Cardiology in the Young

cambridge.org/cty

Navigating the healthcare system with my child with CHD: parental perspectives on developmental follow-up practices

Marie-Eve Bolduc[1,2], Janet E. Rennick[2,3,4,5], Isabelle Gagnon[1,2], Eva Sokol[2], Annette Majnemer[1,2,5,6] and Marie Brossard-Racine[1,2,5,6]

[1]School of Physical and Occupational Therapy, McGill University, Montreal, Canada; [2]Research Institute of the McGill University Health Centre, Montreal, Canada; [3]Department of Nursing, The Montreal Children's Hospital, McGill University Health Centre, Montreal, Canada; [4]Ingram School of Nursing, McGill University, Montreal, Canada; [5]Department of Pediatrics, McGill University, Montreal, Canada and [6]Department of Neurology and Neurosurgery, McGill University, Montreal, Canada

Original Article

Cite this article: Bolduc M-E, Rennick JE, Gagnon I, Sokol E, Majnemer A, and Brossard-Racine M (2024) Navigating the healthcare system with my child with CHD: parental perspectives on developmental follow-up practices. *Cardiology in the Young* **34**: 37–43. doi: 10.1017/S1047951123001051

Received: 15 February 2023
Accepted: 14 April 2023
First published online: 4 May 2023

Keywords:
Congenital heart disease; child development; developmental follow-up; outcome

Corresponding author:
M. Brossard-Racine, School of Physical and Occupational Therapy, McGill University, 5252 Boulevard de Maisonneuve, 3F.46, Montreal, QC, Canada, H4A 3S5. Tel: 514-923-1934, 76295. Email: marie.brossardracine@mcgill.ca

Annette Majnemer and Marie Brossard-Racine shared senior authorship.

Abstract

Background: Parents of children with CHD face several barriers when trying to access the services needed to support their child's development. In fact, current developmental follow-up practices may not identify developmental challenges in a timely manner and important opportunities for interventions may be lost. This study aimed to explore the perspectives of parents of children and adolescents with CHD with respect to developmental follow-up in Canada. *Methods:* Interpretive description was used as a methodological approach for this qualitative study. Parents of children aged 5–15 years with complex CHD were eligible. Semi-structured interviews that aimed to explore their perspectives regarding their child's developmental follow-up were conducted. *Results:* Fifteen parents of children with CHD were recruited for this study. They expressed that the lack of systematic and responsive developmental follow-up services and limited access to resources to support their child's development placed an undue burden on their families, and as a result, they needed to assume new roles as case managers or advocates to address these limitations. This additional burden resulted in a high level of parental stress, which, in turn, affected the parent–child relationship and siblings. *Conclusions:* The limitations of the current Canadian developmental follow-up practices put undue pressure on the parents of children with complex CHD. The parents stressed the importance of implementing a universal and systematic approach to developmental follow-up to allow for the timely identification of challenges, enabling the initiation of interventions and supports and promoting more positive parent–child relationships.

Children with a complex CHD requiring open heart surgery in infancy are at high risk of developmental delays that may affect multiple developmental domains including motor skills, language, cognition, behaviour, and academic skills, which can arise at different time points during childhood and adolescence.[1–3] Although developmental difficulties are often mild to moderate, their frequency remains high, and they are associated with activity limitations at school, in self-care, and in community participation.[3,4] Thus, in recent years, the improvement of developmental outcomes has become a priority for both the clinical and research communities.

