



Experiences of parents of children with hypoplastic left heart syndrome during their treatment: a qualitative study


Original Article

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Abstract

Aim: To investigate the opinion and personal experience of parents of children born with Hypoplastic Left Heart Syndrome and what advice they would give to other parents who have to decide between treatment options. **Methods:** We conducted a qualitative, descriptive and retrospective study by means of a survey directed to parents of children born with Hypoplastic Left Heart Syndrome in a tertiary hospital in Buenos Aires (Argentina). Their answers and data regarding medical procedures were analysed. **Results:** Parents of thirteen out of sixteen patients with Hypoplastic Left Heart Syndrome were surveyed. Norwood surgery had been performed in all the patients, many had received other procedures, and five had died. In relation to the decision-making process, sixty-one percent of parents would recommend other parents to remain at peace after having done everything possible and 54% would suggest to not feel guilt despite the final result. None of the parents would recommend rejecting surgical treatment and choosing comfort care. **Conclusion:** The majority of parents of children with Hypoplastic Left Heart Syndrome would recommend continuing with the therapeutic effort in order to feel at peace and reduce feelings of guilt.

Introduction

Hypoplastic left heart syndrome is a severe heart defect that accounts for 1–3% of congenital heart anomalies and is a major cause of death due to CHD during the first year of life.^{1–4} Birth prevalence is approximately 1 case per 4000–6000 live births.^{5,6}

When diagnosed, the therapeutic options are comfort care, surgical intervention, or termination of pregnancy. The latter option accounts for more than 36% of cases in some series.^{5,7–11}

Without treatment, hypoplastic left heart syndrome is a lethal disease.^{12–14} Surgical interventions have modified the prognosis, and presently, up to 70% of patients can reach adulthood.^{2,15} This therapy includes at least three sequential operations, the Norwood procedure being the first.^{3,5,12,14} This intervention has a survival rate as high as 90% in the best centres.^{13,16} These results are affected by risk factors such as birth weight, diameter of the ascending aorta, and the presence of chromosomal abnormalities or other extracardiac associated diseases.⁷

Decision-making is extremely difficult due to the complexity of the disease.⁵ It is essential to consider the likelihood of survival with the different interventions and also the potential quality of life. The medical perspective differs from that of the parents, who tend to be more optimistic.⁷ Although there are important medical and ethical issues to discuss, parents ultimately have to choose between a medical life-sustaining intervention or comfort care.¹²

There are few qualitative studies exploring the burden of surgical treatment on children born with hypoplastic left heart syndrome as perceived by their parents. For this reason, we investigated the opinions of parents and their degree of satisfaction with the information given by the healthcare team, the decision-making process, the child's quality of life, and their personal experiences considering their familial, social, and religious contexts. The specific objective was to perform a qualitative study about the opinions of the parents of children born with hypoplastic left heart syndrome regarding these factors and what advice they would give to other parents who are faced with making the decision between surgical treatment and comfort care.

Materials and methods

Parental opinion survey

We carried out a qualitative, descriptive, and retrospective study by means of a survey directed to parents of children born with hypoplastic left heart syndrome in a tertiary hospital in Buenos Aires (Argentina). All parents of children with hypoplastic left heart syndrome born between

June 2014 and June 2021 were invited to participate. The starting date was determined based on the last changes of our institutional treatment protocol. The questionnaire is described in Appendix 1.

During this period, 16 patients with hypoplastic left heart syndrome were born in our hospital. None of the parents of these patients chose comfort care. From the potential 16 participants, 13 parents could be contacted by phone and/or e-mail, and all of them agreed to participate. The questionnaire was sent to them by e-mail. Because the patients came from different areas of the country, and due to the geographical extension of Argentina, it was not possible to conduct a personal interview. A database with their answers was created ad hoc.

Survey design and validation

The survey was designed in two pilot phases. The first version was reviewed by 20 parents in order to determine the clarity of the survey, the tactfulness of the wording, the relevance and adequacy of the questions with respect to the objective being investigated, and the ability to complete the survey in a reasonable amount of time. Incorporating the suggestions of the parents, the survey was modified, and the second phase of the pilot study began. The new version was reviewed by 20 Argentinian paediatricians, and their recommendations were included in the final questionnaire.

