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“There’s no acknowledgement of what this does to people”: A qualitative exploration of mental health among parents of children with critical congenital heart defects

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Abstract

Aims and Objectives—The purpose of this study was to explore the psychological impact of parenting a child with a critical congenital heart defect (CHD), and the feasibility and acceptability of integrating psychological services into pediatric cardiology care.

Background—Children with critical CHD are at an increased risk for long-term behavioral, social, and emotional difficulties. Data suggest that this risk is partially attributable to parental mental health, which is a stronger predictor of long-term behavioral problems in CHD children than disease-specific and surgical factors. Parental stress and mental health is thus an important intervention target, especially among high-risk families.

Design—This article presents data from a qualitative study with 25 CHD parents (n = 15) and providers (n = 10).

Methods—Using thematic analysis, semi-structured in-depth interviews were transcribed and coded by the first and second author in order to identify major themes and sub-themes.

Results—Results of the interviews were organized into four major themes: (I) The psychological impact of parenting a child with critical CHD, (II) Factors that influence the psychological impact of parenting a child with critical CHD, (III) How and when to psychologically support CHD parents, and (IV) Feasibility and acceptability of integrating psychological support into CHD care. Providers and parents endorsed the integration of mental health treatment into routine CHD care, and identified several practical issues related to feasibility (e.g., funding, space) that should be considered prior to implementation.

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Conclusions—Parents of children with critical CHD need access to mental health services, and integrating these services into routine pediatric cardiology care is a novel and practical way for parents to receive the treatment they need.

Relevance to clinical practice—Suggestions for how the field of pediatric cardiology could begin to integrate mental health services into CHD treatment are provided.

Keywords

Childhood illness; Integrated Care; Congenital Heart Disease; Parent; Mental Health

Approximately 40,000 children are born every year with a congenital heart defect (CHD) in the United States (U.S.), making CHD the leading cause of birth defect-associated infant illness and death (Centers for Disesea Control and Prevention [CDC], 2016). Of these children, 25% require one or more cardiac surgeries in the first year of life (CDC, 2016), and while the life expectancy of these children has improved considerably over the last decade (Best & Rankin, 2016; Oster et al., 2013), the field is only beginning to understand the lifelong psychological impact of these early medical interventions.

Children with critical CHD (i.e., CHD that requires cardiac surgery in the neonatal period) are at an increased risk for long-term behavioral, social, and emotional difficulties (McCusker, Armstrong, Mullen, Doherty, & Casey, 2013; Shillingford et al., 2008). Data suggest that this risk is partially attributable to parental mental health, which has been shown to be a stronger predictor of long-term behavioral problems in CHD children than disease-specific and surgical factors (e.g., time spent on cardiopulmonary bypass, cyanotic vs acyanotic defect; McCusker et al., 2013). It is well established that compromised parental mental health can lead to long term cognitive and behavioral problems in healthy children (Lyons-Ruth, Wolfe, & Lyubchik, 2000; McPeak, Sandrock, Spector, & Pattishall, 2015; Mirhosseini et al., 2015; Tronick & Reck, 2009), and several theories have been articulated over the last 40 years to explain how parenting stress, parental mental health, and child development are related (e.g., Abidin, 1990; McCubbin & Patternson, 1983). According to Abidin and Burke's (1978) theoretical model of parenting stress, compromised parental mental health can disrupt parent-child attachment, increase dysfunctional parenting behaviors, and result in maladaptive child outcomes. Parental stress and mental health are thus important intervention targets, especially among high-risk families.

Parents of children who experience a major illness or acute injury that necessitates time in an intensive care unit (ICU) experience significantly greater parenting stress and an increased risk for mental health problems, compared to parents of healthy children (Cousino & Hazen, 2013; Lefkowitz, Baxt, & Evans, 2010; Nelson & Gold, 2012; Ward-Begnoche, 2007). For example, whereas the prevalence of postpartum depression in the general population is 10–15%, it is estimated to be 39% among mothers of infants admitted to the neonatal ICU (Lefkowitz et al., 2010). CHD parents may be an especially vulnerable sub-group given the unique financial, familial, and parenting challenges associated with CHD treatment (Wei, Roscigno, Hanson, & Swanson, 2015). Indeed, a systematic review of 30 studies on mental health among parents of children with critical CHD found that up to 80% report clinically significant symptoms of trauma, 25% to 50% report elevated symptoms of depression and/or anxiety, and 30% to 80% report severe psychological distress (Woolf-King, Anger, Arnold, Weiss, & Teitel, 2017).

