) (Spitzer et al 2006) and levels of depression using the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer and Williams 2001). This allowed early assessment of the parents' responses and enabled intervention by the research team to facilitate healthy outcomes. Indicators of the **outcome** of the parents' transition could be explored through **mastery** of new skills and **fluid integrative identities** or identity reformation (Meleis et al 2000).

Semi-structured interviews were conducted at four time-points (Table 2). A face to face interview was undertaken before discharge home to establish rapport with the family; subsequent interviews were mainly by telephone. Interviews were predominantly conducted by the principal investigator, who was based at the University over 30 miles away; two interviews were conducted by the research nurse due to earlier than expected discharge of the infants. Interviews began with introductions and an overview of the interview process. At the first interview (T0) the PI started with '*how do you feel about going home?*' This was followed by administration of self-report tools.

A topic guide (Table 3) was used to elicit responses about the parents' experiences of transitioning from hospital to home relating to the types, patterns and properties of their transition, their perception of the transition, the support systems they have and their individual characteristics. Field notes were recorded following each interview, noting observations made during the interviews and reflecting on the interview experience. After the first two interviews (one conducted each by the principal investigator and research nurse) the key issues arising were the use of closed ended questions and the research nurse deviating from the role of interviewer to become the giver of information and engaging in counselling activities. Ways of avoiding counselling during the interview were discussed and agreed that this would be offered once the interview had ended. A list of example questions based on the MRT

theory were devised, moving from 'unstructured' to semi-structured. The same questions were asked in all subsequent interviews, ensuring consistency; the sequence of delivery was amended as guided by the parents' responses and freedom to explore some of the answers through deeper probing of an issue remained.

Data Analysis

Interviews were audio recorded and transcribed verbatim, initially into a Word document and later directly within QRS NVivo10, used predominantly for data management. Initial thoughts and mind maps were generated and recorded on the transcribed data and later as memos within NVivo10. Interviews were transcribed on an ongoing basis, returning regularly to ensure data familiarisation.

Qualitative analysis

The qualitative data set included 38 interviews, one (at T3) was removed from the analysis as the infant did not go home between surgeries. Braun and Clarke's (2006) six phased step by step approach was used for the qualitative analysis; familiarising yourself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes and producing the report. This was an iterative and reflexive process.

Quantitative analysis

The Statistical Package for the Social Sciences (IBM SPSS Inc.) version 22 for Windows was used for the quantitative data analysis; however, the sample was too small for statistical analysis; therefore, descriptive statistics were employed.

Mixed methods analysis

Qualitative and quantitative data were compared within and across the time points to identify relationships. As the dominant approach was qualitative, the quantitative data were amalgamated as relevant into the themes arising from the qualitative analysis. Four main themes became evident for T0. The same four themes were used as a framework to structure the data analysis within the other three-time points, recognising that they may or may not fit. The analysis at this stage included

reviewing the content of the proposed framework, by looking at individual 'nodes' (NVivo10) to identify *what was said* and *how it was said* to ensure that the coded annotation matched the node and the theme. As well as being tracked through the annotations in NVivo10, it was also cross linked to the field note observations. An inductive approach was undertaken, whereby the themes were highly connected to the data itself; coding was undertaken without fitting into any pre-existing model or pre-conceived ideas (Braun and Clarke 2006:12); reviewing the extant literature was avoided until completion of data analysis. Numerical scores for GAD7, PHQ9, MCS were examined within and across time points and within families, to identify adaptation and adjustment across the time points as well as looking for signs of maladaptation. Patterns within and across families were explored in relation to parental and infant demographics and severity of the infant's CHD condition and cross referenced to the field notes. The order of prevalence for the four key themes was found to be different at each time point and in addition the sub themes were different for each time point also.

Rigor

Creswell and Plano-Clark (2011) recommended that 'validity' was the best term to use in mixed methods studies and suggested strategies to address potential validity issues in data collection, data analysis and interpretation; which were employed in this study.

Trustworthiness.

Guba's (1981) criteria for trustworthiness of a qualitative study provided the framework for design and reporting and corresponded to constructs utilized within positivist research (Shenton 2004): *Credibility (relates to internal validity)* included adopting appropriate and well recognized research methods; random sampling of the participants and triangulation using different data collection tools. Having worked at the study site previously, the researcher was already familiar with the culture of the organization. Debriefing sessions took place monthly at the study site and bimonthly with the PhD supervision team; additionally, peer scrutiny took place within the research team at the study site. A reflective diary was maintained throughout the study and updated following each interview recording a thick description of the

situation. The findings were framed by examination of previous research.

Transferability (relates to external validity/generalisability) background data and a description of the phenomenon being studied, which was the transition from hospital to home. *Dependability (relates to reliability)* overlapping methods were used to allow the study to be repeated, *Confirmability (relates to objectivity)* triangulation was employed to reduce the effects of researcher bias. Description of methods allows the results to be scrutinized. The limitations of the study and the potential effects are discussed. An audit trail of the qualitative analysis was maintained.

