

Original Article

Psychosocial responses of parents to their infant's diagnosis of hypoplastic left heart syndrome

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Abstract *Objective:* To evaluate the psychosocial status of mothers and fathers in response to their infant's diagnosis of hypoplastic left heart syndrome. *Design:* A study on interviews with parents whose children had survived staged surgery. *Setting:* Tertiary hospital paediatric ICU. *Subjects:* A total of 29 parents (16 mothers and 13 fathers) of surviving children. *Intervention:* A semi-structured face-to-face interview was conducted to explore experiences of parents in response to their infant's diagnosis, their interaction with the doctor delivering the diagnosis, their deliberation about staged surgery, and their reasons for this choice. *Measurement and Main Results:* All parents were devastated about their infant's diagnosis, and most (83%) of them said that the time of the diagnosis and the aftermath was the worst time of their lives. Parents reported helpful and unhelpful communication at this time. Although all parents in this study chose surgery for their infant, when faced with the choice, 17 of them made an immediate decision "to protect their infant's life", 8 were initially unsure when their infant was diagnosed in utero, and 4 were unsure when the infant was diagnosed after birth. Parents also experienced loss and other stressors. *Conclusions:* All parents of the infants diagnosed with hypoplastic left heart syndrome experienced intense loss and stressors. Physicians need to be sensitive to the needs and thinking of the parents when discussing treatment options before surgery. The nature of the relationship with the doctor at this time can support parents or be a further source of stress.

Keywords: Intensive care; hypoplastic left heart syndrome; parents; psychological; stress; adaptation

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CONGENITAL CARDIAC DISEASE IS THE MOST COMMON birth defect and occurs in ~1 in 1000 live births.^{1,2} Hypoplastic left heart syndrome accounts for 1% of all congenital cardiac diseases and is the most common severe functionally univentricular anomaly,¹ causing the largest number of deaths due to heart disease in the 1st year of life.³ Palliative staged reconstructive surgery has radically altered the outcomes of infants born with hypoplastic left heart syndrome and there is now more optimism about longer-term survival in these infants. Current

expectations are that 70% of infants may reach adulthood⁴ as medical strategies continue to evolve.⁵

Despite this more optimistic picture, hypoplastic left heart syndrome still presents great challenges.⁶ For example, these children are prone to many complications, including neurodevelopmental impairments,⁷ and a range of disorders, including cognitive deficits; impaired social interaction; core communication difficulties including pragmatic language, inattention, and impulsive behaviour; and impaired executive function.^{8–10} In addition, these children may have impaired brain growth and impaired brain maturation.⁴ New stratification schemes, however, may assist in better specification of outcomes.¹¹

Despite this optimism, a number of doctors remain sceptical about whether surgery should be performed^{12,13} and this has led to discussions about

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the ethics of care. One study considered whether there should be directive or neutral advice in antenatal counselling regarding the management of hypoplastic left heart syndrome, with this paper arguing that there are cogent arguments to remain non-directive in most circumstances following prenatal diagnosis.¹⁴ Currently, palliative care after birth remains an option for these infants.¹⁵

Although many studies have described the clinical management of these children, studies on the experiences of parents of children with heart disease are few and the outcomes are mixed. For example, one study of parents whose child had heart disease reported that their health-related quality of life was significantly impaired in comparison with parents of children who only had minor illnesses.¹⁶ One study on parents' experiences at diagnosis reported the shock and distress that parents felt at this time.¹⁷ Another study on mothers' responses to their infant's cardiac surgery concurred with the findings of stressors at diagnosis and in response to surgery.¹⁸

Other studies on parents who have a child with hypoplastic left heart syndrome found that parents did well despite many stresses and that they used normalisation in the context of Uncertainty.¹⁹ They juxtaposed worrying about their child's vulnerability with marvelling about their child's survival.²⁰ Other studies on parenting described increased vigilance in monitoring these fragile children.²¹

