

Running title: Parents' quality of life after congenital heart defect treatment decision

**Parents' Quality of Life and Health after Treatment Decision for a Fetus with Severe
Congenital Heart Defect**

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Abstract

Objective: This exploratory study examines differences in parents' quality of life by treatment decision and the child's survival outcome in the context of life-threatening congenital heart disease (CHD).

Methods: Parents of a fetus or neonate diagnosed with severe CHD enrolled in the observational control group of a clinical trial (NCT04437069) and completed quality of life (i.e., contact with clinicians, social support, partner relationship, state of mind), mental and physical health survey measures. Comparisons were made between parents who chose comfort-directed care or surgery and between those whose child did and did not survive.

Results: Parents who chose surgery and their child did not survive reported the most contact with their clinicians. Parents who chose comfort-directed care reported lower social support than parents who chose surgery and their child did not survive as well as poorer state of mind compared to parents who chose surgery.

Conclusions: Some aspects of parents' quality of life differed based on their treatment decision. Parents who choose comfort-directed care are vulnerable to some negative outcomes. Decision support tools and bereavement resources to assist parents with making and coping with a complex treatment decision is important for clinical care.

Key Words (3-6): congenital heart defect, parent quality of life, decision making, coping

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1. Introduction

Parents who have a fetus or neonate diagnosed with a life-threatening congenital heart defect (CHD) experience significant psychological distress.¹⁻³ While most CHDs can be repaired and result in good quality of life for the child, a subset of severe, life-threatening CHD diagnoses require early, intensive intervention, with low survival rates (e.g., 12.5% 5-year survival for hypoplastic left heart).^{4,5} Parents of a fetus or neonate diagnosed with severe CHD face an intense treatment decision with lifelong consequences — whether to pursue or forgo potentially life-sustaining interventions.⁶ To inform counseling and support for parents faced with this monumental decision, it is crucial to understand what impact different treatment decisions have on parents' quality of life and health.

A severe CHD diagnosis in a fetus or neonate imposes significant stress and emotional burden on parents who must cope with lost expectations of a healthy child while simultaneously making a life-changing treatment decision.⁷⁻¹⁰ Parents of a child with severe CHD report high psychological distress including post-traumatic stress, depression, and anxiety.^{3,11} While we know that parents experience poorer mental health at the time of the diagnosis and months later³, there is a limited understanding of how each treatment decision (e.g., comfort-directed care vs. surgery) may differentially affect parents' quality of life. Parents who have a surviving child with a chronic illness also face a greater risk for developing a chronic physical illness themselves;^{12,13} however, this risk is not well understood in the context of parents who have a child with severe CHD who survives past their first surgery.

Currently, we have limited knowledge about how parents' treatment decisions contribute to their quality of life after making a life-altering decision for their fetus or neonate with severe CHD. Moreover, most available studies on parental quality of life and health focus on those who

Parents' quality of life after congenital heart defect treatment decision chose surgery, therefore we know less about the quality of life of parents who chose comfort-directed care.^{11,14} Without this knowledge, the development of interventions to help support and maintain parent's well-being will likely remain difficult. The aim of this exploratory study was to address these gaps in the literature by exploring potential differences in parent-reported quality of life and health by treatment decision and survival outcome (i.e., whether or not the child survived after surgery).

2. Methods

This study used data from a clinical trial (NCT04437069) conducted at a children's hospital in the Intermountain West and focused on evaluating the effectiveness of a decision aid intervention. Eligible participants included parents of a fetus or neonate diagnosed with a complex CHD (e.g., hypoplastic left heart syndrome) that cardiologists acknowledged as severe where termination, comfort-directed care, or surgery were viable treatment options. Details on the protocol for parent trial are published elsewhere.¹⁵ For the purposes of this study, only participants enrolled in the observational control group (from 9/2018 to 12/2020) were included in analyses. Control group participants received standard care and were not exposed to the main study intervention testing a decision aid. This study has approval through the University of Utah Institutional Review Board. Three months after participants made their treatment decision, they were asked to complete survey measures using REDCap or via paper survey. REDCap is a secure web application for building and managing online surveys and databases. Medical information was collected through electronic health records.

Study Measures

Demographic questions included self-reported age, gender identity, race, ethnicity, education, and marital status. The fetus' CHD diagnosis was extracted from medical record data.