To reduce biases, it was necessary to support the validity of our tool. For this, we evaluated internal consistency using Cronbach's alpha, with values between 0 (no consistency) and 1 (perfect consistency). Cronbach's alpha for the survey was 0.8, showing adequate consistency.

Data collection and confidentiality

Data were collected from the medical records of patients with hypoplastic left heart syndrome. Information of each patient was recorded regarding: 1) surgical stage: Norwood, Glenn, or Fontan–Kreutzer surgery; 2) total medical interventions (including catheterisation and other procedures); 3) length of stay in the paediatric ICU; 4) duration of mechanical ventilation; 5) duration of extracorporeal membrane oxygenation, if applicable; and 6) outcome (survival or death).

Data from the patients were encoded, and only the authors had access. This study obtained approval from the Institutional Review Board (IRB) of Universidad Austral, Buenos Aires, Argentina (IRB n. P21-012).

Data analysis

Due to the small sample, it was not possible to carry out statistical analysis (i.e., compare dead versus alive groups), so we performed a descriptive analysis using clinical data of each patient in relation with their parents' perceptions.

Results

Parents of 13 patients accepted to participate (100% of the contacted parents and 81% of the potential participants). At the time of the survey, all patients had received the Norwood procedure, and some had received further surgical procedures of the sequential approach (Glenn or Fontan–Kreutzer). Five of these patients had died. Four of the five deceased children had undergone only the Norwood surgery. One of the three children who received extracorporeal membrane oxygenation survived. The median number of days admitted to the paediatric ICU for the deceased

Table 1. Treatment of 13 infants with hypoplastic left heart syndrome.

Medical interventions	n
Total number of Norwood procedures	13
Total number of Glenn procedures	6
Total number of Fontan–Kreutzer procedures	3
Total number of interventions	4 (2.5–8)*
Total days admitted to PICU**	60 (35.5–94.75)*
Total days on mechanical ventilation	18 (6–30)*
Total days with inotropes	28 (16–33)*
Number of patients with ECMO***	3

*Median (IQR Q1-Q3); ** Paediatric ICU; *** Extracorporeal membrane oxygenation.

children was 34 days (IQR: 19.5–91), well below the median of 60 days (IQR: 35.5–94.75) for all children.

Table 1 indicates surgery stage performed on patients with hypoplastic left heart syndrome. It also shows clinical data regarding each intervention, including: total number of days admitted to the paediatric ICU, total number of days with mechanical ventilation, use of inotropes, and need for extracorporeal membrane oxygenation.

Table 2 shows survey answers regarding: information received, decision-making, quality of life, religious belief, and personal experiences. All parents chose to treat their children's hypoplastic left heart syndrome with the surgical sequence. None opted for comfort care. Parents reported that the information received was complete, realistic, and that they were able to understand and articulate the process their child was going through.

In relation to the advice parents would give to other parents, 60% would prioritise survival, none would suggest comfort care, and around 20% would recommend limiting the therapeutic efforts when necessary.

Most parents had an optimistic view regarding the social impact of the child's illness. For example, the responses, "we had good support from family and friends" and "it brought us together as a family," were common compared to more negative comments such as "we had a hard time coping with it emotionally" and "we became disorganised and family life suffered." Fifty-four per cent of parents reported that religious beliefs had a great influence on their decisions.

Finally, we observed some interesting descriptive data in the answers given by parents of deceased children: most (80%) suggest that the priority should be to avoid suffering (none of the parents of living children gave this advice) and to not feel guilty if the child dies (only 40% of the parents of living children gave this advice).

Discussion

Parents of 13 children born with hypoplastic left heart syndrome were surveyed. All had opted to follow surgical staged palliation, and none had chosen to follow comfort care. Five of the 13 children died. An important finding arose from the answers of two questions of the survey considered relevant for decision-making. Specifically, 61% of parents would recommend other parents to remain at peace after having done everything possible and 54% would suggest not feeling guilt despite the final result. These findings highlight two aspects discussed in this paper. The first is parents' sense of self-blame and responsibility for their child's

Table 2. Opinions of parents of 13 infants with hypoplastic left heart syndrome.

