

# The Healing Hearts at Home© Mobile Application Usability and Influence on Parental Perceived Stress: A Pilot Study

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## ABSTRACT

In this study, the Healing Hearts and Home© (HHH©) application was piloted to determine the usability and usefulness of the mobile application and whether the application had an effect on caregivers' coping and stress. A posttest consisting of the Systems Usability Scale (SUS), the Coping Health Inventory for Parents (CHIP), and the Perceived Stress Scale (PSS) was used to collect information on the application usability, coping patterns, and perceived stress. Key informants provided more insight into usefulness. The SUS rating was 86.94 (SD = 6.34). The excellent usability score did not translate into uptake, though interest remained. The PSS scores for the control group 17.11 (SD = 1.69) and the intervention group were 19.11 (SD = 6.51) were not statistically different. None of the CHIP subscales predicted the PSS score. The HHH© application shows potential to reduce stress and improve coping in caregivers in the absence of available in-person intervention.

## KEYWORDS

Caregiver, Congenital Heart Defect, Coping, mHealth, Mobile Application, Stress

## INTRODUCTION

### Background

Congenital heart defects (CHD) are the leading cause of birth defects in the United States (Gilboa et al., 2016). One in four infants are born with a CHD (Gilboa et al., 2016). Children with CHD can be asymptomatic or present with life-threatening symptoms requiring cardiac surgery within the first few days of life. Advances in medical and surgical treatment for these children have decreased their mortality rate and length of hospital stay (Gilboa et al., 2016). This reduction in length of stay, however, has resulted in caregivers, often parents, being required to take on more responsibilities associated with their child's diagnosis and treatment. In addition to routine childcare, a caregiver of a child diagnosed with a CHD must be knowledgeable of their child's diagnosis, treatment plan, nutritional needs, pain management, and how to identify signs of clinical distress (McLellan, 2019). While this information

DOI: 10.4018/IJEHMC.20210501.oa6

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is usually provided to caregivers at the time of the initial diagnosis, the news of the diagnosis can cause caregivers to experience fear, sadness, and stress (McLellan, 2019). These emotional responses result in most caregivers understanding two-thirds of the information provided to them during their child's hospital stay (McLellan, 2019). A recent policy statement from the American Academy of Pediatrics outlined general guidelines for the care of the child with CHD. These guidelines include providing access and information on medications, caregiver cardiopulmonary resuscitation (CPR) training, references to nutritional algorithms to facilitate nutritional support, and the communication of important information regarding the patient's diagnosis, completed and planned interventions, and physical metrics (Lantin-Hermoso et al., 2017).

Currently, much of the information provided to caregivers is in the form of papers or pamphlets. While these materials are adequate, they are cumbersome and may be easily misplaced or forgotten. Furthermore, providing information in such fashion is often ineffective for those with low literacy, or those whose primary language is not English (Nápoles & Stewart, 2018). Recent developments in technology have allowed for the expansion of teaching media literacy to address multiple learning styles.

In recent years, internet technologies, such as mobile applications or social media platforms, have transformed patterns of education, communication, and healthcare delivery (Zhao & Zhang, 2017). In particular, social media platforms increase social support and interconnectivity among individuals (Zhao & Zhang, 2017). While there are resources available via online support groups (e.g., Mended Little Hearts; Little Hearts, Inc.), social media platforms carry the risk of disseminating non-credible, potentially erroneous health information. Families have expressed a desire for clinician guidance toward trusted information on the internet (Park, Kim, & Steinhoff, 2016).

## Related Work

A review of current literature on CHD and mobile applications indicates that research tends to focus on the needs of healthcare providers and patients' self-management. Mobile applications available for CHD patients (e.g., "3D Roadmap to Congenital Heart Disease," Dahku Creations, 2015; "Heartpedia," Cincinnati Children's Hospital Medical Center, 2015; "Our Journey with Heart Surgery," Phoenix Children's Hospital, 2016; "Smart Heart," Maymi, 2016) provide information on the diagnosis and treatment with some written discharge information. Other mobile applications that are available aid in: pain management, remote surgical site monitoring, and logging and tracking of clinical information (Thurnheer, Gravestock, Pichierri, Steurer, & Burgstaller, 2018; Gunter et al., 2018; McCann, McMillan, & Pugh, 2019). Our review of the available applications in the Apple app store or on Google Play, however, found no single mobile application that provided caregiver education, psychosocial, and spiritual support in one centralized location.