Qualitative research with CHD parents can provide an in-depth examination of the factors that increase mental health morbidity in this population, and offer guidance on how best to intervene. Two qualitative studies have examined parenting expectations and experiences among CHD parents. In a study with 14 parents of children prenatally diagnosed with critical CHD, parents were asked about how they coped with the diagnosis and how it impacted their expectations for parenting (McKechnie & Pridham, 2012). Findings revealed that even before the birth of their child, parents were focused on strategies to “regulate the intensity of despair,” which for some parents involved the cultivation of hope, management of negativity, and eventual acceptance of the diagnosis, and for others involved emotion suppression, an impaired ability to accept the diagnosis, and an increased risk for subsequent mental health problems. Extending these findings, Sjostrom-Strong and Terp (2017) interviewed 10 Swedish parents about their experiences parenting a child with a critical CHD two years after their child’s cardiac surgery. Parents explained that while the surgery felt like a “turning point” in their child’s care, it also produced intense feelings of fear and anxiety. The importance of social and emotional support during this time was also highlighted, with parents expressing a desire to connect with other CHD families and to have access to providers that could also provide emotional support (Sjostrom-Strand & Terp, 2017).

Additional qualitative research is needed in order to understand the time at which psychological symptoms for CHD parents are most acute, factors that influence the intensity of these symptoms, and strategies for how to best address mental health in the context of routine pediatric cardiology care in the U.S. There is indeed precedence for the integration of mental health services in adult (Pomerantz et al., 2010; Post, Metzger, Dumas, & Lehmann, 2010), pediatric (Foy, 2010a; Foy, Kelleher, & Laraque, 2010), and neonatal health care settings (Hall, Phillips, & Hynan, 2016), with nurses often playing a significant role in the delivery and/or coordination of such care. The potential of integrating these type of services into pediatric cardiology care has not been explored in the U.S., however. We present here a qualitative study with 25 pediatric cardiology parents (n = 15) and providers (n = 10) designed to gain a better understanding of: (1) the parent’s emotional reactions to various phases of the CHD treatment process, (2) the type and timing of psychological support that would be most useful and (3) the feasibility and acceptability of integrating mental health services into routine CHD care.

Methods

Research Setting

This study was conducted in partnership with The University of California, San Francisco (UCSF) Benioff Children’s Hospital’s Pediatric Heart Center—a multidisciplinary center offering comprehensive care and treatment of infant, child, and adolescent CHD. Parents and providers were recruited via flyers placed in exam rooms, restrooms, and common areas (e.g., family lounge) in the outpatient Heart Center Clinic, the inpatient Cardiac Intensive Care Unit (CICU), and the Transitional Care Unit (TCU). Recruitment also occurred via an email sent to Heart Center faculty and staff informing them about the study, as well as during referrals of Heart Center families to other services. We purposively sampled parents for variability in time since their child's most recent cardiac surgery, age of child, and gender of parent. Providers were also purposively sampled to capture diversity in professional roles, and a range of years spent working in the field of pediatric cardiology. All procedures were approved by the Committee on Human Research at the University of California, San Francisco (approval date: 10/07/2015).

Procedures

Semi-structured in-depth interviews were conducted between October 2015 and March 2016 by the first-author (SWK), a licensed clinical psychologist trained in clinical interviewing procedures and mother of a child with a critical CHD. Participants were interviewed in a private location either in the CICU or TCU within the hospital (e.g., at the child's bedside), in an exam room in the outpatient Pediatric Heart Center Clinic, in a private interview room in a faculty office building across the street from the Children's Hospital, or from the participant's home via Skype. Interviews lasted between 60–90 minutes, were conducted in English, audio recorded, and subsequently transcribed by a professional transcriptionist (transcripts were not returned to participants for comment). The interviewer took notes during the interview and created summary debriefs. All participants were informed that the content of the confidential interviews would not affect care (parents) or employment (providers), and that only the academic research team would have access to the confidential interviews. There was no relationship established prior to study commencement, there were no repeat interviews, and participants were provided with $50.00 remuneration for their time. A written informed consent was obtained from all participants.

Semi-structured interview guide

Both parent and provider interview guides began with an introductory statement about the study, and disclosure of the interviewer's status as a CHD parent and clinical psychologist. The interviewer asked the participants to defer personal questions about her experiences as a CHD parent until the end so that the interview would remain focused on the participant. The interviewer reminded the participants of her willingness to discuss her experiences and/or answer questions once all items from the semi-structured interview guide had been administered. The interview began by asking the participant to provide some background information in order to build rapport (e.g., "tell me a little about yourself"). The interviewer then asked the parents to share their "personal experience of having a child with a congenital heart defect," starting at the time of diagnosis. Responses were probed for times that were most/least difficult and for the parent's psychological response to the CHD treatment process. Parents were then asked about what type of emotional support would have been most useful, when they would have been open to that type of support, and their receptivity to having mental health care integrated into CHD care. Providers were asked an open-ended question about how or if the mental health of the parent impacts CHD care, their opinion about what would be most helpful in managing parents' mental health needs (if any), and their thoughts on the idea of integrating psychological care for parents into CHD treatment.

