

Original Article

# The Experience of Uncertainty in Mothers Caring for Children at Home after Palliative Heart Surgery

Dewi Puriani<sup>1</sup>, Allenidekania Allenidekania<sup>1</sup>, Yati Afyanti<sup>1</sup>

<sup>1</sup>Department of Paediatric Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia.

## ABSTRACT

**Objectives:** Palliative heart surgery is a compelling option for some children with congenital heart disease for which corrective heart surgery is not yet possible due to its complexity. As primary caregivers, mothers have the challenge of providing optimal care to their children at home post-surgery. This study aims to explore the experiences of mothers who are caring for children recovering from palliative heart surgery at home. The research applied descriptive, qualitative and phenomenology design.

**Material and Methods:** This study was conducted in Jakarta. The participants were 15 mothers of palliative heart surgery patients from seven provinces in Indonesia; Jakarta, Aceh, Bali, North Sumatra, West Java, Central Java and Banten. Data were collected using semi-structured interviews through the WhatsApp video call application and analysed using the Colaizzi method.

**Results:** Mothers often felt uncertain about how to provide the best care and felt that their needs for hospital services to assist them went unmet.

**Conclusions:** This study has implications for the development of nursing services related to discharge planning for palliative heart surgery patients.

**Keywords:** Children with congenital heart disease, Experience of mothers, Palliative heart surgery

## INTRODUCTION

Congenital heart disease (CHD) is a birth defect that causes abnormalities in the structure, function and circulation of the heart and large blood vessels. The estimated incidence of CHD in the world is 5–8 per 1000 live births.<sup>[1]</sup> The principle of handling CHD is carried out as soon as possible, through either corrective or palliative heart surgery.<sup>[2]</sup> The goal of palliative heart surgery is to improve the general condition of infants and children who suffer from CHD. At present, palliative surgery is a strong option for some cases where corrective surgery is not yet possible due to the baby's age is still too young or when intracardiac repair may lead a higher mortality risk than staged procedure.<sup>[3]</sup>

There is a high risk of morbidity, growth impairment and even death among infants and neonates who have undergone palliative heart surgery during the waiting period for the next stage of surgery, called the interstage period,<sup>[4]</sup> and 10–18.9% of all palliative heart operations result in death during this time.<sup>[4-6]</sup> Underlying risk factors include respiratory tract

infections that could cause hemodynamic disturbances, CHD complexity, nutritional and feeding disorders, low socioeconomic conditions, premature birth and low birth weight.<sup>[4,7]</sup>

Caring for children at home after palliative heart surgery is a challenge for mothers. They have to manage many factors, including risks due to the shunt insertion performed in most procedures, the child's failure to thrive due to inadequate calorie intake, increased metabolic requirements, and gastrointestinal, genetic and other extracardiac disorders.<sup>[8,9]</sup> Palliative heart surgery procedures require the patient to have surgery more than once, which can affect the psychological, social and even financial well-being of the parents.<sup>[5,10]</sup>

Mothers of children with CHD need support to understand their child's disease and how to manage it day-to-day. They need both access to competent care for their children and the ability to learn from the health-care professionals administering the care.<sup>[11]</sup> so that they can better understand the disease, treatment and potential complications.<sup>[12]</sup> Health-

\*Corresponding author: Allenidekania Allenidekania, Department of Paediatric Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia. [alleni@ui.ac.id](mailto:alleni@ui.ac.id)

Received: 09 July 2021 Accepted: 05 October 2022 Published: 20 January 2023 DOI: 10.25259/IJPC\_453\_20

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-Share Alike 4.0 License, which allows others to remix, transform, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

©2023 Published by Scientific Scholar on behalf of Indian Journal of Palliative Care

care teams need to employ different strategies in conveying information depending on the specific needs of the recipients. In this study, the experience of mothers in this circumstance will be explored using a phenomenological approach to better understand the realities of caring for their children at home after palliative heart surgery for congenital heart defects.