Few studies have examined the psychosocial impact on parents in response to a diagnosis of hypoplastic left heart syndrome in their infant. Some qualitative studies have found that parents "prepared for the worst" (the infant's death)² and grieved for their "imperfect baby".² Other studies have found that parents experience intense stressors at this time.²² The nature of this stress may also be traumatic because such stress occurs among parents of children who have had other cardiac surgery,^{18,23–25} or in parents after their child's admission to the paediatric ICU (PICU).^{26–29}

Infants are diagnosed with hypoplastic left heart syndrome either prenatally or inevitably postnatally. The difference between the impact of these two time periods for parents has not been extensively studied. One study found that there were no differences in parents' reactions, and all parents, irrespective of the time of the diagnosis, grieved for their child with a disability.² Parents of infants who were diagnosed after the infant was admitted to the PICU had the added stress of an alien environment and of additional family stresses.^{30–32}

Few studies have been undertaken of how parents experienced a doctor's communication to them of their infant's hypoplastic left heart syndrome. One qualitative study reported that parents felt stress related to

poor communication characterised as: inadequate information or news that was only factual, concrete and pessimistic, or when palliation was recommended.² Another study on doctor's counselling strategies in the prenatal diagnosis of a major heart abnormality found that information was adequate and clear.³³ Other studies have found that communication in PICU is frequently inadequate,^{31,32,34} and that doctors have difficulty understanding parental anxiety.³⁵

There have been other studies on parents' experiences at the time of a diagnosis of a CHD. Good communication at diagnosis is important and this may have an impact on later parent-child bonding.¹⁷ A recent online survey of 841 parents found that the counselling and demeanour of the cardiologist is important factor in determining whether parents sought a second opinion and that the cardiologist's compassion and empathy was inversely related to the likelihood of seeking this opinion.³⁶ This same study also found that the information given at the diagnosis, the manner in which it is presented, and the parents' understanding of the information are critical factors in shaping parents' perceptions and management decisions.^{18,36} Another study on mothers of children with heart disease suggested that an experienced mental health professional, who is part of the treating team, may be of assistance to the parents.¹⁸

Limited studies have been undertaken on the parents' decision-making process.^{22,37,38} Parents have unique perspectives and ways of coming to their decision about their infant's treatment.³⁷ For example, parents have described feeling that the condition had to be treated; faith in medicine and science; because proceeding was a "no brainer"; the infant was in God's hands; and because "you can't stop now".³⁷ Another study noted the lack of knowledge available to parents about the long-term outcomes at a time when their decision-making processes are compromised by a state of emotional shock and limited time to deliberate.²²

This current study examines four parental phenomena related to the diagnosis: psychosocial responses to the diagnosis; perception of how the doctor delivered the news; differences in psychosocial reactions when the diagnosis delivered prenatally or postnatally; and decision-making processes including the varying periods of deliberation.

Methods

Design and sample

This current article examines the detailed experiences of parents in response to reception of the diagnosis of hypoplastic left heart syndrome for their infants.

Their experiences as a whole including reception of the diagnosis, preoperative period, and postoperative period have been published as parental experiences in the PICU.³⁹

This study involved the retrospective narrative interviews of mothers and fathers in response to their infant's diagnosis of hypoplastic left heart syndrome. It is salient to note that a study on mothers at the time of their infant's diagnosis of a CHD and after cardiac surgery found that the research interview served as a likely therapeutic gain for these parents, where they have the chance of telling their stories.¹⁸ Potential participants were identified from PICU records of infants who had a stage I (Norwood) repair of hypoplastic left heart syndrome between 1983 and 2004. Parents of surviving children who lived in the State of Victoria, Australia, were invited to take part in the study by letter and subsequently by telephone, if they had not responded. There was considerable variance in the ages of the children because the study concerned surviving children. Of all the parents, six couples decided not to participate, two fathers were not involved with their child and not interviewed, and one father declined to be interviewed "because it would be too emotional". The group of respondents consisted of 16 mothers and 13 fathers. Consent included permission to audio tape interviews. At the time of the study all children had been discharged home. Approval for this study was granted by the Institutional Human Research Ethics Committee.