While currently available mobile applications provide basic information on CHD, such as the description of the disease and surgical treatments, none received input from pediatric caregivers, nor were any designed to support pediatric caregivers in general (Paglialonga, Lugo, & Santoro, 2018). Moreover, uptake of eHealth and related mobile applications has been lagging compared to mobile application use for other purposes (Greenhalgh et al., 2017). One possible reason for this is a lack of buy-in from the end user (Park et al., 2016). The inclusion of end users in the creation of eHealth has been shown to improve usability and prevent the adoption of unnecessary features (Norman, 2013).

Our team gathered qualitative data through interviews and focus groups with pediatric caregivers, many of whom were end users and wanted to improve the application for future end users. The data and the user feedback gathered created the foundation for the all-encompassing, multifunctional mobile application, *Healing Hearts at Home*® (HHH®). The goal of creating the HHH® mobile application was to enhance parent/caregiver coping patterns, reduce the stress of parents/caregivers, and improve the clinical outcome of the CHD patient.

## Theoretical Justification for the Mobile Application

The conceptual framework used to develop the mobile application was the transactional model of stress and coping (Lazarus & Folkman, 1987). The constructs that make up the transactional model of stress and coping are the primary and secondary appraisal of the situation, the coping efforts, and the outcome of such efforts (Lazarus & Folkman, 1987).

Lazarus and Folkman (1987) define primary appraisal as the time one evaluates a situation to determine if an event is negative, positive, or irrelevant. If the event is considered a negative one, this initial evaluation considers the harm that has already been inflicted, the anticipated threats, and the challenges to overcome the existing threat. Many caregivers describe the time from diagnosis through their child's first surgeries as an emotional "roller coaster" (H. Wei et al., 2016). A caregiver's primary appraisal is often linked to their ability to understand the child's diagnosis and treatment regardless of severity (Woolf-King, Anger, Arnold, Weiss, & Teitel, 2017).

Lazarus and Folkman (1987) define secondary appraisal as the assessment of the control one has over the outcomes that may be caused by the event/stressor, their control over their emotions, and their self-efficacy. The resources defined by Lazarus and Folkman (1987) are simply those needed to mitigate or eliminate the damaging outcomes of the threat. The financial impact of the child's diagnosis (Woolf-King et al., 2017), the need for long-term care, and social isolation (Jackson, Higgins, Frydenberg, Liang, & Murphy, 2018) often lead to the caregiver's poor secondary appraisal of their ability to mitigate the effects the child's CHD diagnosis will have on the child and the family. Those able to find meaning within the situation, often linked to spirituality, had a more positive appraisal (Wei, Kanthawala, Shupe, & Hussain, 2016). Family support was also found to improve one's stress appraisal (Woolf-King et al., 2017).

