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Parents' experiences of transition from hospital to home after their infant's first stage cardiac surgery: psychological, physical, physiological and financial survival

Abstract (247)

Background: The inter-surgical stage is a critical time for fragile infants with complex congenital heart disease (CHD) but little is known about the impact on parents.

Objective: To explore parents' experiences of the transition from hospital to home with their infant, following stage one cardiac surgery for complex CHD.

Method: A prospective longitudinal mixed methods feasibility study using semi-structured interviews and self-report instruments at four timepoints: before discharge (baseline), 2 weeks post discharge, 8 weeks post discharge and after stage two surgery. Qualitative data were analysed thematically and quantitative data descriptively,

Results: Sixteen parents of 12 infants participated. All parents described signs of acute stress disorder; four parents described symptoms of post-traumatic stress disorder before discharge. Parents' fear and uncertainty about going home was multi-faceted, underpinned by exposure to numerous traumatic events. By 8 weeks post-discharge, parents' feelings and emotions were positive, relieved and relaxed. Mean generalised anxiety and depression scores were higher before discharge; most individual anxiety and depression scores decreased over time. Physiological survival included self-care needs, eating and sleeping properly. Physical survival included preparation of the home environment and home alterations adapting to their infant's equipment needs. Financial survival was a burden, particularly for those unable to return to work.

Conclusion: Patterns of experience in surviving the transition included psychological, physical, physiological and financial factors. Further longitudinal research could test the effectiveness of psychological preparation interventions, whilst encouraging early

consideration of the other factors influencing **parents'** care of their infant following discharge from hospital.

Keywords

Infants

Parents

Cardiac Surgical Procedures

Congenital Heart Disease

Stress Disorders, Traumatic, Acute

Introduction

Every year, approximately 6000 **babies are born with complex, life-threatening congenital heart disease (CHD)** in the US¹. **The incidence of CHD in the UK is 8 per 1000 live births²;** **however, an overall rise in case complexity in relation to low weight (<2.5Kg, p=0.05), functionally univentricular hearts (p<0.01) and higher risk diagnoses (p<0.01) has been identified³.** Those born with functionally univentricular hearts or systemic shunt dependent circulations are at significantly higher risk than any other group of children with CHD³ and will undergo several stages of cardiac surgery. Stage one takes place in the first few days of life, stage two generally between 4-9 months and stage three pre-school, depending on the child's clinical condition; this is a condition **requiring lifelong medical follow up**. The period between the first and second stages of surgery, during the first year of life, is a critical time for these infants³ and this risk persists even after they go home⁴. **Caring for a child with a lifelong condition is associated with ongoing psychological, physical and financial burden for the child and family⁵⁻¹⁴.**

Little evidence exists about parents' psychological functioning at the time of discharge from hospital and during transition to stage two surgery. Some caregivers have reported being relieved about going home and not being anxious before being discharged⁵. Whereas in another study⁶, undertaken one month after the infant's discharge post cardiac surgery, nearly a third of parents experienced trauma symptoms consistent with a diagnosis of Acute Stress Disorder. Three parent recovery profiles from acute and post-traumatic stress have been identified⁷: 'resilient' parents had low distress responses across four time points, from diagnosis to 18 months; 'recovery' parents had significantly higher levels of distress at diagnosis, but these decreased over the first few months and 'chronic' parents were in the clinical range for post-traumatic stress disorder throughout the trajectory⁷. An educational programme prior to a child's first elective cardiac surgery, albeit for low risk surgery, was found to reduce state anxiety in both the fathers and mothers,⁸ perhaps demonstrating the benefit of early intervention.

Financial costs have been identified as a burden by parents of children with CHD in the UK, Germany, Pakistan, Nigeria, USA and China⁹⁻¹⁴. Family finances were affected through cost of transportation to and from hospital, time off work, job changes and loss of income, sibling care costs, medical bills including costs of medicines and disposables and out of pocket medical costs, resulting in some parents borrowing money from family members and friends^{11,14}. Whilst the findings cannot be generalised to the UK due to different healthcare delivery and population demographics, these findings provide global evidence of financial pressures on families of children with CHD.