Interviews

Parents were interviewed once at the location of their choice by the first investigator, a psychologist who had not been involved in the care of the infants or their parents. Interviews were semi-structured and explored stressors, traumatic stress, losses, adaptation of the parents, and their relationship with their infants.

Data analysis

The interview data of individual parents were subjected to "thematic analysis", meaning that themes were identified within the interviews and then analysed, as described by Liamputtong and Ezzy.⁴⁰

Results

Psychosocial responses to the diagnosis

A total of 16 parents learnt of the diagnosis at mid-term of the mothers' pregnancy and 13 were informed after the birth of their infant.

The extent of the impact on parents was such that most parents (83%) said that their infant's diagnosis was the worst event that had ever happened to them and that it was traumatic. For example, a mother commented:

I was so shocked. I was dazed by the whole thing. It was shocking.

Perception of how the doctor delivered the news

Of the parents, eight said that they had a poor relationship with the diagnostician. One parent said:

I found the cardiologist very removed. He was very clinical. He used to say "mother" and "baby".

In all, two parents spoke of a lack of empathy by the doctor; four parents spoke of excessive negativity: "He just kept saying he will die"; and four parents felt distressed that the doctor was advocating a termination.

Several parents who were traumatised found it hard to absorb the news, and one mother did not understand the terminology:

The doctor explained everything but I couldn't understand a word he was saying because I didn't understand medical words. I thought I would look stupid if I asked.

Of the parents, eight felt that the breadth of communication was inadequate. A mother reported that "there was absolutely no information and no encouragement as to where to look".

In contrast, other parents spoke of attitudes and responses that were helpful. For example:

He was fantastic: very understanding, very compassionate, very interested in helping us to make the right decision.

There were three parents who spoke about empathy. For example:

What I remember was they really just felt for you. You could see it in their face.

Another parent was deeply moved by the doctor's suffering about her child's hypoplastic left heart syndrome. There were two parents who spoke about the doctor's kindness as manifested by an offer of a hot drink during discussion about hypoplastic left heart syndrome, whereas another mother spoke about how committed the doctor was to helping her and her partner make the decision that was best for them. Of the parents, three felt relieved when the doctor spoke of hope for the future for their child.

Similarly, five parents spoke about the doctor's respect and understanding in response to their

questions and in the doctor's willingness to go over the same issues again. Parents were also grateful for the care that was humane:

(The cardiologist) just picked me up and walked me into this little room... he drew me pictures and got me a cup of coffee... and a box of tissues... and he explained things.

The summary of the parents' descriptions of what they regarded as being helpful, or unhelpful, from doctors at the time of their infant's diagnosis is detailed in Table 1. Helpful strategies included understanding; compassion; empathy; kindness; feeling that there was a commitment to assisting them; respect; and accessible communication. Tables 2 and 3 describe possible communication strategies and attitudes that may be helpful for parents.

Differences in psychosocial responses when diagnosis delivered prenatally or postnatally

The diagnosis in utero. The intensity of stress was described by one parent as being in a "fog of fear and

loss", and another two parents talked of physiological reactions. For example:

I went to hospital the following night... because I was just vomiting non-stop. It was the stress.

Several mothers reported the pressure they felt about the urgency of the decision because the pregnancy was quite advanced should they wish to have a termination.

In addition, five parents spoke of their fear wondering whether their decision to continue was the "right decision".

Following the decision to continue the pregnancy, new worries emerged and 10 parents talked of their fear that their infant would die: "It was just a waiting game, not knowing". Of them, five mothers said that the joy of the pregnancy was gone, and one father said that he did not enjoy the birth because of anxiety.

One mother said that she was "very flat while she was pregnant". Another mother said that she felt neglected because the focus of attention was on her unborn infant and she felt that her own needs were unrecognised. Of this cohort, four fathers talked of the diagnosis more rationally. Of the parents, three

Table 1. Helpful and unhelpful communication by doctors at diagnosis.