Data Analysis

The first and second author (SWK & EA) met bi-weekly to debrief after interviews, review transcripts, write analytic memos and interview summaries, identify overarching themes in the data, and discuss data saturation. Using thematic analysis (Guest, MacQueen, & Namey, 2011, Miles and Huberman 1994), the analysis team read and re-read interview transcripts and memos to identify major unifying topical areas in the data, and then, triangulating across interviews and cases, a set of sub-themes. Topics were organized into thematic areas, based on interview questions as well as emergent findings. Using the structure of a codebook to operationalize parent and child codes, the themes and subthemes were further defined and examples for coding were explicated and discussed. For instance, the overall theme of "Psychological impact of parenting a child with CHD" was identified as a parent code and defined as "Descriptions of experiencing trauma, anxiety, stress, fear, and/or hypervigilance while parenting a child with CHD." Within that code, the team identified a sub-theme, or child code—"CHD treatment process as profound parenting experience"—which was defined as "framing the child's CHD treatment process in terms of life lessons, and finding existential meaning in the experience." This process was applied to all parent and child codes. Relying on a preliminary form of the codebook, SWK and EA then coded two transcripts together, and an additional two transcripts independently. After discussion of coding discrepancies, further refinement of the codebook and methods for applying the codes, SWK and EA established inter-rater reliability by independently reaching coder agreement at the 90% threshold. Both researchers then coded the remaining transcripts using Dedoose, a qualitative data analysis software program, continuing to meet on a regular basis to compare cases and discuss the data captured through the coding process. The research team also shared preliminary findings with the providers and parents to member check the results of the analysis.

Results

Description of Research Participants

The results of the interviews are summarized in Table 1. We conducted a total of 25 qualitative interviews with parents (n = 15) and providers (n = 10). All eligible participants consented to participate and there were no withdrawals. Providers represented a wide range of disciplines (e.g., cardiology, nursing, child life, social work) and years spent working with children with heart defects (range: 6 months to 20+ years). Of the parents, 10 (67%) were mothers, 5 (33%) were fathers, and there were 4 couples in the study. Of the couples, two had infants (< 1 year old) that were still inpatient subsequent to their first cardiac surgery, and the other two couples had children who were >5 years post-first cardiac surgery (aged 6 and 21 years). The couples were interviewed both together (to describe the facts about their child's CHD history), and individually (to discuss their psychological response). Approximately 73% of the parents reported household earnings of more than $150,000/year and 27% reported household earnings between $15,000 and $60,000/year (reflective of the cost of living in the San Francisco Bay Area). A majority (67%) of the parents had more than one child and 73% of the children were diagnosed postnatally (vs. prenatally). The age range of the CHD children of the parents we interviewed was 3 months to 28 years old, with 40% parenting a CHD infant (<12 months old), 27% parenting a young child (< age 14), and

33% parenting a teen or young adult (age 14+). Table 2 provides descriptive information on the providers and parents interviewed.

Qualitative Findings

Results of the qualitative interviews are organized according to four major themes, and further categorized by sub-themes (see Table 1): (I) Psychological impact of parenting a child with a critical CHD, (II) Factors that influence the psychological impact of parenting a CHD child, (III) How and when to psychologically support CHD parents and (IV) Feasibility and acceptability of integrating psychological support into CHD care.

I. Psychological impact of parenting a child with a critical CHD—All of the parents recalled with vivid detail the diagnosis of their child's heart defect, which was remembered as a time of shock, disbelief, despair, and grief – especially if diagnosed postnatally. Some parents, especially mothers, struggled to understand how the CHD happened, even years later.

> *"And I just remember thinking like, what's happening? What's happening? What's happening? What's wrong? What could possibly – she was so healthy and she looks healthy, she's fine… I was in shock."* **Parent, 04**

> *"So I knew that he was going to be coming with a heart defect. So we just started to prepare ourselves for what was to come…for a little stretch I cried since he is my first baby and I wanted to know, what did I do? I'm not a drinker, I'm not a smoker. I don't do drugs. So, what was it that I did wrong for my baby, my first baby to come out like this? So that was a little bit hard to process."* **Parent, 05**

> *"You know I went through these stages of, I don't know, it almost felt like stages of grief even though nobody had died but maybe it was my perception of the ideal child did die…. I imagine it was my perception of the perfect healthy child. I think that some of that died."* **Parent, 09**

Parents also explained that the hospital stays associated with cardiac surgery, especially the first surgery, were extremely stressful. Many parents described this as the most difficult experience of their life, especially in the hours and days immediately following surgery.

> *"And about half an hour later we went to the Cardiac ICU and we got to see her, which was really hard… So I think that was really the hardest moment of my whole life was just seeing her in there so helpless with a breathing tube and she just looked so small."* **Parent, 14**

In addition to the negative emotional consequences, almost all of the parents interviewed described the threat of losing a child as a profound experience—inspiring admiration of their child's resilience, an appreciation of their own personal inner strength, and reflection on their desire to live their lives more fully.

> *"You learn the value of life I think maybe a little bit more than someone who has just been blessed with a perfectly healthy kid, eating normally, sleeps on time. Not that it's a bad thing for them, I'm happy for them, but I think when you come so close to the unknowns and you're basically – you're relying on those two hands of*

> *the surgeon to you know save your baby's life I think you get a sense of -- it's a sense that those are realities that perhaps others won't relate to unless they've experienced it."* **Parent, 01**

The providers also observed the psychological strain of the CHD treatment process on the parents—especially the time in the cardiac ICU. Providers described the ICU as "intense" and explained that some of the procedures, equipment, and scenes that parents witness can have long-term psychological consequences.