Generalisability Since this study explored the characteristics of parents, it was difficult to make generalisations because the parents were involved in the social phenomenon being studied. These parents had their own interests, motivations and enthusiasms; it was therefore recognized that the idiosyncrasies of the people being studied could have influenced the findings of this study (Thomas 2013). Furthermore, the small sample size in both phases meant that the findings were unlikely to represent the wider population and therefore the extent to which generalisations could be made was very limited (Thomas 2013).

Results

Forty-seven families were eligible, of these: nineteen (40.4%) were missed during the study suspension (n=11) or due to being discharged unexpectedly at a weekend (n=8); fifteen (32%) refused either due to living too far away or 'all being too much'. Sixteen parents of thirteen (27.6%) infants were recruited (twelve mothers and four fathers); however only parents of twelve (25.5%) infants participated. There was variation in the parent and infant demographics (Table 4 and 5).

Analysis of the interviews and self-report tools, resulted in four themes or 'patterns of experience', two of which are reported here: safety and security and love and support. The parents' experiences overlapped and transformation occurred for each pattern over the four time-points. See Table 6 for the two patterns of experience discussed in this paper.

Safety and Security

Over the four time-points, the pattern 'safety and security' related to several sub experiences including: vigilance; family togetherness; uncertainty and being alone

and establishing routines. Behaviours were illustrated that aimed to protect the survival of their infant from the point of diagnosis through to going home after the second stage of surgery. This protection originated in the decision to continue with the pregnancy following an antenatal diagnosis, despite being informed that their unborn infant had a life-limiting condition that would require life-saving surgery in the first few days of life. Parents who received an antenatal diagnosis demonstrated awareness of the survival rates, the palliative nature of the surgery and the need for several operations, and had obtained information from a variety of sources to prepare themselves for the events that lay ahead.

Vigilance

Parents demonstrated safeguarding of their infant through constant vigilance during the hospital stay as well as vigilant behaviours once at home. It was mainly mothers that expressed their need to constantly watch over their baby whilst in hospital, although one father also explained *“I’ve sat in there and I’ve watched and watched”* (father, T0). Whilst another father had spotted how his wife easily became fixated: *“I’ve seen [mum] fixates on various stages of [baby]’s recovery, initially it was the lactic acid levels, sort of like fixating on that for two weeks”* (father, T0). In hospital, vigilance for some parents related to looking out for changes in their baby’s condition and notifying staff of those changes. One mother (T0) talked about watching her baby’s colour and how she knew that he needed a blood transfusion. Another mother’s vigilance (T0) had also enabled identification of signs of deterioration and communication with the doctor: *“when she first got here she was fine and they thought she was doing well and then she dropped and I’d noticed her colour changing all day and I had the doctors up to look at her, because I noticed her nail colour changing”*

In addition to constantly looking for changes from a safety perspective, parents used this vigilance to develop their ability to spot signs of deterioration in preparation for going home. Another mother (T0) also explained why she was being so vigilant in hospital: *“...so erm, this is why I stay close beside her to see all the little different changes that she’s making, if she is poorly I’m gonna know”*. Most mothers talked about wanting to keep their baby close to them at home, especially at night time:

“she’ll be in my room for a long time I think [laughs], when she’s about 5 she might be in her own room!” (T0). One mother (T0) said *“I won’t want to let him out of my sight”* and demonstrated a reluctance to leave him whilst she did other things, such as: [whilst working] *“I’ll have him in one arm”*. Only one mother talked about the future, such as attending baby classes but when asked about leaving her baby with others she said, *“I find it more comforting to be close to her”* (T0). Vigilance continued over time, however, became less evident in parents’ accounts as they became more experienced in knowing what they were looking for, what to do and where to obtain support.

Uncertainty and Being Alone

The major worry and uncertainty for parents prior to going home was the fear of the unknown and related to being on their own at home; without the institutionalized safety and security of the monitors and the lack of immediately available health care professionals if anything happened. Parents had grown used to the security of the hospital environment, they were worried that they would not know what to look out for, what to do or who to call for help: *“it’s just scary, you want to get her home because you want to just be normal but then you don’t want to; because here this is more constant, you watch her, you’ve got monitors on her and stuff and then when you get home you’ve got none of that it’s just you”* (T0).

However, there was evidence that the fear of being alone without the security of the hospital changed over time as parents adjusted to being on their own, as this mother reflects: *“but then after a few days I kind of calmed down regarding like there’s no support there when, you know, like by your side and just concentrating on (baby) himself and on his colour and stuff like that”* (T1).

For some mothers, the fear of being alone also related to the recognition that their partner would need to return to work. Both mothers and fathers talked about establishing routines before the fathers needed to return to work and that those routines might change once that happened: *“it’s just to get support and get a routine going before he does go back to work, which when he does go back it’s going to be part time, so that the help is still there for me you know, when I need him”* (mother,

T1). The initial uncertainties, fears and anxieties about being alone were superseded over time by happiness and positivity, as parents adjusted to being back in the comfort of their home environment, adjusting to new routines and relaxing into family life.

