

The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease

Silvio Simeone¹, Nicol Platone², Marco Perrone¹, Valentina Marras², Gianluca Pucciarelli³, Martina Benedetti², Grazia Dell'Angelo¹, Teresa Rea⁴, Assunta Guillari⁴, Paola Da Valle², Gianpaolo Gargiulo⁵, Stefano Botti⁶, Giovanna Artioli⁷, Giuseppe Comentale¹, Salvatore Ferrigno¹, Gaetano Palma¹, Stefania Baratta²

¹ General and Pediatric Cardiac Surgery Unit, Department of Advanced Biomedical Sciences, Federico II University Hospital, Naples; ² G. Pasquinucci Heart Hospital, Gabriele Monasterio Foundation, Massa; ³ Department of Biomedicine and Prevention, "Tor Vergata" University, Rome; ⁴ Public Health Department, Federico II University Hospital, Naples; ⁵ Haematology and HSCT Unit, Federico II University Hospital, Naples; ⁶ Haematology Unit, Azienda Unità Sanitaria Locale - IRCCS, Reggio Emilia; ⁷ Azienda Unità Sanitaria Locale - IRCCS, Reggio Emilia

Abstract. *Background:* Congenital Heart Diseases (CHDs) afflicting children are estimated in 8 per 1000 live births. Recent advances in surgery and medical treatments allowed an improvement in survival rates leading to changes in diseases management as chronic conditions. Parents involvement during clinical pathways is considered an essential component of care, but frequently they experience stress and anxiety conditions during the care path. These feelings are typical of the pre and peri-operative period, however they don't disappear easily and sometimes they can increase after hospital discharge, affecting the family environment and its behaviors. *Aim of the work:* The purpose of this qualitative study is to examine the lived experience of parents during the time just after their children return home from hospital after undergoing surgery for CHD. *Methods:* Parents were enrolled and interviewed as a prepositive sampling until concept saturation using Cohen's phenomenology approach. A quantitative approach was also applied using SF-12 questionnaire. The study was conducted in two Italian hospitals: the Pediatric Heart Surgery Center of the Fondazione Toscana G. Monasterio Institute in Massa and the Pediatric Cardiac Surgery Center of the Federico II University Hospital in Naples. *Results:* The main themes emerged after the analysis were "happiness and uncertainty"; "chronic psychophysical fatigue"; "the rediscovery of a strong link with health care professionals". *Conclusions:* Fully understand the life experience of these families will allow the implementation of targeted health interventions through the implementation of shared strategies and tools to reduce families and children discomfort after hospital discharge.

Key words: parents, qualitative, children, congenital heart disease, experience

Introduction

The current prevalence of Congenital Heart Disease (CHD) is eight children per 1000 live births (1, 2). The involvement and support of parents of sick children is an essential component of care and is universally recognized in the delivery of correct holistic

assistance by nurse (3). In the last ten years researchers have recorded a net improvement in survival rates of patients undergoing pediatric heart surgery interventions (4). The recent advances in cardiac surgery and pharmacological treatment have been shown to be increasingly effective in treating major congenital heart disease and to be able to change life-threatening

illnesses in chronic diseases (5, 6). Regardless of the type of heart defect a child has, families of children suffering from CHD experience anxiety and stress (7, 8). These feelings are typical of the pre and peri-operative period (9), however once at home, these feelings do not always disappear. When these children return home, mothers, who are often the primary caregivers, experience an increase in workload (10). This is inevitable given the fact that they must work night and day, and this generates additional stress from sleep disruption and chronic sleep deprivation (11). Fear and stress can lead to the development of acute stress disorder (ASD) and post-traumatic disorder (PTSD). Moreover, as with many caregivers of chronic pathologies, a social isolation begins that amplifies the perception of depressive disorders. Parents of children with CHD also reported higher levels of psychological symptoms, such as stress, anxiety and depression, than parents of healthy children (12).

This workload and the negative feelings that may arise within the parental dyad during a child's return home from hospital may affect the family environment and also the child him/herself (10, 13, 14). The children of parents that suffering from PTSD have a greater risk of developing sleep and eating disorders with consequent increase in the number of hospital accesses (12).

The purpose of this study is to understanding the lived experience of parents during the time just after their children return home from hospital after undergoing surgery for CHD.