Improvement of developmental outcomes is dependent on a system that provides timely identification of developmental delays and subsequent referral for interventions. The effectiveness of these interventions is well supported in the literature on other high-risk infant populations, especially when implemented in a timely manner.[5] There is also growing evidence of the effectiveness of early interventions in the CHD population.[6,7] Moreover, children and families can be offered support, resources, and strategies to functionally adapt to some challenges that cannot be remediated.[8]

In an effort to optimise the developmental trajectories of children with CHD, the American Heart Association released a statement emphasising the importance of systematic follow-up services for all children with CHD.[9] This statement indicated that follow-up care for high-risk children with CHD should include surveillance (monitoring of parents' concerns over time), screening (questionnaires), and formal evaluations. The Cardiac Neurodevelopmental Outcomes Collaborative recently proposed to expand the follow-up strategies recommended by the AHA by suggesting new key time points for re-evaluating outcomes at 6, 18, and 36 months, 5, 8–9, 10–11, 13–14, and 18 years as well as additional assessment and screening tools.[10,11] However, studies conducted in various countries have reported on the presence of systemic barriers that limited the implementation of these recommendations.[12–14] In Canada, only half of the tertiary care centres that perform open heart surgery have structured

developmental follow-up programmes for children with CHD.[12] As a consequence, important opportunities for interventions to enhance outcomes may be lost.

A recent study has shown that parents of children with CHD highly value ongoing medical and developmental monitoring.[15] However, no study to date has specifically explored developmental follow-up experiences, needs, and preferences of families of children with CHD. Therefore, it remains unclear if the services offered meet the needs of families. Hence, the aim of this study was to explore the perspectives of Canadian parents of children and adolescents with CHD with respect to the developmental follow-up of their child.

Materials and method

Design

This qualitative study used interpretive description as a methodological approach. This methodology is designed to develop an understanding of human experiences that recognises each experience as constructed and contextual and is applicable to clinical contexts.[16]

Sample and procedure

Parents of children aged 5–15 years with CHD requiring open-heart surgery before 2 years of age and who had received health services in Canada were approached to participate in this study. Parents whose children were born prematurely or with genetic conditions were not eligible because these factors presumably affected the extent and type of developmental follow-up received. Participants were recruited through support groups, associations for families of children with CHD and flyers available in the Cardiology Divisions of selected children's hospitals across Canada. Participants were purposively recruited, from the pool of interested participants, to capture users' experiences across childhood, to represent different geographical locations (urban and rural), children from both sexes. Recruitment ended when no new themes were identified in two subsequent interviews.

Questionnaires including the age and sex of the child with CHD, geographical location, socio-economic information, and developmental challenges encountered were emailed to the families. Parents were asked to return the completed questionnaire prior to their interview. Semi-structured interviews were conducted by videoconference or telephone (see Interview Guide, Appendix A). Interviews were conducted in French or English. Informed consent was obtained from each study participant.

Analyses

Interviews were transcribed verbatim and the transcripts were analysed using NVivo 11 software (QSR International). Data were coded using both inductive and deductive coding. The deductive codes were based on the interview guide questions. Comparative analysis was then used to find commonalities and differences in parents' experiences. This method allowed us to discern commonalities between participants' experiences and preferences while acknowledging individual care experiences and their complexity. New conceptualisations of the parents' perspectives on the developmental follow-up of children with CHD were then developed. Finally, quotes that best represented the data collected were selected and the interpretations were developed. French quotes were translated by the first author. Data collection and analysis took place concurrently in an iterative manner. This allowed for tentative interpretations to be discussed in subsequent interviews, to allow participants to expand, clarify, and/or elaborate on the proposed interpretations.

Results

A total of 38 parents contacted us to participate in the study. Six were not eligible because they did not meet the inclusion criteria. Purposive sampling, using the criteria described above, was performed amongst the remaining 32 parents. We selected fifteen parents of children with CHD now aged 5–14 years (mean 9.4 years) to participate in the study. All interviews were conducted with parents who self-identified as mothers of children with CHD. In three cases, fathers were also present for part of the interview. Interviews lasted an average length of 42 minutes (range: 22–95 minutes). Participants' children were born with a wide variety of CHD diagnoses requiring open-heart surgery and families lived in different regions and had variable socio-economic characteristics (Table 1). All but one child with CHD experienced challenges in one or more of the following surveyed domains: academic performance (n = 10), behaviour (n = 9), gross motor (n = 9), fine motor (n = 9), cognitive (n = 7), and language (n = 6) skills. Four parents also reported that their child with CHD had sleep or sensory disturbances. In terms of developmental follow-up, 12 of the 15 parents had experienced screening and/or formal evaluation for their child at some point, and three had access to surveillance only.

