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# Parents' Journeys of Mastery and Knowledge Construction After Their Infant's First Stage of Surgery for Complex Congenital Heart Disease

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## ABSTRACT

**Background:** A growing body of conceptual evidence over the last decade has increased our understanding of parents' experiences of having an infant with complex congenital heart disease. These concepts include parents' feelings of uncertainty, fear, excitement, and mastery. However, little is known about parents' experiences, confidence, and knowledge acquisition during transition from hospital to home with their infant after the first stage of complex cardiac surgery. A theoretical framework to assess, plan and implement child and family centered care would assist children's cardiac nurses responsible for parental education, discharge planning and coordination.

**Aim:** To explore parents' experiences of the transition from hospital to home with their infant, following the first stage of cardiac surgery.

**Design:** A prospective mixed methods longitudinal design. Semi-structured interviews were undertaken, including administration of the Maternal Confidence Questionnaire at four timepoints: before discharge following stage one cardiac surgery (T0), 2 weeks' post discharge (T1), 8 weeks' post discharge (T2) and after stage two surgery (T3). Qualitative data were thematically analyzed. Descriptive statistics were used to characterize the sample and non-parametric repeated measures analysis of variance was used to analyze changes over time in maternal confidence scores.

**Results:** Sixteen parents of 12 infants participated. Four "patterns of transition experience" emerged, the fourth "Mastery", is discussed in this paper. Mastery can be contextualized in terms of the parents' journeys of knowledge construction, gaining confidence and reflection. Learning was dynamic and transformational, but successful learning and acquisition of knowledge was also dependent upon the parents' ability to absorb, integrate and adjust at any given time. Confidence at T0 was significantly lower than at T1 ( $p = .011$ ), T2 ( $p = .018$ ) and T3 ( $p = .012$ ). There were no significant differences between scores at T1, T2 and T3. Liminality, as a concept, described the between and betwixt time that parents experienced as they were



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preparing for discharge from hospital; excitement to be going home balanced with the fear of being alone and confidence in looking after their fragile infant.

**Conclusion:** Parents of infants with complex congenital heart disease obtain knowledge, confidence, and mastery dependent upon their transition experience and their personal journey through pre-liminal, liminal, and post-liminal phases of discharge from hospital to home. A conceptual framework “Parenting through Transitions – hospital to home” emerged that could assist in structuring assessment of parents’ knowledge and support needs within a coordinated discharge process. Identifying individualized support would promote adaptation and adjustment during transition from the pre to post liminal phase, following their infant’s first stage of complex cardiac surgery.

#### **What’s New**

- Parents learning was dynamic and transformational, learning opportunities overlapped transitional phases of their infant’s journey, but successful learning and acquisition of knowledge was also dependent upon the parents’ ability to absorb, integrate and adjust at any given time.
- The transition from hospital to home and traversing the physical boundary of leaving the hospital for the first time with their infant (liminal phase), was loaded with emotionally traumatic experiences that could not be separated from the transition that was being explored within this study.
- 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 to mastery of a new normal (post-liminal phase), which encompassed competence, integration, and comfort.

## **Introduction**

A growing body of conceptual evidence over the last decade has increased our understanding of parents’ experiences of having an infant with complex congenital heart disease (CHD). These concepts include parents’ feelings of uncertainty, fear, excitement, and mastery (Pridham et al., 2010; Rempel & Harrison, 2007; Rempel et al., 2009, 2012, 2013). Rempel and Harrison (2007) focused on experiences of parenting children with complex CHD, at a time when frameworks based on theory to underpin care were not available around parenting an infant with hypoplastic left heart syndrome (HLHS), due to the newness of the surgical procedures, medical and nursing care. In the early surgical era (Rempel & Harrison, 2007) parents safeguarded their child’s survival through performance of advanced nursing and assessment at home and identified strategies to safeguard themselves. Their worry related to their child’s immediate and ongoing survival and associated parenting stress (Rempel & Harrison, 2007). A later study (Rempel et al., 2012, 2013) included parents and grandparents of infants who underwent an altered surgical procedure for HLHS and were supported at home after discharge within a home monitoring program. The findings resulted in conceptualization of a four phased process of parenting children with HLHS called “parenting under pressure”. The four phases were described as overlapping and recurring throughout their journeys from diagnosis to first surgery, discharge