## Development of the Healing Hearts at Home® Mobile Application

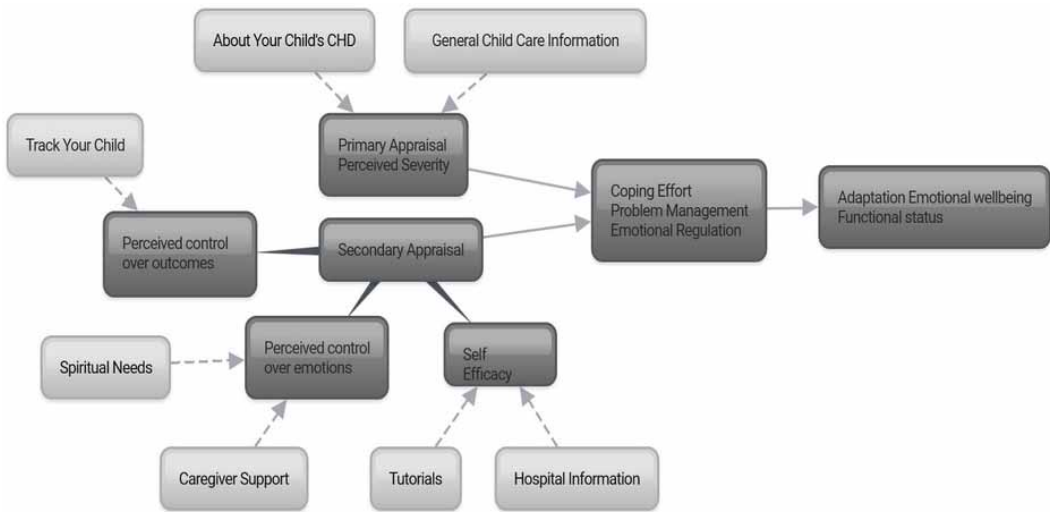
The *HHH*® application includes spiritual care, educational tutorials, tracking of clinical parameters, emotional and psychological support, and follow-up care based on the transactional model of stress and coping. The transactional model of stress and coping was used to determine the need among caregivers for these basic features in the *HHH*® application. Figure 1 shows how the transactional model of stress and coping was used as the conceptual framework for the *HHH*® application and how each of the sections within the *HHH*® application apply to the key construct of the transactional model of stress and coping.

Conceptual framework based on the constructs of transactional model of stress and coping of how caregivers can be supported by a mobile application (Lazarus & Folkman, 1987). Dark grey boxes are constructs of the transactional model of stress and coping. Bold lines indicate sub-constructs. Solid arrows represent direct effects. Light grey boxes indicate potential material in the mobile application. Dotted arrows represent associations between sections of a potential mobile application and constructs or sub-constructs within the model.

The *HHH*® was designed to support a caregiver's primary appraisal through links to reliable websites including the American Heart Association and the Centers for Disease Control and Prevention. *HHH*® could support the caregiver's control over the outcomes caused by the event/stressor through the provision of information on hospital resources, financial resources, and other community resources. *HHH*® could support the caregiver's emotional state through patient stories, connection to local support groups, and through spiritual resources, such as videos, and reading devotionals and connecting with hospital chaplains. Finally, *HHH*® could support a caregiver's self-efficacy through the provision of tutorials for post-surgery care, feedings and medications.

The initial prototype of the mobile application was created using Xcode (Apple Inc., 2020). While this is a simpler program to learn, which allowed for faster revisions, it only produces an application for iOS devices. Eventually, the program was rewritten into NativeScript (Telereik Progress, 2019), a single mobile application framework programming language that can produce applications for both iOS and Android.

Figure 1. Healing Hearts at Home® Mobile Application Framework



*HHH*® is an all-encompassing mobile application for caregivers of children diagnosed with a congenital heart defect. The disease-specific mobile application is intended to be user-friendly and caregiver-centered while guided by clinical need. It is intended to fulfill the current needs of many patients and caregivers. The home page in both English and Spanish can be seen in Figure 2.

The focus of this study was to pilot the *HHH*® application to determine the usability and usefulness of the mobile application and whether the mobile application has an effect on caregivers' coping and stress.

## METHODS

A quasi-experimental design was used to examine the usability of the *HHH*® application, whether the application reduced perceived stress, and how the application influenced coping patterns. This approach was also used due to the logistics in preventing the control group from gaining access to the *HHH*® application while also making the application easy to download and update. Group assignment to either the control group or intervention group was determined by the availability of the *HHH*® application. The caregivers were enrolled in the control group prior to the availability of the *HHH*® application. Once the *HHH*® application became available, caregivers were enrolled in the intervention group. This ensured clear delineation of the groups and reduced the potential of sharing of the mobile application between the groups. A survey was used to collect information on the mobile application usability and user satisfaction, coping patterns, and perceived stress. Key informant interviews of participants in the intervention group were used to provide more insight into the usefulness and ease of use of the mobile application as well as to help identify specific areas of strengths or weaknesses of the mobile application.