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Treatment decision was self-reported by participants in a survey (termination, comfort-directed care, or surgery).

The 3 month survey included the Impact of a Child with Congenital Anomalies on Parents,¹⁶ a validated questionnaire that assesses parents' quality of life, with several domains including: contact with clinicians (Cronbach's alpha [α]=.91; 4 items, e.g., "I am satisfied about my contacts with doctors"), social network support (α =.91; 6 items, e.g., "people around me support me"), partner relationship (α =.94; 5 items, e.g., "I feel my partner sympathizes with me"), and state of mind (α =.86; 4 items, e.g., "I feel guilty"). Response options ranged on a Likert-scale from 1 (strongly disagree) to 4 (strongly agree). The fear and anxiety domain was excluded in these analyses because items were only relevant if the child survived. Higher scores indicate better contact with clinicians, support from their social network, partner relationship, and state of mind.

The short-form 12-item health survey^{17,18} assessed participants' mental (α =.87; 6 items; e.g. "have you felt calm and peaceful?") and physical health (α =.69; 6 items, e.g., accomplished less due to physical health). Higher scores indicate better mental and physical health.

Statistical Analysis

R Studio Version 1.4.1106¹⁹ was used to conduct analyses. Given the small study sample and exploratory nature of this study, formal statistical comparisons between groups were not conducted. However, mean difference estimates with 95% confidence intervals²⁰ are reported to highlight potential directional differences between groups and whether confidence intervals include zero (i.e., signify no effect). Comparisons were made between parents who chose comfort-directed care and parents who chose surgery (both overall and according to whether the

Parents' quality of life after congenital heart defect treatment decision (child did or did not survive). Bivariate correlations between key study outcomes are included in Appendix Table A1.

3. Results

3.1 Demographic Characteristics, Treatment Decision, and Correlations

Of 35 parents enrolled in the observational control arm, 11 did not complete the 3-months post-decision survey (31% attrition) and one was excluded due to a postnatal diagnosis as their experience would likely differ than prenatal diagnoses (Figure 1). The study sample includes 23 parents who were mostly female (78%), non-Hispanic White (87%), married (91%) and had some college education (70%; Table 1). There were 16 who chose surgery, 7 who chose comfort-directed care, and no parents who chose termination.

Table 2 presents mean scores by treatment decision and survival outcome (i.e., for parents who chose surgery, whether or not their child survived) along with mean difference and 95% confidence intervals²⁰ for each study outcome. Bivariate correlations were also computed between quality of life domains and the health survey (see Appendix Table A1). Greater social network support, better partner relationship, and better state of mind were associated with higher mental health scores.

3.2 Quality of Life

3.2.1 Contact with clinicians. Parents who had a child that did not survive following surgery ($M=16.00$) reported higher perceived levels of contact with their clinicians than parents who had a child who survived following surgery ($M=12.91$; difference=3.09; 95% confidence interval [CI]= 0.91 to 5.27) and those who chose comfort-directed care ($M=13.43$; difference=-2.57 95% CI, -4.95 to -0.19). Of note, there was no variability in the scores for parents who

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chose surgery and their child did not survive—all parents selected the maximum response values.

Confidence intervals indicated no differences between other comparison groups.

3.2.2 Social network. Parents who chose comfort-directed care ($M=18.57$) reported lower social network support compared to parents who chose surgery and their child did not survive ($M=23.40$; difference= -4.83 ; 95% CI, -7.37 to -2.29). Confidence intervals were consistent with no difference between other comparison groups.

3.3.3 Partner relationship. Overall, parents rated their relationship with their partner favorably. When comparing by treatment decision, mean scores were similar for each group and confidence intervals were consistent with no difference between groups.

3.3.4 State of mind. Parents who chose comfort-directed care ($M=7.71$) reported poorer state of mind compared to parents who chose surgery ($M=11.27$; difference= -3.55 ; 95% CI, -6.15 to -0.95), particularly compared to parents who chose surgery and their child survived ($M=11.30$; difference= -3.59 ; 95% CI, -6.31 to -0.87). Confidence intervals were consistent with no difference between other comparison groups.

3.2 Mental and Physical Health

Confidence intervals indicated no differences in mental or physical health between groups (Table 2).