Family togetherness

Family togetherness at T0 was connected to parenting (first time parents and parenting roles); bonding with the baby and the other siblings; separation of the mother and baby, separation of the family and longing to be a family and have 'normality'.

Parents of infants who were diagnosed antenatally gave explanations about how they had been not to be able to engage in the 'normal' bonding process at birth because of the immediacy of the situation and the lack of time with their infant before they were rushed off to the specialist center. Despite the pressure of knowing that they could not physically hold their infant, one mother explained her fears and how she needed to be constantly present: *"It was the fear of losing her...it was just going through my head I want to be there, I want to be there, it's like I said, if anything did happen and I wasn't there I would never ever, and I know they say don't ever say unless you've ever done it, but I'd never forgive myself because at the end of the day she needed her mom or her dad there, do you know where I'm coming from?"* (mother, T0).

Whilst emotional bonding took place through constant watching, physical bonding was put on hold until after the surgery and once the baby was back on the ward, this mother further explained: *"that's why I've constantly got her in my arms"* (mother, T0). There was also evidence of a desire to get home so that physical bonding could commence, as one father explained: *"... deep down I'm really looking forward to going home because then we can bond properly"* (father, T0). However, for some the 'bonding' at T0 was more than physical bonding with the infant, it was family bonding and a desire for 'normality': *"I want to take her home and be a normal family"* (mother, T0).

The first-time parents talked about the dichotomy between longing to get home to be a 'normal' parent, but also the benefit of learning and being taught how to parent whilst in hospital: *"it's been good because ... as a first-time mum I didn't have a clue about a lot of things, so I suppose being here they've shown me quite a lot ..."* (mother, T0).

The transformation of 'family togetherness' over time was a move towards what parents described as the 'normality' of family life despite having an infant with complex CHD: *"But we just try to make time for them and individually, like take it in turns playing, you know, and doing things as a family. Doing things altogether. Especially at weekends, we tend to like all get on the settee, get [baby] on the settee and we watch X Factor. So, it's like, just trying to get back to normal, normality and being just a family in the situation we're in"* (mother, T1).

Parents also recognized that over time they had adopted specific roles; some had become 'medical parents', learning about everything medical and technical whilst in hospital and adopting a *nursing role* at home. However, in some cases whilst one parent had adopted the medical role, the other parent had become the *comforter*. One mother's perception was: *"... it just seems to be the mums who hold the child while they're screaming and stuff like that and the dads just kind of are the ones to comfort them after, it's like the good cop, bad cop (laughs)"* (mother, T1). Adopting different roles was associated with 'establishing routines'.

Establishing routines

'Establishing routines' and getting organized was considered an important element of the preparation for going home, as this father explains: *"Just making sure we're organized I think, make sure we've got everything that we need and that it's all there waiting for us, that's my biggest thing making sure that we've got everything we need and that we're fairly organized"* (father, T0). An integral part of establishing routines was identifying individual roles and responsibilities, as this father reveals: *"She's already put me on two weeks of night duties [laughs]"* (father, T1). Additionally, adjustment to being at home with their infant was related to establishing routines: *"... get into some sort of routine and get comfortable at home"* (father, T0). For some of the first-time parents, having an infant with a heart problem did not influence their

development of routines once at home, because they had nothing to compare to. This mother was asked whether there was anything that made it difficult at home, such as the feeding or medications, she explained: *"I guess, I don't know, I guess for other people it would have been difficult, but I know it kind of goes back on what I've said; but because it was my first it was kind of like routine, it was just incorporated into what I was doing anyway so it didn't really seem different"* (mother, T1).

By the time the infants were going home after their second stage of surgery (T3) most parents acknowledged that their home routines had made *'being alone'* easier. One mother reflected on her first experience of going home and said: *"... once we got him home and we got into the routine it was perfectly fine, [I] just took to it [motherhood] quite quickly"* (mother, T3). Some parents also experienced a faster transition to their home routines after the second stage of surgery, demonstrating adjustment and adaptation: *"It was just, yeah, it took a couple of days to get ..., you know, transitioned into a routine again"* (mother, T3). An integral part of *'establishing routines'* during the transition from hospital to home was the nature of the home environment and the simultaneous development of survival strategies.

Love and Support

Love (met or unmet) was associated with the love, intimacy, closeness and supportiveness of the parental relationship; and the relationship, love and closeness with their other children and between siblings. Support was connected to the help received from family and friends, other cardiac parents; and Health Care Professionals (HCP); it encompassed care and compassion; information and guidance; sympathy and empathy.

Parental relationships

As would be expected parental relationships were affected by the demanding hospital experience; as well as the lack of home comforts and *'space'*, as these two parents' quotes demonstrate: *"We didn't communicate very much. I suppose because we were both very tired"* (father, T2), whilst the mother said: *"I think it had an effect on our relationship, I think it put a lot of strain on our relationship"* (mother, T2). For other parents, hospitalization had a more positive effect, for example: *"it's brought us closer*

together, I'd say, we're finding each other's weaknesses and ... I'd say, I've heard you say it's brought us closer together" (mother, T2).