Surveyed items	Answers
Partner relationship	92% Live together
Mean of number siblings (excluding patient)	1.9 (1)*
About the information received	
Prenatal diagnosis	77%
Was abortion offered?	50%
How did you receive the diagnosis?	61% It was a surprise
Information before the first surgery	77% It was very complete
Information received about severity and prognosis	100% Realistic
Were you able to elaborate on the information received?	85% Was able to elaborate on it a lot
Did you seek a second medical opinion?	41%
Decision-making and quality of life of the infant	
The most influential factor	61% To be at peace knowing we had done everything possible 54% That the child has a good quality of life
How did the medical team answer your questions?	92% Satisfactorily
Who defined the treatment?	100% It was a joint decision with the physicians
Participation in decision-making	76% Were satisfied in the way of participation
Other factors about decision-making	69% Decided mainly based on medical factors
Opinion of others (family members)	92% Did not seek the opinion of others
Child's current quality of life (living infants only)	71% Very good
Personal experience and religious beliefs	
Social impact of the disease	77% We had good support from family and friends 69% Brought us together as a family
Experience to share with parents of infants with HLHS	61% That the priority is for him/her to survive 54% That they should not feel guilty regardless of the child's outcome
Did you feel ready to take your child home?	77% Felt prepared
Influence of religious beliefs	54% Very much

*Standard deviation.

outcome and the way they receive information from the medical team. The second aspect concerns the suffering and quality of life of the child as perceived by the parents. This aspect is discussed in three ways: (1) through the parents' search for support from other family members and religion; (2) through the search for hope in the face of the serious illness diagnosed prenatally, and finally; and (3) through the need to limit the therapeutic effort when the expected benefits are not achieved.

A high incidence of self-guilt has been reported in parents of disabled or critically ill newborns.¹⁷ Due to the fact that without treatment hypoplastic left heart syndrome is a lethal disease,¹²⁻¹⁴ it is interesting to highlight that parents who were surveyed stressed the need to feel at peace without blaming themselves in cases of failure. Blame is associated with other feelings such as stress and regret.¹⁸ Parents may also feel impotence for the impossibility of avoiding the death of their children.¹⁹ This seems particularly relevant in this study where 40% of the children died. How is it possible for parents to reach peace? Parents usually do not have enough time to prepare themselves for a bad outcome during the neonatal period, highlighting the importance of prenatal diagnosis and counselling. Parents who have longer time to

prepare themselves for the possibility of their children dying feel less guilt¹⁷ and might find peace more easily. Another way of feeling at peace could be achieved by doing everything medically possible based on the fact that two-thirds of parents surveyed associate the feeling of being at peace with having done everything possible to save their child.

Parents feel a heavy emotional burden from the responsibility of caring for their ill children. This can be manifested in feelings of fear, insecurity, or fatigue.^{2,20,21} Interestingly, parents who completed our survey would suggest to their peers that after having done their best, they should be at peace, even when the treatment is unsuccessful. The factor that most influenced decision-making was "staying at peace after doing their best."

Of all the advice these surveyed parents would give to other parents, a frequent recommendation was to do everything possible for their children to survive. We hypothesised that the complexity of this condition and invasiveness of the treatments would make some parents reconsider the process and choose comfort care instead. However, 61% of the parents chose to prioritise the chance of survival and none of them chose comfort care. These recommendations seem particularly relevant considering that five

patients had died by the time the survey was conducted and that some of them had received multiple interventions. In any case, this response may be biased by the fact that all parents in this study chose surgical palliation. Parents who choose palliative care may have a different opinion that is not represented in this study.

Some authors have described the importance of communicating the precise prognosis in order to allow relatives to make these challenging decisions with the best information.⁷ We supposed that parents would consider the information given too optimistic; instead, 100% considered it to be sufficient and realistic. Although it is only descriptive data, it suggests that parents made their decisions having understood the risks.

