



An mHealth, patient engagement approach to understand and address parents' mental health and caregiving needs after prenatal diagnosis of critical congenital heart disease

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ABSTRACT

Objective: To provide an overview of the development of the Preparing Heart and Mind™ (PHM™) care program designed for parents with a prenatal diagnosis of critical congenital heart disease (CCHD) and describe issues of parental concern, caregiving competencies, and type and timing of PHM™ topics.

Methods: Guided participation theory underpinned intervention development and a mixed methods pilot of a novel, nurse-guided mHealth intervention. Parents were enrolled from the third trimester of pregnancy–12 weeks postnatally. Online surveys, session transcripts, and app use were descriptively analyzed.

Results: The sample included 19 mothers/birthing persons and 15 caregiving partners randomized to the intervention group. In 49 sessions, mental health/wellbeing (94%) and condition-specific information (86%) were top issues. Many caregiving competencies were developed, with mothers/birthing persons often focused on feeding (86%). Regulating emotions and co-parenting consistently needed support. PHM™ topics of preparing for hospitalization (47%) and handling uncertainty (45%) were most discussed. Two cases further characterize findings.

Conclusion: Nurse-parent collaborative understanding of issues emphasized the need for mental health assessments. Prenatal intervention opportunities were underscored through discussions of caregiving issues and PHM™ topics.

Innovation: PHM™ represents an innovative approach that holds promise for supporting parents' mental health and caregiving needs outside the healthcare setting.

1. Introduction

Congenital heart disease is the most common structural birth defect. Approximately 40,000 infants are diagnosed annually in the United States, including 25% with critical congenital heart disease (CCHD) [1]. CCHD requires surgical intervention within the infant's first year of life and ongoing medical management. Despite improvements in survival rates, infants with CCHD remain at substantial risks for impaired growth and development [2].

Most parents learn of the CCHD diagnosis prenatally [3] and

continue pregnancy [4]. After this fetal diagnosis, compromised parental mental health (e.g., symptoms of anxiety, depression, traumatic stress) is a significant issue [5–10], and the transition to parenthood has been described as “walking on an emotional tightrope” [11]. It is broadly acknowledged that parent mental health is integral to early caregiving and promotes fetal and infant growth and development [12]. Following a CCHD diagnosis, parents face unfamiliar and unpracticed caregiving for these medically fragile children, and struggle to manage their mental health while undertaking numerous caregiving challenges [11,13–15]. Moreover, across the perinatal time, parents have recounted

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inconsistencies in care, unmet expectations of healthcare providers, and difficulties in expressing agency as parents [11]. Fetal care counseling is not consistently delivered and no evidence-based practices are standardized [16-19]. There is a clear need for accessible, family-centered perinatal interventions that effectively engage parents to determine their needs, provide necessary health information, and support development of caregiving competencies during a challenging time [20].

Despite the challenges these parents face and the threats to infant growth and development, only six mental health interventions including parents of infants with CCHD have been found [21-26]. These interventions were mostly in-person, postnatal, and either demonstrated high risk for bias [27] or no significant impact on outcomes [26]. An additional report described parents' preferences for a mobile health (mHealth) application (app) after a prenatal diagnosis, however, the preliminary design and functionality achieved was not detailed [28].

mHealth apps are increasingly employed to extend healthcare beyond clinic walls and have potential to reduce healthcare inequities and costs [29,30]. Using mHealth apps could be especially valuable to parents who feel isolated, a lack of control over their circumstances, or stymied in their efforts to prepare for their critically ill infants [11,13,14]. Designed to provide support, information, and additional resources, mHealth apps could improve care for parents and families after a fetal CCHD diagnosis.