To address some of the deficits in the evidence base, our aim was to explore parents' experiences of the transition from hospital to home with their infant, following the first stage of cardiac surgery through to stage two^{15,16}. This paper presents one of four emerging 'patterns of experience', described as 'survival', which referred to elements needed by family members to survive or exist during the transition from hospital to home, rather than survival defined in terms of mortality and morbidity. This included their psychological needs (health and

wellbeing; the impact of positive and negative emotions and feelings); their physiological needs (food, water, sleep), their physical needs (housing, home comforts, transport) and their financial needs (money, benefits, employment).

Methodology and Methods

Design and participants

A prospective longitudinal design was used within a mixed methods feasibility study. The principal aim of the feasibility study was to obtain sample size calculations for a future multi-centred randomised controlled trial. The secondary aims included testing the feasibility of a parental early warning tool within a home monitoring programme for infants with functionally univentricular hearts or systemic shunt dependent lesions^{15,16} and exploring parents' experiences of the transition from hospital to home with their infant following first stage cardiac surgery. Ethical approval was granted by the West Midlands - Solihull NRES committee. Parents were eligible for inclusion if their infant was being prepared for discharge following first stage cardiac surgery for complex CHD (functionally univentricular heart or systemic shunt dependent lesion); they could speak and read English and were not involved in another research project. The feasibility study was conducted over a 15-month period at a specialist children's cardiac centre in the United Kingdom. Heart Research UK funded the equipment (digital scales and pulse oximeters) and a research nurse (RN) (0.6 full time equivalent) to manage the day to day running of the feasibility study.

Interviews

The Middle Range Transition Theory¹⁷ informed design of the interview schedule (table 1) to explore the type, patterns and properties of the parents' transitions, identifying processes that moved them towards health or vulnerability and risk. Indicators of the outcome of the parents'

transition were explored through mastery of new skills and changeable or reformed identities¹⁷. Interviews were conducted at four timepoints: before discharge (T0), 2 weeks post discharge (T1), 8 weeks post discharge (T2) and **before discharge from hospital** after stage 2 surgery (T3). Parents were offered the opportunity to be interviewed separately or together.

Two interviews (T0) were conducted by the RN, due to earlier than expected discharge of the infants. The principal investigator (PI) was based at the University over 30 miles away and unable to get to the hospital in time. After the first two interviews (one conducted each by the PI and RN), key issues arising were the use of closed questions and the RN deviating from the interviewer role to an information giver and counsellor role. An example question list was developed to avoid closed questions but allowing sequencing flexibility and deeper probing. The interviewer role was reiterated, **and** parents were directed to the participant information leaflet for available support services. The RN undertook one further interview at T0, all interviews at T1, T2, T3 were undertaken by the PI.

The interviews were audio-recorded with parents' consent and transcribed verbatim; reflective field notes were kept throughout the study.

The Instruments:

Parent and infant demographic data (table 2) were collected at baseline (T0) from medical and nursing records. Parents were asked to complete self-report instruments at each interview, both chosen because they have been successfully used to assess psychological burden on parents of children with chronic illness¹⁸⁻²⁰: the Generalised Anxiety Disorder (GAD7)²¹ **comprising** 7 questions to measure severity of generalised anxiety disorder, assessing symptom severity and monitoring change over time and the Patient Health Questionnaire (PHQ-9)²² **comprising** 9 items representing the criteria upon which the DSM-IV depressive disorders are based and used to make a tentative diagnosis of depression in at-risk

populations. GAD7 scores of 5-9 indicate mild anxiety, 10-14 moderate anxiety and 15-21 severe anxiety. PHQ9 scores can range from 0 –27, with scores of 0-4 indicating no depression, 5–9 mild depression, 10 –14 moderate depression, 15–19 moderately severe depression and >20 severe depression

Data analysis:

A six-phased approach to thematic analysis²³ was used for the qualitative data: familiarisation 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. Descriptive statistics were used to characterize the sample. The sample size was too small for further statistical analysis.

Quality/trustworthiness:

Strategies to address potential validity issues in data collection, data analysis and interpretation of mixed methods studies²⁴ and criteria for addressing trustworthiness²⁵ within the qualitative methods were used, including: utilising appropriate and recognised research methods; triangulation; de-briefing sessions with the research team, keeping a reflective diary and recognising researcher positionality (table 3).