The transition home was associated with survival whilst establishing family togetherness through the development of routines; positively influencing the resilience of the parental relationship. For some couples, this took longer than others and perceptions of the impact over time altered within relationships, for example at T1 one father said: *"So now he's [baby] home it's a bit easier, a bit more time to relax as well"*. And at T3 the mother said: *"...we're starting to create a routine that will work for both of us ...I think it's helped our relationship so we're not arguing so much now [laughs]"*.

Siblings' attention needs

Siblings received *love and attention* from other members of the family, especially grandparents, whilst the baby and parents were in hospital. However, there was evidence of an association with the sibling's and parents' psychological health and wellbeing (survival) and the impact of separation on family togetherness (safety and security). Re-establishing the 'family' prior to discharge was deemed important; several siblings stayed in the hospital for the last few days, for example: *"...all of us leaving as a family"* (mother) *"yes that was nice"* (father) *"something she [sibling] shared as well"* (mother, T1).

Once home parents' accounts included ensuring the availability of 'love and attention' for the sibling: *"... we're also conscious of making the time to just spend a little bit of quality time with her as well as sort of almost keeping (baby) out of the equation"* (father, T1).

Family and friends

The pursuit and provision of support altered over time; in the initial transition phase from hospital to home, parents sought support mainly from family and friends. Grandparents were the greatest source of support, many of whom lived nearby and could help around the home, caring for siblings, assisting once the father returned to

work and as their and parents' confidence increased providing short breaks by looking after the infant so that parents could get out to shop or attend appointments.

Institutional support

Parents also obtained support for cardiac - related advice from the specialist nurses, for example: "...that point of contact for peace of mind to say, she's doing this, based on that information I'm giving you, what do you suggest, does this sound about right, even if it's someone to sound off to and they go 'yeah that's fine'" (mother, T2) and were aware that community HCPs were less knowledgeable about the cardiac problem. Health visitors, community children's nurses and General Practitioners were however, sources of support for 'normal' new baby advice and monitoring.

Other cardiac parents

Institutional support became less needed as time progressed, whereas other cardiac parents became a major source of friendship and support. This strong 'cardiac parent community' interacted predominantly via social networking sites and text messaging; sharing good and bad news stories between parents who had formed friendships in the hospital environment and who understood each other: One father explained how difficult previous friendships had become because of a lack of understanding: "*it's just a whole other level and trying to emphasise that it's a completely different ball game [to parenting a well-child] and it's not even in the same ball park it's quite – yes that can be a little bit frustrating I think*" (father, T3).

Discussion

The main finding from this study of parents' experiences of their transition from hospital to home, reflected the findings of Messias et al (1995), in that the transition process was multi-faceted, with complex unanticipated transitional experiences becoming superimposed on those that were expected; resulting in a roller coaster of emotions. Numerous physical, emotional and social boundaries and borders were evident, such as the physical and emotional barriers to bonding in the early days of their infant's life. The multiple types and dimensions of transition (Meleis et al 2000) for these parents included: *developmental* (new baby, parenthood, sibling relationships, becoming a medical parent); *health/illness* (baby's cardiac diagnosis and surgery, fragility of their

baby, mother's health and wellbeing following labour, psychological functioning of father, siblings and wider family); *situational* (maternity unit, ward and intensive care unit, discharge to home or local hospital) and *organizational* (hospital culture, ward culture, intensive care culture, culture of being a hospitalized cardiac parent, community/local hospital culture). A variety of social constructs impacted upon their transition and became either facilitating or inhibiting factors (Meleis et al 2000). These related to the 'world' in which they lived; such as the cardiac parent community within the hospital; the social world outside the hospital and the experiences of those parents that were new to parenthood (novice) versus the parents with other children (experienced). The family's personal situations (home and support), ethnicity, (cultural beliefs and attitudes), socioeconomic status (postcode deprivation index), education (preparation and knowledge) also differed (see Table 4) and, therefore, influenced the individual transitional experiences of going home. There was no independent variable (demographic) that functioned within all the social processes involved in the transition.

The pattern 'safety and security' resonates with the findings of Rempel and Harrison (2007), Rempel et al (2009, 2012a, 2012b, 2012c), Lee and Rempel (2011), Meakins et al (2015) and Pridham et al (2010), who described safeguarding as protecting, safety, vigilance, monitoring and survival; as well as uncertainty and vulnerability.

Parents' major worry and uncertainty about going home was the fear of being alone, the fear of not knowing what to do if something happened and the fear of not knowing who to contact for advice. Parents described intense and mixed emotions prior to their infants' discharge home, portraying the turbulence of the pre-transition condition, including 'numbness', feeling 'disconnected from life' and feeling 'too distressed and emotional to really listen'. Parents were used to the safety of the hospital environment and the security of knowing that there was always someone there to help them when required. This reflects the view that parental uncertainty is managed by parents through information management; where parents intensively pursue information about their child's illness (Stewart and Mishel 2000). However, parents were concerned that they did not have enough information, knowledge or skill to guide them once at home and on their own with their infant.