2. Objectives

The first objective of this report was to provide a brief overview of the development of the Preparing Heart and Mind™ (PHM™) care program, a novel intervention delivered using a nurse-guided mHealth platform, designed for parents with a prenatal diagnosis of CCHD. The second objective was to draw from pilot data on the intervention sessions to describe issues of parental concern, caregiving competencies, and the type and timing of PHM™ topics. An improved understanding of parents' needs and how care program content was used and tailored will be useful for informing further care program development.

3. Intervention development

We used a multi-staged person-based approach [31] to develop and test the PHM™ care program to provide support and information to parents in the context of a prenatal diagnosis and subsequent birth of an infant with CCHD. Although the following stages are outlined linearly, the process was iterative.

3.1. Planning stage

The planning stage involved the identification of intervention content based on relevant literature [11,14,32-40] and instrument development [41] conducted with parents who received a fetal CCHD diagnosis. Preliminary intervention content was shared during semi-structured consultations with healthcare providers (pediatric cardiologists, neonatologists, maternal-fetal care nurses, and social workers), scholars (experts in guided participation theory, intervention science, parent-child relationship, and infant feeding), advocacy group members, and parents of children with CCHD. These consultations offered direction for prioritizing the type and timing of content, revealed gaps, and provided ideas for the design stage (e.g., organization/functionality). Along with these consultations, the literature available at that time [11,13,15,17,21,25,34-37] also informed our understanding of the variations in usual care services, the strengths and limitations of in-person, phone, or telehealth support, as well as the outcomes of other interventions (e.g., infant feeding and development, parents' problem-solving, mental health).

3.2. Design stage

In the design stage, we focused on applying guided participation for clinical practice theory [42-44] using an mHealth approach, with the goal of improving mental health outcomes for parents after a prenatal CCHD diagnosis. We pursued this direction because an mHealth-based intervention could increase parents' access to information and resources without the time constraints of clinical settings and allowed parents to select and titrate content to meet their individual needs. We created content in the form of text, diagrams, images, videos, and resource links to address parents' needs as novices/learners in the context of an intensely emotional experience. We initiated many forms of mapping (e.g., paper notes and sketches, computer diagrams) to develop and organize intervention content, and worked with a local software firm to generate preliminary designs. Intervention content was then structured for clickable wireframe prototypes for a mobile format (see prototype examples; Supplemental Fig. 1) while iteratively eliciting feedback from parents and healthcare providers to verify key elements for app design and functionality.

3.3. Development and evaluation stage

During the development and evaluation stage, we refined the intervention components, used the wireframe prototype for evaluation, created an app, and focused on further evaluation to make improvements and ensure acceptability and usability. A small mixed methods study employing the clickable wireframe prototype with parents and healthcare providers allowed us to explore acceptability of content through semi-structured use case scenarios (i.e., how users could/would want to navigate and interact with app content). We elicited a range of suggestions and criticisms and collected preliminary usability data to determine improvements for design. This process also led to incorporating an expert who could provide tailored support and information for parents beyond the clinical setting, and we began to develop protocols for a nurse guide role.

As app development progressed, we partnered with industry patient engagement leader GetWellNetwork, Inc. Additional prototypes were developed and the finalized PHM™ care program was built on GetWellNetwork's proprietary platform with patient engagement software that we used to enhance the use of guided participation. In parallel with building the PHM™ care program, we designed a mixed methods, randomized controlled pilot study of the care program intervention, which combined the app and real-time presence of specially-trained nurse guides. This intervention, which applies guided participation theory to support parents across the prenatal-postnatal timeframe, is unique. The PHM™ care program content and intervention session protocols as well as all study materials were prepared specifically for use with this population, and have not been used in any prior study. Pilot data were collected to better understand parents' needs and how a nurse-guided mHealth approach could address these needs, as well as to test acceptability and feasibility, and estimate effect sizes for future study [45].

3.4. Trialing stage

Findings from the pilot study are informing necessary modifications for this intervention and the design of a larger trial. If evidence of improved outcomes for parents and their infants is established, the goal of future implementation would be to expand access to the PHM™ care program as supportive mHealth care.