## MATERIAL AND METHODS

A descriptive and phenomenology design was used to focus on the lived experience of each participant. Purposive sampling was used to recruit the mothers involved in this study. A total of 15 mothers were interviewed over a period of 4 months. Their ages ranged from 30 to 46 years and all cared for their children at home for at least 1 year after palliative heart surgery. The ages of the children at the time of the study ranged from 30 months to 11 years. The palliative heart surgery procedures that were performed included the Bidirectional Cavo Pulmonary Shunt (BCPS), Blalock-Taussig Shunt and Fontan/Hemifontan procedure among others.

This study obtained ethical approval from the Ethics Committee of the Faculty of Nursing at Universitas Indonesia. Before data collection, researchers collaborated with administrative officers at a cardiovascular centre in Jakarta and the administrator of the WhatsApp group 'Jantung Istimewa' to obtain data on potential participants. They then contacted the candidates through WhatsApp Messenger to explain the research. Informed consent was then obtained for audiotaped interviews. The ethical principles of anonymity, confidentiality, non-maleficence, autonomy, beneficence and justice were upheld. Data validation was achieved through credibility, dependability, confirmability and transferability.

For data collection, a semi-structured in-depth interview with an open-ended question was conducted in Jakarta through the WhatsApp video call application with each participant. Each interview was conducted in Bahasa Indonesia, lasted about 30–60 min and was recorded using the T60 Digital Voice Recorder. There were no physical or emotional barriers in collecting the data among the 15 participants. The recorded interviews were then transcribed verbatim and analysed using the Colaizzi method.

## RESULTS

The two main themes identified in this study are as follows: Mothers often felt uncertain about how best to take care of their children post-surgery, and they did not feel their needs for hospital services and assistance were met.

### Feelings of uncertainty

Mothers often felt uncertain when caring for children after palliative heart surgery. All study participants stated that they did not have sufficient knowledge and information about scheduling and plans for further operations. The

following statements from participants confirm this: '...the catheterisation has been done from 2018 until now; there is no certainty about the upcoming surgery. It's been 2 years. Hopefully, there won't be a repeat catheterisation anyway...' (Participant 11) and '...the doctor said there will be a second operation-and even a third...' (Participant 12)'. Some felt confused and wondered about the series of steps that needed to be taken before their child could have the next procedure. This was seen in a statement from Participant 2:

'...we as the patient's parents do not know the actual plot of how to hasten to carry out the surgery...' (Participant 2). Almost all the mothers expressed anxiety about caring for their children at home. They were particularly worried by the possibility that their child would die while waiting for the next procedure, as evidenced by one participant's statement: '...If my child has had the surgery, it's like we're satisfied he didn't die waiting...' (Participant 3). There was also concern that operations could cause new problems in the future: 'It feels really sad, I think that the first operation was so sad... seeing my child being operated on and yet there were still problems...kidney problems, lung problems. O Allah, I felt so sad...' (Participant 5).

Some mothers dealt with denial and had trouble believing that their child needed to undergo additional surgery. In their minds, their children seemed to be doing better after their original surgery and further procedures did not seem necessary: '...Especially now that the child is healthy, seems to be healthy and already gaining weight...her development is good, her activity is good...does she need another operation?...' (Participant 10).

Some mothers dealt with denial and had trouble believing that their child needed to undergo additional surgery. In their minds, their children seemed to be doing better after their original surgery and further procedures did not seem necessary: '...Especially now that the child is healthy, seems to be healthy and already gaining weight...her development is good, her activity is good...does she need another operation?...' (Participant 10).

### Unmet needs for hospital services

These mothers have a considerable need for hospital services that seems to go unfulfilled. Several mothers mentioned a desire for clarity in terms of further action plans from the hospital. Mothers wanted to feel more secure in their connection to the hospital and to the surgeons performing the procedures. They expressed a desire to be able to ask questions of the surgeon in regards to when their children would be having additional surgery, among other things. One mother stated this in the following quote: '...I need his (surgeon) phone number, to ask him directly to make sure of my child's queue order...' (Participant 3). They also expressed a desire for the presence of parties from the hospital who would follow-up after surgery, as stated by one mother: '...I want someone from the hospital to follow-up, at least we feel that we are being monitored...' (Participant 7).