home, awaiting and experiencing further surgery (Rempel et al., 2013). A theoretical framework of five facets of parenting was established to inform development of future parent interactions (Rempel et al., 2012) including “survival parenting, hands off parenting, expert parenting, uncertain parenting and supported parenting”. Pridham et al. (2010) also presented concepts for a theoretical model for parental support for parents of infants with complex CHD. This theoretical model was underpinned by attachment-caregiving theory, drawing on the behavioral system of caregiving, the internal working model of parenting and motivation. Despite differences in the samples (Pridham et al., 2010; Rempel et al., 2012, 2013) and no information about the surgical era (Pridham et al., 2010) there are some similarities in the two models such as mastery of skills, vigilance, support, safeguarding survival of the infant, self, couple, and family.

The two models (Pridham et al., 2010; Rempel et al., 2012, 2013) have emerged from Canada and North America, where health care systems differ to the National Health Service in the United Kingdom (UK). In the UK, CHD Standards and Service Specifications were published in 2016 (NHS England, 2016) and include standards around planning discharge and provision of support for families. Having a theoretical framework upon which to assess, plan and implement care would assist the nurse in the UK responsible for planning discharge to meet the standard of “coordinating the process and linking with the child/young person and their family” (L13, L1) (NHS England, 2016). Furthermore, this could assist the Children’s Cardiac Nurse Specialist to meet the standard relating to assessing parents’ needs, enabling individualized psychosocial support to promote family (and child/young person’s) adaptation and adjustment (H14 L1, p. 208) (NHS England, 2016).

A mixed methods study exploring parents’ experiences of the transition from hospital to home with their infant following first stage cardiac surgery (Gaskin, 2018; Gaskin et al., 2021) identified four “patterns of transition experience”: safety and security (Gaskin, 2018) love and support (Gaskin, 2018) survival (Gaskin et al., 2021) and mastery. This paper presents the parents’ journey of mastery and construction of knowledge after their infant’s first stage of surgery and how liminality, defined as “moving through a betwixt and between time” (Hockey, 2002). The findings of this study informed the development of a conceptual framework called “*Parenting through transitions – hospital to home*”, supporting and progressing the findings of other research studies, highlighted above (Pridham et al., 2010; Rempel & Harrison, 2007; Rempel et al., 2009, 2012, 2013).

## Methodology and methods

### *Design and participants*

A prospective mixed methods longitudinal design was used to study a cohort of parents being discharged home with their infant from a tertiary children’s cardiac surgery center in the United Kingdom following the first stage of cardiac surgery for complex CHD (Gaskin, 2018; Gaskin et al., 2021). Parents were eligible to participate within the 15 month recruitment timeframe (pre-COVID19), if their infant had undergone the first stage of cardiac surgery for complex CHD [functionally univentricular heart and systemic shunt dependent lesions] during the neonatal period (0–4 weeks), if they could read and understand English and could give informed consent. 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 (REC reference: 12/WM/0375, IRAS 92 184). The participant information sheet provided details of support available to parents, including the charity helpline for Little Hearts Matter.

### **Data collection**

Demographic data (Gaskin, 2018; Gaskin et al., 2021) were collected at baseline (T0) by the Research Nurse before semi-structured interviews were conducted at four time points: before discharge following stage one cardiac surgery (T0); two weeks after discharge (T1); eight weeks after discharge (T2) and after stage two surgery (T3). The interview guide was developed in collaboration with the research team, PhD supervisory team and external advisory group. The Middle Range Transition Theory (Meleis et al., 2000) informed design of the interview topic guide (Table 1) to explore the type, patterns, and properties of the parents' transitions, identifying processes that moved them toward health or vulnerability and risk. The interviews were audio-recorded and transcribed verbatim using QRS NVivo10.

