



Caregiving for Interstage Infants: A Continuous Process of Compromise During the Pandemic

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Abstract

Background: Infants born with single ventricle heart disease require in-home medicalized care during the interstage period (time between the first and second staged heart surgery). These caregivers rely on extended family, friends, and hired caretakers to provide respite time. However, the coronavirus pandemic removed these families' options due to stay-at-home and social distancing directives. We explored the caregivers' experiences during the interstage period, including impacts on their lifestyle, as they managed their infants' critical needs during the coronavirus disease 2019 pandemic. **Method:** In-person or telephonic interviews of 14 caregivers interviewed once or twice were conducted between November 2019 and July 2020. Constructivist Grounded Theory methodology guided both data collection and analysis for the inductive and abductive exploration of caregivers' experiences. **Results:** Data analysis led to the development of 2 concepts: *Accepting and adapting to a restrictive home environment* and *Reconciling what is and what is yet to come*. Refinement of the relationship between the 2 concepts led to the development of a theory grounded in the words and experiences of the participants called: *A Continuous Process of Compromise*. **Conclusions:** Our findings increase understanding of caregivers' experiences related to psychosocial and lifestyle impacts and the need for additional support during the interstage period.

Keywords

congenital heart disease, hypoplastic heart syndrome, Norwood procedure, home monitoring

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Introduction

Single ventricle heart disease (SVHD) refers to a group of congenital heart defects in which the heart functionally has only one ventricular chamber. SVHD has an incidence of 0.8 cases per 1000 live births.¹ The majority of SVHD requires 3 or more staged palliative surgical procedures before 4 years of age. The time between the first and second stage surgery, known as the interstage period, has the highest associated mortality.¹ The development and implementation of home monitoring programs have improved survival up to 80% to 90% during the interstage period.¹⁻³ Home monitoring includes interdisciplinary care coordination and educating parents as home caregivers. Caregivers are trained to use a pulse oximeter and weight scale and are asked to record respective parameters along with feeding volumes each day, target parameters, and "red flags" that reflect a change in the infant's clinical condition that should prompt caregivers to seek immediate medical attention.^{2,3} Consequently, interstage monitoring has shifted the burden of care to the home, adding stress to everyday life with potential clinical implications. Infants with SVHD are at higher risk for hospital readmission due to contracting a cold or the flu. Hence, many caregivers take extra precautions to keep their infants healthy and avoid potential exposure to

illness. This often results in being confined at home and avoiding social gatherings, affecting the caregivers' psychological and social well-being.⁴

Due to the coronavirus disease 2019 (COVID-19) pandemic, parental stress and adjustment to caring for a medically complex infant may be heightened. Caregivers often rely on extended family, friends, and hired caretakers to provide relief or respite time. However, the pandemic removed these options due to stay-at-home and social distancing orders across the country. Although the protective measures for a viral illness and COVID-19 are the same, the novelty and aggressive replication of the latter could be associated with additional stress and uncertainty to caregivers during the interstage period.

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During the interstage period, the well-being of caregivers and families may be at risk for adverse consequences, including financial hardship, social isolation, disruption of family support, and threats to livelihood. However, little is known about the impact of interstage home monitoring on caregivers and their families, and even less is known about managing this during a global pandemic. Thus, we explored caregivers' experiences during the interstage period, including impacts on their lifestyle, as they managed their infants' critical needs during the COVID-19 pandemic.

Patients and Methods

Two Institutional Review Boards approved this study (hospital study site and the academic affiliation). Primary caregivers over the age of 18 years whose infants underwent first-stage palliation surgery for SVHD were recruited 2 to 4 months after discharge from a large children's hospital in Southern California between November 2019 and July 2020. After obtaining written informed consent, caregivers completed the sociodemographic form,⁵ the Parenting Stress Index-Short Form (PSI-SF)⁶ and General Anxiety Disorder-7 (GAD-7)⁷ questionnaires to gain insight into the levels of stress and anxiety of caregivers at the time of the interviews. Participants were interviewed at a time and place of their choosing by the principal investigator (PI). All interviews were audio-recorded; approximately half were done in-person and, due to the COVID-19 pandemic restrictions put into place 4 months after data collection began, the other half were conducted telephonically. A certified hospital interpreter participated in interviews with 3 Spanish-speaking participants. Each participant received a \$30 gift card after completing the questionnaires and interview.