> *"If you think of some of the things that our parents actually see…I mean it's tough for me to get used to some of the visions. If you have a child on ECMO* [extracorporeal membrane oxygenation] *or some kind of advanced life support that's hard to look at unless you can just shut it. And I can do this, I can shut it down and say, this is a patient, this is physiology, this is a machine that I'm taking care of right now. And I do okay with that. But if you let that shield down and you look at this child who has the blood being sucked out of him in one tube and pumped into him another and a parent has to see that? They will never forget that. I mean that is – and not just never forget it, they will be forever traumatized by that vision."* **Provider, 109**

> *"But when you're in the ICU for so much time there's a child and the warning bells going off all the time it is just incredibly stressful…But you know you go home and you hear these things going on and it is PTSD. Absolutely….and there is no acknowledgement of what this does to people."* **Provider, 101**

II. Factors that influence the psychological impact of parenting a CHD child—

Parents and providers discussed unique challenges faced by some CHD families that can exacerbate the psychological impact of the CHD treatment process. The three issues most commonly cited were distance of the primary residence from pediatric cardiology care, poor communication or miscommunication with the cardiac treatment team, and having additional children at home. Given that most specialized pediatric cardiology care clinics serve a large catchment area, many families must travel from several hours away to receive care, having to take additional days off work for outpatient appointments, coping with time away from family members and other children during hospitalizations, and facing the need to find short-term, affordable housing during hospital stays. Here, a parent describes staying in the child's room due to an inability to locate local affordable housing.

> *"And so coming here was a little bit stressful because I'm like, okay, well where we gonna stay?…. We slept in here (the child's hospital room). We slept in there. And then with the ICU it's a rule only one parent can sleep, which I don't understand what that is… And how am I supposed to be there for my child emotionally if I don't self-care and self-care requires rest."* **Parent, 05**

The pediatric cardiology providers and the broader treatment team were also identified as having a meaningful impact on the parent's emotional response to their child's CHD treatment. From the parent's perspective, providers fell into one of two categories: intensely committed or emotionally disengaged and "robotic." The providers in the former category engendered a deep loyalty and trust from the families they serve, while the providers in the latter category were described as contributors to the stress and anxiety associated with CHD treatment.

> *"I'm sorry, Dr. X is like grandpa. He cares for M. And his care has been so excellent….He would think nothing to call the house and ask questions or whatever. Or I'd call and talk to his secretary and he'd call us back. It might be 9:30 at night or it might be whenever, it didn't matter. He's an advocate."* **Parent, 08**

> *"I did feel a little like, you know I'm a human, I'm, you know, here with my very small baby that you're going to be operating on and I just want to be treated like… I felt like all of my emotions were being minimized…And that wasn't a fair way to feel. Because we were going through something difficult and it was okay for me to be experiencing those emotions and I didn't want to feel like something was wrong or I should be ashamed for being emotional about it."* **Parent, 14**

In some cases, poor within-treatment team communication worsened parental anxiety. Scheduling miscommunications between the inpatient and outpatient teams, differences of opinion between providers, and cancelling and/or rescheduling of appointments were all identified as decreasing trust and confidence in the treatment team, and resulting in feelings of mistrust in the parent-provider relationship.

> *"So yes, I definitely have had experiences where the families have heard different messages from different players and felt like they contradicted. Sometimes they don't contradict it's just an interpretation that they're contradictory. And that can escalate anxieties horribly."* **Provider, 110**

Parents who experienced empathy and clear, ongoing communication from their providers expressed a sense of comfort and fewer anxieties during the course of their child's treatment. Here a mother describes a cardiologist with whom she had developed a close and collaborative relationship over many (20+) years of her child's CHD treatment:

> *"She's (CHD child) always had his cellphone number since she's had a cellphone; And like I said (CHD child) thinks he (cardiologist) walks on water. I think he's wonderful and I am very grateful for him every day of my life."* **Parent, 06**

Finally, about half of the parents had more than one child. While the logistics of caring for a medically compromised child, in addition to caring for one or more children, were described as difficult, the majority of parents identified the siblings as a helpful reminder that day-to-day life must go on as normally as possible.

> *"What would have made this worse, the whole situation worse was if (CHD child) was our first. Because we derived so much comfort and therapy from (the older sibling of CHD child), it was unbelievable. I would come home and she would say, mom, be a cat and crawl around on the floor."* **Parent, 03**

These families were able to stay engaged with activities that were unrelated to the CHD child's illness, which was protective against psychological distress.

III. How and when to psychologically support CHD parents—The times that parents identified as being most in need of professional psychological support were also the times they identified as the most difficult parts of the CHD treatment process: diagnosis, cardiac surgery, and the transition from the hospital to home-based care.