Being able to better connect with hospitals would help mothers feel more secure about the details of the future surgeries was one thing that was asked by all participants. This is confirmed by the following participant statements: '... Every time we do the follow-up control, I ask whether the results of the surgical conference will come out, it was said

that it hasn't come out yet, I'm confused about where else to ask...'. (Participant 2) and 'Well, I hope that through the WhatsApp message, we will know the schedule, the operating schedule at least, next month or when so we do not wait in uncertainty...'. (Participant 15).

For these mothers, the need for clarity in terms of whether further surgery will be required, and, if not, what will be required has not been met. They usually end up waiting for long periods of time and receiving insufficient information, as one mother stated, 'I want the operation done immediately... because we've been waiting for more than a year...we already completed administrative matters, so we just have to wait for a call, said the surgeon.' (Participant 4).

The lack of information as to when the next operation will be performed has an impact on the diagnostic tests that must be repeatedly performed as a condition of the operation. This pressure was felt by most mothers and shown by the participant statement as follows: '...The catheterisation, it has been 3 times.it was last year in July, I do not know, there was no news on the schedule...'. (Participant 9).

## DISCUSSION

While caring for their child at home after palliative heart surgery, there is a sense of uncertainty and anxiety for the mother. These feelings arise primarily because of the lack of clarity as to when the next step in the process of care for the child will happen.<sup>[13]</sup> Research that has been conducted by Jackson *et al.*,<sup>[14]</sup> found a direct relationship between the level of complexity of the CHD and, therefore, the necessity of repeated surgical procedures with the level of uncertainty experienced by families, especially parents. They observed that uncertainty was felt by all mothers regarding the diagnosis, type and schedule of subsequent actions that the child had to undergo, such as recatheterisation plans, subsequent operations and the number of times; they had to carry out follow-up controls.

This study illustrates that most mothers who have children with complex CHD that have undergone palliative heart surgery feel the need for clarity on the type and estimated timeframe for subsequent procedures because they need to prepare themselves and their children, especially if they live far from the heart centre. However, this is not always easy, because there are many factors in play when determining the scheduling of the next heart surgery. These include the individual clinical conditions of the child related to growth and development, nutritional status and the results of post-previous palliative heart surgery diagnostic tests related to the size of the pulmonary artery anastomosis, the presence of systemic collateral to the pulmonary, as well as other associated heart malformations.<sup>[15,16]</sup>

Uncertainty also arises in mothers due to unclear timelines and lack of specificity. Mothers often felt that they did not understand the actual course of action, which resulted in

repeated complementary diagnostic procedures such as cardiac catheterisation and ear-nose-throat and dental examinations, which, in turn, increased costs and created feelings of being stuck for both mother and child. Diagnostic procedures performed on pre-cardiac surgery patients, such as cardiac catheterisation, are not often done, and therefore result in a higher level of uncertainty when compared to more commonly performed procedures. It takes familiarity formed from experiences in this particular environment to avoid uncertainty.<sup>[13]</sup> In the context of a palliative cardiac post-operative care environment, diagnostic procedures and disease complexity can hinder the development of this familiarity, leading to uncertainty for the mother.

The mother also feels anxious when caring for children at home after palliative heart surgery. The anxiety that arises is, of course, based on the fear of something bad happening to the child. There are many potential risks, such as the failure of the next operation, the possibility of the child's death and new issues arising after surgery. This finding is in line with the previous research by Cantwell-Bartl and Tibballs,<sup>[17]</sup> which states that parents who care for children at home after palliative surgery for CHD live with a lot of stress, including anxiety about the possibility of the death of the child even if the child is in good condition.

