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Diagnosis to death: family experiences of paediatric heart disease

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Abstract

CHD remains one of the leading causes of mortality of children in the United States. There is limited research about the experience of parents from the diagnosis of their child with CHD through the death of their child. A prior study has shown that adults with heart failure go through a series of four transitions: 1) learning the diagnosis, 2) reframing the new normal, 3) taking control of the illness, and 4) understanding death is inevitable. In our qualitative study, we performed semi-structured interviews with parents who have a child die of CHD to determine whether the four transitions in adults apply to parents of children with CHD. We found that these four transitions were present in the parents we interviewed and that there were two novel transitions, one that proceeded the first Jones et al transition ("Prenatal diagnosis") and one that occurred after the final Jones et al transition ("Adjustment after death"). It is our hope that identification of these six transitions will help better support families of children with CHD.

Introduction

CHD is the most common birth defect in the United States.[1] Treatment for CHD has seen dramatic advances in the past six decades. Children with simple heart defects can hope to live a long life and many children with more severe complex heart defects are living into adulthood.[2] Despite these advances, CHD remains one of the leading causes of death in infants in the United States.[3,4] Because the clinical course following the diagnosis of paediatric CHD is highly variable, some families have only hours with their child while others have years. While the majority of children who die from CHD still die in infancy, recent studies have shown increasing age at death as more palliated infants are surviving longer.[2] Most childhood deaths from heart disease occur in ICUs following discontinuation of life-sustaining treatments after a prolonged hospitalisation, often involving multi-organ failure and mechanical circulatory support.[5] Astonishingly, one study of bereaved parents whose children with CHD died following prolonged ICU stays demonstrated that almost half of the parents did not consider death as a possible outcome for their child and that most parents did not realise their child had a high likelihood of dying until two or fewer days before death.[6] This shortened preparation time has been shown to increase the risk of long-term depression in parents.[7]

Little research has examined the experiences of parents between the time of their child's initial diagnosis to death, leaving gaps in our understanding of how we can communicate with and support families most effectively as early as possible about the risk or likelihood of death. Existing data from adults with heart failure suggest that patients and families experience four common psychological, emotional, and cognitive transitions after a life-limiting cardiac diagnosis: 1) learning the diagnosis, 2) reframing the new normal, 3) taking control of the illness, and 4) understanding death is inevitable.[8] Patients and families were particularly vulnerable as they moved between transition periods, and serious medical discussions and decisions were overwhelming during those times. Unfortunately, these periods often coincided with clinical decompensations and clinician efforts to address goals of care.[8] This work offers important guideposts for adapting clinicians' counselling so that can map more clearly onto the stages of coping that characterise patient and family experiences.

The objective of this study was to expand our understanding of the family experience of CHD from the time of diagnosis to death. We sought to determine whether the four transitions, as

Table 1. Participant characteristics

	Child age at death	Prenatal versus Postnatal diagnosis	Length of terminal hospital stay	Type of heart disease	Prior surgeries in terminal hospital stay	Ventilated at death	ECLS at death	Dialysis at death	Neurological injury	End of life
1	< 1 month	Post	1–2 months	Single-ventricle physiology	Three	Yes	Yes	Yes	No	Discontinuation of life-sustaining therapy
2	> 2 years	Post	1–2 months	Cardiomyopathy	Two	Yes	Yes	Yes	No	Death on ECLS without resuscitation
3	< 1 month	Pre	< 1 week	Single-ventricle physiology	None	Yes	No	No	No	Failed active resuscitation
4	6–12 months	Post	< 1 week	Cyanotic biventricular	None	Yes	No	No	No	Failed active resuscitation
5	6–12 months	Pre	1–4 weeks	Single-ventricle physiology	One	Yes	Yes	Yes	Yes	Discontinuation of life-sustaining therapy
6	< 1 month	Pre	< 1 week	Single-ventricle physiology	None	Yes	No	No	No	Discontinuation of life-sustaining therapy
7	1–6 months	Pre	1–2 months	Single-ventricle physiology	One	Yes	Yes	Yes	Yes	Failed active resuscitation
8	> 2 years	Pre	< 1 week	Single-ventricle physiology	One	Yes	No	No	Yes	Discontinuation of life-sustaining therapy
9	< 1 month	Pre	< 1 week	Single-ventricle physiology	None	Yes	No	No	No	Comfort care with treatment limitations
10	1–6 months	Pre	1–2 months	Cardiomyopathy	None	Yes	No	No	Yes	Discontinuation of life-sustaining therapy