Safety and security, also related to safeguarding their infant through vigilance; where parents described 'constantly watching' their infant, both in the hospital and once

they were home. Linking vigilance to uncertainty, Carey, Nicholson and Fox (2002) hypothesized that mothers responded to the persistent uncertainty by sustained vigilance through monitoring their infant's ongoing health status. Furthermore, this vigilance is supported in Stewart and Mishel's (2000) definition of parental uncertainty through parents' fervently observing HCPs for cues about their child's condition. This aspect of maintaining safety or safeguarding precarious survival (Rempel and Harrison 2007) was also evident in parents' accounts of their experiences throughout the time line from discharge (T0) to going home post stage two surgery (T3).

Whilst the parents did discuss uncertainty about their infant's clinical outcomes, this uncertainty was more situational and related more to the physical transition of going home, which would be expected given the nature of the questioning in terms of the research question. However, there are similarities here to the third dimension of uncertainty proposed by Mishel (1981) regarding the complexity in what information is known (parents' knowledge and preparation), the system of care (family - centered) and the relationship with health care providers (becoming more distant as they transition to home). Furthermore, Mishel (1981, 1988) suggested that uncertainty is influenced by the individual (their mental health and personal beliefs), the illness (perceived severity and intensity of treatment) and environmental factors (such as social support, relationships with HCPs and sociocultural aspects). These influencing factors also reflect the properties of transition and facilitating or inhibiting transition conditions (Meleis et al 2000); so, one might conclude that successful adjustment and adaptation to transition could also be related to the management of uncertainty.

Uncertainty has featured in the research evidence regarding mothers of children with CHD since the 1960s (Glaser, Harrison and Lynn 1964, Linde et al 1966, Gudermuth 1975, Carey, Nicholson and Fox 2002, Rempel et al 2009, 2012a) and, therefore, is not a new phenomenon. However, the definition of uncertainty for these parents was different to that identified in the work of Rempel et al (2009), where uncertainty related to the uncertain outcomes for their infants. The Rempel et al (2009) study took place 15 years ago; at that time, the clinical outcomes were more uncertain for this group of infants because the surgical procedures were relatively new and there was little available evidence about short or long-term outcomes. Whereas for the

parents in this study, there is more contemporary information available about the expected outcomes, benefits and risks of surgery for infants with complex CHD (Brown et al 2015, LHM, 2015). However, despite the availability of information a recent qualitative study found that parents, and professionals working in non-tertiary settings, lacked the information necessary to respond to a deteriorating infant; contributing to the stress of parenting these vulnerable infants at home (Tregay et al 2015). Also, a survey of surgeons in major European centers, to identify their attitudes regarding management of HLHS and how they counsel parents, demonstrated a wide variation and marked inconsistency in the information given to parents as part of the process of counselling across Europe (Murtaza and Elliott 2011). Therefore, uncertainty regarding the clinical outcomes for infants with complex CHD, are likely to depend on the beliefs of HCPs in the center in which they receive the diagnosis and treatment. These inconsistencies remain to be resolved if parents are to make fully informed decisions for their child.

In this study, parental attachment, or bonding with their infant was connected to 'family togetherness' within the 'safety and security' pattern of parental experience, however, this overlapped with family support and the parent-child relationship within 'love and support'. Physical and emotional barriers to parent-child interactions were also identified by Rempel et al (2012a); who found that parents had a desire to nurture their child, whilst wanting to protect themselves in case their baby did not survive. These tensions were not evident in this study; instead parents talked altruistically about putting their infants' survival ahead of their own needs or health and wellbeing. These findings have implications for HCPs in relation to the implementation of family - centered care and assisting parents to bond with their infant in the early days of life.

Family togetherness also related to a desire for normalcy. In the pre-discharge interview (T0) this desire related to wanting to go home to start family life for the novice parents and a desire to return to 'normal' family functioning for the experienced parents. Thereby, normalisation emerged as a social construct that related to either developing normal parenting behaviours or maintaining normal family dynamics by engaging in activities that the family had engaged in before. Lee and Rempel (2011) recognized this normalisation as a behavioural process that was aimed at ensuring a normal upbringing for their child; whilst facilitating acceptance of their child outside the family unit. Parents in this study did not disclose feelings of needing acceptance from

outsiders, this may have been due to the stage of treatment compared to the parents in the Lee and Rempel (2011) study, some of whom had children who were five years of age and had undergone the third stage of surgery.