Helpful doctor's communication	Unhelpful doctor's communication
Using the parent's and the infant's names	Clinical detached communication with a lack of real engagement
Assisting parents to make the best decision for their family	Excessive negativity without a balanced picture of the current outcomes for children with hypoplastic left heart syndrome
Empathy and compassion	Advocacy for a termination without sensitivity to what the parents may be thinking
Respectful care	Communication that entailed too many clinical words
Information explained clearly in an accessible manner, including the use of drawings	Communication that was inadequate about the nature of hypoplastic left heart syndrome
A willingness to answer all questions	No suggestions about where to access further information
Actions of kindness, for example, offering a hot drink	
Conveying the possibility of hope for the future	

Table 2. Guidelines of good communication: first meeting between cardiologist and parents at diagnosis of HLHS.

Communication needs to be respectful, unrushed, sensitive, and personal. Do the parents need an interpreter?
Take a support staff member with you to meet the parents, for example, a nurse or allied professional who could support the parents over time
Introduce yourself and the staff member to the parents, calling them by name and the name of the infant: "Hello Mr and Mrs Amini. I am Dr Ann Nguyen. I am a Senior Heart Doctor and I am here to talk to you about Mustafa"
Take the parents to a quiet attractive room where there will be no interruptions. Offer them a cup of tea
Acknowledge that you have the result of the scan, and there is news that will be difficult for them. This will assist in their preparation for the difficulty of the diagnosis
While maintaining eye contact, tell the parents that you are sorry to have to tell them that their infant has a heart condition called HLHS, which means that the heart vessels are not working well
Parents will be thinking, "Is he or she going to die?" or "Can this be fixed?"
Explain clearly and simply. Communicate life expectancy, possible complications, as well as optimistic information. It may be helpful for parents to see a photo of a child with HLHS, as they may imagine that the child looks physically disabled
Allow space for sorrow, shock, or other feelings
Note that parents will not be able to absorb much information due to grief, shock, and trauma. Tell them you will return tomorrow to discuss further
Parents may wish for some time alone with their partners, with or without the support staff member

HLHS = hypoplastic left heart syndrome

Table 3. Guidelines of good communication: second meeting between cardiologist and parents at diagnosis of HLHS.

Ask the parents what they have been thinking and whether they have questions?
Tell the parents about the possible life trajectory for their child and treatment if they choose surgery
Do a diagram of an HLHS heart, if this seems helpful for parents
Talk about the experiences of some other parents. For example, studies have found that some parents are grateful that surgery was available, and have found resources in themselves and joy in their child. Other parents have decided on a termination or palliative care after birth
Remember that some parents will make a choice immediately and others will be want assistance to make the decision
Mention the urgency of the decision
Talk about other sources of information, for example, written information and the internet
An HLHS group within the hospital
Answer questions, leaving time for discussion
Acknowledge that this is very difficult news for the parents to hear, that it is also very hard when this news is unexpected, and that the parents are not to blame in any way for this diagnosis
Make a time to meet with the parents again if they have not made a decision. Ask if they wish to speak to anyone else, such as a pastoral care person, the surgeon at this stage, members of their family. Communicate personal care. For example, that you will be mindful of them

HLHS = hypoplastic left heart syndrome

were confused after the birth because the infant seemed robust and they hoped that there had been a mistake. All mothers said that they felt loss when their infants were taken away for treatment after birth.

The diagnosis after birth. These parents were unprepared for the multiple stressors at this time and for the time ahead:

You're in shock... you had a Caesarean, you haven't got time to wrap your head around stuff, and you're told all this information and told you need to make decisions quickly.

These parents described intense reactions: For example: "It felt like everything had been ripped apart". These parents had to cope with the clinical collapse of their infant after birth, the diagnosis, the urgency of the decision about treatment, and for family organisation. This was particularly stressful for the rural families whose homes were many kilometres from the hospital.

Despite the parents' reactions of sorrow, shock, and trauma, some parents discussed responses that indicated steps towards their adaptation. Parents spoke about the attitudes and communication of the diagnostician and other sources of support. These included family, social, and religious supports. One parent felt empathy for the doctor who had to deliver the bad news:

It is just awkward having to tell parents something like that.