All interviews were conducted by the Principal Investigator (PI), except for two interviews (at T0) conducted by the Research Nurse (RN) because of earlier than expected discharge of the infants. The PI (KG) was based at the university more than 30 miles away and unable to get to the hospital in time. Interview training had been provided for the RN with particular emphasis on open questions and staying in the interviewer role rather than deviating to a counselor role, directing parents to the participant information leaflet for available support services. A date and time for the subsequent telephone interviews was arranged at the end of each interview; after two attempts to call with no response the parent was deemed not available. The final interview was arranged by the Research Nurse, and undertaken by the PI, after the second stage of surgery had been conducted and they were ready to go home; they were given the choice of a face to face or telephone interview.

### **Instruments**

Confidence in the parenting role was measured at each of the timepoints using the Maternal Confidence Questionnaire [MCQ] (Badr, 2005). Few tools have been developed and psychometrically tested to assess maternal confidence (Parker et al., 1992). The scale consists of 14 items: each item is answered on a 5-point scale from 1 = never to 5 = a great deal. The scale measures maternal confidence in parenting skills and the mother's ability to recognize her infant's needs. After reversing the two negatively worded items

**Table 1.** Interview topic guide.

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*Topic guide: Face to face interviews with parents participating in the study before discharge from hospital (Baseline T0).*  
 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)

*Topic Guide: Telephone interviews after discharge (T1, T2) and face to face or telephone (T3)*  
 How do you feel about the transition and adaptation to being at home with your infant now?  
 – Balance of resources and deficits  
 – Differences in pre and post transition environment  
 – Perceptions (change in role, affect, source, timing, onset, duration, degree of stress)  
 – What support systems do they have (intimate, family, friends, institutional, physical environment)  
 – Individual characteristics (parent demographics, previous experiences, knowledge and understanding)

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(items 10 and 12), a total score is derived from the mean of the totaled 14 item scores. Total scores vary from 14 (lower maternal confidence) to 70 (higher maternal confidence) and means vary between 1 and 5 for each question. The MCQ is uni-dimensional with a higher score indicating a higher perceived competence (Badr, 2005). Face and content validity have been evidenced (Zahr, 1991). The scale has been used in more than 40 research studies, establishing reliability and validity; it has also been translated into 9 languages (Meleis et al., 2000). The MCQ has been used in one other study (Fonseca et al., 2013) including both mothers and fathers of infants with a congenital anomaly (17.8%,  $n = 16$  with CHD). In this latter study, the dimension “Evaluation of the Parenting Experience” was excluded because its Cronbach’s alpha was only .56 for the comparison group. For the remaining dimensions, values for Cronbach’s alpha ranged from .75 (Caretaking Tasks, clinical group) to .84 (Knowledge of the Infant, comparison group).

### **Data analysis**

#### **Qualitative analysis**

Criteria for trustworthiness of a qualitative study provided the framework for design and reporting (Guba, 1981) and corresponded to constructs utilized within positivist research (Shenton, 2004). A six-phased approach was used to become familiar with the data: generate initial codes; search for themes; review themes; define and name themes; and produce the report (Braun & Clarke, 2006).

#### **Quantitative analysis**

The Statistical Package for the Social Sciences (IBM SPSS Inc.) version 26 for Windows was used for the quantitative data analysis. Descriptive statistics were used to characterize the sample and non-parametric repeated measures analysis of variance was used to look at changes over time in maternal confidence scores.

#### **Mixed methods analysis**

Comparison occurred within and across the time points to identify relationships between the qualitative and quantitative data. As the dominant approach was qualitative, the quantitative data were amalgamated as relevant into the patterns arising from the qualitative analysis.

The analysis by the PI (KG) was independently verified by the Chief Clinical Investigator (DB), external advisor (JW) two members of the PhD supervisory team (GF and TK).