Parenting Stress Index-Short Form. The PSI-SF is a 36-item inventory tool that measured the stress level experienced by caregivers at the time of the interviews. The tool has 4 domains or subscales: parental distress, parent-child dysfunctional interaction, difficult child, and total stress. A score at or above the 85th percentile is considered high, and scores at or above the 90th percentile indicate clinically significant stress that may warrant professional consultation.⁶

General Anxiety Disorder-7. The GAD-7 is a validated 7-item questionnaire that measures the severity of symptoms related to generalized anxiety disorder. The score ranges from 0 to 21 (cut-points: 5 = mild, ≥ 10 = moderate, ≥ 15 = severe).⁷

Qualitative Methods and Data Analysis

Constructivist Grounded Theory methodology informed by Symbolic Interactionism^{8,9} guided data collection and analysis. Inductive and abductive approaches were used to generate a theory grounded in data gathered through participant interviews⁸ (Figure 1). The PI developed an intensive interview guide with open-ended questions⁸ that was informed by the literature plus clinical and methodological experts.

Interviews were digitally recorded, transcribed verbatim by a professional transcriptionist, de-identified, checked for accuracy, and coded line-by-line.⁸ Guided by the Grounded Theory methodology, we sampled for meaning and lived experiences rather than to fulfill a particular number of participant interviews. Simultaneous to data collection, we conducted initial and focused coding and incident-by-incident coding. We continuously engaged in constant comparison of data with data and codes with codes. We used various analytic techniques to scrutinize the data to gain an in-depth understanding of meaning to develop concepts and their properties.

Moving from the concrete (transcribed interviews) to the abstract (concepts with properties) shown in Figure 1, we identified the most significant and frequently developed codes within the first 7 interviews, which formed 23 focused codes.⁸ We used Excel spreadsheets to systematically list and compare data grouped by each focused code. From this, we narrowed the list of 23 to 12 focused codes. We systematically examined nuances and similarities using a constant comparison of data within each of the 12 focused-code groups.⁹ This led to the development of 2 salient concepts that were in dynamic relation to each other. Using abduction,⁸ we repetitively compared our emerging interpretations with actual quotations to refine articulation of the concepts and their properties, using data from all participants (P).⁹ Then, we recognized the need for more data to clarify specific aspects of some properties. Hence, we used theoretical sampling⁸ and conducted 4 additional interviews (P1, P2, P5, P10), gaining more understanding of specific properties through deeper analysis. We reached full articulation or saturation of the concepts and properties after the 18th interview leading to a situation-specific theory.^{8,9} To enhance methodological rigor, each research team member collaborated in each stage of coding and analysis and reflexive memos were written to reduce assumptions that might have affected the coding process.⁸ Atlas.ti software¹⁰ was used to organize all data and codes. Descriptive statistics presented the participants' demographic characteristics, PSI-SF, and GAD-7 scores.

Results

Demographics, Stress, and Anxiety Symptoms

Of the 14 caregivers in our sample (10 mothers and 4 fathers), 4 were interviewed twice for a total of 18 interviews (mean length of interview = 64 min [range 45-95]). Most caregivers were between ages 19 and 44 (mean 28 ± 7.8), unmarried (78%), Latinx/Hispanic (64.3%), and spoke English (71.4%). Most had public insurance (64.3%) and earned under \$30 000 per year (42.8%). The mean PSI-SF total score was 70.6 (± 16.5 ; 35-50th percentile), and subscales Parental Distress 26.7 (± 8.9), Parent-Child Dysfunctional Interaction 18.7 (± 5.9), and Difficult Child 25.2 (± 6.7), indicating caregivers experienced "typical" levels of stress. The PSI-SF also showed a sample mean for the Defensive Responding subscale score of >10 , indicating an unbiased response to the questionnaire.⁶ The GAD-7 showed 50% reported mild anxiety (Table 1).