Results

Forty-seven families met the inclusion criteria of whom 13 were recruited into the study, however only parents of 12 infants (n=12 mothers; n=4 fathers) participated. Exclusions were due to parent refusal or withdrawal due to feeling overwhelmed (n=15) or could not be accessed by the research team at timing of discharge (n=19). Some parents did not complete all four interviews due to readmissions to hospital or not being contactable (table 4). The time from first to second stage surgery varied from 32-251 days (mean 140; SD 66.6) due to the

severity of the infants' CHD and deterioration in clinical condition. There was diversity within the sample in terms of mothers' age (fathers' age was not obtained), parity, distance from home to the specialist surgical centre, postcode deprivation index (indicates those living in most deprived areas of the country²⁶), employment status and education (see table 2). Three quarters of mothers were White Caucasian (n=10, 83.3%); most were living with their partner (n=11, 91.7%) and were either a homemaker or taking maternity leave (n= 11, 91.7%).

Interviews:

Four 'patterns of experience' emerged from mixed methods analysis of the interview and self-report questionnaire data. These were: safety and security; love and support¹⁵; survival; and mastery (unpublished). The 'Survival' pattern of experience is presented in this paper; the qualitative data will be used to structure the presentation of findings with descriptive statistics presented concurrently.

Survival

Psychological needs

Parents' *health and wellbeing* was associated with the impact of negative and positive emotions and feelings. Parents' levels of anxiety (GAD7) and depression (PHQ9) at the four interview time points are presented alongside their quotes below. Mean parental anxiety (GAD7) scores were higher before discharge (T0) (mean 7.8; SD 5.9) compared to the mean GAD7 scores at T1 (mean 4.3; SD 4.6), T2 (mean 4.9; SD 5.1) and after their infant's stage two surgery (T3) (mean 3.1; SD 3.7). However, there was a slight rise in the mean at T2 (8 weeks after discharge); whereas at T3, after stage 2 surgery, it was lower. Furthermore, mean parental depression scores (PHQ9) were also higher before discharge from hospital (T0) (mean 10.2; SD 6), than at each of the following measurement time points T1 (mean 3.2; SD 4.2), T2 (mean 6.3; SD 5.8) and T3 (mean 3.6; SD 4.5); PHQ9 scores also increased at T2 before dropping again at T3.

At the first pre-discharge interview (T0), **all** parents described mixed emotions about going home, including fear and uncertainty, whilst also describing their ‘happiness and excitement’ about going home (Box 1)

Box 1

‘I’m happy because I want to take her home and be normal, but then I’m scared because if anything happens to her, then it’s just me to deal with it so’ (mother 5, T0, mild anxiety and moderately severe depression)

‘I’m excited, but I’m a little bit nervous, I think just generally because it’s my first baby and stuff like that. Obviously because of his heart problem as well, but no, I don’t feel like really really nervous’ (mother 9, T0, no anxiety or depression).

Whilst the study aimed to explore the period of transition from hospital to home, for some parents the emotions experienced during exposure to traumatic events from the point of diagnosis, birth, surgery and the ‘rollercoaster’ post-operative recovery could not be separated from how they were feeling about going home for the first time (Box 2).

Box 2

For example, when asked how he felt about going home one father said: *‘I can’t express, it’s good place, feels good, I can’t wait...I’ve got kids outside of our relationship and I’ve never had any of them like this, so for me it’s a learning process. It also makes you bow on the appreciative side of life, it’s actually taught me a lot of things, I’ve cried a lot, I’ve looked at other people I feel like crying now’.* (Father **C, T0, no anxiety, moderate depression**)

At this point he burst into tears, and the interview was paused. The emotional experiences of the past few weeks were still raw.

Parents also described self-directed emotions including guilt and self-blame, and fear of losing their infant (Box 3).

Box 3

"I've got time to myself to be constantly thinking about what did I do wrong, what did I do wrong in my pregnancy. I took all the vitamins, I ate healthy, I did exercise and everything to the book with this pregnancy and ... I was just ... I was crushed ... I think that's what it was" (mother 1, T0, mild anxiety and depression).