Anxiety can also be a consequence of denial in the mother, resulting from a feeling of distrust in the diagnosis. According to Wei *et al.*<sup>[18]</sup> one of the critical moments for parents who have children with CHD is when they are first given the diagnosis. The mother is then able to adapt to the new situation and gain perspective once she begins to understand the condition of the child. So if, after this time, there is still anxiety in the mother, this does not come simply from the severity of the illness, but rather from the way the mother adapts as an individual.<sup>[19-21]</sup>

The impact of post-operative conditions can also be felt by non-nuclear family members and some close friends.<sup>[22]</sup> Some mothers expressed feelings of anxiety that had been communicated to them by grandparents in regards to the condition of their grandchild. Some of the questions that can indicate anxiety include 'Is it necessary to have another operation? Is not the child already healthy, already gaining weight?' This lack of understanding from other family members then creates more stress for the mother. Mishel<sup>[13]</sup> states this through his theory that the support system influences uncertainty, whether directly or indirectly. The support system inadvertently creates additional uncertainty when there is ambiguity and lack of information about the condition of the child.

Mothers have expressed several needs for hospital services that go unfulfilled while they are caring for their children at home after surgery. These include a desire for easy connection with the hospital, including a monitoring of the condition of their child by the hospital while the child is being treated at home,

accessibility of cardiac services in rural areas, better access to information regarding queues of action and clarity regarding supporting diagnostic examinations. These unmet needs demonstrate that there are obstacles in the interaction between parents and the hospital. Parents often do not know who to contact and can feel unsure about the accessibility and capacity of certain hospital services that they deem essential.<sup>[23]</sup>

Some mothers expressed their desire to be able to make direct contact with the heart surgeon to better make decisions regarding the schedule and plan for the next stage of heart surgery. They also generally hoped that the hospital would contact them to carry out direct monitoring of the condition of their children, as well as optimise of heart services in their particular regions. This desire comes from the fact that, even though alternate heart services are available, there is still an obligation to the hospital where the operation took place. The inability of mothers to have quick and direct access to medical personnel at the hospital where their child is being treated can increase anxiety.<sup>[24]</sup>

In this study, uncertainty can be defined as the psychological effects that have been seen in most mothers that are caring for their children after palliative heart surgery. This sense of uncertainty begins when CHD is first diagnosed, is exacerbated by having to make decisions on palliative action and continues into post-surgical treatment at home. The child's return home leaves question marks for the mother in regards to whether it is possible for the child's heart to ever be 'perfect,' which leads to a spiral. The mother then wonders if 'perfection' is possible, when the procedure to achieve 'perfection' will be carried out, or if it is enough to hope for a miracle so that the child does not need to undergo surgery again. Improvement in the child's condition can exacerbate these questions. In this uncertain condition, mothers still have to find a way to get access to services that may be out of their reach. When health-care professionals are able provide support and answers to the mothers, a sense of security is created.<sup>[11]</sup>

There are several similarities in theme between this study and previous research conducted by Wray *et al.*<sup>[25]</sup> in the UK. Wray's research also produced an overview of the psychological impact of child care at home after CHD-related heart surgery on parents. Wray's study is also related to stress stemming from lack of parental knowledge about the child's condition, uncertainty of how to care for the child once they return home and the burden on parents to be 'up-to-date' on the child's condition and able to prepare adequate information when dealing with healthcare workers. However, what distinguishes it from this study is that, in Wray's study, parents felt more knowledgeable to begin with regarding the condition and treatment of their children. This is because before leaving the heart centre, parents were provided with contact information for cardiac nurses at the local hospital, in addition to non-medical support, namely peer groups.

The uncertainty of disease prognosis is a challenge for nurses who provide care for chronic conditions.<sup>[26]</sup> CHD complex is a chronic condition that requires a nurse to have an active role in the care process, especially for those patients who require palliative heart surgery. This research has implications for the development of nursing science, especially the development of Standard Operating Procedures for nursing care regarding post-palliative cardiac surgery discharge, planning related to problems that may arise after palliative heart surgery for CHD patients, as well as meeting the expressed needs of mothers for special services through preparation for the post-surgery period through a family-centred care approach. For this reason, it is important that, when conducting post-cardiac surgery discharge planning assessments in children, nurses pay attention to the different needs of each CHD case. Ideal discharge planning begins at the time the child enters for care before heart surgery and includes the assessment of parents' ability to adjust to changes in the child's health status.<sup>[22]</sup>