## **Results**

Parents of 13 infants were recruited (from forty-seven families meeting the inclusion criteria); one parent was removed from analysis as they did not participate, resulting in 16 parents (12 mothers, 4 fathers) participating. Completion of interviews (Table 2) and report tools varied due to readmissions of the infant to hospital or non-availability of the parents. The qualitative data set included 38 interviews. Mean duration of interviews was: T0: 21 mins (SD 9); T1: 19 mins (SD 12), T2: 22 mins (SD 10), T3: 31 mins (SD 12). The increase in duration may have been due to parents’ improved confidence and as T3

**Table 2.** The number of completed self-report tools and interviews at T0, T1, T2, T3.

	Mothers Completed MCQ	Fathers completed MCQ	Mothers completed interviews alone	Fathers completed interview alone	Mother and father interviewed together
T0	12 (100%)	4 (100%)	8		4
T1	9 (75%)	4 (100%)	7	1	2
T2	7 (58%)	3 (75%)	4		3
T3	9 (75%)	2 (50%)	7		2
<b>TOTAL</b>	<b>37</b>	<b>13</b>	<b>26</b>	<b>1</b>	<b>11</b>

Reasons for non-completion:

Infant was not discharged home, interviews not conducted at T1, 2 or 3.

Infants have been readmitted to hospital at T2 ( $n = 2$ ).

Mothers not contactable at T1 ( $n = 2$ ), T2 ( $n = 2$ ), T3 ( $n = 2$ ).

Father not available at T1 ( $n = 1$  for interview but completed MCQ), T2 ( $n = 1$ ), T3 ( $n = 2$ ).

interviews were conducted after second stage surgery, parents were feeling more relaxed. Parents' and infants' demographics are presented in [Table 3](#).

The fourth theme "Mastery" is reported here. Mastery can be contextualized in terms of the parents' journeys of knowledge construction, gaining confidence and reflection. Parents' quotes are illustrated in [Table 4](#).

### **Knowledge construction**

Knowledge construction commenced from the time of their infant's diagnosis. Parents' experiences of learning, knowing, and understanding their infant's diagnosis were dependent upon when they received the diagnosis; the social situation; who was involved in providing the information; and how the information was given and where.

Knowledge construction was not only an explicit transfer of information but tacitly embodied through their emotions and feelings of shock and devastation. Experiential learning (both explicit and tacit) continued in the ward environment as parents asked questions and eagerly watched and learned from the nursing and medical staff to ensure safety and security once they were discharged home. Parents also learned from the experiences of other parents, the excitement of another infant being discharged or the distress of another infant's death, as well as through sharing their collective parenting experiences. They learned the social and cultural norms of being in hospital; being a "cardiac parent" and being part of a socially constructed community of medical parents.

For parents transitioning home with their infant, ("pre-liminal phase") there were physical boundaries, such as crossing the threshold of the ward into the outside world, possibly for the very first time with their fragile baby. These parents and their infants had already transitioned across several physical and situational boundaries since their infant's birth, such as retrieval and transfer from the maternity unit, and transition to the ward from intensive care. Parents had faced a roller coaster of emotionally traumatic events. So, 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 transition that was being explored within this study.

However, for some families, transition from hospital to home was a constraint but it was also enabling. Liminality occurred for parents at the point of being told that they could go

**Table 3.** Parents' and infants' demographics data.

Demographic	Mother n (%)	Father n (%)
<b>Parent's Age</b>		
• 20–25	3 (25%)	
• 26–30	4 (33.3%)	
• 31–40	5 (41.7%)	
• Not known		4 (100%)
<b>Multipara</b>	7 (58.3%)	
<b>Parent's Health</b>		
• Fit and healthy	10 (83.3%)	2 (50%)
• 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%)
<b>Living Arrangements</b>		
• Living with partner (married or unmarried)	11 (91.6%)	3 (75%)
• Not stated	1 (8.3%)	1 (25%)
<b>Distance from home to the specialist heart hospital</b>		
• Less than 20 miles	6 (50%)	1 (25%)
• 20–30 miles	2 (16.7%)	
• 30–40 miles	2 (16.7%)	1 (25%)
• 50–100 miles	2 (16.7%)	2 (50%)
<b>Employment</b>		
• Employed for wages	0	2 (50%)
• Self-employed	1 (8.3%)	1 (25%)
• A homemaker	8 (66.7%)	0
• Maternity/paternity leave	3 (25%)	0
• Sick leave	0	1 (25%)
<b>Education</b>		
• School (up to 16 years)	4 (33.3%)	
• School/College (up to 19 years)		
• Higher Education	5 (41.6%)	2 (50%)
• Not known	3 (25%)	2 (50%)
<b>Ethnicity</b>		
• White – British	9 (75%)	1 (25%)
• White – Irish	1 (8.3%)	
• White – European	0	1 (25%)
• Black British	1 (8.3%)	
• Black Caribbean	1 (8.3%)	1 (25%)
• British Asian	0	1 (25%)
<b>Infant's Birth and Medical Information</b>		
Demographic	n(%)	
<b>Time of Diagnosis</b>		
Antenatal	11 (91.6%)	
Postnatal	1 (8.3%)	
<b>Female</b>	7 (58.3%)	
<b>Male</b>	5 (41.6%)	
<b>Gestation</b>		
35+	1 (8.3%)	
36+	1 (8.3%)	
38+	4 (33.3%)	
39+	3 (25%)	
40+	2 (16.6%)	
42+	1 (8.3%)	
<b>Birth weight</b>		
2–2.5 Kg	4 (33.3%)	
2.6–3 Kg	2 (16.6%)	
3.1–3.5 Kg	4 (33.3%)	
4.1–4.5 Kg	2 (16.6%)	
<b>Diagnosis</b>		
Hypoplastic Left Heart Syndrome	10 (83.3%)	
Hypoplastic Right Heart	1 (8.3%)	
Tetralogy of Fallot	1 (8.3%)	