Several parents used a positive interpretation of a doctor's behaviour. For example, some parents excused the doctor's emotional distance because of his focus on the clinical details, and another parent said that it was understandable that the doctor was so negative:

It is unknown what the future's going to hold. So I can understand the medical profession being grim about it.

Another mother found the doctor emotionally disengaged, but soothed herself by considering that the doctor was a "mastermind" who used all his superior resources to evaluate the infant's heart.

All of these parental comments indicate the capacities within parents that seek the positive. Other parents had other ways of assisting themselves. One parent said that she needed to spend time by herself "to keep myself strong and look after myself and my family", and five parents spoke about doing their own research on hypoplastic left heart syndrome. Some parents used cognitive strategies to help them adjust. For example, some parents reflected that they were powerless to change the infant's condition, and therefore should accept it. Some other parents spoke about religious concerns and to trust God. One father said he disengaged from negative thoughts:

I knew there was something they could do so I trusted and hoped and I tried to get on with it without thinking too much about it.

One father spoke about the juxtaposition of hope and despair, while attempting to hold hope for his infant:

We were always confident. Well you always think things will go well... In some ways you prepare yourself for the worst and hope for the best.

Other parents found that once the infant was born, it helped them to hold and touch their infant and strengthened their commitment to their infant. Of the mothers, four said that they felt that surgery was the only option once they had spent time with their infant. For example, a mother said:

As the days went on after diagnosis we get got closer and closer to him... It was too hard not to go ahead.

These comments have pointed to the way some parents had begun to adapt to their infant's hypoplastic left

Table 4. Timing and deliberation about staged surgery.

Timing and deliberation of the decision about staged surgery	Numbers
Parents who felt immediately that staged surgery was the only option	17
Parents who were unsure when the infant was in utero	8
Parents who were unsure when the infant was diagnosed after birth	4

Table 5. Timing and rationale for surgery.

Timing of decision	Parents' rationale
Parents who made an immediate decision after they heard about the diagnosis	Do not want the infant to die It is about being a "good parent" Just felt impelled: "Having him for a little while is worthwhile" It is fate and fate has to be accepted For spiritual ethics: "It is God's will to protect the infant" Do not want to regret not doing all we could
Parents who were unsure about staged surgery when the infant was diagnosed in utero	Unsure, with no reason given Has to be the mother's choice Have to meet another child with hypoplastic left heart syndrome before deciding
Parents who were unsure about staged surgery when the infant was diagnosed after birth	Too late once the infant has been born to discontinue The infant is now born and you have to give her a chance Unsure about quality of life

heart syndrome. These responses did not mitigate the suffering but coexisted with the pain they experienced.

Decision-making processes

In all, 24 parents felt that they had had an active part in choosing surgery as distinct from being excluded from making the decision. The remaining five parents did not speak about participation in the decision.

Table 4 describes the parents' reactions and their deliberation process at the time of the diagnosis when they heard that there was a surgical option. Of the 24 parents, 17 said that when they heard about the infant's diagnosis, they immediately chose the surgical option, whereas some other parents were unsure. In this cohort of parents, eight said that they were uncertain about their decision at the mid-term of the pregnancy, and four parents said that they were unclear about treatment when the infant was diagnosed after birth.

Particular themes emerged related to the rationale of choosing surgery, as described in Table 5.

Parents who made an immediate choice with the doctor after the diagnosis. There were six parents who spoke about wanting to prevent their infant from dying, and another two parents simply said that they were impelled to go ahead with surgery. For example:

There wasn't an issue for us. It was definitely yes. I couldn't carry a child all the way through and then watch the child die.

Of the parents, two spoke about their desire to be "good parents". These parents seemed to suggest that to do "the best" for their infant was the responsibility of "good parents", and "good parents" desired to save their infant from harm (death). Another two parents spoke about protecting the infant's life. It was not clear whether parents recognised that after the infant had surgery, the infant could still die, but one parent was clear and said:

I was adamant that my child was going to have surgery... Even if I had him for a little while, I thought it was better to have him for that amount, than not to have him at all.