Although parents of children with CHD expressed gratitude and were very satisfied overall with the care their child had received for their cardiac condition, most of them voiced concerns regarding the developmental follow-up they received. Two main themes provided an overview of the perspectives of parents on their child's developmental care:

A. Perspectives on current developmental follow-up care: Limited accessibility from identification to intervention;
B. Increased parental burden: Struggling to fill the gaps in developmental follow-up while seeking to establish a sense of normalcy.

Perspectives on current developmental care: Limited accessibility from identification to intervention

Lack of systematic and responsive developmental follow-up services across childhood

Even if most parents reported having access to a formal evaluation for their child through public services, private resources, or research studies, many parents expressed concerns with the absence of a systematic approach to developmental follow-up for all children with CHD at risk of developmental delays.

> *"I wish it was more just universal, that all kids get referred into whatever the program is in their community, at least for a primary assessment. In my ideal world, that is just more standard of care as opposed to something that you have to wait for a problem to be discovered and know how to navigate the system to get there . . . ."* (Participant 8)

Parents also voiced disquiets with regard to the responsiveness of current practices to formally identify the developmental delays or challenges their child was experiencing. They expressed that, sometimes, when they brought up concerns with their healthcare professionals, they preferred to wait and see if the problems their

https://doi.org/10.1017/S1047951123001051 Published online by Cambridge University Press

Table 1. Cardiac diagnoses and family demographics.

Child's primary congenital heart diagnosis*	5 Single ventricle physiologies
	• hypoplastic left heart syndrome
	• double outlet right ventricle
	10 Two ventricle physiologies
	• bicuspid aortic valve
	• ventricular septal defect
	• transposition of the great arteries
	• tetralogy of Fallot
	• arch interruption type A
	• severely dysplastic mitral valve
	• truncus arteriosus
Province of residence	2 Alberta
	7 British Columbia
	1 New Brunswick
	5 Quebec
Geographical regions	8 Rural (≥50 km from urban centre)
	4 Suburban (<50 km from urban centre)
	3 Urban (population >100,000)
Mother's highest level of education completed	0 High school completed
	8 CEGEP, College certification, or technical programme
	2 University graduation or standard 4-year college
	5 Graduate school (graduate degree)
Father's highest level of education completed	2 High school completed
	9 CEGEP, College certification, or technical programme
	1 University graduation or standard 4-year college
	3 Graduate school (graduate degree)
Family income	1 $20,000$–$39,999
	2 $40,000$–$59,999
	1 $80,000$–$99,999
	8 Above $100,000
	3 Prefer not to answer

CEGEP = Collège d'enseignement général et professionnel.
*As reported by parents.

child was facing would resolve by themselves. In these situations, they felt that they had to insist on obtaining a referral for further assessment or intervention. Therefore, most parents, especially first-time parents, stressed the importance of systematic developmental follow-up at key timepoints throughout childhood.

Conversely, two parents, including one whose child did not experience challenges, expressed that those formal evaluations can sometimes be stressful for both the child and the parents and that adding additional hospital visits can also be overwhelming, especially in the first years of life. In addition, one parent who was part of a research project found that using multiple questionnaires that often overlapped was both frustrating and time-consuming for them.

Parents were aware and sensitive to the lack of resources in the healthcare system. In response to this barrier, parents suggested a tiered approach where they could start with screening questionnaires and follow up with a formal evaluation only if the questionnaire raised concerns. Nevertheless, they insisted that an in-depth assessment of their child's challenges was essential before school entry. Furthermore, some participants identified the importance of a centralised follow-up process to facilitate the circulation of information between professionals to avoid having to describe difficult moments they had gone through on multiple occasions.