The concept of family togetherness contained multiple realities, especially for the experienced parents. These parents talked about the conflicting emotions whilst in the hospital, relating to the more urgent care needs of their fragile infant and balancing these with the needs of the other siblings. There was evidence of guilt that they could not be with their other child or children and separation anxiety. However, the siblings were being cared for at home by other family members, mainly grandparents; who lived close by and were a great source of support for these families. Grandparents 'stepping in as needed' was also identified as a core category of grandparenting siblings of children with CHD by Ravindran and Rempel (2010); where they would adopt the parent role to attend to the child's daily needs whilst the parents were preoccupied with their fragile and hospitalized infant. This was referred to by Ravindran and Rempel (2010) as 'triple concern', where not only did the grandparents have a concern for their adult children and the sick infant; they also had concern for the siblings, providing relief and reducing the stress for the parents whilst in hospital (Ravindran and Rempel 2010).

In contrast, the first-time grandparents of first born infants with CHD in this study (n=4) had a different supportive role, which was mainly to emotionally support their adult children whilst the sick infant was in hospital. This was referred to by Ravindran and Rempel (2010) as 'double concern', arising from the conceptualisations of Hall (2004a, 2004b). In later interviews (T1, T2 and T3) the role of these grandparents changed as they began to gain confidence looking after their fragile grandchild, and could relieve the caretaking duties for their adult children; allowing the couple to have time alone, thereby enhancing their relationship and enabling them to regain intimacy.

The health and wellbeing of the sibling was discussed by parents in relation to the psychosocial impact of the situation. Five parents discussed the manifestation of behavioural changes in their other child, which they believed were related to factors such as anxiety, anger, jealousy, lack of understanding, feeling left out and resentment, especially whilst they were in hospital with their sick infant. These changes reflect parents' perceptions of the impact on healthy siblings, identified by

Wray and Maynard (2005) albeit in a study of parents of older children with a variety of forms of CHD. Parents also identified that: extra attention was given to the sick child; they were prevented from doing things as a family; the fear of getting too close to the sick sibling; feeling that the sick child did not have same rules to adhere to; intolerance and insecurity; some of which may have related to longer term impacts and outcomes (Wray and Maynard study 2005). In contrast in this study, improvements to sibling behaviour were identified after the family had been discharged home and this was perceived to be the positive effect of love and the support of being together as a family.

It was evident that 'home comforts' had enhanced parents physical and psychological wellbeing, as they described the benefit of having '*time out*' and '*getting enough sleep*'. Parents also described an adjustment to the changes at home by adopting different roles and establishing routines. For one couple, regaining home comforts and establishing routines rescued the precariousness of the parental relationship, that had deteriorated whilst the infant was in hospital. This family did not have the close (emotionally or geographically) support of grandparents or friends; however, the transition from hospital to home relieved other stressors. For example, the father worked and travelled daily to the hospital resulting in them having very little time together; causing feelings of guilt for the father and resentment, anger and isolation for the mother. Going home reduced the daily commute for the father and gave them more time together as a family; this enabled the father to take part in caring activities, giving the mother time to herself and reducing the guilt and resentment. Establishing routines enabled the parental support to be restored within their relationship as they adjusted and adapted to the transition and developed their knowledge, confidence and mastery of the situation.

Limitations

Being available to conduct the first interview before parents and their infant were discharged was not always easy to anticipate or plan. For this reason, two of the interviews at T0 were conducted by the research nurse, potentially reducing consistency in the interviewing approach. However, the research nurse observed several interviews conducted by the principal investigator, to ascertain what was required and how to conduct the interview; and an interview schedule was used for

consistency. Being a novice interviewer meant that the first two interviews were a learning curve. A common pitfall of many novice nurse-researchers is recognized as the struggle to move from the clinical role to that of a non-clinical researcher (Tod 2006), however, it was important to be aware of the impact it may have on the quality of subsequent interviews if it was not addressed. This led to improvement of the interview schedule based on what was learnt during the first two interviews, to engage in deeper probing of points raised by the parents.

Telephone interviews were more difficult with some parents, in terms of keeping the conversation going. This may have been related to being a novice interviewer as well as recognising that the parents may have had other better things that they wanted or needed to do and therefore not wanting to impose or take up too much of their time. Including only English-speaking families was a limitation both in terms of not being able to find out about the experiences of parents from other cultures but also as it limited the number of parents that could be approached to take part in the study. Not all parents participated in all four interviews, there were a variety of reasons for this, although these were not all verbalized. For example, the infant had been readmitted to the hospital or was not discharged at all; parents may have felt too overwhelmed once they were at home to take part in the study; parents may have been too busy with 'life' to take part; parents may have wanted to forget about the hospital experience and did not want to talk about it. One parent was very nervous about being 'interviewed' before discharge and therefore her interpretation of the word 'interview' may have impacted upon her lack of participation with the other three interviews.

Practice implications

The findings from this study offer several insights and recommendations for nursing practice. Firstly, nurses need to recognize the significant physical, social, psychological and logistical impact that transitioning from hospital to home for the first time, with a fragile infant has on parents' 'safety and security' and 'love and support' and their ability to adjust and adapt to the transition. Parents' experiences are individual and depend on numerous transitional factors and therefore nurses need to

ask about potential sources of stress before the family is discharged. By assessing sources of anxiety or uncertainty, nurses can identify and offer parental support such as information giving, sign posting to services or provision of health care resources at home; alongside the medical support required for the infant, to ensure that discharge care is truly patient and family - centered. Further research is needed to determine the effectiveness of educational frameworks for HCPs within congenital cardiac networks in the UK, including primary and secondary care, to positively influence the provision of individualised family - centered discharge care.