(Continued)



**Table 3.** (Continued).

Demographic	Mother n (%)	Father n (%)
<b>Other non-cardiac defects</b>	5 (41.6%)	
<b>Genetic abnormality</b>	3 (25%)	
<b>Specialist Hospital Admission Route</b>		
Retrieval team*	12 (100%)	
<b>Pre-operative management</b>		
Mechanical ventilation	6 (50%)	
Prostaglandin infusion	12 (100%)	
Inotropic support	5 (41.6%)	
Acidosis	8 (66.6%)	

\*retrieved from the maternity hospital and transferred to children's hospital by specialist pediatric intensive care retrieval team.

home with their baby; this was not accounted for in the middle range transition theory but refers to the “liminal phase.” For a while, some parents were in an uncertain place where they could not visualize what was ahead and how it would feel, and this created anxiety and fear at the same time as excitement. For these parents the transition from hospital to home was a crossing point from a place of safety and security into the unknown, uncertain place. 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. Parents 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 theirs, was frightening, irritating, and isolating.

Once home, further experiential learning occurred: establishing their own routines, learning to cope without the safety net of the monitors, alarms, and readily available specialist knowledge in hospital. But knowing that specialist advice was available at the end of the phone. They learned to cope on their own, to source love and support from other places and to develop personal knowledge of their infant's individualized needs. This knowledge became cognitively more explicit, as they learned to understand the signs and symptoms they were observing and hearing.

Parents already bound by the cardiac parent community had to decide whether to integrate the explicit and tacit knowledge and information presented to them by different social constructs, such as individuals with only “normal baby experience” and other cultural and social environments (knowing the diversity of environments and organizing days out around giving medications and feeds). An important element of this learning was the shift in their sources of support and the integration of knowledge, as parents began sharing their experiences and listening to others in the wider “cardiac parent community” via social networking sites.

### **Confidence**

Parents' confidence levels (MCQ) at the four interview time points are presented alongside their illustrative quotes (Table 2). Confidence (MCQ) scores could range between 14–70,

**Table 4.** Illustrative quotes.***Learning from the time of diagnosis***

I didn't know anything about it at all, but now yeah, especially when they referred me to the women's hospital and I saw the doctor there, [name], yeah and she was really really good, she went into a lot of detail and explained it really well (mother 9, T0, MCQ 58)

I sort of deal with well what is it you know, what can they do, what can't they do and all that sort of side of it so I don't, whether it helped or not I don't know, whether sometimes knowledge can be you know, too much (father D, T0, MCQ 50).

***Dissociation of thoughts***

... it feels like I'm still in a nightmare that I'll wake up any minute and I'll still be pregnant (mother 1, T0, MCQ 70).

... it's like a standstill, you're like 'where am I?' you're on like a standstill, I was just focused on that one cot. I wasn't even daring to look around me. Oh, God no, all I seen was these big machines and I thought I'm not even looking, I was like I'm not looking nowhere, my eyes, it was horrible (mother 11, T0, MCQ 52).