4. Methods

4.1. Sample

Research team members who provide patient care at maternal-fetal clinics affiliated with two large urban healthcare centers located in an

Table 1
Description of Preparing Heart and Mind™ app topics and parent stories.

Topic	Description
Prenatal	
1 Introduction to the Care Program	Introduction to care program, the nurse guide and how topics are structured into four parts; Introduction, Helpful to Know, Parent Stories, Something to Think About <i>Parent story: Being positive and forming new ideas about family life</i>
2 Handling Uncertainty	Description of what is known about handling uncertainty in illness and considerations for applying familiar and productive strategies to handling uncertainty <i>Parent stories: Deciding who to tell and how much to tell others, feeling stuck and alone, having changing emotions and feelings for the baby, dealing with partner disagreements or different expectations, protecting what can be normal, and needing to take one day at a time</i>
3 Orienting	Explanation of healthcare team roles, videos and other resources related to understanding a heart disease diagnosis <i>Parent stories: Finding enough diagnostic information, reading about what to expect can feel good or bad, questioning, satisfaction with care team, managing family involvement, being involved in decisions and planning, having overwhelming emotions</i>
4 Making Decisions	Suggestions for self and couples on how to make decisions <i>Parent stories: Being on the same page as partners, trying to be brave in scary situations, seeing the baby as a person beyond their diagnosis, making decisions together and sharing information between partners</i>
5 Working Through Emotions	Strategies for acknowledging and managing emotional distress, feeling stuck, and guilt; Suggestions on how to seek support from others <i>Parent story: Finding a support system, dealing with hurtful words during a difficult time, explaining parents wishes to others who may not understand what they are experiencing, handling baby's diagnosis when a partner is losing faith, feeling the need to be strong to support others when both people are experiencing strong emotions, managing grief and guilt</i>
6 Becoming a Parent	Description of becoming a parent of a baby with a heart condition, suggestions on connecting with baby before birth, introduction to different forms of feeding, recommendations on co-parenting <i>Parent story: Identifying traits of the baby, making plans for feeding the baby, balancing the needs of the family and the needs of your partner, navigating what the future holds, holding on to hope</i>
7 Preparing for Birth	Explanation on making birth plans and what the birthing experience may look like, introduction to skin-to-skin, preparation on the possibility of separation post-birth <i>Parent story: Dealing with disappointment, seeing how difficult situations can strengthen relationships, feeling worried about what could happen, preparing for how birth will change the relationship with your partner</i>
8 Preparing for Hospitalization	Description of the healthcare team in the hospital, illustration of the neonatal intensive care unit (NICU), suggestions on what to plan prior to baby's hospitalization, introduction to visitor policies in the hospital, suggestions on giving updates to friends and family <i>Parent story: Finding strength as a parent or family, being there for baby in the hospital, figuring out how to handle everything, becoming a parent in the hospital with many other people involved</i>
9 Preparing for Surgery	Suggestions on how to prepare for hospitalization, what to ask the surgeon, how to prepare siblings, and what to expect during surgery; description of what to expect post-surgery in the ICU and what recovery looks like; reminders on playing the active role of a parents and the importance of taking care of yourself <i>Parent story: Keeping the family going, handling emotions and worry as surgery gets closer, hoping for the best while preparing for the worst, feeling like life is on hold with baby's health concerns</i>
Postnatal	
1 Being in the Hospital	Descriptions of common experiences and feelings during hospitalization, strategies on how to navigate emotions <i>Parent stories: Feeling helpless and/or alone at the bedside, managing differing perspectives since receiving a diagnosis</i>
2 Caring for Your New Baby	Suggestions for bonding with baby in the hospital setting, caregiving concerns for an infant after surgery and hospital discharge to home <i>Parent stories: Finding your footing as a parent, learning to take care of a newborn in a hospital setting, managing hospital versus home life with your partner</i>
3 Feeding Your Baby	Condition-specific and supportive information on direct breastfeeding, pumping and providing human milk, formula and fortification, feeding tubes <i>Parent stories: Managing pumping and breastfeeding in the hospital, having difficulties with breastfeeding, using multiple feeding methods</i>
4 Working Through Emotions After Birth	Common emotions parents experience in the ICU, supportive outlets, confidence in caregiving abilities, comparison of parent's perspective with the perspective of the healthcare team <i>Parent stories: Understanding different ways of processing child's diagnosis and care, reflecting on one's experiences since receiving the diagnosis, sharing experience with friends and family, having different hopes for baby</i>
5 Handling Uncertainty After Birth	Balance of illness-related care and non-illness related care in the hospital, adaptation to a divided household, ups and downs in the course of illness, possible adjustments in the healthcare team <i>Parent stories: Experiencing some normalcy, struggling with unknowns in the plan of care, worrying about developmental milestones, leaning on your partner</i>
6 Leaving the Hospital	Preparation for new responsibilities and worries at home, medical care at home, contact and visits with the healthcare team, signs and symptoms to watch out for in baby's status, protection from illness, transition from illness-related role in hospital to being a parent at home <i>Parent stories: Managing mixed emotions about going home, finding a balance between medical care and parenting</i>