Supporting developmental needs: From community resources to education for parents and educators

Parents referred to intervention services were often confronted by the scarcity of resources both in the healthcare and educational systems. Participants reflected that the subtleness of challenges associated with their child's CHD and the absence of formal diagnoses for their developmental challenges may contribute to the difficulties in accessing the resources.

> *"We squeaked until we were able to get something [resources] because they often overlook kids that [have moderate difficulties], because they aren't as bad as other kids, or they feel that other kids are in more need of, and it's the kids that are in need but just kind of on the borderline that fall through the cracks".* (Participant 10)

The presence of waitlists for resources was also problematic, especially when referrals were not made in a timely manner. For families who lived further from large urban centres, the limited accessibility to professionals was even more striking.

Some parents had access to resources they appreciated. Parents from two provinces (British Columbia and New Brunswick) mentioned they could self-refer to a developmental follow-up programme or rehabilitation services for the first 3–5 years of life depending on the province. Other parents had access to community services to support their child development. For example, one parent had a weekly inclusive physical literacy class offered by students from various backgrounds such as kinesiology and physiotherapy, through a programme affiliated with their local college. Community services such as swim therapy were also found to be beneficial by parents of children with CHD. Finally, parents suggested that providing them with the tools and strategies to best support their child's development would be valuable.

Increased parental burden: Struggling to fill the gaps in developmental follow-up while seeking to establish a sense of normalcy

Parents of children with CHD expressed that they experienced high levels of stress. Initially, their stress was caused by their child's heart condition, the diagnosis, perinatal circumstances, and surgery. However, after this critical period, most parents began feeling anxious about their child's development. Many participants explained that the limitations in current developmental follow-up practices resulted in increased parental burden and stress as they had to fill these gaps if they wanted their child to receive the care they needed. Since developmental follow-up mostly took the form of surveillance, parents felt that the responsibility of identifying delays rested on their shoulders. Some parents identified that they had lower expectations for their child with CHD. Conversely, other parents felt that they were constantly keeping

https://doi.org/10.1017/S1047951123001051 Published online by Cambridge University Press

a critical eye on their child's development to ensure they could report any observed concerns to their healthcare practitioner. Identifying delays seemed especially difficult and stressful for first-time parents who did not have a point of comparison. This became an important source of stress for them.

> *"He was my first child, he had a major heart condition, I felt like such a first-time mom . . . I'm going to cry . . . who didn't have a lot of other moms going through the same thing. So it's really hard to know what is normal, and what is not normal."* (Participant 6)

Parents also expressed that they did not have the same opportunity to spend quality time with their child as a baby due to the stress they were experiencing, a decreased sense of empowerment and their child's critical health. One parent highlighted that the education on the medical management of their child they received completely eclipsed the education on the general infant care first-time parents typically receive.

> *"My son was our first child, so they forgot the normal things you need to do with a baby and the normal steps. Your child is so sick that at first it is like survival, but they must not forget that you are going home anyway with a baby, you have to take care of this baby. I need the basics. The other parents, they showed them how to wash their babies before they go home. We haven't been shown anything. I knew how to give her injections and gavage, but all the normal things were forgotten. [. . .] I find that there is this side there that they should not forget also, the human being."* (Participant 5)

Given the limited access to resources, parents often became advocates for their child to acquire the services they needed. The lack of systematic and centralised follow-up systems meant that parents had to navigate the healthcare system to find the resources they needed to support their child. Parents also felt they had to take on the roles of case manager to coordinate their child's appointments and ensure information was communicated to all professionals. The interviewees reported an overall sense of being overwhelmed by time and energy required by the multiple roles and the added responsibilities that they must take on. Some mothers even had to stop working given the amount of time required for these additional responsibilities.