Secondly, parents need to be engaged early in the discharge planning process and given the opportunity to express their needs, so that care for them and their infant can be individualized. Thirdly, involving grandparents in the pre-discharge planning may support the implementation of patient and family - centered care. Nurses also need to be aware of the impact on siblings and the wider family and provide appropriate support for them too. Implementation of a standardized discharge package and educational programme, currently being designed to prepare parents for their infant's interstage discharge, needs to be evaluated. Additionally, the transitional experiences of non-English speaking families, need to be explored such that discharge advice and support can be tailored to their cultural needs.

Conclusion

Transition from hospital to home was complex and multi-faceted, with unanticipated physical and emotional transitions superimposed upon those that were expected; resulting in a roller coaster of emotions. The major worry and uncertainty for parents about going home was their infant's *safety and security*, and included the fear of being alone, the fear of not knowing what to do if something happened and the fear of not knowing who to contact for advice.

Successful adjustment and adaptation to the transition home may be improved through effective management of parents' uncertainty by health care professionals. Provision of individual, infant appropriate and family – centered preparation before discharge home is key; considering *love* (their needs and the sibling's) *and support*, by involving grandparents, family and friends.

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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.	

Table 2 Interview Time Points

Time	Time point/Place	Interview Schedule
T0.	Baseline assessment at time of giving informed consent/ Prior to discharge In hospital	<ul style="list-style-type: none"> • Baseline demographics completed by the research team after informed consent had been obtained • Semi-structured interview conducted to ascertain parents' perceptions of their infant's discharge and transition home • Measure potential parental anxiety using GAD7 • Measure potential parental depression using PHQ-9 • Measure parental confidence using 'Maternal Confidence Questionnaire'
T1	Two weeks after discharge Parents at home – telephone interview	<ul style="list-style-type: none"> • Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge and transition home • Measure potential parental anxiety using GAD7 • Measure potential parental depression using PHQ-9 • Measure parental confidence using 'Maternal Confidence Questionnaire'
T2	Eight weeks after discharge Parents at home – telephone interview	<ul style="list-style-type: none"> • Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge and transition home • Measure potential parental anxiety using GAD7 • Measure potential parental depression using PHQ-9 • Measure parental confidence using 'Maternal Confidence Questionnaire'
T3	At the end of participation in the study (when their infant returns for stage 2 surgery)	<ul style="list-style-type: none"> • Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge and transition home • Measure potential parental anxiety using GAD7 • Measure potential parental depression using PHQ-9 • Measure parental confidence using 'Maternal Confidence Questionnaire'

Table 3

Interview Guide - Face to face Interviews with parents participating in the study before discharge from hospital (T0)

Introduction

Obtain Verbal Consent to Continue (check if both parents present that they are happy to be interviewed together)

Interview Schedule:

Explain how the interview will progress and how long it will take

Part 1 Quantitative Data Collection

1. How anxious, depressed and confident do you feel about looking after your infant at home?
 - a. Parents will be asked to complete the following questionnaires (explanation will be given)
 - i. GAD7
 - ii. PHQ9
 - iii. Maternal Confidence Questionnaire

Part 2 Qualitative

2. How do you feel about the transition of going home with your infant for the first time?
 - a. Perception of the transition (change in role, affect, source, timing, onset, duration, degree of stress)
 - b. What support systems do they have (intimate, family, friends, institutional, physical environment)
 - c. Individual characteristics (parent demographics, previous experiences, knowledge and understanding)
3. Please can you tell me how you feel about being involved in the project?
 - a. Have the parents got any anxiety related to being part of the project?
 - b. Is there anything else the parents need before going home in relation to the project?

Terminate the interview

Arrange date and time for the telephone interviews (at T1, T2, T3)

Thank the parents for their time, ensure they have contact details for Principal Investigator