Introduction

Preparing Heart and Mind™ 1.3 Let's Get Started!

Every prenatal chapter in the care program is open for you to use during pregnancy. You will see that some chapters make more sense at certain times. Your nurse will send you messages to suggest a chapter each week. Your nurse might also send extra resources, based on your needs.

As your due date nears, you will see new chapters open up. These will focus on things that you need to know after birth.

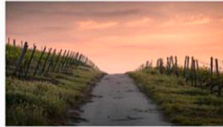
Care tip ▶

You will always have access to earlier chapters in the care program. You can go back to review, or look ahead at what is coming up.

Preparing Heart and Mind™ 1.4 Helpful to Know

We want to make sure that you have the right information at the right time. In each chapter of the care program, you will see videos, care tips, and stories from other parents.


You will also find sections called "Helpful to Know," which gives information and tips to help you prepare to parent your new baby. You will learn about your baby's diagnosis, your healthcare team, how to manage emotions, and what to expect in the hospital.



Preparing Heart and Mind™ 1.6 Parent Stories

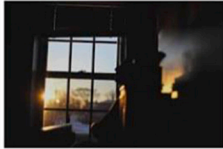
Parent stories are based on conversations we have had with parents like you. You will read about experiences that parents and caregivers have had after finding out about a serious health concern for their child. You might have similar experiences. You will also have your own, unique feelings and thoughts.

The names and some of the details in these stories have been changed to protect parents' privacy.



Preparing Heart and Mind™ 1.9 Something to Think About

At the end of each chapter, we will leave you with one last question to think about on your own time. For example, a question might be: "When you faced a situation that was different than you thought it would be, how did you react?"



These questions are meant to support your thinking and help you reflect. You may choose to talk about what's on your mind, but you don't have to.

Helpful To Know

5.4 Getting Stuck

Below are some common ways that people can get stuck when trying to deal with strong, or complex emotions:

- Thinking about the problem over and over again
- Focusing on the negative parts of a situation
- Avoiding the problem, or pretending that the problem doesn't exist
- Pushing down uncomfortable feelings
- Not ever talking about how you feel

Do you use any of these strategies? Does your caregiving partner?


Care tip ▶

[Click here](#) to learn about more ways to manage emotions.


8.6 Visitors

Hospital visitors: Visitors at the hospital can be so important and they are usually welcome. But sometimes there are restrictions, like during flu season. Who will visit you? Your visitors should be people who can provide support and comfort, keep you from feeling alone, and do special things to help get you through a hard time. Who would you like to have visit you when your baby is in the hospital?