4. Discussion and Conclusion

4.1 Discussion

Parents of a fetus or neonate diagnosed with complex CHD are at risk for experiencing significant strain on their mental health as a result of having to choose between termination, comfort-directed care, or surgery. This exploratory study begins to address the critical need to understand how to adequately support families who have made various treatment decisions and

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face different outcomes with their affected children to improve their quality of life. To do so, our findings illustrate some potential differences that are important to consider. Overall, parents who chose comfort-directed care reported less contact with clinicians, lacked social support and reported a poorer state of mind compared to parents who chose surgery. Notably, parents who chose surgery and their child did not survive reported the highest level of contact with clinicians. Future research needs to examine this in further detail and address if there is a need for enhanced support and counseling for parents who chose comfort-directed care and the potential for healthcare professionals to provide more equitable support across treatment decisions.

While there were differences in parents reported contact with clinicians, it is unclear what contributed to those differences. It is possible that parents who chose comfort-directed care naturally interact less within the healthcare system because they may have more contact with hospice and are not meeting with surgeons, which reduces the opportunity for contact with their clinicians. Parents have also reported that clinicians do not discuss comfort-directed care much as a treatment option.²¹ Palliative care specialists are not regularly integrated into care and are underutilized,²² but could further enhance support to parents who choose comfort-directed care alongside cardiology specialists. Decision aids are an additional strategy that could be used to improve patient-clinician communication and shared decision making, which provide information about each treatment option, potential questions to ask clinicians, and exercises to help parents identify their values and goals related to care. Decision aids can be delivered outside of the clinic to provide additional time for families to learn about their options and facilitate shared decision making with their clinicians.¹⁵

Parents who chose surgery and whose child did not survive reported maximum levels of contact with their clinicians suggesting that the parents felt well-supported by their clinicians.

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There may be areas of improvement for parents who chose comfort-directed care and for parents who chose surgery whose child survived. Parents whose child undergoes surgery and have to manage subsequent home care report challenges from extreme caregiving demands and having to learn disease management.²³⁻²⁵ This could potentially underlie the observed differences within the surgery group. Implementing video- or telephone-based homecare support programs²⁶ may be one cost-effective method for improving support for parents who have to learn home care and disease management following surgery for their child.

Parents who chose comfort-directed care reported less social network support compared to parents who chose surgery and their child did not survive. These findings are particularly striking given that the survival outcome of the child was the same in both groups, yet parents who chose comfort-directed care perceived less support than parents who chose surgery. Attitudes surrounding perceived active (i.e., surgery) vs. passive (i.e. comfort-directed care) treatment may be driving these differences.^{27,28} Increased implementation and availability of hospital-based bereavement services such as making phone calls, providing resource materials, and connecting families to appropriate support groups could be one method for supporting parents after the death of their child.²⁹

There are mixed findings within the literature on the family functioning and quality of partner relationships among families of a child diagnosed with CHD. Some studies have found negative impacts, while others have found greater family cohesion and support.^{30,31} Overall, parents within the study reported that they mostly had high-quality relationships with their partner. Exploratory findings also indicated no differences by treatment decision for partner relationship, which can offer important and reassuring information for parents as they consider these critical decisions. These preliminary findings can help with counseling parents to know that

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regardless of what treatment decision parents make they can still maintain the quality of the relationship with their partner.

Parents who chose comfort-directed care also reported a poorer state of mind and had mental health scores that were between 10 to 11 points lower than parents who chose surgery and their child survived. Grief and distress from losing their child could be contributing to differences between these groups. Although the confidence intervals did not meet criteria to confirm statistically significant differences, scores in this study sample ($M = 29-41$), were low relative to the general young adult U.S. population (e.g., $M=52.9$).^{17,18} Considering the lower state of mind scores among these parents and associations with mental health scores from our findings, there still appears to be clinically meaningful differences regarding their mental health. These findings suggest the need for additional research and development of interventions to support parents who choose comfort-directed care.

Although a previous study found that caregivers of a child with a chronic disease were at risk for poorer physical health themselves,^{12,13} parents' physical health scores did not differ and were mostly similar to the average U.S. population. Given that data were collected within a 3-month time frame and among young adults, these findings offer limited insight into the impact on physical health as such an effect may not occur that quickly or in this particular age group. Future studies with a longer follow-up time point, may address the impact on physical health.