> *"In the beginning there should be someone that kind of like guides you through, because that's a lot to process….you know somebody at the beginning to help you deal with those things and process them and develop some type of therapeutic plan with you, something like that."* **Parent, 05**

> *"It would have been I think very helpful again to be put in touch with somebody that could say, okay, you're going to experience this and to kind of be ready for it and to feel like my thoughts were validated and normal. I mean not to say that I've ever really been through an official depression but the closest thing I came through was in that time period (during the hospital stay associated with cardiac surgery)."* **Parent, 09**

Connection with other parents of children with CHD was the most commonly suggested strategy for psychological support. Parents also expressed a desire to help other CHD families, especially during hospital stays, and felt strongly that hearing about the CHD treatment process from the perspective of another parent was a major unmet need.

> *"I kept asking if there was a parent I could talk to, someone that wasn't a doctor or a nurse that could tell me what it would be like from a mom's perspective, or a parent's perspective just because I wanted a non-medical explanation of what I was going to go through."* **Parent, 14**

Parents also expressed a desire for working with a specialized mental health provider who has experience with CHD parents and/or parents of other medically compromised children. The clinician's experience with the specific issues and events faced by the families was deemed important for understanding their unique challenges and tailoring of treatment accordingly.

> *"And so I think what would have been helpful would have been to just sort of – and I actually tried to work with a social worker to get a list, you know a list of names of people who have experience working with families who have been in our situation. So I kind of early on felt like I'm going to need to have somebody to talk to."* **Parent, 04**

IV. Feasibility and acceptability of integrating psychological support into CHD care—Parents were highly receptive to the idea of having an integrated mental health provider check-in with them during their child's cardiology appointments, especially while inpatient for cardiac procedures, many of which result in long hospital stays and time spent at the bedside.

> *"For me I would have used that. And just because I was too young and inexperienced to really know what I was feeling was normal and I just – looking back on it I think that it would have saved me a lot of heartache and grief…."* **Parent, 09**

Parents also noted that the offering of these services should be done with respect for the parent's time and readiness. Several parents stated that the service should be offered as a menu of options that can be accessed when and if the parent is ready.

> *"I really think it speaks to the importance of like having an intuitive sense of what people are and are not ready for. And meeting people where they're at and not pushing. You don't know how you're going to process this until you're in it and the providers need to be really respectful of the parents' process and what they want and need….little reminders that you're here and you're a service and you're thinking of them, or something. Like leaving a note in the room when they're not there. Something like that where they're like, I'm here for you. I am respecting your space but just please know that this is a service to you and whenever you want it, on your time, when you are ready."* **Parent, 03**

Providers viewed an integrated mental health provider as something that the treatment team would find very useful, especially if the provider was physically present in the clinic, serving as a reminder of the availability of the service. The co-location of the mental health provider was also described as optimal for allowing providers to refer parents acutely in need of psychological services.

> *"I think it would be great if we had a regular mechanism…we need a social worker or psychologist who is just at our Heart Center who should screen every goddamn parent who walks in the door….I mean we have faculty meetings twice a month, if you came to our faculty meetings (and said that) we have a full time person to help you with your needs for your families and your patients everybody would like applaud. Stand up and applaud. It would be a huge thing."* **Provider, 109**

Providers noted several concerns related to the practical feasibility of an integrated care model. Limited physical space within the pediatric cardiology clinics, unavailability of mental health providers during non-regular working hours, and, especially, lack of funding for mental health support, were identified as potential barriers to implementation.

> *"I don't think there would be any question that people would be grateful for it…but who is gonna pay for it. And that's usually how it goes around here."* **Provider, 109**

There was also concern about how to provide continuity of care for parents once they leave the pediatric cardiology clinic, especially given that most CHD clinics service a wide geographical area. Providers and parents suggested the use of telemedicine and/or web-based approaches to providing ongoing mental health care outside of the CHD clinics to address this issue.

Discussion

The parents and providers we interviewed described the CHD treatment process as having a pronounced and long-term impact on the mental health of the parents. Consistent with the quantitative (Woolf-King et al., 2017) and qualitative (Sjostrom-Strand & Terp, 2017) literature discussed previously, symptoms of anxiety, depression, and trauma were mentioned throughout the interviews, and were reported as most acute during diagnosis, hospital stays associated with cardiac surgery, and the transition from hospital to home. The isolation, fear, and hypervigilance that characterizes the time leading up to, and immediately following, cardiac surgery has the potential to become chronic, increasing the risk for adverse developmental outcomes among children (Lyons-Ruth, Wolfe, & Lyubchik, 2000; McPeak, Sandrock, Spector, & Pattishall, 2015; Mirhosseini et al., 2015; Tronick & Reck, 2009). Connecting these parents to care at key points in the treatment process (e.g., upon diagnosis, during hospital stays) would thus not only alleviate mental health symptoms among a high-risk group, it may also be an important part of the child's CHD treatment, mitigating the well-documented increase in risk children with CHD have for behavioral, social, and emotional difficulties long-term (McCusker et al., 2013; Shillingford et al., 2008).