## Procedures

The setting for this study is a Level 1 trauma academic medical center that also specializes in behavior health, cancer, cardiac, perinatal services, acute rehabilitation, and transplantation. The tertiary care facility performs approximately 250 congenital heart surgeries a year. The protocol and consent procedures were approved by the Institutional Review Board at Loma Linda University. A convenience sample of caregivers was recruited by clinicians either during the child's post-surgery hospital stay

Figure 2. Home page of the Healing Hearts at Home® mobile application in English and Spanish



in the cardiothoracic intensive care unit at an academic medical center or during a follow-up visit. All participants were offered a \$5 gift card once the survey was completed.

### Participants

The control group of 16 participants was invited to participate in the study prior to the release of the *HHH*® application at the time of their follow-up appointment with the physician, four to six weeks after their child's surgery. These participants were only asked to complete an online survey, described later, on their perceived stress and coping four to six weeks after their child's surgery. These participants did not use the *HHH*® application prior to completing the stress and coping survey. Participants were given access to the *HHH*® application once they completed their survey participation and the application had been released. Control group participants' responses provided a baseline for perceived stress and coping patterns. Participants were emailed or texted the online survey link four to six weeks after the date of their child's surgery to ensure data were collected during the same time period as the intervention group. Control group participants were asked only about their coping patterns and perceived stress.

The intervention group consisted of 31 participants who were invited to use the application while their child recovered from surgery. Participants in the intervention group were given access

to the *HHH*® application at the time of consent and then were asked to complete a survey about the *HHH*® application usability, user satisfaction, coping patterns, and perceived stress. The survey was sent by email followed by a text message four weeks after the child was discharged from the hospital. This allowed the caregiver time to use the *HHH*® application while also limiting some reduction in perceived stress as a result of time. Weekly follow-up emails and text messages to caregivers who had not completed the survey were sent up to three months after the child was discharged.

### Key Informant Interviews

A semi-structured interview guide was developed to gather further information on the usability of the *HHH*® application and how caregivers used the application. Participants in the intervention group who completed the posttest were contacted by phone and invited to participate in a short interview. Two caregivers provided interviews, at which point it was determined that data saturation was reached. Participants were not paid to provide interviews.

### Assessment of *HHH*® Usability and Parental Stress and Coping

Participants were given a post-survey four to six weeks after their child's surgery. The survey included the scales for three main outcomes of interest: application usability, stress, and coping. For the usability variable, we used the System Usability Scale (SUS), which is a ten-item scale used to determine the subjective evaluation of the usability of a technological system (Brooke, 1996). This validated tool uses Likert-scale responses, which present a simple and quick way to evaluate the mobile application. The final score is continuous; higher scores indicate that a program is more user friendly. This scale was not included with the post-survey given to the control group as they did not have access to the mobile application for evaluation.

Stress was measured with the Perceived Stress Scale (PSS)—a ten-item questionnaire that measures the degree to which a person perceives their life to be stressful (Cohen, Kamarck, & Mermelstein, 1994). The final score is continuous; higher scores indicate higher perceived stress.

The Coping Health Inventory for Parents (CHIP) was used to measure caregiver coping patterns (McCubbin et al., 1983). CHIP is a 45-item questionnaire that uses four-point Likert scale responses to determine a person's coping behavior and patterns (McCubbin et al., 1983). The statements present different coping behaviors and patterns, and a continuous score is computed for each of the three coping patterns based on the caregiver's rated "helpfulness" of the behavior. The three coping patterns are (a) maintaining family integration, cooperation, and optimistic definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and (c) understanding the medical situation (McCubbin et al., 1983). A higher score in the pattern indicates a higher reliance on the pattern as a coping mechanism.