Limitations of the present study were that we had a small sample size due to the rarity of the condition, having a single-site for the study, and challenges regarding longitudinal follow-up for parents navigating and coping with complex decisions and outcomes. While this limited our power to conduct a broader range of statistical analyses, we believe these exploratory findings are important to share as they begin to uncover parents' experiences during a critical treatment

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decision that have not been previously explored. Conducting a larger-scale longitudinal study, perhaps through the development and maintenance of a registry of parents who received a complex CHD diagnosis for their fetus or neonate, will be necessary to achieve robust power for statistical analyses. Lastly, the contact with clinicians subscale did not specify the type of clinician or the timing related to parents contact with clinicians. Future research should consider collecting more specific data to better understand communication deficits and at which time point parents need additional support (e.g., pre or post-decision).

4.2 Conclusions

The aim of this exploratory study was to add to the limited literature on how parent's quality of life may differ based on the life-altering treatment decision for their fetus or neonate diagnosed with complex CHD. Some aspects of parents' quality of life differed based on their treatment decision as well as the outcome of this decision. Parents who chose comfort-directed care are vulnerable to experiencing poorer social network support and quality of life. Developing interventions and resources, such as decision support tools and bereavement resources, are important next steps to improve coping for parents who choose comfort-directed care.

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Declarations of interest

The authors have indicated they have no financial relationships and no potential conflicts of interest relevant to this article to disclose.

Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees from the University of Utah Institutional Review Board.

References

1. Biber S, Andonian C, Beckmann J, et al. Current research status on the psychological situation of parents of children with congenital heart disease. *Cardiovascular diagnosis and therapy*. 2019;9(Suppl 2):S369-S376. doi:10.21037/cdt.2019.07.07
2. Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: A literature review. *Heart & Lung*. 2015;44(6):494-511. doi:10.1016/j.hrtlng.2015.08.005
3. 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. *Journal of the American Heart Association*. 2017;6(2)doi:10.1161/JAHA.116.004862
4. Oster ME, Lee KA, Honein MA, Riehle-Colarusso T, Shin M, Correa A. Temporal trends in survival among infants with critical congenital heart defects. *Pediatrics*. 2013;131(5):e1502-e1508. doi:10.1542/peds.2012-3435
5. Best KE, Rankin J. Long-Term Survival of Individuals Born With Congenital Heart Disease: A Systematic Review and Meta-Analysis. *Journal of the American Heart Association*. 2016;5(6)doi:10.1161/JAHA.116.002120.
6. Andrews RE, Simpson JM, Sharland GK, Sullivan ID, Yates RW, Yates RWM. Outcome after preterm delivery of infants antenatally diagnosed with congenital heart disease. *Journal of Pediatrics*. 2006;148(2):213-216. doi:10.1016/j.jpeds.2005.10.034
7. Connor JA, Kline NE, Mott S, Harris SK, Jenkins KJ. The meaning of cost for families of children with congenital heart disease. *Journal Of Pediatric Health Care: Official Publication Of National Association Of Pediatric Nurse Associates & Practitioners*. 2010;24(5):318-325. doi:10.1016/j.pedhc.2009.09.002
8. Brosig CL, Whitstone BN, Frommelt MA, Frisbee SJ, Leuthner SR. Psychological distress in parents of children with severe congenital heart disease: the impact of prenatal versus postnatal diagnosis. *Journal of Perinatology*. 2007;27(11):687-692. doi:10.1038/sj.jp.7211807
9. Kolaitis GA, Meentken MG, Utens EMWJ. Mental Health Problems in Parents of Children with Congenital Heart Disease. *Frontiers in pediatrics*. 2017;5:102. doi:10.3389/fped.2017.00102
10. Alkan F, Sertcelik T, Yalın Sapmaz S, Eser E, Coskun S. Responses of mothers of children with CHD: quality of life, anxiety and depression, parental attitudes, family functionality. *Cardiology in the young*. 2017;27(9):1748-1754. doi:10.1017/S1047951117001184
11. Gregory MR, Prouhet PM, Russell CL, Pfannenstiel BR. Quality of life for parents of children with congenital heart defect: A systematic review. *Journal of Cardiovascular Nursing*. 2018;33(4):363-371.
12. Brehaut JC, Kohen DE, Garner RE, et al. Health among caregivers of children with health problems: findings from a Canadian population-based study. *American Journal of Public Health*. 2009;99(7):1254-1262. doi:10.2105/AJPH.2007.129817
13. Brehaut JC, Garner RE, Miller AR, et al. Changes Over Time in the Health of Caregivers of Children With Health Problems: Growth-Curve Findings From a 10-Year Canadian Population-Based Study. *American Journal of Public Health*. 2011;101(12):2308-2316. doi:10.2105/AJPH.2011.300298