While parents and providers were receptive to the concept of integrating mental health services into pediatric cardiology care, there were also some concerns with regard to the logistics of implementation. The practice of screening for, and some cases managing, behavioral health concerns has become more common in pediatric primary care settings (Foy, 2010b), neonatal ICUs (Hall et al., 2016), and, most recently, European pediatric cardiology care settings (Utens, Callus, Levert, De Groote, & Casey, 2017). The process by which these practices were adopted may be a useful model for the implementation of similar changes in pediatric cardiology (Foy, 2010a; Foy et al., 2010). For example, the National Perinatal Association (NPA) developed several "essential recommendations" for the integration of comprehensive parental psychosocial support in the NICU which included a parent-to-parent peer support program with a paid parent support coordinator, a dedicated Master's-level social worker and a PhD-level clinical psychologist, a goal to have all parents meet with a mental health professional within 1–3 days of admission, and a commitment to connecting every family to some type of follow-up psychosocial support upon discharge. The Association for European Paediatric and Congenital Cardiology (AEPC) has also developed a set of guidelines related to the implementation of multidisciplinary family-centered psychosocial care. The AEPC recommends psychological treatment for CHD parents and patients by specialized nurses and licensed psychologists, and a "holistic" treatment of the patient and the family from the time the defect is detected, through management of CHD into young adulthood (Utens et al., 2017). There is thus a strong precedent for incorporating mental health services into pediatric medical care settings in the U.S. and Europe, indicating that the issues raised in our interviews can be systematically addressed.

To maximize the benefits of integrated mental health care for CHD parents, the content, format, and delivery of the care must be tailored to the unique needs of this population. The parents we interviewed provided several key insights: (1) CHD parents want to be connected to each other for support. Establishing a peer mentor program and/or having a web-based support group or listserve would allow parents to offer and receive emotional and material support from each other, and address this missing element of CHD care. (2) The psychological care must be accessible in locations and at times that can accommodate the needs of the parents. Offering telemedicine-based services, availability during non-traditional business hours, and/or therapy appointments in the child's hospital room would allow parents to engage with mental healthcare in a way that is feasible and convenient. (3) The mental health providers should have experience working with parents of children with complex medical needs. Many of the parents expressed concern that a mental health provider who was not aware of the unique challenges of parenting a medically compromised child would fail to understand their needs. A list of appropriate providers could be distributed with materials that parents already receive as part of their child's CHD care. If there are a lack of mental health providers who have experience working with hospitalized families in the area, trainings could be developed that would allow providers to visit the ICU, speak with affected families, and consult with the CHD treatment team. (4) The interventions should be tailored to mental health issues commonly experienced by these parents (i.e., trauma, parenting stress, anxiety). We could find only two psychological interventions that have been developed specifically for parents of children with critical CHD (Burke et al., 2014; McCusker et al., 2010), neither of which has been subjected to a randomized clinical trial. Future intervention development work should consider tailoring existing psychological interventions that have been implemented in other medical settings (e.g., cognitive behavioral therapy) and/or interventions that have shown efficacy in general NICU settings (e.g., Gimenez & Sanchez-Luna, 2015; Melnyk et al., 2006). (5) Pediatric cardiology providers should strive to establish open, clear, and frequent communication that acknowledges the parent's emotional response to the CHD treatment process. This suggestion has been observed in general NICU settings as well (Ward, 2005), with trust and communication between parents and medical providers identified as essential elements of ethical and shared decision making.

Study limitations

The findings from our study should be interpreted in the context of several limitations. First, while efforts were made to purposively sample a variety of providers and demographically diverse parents at various stages of the CHD treatment process, and to continue recruitment until theoretical saturation, we acknowledge that the views expressed herein may differ from parents/providers sampled in another hospital and/or geographical area. Second, while four couples participated in our interviews, we did not have enough data to draw conclusions about how CHD affects the parenting relationship. Although this was not a primary aim of the current study, relationship quality is likely an important moderator of the psychological effects of parenting a CHD child, and the results presented here do not reflect this. Our findings also exclude other important subsets of CHD parents. For example, while non-English speaking parents were described as being disproportionately affected by the CHD treatment process, we did not interview any non-English speaking parents nor did we interview any non-U.S. citizens. The psychological impact of the CHD treatment process on these parents is likely more extreme than the parents we interviewed given language barriers in communication with providers and other parents, as well as out-of-country travel inhibiting access to social and/or familial support. Further, our sample did not include any parents of children with single ventricle physiology or children requiring heart transplants, which are sub-groups within critical CHD that face additional psychosocial stressors. The findings reported here do not adequately represent their experiences and the level and type of mental health services that may be most useful to them. Finally, the interviewer's status as a parent of a child with a critical CHD likely influenced participant responses. All of the participants were curious about the interviewer's personal experiences and how those experiences resulted in the aims of the current study. Parent interviewees were enthusiastic about connecting with another CHD parent, which increased rapport and level of personal self-disclosures in the interview, and may have also resulted in socially desirable responding that skewed the results in favor of integrated care.