Methods

Theoretical basis and sampling

For the purpose of conducting this study, we used the phenomenology of Cohen (15), which unites the descriptive phenomenology of Husserl and the interpretative phenomenology described by Gadmer. We chose this method in order to obtain a deeper understanding of both the lived experience and the meaning that people attach to that experience (16).

We used purposive sampling to recruit participants within two hospitals where children were given

cardiac surgery. Participant meeting the following inclusion criteria were enrolled in the study:

- 1) participants had to be considered by Italian law to be "of age";
- 2) had to be able to speak and understand Italian;
- 3) parents had to discharged as a result of surgical intervention from one to three months preceding the interview;
- 4) they must have expressed their willingness to participate in the study through signing a form to give their informed consent.

The exclusion criteria were: 1) the unwillingness to participate in the study; 2) the willingness to withdraw from it (at any time).

We informed participants that they could withdraw from the study at any time and that this would not compromise the assistance delivered by the hospital in any way.

We guaranteed total anonymity and explained the study type, its aims, and the mode of data collection, analysis and retention. This study fully complied with the principles of the Declaration of Helsinki.

Data collection and analysis

Before data collection, each researcher involved in the study ran a "bracketing" procedure in accordance with the methodology. That is, each researcher transcribed their own prejudices about the topic with the purpose of to set aside it, so that their extrapolation of the themes would not be unduly influenced by their personal attitudes and beliefs (15).

After this phase, four authors conducted the first in-person interviews. Researchers contacted the parents of the children who underwent *cardiac surgery* intervention a few days before their discharge to mention the study and ask their permission to be reconducted. After spending a month after discharge, researchers contacted the parents and made an appointment for interview. The interviews were conducted in a place chosen by participants in order to put them at ease.

Researchers conducted the interviews through a single open question in order to give maximum freedom of expression to participants (15). For the entire duration of the interview, interviewers maintained a welcoming attitude in order to facilitate honest and

open description of experiences. All interviews were audio-recorded. During and immediately after the interviews, researchers recorded notes in their research diaries and made field notes on the environment, interview, body language and their reflections. All interviews had a duration of about 30 minutes. We reached data saturation (17) at the 24th interview.

After participants signed the informed consent form, interviewers gathered all of their socio-demographic information and administered the SF-12 questionnaire (18). The SF-12 questionnaire is the short version of the SF-36 questionnaire (19). Using 12 of the 36 original questions, it asks participants to answer how it feels and how it is possible to carry out normal activities of living, considering the day on which they completed the questionnaire and the previous four weeks. Its score is composed of two synthetic indexes, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The advantages of this questionnaire, which is recommended for self-administration, are its brevity and relative ease of use. This instrument has been translated and validated for the Italian population (20, 21).

The interviews were transcribed word for word. All researchers immersed themselves in the data, reading and re-reading interview transcripts and field notes in order to proceed with the extrapolation of the themes. All themes were discussed among researchers until they reached an agreement. There were not discrepancies in this phase the validity of themes was obtained by requesting confirmation from the participants who were interviewed. All participants verified and confirmed the accuracy of the themes we extrapolated. The last phase of the analysis was the drafting of this manuscript.

Results

Participants were mainly women (75%), who were mothers of children who underwent cardiac surgery. The average age of the sample was approximately 38 years, and participants had a middle to high level of education. Almost all subjects were married or cohabiting and half had other children, but no one with congenital heart disease. The average duration of the hos-

pitalisation of participants' children was about 37 days, with a range between three and 120 days. At discharge only one child was resigned with device (Table 1).

Results of our start up analysis through the SF-12 administration are summarized in Table 2.

From analysis of the interviews, four main themes emerged. These were happiness and uncertainty about their child's return home, chronic psychophysical fatigue, the rediscovery of a strong bond with health operators and the desire to control their children constantly. Also, in parenting dyads to "first experience" to these main themes there was a sub-theme of constantly monitoring the weight of the child.

Happiness and uncertainty about the return home

All participants described an initial feeling of joy upon returning to their homes. However, the whole sample admitted that immediately after this joy was a feeling of fear that could be characterized as uncertainty. The return home represented to participants the reconquest of their spaces and habits and the reconquest of healing, but participants also described the feeling of being alone with their child. They felt that they had lost the immediate support of the entire team of caring hospital staff. A quotation that illustrates this main theme is: "...that is beautiful, back home, at last! Your home is always your home, even if at the beginning I was not for nothing quiet...the day of discharge I was almost terrified, a thousand questions, a thousand fears... joy and then still afraid...two things so opposite that lived together inside me..." (AZ01).