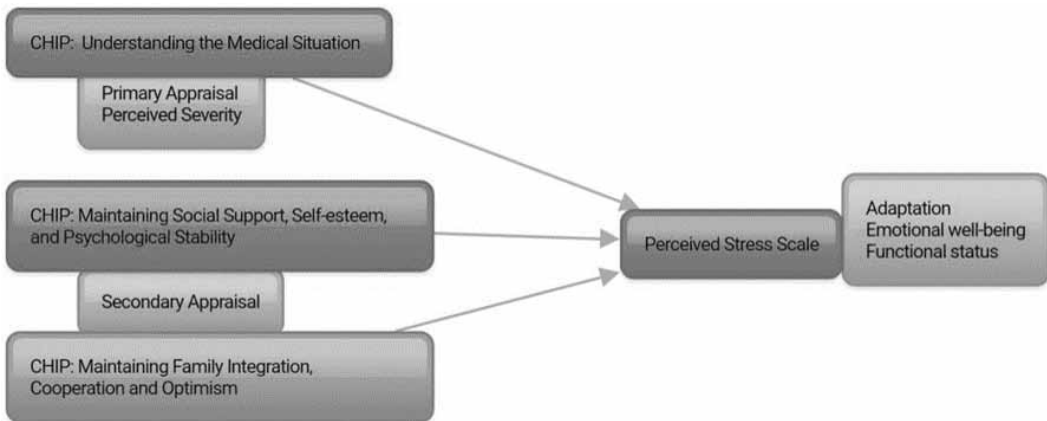
The transactional model of stress and coping, described earlier, was also used in this pilot study to examine how the *HHH*® application influences a caregiver's coping patterns and ultimately how this influences the caregiver's perceived stress. The three variables discussed above were studied during this pilot test. Figure 3 depicts how each of the variables was associated with the transactional model of stress and coping.

This figure displays how the CHIP questionnaire will be used to determine the coping patterns of caregivers who use and do not use the mobile application. These coping patterns will be compared with the PSS questionnaire, which will be used to determine the perceived stress of caregivers.

## RESULTS

Clinicians recruited 53 participants whose child was being treated at the hospital during the time. The age of the child at surgery, the child's diagnosis, and The Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery (Whitehead, Julious, Cooper, & Campbell, 2016) category (O'Brien et al., 2015) can be seen in Table 1.

Figure 3. Coping Patterns and Perceived Stress



During the recruitment of the control group, 16 caregivers consented to participate in the study. All caregivers provided a valid email and cell phone number to allow for the survey and reminders to be sent. From this group, ten (62.5%) caregivers completed the survey. During the recruitment of the intervention group, 37 parents consented to participate. All participants provided a valid email and cell phone number to allow for the link to the *HHH*<sup>®</sup> application download and posttest to be sent. From this group, 11 (26.31%) participants completed the posttest; 3 other participants completed part of the posttest survey. The information was used for the analysis when possible. All caregivers were parents of the child with the CHD. The demographics of the caregivers who completed the surveys can be seen in Table 2.

### *HHH*<sup>®</sup> Application Usability

General usability was measured using the SUS (Brooke, 1996). Ten participants completed the SUS and gave the *HHH*<sup>®</sup> application an average score of 86.94 (SD = 6.34), which equates to an excellent rating (Lewis, 2018). Two fathers participated in key informant interviews to give more details on the usability and usefulness of the *HHH*<sup>®</sup> application. The interviews were conducted to elaborate on the usability of the mobile application. Both caregivers found the mobile application to be easy to use; however, they did not find the mobile application useful. One parent noted:

*It was ok. It wasn't the best, but it wasn't the worst. We didn't use it super often. We downloaded it, but a lot of the information we got was the same we got from our own Google kind of researching.*

Another noted:

*I know digital is a bit easier, but seeing the paperwork and holding it in my hand, I was a bit more comfortable with that, I think.*