> *"That's why I chose not to work [. . .], so I can have a little bit more time to be a case manager for my little one. [. . .] It's a lot for families. It's really a lot. It sucks your energy, I tell you. Emotionally, it drains you."* (Participant 7)

The parents expressed that these challenges not only have a profound impact on them, on their child with CHD, but also on the overall family dynamics and on other siblings. A number of parents shared how important community resources such as support groups with other parents of children with CHD are during these difficult times.

> *"We were very fortunate that as soon as we got the diagnosis, they connected us to [another family]. Obviously, everybody's experience is unique, but I do feel that's [. . .] important, it's almost like having a pillow for landing. Just to know you can talk to some people who had similar experiences . . . "* (Participant 14)

Discussion

Participants in this study stressed the importance of implementing systematic, accessible, and responsive developmental follow-up services, where information on the child and available resources is centralised and accessible across Canada. Without such a system, the burden of identifying delays and adequately supporting the needs of children with CHD falls on the shoulders of the parents, increasing their stress and ultimately impacting the entire family. As the healthcare focus for children with CHD expands beyond survival to improving developmental outcomes, it is important to ensure that family-centered care is authentically used across institutions. To our knowledge, this is the first study to report on the impact of the current gaps in services for children with CHD on the families and to describe parental perspectives of optimal follow-up for children with CHD in Canada.

Systematic developmental follow-up is required to identify challenges in a timely manner so that the resources can be put in place to support development, thus avoiding gaps in continuity of care. Although current guidelines[9–11] recommend formal evaluation at various time points during childhood, some parents suggested a tiered approach in which formal evaluation would be used only when screening results indicate suspicion of delays rather than systematic formal evaluations at all key time points. This approach has been successfully implemented in other countries[13] and could offer a cost-effective alternative to ensure that challenges are identified early before they have long-term consequences on the child. This process may also be less stressful and burdensome for the parents of children who experience fewer challenges and for youth with CHD. Hence, a thorough analysis of current barriers to implementation of systematic developmental follow-up approaches and a reflection on how the recommendations could be adapted to different contexts is warranted.

Parents were also concerned with the limited availability of resources to stimulate their child's development or interventions for identified difficulties both in the healthcare and school systems. This need for enhanced support throughout childhood and adolescence has also been reported by youth with CHD.[17] Enhancing the accessibility of resources within the school system needs to be formally examined in future studies. Nevertheless, the parents have identified various strategies that rely on education, community resources, telehealth, and other technologies that could be put in place to support their child's needs.

The participants in this study reported a heavy burden related to managing the care of their child with CHD. Parents expressed that they had to assume new roles such as case managers, administrators, or advocates, as a direct consequence of the current gaps in developmental follow-up practices. This is line with a previous Swiss study in which parents reported feeling exhausted from additional responsibilities with regard to the neuromotor development of their infant with CHD.[18] The increased burden resulted in increased levels of stress for participants in our study. This could explain, in part, the increased level of parental stress, anxiety, and depression reported in previous studies.[19,20] Studies have shown that parental stress is associated with the child's cognitive ability and behaviour.[21,22] Hence, this study further supports the need for screening for parental mental health and access to psychological and social supports for their child to be included as part of family-centered care. Those supports should include education on parental self-care and personal resilience as well as the promotion of healthy child development and supports for successful social participation.[23] Furthermore, the lack of quality time with their child and a decreased sense empowerment and self-efficacy was described as having an impact on the parent–child relationship by study participants. This could result in changes in parenting

https://doi.org/10.1017/S1047951123001051 Published online by Cambridge University Press

styles and decreased attachment between the mother and child.[24] Finally, welcoming a child with CHD may be associated with changes in family functioning.[25,26] A recent systematic review reported psychosocial well-being to be negatively impacted in 40% of siblings of children with CHD.[27] Thus, assessment and support for siblings also need to be considered. The paediatrics post-intensive care syndrome model can provide a framework for comprehensive family-centered care.[28]

This study presents some limitations. Indeed, our sample consisted almost exclusively of mothers and may not represent the views of fathers of children with CHD. Nevertheless, the mothers often described the experience they had as parents or as a family and some fathers were present during a portion of the interviews. In addition, despite our far-reaching recruitment strategy, we could not enroll participants from all 10 Canadian provinces; therefore, potential gaps and strategies that exist in provinces from which we did not have participants may have been missed.