ECLS = extracorporeal life support.

described by Jones et al in adult patients and families, apply to families of children. This will allow us to develop and test targeted ways to better support these families.

Methods

We recruited parents of children who died from CHD between the years 2010 and 2017 at two academic children's hospitals. Eligible families received study information by mail, and interested parents contacted the study team and provided written consent. Institutional Review Board approval was obtained from one site and a collaborative agreement was obtained from the second site.

Participants completed a semi-structured telephone interview. Interview questions targeted the domains of quality of life, coping, hopes, worries, family supports, decision-making, and communication with the medical team. Because the work of Jones et al. suggests that transition periods are vulnerable time points for decision-making, we specifically asked about the times surrounding learning the diagnosis, life-changing moments, end-of-life period, and after their child's death.[8]

We also reviewed children's charts for information about the terminal hospital stay.

Conventional content analysis was performed.[9] Two authors individually assigned codes to a subset of transcripts, then jointly reviewed and grouped codes into code families. Similar code families were combined into themes. We specifically coded our a priori themes of the transitions as described by Jones et al. Representative quotations illustrate key themes.

Results

One hundred fifty-three letters were mailed to parents of children who died from CHD. Twenty-four parents contacted the study team for more information. Ten parents completed a full interview. Of these, nine interviews were audio-recorded; one interview was not recorded per parent request and parent answers were captured by handwritten notes. Interviews occurred between 6 months and 7 years after their child's death. Table 1 describes characteristics of the children. Ages of the parents ranged from 29 to 46 years. Seven parents identified as White. The highest level of education for the parents interviewed were one high school graduate, five college graduates, two masters' degrees, and two doctorates.

The four transitions experienced by adults with critical heart disease as identified by Jones[8] were found to be present for the parents we interviewed. In addition, we identified two novel distinct transitions unique to paediatric CHD, one that proceeded the first Jones et al transition ("Prenatal diagnosis") and one that occurred after the final Jones et al transition ("Adjustment after death"). These transitions were not identified a priori but were spontaneously described by the majority of families. Unlike the linear progression through the transitions as described by Jones et al in adult patients and families,[8] we found that parents experienced "Finding A New Normal" and "Taking Control" more than once. Parents often re-entered these transitions after significant medical events, after realising that their child's death was likely and even after the child's death.

Table 2 demonstrates parent's experiences that were characteristic of each transition, with related potential strategies for clinicians to support parents.

Transition 1. Learning the diagnosis prenatally

Eight of our 10 parents received the diagnosis of CHD in the prenatal period. Parents reported this as an experience of balancing both maternal and fetal concerns. Some parents reported difficulty reconciling their clinician's pessimism about the diagnosis with the joy they previously had about the pregnancy. One mother felt like a

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Table 2. Strategies for clinicians to support parent's experience during the six transitions