"It was awful, it was like I'd given birth to a baby and given her away [pause] but we knew it was for the right reasons, I'd rather do that, than her be in my arms and then I've lost her" (mother 10, T0, moderate anxiety, mild depression).

Some parents used the words 'painful', 'shocking', 'helpless', 'scared', 'fear', 'worried', 'not prepared'. Four parents described their 'shock' and 'devastation', and for these parents there was evidence of detachment and dissociation, parenting from afar and the trauma of lasting images arising from the intensive care period (Box 4).

Box 4

"I think I sat for 24 hrs. with him downstairs in intensive care and the images ... won't leave my head ... and that's what's like torture, that is" (mother 3, T0, mild anxiety and moderate depression).

"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, no anxiety or depression).

By the time that the infants had undergone stage 2 surgery parents generally described their feeling and emotions as positive, relieved and relaxed (Box 5).

Box 5

'I'm absolutely, much more comfortable, much more relaxed and all in, all settled and hopefully the next few weeks I'll be putting her into her own room as well. So, I'm definitely feeling much more relaxed and then some days to be honest you do kind of forget that there's a serious heart problem there because you don't really notice it' (Mother 7, T3, no anxiety or depression).

Parents reflected on their earlier worries about the first discharge and how their stress had reduced, *'when you get home and get used to it, you don't get scared again; you get yourself routine into things, enjoying the little, nice cuddles at home it feels great' (Mother 6, T3, mild anxiety no depression).*

Physical and physiological needs

Physical and physiological needs are explored together as they are closely interrelated. Parents' physiological needs were affected during the hospitalization due in part to constraints of living in the hospital environment, as well as their concerns for their infant's physiological survival, resulting in a lack of sleep and not eating properly (Box 6).

Box 6

"... I was swaying side to side and I couldn't focus on anything ... [because] I was just... I was just really feeling really poorly myself ... but in that situation you kind of think, no ... forget me, your baby's like ...severely poorly, I'm sitting here and [I'm not] moving and then as I say I ended up on the floor and ...I was dehydrated and everything, so ... you know I've been giving other moms advice you know, drink plenty eat your food, [because] you're no good if you end up on the floor" (mother 1, T0, borderline moderate anxiety, mild depression).

On reflection, this mother (Box 6) recognised that her physiological needs were important during the stressful events immediately after the infant's birth.

One father recognised a link between returning to work and a decline in his health and wellbeing and an increase in anxiety. One of his colleagues has severe CHD and was empathetic and supportive regarding the situation. Survival for this father related to recognising the need to look after himself physically, physiologically and psychologically (Box 7).

Box 7

“for me to actually make the decision that I needed to have some more time off ... well not just my health but it’s (baby’s) health as well because with her feeding regime, [it] effectively runs through the night, [it] started to get to the point where I was sleeping through alarms and obviously, I can’t let that slip” (father D, T2, no anxiety).

Some parents described a longing for their physical ‘*home comforts*’. There was also evidence of ‘nesting’ as mothers described preparing the home for discharge; however, very few physical changes were made at this stage to the home environment, other than cleaning, heating and organizing the space. Physical home comforts ‘*it’s just nice to be back in your own bed*’ (Mother 7, T1, no anxiety or depression) and ‘*we got to be in our own bed*’ (Father A, T2, no anxiety or depression), ‘*being able to make a cup of tea*’, ‘*not having to share a shower*’ facilitated an improvement in physiological functioning over time. Conversely, adjusting to changes to the physical environment of the home, due to the amount of equipment required, was challenging for some (Box 8).

Box 8

‘my homeward delivery (laughing) 929 items and yeah, so we’ve kind of moved some stuff about and, yeah, we’ve got it in, and it’s hidden away from the children’ (Mother 1, T3, no anxiety or depression).

Another father (B at T3, moderate anxiety and depression) said: *'we've just got used to all the stuff, it's there, it's part of life you know, we go into the hallway, you've got like a crate of...'* whilst his partner said: *'no that's you, I'm not used to that, I want it removed [laughs] and every time I remove it something replaces it [laughs]'*.