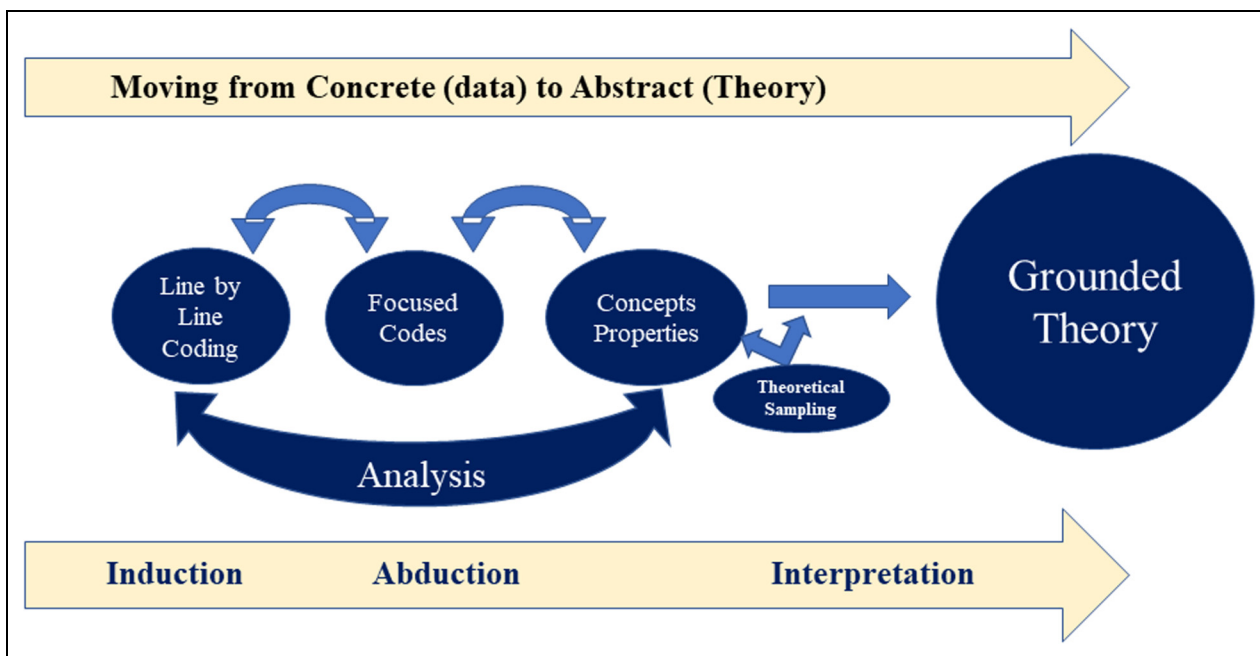


Figure 1. Constructivist grounded theory approach: Concurrent data collection and analyses.

Grounded Theory: Caregiving for Infants With SVHD in the Interstage Period During COVID-19: A Continuous Process of Compromise

Our sample of caregivers described various ways they promoted their infants’ health and safety during the interstage period. Based on participants’ experiences, we developed a grounded theory titled, *Caregiving for Infants with SVHD in the Interstage Period during COVID-19: A Continuous Process of Compromise* (Figure 2). It consists of 2 concepts: *Accepting and adapting to a restrictive home environment* and *Reconciling what is and what is yet to come*. See Table 2. All participants’ names were replaced with a numeric code (P1, P2, etc).

Accepting and adapting to a restrictive home environment

Properties. “It’s just normal”: Being vigilant became normalized due to COVID-19. The caregivers in our sample had the goal of protecting their infants from getting sick. Many participants believed that the only way to keep a safe space between their infant and other threats was continued vigilance to avoid physical contact with others, even friends and family members. Overall, the caregivers learned that their infants’ vulnerabilities meant restricting their activities outside and inside the home. One caregiver (P7) said, “I just want to do it myself, and I did not want them to visit my home because I don’t want my baby to get sick from them.”

Participants reported they worked hard to adapt to the restrictions. Eventually, being vigilant became part of their everyday life. However, the COVID-19 pandemic brought a meaningful change because their private experiences with vigilance became a public necessity for the entire nation. For one mother (P14),

comparing her experience before and after the pandemic was pivotal in her self-understanding. She and her husband had put much effort into fostering a home life within the parameters given to them at the hospital. They hoped it would start to feel “normal” at some point despite the ongoing difficulties. However, when the COVID-19 restrictions were put into place everywhere, she found it added value to her efforts and gave them an advantage that the rest of the country did not have. She said, “It feels like we practiced for the whole quarantine situation going on now!” Similarly, one father (P11) in our sample described his experience and expressed gratitude that all their vigilant efforts served as training for the pandemic restrictions. He said, “we’re, like, in training for this. So, for us, it’s a walk in the park.” Thus, the caregivers found that their heightened vigilance to protect their vulnerable infant became normalized due to similar restrictions imposed on society due to COVID-19, bringing a form of acceptance they had not expected.