Chronic psychophysical fatigue

Another common theme present in the accounts of all participants was the feeling of chronic psychophysical fatigue. For all participants, the return home generated an increase in their workload that led to chronic tiredness. Participants described this tiredness as both physical and mental. Participants said they felt trapped in a vicious circle generated by an overload of work, just as a mother told us, "now as it is now a bit better ... but I've always been tired ... my body, my mind, I always head with my child, a thousand thoughts, we had to care for all, trivial things and more serious... wash it,

Table 1. Socio-demographic characteristics

		Frequency	Percentage	Mean (DS)	Range
Age				37.18 (8.976)	18–49
Parental Role	Father	6	25%		
	Mother	18	75%		
Highest Level of Education	Elementary	4	16.7%		
	Middle	8	33.3%		
	Hight	2	8.3%		
	University	10	41.7%		
Civil Status	Married	16	66.7%		
	Single	2	8.3%		
	Cohabiting	6	25%		
Other Children	Yes	12	50%		
	No	12	50%		
Other Children with CHD	Yes	0	0		
	No	12	100%		
Religion	Catholic	24	100%		
Average Hospitalisation Days				37Dd(25.39)	(3-120)
Resigned with the Deans	No	23			
	Yes	1	4.1%		

Table 2. Average SF12 Score

SF-12	Mean (\pm SD)
PCS	42.9 \pm 10.2
MCS	42.7 \pm 12.2

change it, follow every his step. In the night you no more sleep, a little to control him, a little for the thoughts that slip into your head. Then suddenly it comes again in the morning and starts ... home, husband, the child and other thousand things, in short this cycle never interrupts ...”(BX02).

The rediscovery of a strong bond with health operators

Almost as a consequence of the first theme extrapolated, study participants admitted to having noticed the absence of healthcare professionals dedicated to the assistance of their child. That presence that seemed superfluous now makes its absence felt. Professionals dedicated to helping silently had become part of their everyday life and had become almost like family. A mother told us, “...and then...suddenly...here

is to think of those nurse...you find them on the internet, the calling, you realize that you are missing their words, those words that have given to you the strength to face the difficulties, to go forward and be serene here today...it is true it is their job but is a sensation beautiful have the certainty that some of them...can you say friends? In short we became friends...and I am happy...”(EU05).

Wanting to control constantly

Another theme emerged is that participants felt a constant need to check everything that happened and everything that rotated around their child. Initially, this seemed to be a desire to enjoy the moment since the danger had been escaped, participants had new vision for the little things in life. Then, for all participants, this seemed to transform into a constant desire to control their child so that everything was under control and nothing could disturb what they expected. This constant control seemed to be parents' response to their fears, as reported by one of the participants, “...I want to enjoy every moment, I do not think to tomorrow or to the future...I want to live my son one day at a time

without thinking about other things... I would like to be with him when he is in school when he plays at the park when he relates to others ... in short, at any time of the day, but unfortunately sometimes it is not possible.... and I feel terribly guilty of this.... because I think that she could be feels bad ... when I'm with him I have everything, I have everything..."(A1).

Constant monitoring of their child's weight

The theme that emerged only in those who participated in the "first experience" was constant weight monitoring. The parents of children who underwent cardiac surgery for the first time and discharged waiting a possible second intervention reported this theme. It seems that for them, weight was a fundamental parameter, it is immediately measured for the purposes of correct management at home. To proper preparation for a new shelter is only the weight of your baby. A participant told us, "...I know that it is strange, but now do everything and you think of the weight of your child... and you think that if he increases is good, otherwise what is wrong? If it does not increase in weight is because I get something wrong? And at the end you find yourself weigh before eating, after eating, but not only, you weights he after a snack before and after the diuretic...so the weight is at the center of my thoughts because if it not increases in weight will not be able to do the next surgery, and I am afraid, I fear..." (CW03).