### Stress and Coping Patterns

Stress was measured using the PSS (Cohen et al., 1994). Ten caregivers in the control group and eight caregivers in the intervention group completed the PSS. The average PSS score for the control group was 15.40 (SD = 2.28) and for the intervention group was 19.11 (SD = 6.51). Initial review showed no statistical difference between the groups ( $p = .76$ ); however, reviewing the data, one participant in the control group had an extreme PSS score of 0, which is unlikely given that the general US

**Table 1. Child Information**

	<b>Control Not Completed (n = 6)</b>	<b>Intervention Not Completed (n = 26)</b>	<b>Control Completed (n = 10)</b>	<b>Intervention Completed (n = 11)</b>
Age <sup>a</sup> at surgery (range)	0.23 (0.20–3.00)	1.00 (0.30–60.00)	5.00 (0.50–180.00)	2.00 (0.25–6.00)
Diagnosis (%)				
Atrioventricular Septal Defect	1 (16.7%)	1 (3.8%)	2 (20.0%)	0
Coarctation of the Aorta	1 (16.7%)	4 (15.4%)	0	1 (9.1%)
Double Outlet Right Ventricle	0	1 (3.8%)	0	1 (9.1%)
Hypoplastic Left Heart Syndrome	1 (16.7%)	0	1 (10.0%)	3 (27.3%)
Interrupted Aortic Arch	0	3 (11.5%)	0	0
Patent Ductus Arteriosus	1 (16.7%)	1 (3.8%)	0	0
Tetralogy of Fallot	0	6 (23.1%)	0	1 (9.1%)
Transposition of the Greater Arteries	0	1 (3.8%)	0	1 (9.1%)
Truncus Arteriosus			1 (10.0%)	0
Total Anomalous Pulmonary Venus Return	1 (16.7%)	2 (7.7%)	1 (10.0%)	0
Ventricular Septal Defect	0	1 (3.8%)	1 (10.0%)	1 (9.1%)
Interrupted Aortic Arch	0	0	1 (10.0%)	0
Multiple/Other	1 (16.7%)	6 (23.1%)	3 (30.0%)	0
STAT <sup>b</sup> Category (%)				
Category 1 <sup>c</sup>	1 (16.7%)	6 (23.1%)	4 (40.0%)	1 (9.1%)
Category 2 <sup>d</sup>	1 (16.7%)	11 (42.3%)	0	2 (18.2%)
Category 3 <sup>e</sup>	1 (16.7%)	1 (3.8%)	0	1 (9.1%)
Category 4 <sup>f</sup>	2 (33.3%)	5 (19.2%)	4 (40.0%)	5 (45.5%)
Category 5 <sup>g</sup>	1 (16.7%)	3 (11.5%)	2 (20.0%)	2 (18.2%)

<sup>a</sup>Age given in months

<sup>b</sup>STAT categories as determined by the Thoracic Surgeons–European Association for cardio-thoracic surgery (Whitehead et al., 2016)

<sup>c</sup>Category 1: Patch repair of Atrial Septal Defect (ASD) or Ventricular Septal Defect (VSD) pulmonic valve replacements

<sup>d</sup>Category 2: Ross procedure, Fontan procedure, tricuspid valve repair

<sup>e</sup>Category 3: Complete AV Canal (AVC) repair, Arterial Switch Operation (ASO), lung transplant

<sup>f</sup>Category 4: Blalock-Taussig (BT) shunt, heart transplant, truncus arteriosus repair

<sup>g</sup>Category 5: Heart and lung transplant, Norwood procedure, truncus plus interrupted arch repair

population presents a baseline PSS score of 16.15 (Cohen & Janicki-Deverts, 2012). Eliminating this extreme outlier, the average PSS score for the control group became 17.11 (SD = 1.69). While eliminating the outlier did not result in a statistical difference between the two groups; the scores for both the control and intervention groups do trend higher than the general population's average of 16.15. This trend was not statistically significant when compared to the general US population (Cohen & Janicki-Deverts, 2012). As all but two participants were female, the general population PSS score for females was used in the comparison.