Transition	Parent's experience	Proposed strategies
1. Learning the diagnosis prenatally	• Overwhelming • A process, not a single moment • Hard to get "bigger picture" given uncertainty prior to birth • Given uncertainty, hope, and joy during pregnancy is important	• Allow adequate and recurrent times to discuss diagnosis • Continuously re-evaluate parents' understanding • Palliative medicine integration for "big picture" discussions and psychosocial supports when likelihood of poor outcome.
2. Learning the postnatal diagnosis	• For those with prenatal diagnosis learning the diagnosis happens again after birth • For postnatal diagnosis, it is a blur	• Expect that even parents with prenatal counselling may have new confusions about diagnosis • Continuity doctor helpful to build on understanding of diagnosis over time
3. New normal	• Parent/family identity • Living with uncertainty • Changing with child's medical condition	• Expect parent anxiety about their evolving parent role • Ask parents how they are adjusting to the changes in their life • Validate that living with uncertainty is very hard • Re-evaluate child and families' new normal as medical condition changes • Utilising palliative medicine for families having a hard time with uncertainty
4. Taking control	• Specific plans/roles in the child's medical care • Hope	• Recognize parental preferred coping mechanisms • Suggest use of QPL to organise conversations with medical team • Support parents hope while discussing realistic expectations • Utilising palliative medicine for families who feel overwhelmed or helpless
5. Learning death is likely	• Variable realisation, if realisation at all • Parents thinking they alone made decision to discontinue life-sustaining therapies	• Early palliative medicine involvement • Shared decision-making to unburden parents
6. After death	• Guilt • Legacy/meaning making	• Anticipatory guidance • Bereavement support • Legacy opportunities in family advocacy, family support, education, and research opportunities

QPL = question prompt list.

"guinea pig" due to intensive fetal monitoring and testing. Some parents were distressed that diagnostic uncertainty could not be resolved until after birth.

> Parent 7: "I first received the fact that he had a heart defect at my 20 week ultrasound. It kind of put a stop to everything that day."
> Parent 9: "The [diagnosis] was scary. It was overwhelming, lots of uncertainty, his diagnosis came before he was born so we still had about five months of anticipation . . . .It was still very much a great unknown we were heading in to."
> Parent 5: "They told us from the beginning that it might be really bad or it might be really OK but it was really hard to tell because she was so tiny, until she came out how bad it was and then they would make a plan after that."
> Parent 1: "I felt like they didn't really explain a lot. It was more of them just doing a lot of tests."

Transition 2. Learning the postnatal diagnosis

For families who learned the diagnosis prenatally, the birth of their child then triggered a second stage of "learning the diagnosis." For parents who did not have a prenatal diagnosis, this was their entry into the transition "learning the diagnosis."

Two families with no prenatal warning were traumatised by the neonatal diagnosis, which often occurred quickly (e.g., one mother was still in the delivery room). This was a chaotic and frightening contrast to what they had expected for their birth experience. Parents were overwhelmed, and again this involved a balance of maternal and infant concerns as women were still recovering from delivery.

Three infants died before they were 1 week old. For these parents, "learning the diagnosis" occurred simultaneously with "realizing that death was likely." For neonates who died soon after birth, mothers struggled to balance their own post-partum recovery with trying to spend every minute possible with their infant. Mothers grieved the physical separation that occurred in the neonatal period.

> Parent 4: "They took me to [cesarean section] and I guess it was a pediatric cardiologist came in and said, 'We think there is something wrong with her heart," and then everything got very blurry from then"
> Parent 4: "She started to decline and they made the choice to put her on ECMO very quickly and in fact it was so quick they had to call for consent they couldn't even get us to sign anything. That was the second day . . . It all kind of runs together."

Transition 3. Finding a new normal

Parental attempts to cope with their child's illness by creating a "new normal" evolved throughout their child's life, particularly after any significant event.

Fetal diagnosis sometimes altered the mother's self-identity, as she became a "high risk pregnancy." Women had to adapt to intensive maternal and fetal monitoring and prepare for a highly medicalised birth that may occur far from home and family. The uncertainty about their child's diagnosis and prognosis undermined planning for life with a new baby. Pre-diagnosis plans, for example, to buy a new house for the expanding family, met with the possibility that the infant might not come home. There were also families who became more mindful of their pregnancy to enjoy every minute with their child even before birth.

Most parents describe finding a "new normal" pregnancy after adjusting to the prenatal diagnosis. Most parents described imagining and hoping for the best life possible for their unborn child given the limitations of heart disease.