Table 4 Parents' demographics data

Demographic	Mother n (%)	Father n (%)
Parent's Age		
• 20-25	3 (25%)	X ¹
• 26-30	4 (33.3%)	X
• 31-40	5 (41.7%)	X
Primipara	5 (41.7%)	
Multipara	7 (58.3%)	
Parent's Health		
• Fit and healthy	10 (83.3%)	2 (50%)
• Congenital Heart Disease	0	0
• Chronic illness (e.g. Diabetes, Asthma, Adult Heart Disease e.g. high BP)	1 (8.3%)	1 (25%)
• Mental Health problems (e.g. Depression, Schizophrenia)	1 (8.3%)	1 (25%)
Living Arrangements		
• Living with partner (married or unmarried)	11 (91.6%)	
• Not stated	1 (8.3%)	
Distance from home to the specialist heart hospital		
• Less than 20 miles	6 (50%)	
• 20-30 miles	2 (16.7%)	
• 30-40 miles	2 (16.7%)	
• 50-100 miles	2 (16.7%)	
Postcode deprivation index score**		
0-5,000 (highest deprivation - top 20%)	3	
5,000 – 10,000	1	
10,000-15,000	3	
20,000-25,000 (lowest deprivation – lowest 20%)	1	
Employment		
• Employed for wages	0	6 (50%)
• Self-employed	1 (8.3%)	2 (16.6%)
• Out of work but not currently looking	0	1 (8.3%)
• A homemaker	8 (66.7%)	0
• Maternity/paternity leave	3 (25%)	0
• Sick leave	0	3 (25%)
Education		
• Secondary school to 16 (GCSE equivalent)	4 (33.3%)	3 (25%)
• Sixth Form/College (A levels, BTEC, IB)	5 (41.6%)	4 (33.6%)
• Bachelor's degree (BA, BSc)	3 (25%)	1 (8.3%)
Ethnicity		
• White – British	9 (75%)	7 (58.3%)
• White - Irish	1 (8.3%)	0
• White - European	0	1 (8.3%)
• Black British	1 (8.3%)	1 (8.3%)
• Black Caribbean	1 (8.3%)	1 (8.3%)
• British Asian	0	1 (8.3%)
• Kurdish	0	1 (8.3%)

¹X denotes missing data

**The postcode deprivation index (index of multiple deprivation) was calculated using an online tool in 2013; where a score of 1 was the most highly deprived residential area. This provided information about possible socioeconomic factors that might have impacted on the parents' experience.

Table 5 Infant's Birth and Medical Information

Demographic	n (%)
Time of Diagnosis	
Antenatal	11 (91.6%)
Postnatal	1 (8.3%)
Female	7 (58.3%)
Male	5 (41.6%)
Gestation	
35+	1 (8.3%)
36+	1 (8.3%)
38+	4 (33.3%)
39+	3 (25%)
40+	2 (16.6%)
42+	1 (8.3%)
Birth weight	
2-2.5Kg	4 (33.3%)
2.6-3Kg	2 (16.6%)
3.1-3.5Kg	4 (33.3%)
4.1-4.5Kg	2 (16.6%)
Diagnosis	
Hypoplastic Left Heart Syndrome	10 (83.3%)
Hypoplastic Right Heart	1 (8.3%)
Tetralogy of Fallot	1 (8.3%)
Other non-cardiac defects	5 (41.6%)
Genetic abnormality	3 (25%)
Specialist Hospital Admission Route	
Retrieval team	12 (100%)
Pre-operative management	
Mechanical ventilation	6 (50%)
Prostaglandin infusion	12 (100%)
Inotropic support	5 (41.6%)
Acidosis	8 (66.6%)

Table 6 Key patterns of parents' experiences arising at the four time-points

T0 (n= 12 interviews)	T1 (n= 9 interviews)	T2 (n= 7 interviews)	T3 (n= 9 interviews)
Safety and Security	Safety and Security	Safety and Security	Safety and Security
<ul style="list-style-type: none"> • Uncertainty and being alone • Family togetherness • Vigilance 	<ul style="list-style-type: none"> • Establishing routines • Vigilance • Need for Security • Being a parent 	<ul style="list-style-type: none"> • Vigilance • Medications • Establishing routines 	<ul style="list-style-type: none"> • Vigilance • Family togetherness • Establishing routines
Love and Support	Love and Support	Love and Support	Love and Support
<ul style="list-style-type: none"> • Family and friends • Institutional support • Friends • Parent Support groups 	<ul style="list-style-type: none"> • Institutional support • Family support • Parent Support (Groups and other cardiac parents) • Friends 	<ul style="list-style-type: none"> • Family support • Community HCPs • Parent Support (Groups and other cardiac parents) 	<ul style="list-style-type: none"> • Family support • Other cardiac parents • Partner support • Institutional support
Love	Love	Love	Love
<ul style="list-style-type: none"> • Siblings' attention needs • Parental relationship 	<ul style="list-style-type: none"> • Sibling love • Parental relationship 	<ul style="list-style-type: none"> • Parental relationship 	<ul style="list-style-type: none"> • Change to parental relationship • Sibling love of baby

Glossary of Terms

Community Children's Nurse

Community children's nurses are registered children's nurses, with specialist community nursing qualifications and experience. They generally work within a team to care for children in their own homes, in a specific geographical region linked to a primary health care trust (NHS England, 2015).

Health Visitor

Health Visitors are registered nurses, with specialist qualifications in Community Health, which includes child health, health promotion and education. They work within the primary health care team (NHS Careers, 2017a)

General Practitioner

General practitioners are qualified doctors with specific training, who work within the primary care setting and are the first point of contact for most patients. They provide

primary and continuing medical care for patients in the community; referring patients to hospital clinics for further assessment or treatment (NHS Careers, 2017b).