Adjusting to going home also focused on the 'normal' physiological needs of their infants *"I'm trying to keep being a normal mom the same you know, cuddles, lots of cuddles and just doing normal baby things with him, with bath time and routine and things like that"* (mother 1, T1, borderline moderate anxiety and mild depression)

Some parents with other children felt that parenting was no different to before: *"There's no difference really for me, just her medication 'cos at the end of the day she's just another little baby"* (father B, T1, mild anxiety and depression) The mother reaffirmed the perceived 'normality' *"She still does baby stuff doesn't she ... you couldn't really tell, unless you saw her ... saw the scar, I don't think you'd know any different would you really"* (mother 3, T1, no anxiety, mild depression).

Another parent explained how looking after her baby's 'normal' physiological needs was relaxing for them both (Box 9).

Box 9

"I'm sort of letting her dictate to me when she's ...hungry, when she wants to play and when she wants to sleep, and I think it's not only made her more relaxed and get on with things, it's also helped me out as well. I think at the end of the day I've come home and gone right we'll just treat her as we would have done with any normal baby or any normal child. You know she's still got the same sort of needs, still needs to be fed, changed, cuddled and everything like that so ... it's kind of been a case of we'll respond to what she wants, she'll tell us when she's tired, she'll tell us when she's hungry or whatever else, so we're letting her pretty much

tell us what she wants and when, so it's been quite relaxed in that respect" (mother 6, T1, mild anxiety, no depression).

Whilst normal parenting to meet their infant's physiological needs was important, enhanced cautiousness regarding infection was evident; the home and siblings' hands were 'kept clean'; associated with vigilance, health and wellbeing in the home environment. Improvement in physical and physiological 'survival' was evident over time, through establishing routines to meet the family's physiological needs, balanced with housekeeping and managing the family's finances.

Financial needs

There was variation in the significance of finances in relation to day to day needs whilst their infant was hospitalized, and this linked in some cases with the impact on parents' employment, but also the cost of travelling: *'maybe [spent] a bit more in petrol and things like that because of travelling to the hospitals and stuff'* (mother 3, T3, no anxiety or depression). Financial impact also related to household bills: *'keeping the house warm as well and, especially now, the winter's coming. You know, I can put £50, £60 in the gas alone, but it'll need to be done [because] the likes of [baby's name] and, so yeah, it is going to be financially difficult'* (mother 1, T3, no anxiety or depression).

Several fathers returned to work having fully exhausted their holiday entitlement, whereas others were 'signed off sick' to provide support at home. For some, sick leave was fully paid: *"his work has actually been really, really, considerate. They've allowed him time off without taking money from him, so that he can attend all of the hospital appointments that we had. So, his work have been really considerate"* (mother 2, T1 severe anxiety and depression); whilst others received nothing, impacting on their financial survival and adding further to their stress: *"They were [paying him] until July and then it all stopped so we have had a struggle, a big struggle. I'm not, [I ain't] going to lie, it has been really hard"* (mother 1, T3, no anxiety or

depression). Some parents noted the importance of associated benefits they received as well as help from their family: “we get a disability living allowance for [infant] plus her benefits so, it doesn't cost any more than a normal baby would” (mother 3, T3, no anxiety or depression); “but our parents give us money if we need it so we're lucky there” (father B, T3 mild anxiety and depression). One mother lived alone and had envisaged being able to continue managing her business once home, but at T2 described the significant negative financial impact of not being able to work and the resultant additional stress of handling bailiffs (Box 10)

Box 10

“I was working like 80 hours a week on the business, now I'm not able to do anything pretty much, obviously because when he's up he needs constant attention. Now the business isn't doing very well and that's having an impact on the housing benefit, I was paying myself £50 a week but because the sales aren't coming in. I can't pay myself anything anymore. They're going through my claim with a very fine-toothed comb, because I said I haven't been paid since September; my housing association is now seeking a warrant for possession...I've had bailiffs on my door last week for council tax, they tried to seize my car” (Mother 8, T2, mild anxiety, moderate depression).

Discussion

At the time of discharge, a pattern of experience emerged that related to psychological, physical, physiological and financial ‘survival’. Parents’ experiences started at the point of diagnosis of CHD for their infant; these underpinned their feelings about going home, resulting in a multi-faceted transition from hospital to home^{15,16}. Social constructs facilitating or inhibiting their transition included parity (new parents versus parents with other children); the family's personal situations (home and support); and socioeconomic status (postcode deprivation). However, there was no independent demographic that functioned across all social processes within the transition¹⁵.