***Experiential learning before discharge***

you know, to try and get into my brain exactly what is the matter with him, what they've done, what procedure was done... and what the surgical procedure was done and what the next one and so like from a medical point of view... I know what's going on with him... I don't fully understand it because I'm not medical, but to try and get in my head so I know exactly what to look for when we are at home (mother 1, T0, MCQ 70)

"I think from being here I've picked up some of the tools and how to spot and doing simple things like putting a hand on her and checking her breathing" (mother 7, T0, MCQ 60)

***The liminal phase***

I think because we left it so late going home even though we were discharged like midday, but we didn't actually get home until like half past 8 (father D, T3, MCQ 69)

... [we were] clinging on to straws (mother 10, T3, MCQ 70)

***Experiential learning at home***

I do a bit more for him at home, I just basically get on with it at home... it just... it just feels more comfortable and I feel more confident in my abilities to like do his medicines and things like that now (Mother 2, T1, MCQ 49)

I did the school run and everything and he's in bed so I've been able to cope on my own with 3 medications going down, feeding her, sorting (child) out, getting (child and baby) into the car by half past 8 so I can do it (mother 10, T1, MCQ 70) now we feel confident enough that we know the signs to check for and the traffic light system ourselves and kind of know where it would be in the book (Mother 5, T2, MCQ 64)

we're obviously constantly learning what (baby) needs and we know when she's grizzly and what to check and things like that... we're at a stage where I think we sort of know her more than anything, know what's normal for her (Father D, T2, MCQ 69).

***Learning in different environments***

I don't really like taking him out at the moment, because of the cold and things like that, so when he gets a bit bigger and his immune system is a bit better then yeah (mother 8, T1, MCQ 70)

we've been quite fortunate, the timings been quite good in that the new shopping precinct has just opened up, so we went in there to have a look round and we've been visiting family and stuff (father D, T1, MCQ 62)

we went to [shop name] just now and there was a kid coughing there and it was like 'oh keep away from me!' so we moved (mother 10, T1, MCQ 70)

I find it easier to go to someone's house rather than out to town or something, it's more comfortable to give his meds and stuff (mother 9, T2, MCQ 65).

***Other sources of Support***

no one else understands (mother 10, T2, MCQ 70)

it's called Young at Heart and it's children's hospital heart charity and I'm in their group on Facebook but I haven't really spoken yet but I've looked in there and stuff and then I'm in a group on baby centre as well (mother 9, T2, MCQ 65)

I don't know, like it's kind of support you see; just knowing that other people in common knowing exactly what you're going through, because friends and family support you, but they can't fully understand it (mother 9, T3, MCQ 69)

... we get a lot [support] on Facebook don't we really, you can see everyone going through what you're going through and if you're not sure on something you can ask them you know, they might have had it or... (mother 3, T3, MCQ 68).

... a few days ago I started to look into child care and him going to school and things and obviously I went onto the LHM website and I kind of realised how daunting it can actually be having your child go to school and things like that, and making sure that they're aware of the situation and they can cope when something happens and things like that so... getting advice from parents that have gone through it, you know, it's very helpful (mother 8, T3, MCQ 68).

***Process of integration***

[I'm] definitely more aware of different things regarding his condition, [his] heart... it opened my eyes to things...

I think I was angry and I was angry when I went home because I thought why didn't they pick it up? [antenatally]. But then I just thought one day, well it wouldn't have made any difference... we'd have still been here for four months... So I'd have known more about it and I probably wouldn't have enjoyed the pregnancy... (mother 1 T3 MCQ 66)

higher scores equated to higher levels of confidence. There was an increase in mean MCQ from T0 (50, SD 7.86) to T1 (mean 57, SD 6.24) and a decrease in MCQ for some parents at T2 (mean 57, SD 3.81). There was an increase in mean MCQ scores at T3 (mean 60, SD 4.69). A one-way ANOVA indicated a significant difference between scores across the time points ( $p = .005$ ) for mothers. Post-hoc Wilcoxon tests to determine where the differences were indicated that confidence at baseline, T0, was significantly lower than at T1 ( $p = .011$ ), T2 ( $p = .018$ ) and T3 ( $p = .012$ ). There were no significant differences between scores at T1, T2 and T3. Although not significant, there was a trend of increasing confidence scores over time. A one-way ANOVA was not performed for fathers' confidence scores as complete data were only available for two fathers across the four time points.