Families who receive complex diagnoses need support, guidance, and understanding to help them cope with the situation.^{2,22} In our study, in spite of parents having been taken “by surprise” by the diagnosis of hypoplastic left heart syndrome, they seemed to have had enough time to process the information and to participate mindfully in the decisions. For some, having a prenatal diagnosis may have helped them be better prepared.^{8,21} In addition, they felt satisfied with their role and participation in the care of their children, and they felt they had the opportunity to make decisions together with the medical team. Research has shown that families must be given all the information to be able to actively participate in the decision-making process. It is to their benefit when the medical team communicates information with empathy, compassion, and kindness.^{2,23}

As survival has increased during the last decades, optimisation of quality of life has become a critical parameter of therapeutic success.^{24,25} Parents of the surveyed population considered quality of life as one of the most influential factors when making their decision regarding treatment. Quality of life seems to vary at different moments, and its assessment may differ even between mothers and fathers.²² Common quality of life parameters are related to the physical, psychological, and social functioning affected by the disease and its treatment.²⁴ Among CHDs, hypoplastic left heart syndrome carries the highest risk of neurodevelopmental impairment. At 6 years of age, children with this diagnosis show more abnormalities of adaptive behaviour and lower functional and health-related quality of life compared to the general population.²⁶ In contrast, our results show that 100% of parents of survivors consider their children to have a very good or good quality of life.

Seventy-seven per cent of respondents considered that they had good support from their family and friends. Emotional assistance is crucial for parents of critically ill children.¹⁹ The presence of family, friends, and, in some cases, a religious guide contributes not only as emotional support but may also influence decision-making.^{5,20} Fifty-four per cent of the surveyed parents considered faith to be very influential on their decisions. In critically ill children, parental religious beliefs are associated with a significantly increased probability of deciding to save the infant at all costs.²⁷ It is possible that our findings (prioritizing survival) are influenced by cultural and religious beliefs. Argentina is a country of immigrants. Most Argentines descend from immigrants coming from diverse European countries, particularly Italy and Spain, whose cultures largely influence ethical attitudes and behaviours.²⁸ Eighty-one per cent of Argentines belong to some religion and 63% are Catholic. Of the total number of people who practice a religion, 11% attend worship services once a week.²⁹

Fifty per cent of mothers with a prenatal diagnosis of hypoplastic left heart syndrome in this report were offered termination of pregnancy. According to some studies, between 60 and 70% of

physicians would terminate the pregnancy in the face of a hypothetical prenatal diagnosis of this disease.^{7,9} Moreover, this rate of pregnancy termination increases when CHD is accompanied by other malformations.⁸ The most important factor for parents to choose pregnancy termination seems to be the perceived anticipated distress to the affected child and the perception of a negative effect on parents and siblings.⁷ Parents and doctors may have different perceptions. Surgical treatment, which now has an increased likelihood of survival, is a hopeful alternative to pregnancy termination.

The perception of suffering can lead parents to limit therapeutic efforts, especially with the prolongation of intensive care. Parents who have enough time to process the situation and have the possibility to participate in decision-making could want this option.³⁰ It was interesting to see that among the parents we surveyed, those of deceased children prioritised the avoidance of suffering. This highlights how perceptions may vary depending on personal experiences and could explain the choice of limiting therapeutic efforts in certain cases.

The study has some limitations. It was conducted in a centre with a low volume of surgeries for hypoplastic left heart syndrome (defined by fewer than 10 procedures per year⁷). In addition, as most patients were referred for surgery, these families had already made the decision to proceed with treatment, and families who could have made another decision may not be included. As such, the results of this study may only be interpreted within the context of parents who chose surgical palliation and are not representative of opinions of parents who choose comfort care. Finally, our survey was limited to one paediatric ICU.

Despite these limitations, this study, conducted in a tertiary centre, shows that the majority of parents of children with hypoplastic left heart syndrome would recommend continuing with the therapeutic effort in order to feel at peace and reduce feelings of anxiety. It is important for the healthcare team to support families throughout this process, always offering different treatment options and emphasising avoidance of suffering and therapeutic obstinacy.

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Conflicts of interest. None.

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Appendix 1: Final Questionnaire¹

This survey was conducted for academic purposes, aimed at ascertaining the opinions of parents of children with hypoplastic left ventricle treated in a high-complexity hospital.