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14. Andonian C, Beckmann J, Biber S, et al. Current research status on the psychological situation of adults with congenital heart disease. *Cardiovascular diagnosis and therapy*. 2018;8(6):799-804. doi:10.21037/cdt.2018.12.06
15. Delaney RK, Pinto NM, Ozanne EM, et al. Study protocol for a randomised clinical trial of a decision aid and values clarification method for parents of a fetus or neonate diagnosed with a life-threatening congenital heart defect. *BMJ open*. 2021;11(12):e055455. doi:10.1136/bmjopen-2021-055455
16. Mazer P, Gischler SJ, Koot HM, Tibboel D, van Dijk M, Duivenvoorden HJ. Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis. *Health and quality of life outcomes*. 2008;6:102. doi:10.1186/1477-7525-6-102
17. Care RH. 12-Item Short Form Survey (SF-12).
18. Jenkinson C, Layte R, Jenkinson D, et al. A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? *Journal of public health medicine*. 1997;19(2):179-186. doi:10.1093/oxfordjournals.pubmed.a024606
19. Team R. *RStudio: Integrated Development Environment for R*. RStudio.
20. *rstatix: Pipe-Friendly Framework for Basic Statistical Tests*. . Version 0.7.0. 2021. Accessed September 29, 2021. <https://CRAN.R-project.org/package=rstatix>
21. Delaney RK, Pinto NM, Ozanne EM, et al. Parents' decision-making for their foetus or neonate with a severe congenital heart defect. *Cardiology in the Young*. 2021:1-8. doi:10.1017/S1047951121003218
22. Marcus KL, Balkin EM, Al-Sayegh H, et al. Patterns and outcomes of care in children with advanced heart disease receiving palliative care consultation. *Journal of Pain and Symptom Management*. 2018;55(2):351-358. doi:10.1016/j.jpainsymman.2017.08.033
23. Rempel GR, Ravindran V, Rogers LG, Magill-Evans J. Parenting under Pressure: a grounded theory of parenting young children with life-threatening congenital heart disease. *Journal of Advanced Nursing (John Wiley & Sons, Inc)*. 2013;69(3):619-630. doi:10.1111/j.1365-2648.2012.06044.x
24. Wei H, Roscigno CI, Swanson KM, Black BP, Hudson-Barr D, Hanson CC. Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing. *Heart & Lung*. 2016;45(2):154-160. doi:10.1016/j.hrtlng.2015.12.007
25. Sjostrom-Strand A, Terp K. Parents' Experiences of Having a Baby With a Congenital Heart Defect and the Child's Heart Surgery. *Comprehensive child and adolescent nursing*. 2019;42(1):10-23. doi:10.1080/24694193.2017.1342104
26. McCrossan B, Morgan G, Grant B, et al. A randomised trial of a remote home support programme for infants with major congenital heart disease. *Heart*. 2012;98(20):1523-1528. doi:10.1136/heartjnl-2012-302350
27. Tomlinson D, Bartels U, Gammon J, et al. Chemotherapy versus supportive care alone in pediatric palliative care for cancer: Comparing the preferences of parents and health care professionals. *Canadian Medical Association Journal*. 2011;183(17):E1252-E1258. doi:10.1503/cmaj.110392
28. Zikmund-Fisher BJ, Sarr B, Fagerlin A, Ubel PA. A matter of perspective: choosing for others differs from choosing for yourself in making treatment decisions. *Journal of general internal medicine*. 2006;21(6):618-622. doi:10.1111/j.1525-1497.2006.00410.x
29. Donovan LA, Wakefield CE, Russell V, Cohn RJ. Hospital-based bereavement services following the death of a child: A mixed study review. *Palliative Medicine*. 2015;29(3):193-210. doi:10.1177/0269216314556851

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30. Sood E, Lisanti AJ, Woolf-King SE, et al. Parent mental health and family functioning following diagnosis of CHD: a research agenda and recommendations from the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiology in the young*. 2021;31(6):900-914. doi:10.1017/S1047951121002134