Confining self to home as the right way to protect. When discussing the strategy of confining themselves to home, many participants talked about right and wrong actions. One parent (P16) said staying home was the “right thing to do” to keep their infant healthy in anticipation of the second-stage surgery. Caregivers had strong feelings about protecting their infants from returning to the hospital due to complications or infections. One mother (P9) admitted she struggled with the boundaries of “bad” versus good or right. In the end, she noted that her feelings helped determine how to compromise and decide what to do.

I know it’s not bad to take her out, but I feel better keeping her home. We don’t take her out just because there’s always a big

Table 1. Demographic, Socioeconomic, and Psychosocial Characteristics of Interstage Caregivers (n = 14).

Characteristics	Mean ± SD or n (%)
Age (range 19-44 years)	28 ± 7.8
Parent/caregiver	
Father	4 (28.6)
Mother	10 (71.4)
Race/Ethnicity	
African American	2 (14.3)
Caucasian/White European	3 (21.4)
Latinx/Hispanic	9 (64.3)
Highest Level of Education	
Partial or College/University	8 (57.2)
High School	4 (28.6)
Junior High School	2 (14.3)
Primary Language	
English	10 (71.4)
Spanish	4 (28.6)
Marital status (not married)	11 (78.6)
Partner relationship	
Single-living with a partner	8 (57.1)
Single-living without a partner	4 (28.6)
Not applicable	2 (14.3)
Health insurance	
Public	9 (64.3)
Private	5 (35.7)
Household income	
Under 30K	6 (42.8)
31K to 50K	3 (21.4)
81K to 100K	1 (7.1)
Over 100K	2 (14.3)
Decline/not sure	2 (14.2)
General Anxiety Disorder-7 (anxiety severity)	
None (<5)	7 (50)
Mild (5-9)	2 (14)
Moderate (10-14)	2 (14)
Severe (≥15)	3 (22)
Parenting Stress Index-Short Form	
Defensive responding	>10
Parental distress	26.7 ± 8.9 (50%)
Parent-child dysfunctional Interaction	18.7 ± 5.9 (35%)
Difficult child	25.6 ± 6.7 (47%)
Total score*	70.6 ± 16.5 (43%)

*Percentile range: Typical stress = 15 to 80, High stress = 81 to 89, Clinically significant = 90 to 100.

crowd. We don't go anywhere unless we really have to, like buying certain things for the kids or groceries or a doctor's appointment.

Staying home was not easy, but caregivers found ways to make it work. For example, some parents gave up their preference for attending religious services together as a family and found a compromise. One parent (P5) explained, "We like going to church together as a family, and we haven't, 'cause we don't wanna take him to church, so he's [husband] going one day, and I go the next." However, unlike the rest in our sample, 2 caregivers described themselves as "homebody." Staying home was already comfortable for them. As one of

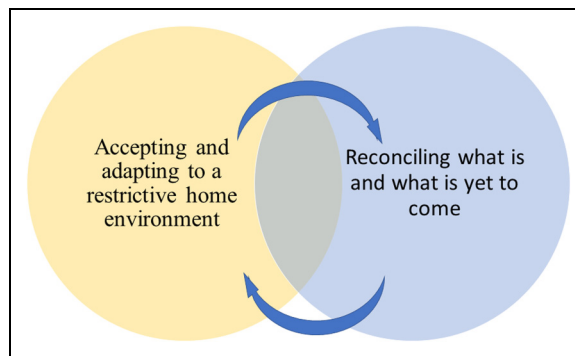


Figure 2. Grounded theory: caregiving for infants with single ventricle heart disease in the interstage period during COVID-19: A continuous process of compromise.

Table 2. Grounded Theory: A Continuous Process of Compromise —Concepts and Properties.