> Parent 7: "We were already getting geared for what kind of things we could expose him to, piano lessons, or . . . Whatever we could throw his way to help him live it to the fullest."

After birth, the "new normal" was informed by a definitive diagnosis and more prognostic certainty. For parents whose newborns remained critically ill until death, parents reported their values regarding an "acceptable quality of life" evolved as they

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witnessed their infant's pain, sedation, unconsciousness, or neurologic injury.

For children who survived the neonatal period, the "new normal" included repeated and prolonged hospitalisations and escalating complications. Two families perceived their children as vulnerable and avoided events and experiences that might trigger desaturations and decompensations.

> Parent 0: "But as a parent you can only hope, you have to plan, you have to think long term. You can't live on that knife's edge."
> Parent 4: "I remember I guess coming home from the hospital one day and in my head I was simultaneously planning a welcome home party for her and her funeral."
> Parent 8: "I just wanted him to just be as healthy as possible. I mean, I didn't try to treat him any differently as far as doing things. I mean, we could . . . We traveled. We went to different places. We went camping."
> Parent 8: "He was always playing and talking. He would go up and give strangers a hug and . . . I think he really enjoyed himself. He really liked school, being outside. I have this picture of him when it snowed, really snowed for the first time. And he saw it and he wanted to go outside. He was just in a T-shirt and his underpants."

Transition 4. Taking control

Similar to creating a "new normal," parents often coped with their child's illness by asserting control. This experience also evolved throughout their course of their child's life and often changed most dramatically after significant events.

Parents asserted control following the diagnosis in several ways. Pregnant women made choices about bed rest or work, developing priorities about protecting the pregnancy versus preserving family routines and life. Some made formal birth plans to control the delivery experience, especially if neonatal death was a possibility. Several chose to avoid any end-of-life planning and the uncertainty of the diagnosis, hoping the fetal diagnosis was not as severe as the doctors thought or imagining a different but still high quality of life for their child.

After birth, families became "hospital parents," which meant being physically present whenever possible, providing the infant comfort and companionship, consuming all information about their infant's progress, and participating in medical decisions. "Hospital parents" also took control by "living in the moment," both to manage anxiety about the future and to cherish potentially limited time with their infant. Parents remember holding, bathing, and reading to their infant as essential activities within their control.

All parents described engaging with the medical team to support their child's care as a form of taking control. Different types of engagement ranged from helping to interpret their child's discomfort/ pain, advocating for additional treatment options, or requesting family meetings.

Finally, parents chose to remain hopeful for their child, regardless of clinician predictions. Parents hoped for disproved diagnoses, better-than-expected treatment responses, or novel future therapies (eg. "3-D organs").

> Parent 0: "Not quite lower your expectations but really picking your priorities. So our hope then was just that we wanted him to laugh and smile. Because if he can do that, that would be warm to our hearts."
> Parent 4: "I guess it became less about her future down the road and just let's get through the next day, let's get through the next day."
> Parent 2: "I was helping with communication between teams"
> Parent 6: "I would kiss him on the forehead and hold his hand and I would read to him. But I couldn't' hold him, I couldn't have my baby in my arms."

Transition 5. Realising that death was likely

Some parents treated their pregnancy as if it could be their infant's "entire lifespan." Others were distressed that this possibility was overemphasised. Parents who had medical training or who knew someone whose infant or child had died were more likely to accept their infant's potential death than families without prior personal experiences.

Some parents remembered knowing that their child could die well before clinicians broached it. Some prepared for potential death with each new surgery, knowing that it was never certain their child's heart would restart after coming off bypass. Families described variable ways of preparing for their child's death: asking what dying might look like, formulating end-of-life goals, holding the infant as much as possible, religious and cultural ceremonies, and preparing siblings.

A substantial group of parents did not understand that their child's death was a possibility even while the children became critically ill on multiple forms of organ support. Some had received very serious fetal diagnoses (e.g., hypoplastic left heart syndrome) but did not remember being told, or were not able to internalise, the condition could be fatal at any time. Parents who felt unprepared for their child's death remember it as rushed, overwhelming, and shocking.