From a psychological perspective, health and wellbeing were linked to the impact of positive and negative emotions layered from a range of traumatic experiences relating to their infant. All parents described mixed emotions, from 'fear and uncertainty' to 'excitement and happiness' about going home. Uncertainty has been associated with parental psychological distress, measured by anxiety, depression and helplessness²⁷ as well as post-traumatic stress disorder (PTSD)²⁸. Fear is an essential component of the response to an over-whelming life-threatening event²⁹; and this fear response was evident in all parents' accounts of their experiences, especially when they described the time of receiving their infant's diagnosis, birth and first stage of cardiac surgery. Over time, from stage 1 to stage 2 surgery, emotions described by parents became more positive, as they relaxed looking after their infant. The quantitative findings reflect the qualitative descriptions, with mean GAD7 and PHQ9 scores being higher before discharge (T0) for both mothers and fathers, compared to the mean GAD7 and PHQ9 scores once they were back at home (T1, T2) and after their infant's stage two surgery (T3).

Four parents (mothers 1, 10, 11; father B) in this study described experiences (at T0) that demonstrated signs of post-traumatic stress disorder: anxiety, depression, agitation, shock, helplessness, detachment and dissociation³⁰. However, by T3 two of these mothers had no anxiety/depression; the third was not contactable. Consistent with other studies^{7,31} a 'chronic' group of parents (25%) remained in the clinical range of symptoms suggestive of post-traumatic stress disorder across the timepoints for GAD7 and PHQ9; two parents (2, B) across T0-T3 and two parents (5, 8) across T0-T2 (parent 8 was not contactable at T3). Being given a diagnosis of a life-threatening illness for your child has been identified as a cause of post-traumatic stress disorder (PTSD)^{32,28} but not everyone experiencing a fear response will develop PTSD²⁸. These acute stress symptoms are also consistent with the findings of Franich-Ray et al (2013)⁶ who found that approximately one-third of parents who completed the Acute Stress Disorder Scale one month after their infant had been discharged from

hospital following cardiac surgery experienced trauma symptoms consistent with a diagnosis of acute stress disorder. Early responses (anxiety, depression, agitation, shock, and conversion and dissociation) are considered socially acceptable and expected given the severity of the situation but should communicate a need for help³⁰.

Parents in this study scoring high on GAD7 (>10) or PHQ9 (>10) were given support by the specialist cardiac nursing team and with consent, their General Practitioner was contacted and informed of their elevated scores. One of the mothers refused for her General Practitioner to be informed, as she was worried about being labelled in the community as an 'anxious mother'. In other studies, mothers receiving person-centred and family centred care³³ and pre-operative educational interventions⁸ felt more supported and were more likely to adapt to the stress of parenting a child with CHD.

Whilst the aim of this study was not to specifically identify parents at risk of PTSD, the findings indicate a need for health care practitioners to recognise potential predictors of parental PTSD early, so that appropriate support can be offered for both parents. Support would assist parents to modulate their responses and assist in adaptive processes where there is a high risk of psychological maladaptation. Numerous other studies have also identified the need for early interventions^{4,5,7,34}. Helfricht et al (2008)³⁵ found that acute symptoms of PTSD shortly after discharge, in parents of children aged 0-16 years undergoing cardiopulmonary bypass, were a major risk factor for the development of chronic PTSD; their recommendations reflect the implications for practice recommended here.

In addition to psychological health and wellbeing, staying in hospital with their infant negatively impacted some parents' physiological health (food, sleep), with some parents recognising that they did not look after their own health due to concerns for their infant. Despite decades of focus on family centred care³⁶ and recognition of the importance of looking after the welfare of parents so that they can look after their children, including enabling rest in a home-from-home environment, there are few available studies exploring the physiological impact of being

in hospital with a child³⁷⁻³⁹. Type of support and accommodation are based on the hospital, parent and child factors; however, varying relationships between accommodation type and patient experience have been identified in the USA and Canada⁴⁰⁻⁴². In Denmark, families that stayed in a hospital family house described it as a *safe haven* and a place to breathe freely, where the whole family could be together⁴³. In our study, it was mostly only one parent who stayed with their infant, impacting on everyday life, dividing the family and influencing togetherness. Unsurprisingly, parents' happiness about going home included looking forward to their home comforts, sleeping in their own bed and returning to or developing family togetherness¹⁵.