Concepts	Properties
Accepting and adapting to a restrictive home environment	<ul style="list-style-type: none"> • "It's just normal!": Being vigilant becomes normalized due to COVID-19 • Confining self to home as the right way to protect • Reckoning with the awkwardness of the social distance process
Reconciling what is and what is yet to come	<ul style="list-style-type: none"> • Living in a suspended state • Struggling with conflicting feelings • Looking beyond the "Interstage Period" with hope and trepidation

the caregivers (P13) said, "I was always just a home person, so it's not really a problem for me." Other participants found staying home less desirable, but it was a sacrifice or compromise they felt compelled to make. As one caregiver (P2) commented, "I don't hang out anymore. I don't do a lot of stuff that I used to."

Reckoning with the awkwardness of the social distance process. Fear was a primary motivation for caregivers. They took measures via social distancing to avoid contact with others who could make them or their infant sick. One father (P4) described how careful he was to avoid any possible contact with someone who might be sick. He asked visitors specific questions, which he described as follows: "Before you touch him, did you wash your hands? Have you been sick in the past couple of days?" Many participants became even more vigilant when the COVID-19 pandemic started. As one caregiver (P14) explained,

A couple of times, we would feel that seeing people was okay if they were not holding him, or [if] we kind of vetted out if it was okay. That's been the hardest thing; it creates an extra barrier to nurturing friendships because you always check; it creates

awkwardness when you're always questioning people about their health and who they've been around.

Many caregivers avoided joining social gatherings because "vetting" attendees led to an uncomfortable situation. As one caregiver (P8) explained, "*Having an interstage baby and having a hypoplastic baby is all-encompassing; it's all you ever really talk about.*" She explained that this was foremost in her mind whenever she talked to her friends as she tried to determine who was safe to be around her child. One caregiver (P16) said the work of determining who could or could not come into her home also had financial repercussions. She and her husband both worked from home, styling and cutting hair. However, due to their infant's condition, she had to decide whom she would or would not allow into her house, which was very stressful and difficult. Many caregivers in the study chose to stay socially connected with family and friends who do not live in their homes by calling, using video chat, or staying connected through social media. As one mother (P13) said, "*Since the stay-at-home order, we Facetime and text. We don't go to their house, and they don't come to our house.*"

Reconciling what is and what is yet to come

Properties. Living in a Suspended State. Participants felt uncertain and worried about their infants' future and possible surgical outcomes. One caregiver (P5) felt that "*life is kind of paused, not sure how it will go.*" Many put family plans on hold because they had to stay home until the infant was ready for the second surgery. Caregivers felt uncertain about their infant's surgical outcomes and imagined the worst-case scenario. One father (P4) stated,

He's relying on a man-made shunt that could give out. We're not actually guaranteed the next day with him. We've heard many stories where babies post-Norwood go through cardiac arrest, and they don't make it to the second surgery.

Participants explained that each day brought challenging experiences, but they learned they could only deal with what was before them. As one mother (P8) remarked,

Everything about my life has been put on hold essentially to take care of my son. Your time is compromised because you're taking care of a new life, and everything just doesn't matter at that point.

This mother's view shows how caregivers coped with the current reality of life by prioritizing their infant while simultaneously putting off their own needs. This suspended them in time as they faced 1 day at a time during the interstage period.

Struggling with conflicting feelings. Participants reported that they experienced constant worrying about their infants when taking care of them, including worries about the crucial need to gain weight. Under typical circumstances, they would have turned to friends or family for emotional and social support, but because they feared sick contacts, many caregivers in our sample avoided getting together with others even though

this meant they gave up intimate discussions they otherwise would have had. They saw the trade-off and had to weigh the pros and cons. This contributed to an emotional aloneness. Additionally, some caregivers felt alienated from confidantes. For example, a first-time mother (P5) struggled with feeling misunderstood. Her own sister expressed astonishment about the difficulties of caring for her infant as if it was impossible to comprehend.

I feel like when she [sister] said, 'I would never be able to do it. How do you do it?' And it feels like people look at you as the special people who can handle that kind of thing when really if it happened to you, you'd do it. I think mostly, it's sort of isolating, where you feel like no one quite gets it.