Discussion

The purpose of this study was to describe the lived experience of parents of children with heart disease who had returned to their homes after being discharged from hospital after heart surgery. Studies have concentrated on the diagnosis of congenital heart disease (22) and on the process of hospitalization (23), but little attention has been paid up until now to the experience of returning home. All participants surveyed admitted that the feeling of joy that comes from being able to return home transformed into a feeling of uncertainty. This is typical of those who must face a new situation without feeling safe. Just as in studies that investigate the hospital experience of these par-

ticipants (23), the fear of the unknown seems to dominate. The rediscovery of a strong bond with healthcare professionals dedicated to the assistance of their own child may be a theme because of the relationship that is established between parents and hospital personnel during the hospitalization of children (24, 25).

Chronic psychophysical fatigue is a typical experience of primary carers.

These results were also confirmed by the SF 12 scale. The average results of the participants show that these subjects report a perception of quality of psychological condition "below normal"; they having average scores below the level considered normal in the physical state (Physical Component Summary - PCS) and in psychological state (Mental Component Summary - MCS).

The increase in workload and desire to try to reconcile their private lives with this new role is typical of all participants who found themselves in this position (26, 27). Healthcare providers should identify these issues and offer structured educational programs to help families deal with such situations. In the specific case of heart surgery, the lived experiences of parents post-discharge emphasize the need for educational programs designed to support parents once their children have returned home (10). These programs have also been suggested for parents who feel the constant need to monitor their child's body weight (10). Regardless of whether children have been discharged with or without a device for power, fear related to the possible loss of weight is strongly present in these parents and is a source of stress that has been recognized in previous research (10). It seems that many experiences related to the hospitalization of cardiopathic children continue at home during the period after discharge. At this stage, supportive networks between professionals and parents, or even between parents and parents, seem to be an ideal solution for such situations (10).

This multicenter study showed similar results regardless of the geographical area where enrolled the participants. It seems therefore that the lived experience of parents is similar regardless of the hospital, welfare network, region and local health service. A common request expressed by parents was the desire for information and the desire to be prepared through specific educational programs.

Conclusion

Understanding the lived experience of parents whose children have recently been discharged after undergoing cardiac surgery for congenital heart disease can direct the design of specific educational programs designed to improve long term welfare outcomes in the dyad of care. The understanding of this lived experience also immediately allows a correct holistic approach to nursing care. Understanding the areas of support sought by parents of children undergone to cardiac surgery and discharged to home will direct nurses to specific areas of intervention and support within the care process.

Limitations

This multicenter study has the capacity to compare participants' unique experiences of programs of hospital discharge indirectly, however as the discharge programs in this study were not standardized, it is difficult to relate the results with these procedures.

The study's limitation is that it has not distinguished the various CHDs and any assistance issues that have occurred during surgery or during the post-operative period. This certainly could have influenced the experiential experience of the respondents.