> Parent 2: "There was no end of life care just ECMO . . . It was awful, we went from ECMO to funeral home without palliative care."
> Parent 1: "I didn't want her to suffer, either. I wanted her to be as comfortable as possible and just surrounded by love in her last hour of her life."
> Parent 7: "My hopes were still kinda delusional for a little bit. Like, this is wrong, but after he did die my denial was gone."
> Parent 3: "I think my husband and I had the conversation before the doctors had the conversation. About what we were comfortable doing . . . so I think we spoke about it before they were necessarily ready to talk about it"

Transition 6. Adjustment after death

Parents described several common paths of adjustment after their child's death. Many parents had some way of ensuring their child would not be forgotten, such as starting non-profits in memory of their child, working in bereavement groups to help support parents who more recently lost a child or bringing toys to children in the hospital on the birthday of the child they lost. Many families also mentioned the importance of memory work that was done with their child like hand moulds, sibling handprints, and photographs. Parents focused on helping their other children understand the death and to move forward. Several discussed becoming pregnant again, an experience that revived memories and worries. A minority of parents felt that they were still struggling with their child's death, particularly with survivor's guilt and guilt for moving on.

> Parent 7: "I push through it for my children 'cause they deserve a great childhood and they got robbed too."
> Parent 6: "If I can help someone else go through this it helps me at the same time. And I know my son is still helping others as I can help them."
> Parent 6: "Hitting the milestones, now I realize my grief has changed and its actually harder in a different way. Cause now I'm watching my children hit the milestones I never got to see for him."
> Parent 4: "We go back every year on her birthday. We take goodies for the nurses and presents for the kids that are there that the child life specialists can distribute as they feel fit."

Overarching themes

During each of the transitions, parents repeatedly brought up similar issues. Three overarching themes emerged as important contributors to their experience of their child's condition

Communication with medical teams

Communication with the medical team shaped much of parents' experiences of their child's diagnosis, illness, and death.

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Regardless of when parents learned the diagnosis, they struggled with the overwhelming amounts of information and new clinicians, whom they did not have a relationship with, at a time when emotions were overwhelming. Parents of hospitalised children were aware of challenges from the frequent changes in the medical teams, particularly failures in communication between new teams and between subspecialty teams. Some parents felt that their observations of their child were lost in team transitions. Parents felt the added responsibility of trying to bridge these communication gaps and lack of continuity.

> Parent 0: "Our biggest struggle with communication usually was about the fact we had all these different silos and each one worked independently. Teams change so frequently. There is no longitudinal person, it would be great if there was a "meta doctor" a person who followed [child] throughout the whole course and was a point person."
> Parent 3: "Attending's go different amounts of times; sometimes it's such a short time, like a week. They are at first catching up, and then they are leaving, and there were times that we felt like nothing was being done."

Family needs

A diagnosis of CHD profoundly affected not just the fetus or newborn, but the entire family. Parents, siblings, grandparents, and other extended family were all affected, which in turn impacted home life and schedules, jobs, financial concerns, childcare needs, and interpersonal relationships. During every transition, parents described weighing the needs of the entire family against those of the fetus or child. While parents often prioritised fetal or infant interests, they were always considered in the context of the consequences for the entire family.

> Parent 3: "My mother actually moved in with us. So I had the luxury about not having to worry about my kids at home."
> Parent 0: "We weren't able to be at the hospital around the clock cause we had other kiddos. We would have to tag team in the lobby so every visit was 4-5 hours. We would get there, situate in the lobby, one parent would run in, get the updates, cuddle and then tag team with the other parent and the other parent would get to go in and see him."