Conclusions

Parents of children with critical CHD need access to mental health services, and integrating these services into routine pediatric cardiology care is a novel and practical way for parents to receive the treatment they need. The field of pediatric cardiology would benefit from the development of a task force or working group on the integration of mental health services, which could rely on other areas of pediatric medicine and the AEPC psychosocial working group as a guide for implementation. As suggested by the AEPC, nurses are an essential component of an integrated care model, providing front line inpatient and outpatient psychosocial support to the parents and, when needed, referral to licensed mental health providers on the treatment team. As the field works towards these systemic changes, in the short-term, the formation of parent mentoring programs, clinic-based listserves, and/or parent support groups (in-person or internet-based) would provide immediate access to peer support in a way that is feasible and relatively easy to implement. Such comprehensive support for CHD families has the potential to improve the long-term behavioral, social, and emotional health of children with critical CHD, while also enhancing the well-being of their parents.

Relevance to clinical practice

This study makes visible the mental health needs of CHD families from the perspective of both parents and providers. Mental health services should be integrated into inpatient and outpatient pediatric cardiology care as part of a comprehensive, family-centered approach to treatment. Nurses can take an active role in moving towards an integrated care model by receiving training in mental health screening and brief interventions, and advocating for mental health services nested within pediatric cardiology care settings.

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References

Abidin RR. Introduction to the special issue: The stresses of parenting. Journal of Clinical Child Psychology. 1990; 19(4):298–301.

Abidin, RR., Burke, WT. The development of the Parenting Stress Index; Paper presented at the annual meeting of the American Psychological Association; Toronto. 1978.

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):e002846. [PubMed: 27312802]

Burke K, Muscara F, McCarthy M, Dimovski A, Hearps S, Anderson V, Walser R. Adapting acceptance and commitment therapy for parents of children with life-threatening illness: Pilot study. Family Systems and Health. 2014; 32:122–127.

Cano Gimenez E, Sanchez-Luna M. Providing parents with individualised support in a neonatal intensive care unit reduced stress, anxiety and depression. Acta Paediatrica. 2015; 104(7):e300–e305. [PubMed: 25703857]

Centers for Disease Control and Prevention (CDC). Congenital Heart Defects. 2016. Retrieved from https://www.cdc.gov/ncbddd/heartdefects/data.html

Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: a systematic review. Journal of Pediatric Psychology. 2013; 38(8):809–828. [PubMed: 23843630]

Foy JM. Enhancing pediatric mental health care: algorithms for primary care. Pediatrics. 2010a; 125(Suppl 3):S109–125. DOI: 10.1542/peds.2010-0788F [PubMed: 20519563]

Foy JM. Enhancing pediatric mental health care: report from the American Academy of Pediatrics Task Force on Mental Health. Introduction. Pediatrics. 2010b; 125(Suppl 3):S69–74. DOI: 10.1542/peds.2010-0788C [PubMed: 20519564]

Foy JM, Kelleher KJ, Laraque D. Enhancing pediatric mental health care: strategies for preparing a primary care practice. Pediatrics. 2010; 125(Suppl 3):S87–108. DOI: 10.1542/peds.2010-0788E [PubMed: 20519566]

Guest, G., MacQueen, KM., Namey, EE. Applied thematic analysis. Sage; 2011.

Hall SL, Phillips R, Hynan MT. Transforming NICU Care to Provide Comprehensive Family Support. Newborn and Infant Nursing Reviews. 2016; 16(2):69–73.

Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the Neonatal Intensive Care Unit (NICU). Journal of Clinical Psychology in Medical Settings. 2010; 17(3):230–237. [PubMed: 20632076]

Lyons-Ruth K, Wolfe R, Lyubchik A. Depression and the parenting of young children: making the case for early preventive mental health services. Harvard review of psychiatry. 2000; 8(3):148–153. [PubMed: 10973939]

McCubbin HI, Patterson JM. The family stress process: The double ABCX model of adjustment and adaptation. Marriage & Family Review. 1983; 6(1-2):7–37.

McCusker CG, Armstrong MP, Mullen M, Doherty NN, Casey FA. A sibling-controlled, prospective study of outcomes at home and school in children with severe congenital heart disease. Cardiology in the Young. 2013; 23(04):507–516. [PubMed: 23083543]

McCusker CG, Doherty NN, Molloy B, Rooney N, Mulholland C, Sands A, 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 and development. 2010; 36(1):110–117.

McPeak KE, Sandrock D, Spector ND, Pattishall AE. Important determinants of newborn health: postpartum depression, teen parenting, and breast-feeding. Current opinion in pediatrics. 2015; 27(1):138–144. [PubMed: 25564189]

Melnyk BM, Feinstein NF, Alpert-Gillis L, Fairbanks E, Crean HF, Sinkin RA, Gross SJ. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. Pediatrics. 2006; 118(5):e1414–e1427. [PubMed: 17043133]

Miles, M., Huberman, A. An Expanded Source Book: Qualitative Data Analysis. 2. Thousand Oaks: Sage; 1994.

Mirhosseini H, Moosavipoor SA, Nazari MA, Dehghan A, Mirhosseini S, Bidaki R, Yazdian-anari P. Cognitive Behavioral Development in Children Following Maternal Postpartum Depression: A Review Article. Electronic physician. 2015; 7(8):1673. [PubMed: 26816593]

Nelson LP, Gold JI. Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: a review. Pediatric Critical Care Medicine. 2012; 13(3):338–347. [PubMed: 21499173]

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. 2013:2012–3435. peds.