Conclusion

The limitations of current developmental follow-up practices put undue stress and burden on Canadian parents of children with complex CHD. The parents stressed the importance of implementing a universal and systematic approach to developmental follow-up to allow for timely identification of challenges, enable initiation of interventions and supports, and promote more positive parent–child relationships. It is now essential that we identify strategies to facilitate the implementation of systematic approaches to developmental follow-up across the Canadian provincial healthcare systems.

Acknowledgements. We would like to thank the families who participated in our study.

Financial support. This study was supported by the Richard and Edith Strauss Canada Foundation. Marie-Eve Bolduc was supported by a scholarship from the Fonds de Recherche Québec-Santé and Foundation of Stars. Marie Brossard-Racine is supported by a Canada Research Chair in Brain and Child Development from the Canadian Institute of Health Research.

Conflicts of interest. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the McGill University Health Centre Research Ethics Board #2020-5921.

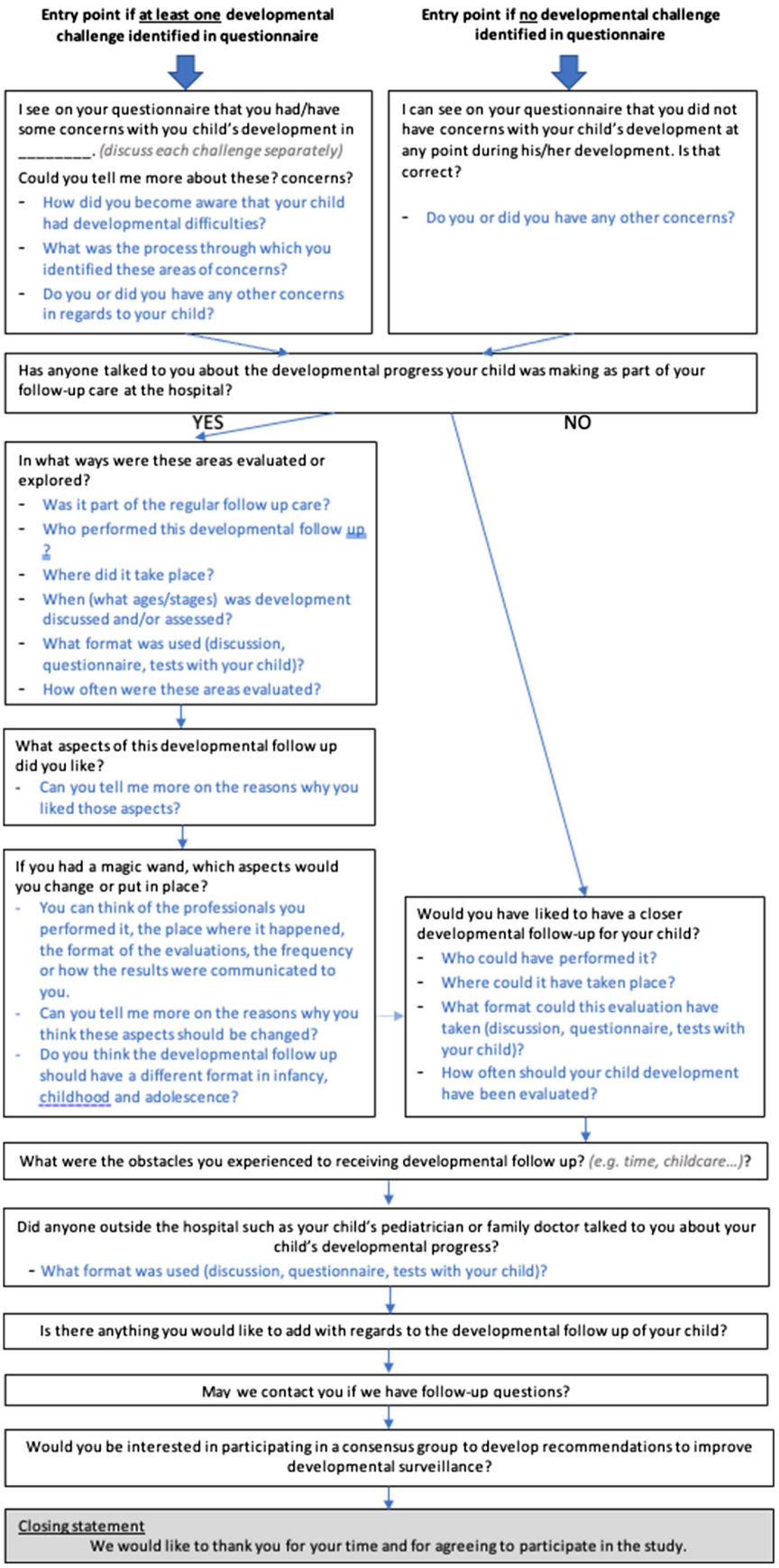
References

1. Latal B. Neurodevelopmental outcomes of the child with congenital heart disease. Clin Perinatol 2016; 43: 173–185. DOI 10.1016/j.clp.2015.11.012.
2. Bolduc M-E, Dionne E, Gagnon I, Rennick JE, Majnemer A, Brossard-Racine M. Motor impairment in children with congenital heart defects: a systematic review. Pediatrics 2020; 14610.1542/peds.2020-0083.
3. Bolduc ME, Rennick JE, Gagnon I, Sokol E, Brossard-Racine M, Majnemer A. Identifying developmental challenges of youth with congenital heart defects: a patient-oriented perspective. Child Care Health Dev 2023; 49: 258–267. DOI 10.1111/cch.13037.
4. Liamlahi R, Latal B. Neurodevelopmental outcome of children with congenital heart disease. Handb Clin Neurol 2019; 162: 329–345. DOI 10.1016/B978-0-444-64029-1.00016-3.
5. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Database Syst Rev 2015; 2015: CD005495. DOI 10.1002/14651858.CD005495.pub4.
6. Jobson MC. Effectiveness of behavioral intervention among congenital heart defect children. J Psychol Res 2021; 3: 23–28. DOI 10.30564/jpr.v3i2.3022.
7. Fourdain S, Caron-Desrochers L, Simard MN, et al. Impacts of an interdisciplinary developmental follow-up program on neurodevelopment in congenital heart disease: the CINC study. Front Pediatr 2020; 8: 539451. DOI 10.3389/fped.2020.539451.
8. Shevell M, Majnemer A, Platt RW, Webster R, Birnbaum R. Developmental and functional outcomes at school age of preschool children with global developmental delay. J Child Neurol 2005; 20: 648–653. DOI 10.1177/08830738050200080301.
9. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. Circulation 2012; 126: 1143–1172. DOI 10.1161/CIR.0b013e318265ee8a.
10. Ilardi D, Sanz JH, Cassidy AR, et al. Neurodevelopmental evaluation for school-age children with congenital heart disease: recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiol Young 2020; 30: 1–14. DOI 10.1017/S1047951120003546.
11. Ware J, Butcher JL, Latal B, et al. Neurodevelopmental evaluation strategies for children with congenital heart disease aged birth through 5 years: recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiol Young 2020; 30: 1609–1622. DOI 10.1017/S1047951120003534.
12. Bolduc M-E, Rennick JE, Gagnon I, Majnemer A, Brossard-Racine M. Canadian developmental follow-up practices in children with congenital heart defects: a national environmental scan. CJC Pediatr Congenit Heart Dis 2022; 1: 3–10. DOI 10.1016/j.cjcpc.2021.11.002.
13. Eagleson K, Campbell M, McAlinden B, et al. Congenital Heart Disease Long-term Improvement in Functional hEalth (CHD LIFE): a partnership programme to improve the long-term functional health of children with congenital heart disease in Queensland. J Paediatr Child Health 2020; 56: 1003–1009. DOI 10.1111/jpc.14935.
14. Knutson S, Kelleman MS, Kochilas L. Implementation of developmental screening guidelines for children with congenital heart disease. J Pediatr 2016; 176: 135–141.e2. DOI 10.1016/j.jpeds.2016.05.029.
15. Williams TS, McDonald KP, Roberts SD, et al. From diagnoses to ongoing journey: parent experiences following congenital heart disease diagnoses. J Pediatr Psychol 2019; 44: 924–936. DOI 10.1093/jpepsy/jsz055.
16. Thorne S. Interpretive Description. Left Coast Press, Walnut Creek, CA, 2008: 272 pp.
17. Bolduc M-E, Rennick JE, Gagnon I, Sokol E, Brossard-Racine M, Majnemer A. Identifying developmental challenges of youth with congenital heart defects: a patient-oriented perspective. Child Care Health Dev 2022; 49: 258–267.
18. Mitteregger E, Wehrli M, Theiler M, et al. Parental experience of the neuromotor development of children with congenital heart disease: an exploratory qualitative study. BMC Pediatr 2021; 21: 430. DOI 10.1186/s12887-021-02808-8.
19. Woolf-King SE, Anger A, Arnold EA, Weiss SJ, Teitel D. Mental health among parents of children with critical congenital heart defects: a systematic review. J Am Heart Assoc 2017; 6: e004862. DOI 10.1161/JAHA.116.004862.
20. Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: a literature review. Heart Lung 2015; 44: 494–511. DOI 10.1016/j.hrtlng.2015.08.005.
21. 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: 197–204. DOI 10.1016/j.pediatrneurol.2008.09.014.