Another two parents talked of fate: the infant's hypoplastic left heart syndrome was part of fate that had to be accepted, and therefore surgery was desired. There were two other parents who spoke about spirituality that resulted in his desire to protect their infant's life. For example:

We said this child is created by God. If we terminate, it is like interfering with God's will. What God has given us we have to accept.

There were other responses. One parent said simply that she decided to "go ahead" with no reasons given. Another mother said that she "didn't want to regret it". This suggests that she did not want to regret not doing all she could for her infant and this theme may connect to the desire to be a "good

mother". One other mother said that she and her husband did not have time to think about the choices when their infant was diagnosed after birth.

The parents who were unsure about staged surgery when the infant was diagnosed in utero. There were six parents who said that initially they were unsure about their choice of surgery when the diagnosis was made during the mother's pregnancy, and two other parents (a couple) decided to wait until their infant was born before deciding about surgery, with the option of palliative care. The mother wanted to meet an older child with hypoplastic left heart syndrome before deciding.

Parents who were initially unsure about surgery when the infant was diagnosed after birth. When the infant was diagnosed after the birth, three parents were unsure about surgery. One mother said that if she had known at mid-term of the pregnancy she may not have continued. Her husband echoed the same thoughts. Another mother was unsure about surgery because of a fear about the infant's quality of life, but when she saw another child with hypoplastic left heart syndrome, she said that her fears were allayed and she commented that "there wasn't really a choice. We had to let him have the chance". Her comment, and the previous comment about the parents' witness to the infant's struggle for life, made it very difficult for some parents to refuse surgery.

In summary, most parents made an immediate choice for surgery after being informed of the diagnosis and the main rationale was to "prevent their infant from dying". The underlying thought processes, however, varied. Most parents, who were unsure about surgery when the infant was in utero, did not speak about their reservations at this time; one father, however, left the choice to his wife, and another mother wanted to meet another child with hypoplastic left heart syndrome first, although it was not clear what she wanted reassurance about. When infants were diagnosed after birth, parents felt compelled to continue with active treatment and staged surgery.

Discussion

This study has examined the psychosocial responses of parents to the diagnosis, the parents' perceptions of how the doctor delivered the news, the differences in responses between the two times of diagnosis, and the parents' decision-making process.

Although our study was conducted after (successful) surgery for their infants, we maintain that all parents experienced intense stresses at the time of the diagnosis. This is consistent with other studies on parents whose infants were diagnosed with hypoplastic left heart syndrome^{2,22} or with a congenital

heart defect^{17,41,42} and that parents experienced grief.^{2,17,38} The majority of the interviews reflected traumatic stress symptoms, and we found in a previous publication that some parents went on to develop a full-blown post-traumatic stress disorder.^{31,39} There were a number of factors that could have contributed to this, for example, the infant's admission to a PICU and the infant's appearance after surgery. We claim that a major contribution was the diagnosis, as the majority of parents said this was the case, and that most said the diagnosis was the worst event that they had experienced. To assess the reception of the diagnosis alone, it would be necessary to evaluate parents before surgery and before their admission to the PICU. This level of traumatic stress is very high, but traumatic stress has also been found in other parents whose child was in the PICU,^{26,28,29,39,43} or in response to their infant's cardiac surgery.^{18,23–25} The highest incidence of parental traumatic stress in this study may be attributable to the multiple intense stressors, particularly if the infants had not been diagnosed "in utero". The incidence of stress and suffering for parents highlights the need for strategies that may protect parents, such as staged information and psychological first aid after the diagnosis and during the child's hospitalisation. During and after the diagnosis, there could also be a long-term nurse to support parents over time and access to psychology, social work, and pastoral care. After discharge, hospitals should advocate and organise a range of health professionals in the community, involving, for example, community health teams, nurse liaison, psychological counselling, and family support programmes.