Table 2. Caregiver Demographics

	Control (n = 10)	Intervention (n = 11)
Age in years (SD)	30.00 (6.42)	28.45 (4.72)
Gender (%)		
Male	1 (10.0%)	2 (18.2%)
Female	9 (90.0%)	9 (81.8%)
Race (%)		
Caucasian	3 (30.0%)	3 (27.3%)
Black or African American	1 (10.0%)	0
Hispanic	4 (40.0%)	8 (72.7%)
Native American	1 (10.0%)	0
Not Answered	1 (10.0%)	0
Education (%)		
High School or GED	6 (60.0%)	6 (54.5%)
4 Year Degree	2 (20.0%)	1 (9.1%)
Graduate Degree	1 (10.0%)	1 (9.1%)
Not Answered	1 (10.0%)	3 (27.3%)

Note. This table shows the general demographics of the caregivers who completed the surveys in the control and intervention groups.

Coping patterns were measured using the CHIP (McCubbin et al., 1983). Ten caregivers in the control group and nine caregivers in the intervention group completed the CHIP questionnaire. Comparing the mean scores between the control and intervention groups for each subscale showed no significant differences between the CHIP subscale scores. The results are shown in Table 3.

Using linear regression, none of the CHIP subscales predicted the PSS score for either the control or intervention group. Although our results did not show significant differences in the PSS scores between the control and intervention groups, interviews did indicate the *HHH*<sup>®</sup> application provided some comfort. As one parent noted:

*Just knowing that there's something else available night and day, is really helpful. It's really comforting to know that there's an extra resource there.*

Both caregivers who were interviewed stated, as the *HHH*<sup>®</sup> application was not designed exclusively for their needs, it simply served as an additional tool provided to them. One parent noted:

*We used it when we needed to, if there was something that we missed.*

The other parent stated:

*We're kind of using it in unison with other things too.*

The lack of specificity to their child's condition was one of the reasons the *HHH*<sup>®</sup> application was not used exclusively. One caregiver noted:

**Table 3. Coping results**

	<b>Control (n = 10) Mean (SD)</b>	<b>Control B</b>	<b>Intervention (n = 9) Mean (SD)</b>	<b>Intervention B</b>
CHIP Subscale 1	37.80 (5.51)	-0.846	37.44 (8.05)	1.625
CHIP Subscale 2	31.60 (10.41)	0.295	38.44 (10.27)	-0.563 <sup>b</sup>
CHIP Subscale 3	19.50 (4.40)	0.348	18.889 (6.29)	-0.261
PSS Score	17.11 (1.69) <sup>a</sup>		19.11 (6.51)	

*Note.* This table shows the mean and standard deviation for the CHIP subscales and the PSS.

<sup>a</sup>The PSS mean and standard deviation does not include an extreme outlier who scored 0.

<sup>b</sup>For the model,  $R^2 = .68$  and  $p = .059$ . For the subscale  $p = .026$ .

*Maybe if it was only for my child's disease and operation that he had, it might have been a different story.*

The other caregiver stated:

*If we were able to sign in, and then we were able to see topics that would be more relevant to us, instead of everything available on the homepage, it would work better.*

## DISCUSSION

The SUS score showed success in the usability of the *HHH*® application; however, this score did not seem to translate into consistent uptake by caregivers. P. Wei et al. (2016) identified nine themes that potentially facilitated or impeded continued use of a mobile application. Specifically, they noted that health application users valued having data that was personalized and tailored to them. Health application users most liked when the health application provided information they would not otherwise have. This was echoed by our key informant interviews, as noted in the quotes above. This project was not funded, so we were limited in what features we were able to incorporate into the application.

When compared to the CHIP scores of caregivers of children with CHD measured by Sira, Desai, Sullivan, and Hannon (2014) using a one-sample t-test, our intervention group scored significantly higher (29.4, SD = 8.26) on the CHIP subscale 2 ( $p = .03$ ). One area that seemed to lower the PSS score in the intervention group was CHIP subscale 2, maintaining social support, self-esteem, and psychological stability, although this was not a statistically significant finding. Scoring higher on the CHIP subscale 2 seemed to lower the PSS score. This could be a reflection of the connectivity of social media today; however, our small sample size makes it difficult to determine if this value is a true reflection of the difference between the two groups.