She did not want to be considered "*special,*" as if she was abnormally able to handle difficult things in life. Rather, she wanted to be understood by her sister as a person facing a life challenge just as anyone else would. The ensuing feeling of isolation from an otherwise trusted person brought difficult feelings of inner conflict.

In our sample, a working mom (P7) spoke about how she wanted some freedom in her regimented life, only to have the feeling evaporate as soon as it arose when she became grounded in her connection to her infant. She explained, "*... but there's times where I wish I could just be free again and just be able to get up and go and not have to worry.*" One father (P15), who lived with his mother, found himself reconciling his feelings about his life before and after becoming a parent. He explained, "*I was used to not having to deal with anything at home – just being able to do anything I wanted, whenever I wanted.*" The process of straddling conflicting feelings was a daily lived experience that called for emotional and social compromise for this father, as it was for the many in our sample.

Looking beyond the "Interstage Period" with hope and trepidation. While participants anticipated their infants' subsequent surgeries, foremost in their thoughts were keeping their infants healthy and maintaining their weight gain to be clinically ready for the second stage surgery. One father (P1) said, "*Basically, I don't focus so much on the future, but take it one day at a time.*" He focused on the future hoping that they would be able to "*breathe a little bit after the next surgery.*" Many participants projected hope that their infant would be a "*normal child after the second surgery.*" This might have been due to an optimistic coping style or misinterpretation or difficulty processing complex medical information. One mother (P7) shared her reasons for believing the future would be better for her and her infant, saying, "*She'll be bigger, and she will be eating well. So, we won't get so tied down at home.*" Others anticipated a life free from worries about their child's struggles with maintaining good oxygenation and thoughts of dying due to shunt failure.

Some participants talked about their eagerness for their infant to go through the second surgery but at the same time reported that it was a source of anxiety. One caregiver (P17) summed up the trepidation that many caregivers felt by saying,

I'd like for him to have his second surgery soon, but I'm worried that he's going to go through the same thing again, just like the first surgery. And it's very complicated. It worries me that he may not make it.

The very act of desiring the subsequent surgery to be done as soon as possible was accompanied by a fear of the worst possible outcome. Caregivers did not know what was in store, and they were aware that their infant could die during, or as a result of, the next surgery. Regardless of this trepidation, caregivers leaned into an image of a desirable future and hope, saying, "I think it will get easier after the fact." (P7)

Discussion

Our findings describe caregivers' experiences during the interstage period of their infants with SVHD amidst the COVID-19 pandemic. The diversity of our sample (Black, White, Latina mothers of diverse ages, and health insurance) brings insight that expands the literature. Caring for an infant is stressful under normal circumstances which can be intensified if the infant has complex medical needs.^{4,11} This stress was, in some ways, further heightened during the pandemic, leading caregivers in our sample to adopt hypervigilant practices to protect their infants.¹² Thus, our participants entered what we termed, *A Continuous Process of Compromise* related to social and family restrictions as they tended to their infants' health and safety. Learning to accept and adapt to a restrictive home environment was ongoing as they reconciled their current reality with what was yet to come with the second surgery. Figure 2 depicts our theory, including 2 simultaneous experiences featured as concepts (shown by the overlapping circles) that fed into and fueled each other in a continuous cycle (shown by the arrows).

To avoid hospital admissions, the caregivers in our sample identified the need to restrict their home environment to keep their infants safe and healthy during the interstage period. They achieved this goal by being vigilant in maintaining a safe space between their infants and others. It was a difficult process and led to awkward interactions while they vetted who could be around their infants among their family and friends. While not unique to caregivers of infants or children with congenital heart disease,¹³ the vigilance of our participants turned into *hypervigilance* in the face of a nationwide pandemic with potentially fatal consequences. Vetting family and friends became a time-consuming part of each caregiver's everyday experience.

The process of social distancing made caregivers vulnerable to isolation. A similar finding was found in a study that identified "isolation" as a theme in online discussions with parents of children with congenital heart disease after surgery.¹⁴ The emotional burden of feeling "alone" while caring for a medically fragile infant was also found in other studies with caregivers in the initial period after their infants' hospital discharge.^{15,16} Our study highlights how caregivers gradually developed

adaptive skills for caring for their high-risk infants after severe social and family lifestyle disruption.