This study found that the level of maternal anxiety increased when caring for children at home after palliative heart surgery, due in large part to uncertainty and the difficulty of obtaining access to information from competent parties at the hospital. These findings parallel the isolated experiences of parents in England when they faced difficulty in accessing post-discharge health services after cardiac surgery in children with CHD.<sup>[25]</sup> In Wray's study, effective interventions are suggested to strengthen the families' ability to provide care and cope with stress based on each families' needs and priorities. These include the implementation of support programmes, psychological counselling, family-centred empowerment programmes, the introduction of social support services and regular interaction with a health-care provider.<sup>[27]</sup>

### Research limitations

Several limitations were dealt with in this study. There is a risk of bias, since the researcher is also a nurse who was in charge of the room where a participant's child was cared for; so, when collecting data, few of the participants saw the researcher as a nurse, not as a researcher.

Result validation was done by providing the results of the data analysis in the form of themes to the participants through a WhatsApp application message, telephone call or video call depending on each participant's situation; not all the mothers could open files sent electronically.

There were also limitations in terms of the variation in the participants in this study. First, among the 15 participants, only two of them were working mothers. Second, palliative heart surgery in children is still dominated by one procedure, BCPS, so the experience of mothers who care for children after other palliative heart surgeries is less explored. However, variations in terms of age and diagnoses of children provide sufficient generalisation aspects.

In terms of data collection, it was possible for the researchers to observe housing conditions and patterns of interaction between the mothers and their children through the use of online media such as WhatsApp video calls, although this could not fully replace traditional face-to-face observations. This resulted in limited in-depth interview fulfilment in addition to receiving shorter responses from participants.

## CONCLUSION

Researchers have explored the experiences of mothers in caring for children at home after palliative heart surgery and two main concerns repeatedly presented themselves. Mothers often feel uncertain and anxious and have unmet needs for hospital services, especially in regards to receiving relevant information. The role of nurses is very important in the ongoing assessment of information needs and in facilitating family connection with the hospital, especially in post-palliative heart surgery circumstances. Further research can be carried out to evaluate the effectiveness of discharge planning in post-palliative heart surgery.

## Declaration of patient consent

Patient's consent not required as there are no patients in this study.

## Financial support and sponsorship

This research was financially supported by the PUTI Grant Universitas Indonesia 2020.

## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

- Rohit M, Shrivastava S. Acyanotic and cyanotic congenital heart diseases. *Indian J Pediatr* 2018;85:454-60.
- Djer MM, Madiyono B. The congenital heart disease management. *Sari Pediatri* 2000;2:155-62.
- Yuan SM, Jing H. Palliative procedures for congenital heart defects. *Arch Cardiovasc Dis* 2009;102:549-57.
- Nieves JA, Uzark K, Rudd NA, Strawn J, Schmelzer A, Dobrolet N. Interstage home monitoring after newborn first-stage palliation for hypoplastic left heart syndrome: Family education strategies. *Crit Care Nurse* 2017;37:72-88.
- Stoffel G, Spirig R, Stiasny B, Bernet V, Dave H, Knirsch W. Psychosocial impact on families with an infant with a hypoplastic left heart syndrome during and after the interstage monitoring period-a prospective mixed-method study. *J Clin Nurs* 2016;26:3363-70.
- Ugonabo N, Hirsch-Romano JC, Uzark K. The role of home monitoring in interstage management of infants following the norwood procedure. *World J Pediatr Congenit Heart Surg* 2015;6:266-73.
- Brown KL, Smith L. The patient journey to home after major cardiac surgery in infancy. *Prog Pediatr Cardiol* 2018;48:8-13.
- Hebson CL, Oster ME, Kirshbom PM, Clabby ML, Wulkan ML, Simsic JM. Association of feeding modality with interstage mortality after single-ventricle palliation. *J Thorac Cardiovasc Surg* 2012;144:173-7.
- Weston C, Husain SA, Curzon CL, Neish S, Kennedy GT, Bonagurio K, *et al.* Improving outcomes for infants with single ventricle physiology through standardized feeding during the interstage. *Nurs Res Pract* 2016;2016:9505629.
- Denniss DL, Sholler GF, Costa DS, Winlaw DS, Kasparian NA. Need for routine screening of health-related quality of life in families of young children with complex congenital heart disease. *J Pediatr* 2019;205:21-8.e2.
- Bruce E, Lilja C, Sundin K. Mothers' lived experiences of support when living with young children with congenital heart defects. *J Spec Pediatr Nurs* 2014;19:54-67.
- Armijo PP, León MR, Rodríguez CC. Instrument to assess educational programs for parents of children with congenital heart disease undergoing cardiac surgery. *Arch Argent Pediatr* 2017;115:439-45.
- Mishel MH. Uncertainty in illness. *Image J Nurs Sch* 1988;20:225-32.
- Jackson AC, Higgins RO, Frydenberg E, Liang RP, Murphy BM. Parent's perspectives on how they cope with the impact on their family of a child with heart disease. *J Pediatr Nurs* 2018;40:e9-17.
- Fraser CD Jr., McKenzie ED, Cooley DA. Tetralogy of fallot: Surgical management individualized to the patient. *Ann Thorac Surg* 2001;71:1556-61; discussion 1561-3.
- Ni ZH, Lv HT, Ding S, Yao WY. Home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations: A qualitative descriptive study. *PLoS One* 2019;14:e0213154.
- Cantwell-Bartl AM, Tibballs J. Parenting a child at home with hypoplastic left heart syndrome: Experiences of commitment, of stress, and of love. *Cardiol Young* 2017;27:1341-8.
- Wei H, Roscigno CI, Swanson KM. Healthcare providers' caring: Nothing is too small for parents and children hospitalized for heart surgery. *Heart Lung* 2017;46:166-71.
- Mishel MH. Reconceptualization of the uncertainty in illness theory. *Image J Nurs Sch* 1990;22:256-62.
- Mishel MH, Clayton MF. *Theories of Uncertainty in Illness*. 2<sup>nd</sup> ed. New York: Springer Publishing Company; 2008. p. 2018-9. Available from: <https://www.remote-lib.ui.ac.id:2076/docview/189491287?accountid=17242>
- Stewart JL, Mishel MH. Uncertainty in childhood illness: A synthesis of the parent and child literature. *Sch Inq Nurs Pract* 2000;14:299-319; discussion 321-6.
- Wong DL. *Wong's Essentials of Pediatric Nursing*. Missouri, United States: Mosby; 2001.
- Kosta L, Harms L, Franich-Ray C, Anderson V, Northam E, Cochrane A, *et al.* Parental experiences of their infant's hospitalization for cardiac surgery. *Child Care Health Dev* 2015;41:1057-65.
- Lushaj EB, Nelson K, Amond K, Kenny E, Badami A, Anagnostopoulos PV. Timely post-discharge telephone follow-up is a useful tool in identifying post-discharge complications patients after congenital heart surgery. *Pediatr Cardiol* 2016;37:1106-10.
- Wray J, Brown K, Tregay J, Crowe S, Knowles R, Bull K, *et al.* Parents' experiences of caring for their child at the time of discharge after cardiac surgery and during the postdischarge period: Qualitative study using an online forum. *J Med Internet Res* 2018;20:e155.
- Suryani RL, Allenidekania A, Rachmawati IN. Phenomenology study on nurses' experiences in understanding the comfort of children at the end-of-life. *Indian J Palliat Care* 2018;24:162-6.
- Dalir Z, Heydari A, Kareshki H, Manzari ZS. Coping with caregiving stress in families of children with congenital heart disease: A qualitative study. *Int J Commun Based Nurs Midwifery* 2020;8:127-39.

**How to cite this article:** Puriani D, Allenidekania A, Afyanti Y. The experience of uncertainty in mothers caring for children at home after palliative heart surgery. *Indian J Palliat Care* 2023;29:46-50.