Parental guilt

Parental guilt was a predominant emotion related to the child's life and death. This guilt fell largely into two categories. First, some parents still believed that if they had done more, their child might have lived. These parents worried that they had not voiced concerns early enough, had not researched alternative treatment options, or had not helped the medical team function well enough. Second, some parents regretted that they had not optimised their time with their child, either because of infant transfer to a distant hospital, or because they had not known or believed that time with the child would be short.

> Parent 7: "There is a lot of guilt involved with surviving, like a survivor's guilt. It's not right to bury your child, and you feel guilt in having more children. And you love that child, then you feel shame. You feel guilt in celebrating anything"
> Parent 3: "When I was at home I felt guilty I wasn't there and when I was there I felt guilty I wasn't home."
> Parent 4: "We expected it to be hard to see her like she was, expected to have to make hard decisions, to hear hard news, you know. But you don't expect to feel that tug that you need to be home with the other kids, or need to be at the hospital with her. Sometimes it just felt like we were doing everything wrong."

Discussion

Few studies have explored the experiences of parents from the time of their child's diagnosis of CHD to the time of their child's death. The work of Jones et al[8] with adult patients and families suggests that there are four common and discreet experiences after a diagnosis of serious heart disease, and that identifying these discreet transitions may be helpful to designing interventions that promote readiness for disease progression. In this study, we found two additional transitions that many paediatric families experienced, highlighting additional opportunities for our support of these parents. Importantly, we found that families often revisit transitions after significant medical events like a child's surgery or intensive care admission. It is important then for paediatric clinicians to be able to gauge a family's current stage of coping and to be ready for transitions forwards, and backwards, in the cycle. Below we review steps that clinicians can take to support families throughout their child's disease trajectory and in Table 2, we highlight proposed strategies.

Partnering with families at diagnosis

At the time of diagnosis, we found that parents experience intense emotions and may not be ready to hear detailed information about prognosis. Clinicians must anticipate, then, that meaningful understanding of the broad spectrum of possibilities is unlikely to occur during a single office visit. When possible, prognostic information should be repeated multiple times, preferably by different clinicians in different ways. Clinicians should be cognizant that prenatal diagnosis disrupts a time of hope and expectation and imposes stressful testing and monitoring on parents.

Even if families have received prenatal counselling, uncertainty is inherent in the prenatal diagnosis and clinicians should anticipate that families will return to the earliest stage of adjustment, that of learning the diagnosis, all over again after birth. Neonatal diagnosis occurs when women are still recovering from delivery and have limited sleep, both of which are stressors that will affect parent's understanding. Meert et al have shown that parents value clinician availability, approachability, and empathy when learning critical diagnoses.[10] Prenatally, a therapeutic alliance may be built with additional meetings or phone calls with families simply to review the diagnosis and spectrum of outcomes for their child. In the hospital, therapeutic alliance could include proactive time spent at the bedside and regular follow-up. Next steps require rigorous evaluation of these parent supports.

Multi-team clinical collaboration can be overwhelming to some parents. Data suggests that, when patients are managed by multispecialty teams, clinicians often assume that another clinician has updated the parents even though this has not occurred.[11,12] Assigning individuals specifically to communicate with families may be able to overcome that risk, such as a continuity intensivist or continuity cardiologist. Clinicians should also note that families find relief in talking about their emotions regarding diagnosis, particularly with physicians.[13]

Communication skills training can augment clinician ability to actively listen and discuss emotional topics with families.[13] In situations in which a poor outcome becomes likely, early palliative care involvement may be an effective way to support communication, decision-making, and parental preparation for the possibility of a child's death from their illness. This early integration can help with parental adjustment to a life-threatening diagnosis regardless

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of eventual outcome.[14,15] The American Academy of Pediatrics has recommended that palliative care be part of the interdisciplinary team at the time of diagnosis for the children not only with terminal illnesses but also with life-threatening or life-shortening illnesses.[16]

Helping families finding their new normal

After receiving the diagnosis of CHD it can be difficult for parents to navigate what that means for them as individuals and as a family. The "finding the new normal" transition was characterised by a need for parents to redefine their own identity as a parent of a child with a serious medical diagnosis. This phase is fluid and the new normal is constantly being redefined for the child, parents, and their families.