Pomerantz AS, Shiner B, Watts BV, Detzer MJ, Kutter C, Street B, Scott D. The White River model of colocated collaborative care: A platform for mental and behavioral health care in the medical home. Families, Systems, & Health. 2010; 28(2):114.

Post EP, Metzger M, Dumas P, Lehmann L. Integrating mental health into primary care within the Veterans Health Administration. Families, Systems, & Health. 2010; 28(2):83.

Shillingford AJ, Glanzman MM, Ittenbach RF, Clancy RR, Gaynor JW, Wernovsky G. Inattention, hyperactivity, and school performance in a population of school-age children with complex congenital heart disease. Pediatrics. 2008; 121(4):e759–767. DOI: 10.1542/peds.2007-1066 [PubMed: 18381503]

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. 2017:1–14.

Tronick E, Reck C. Infants of depressed mothers. Harvard review of psychiatry. 2009; 17(2):147–156. [PubMed: 19373622]

Utens EM, Callus E, Levert EM, De Groote K, Casey F. Multidisciplinary family-centred psychosocial care for patients with CHD: consensus recommendations from the AEPC Psychosocial Working Group. Cardiology in the Young. 2017:1–7.

Ward F. Parents and professionals in the NICU: Communication within the context of ethical decision making—An integrative review. Neonatal Network. 2005; 24(3):25–33.

Ward-Begnoche W. Posttraumatic stress symptoms in the pediatric intensive care unit. Journal for Specialists in Pediatric Nursing. 2007; 12(2):84–92. [PubMed: 17371552]

Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: a literature review. Heart & Lung: The Journal of Acute and Critical Care. 2015; 44(6):494–511. [PubMed: 26404115]

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):e004862. [PubMed: 28151402]

What does this paper contribute to the wider global clinical community?

- This study contributes to a greater understand of the psychological morbidity among families of children with critical congenital heart defects (CHD), and factors that influence this morbidity.
- This study provides insight into the feasibility and acceptability of integrating mental health services into pediatric cardiology care from the perspective of both CHD parents and providers.
- The integration of mental health services into pediatric cardiology care settings is a practical way to connect CHD families to mental health services.

Table 1

Summary of themes and sub-themes from qualitative interviews with parents (n = 15) and providers (n = 10) of children with critical congenital heart defects (CHD)

Major theme	Sub-themes
I. Psychological impact of parenting a child with a critical CHD	• Diagnosis, cardiac surgeries, and ICU stays are times of highest psychological distress • CHD treatment process as a profound parenting experience
II. Factors that influence the psychological impact of parenting a CHD child	• Distance of primary residence from CHD care • Communication with CHD treatment team • Having additional children at home
III. How and when to psychologically support CHD parents	• Times during the CHD treatment process that support would be most useful • Types of support that would be most useful
IV. Feasibility and acceptability of integrating psychological support into CHD care	• Parent receptivity to a mental health provider checking in during child’s medical appointments/hospital stay • Importance of a mental health provider respecting parent readiness for treatment • Receptivity of providers to a co-located mental health professional • Provider concerns about feasibility of implementation and continuity of care

Table 2

Descriptive information for parents of children with critical congenital heart defects (CHD) who participated in qualitative interviews (N = 15)

Variable	Mean (st. dev.)	Category	%(n)
Parent age	40.20 (10.39)		
Parent gender		Mother	65% (10)
		Father	33% (5)
CHD child's age (years)	9.19 (9.35)	Infant (<1 year)	40% (6)
		Child (<13 years)	27% (4)
		Teen/YA (>13 years)	33% (5)
Income		15,000–60,000/year	27% (4)
		150,000+/year	73% (11)
Total # of children		1 (CHD child)	33% (5)
		>1 child	67% (10)
Timing of CHD diagnosis		Prenatal	27% (4)
		Postnatal	73% (11)
Trauma (PCL-C)	10.93 (3.95)	Positive	33% (5)
		Negative	67% (10)
Alcohol use (AUDIT-C)	2.53 (2.17)	Hazardous alcohol use	47% (7)
		Non-hazardous use	53% (8)
Anxiety (GAD-7)	4.93 (4.15)	No symptoms	47% (7)
		Mild symptoms	33% (5)
		Moderate symptoms	20% (3)
Depression (PHQ-9)	3.07 (3.17)	Minimal symptoms	73% (11)
		Mild symptoms	20% (3)
		Moderate symptoms	7% (1)

Note. CHD = congenital heart defect; PCL-C = 6-item version of the Post-traumatic Stress Disorder Checklist-Civilian Version; AUDIT-C = Alcohol Use Disorders Identification Test – Consumption; GAD-7 = Generalized Anxiety Disorder 7-item Scale; PHQ-9 = Patient Health Questionnaire; MSSS = Multidimensional Scale of Perceived Social Support; PSS = Perceived Stress Scale; DAS = Dyadic Adjustment Scale; YA = young adult.