22. Golfenshtein N, Hanlon AL, Deatrick JA, Medoff-Cooper B. The associations between infant development and parenting stress in infants with congenital heart disease at six and twelve months of age. J Pediatr Nurs 2020; 51: 1–7. DOI 10.1016/j.pedn.2019.11.012.
23. Gramszlo C, Karpyn A, Demianczyk AC, et al. Parent perspectives on family-based psychosocial interventions for congenital heart disease. J Pediatr 2020; 216: 51–57.e2. DOI 10.1016/j.jpeds.2019.09.059.
24. Schmitz K. Vulnerable child syndrome. Pediatr Rev 2019; 40: 313–315. DOI 10.1542/pir.2017-0243.
25. Jackson AC, Frydenberg E, Liang RP, Higgins RO, Murphy BM. Familial impact and coping with child heart disease: a systematic review. Pediatr Cardiol 2015; 36: 695–712. DOI 10.1007/s00246-015-1121-9.
26. Werner H, Latal B, Valsangiacomo Buechel E, Beck I, Landolt MA. The impact of an infant's severe congenital heart disease on the family: a prospective cohort study. Congenit Heart Dis 2014; 9: 203–210. DOI 10.1111/chd.12123.
27. Schamong AS, Liebermann-Jordanidis H, Brockmeier K, Sticker E, Kalbe E. Psychosocial well-being and quality of life in siblings of children with congenital heart disease: a systematic review. J Child Health Care 2022; 26: 319–337. DOI 10.1177/13674935211012933.
28. Manning JC, Pinto NP, Rennick JE, Colville G, Curley MAQ. Conceptualizing post intensive care syndrome in children-the PICS-p framework. Pediatr Crit Care Med 2018; 19: 298–300. DOI 10.1097/PCC.0000000000001476.

https://doi.org/10.1017/S1047951123001051 Published online by Cambridge University Press

Appendix A.: Interview Guide



https://doi.org/10.1017/S1047951123001051 Published online by Cambridge University Press