Child visitors: If you have other children, it's important to help them know what to expect. Having a new baby in the family is a big adjustment, and the hospital can be a scary place for children. Ask your care team about child life specialists, who can help you plan for visits from your other children.



11.5 Getting Started with Breastfeeding



How To Breastfeed
Run Time: 1:33

This video gives information about how to breastfeed a new baby. It focuses on healthy babies, but has good tips for any new parent.


Care tip ▶

If you can't breastfeed right away, you can do things to help your baby learn to breastfeed later, like pumping human milk and doing oral cares. You will be able to read more about these things in the following pages.

15.5 Preparing Your Family

If you have other children at home, you may need to make plans for childcare. Most parents need to take time off of work. Some families are able to "tag-team," with one parent at the hospital, and another at work or home with other children. You might also ask family members and friends to help out.

It's best to try to make plans for childcare and work in advance. Surgery and hospitalization can be a very busy time. If you don't have people who can support you in this way, ask your healthcare team. The social worker may be able to connect you with people who can help. The social worker can also help you talk to your employer.




Parent Stories

1.8 Margot: A New Dream

I talk with my husband when we take our walks in the woods. Together, we are focusing on the good things that lie ahead. We are positive people. Our daughter's heart issue is not clear right now, but it seems fixable.

We can still do what we want to do as a family, but maybe with some small changes. The things we have dreamed about doing with our daughter, like traveling, and camping - we can still do this!

I'm worried about my husband though. Sometimes he seems so sad, almost in despair. We usually try to focus on the positive, but right now he doesn't always seem to be on the same page as me.




3.11 Amira: Feeling Overwhelmed

When I first got the news that my baby only has half a heart, I think I was in shock. I can hardly even remember what the healthcare team said to me - I just got out of there as soon as I could, got in my car, and cried. Now I'm feeling stronger, and more determined to do whatever I need to do for my baby. It's going to be hard though.

There are so many appointments to go to, and the hospital is three hours away!

It seems like there is a lot to think about - they said the baby might be in the hospital for weeks after he's born. I don't know who is going to watch my other three kids after school if I'm not home. My boss won't like it if I'm taking so much time off work. I'm afraid I'll lose my job if I miss work to go to the hospital. I can't imagine being three hours away from my new baby every day. I feel really overwhelmed right now.




4.9 Jon and Naomi: My Daughter is a Person, Not a Disease

We were talking with the genetic counselor at one of our appointments, and she was like, "Oh, I am so sorry. Can I give you guys a hug?" I think it hit us then. We don't want her pity. We don't want anyone's pity for us or our baby.

I guess I already see myself as a dad to a child with special healthcare needs. I will do whatever I can to make sure we have the best healthcare - and we are perfectly capable of making the right decisions with the healthcare team.

I will make sure to help people see our daughter as a person, a strong girl, not as a kid with a terrible heart disease.



15.14 Malik: Keep Family Life Going

This baby will be our second child. The hospital where he'll have surgery is three hours away. I don't have time to take off from work for the surgery. I need to keep my job for the insurance. My girlfriend can be at the hospital full time with the baby. The doctors have told us that the baby could be in the hospital for quite awhile after the surgery.

I'll be taking our older daughter to school each morning, and then picking her up from daycare in the evening, after I get off work. We have some family in town, but they can't help as much as we would like. I'm really starting to worry about how I will ever have time to see my girlfriend or the baby. It seems like we're both basically going to be single parents for a while. But there is no other choice for myself, my girlfriend, or my kids.




Fig. 1. Preparing Heart and Mind™ care program app examples.