We observed that parents were stressed in response to the doctor's skills that reflected poor or inadequate communication, information that was only factual, concrete or pessimistic, or when palliation was advocated. These findings confirm the work of an earlier study.² We also observed that it was stressful for parents when there was a lack of real engagement, excessive clinical words, when the breadth of information was inadequate, and where there was no guidance about where to access further information. In contrast, we observed that parents benefited by sensitive personal engagements with the doctor, where there was empathy, compassion, and kindness, and when the parents felt that the doctor wanted to help them make a decision that was best for themselves. Although it was not clear how the doctor's manner had an impact on the parents' management decision, it is clear that parents benefited from effective communication.³⁶ Finally, parents benefited when the doctor could gauge how much information they could assimilate and guided them to more information.

Parents valued communication that was humane and sensitive and it seemed to help them to mobilise their own resources. Physicians may benefit from education in psychology⁴⁴ and from learning strategies that may protect vulnerable parents. They may also benefit from assistance from a mental health professional that assists them to tell her stories about the infant's treatment, and that this is a valuable, brief, and very cost-effective therapeutic intervention.¹⁸ This assistance could be of most help 12 months after diagnosis, as parents need to focus on their infant's survival in the early months.

The timing of diagnosis, whether in utero or post-birth, did not affect the distress of parents. However, in contrast with other studies that detected no differences in parents' reactions between the two times,² we observed that parents whose infant was diagnosed after birth had many unfolding unexpected stressors at this time, including the clinical collapse of the infant after birth, the alien environment of the paediatric intensive care, the urgency of the decision about treatment, the medical treatment and surgery, and the appearance of the infant in response to treatment.³⁹ This current study did not specifically find that parents "prepared for the worst" (their infant's death),² but it did find that parents were very anxious about its possibility.

Most parents made an immediate decision for surgery "to protect the infant's life". However, very few parents spoke about any communication concerning palliative care and what palliative care could involve. Parents seemed to believe that "being good parents" meant that they had to save their infant, whereas communication could involve that being "good parents" could also involve the choice of palliative care. The underlying reasons for the immediate choice of surgery varied, which concurs with other studies on parents' choices at this time³⁸ and reflected the individual parents' fundamental attitudes. There could have been other more complex reasons, which could be unconsciousness and a parent's formative experiences. It was possible that some parents harboured ambivalent or detached feelings that were not spoken about, apart from two parents who seemed to be saying that they would have chosen a termination if the infant had been diagnosed in utero.

We also found that the research interview served as a likely therapeutic gain for these parents,¹⁸ and many parents expressed gratitude for the researcher's interest in their experiences.

It is noteworthy that parents remembered the details of the diagnosis and the responses of the cardiologist in some cases many years after this time and in one case 19 years later. This highlights the significance of the time for these parents and the importance of sensitive care.

Study limitations

This study has limitations: all of the parents' experiences relied on retrospective memory; the sample size was small; the Structured Clinical Interview for Diagnosis test has not been validated with this population; the parents were interviewed at different time periods after discharge of their child from hospital, and this study has only involved parents of surviving children. Further studies could be longitudinal and involve a larger sample. It would be salient studying and contrasting the experiences of parents whose infant had died, either as a result of complications after surgery, or a result of the parents' choice of palliative care. It would also be useful to study parents who chose intervention and the patient died.

Conclusion

The majority of parents who had chosen surgery for their infant with hypoplastic left heart syndrome had made their choice immediately after speaking with the doctor, irrespective of whether the diagnosis was made before or after their infant's birth. Some of the parents, however, delayed their decision. Irrespective of the time of diagnosis, all parents experienced intense loss and stressors. The majority of parents said that reception of the diagnosis and the immediate aftermath was the worst experience of their lives. Physicians need to be sensitive to the needs and thinking of the parents when discussing treatment options. The nature of the relationship with their doctor can be a further source of stress, or be a major source of support to these vulnerable parents.

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Ethical Standards

Permission for this study was granted by the Institutional Human Research Ethics Committee.

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