References

1. Dolk H, Loane M, Garne E; European Surveillance of Congenital Anomalies (EUROCAT) Working Group. Congenital heart defects in Europe: prevalence and perinatal mortality, 2000 to 2005. *Circulation* 2011; 123(8): 841-9. doi: 10.1161/CIRCULATIONAHA.110.958405.
2. Hoffman JJ, Kaplan S. The incidence of congenital heart disease. *J Am Coll Cardiol* 2002; 39(12): 1890-900.
3. Kosta L, Harms L, Franich-Ray C, Anderson V, Northam E, Cochrane A, Menahem S, Jordan B. Parental experiences of their infant's hospitalization for cardiac surgery. *Child Care Health Dev* 2015; 41(6): 1057-65. doi: 10.1111/cch.12230.
4. Brown KL, Crowe S, Franklin R, et al. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. *Open Heart* 2015; 2:e000157.
5. Chen CW, Li CY, Wang JK. Growth and development of children with congenital heart disease. *J Adv Nurs* 2004; 47(3): 260-9.
6. Majnemer A, Limperopoulos C, Shevell MI, Rohlicek C, Rosenblatt B, Tchervenkov C. A new look at outcomes of infants with congenital heart disease. *Pediatr Neurol* 2009; 40(3): 197-204. doi: 10.1016/j.pediatrneurol.2008.09.014.
7. McCusker CG, Doherty NN, Molloy B, Rooney N, Mulholland C, Sands A, Craig B, Stewart M, Casey F. A controlled trial of early interventions to promote maternal adjustment and development in infants born with severe congenital heart disease. *Child Care Health Dev* 2010; 36(1): 110-7. doi: 10.1111/j.1365-2214.2009.01026.x.
8. Wernovsky G, Shillingford AJ, Gaynor JW. Central nervous system outcomes in children with complex congenital heart disease. *Curr Opin Cardiol* 2005; 20(2): 94-9.
9. Mussatto K. Adaptation of the child and family to life with a chronic illness. *Cardiol Young* 2006; 16 Suppl 3: 110-6.
10. Hartman DM, Medoff-Cooper B. Transition to home after neonatal surgery for congenital heart disease. *MCN Am J Matern Child Nurs* 2012; 37(2): 95-100. doi: 10.1097/NMC.0b013e318241dac1.
11. Meltzer LJ, Mindell JA. Impact of a child's chronic illness on maternal sleep and daytime functioning. *Arch Intern Med* 2006; 166(16): 1749-55.
12. Kolaitis GA, Meentken MG, Utens, Emwj. Mental Health Problems in Parents of Children with Congenital Heart Disease. *Front Pediatr* 2017; 5: 102. doi: 10.3389/fped.2017.00102
13. Vrijmoet-Wiersma CM, Ottenkamp J, van Roozendaal M, Grootenhuys MA, Koopman HM. A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiol Young* 2009; 19(6): 608-14. doi: 10.1017/S1047951109991831.
14. Davis D1, Davis S, Cotman K, Worley S, Londrico D, Kenny D, Harrison AM. Feeding difficulties and growth delay in children with hypoplastic left heart syndrome versus d-transposition of the great arteries. *Pediatr Cardiol* 2008; 29(2): 328-33.
15. Cohen MZ, Kahn D and Steeves R. Hermeneutic phenomenological research: A practical guide for nurse researchers. Thousand Oaks, California: Sage, 2000.
16. Simeone S, Coehn MZ, Savini S, Pucciarelli G, Alvaro R, Vellone E. The lived experiences of stroke caregivers three months after discharge of patients from rehabilitation hospitals. *Prof Inferm* 2016; 69(2): 103-12. doi: 10.7429/pi.2016.692103.
17. Porter E, Cohen M. Phenomenology. (2013) In: Trainor A, Graue E, eds. *Reviewing Qualitative Research*.
18. Ware JE Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996; 34(3): 220-33.
19. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992; 30(6): 473-83.
20. Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, Bullinger M, Kaasa S, Leplege A, Prieto L, Sullivan M. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the

- IQOLA Project. International Quality of Life Assessment. *J Clin Epidemiol* 1998; 51(11): 1171-8.
21. Kodraliu G, Mosconi P, Groth N, Carmosino G, Perilli A, Gianicolo EA, Rossi C, Apolone G. Subjective health status assessment: evaluation of the Italian version of the SF-12 Health Survey. Results from the MiOS Project. *J Epidemiol Biostat* 2001; 6(3): 305-16.
22. Fernandes JR. The experience of a broken heart. *Crit Care Nurs Clin North Am* 2005; 17(4): 319-27, ix.
23. Kosta L, Harms L, Franich-Ray C, Anderson V, Northam E, Cochrane A, Menahem S, Jordan B. Parental experiences of their infant's hospitalization for cardiac surgery. *Child Care Health Dev* 2015; 41(6): 1057-65. doi: 10.1111/cch.12230.
24. Hollywood, M. & Hollywood, E. The lived experiences of fathers of a premature baby on a neonatal intensive care unit. *Journal of Neonatal Nursing* 2011; 17: 32-40.
25. Cleveland LM. Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs* 2008; 37(6):66-91. doi: 10.1111/j.1552-6909.2008.00288.x.
26. Plank A, Mazzoni V, Cavada L. Becoming a caregiver: new family carers' experience during the transition from hospital to home. *J Clin Nurs* 2012; 21(13-14): 2072-82. doi: 10.1111/j.1365-2702.2011.04025.x.
27. Kerr SM, Smith LN. Stroke: an exploration of the experience of informal caregiving. *Clin Rehabil* 2001; 15(4): 428-36.

Received:

Accepted:

Correspondence:

Pucciarelli Gianluca, RN, MSN, PhD

Dipartimento di Biomedicina e Prevenzione,

Università di Roma Tor Vergata.

E-mail: g.pucciarelli81@gmail.com