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upper Midwestern state and a Southern state introduced the study to potentially eligible participants in person, by phone, or through MyChart (a secure online healthcare portal). Potentially eligible participants were also able to self-refer through links on a research brochure or university-based website. Eligible participants were mothers/birthing persons (M/BPs) between 24 and 33 weeks of pregnancy, English speaking, >18 years old, and planning to deliver and care for an infant with CCHD. Caregiving partners' (CPs) participation was invited but not required. Eligibility was not affected by additional non-lethal anomalies or genetic conditions. Participants were excluded from the study if a less severe diagnosis (e.g. not critical CHD, not requiring surgery <1 year) was confirmed, or if fetal or infant death occurred. All participants were screened and verified for eligibility. Eligible and interested participants completed a REDCap eConsent process with a nurse on the research team over the phone. After consenting, participants were randomized to the intervention or control group. Those in the control group received usual care and those in the intervention group were assigned a nurse guide and were provided with access to the PHM™ app. The current report focuses on participants randomized to the intervention group who participated in the study between October 2020–October 2022.

4.2. PHM™ care program

The PHM™ care program was piloted with nurses who held bachelor's or master's degrees and engaged in specialized training that included the online Guided Participation for Clinical Practice program (~4 h), two in-person half-day sessions (~10-h), and required readings before the intervention began.

The PHM™ app platform included interactive parent-facing content and a healthcare provider dashboard. As outlined in Table 1, PHM™ app content covered 15 topics (9 prenatal, 6 postnatal), with sub-sections (i. e., *Parent Stories*) within each topic (PHM™ app examples; Fig. 1). An additional 17 topics provided condition-specific information on heart anatomy and function (e.g., Tetralogy of Fallot; Hypoplastic Left Heart Syndrome) to tailor the care program. Patient engagement invited responses to pre-scheduled check-in messages from the nurse guide, questions about using the care program, and questions about one parent story per care program topic. The healthcare provider dashboard supported anytime messaging between the nurse guide and parent and allowed the nurse guide to view engagement analytics (e.g., check-in responses, PHM™ topics viewed).

4.3. Intervention delivery

The nurse guide used semi-structured protocols to conduct three audio-recorded remote sessions (2 prenatal, 1 postnatal) with individual parents or parent dyads in the intervention group using video conferencing (i.e., Zoom). Remote sessions required device (e.g., smartphone, tablet) connection to the internet and were conducted with the nurse guide in a private location, while parents joined from a location of their choice that was private and comfortable for them (e.g., home, car). Each nurse had a caseload, working consistently with the same parents to support relationship-building and sensitive tailoring of intervention sessions. During the first session, the nurse ensured that each parent set up secure access to the PHM™ app, and together, the nurse and parents navigated the app and reviewed the introductory topic. By design, prenatal and relevant condition-specific topics were immediately available to these parents, with postnatal topics available later (± 2 weeks of birth).

The nurse used guided participation processes [42–44] during sessions and through check-ins and messaging to inform tailoring of the intervention. During each session, the nurse guide sought to identify issues of parental concern and assess caregiving development based on what parents were mentally working on (e.g., needs, concerns, questions) regarding their child. Nurses used open-ended questions (e.g., “I know that parents have a lot on their minds at this time, and I want to

know how I can be supportive - so, I am wondering what you have been thinking about the most lately.”) to invite parents into conversation. The nurse specifically employed guided participation by connecting with parents and joining attention to what was on their minds, and provided new information while directing parents to related app topics. Guided participation also involved understanding perspectives and bridging a parent's previous knowledge to that which was unfamiliar or unknown. By intentionally creating and maintaining a collaborative relationship, the nurse found opportunities to support caregiving by scaffolding problem-solving and transferring responsibilities to parents so they could take on new tasks, goals, and/or ways to communicate. Nurses engaged in regular reflective practice meetings to review sessions with research team members and experts on guided participation to understand parents' needs, identify useful strategies for tailoring, and ensure intervention fidelity. Additionally, some attrition was anticipated. If ineligibility occurred as the study progressed (e.g., change in diagnosis, infant death), the nurse guide contacted parents and sensitively explained that further study-related communications and access to the PHM™ app would end. Condolences were offered and a sympathy card was sent to parents following infant death.