### **Reflection and looking to the future**

In the accounts at T3 it became evident that emotional learning was taking place, parents could reflect on their feelings and emotions at T0 and recognize how they had moved on; knowing what they did now, they wondered why they had been so fearful about going home for the first time. Parents' accounts at T3 demonstrated positivity more than negativity and a shift in focus toward looking to the future, recognizing that there was still some learning and uncertainties ahead. A process of integration was identified at T3, where parents could assimilate the emotional, experiential, and cognitive learning that had taken place, resulting in the development of knowing and creation of knowledge.

The time frame in achieving this "post liminal," new-normal was different and dynamic for each family, but so was the length of time that they were at home with their fragile infant between the first and second stages of surgery. Whilst there were some similarities identified through the inductive qualitative analysis, the key message was the diversity of each family's experience. They had different ways of coping, different demographics, different family resilience strategies, different support mechanisms and different values and beliefs.

### **Discussion**

The first main finding was that the concept of knowledge construction, resulting in increasing confidence and mastery for these parents, was one building block in the theory of transition from hospital to home. Confidence levels were significantly lower before parents were discharged home with their infant (T0), compared to confidence levels at each of the other three time points. So other building blocks of each parent's multi-faceted transitions needed to be considered due to the various nuances of the parents' experiences (Gaskin, 2018; Gaskin et al., 2021). Thus, whilst the transition related to the *physical* transition from hospital to home, here transition was also identified as a journey through the construction of knowledge from the point of diagnosis and varied depending upon individual parental characteristics, therefore learning was not simply information transfer.

Transmission of the professional's knowledge cannot be assumed as sufficient for parents to fully understand the implications of having an infant with complex CHD (Giordan et al., 1999). Ayra et al. (2013) explored the expectations of parents and cardiologists regarding education and counseling and found that parents would have preferred more than cardiologists perceived them to want. Twaddell (2013) explored parents' information needs in comparison to information given by HCPs during their infant's hospitalization and after their infant's discharge; parents looked for information relating to their infant's changing

needs and condition and wanted consistent information about the condition of their infant in terms they understood. Likewise, Tregay et al. (2016) qualitatively assessed the discharge processes and post-discharge care in the community for infants discharged after CHD surgery in the first year of life. Written documentation from tertiary centers frequently lacked crucial information and contained too many specialist terms, further demonstrating that these parents want consistent and individualized information.

In our study, parents came to the situation with their own ideas and experiences that influenced their knowledge construction (Arya et al., 2013) perhaps reflecting constructivist models of learning. It was not only the scientific concepts impacting on their infant’s survival that parents needed to learn, but they also needed to learn to be parents of an infant with complex CHD and the minutiae that accompanied the responsibility, throughout the multi-faceted transitions that they experienced. The maternal confidence questionnaire (Badr, 2005) focuses on “knowledge, skills, and feelings”, suggesting that the significantly lower confidence levels prior to discharge home (T0) may have related to parents’ lack of knowledge, lack of skills and mixed emotions (feelings) before going home.

For parents in our study, learning was dynamic and transformational; learning opportunities overlapped transitional phases of their infant’s journey, but successful learning and acquisition of knowledge were also dependent upon the parents’ ability to absorb, integrate and adjust at any given time. Feelings about going home referred to their fears (Gaskin et al., 2021) lack of preparation for discharge and concerns about looking after their fragile infant at home on their own, balanced with their excitement about the situational change from the institutionalized hospital environment to the physical and psychological comforts of their own home. We identified a time of “liminality” when parents were moving through a liminal space (Turner, 1967, 1969; Van Gennep, 1960); in contrast, to the “false optimism” discussed by Lee and Rempel (2011). This betwixt and between time enabled the parents to develop, maintain and restore a sense of self and control such that they were ready to face the hurdle of the transition from hospital to home.