Clinicians should anticipate that the values that parents use to make medical decisions may shift as their "new normal" evolves. For example, clinicians should not expect that a "do everything" value expressed at the time of diagnosis will be the same value driving medical decision-making at a later point in the disease process. It is important to review prognosis and reassess parent goals and values regularly, especially following significant clinical changes or prolonged hospitalisation. Palliative medicine teams can assist through longitudinal relationships with families as their goals and values evolve.[17] Some families may have difficulty during this transition finding their new parenting identity, this may lead to maladaptive behaviours and negative emotions.[18] Recognising the reasons for these emotions is fundamental to maintaining a therapeutic alliance and helping families negotiate a new normal

Empowering parents

During times of uncertainty, parents benefit from focusing on controlling what they can. Families of critically ill children in the ICU have reported that being a good parent means advocating for their child, focusing on their child's quality of life, and putting their child's needs above their own.[19,20] This concept aligns with what parents told us about how they took control despite a frightening diagnosis. Some families created birth plans. Many committed to being present for hospital rounds or medical appointments. Some took on a role of advocacy with the medical team. Nearly, all used hope to control the dialogue about uncertainty, which can sometimes be challenging for goals of care discussions but also is a great coping mechanisms for some families.[21] Medical teams should be alert for and support these strategies. Clinicians can enhance family control by facilitating high-quality communication with the medical team, by encouraging active participation in clinician rounds and using tools like Question Prompt Lists. Question Prompt Lists have been used in other settings to help families drive conversations.[11,12,22] Question Prompt Lists, which generally include questions that other families have wanted to know from clinicians, can also normalise early discussion of prognosis by including questions about death.

Clinician support when death becomes likely

In this cohort, parents experienced the transition of realising that their child's death was likely various ways. Some needed to use hope and denial as necessary coping mechanisms to be able to be present with their dying child. Others had end-of-life discussions within their family before the medical team addressed them. It is important for clinicians to have an individualised understanding of each family in order to engage them in meaningful conversations about the possibility of their child's death. This can include knowing how families like to hear information, their current understanding of their child's clinical state, how they cope with information and their hopes and worries overall for their child. Palliative care teams are often experts in shaping end-of-life discussions that are tailored to each family; they can provide family support and clinician mentorship in this regard.[15]

After the child's death

Families described an ongoing role that medical teams can play after a child's death. Families often seek ways for their child's memory to live on, including participating in fundraising, parent support groups or research activities. Our findings showing the burden of guilt in these parents suggests opportunities for anticipatory counselling and bereavement support. Forming paediatric cardiology bereavement groups could help some families, as could proactive opportunities for legacy building. Kreicbergs et al reported that most families are positively impacted by participating in studies about the death of their child;[23] intentionally including parents as research partners could strengthen studies of family-reported outcomes. We suspect that our identification of a novel transition "adjustment after death" may be due to the fundamental difference between a child's death and that of an adult. Adults have lived their life and their memory lives on via their accomplishments and long life. Children have not had that opportunity so families may feel strong purpose in creating meaning of their child's short life.

Limitations

We acknowledge limitations to this study. Mailing envelopes using the last known address may bias participation of families of higher socio-economic status. There may be non-response bias with mailed surveys of those unwilling or unable to participate. Generalisability is limited by the small number of participants, and the fact that the majority of participants were well educated and White.

Conclusion

A diagnosis of paediatric congenital heart disease is life altering for the child and their families. Our study suggests that interactions with clinicians are a key driver of parent's experience, from the time of their child's diagnosis to their death. Relationship building, high-quality communication, and being ready for evolving family goals and values can help families face the challenges of their child's illness. For parents of children who die from heart disease, we found six common phases with discrete features. Understanding these phases and features can help clinicians to tailor their interactions with families based on the specific needs and vulnerabilities of each phase.

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