4.4. Measures

Data for this report were collected proximate to each of three intervention sessions and > 2 weeks apart: 27–34 weeks of pregnancy, 32–36 weeks of pregnancy, 2–8 weeks after birth. Parents completed an online survey to self-report baseline data including demographics and fetal diagnostic/health information prior to intervention session 1. A subsequent parent survey provided infant diagnostic/health updates before session 3. Parents received gift card payments following survey and session completions. Pediatric cardiologists (MBA, AAMS) used electronic health record data to verify fetal/infant diagnoses.

Data included for this report were collected through online surveys generated for the study to document issues of parental concern and caregiving competencies entered by the nurse guide immediately following each session. A selection of eight categories of issues (e.g., Mental health/wellbeing, Condition-specific information, Dyad relationship), each specified with definitions, were generated based on earlier work during the planning and design stages of intervention development. Seven caregiving competencies (e.g., Giving care to the fetus/infant, Emotional regulation, Co-parenting) with 3–8 corresponding sub-competencies adapted from Pridham and colleagues [42] were assessed and documented in the survey as present/functioning, developing/needing support, or not applicable. The survey also accommodated narrative entries to ensure all relevant information about the sessions was captured. For illustrating the cases, app analytics provided data on topics viewed and audio recordings of intervention sessions were transcribed verbatim using NVivo (QSR International Pty Ltd., Release 1.6) and de-identified for analysis. Transcripts of sessions with two families, selected for variation and richness, were used to illustrate cases and further address the second objective of this report.

4.5. Analysis

Descriptive statistics (i.e., n, %) of sample characteristics, survey, and app analytic data were computed in R (version 4.2.1). Narrative survey data were reviewed and summarized to further understand and interpret issues of parental concern and caregiving competencies. The broader pilot study analysis of session transcripts involved a team-based approach (ACM, JD, AS) applying qualitative methods including directed content analysis with a coding manual for primary independent coding followed by secondary coding to verify, add to, or dispute completed primary coding [46,47]. Drawing from that analysis, six session transcripts became the focus for the two case exemplars with illustrative quotations in this report. Codes generated to capture issues of parental concern and corresponding representative quotations were

determined through discussions among two or three coders to reach consensus, as needed. The healthcare provider dashboard data on PHM™ topics viewed outside the sessions were used to augment description of the cases.

4.6. Ethical considerations

This study was approved by institutional review boards at the University of Minnesota and Baylor College of Medicine. All study participants provided written informed consent.

5. Results

5.1. Sample characteristics

A total of 19 M/BPs and 15 CPs were included, of which 26% self-identified as Asian, Black, or Indigenous (see Table 2). Among the 20 infants of these parents, which included one set of twins, 25% had a primary fetal diagnosis of single ventricle physiology. All parents initiated secure access to PHM™ during session 1. A total of 49 sessions were completed, each lasting 30–90 min. Five infants were born before the second session. Third session participation was reduced to 16 M/BPs as two infants became ineligible due to less severe diagnoses, and one infant died.

5.2. Issues of parental concern

Issues discussed across the three sessions are illustrated in Fig. 2.

Table 2
Sample Characteristics (N = 34).

	n (%) or median (IQR)
Pregnancy status	
Mother/birthing person	19 (56)
Caregiving partner	15 (44)
Age	33.5 (32–36.5)
Race	
Asian, Black, or Indigenous	9 (26)
White	24 (71)
Another Race	1 (3)
Ethnicity	
Hispanic or Latino/a	3 (9)
Not Hispanic or Latino/a	31 (91)
Education	
High school, GED	4 (12)
College (2-year associate)	7 (20)
College (4-year bachelor's)	19 (56)
Graduate degree	4 (12)
Income	
<\$50,000/year	1 (3)
\$50,000–\$89,999/year	6 (18)
\$90,000–\$129,999/year	7 (21)
>\$129,999/year	20 (59)
Insurance	
Commercial	29 (85)
Government	5 (15)
Marital status	
Married	24 (71)
Partnered	10 (29)
Infant cardiac diagnosis ^a	
Biventricular ^b	15 (75)
Single ventricle	5 (25)

Abbreviation: GED = general educational development.