The data remained confidential to the interviewer and no personal information was disclosed to protect anonymity.

GENERAL INFORMATION

Interviewee: Mother Father Both
 Mother’s date of birth:/ . . . /
 Father’s date of birth:/ . . . /
 Mother’s level of education:
 Father’s level of education:
 How is your family constituted (number of children and age; do mother and father live together; do they live with other family members)?

INFORMATION RECEIVED

- 1) When was your child’s illness diagnosed?
 - a. Prenatal
 - b. Postnatal
- 2) If your child’s illness was diagnosed prenatally, were you offered to terminate the pregnancy?
 - a. Yes
 - b. No
- 3) How did you receive the information that confirmed that your child had left ventricular hypoplasia? (Check the answer(s) that most identifies you)
 - a. “We took it as something which we would have to live with”
 - b. “It came as a surprise”
 - c. “We didn’t know what to do”
 - d. “We took it as a punishment”
 - e. “We took it as an opportunity to learn”
 - f. Others:
- 4) Before the first surgery, was the information given by the professionals sufficient? (Mark with a cross: 1 if you totally disagree and 5 if you totally agree).

1	2	3	4	5
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- 5) How was the transmission of information provided by the medical team regarding the severity and prognosis of your child’s illness?
 - a. Optimistic
 - b. Realistic
 - c. Pessimistic
 - d. Neutral
- 6) Before the first surgery, were you able to elaborate on the information received by understanding the process your child was going through?
 - a. A lot
 - b. A little
 - c. Not at all

¹Question 14 (about quality of life of the child) was not delivered to parents of diseased children.

- 7) After receiving the medical information about your child's illness, did you seek a second medical opinion?
- Yes
 - No

DECISION-MAKING PROCESS

- 8) Which of the following reasons most influenced decision-making about your child?
- That he/she survive longer
 - That he/she not suffer
 - That he/she have a good quality of life
 - That we be at peace knowing we had done everything possible
 - Others:
- 9) Were you able to ask questions and were they answered satisfactorily?
- Yes
 - No
- 10) Do you consider that your opinion was taken into account by the medical team to define the treatment?
- They took the decision we proposed
 - It was a decision we made together
 - They made the decision without taking our opinion into account
- 11) Would you have liked to participate in other ways in the decision-making process?
- Yes, but I did not have the opportunity
 - Yes, but it would have required more time for elaboration
 - No, I preferred to let the physicians make the decisions
 - No, I felt comfortable in the way I participated
- 12) Were there non-medical factors that influenced your decision-making?
- Yes
 - No
- Which ones?
- 13) Did the opinion of other members of your family (grandparents, children, siblings, etc.) influence your decision-making?
- Yes
 - No
- In what way?

QUALITY OF LIFE AND RELIGIOUS BELIEFS

- 14) How do you rate your child's current quality of life?
- Very good
 - Good
 - Neither good nor poor
 - Poor
 - Very poor
- If you wish, please justify your answer:
- 15) Do your religious beliefs influence your decisions?
- A lot
 - Somewhat
 - Not at all
 - I have no religious beliefs

PERSONAL EXPERIENCE

- 16) What has been the social impact of your child's illness? (You can check one or more options)
- We had a hard time coping with it emotionally so as to not isolate ourselves from others
 - We became disorganized and family life suffered
 - It mainly affected our work
 - We had good support from family and friends
 - It brought us together as a family
 - We felt the presence of God and lived in peace
- 17) If you knew parents who were going through the first phase of the same disease as your child, what experience would you share with them? (You can check one or more options)
- That the priority is for him/her to survive
 - That they should not start surgical treatment and only receive comfort care
 - That they should know how to limit treatment if necessary
 - That the priority should be to avoid suffering
 - That they should not feel guilty regardless of how their child's disease evolve.
 - Other experiences:
- 18) Were you adequately prepared to take your child home after the interventions were performed?
- Yes
 - No
- 19) Is there anything else you would like to share that is not contained in the questionnaire?

Thank you for completing this survey. The information collected is very important to improve our work and to be closer to our patients and families who are going through this disease.