Whilst processes of parents moving “from one place to another” had been identified in the models “Parenting Under Pressure” and “Facets of Parenting” (Rempel et al., 2012, 2013) and perhaps as motivational categories (Pridham et al., 2010) none of the extant evidence identified liminality as a concept or as a means of contextualizing the transitional parenting experience. A conceptual framework emerged (Figure 1) called “Parenting

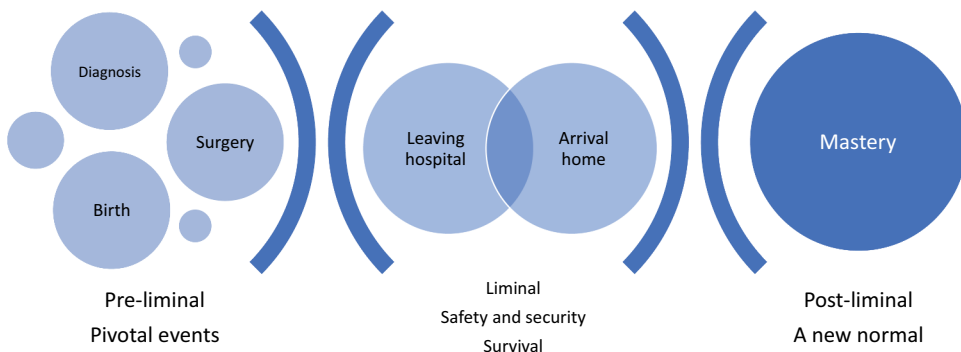


Figure 1. A conceptual framework: Parenting through transitions - hospital to home.

*through Transitions – hospital to home*”, representing a dynamic model of transition, incorporating the concept of liminality and parental experiences of transition through a pre-liminal phase, liminal phase, and post-liminal phase.

Mastery (post liminal phase) also related to “reflection and looking to the future”. Parents’ accounts at T3 demonstrated that the space or distance from their infant’s hospitalization had afforded them the opportunity to undergo a process of rational analysis of their earlier experiences (Jordi, 2011). It was evident that this reflective process was cognitive and included the richness and complexity of their feelings (Gaskin et al., 2021) induced before and during the traumatic events they experienced. Jordi (2011) argues that the individuality of our experiences provides us with tacit knowledge that enables us to have awareness of who we are and that this implicit knowledge also materializes explicitly, resulting in cognitive construction of its meaning becoming evident in language, which reflects the findings here.

Whilst parents learnt cognitively and emotionally from other cardiac parents in hospital, there was a shift in the sources of advice and support that parents utilized over time. External engagement with other cardiac parents and parent support groups increased as the parents became more confident. In addition, the mechanism of obtaining advice and support became more virtual, with parents choosing to communicate with other cardiac parents via online social networking sites. Some parents actively sought electronic resources and Applications that they could utilize to support the constant monitoring of their infant. Online systems are currently being explored as a method of providing support post-discharge alongside an early warning tool for parents to use at home to assess and monitor their infants, called the Congenital Heart Assessment Tool (Gaskin et al., 2022, 2018; Smith et al., 2022).

## Limitations

Telephone interviews were more difficult with some parents in relation to keeping the conversation going. Including only English-speaking parents limited the number of parents that could be approached as well as limiting the nature of experiences identified. Not all parents participated in all four interviews, for a variety of reasons. One parent was very nervous about being “interviewed” before discharge and her interpretation of the word “interview” may have impacted on her lack of participation with the other three interviews. The one-way ANOVA for maternal confidence scores only included those mothers with complete data sets ( $n = 6$ ); as there were only two complete data sets for fathers this precluded further analysis of these scores.

## Conclusion

Parents of infants with complex CHD obtain knowledge, confidence, and mastery dependent upon their transition experience and their personal journey through pre-liminal, liminal, and post-liminal phases of discharge from hospital to home. Parents need to be effectively and individually prepared for the intricacies of being a cardiac parent and to identify signs of clinical deterioration before their infant is discharged. However, for discharge preparation to be successful and consistent, nurses need to have knowledge of learning theories, coaching and guidance skills to effectively teach parents about their infant’s condition and what to look out for.

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