Using the *HHH*® application could help caregivers maintain social support within their established network by providing a way to for them to educate those not familiar with their child's condition. The interviews supported the possibility that the *HHH*® application could aid in the maintenance of social support. Both interviewed caregivers noted that the *HHH*® application was something that could be easily shared with other family members or friends. One caregiver noted:

*Like if my parents had to watch our kids, like if we had to leave, it was helpful for that.*

The other caregiver stated:

*It's really easy to share. It's an app so anybody can get it. It's not like a piece of paper you have to send.*

The general premise behind the use of the *HHH*® application was to provide a more self-reliant, caregiver-led approach to stress reduction. The complexity of the approach and the individual needs of the families, however, made it difficult to obtain follow-up questionnaires, specifically from the intervention group, who were required to follow-up four to eight weeks after discharge. Because some in the control group were immediately eligible to complete questionnaires at consent, little follow-up was needed. While survey completion by the control group was similar to general online survey completion rates of 50.9% seen in a similar study by Loban, Mandefield, Hind, and Bradburn (2017), the intervention group saw a significantly lower survey completion rate.

One potential reason for this is that our mobile application focuses on caregivers of neonates, infants, and toddlers. These parents not only have to meet the demands of caring for a newborn or toddler, but are also challenged by the increased demand to care for a medically fragile child. Menon et al. (2012) found caregivers of cardiac surgery patients were less likely to provide consent to research. While we did not have problems with finding caregivers willing to participate in our study, the lower rate of completion of the survey may be a reflection of the lower participation rate seen by Menon and colleagues (2012). This lower completion rate should be considered when scaling up for a larger study. Moving forward towards a larger study, timing the questionnaire with a clinical visit or follow-up phone call may increase the survey completion rate.

The primary limitation in this study was the small number of participants who completed the study. This limited our ability to detect any statistically significant differences between the control and intervention groups. The intent of a pilot study is to examine the feasibility of the approach (Leon, Davis, & Kraemer, 2011). The data collected are intended to validate the approach and instrumentation and cannot necessarily facilitate hypothesis testing. The study was also limited as it was restricted to a convenience sample of caregivers of children treated at a single center. This will limit the generalizability of the findings. The general design of the application, however, may be applicable to other areas within the hospital as well as other hospitals. Finally, interviews may be subject to recall bias. Further research will be needed to determine any correlation between the use of the *HHH*® application, improved coping, and improved health outcomes of the child.

## CONCLUSION

The creation of the *HHH*® application to support caregivers can help reduce stress and improve coping in the absence of available in-person intervention. Our study showed that social connections with other families may help improve coping abilities and reduce their perceived stress. Additionally, the study showed that caregivers were interested in a more personalized mobile application. This could potentially be created using machine learning or other adaptive programming. As technology improves and costs decrease, abilities like these could be added to the *HHH*® application to tailored it to the user's needs. Finally, this study showed continued interest in the *HHH*® application. This continued interest in mobile applications provides a new avenue for clinicians and health educators to reach out to the underserved pediatric caregiver population.

## ACKNOWLEDGMENT

We would like to thank Arturo Concepcion, PhD, and the student design teams at California State University, San Bernardino, for development of the initial prototypes used in our study. We would also like to thank Laurentiu Popescu for his work on the final prototypes including the prototype used in the pilot study. Finally, thank you to Carl Ricketts for his input on the spiritual section of *Healing Hearts at Home*®. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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## APPENDIX

### Abbreviations

CHD – Congenital Heart Defect

CHIP – Coping Health Inventory for Parents

CPR – cardiopulmonary resuscitation

HHH<sup>®</sup> – Healing Hearts at Home<sup>®</sup>

PSS – Perceived Stress Scale

SUS – System Usability Scale

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