For our participants, the process of acceptance and adaptation to a restrictive home environment was the experiential beginning of a *continuous process of compromise*. As participants navigated the restrictive home environment, they found themselves caught between desiring to socially distance and longing to be with their family and friends. Thus, they lost valuable support systems (family, friends, faith-based gatherings) that would have ordinarily been available to them. To manage the day-to-day challenges, caregivers were forced to make compromises such as leaving their job, reducing work hours, changing their living arrangements, altering daily schedules, and choosing between their own health needs and those of their infant. These compromises are not necessarily unusual for first-time parents as they navigate parenthood; when they bring the infant home, parents realize the sacrifices and selflessness needed to raise a child. But they were pronounced for our participants.

Many families faced similar compromises during the COVID-19 pandemic, such as working from home, assisting children in remote education, and getting by despite reduced daily resources, plus being unable to enjoy family outings or vacations.^{17,18} However, compromises were compounded by fears of sudden death during the interstage period plus the possibility of contracting COVID-19.

Our participants had to reconcile the reality of their infants' status in the present with their looming fears of what was yet to come. They were forced to confront the reality of caring for their medically complex infant, knowing any red flag could pop up at any moment and lead to unexpected hospital readmission or a sudden emergency requiring an immediate response while awaiting a pending operation with an uncertain outcome. The work to reconcile these realities of what is and what is yet to come, involved accepting both as part of the process.

Despite limited financial resources and pandemic stressors, our participants reported stress levels on the PSI-SF considered typical⁶ and about half reported mild anxiety (based on GAD-7⁷). This is remarkable in the context of the heavy load on their shoulders in the interstage period. In contrast, 33% of mothers and 16% of fathers caring for their infants at home 1 month after cardiac surgery who participated in a different study reported trauma symptoms associated with acute stress disorders.¹⁹ Indeed, the care demands of the infants were high for our sample, but they may have experienced an adjustment period to home life when we interviewed them 2 to 4 months after hospital discharge. The lower levels of reported stress could have been related to individual resources and inherent resilience.^{20,21}

Our theory, *A Continuous Process of Compromise*, is grounded in the words and experiences of participants but may apply to other groups of high-risk infants and children for whom morbidity and mortality are real threats. For example, other studies with caregivers of premature infants²² and pediatric cancer patients²³ also demonstrated parental feelings of isolation related to protecting their infants from exposure to illness from people outside their homes. However, the

theory that resulted from our analysis emphasizes how caregivers perceived uncertainty, change, and crisis as normal, rather than exceptional.

The process of compromise was experienced as dynamic; caregivers were continuously responding to ongoing threats in their everyday life with their infants. They learned to adapt to the restrictions brought upon them by home confinement and in the process, developed ways to get through this difficult time. Simultaneously, participants grappled with accepting their current situation while also thinking about the second staged surgery yet to come. Throughout, sacrifices made by caregivers were endured for the sake of their infant's healthcare needs and eventually were accepted as part of the process. Despite the limited social support available due to the pandemic, the caregivers continued to demonstrate optimism for the outcome of their infant's second surgery.²¹ While we did not collect data on the timing of infants' cardiac diagnoses, future research could explore possible differences in caregiver experiences when made pre versus postnatally.

Our study has some notable strengths, including the ethnically diverse caregiver participants, fathers as primary caregivers. Furthermore, we used induction and abduction to generate a theory through the rigorous grounded theory approach. However, the PI had indirect clinical encounters with caregivers while hospitalized, which may have impacted how participants were viewed and created additional bias. Our investigative team remained attentive to this insider status during data analyses. Furthermore, in light of the pandemic, participants may have followed a higher level of restrictions than they would have if they were experiencing the interstage period at a time before the pandemic. However, the participants were able to differentiate changes in their lives before and after the pandemic restrictions were enforced. Our study responded to the American Heart Association Interstage Home Monitoring Scientific Statement²⁴ for needed research that addressed the caregiver experience to identify ways to improve home monitoring programs for infants with SVHD.

Conclusion

Caregivers of infants with SVHD during the interstage period faced challenges related to social and family relationships resulting in a *process of continuous compromise* to maintain their infant's health during the pandemic. This theory brings an understanding of parents' experiences, skills, coping, and adaptation as caregivers to their interstage infants.

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