31. Riikonen A, Aho AL, Rantanen A. The relationship satisfaction of parents to children with congenital heart disease. *Interpersona: An International Journal on Personal Relationships*. 2019;13(1):57-71. doi:10.5964/ijpr.v13i1.325

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Table 1

Baseline characteristics of the study participants

Characteristic	Study sample (N=23)	Attrition sample (N=11)
Age — years		
Mean	27±4	28±4
Median	26	26
Interquartile range	26–29	26–32
Gender — no. (%)		
Female	18 (78)	9 (82)
Male	5 (22)	2 (12)
Race/Ethnicity — no. (%)		
Non-Hispanic White	20 (87)	10 (91)
Hispanic: White	2 (9)	1 (9)
Hispanic: Other race	1 (4)	-
Education — no. (%)		
Some high school education or less	4 (17)	-
Some college or 2-year degree	8 (35)	7 (64)
4-year degree or higher	11 (48)	4 (36)
Marital Status — no. (%)		
Currently married	21 (91)	9 (82)
Never married	2 (9)	1 (9)
Divorced	-	1 (9)
Fetus' CHD diagnosis — no. (%)		
Hypoplastic left heart syndrome or hypoplastic left variant	12 (63)	5 (45)
Ebstein's anomaly/dysplastic tricuspid valve with severe regurgitation	3 (15)	2 (18)
Tetralogy of Fallot with absent pulmonary valve	1 (5)	1 (9)
Pulmonary atresia with intact ventricular septum	1 (5)	1 (9)
Heterotaxy, single ventricle	1 (5)	1 (9)
Complex single ventricle	1 (5)	1 (9)

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Table 2

Outcome measures according to treatment decisions and survival outcome

	Comfort-directed care (N=7)	Surgery (N=16)	Survived (N=11)	Did not survive (N=5)	Comfort-directed care vs. Surgery	Comfort-directed care vs. Surgery, Did not survive	Comfort-directed care vs. Surgery, Survived	Surgery, Did not survive vs. Surgery, Survived
					<i>Mean difference estimate (95% CIs)</i>			
ICCAP								
<i>Higher scores indicate better perceived status</i>								
Contact with clinicians (Range: 4 – 16)	13.43±2.57	13.88±3.03	12.91±3.24	16.00±0.00	-0.45 (-3.10 to 2.21)	-2.57 (-4.95 to -0.19)	0.52 (-2.42 to 3.46)	3.09 (0.91 to 5.27)
Social network (Range: 6 – 24)	18.57±2.70	21.38±3.90	20.45±4.41	23.40±0.89	-2.80 (-5.79 to 0.18)	-4.83 (-7.37 to -2.29)	-1.88 (-5.44 to 1.67)	2.95 (-0.09 to 5.98)
Partner relationship (Range: 5 – 20)	18.57±2.44	18.50±2.03	18.27±2.20	19.00±1.73	0.07 (-2.28 to 2.42)	-0.43 (-3.11 to 2.26)	0.30 (-2.18 to 2.78)	0.72 (-1.54 to 3.00)
State of mind (Range: 4 – 16)	7.71±2.36	11.27±3.26	11.30±2.87	11.20 ±4.32	-3.55 (-6.15 to -0.95)	-3.49 (-8.76 to 1.79)	-3.59 (-6.31 to -0.87)	-0.10 (-5.36 to 5.16)
SF-12								
<i>Higher scores indicate better mental and physical health</i>								
Mental health (Range: 0 - 100)	29.13±13.7 6	40.37±11.8 9	41.00±10.86	38.97±15.23	-11.23 (-24.56 to 2.10)	-9.84 (-29.53 to 9.86)	-11.87 (-25.45 to 1.71)	-2.03 (-20.58 to 16.51)
Physical health (Range: 0 - 100)	53.11±5.29	50.21±8.16	51.27±8.58	47.89±7.48	2.90 (-3.11 to 8.92)	5.23 (-4.04 to 14.5)	1.85 (-5.08 to 8.78)	-3.37 (-12.95 to 6.19)

Note. Plus-minus values are means ±SD; 95% Confidence Intervals which do not include zero are emphasized with bolded text; ICCAP=impact of a child with congenital anomalies on Parents, SF-12=short-form 12-item health survey.

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Figure 1. Consort diagram for study recruitment, enrollment, and final analytic sample.