Another key finding was the importance of the physical impact of going home with an infant following first stage cardiac surgery. All parents described preparing their home environment for discharge. For some, this related to what might be considered normal 'nesting' and preparation for going home with a new baby. But for other parents, particularly those going home with digital scales, pulse oximeters and the consumables required for medications and feeding, the space taken up by equipment and the implications of medicalizing their home environment, physically, psychologically and aesthetically, was noteworthy. In the longer term there were costs involved with either alterations of the home environment to create extra space or consideration of moving to a bigger property to cope with the extra equipment. The financial impact of going home with their infant following complex cardiac surgery was described by some parents **and included** increased household costs and travel costs balanced against a loss of earnings. These findings reflect those of other global studies that identified acute economic burdens of care, with high 'out of pocket' expenses affecting parents' finances and emotions⁹⁻¹⁴.

There are implications of these findings for practice, in relation to supporting parents⁴⁴ early in the pathway to recognise their own physiological, physical and financial needs before their infant is born and admitted to hospital for surgery, which is difficult for those who receive a postnatal diagnosis. Parents need to be informed of additional costs related to being in

hospital, the potential impact on employment and family functioning. Cardiac clinical nurse specialists and family support workers are best placed to support parents, alongside parent support groups⁴⁵. Ward nurses can learn about the family's individual needs through family centred care, to provide appropriate advice and support prior to discharge home.

Limitations

The feasibility study had a small sample; therefore, inferential statistical analysis of the quantitative data was not appropriate. The infants' clinical course could not be directly compared, as time from first to second stage surgery varied from 32-251 days (mean 140; SD 66.6); reflecting the varying severity of the infants' CHD, changing clinical condition and need for stage two surgery. Whilst self-report measures are potentially a limitation, the data were analysed alongside qualitative data. Finally, some parents refused to participate because they felt unable to take part due to being overwhelmed by their situation. These parents may have had higher anxiety and depression scores, potentially needing additional psychological support, but also meaning that our findings may not be representative of this complex population.

Conclusions and implications

This feasibility study was the first to explore parents' experiences longitudinally, following discharge of their infant after stage 1 cardiac surgery until stage 2 surgery for complex CHD. The results of this study confirm that parents experienced intense and mixed emotions prior to their infants' discharge home, portraying the turbulence of the pre-transition condition and a liminal space which included feeling 'numbness', 'disconnected from life' and feeling 'too distressed and emotional to really listen'.

Some parents adapted to their transition over time; adaptation was demonstrated through an overall reduction in mean anxiety and depression scores. However, individual scores provided

a different picture and suggested that maladaptation had occurred for some parents. The reported levels of fear experienced by parents at the point of discharge (T0) was evident for all parents in the study and therefore it is fair to conclude that all parents were worried about going home despite their individual situations. Parents also found living in the hospital environment impacted on their physiological health and wellbeing and their financial 'survival', creating additional stress at an already difficult time.

Nurses are best placed to assess parents' psychosocial functioning, explore family resilience and factors that may impact upon them whilst they are resident in the hospital environment, and on their adjustment and adaptation at home during the inter-stage period⁴⁴⁻⁴⁶. Nurses can educate parents⁴⁴⁻⁴⁵ more comprehensively in preparation for discharge and provide supportive patient and family centred care using a therapeutic communication style. Furthermore, nurses can facilitate referral of parents with clinical levels of anxiety for psychosocial support. The results of this study can guide further development of models of assessment to initiate more focused parent support in the cardiac ward setting and during the liminal space in between preparation for discharge and going home between the first and second stages of surgery.

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What's New

- Parents' psychological health and wellbeing were linked to the impact of mixed emotions, layered from a range of traumatic experiences relating to their infant
- Staying in hospital with their infant can negatively impact parents' physical and physiological health
- Physical, physiological and financial factors can influence family resilience, adjustment and adaptation to going home with their fragile infant