^a Parents in this sample had a total of 20 infants with fetal CCHD diagnoses, including 1 set of twins.

^b Primary biventricular diagnoses included atrioventricular septal defect, coarctation of the aorta, double outlet right ventricle, tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, and pulmonary stenosis. Primary single ventricle diagnoses included hypoplastic left heart syndrome and pulmonary atresia.

Overall, the top issues of parental concern were managing mental health/wellbeing (94%), needing condition-specific information (86%), considering the dyad relationship (61%), and determining social support (61%). Narrative data underscored an additional high priority issue of infant feeding, which was not specified a priori.

5.3. Caregiving competencies

Table 3 shows the top caregiving competencies and sub-competencies across sessions. The most well-developed competencies and sub-competencies were associated with knowing and relating to the fetus/infant as a person (affection and warmth: M/BPs = 100%, CPs = 94%; references fetus/infant as a person: 94%, 94%), giving care to the fetus/infant (specialist care: 100%, 97%; environmental supports: 85%, 85%), and co-parenting (shared understanding of diagnosis: 89%, 91%; agreement: 85%, 85%). For M/BPs, giving care to the fetus/infant by making plans for feeding (86%) was a well-developed sub-competency. For CPs, regulating emotions through verbalizing acceptance of the diagnosis (97%) was a competency.

Sub-competencies related to regulating emotions (expresses emotions: 39%, 41%; skills for uncertainty: 35%, 37%; reflects on thoughts and feelings: 33%, 44%) and co-parenting (division of labor: 50%, 42%) needed support for development across sessions. For M/BPs, co-parenting competencies related to caregiving satisfaction (45%) and dyad communication (41%) specifically required support. For CPs, giving care to the fetus/infant by making plans for feeding (52%) was less developed.

5.4. PHM™ topics

Fig. 3 shows the PHM™ topics used or recommended in the sessions, with preparing for hospitalization (47%) and handling uncertainty (45%) incorporated most frequently. It became clear early in the study that the feeding topic was insufficient to support parents' needs. Additional CCHD-specific infant feeding resources, especially for breastfeeding, were provided to fill this gap.

5.5. Cases

The following cases are exemplars of sessions with two parent dyads, identified by pseudonyms, who had infants prenatally diagnosed and born in 2021. These parents were similarly impacted by COVID-19 restrictions. Tables 4 and 5 further characterize the cases with top issues illustrated by quotations, caregiving competencies needing support, and PHM™ topics discussed by session.

5.5.1. Case 1

Kalia and Devon were in their 30s and both have a 4-year bachelor's degrees. They became parents to a son, their first child, with a primary diagnosis of double outlet right ventricle. Devon maintained a stoic presence during the two sessions he attended. Kalia described working on issues of mental health/wellbeing, dyad relationship, and infant feeding. Competencies most needing support were regulating emotions, engaging and communicating with others about needs, co-parenting, and feeding (see Table 4). Kalia used PHM™ throughout the perinatal time, viewing 100% of the prenatal, condition-specific, and first 3 postnatal topics, and 85% of postnatal topic 4. Devon viewed 100% of prenatal topics 1–8, 39% of topic 9, and 20% of postnatal topic 1.

5.5.2. Case 2

Jean and Alan were also in their 30s with a 2-year associate degree and high school diploma respectively. They became parents to a daughter with a primary diagnosis of hypoplastic left heart syndrome. Jean has an older healthy child from a previous relationship who lives in their household. Mental health/wellbeing and the dyad relationship were top issues, along with condition-specific information, social

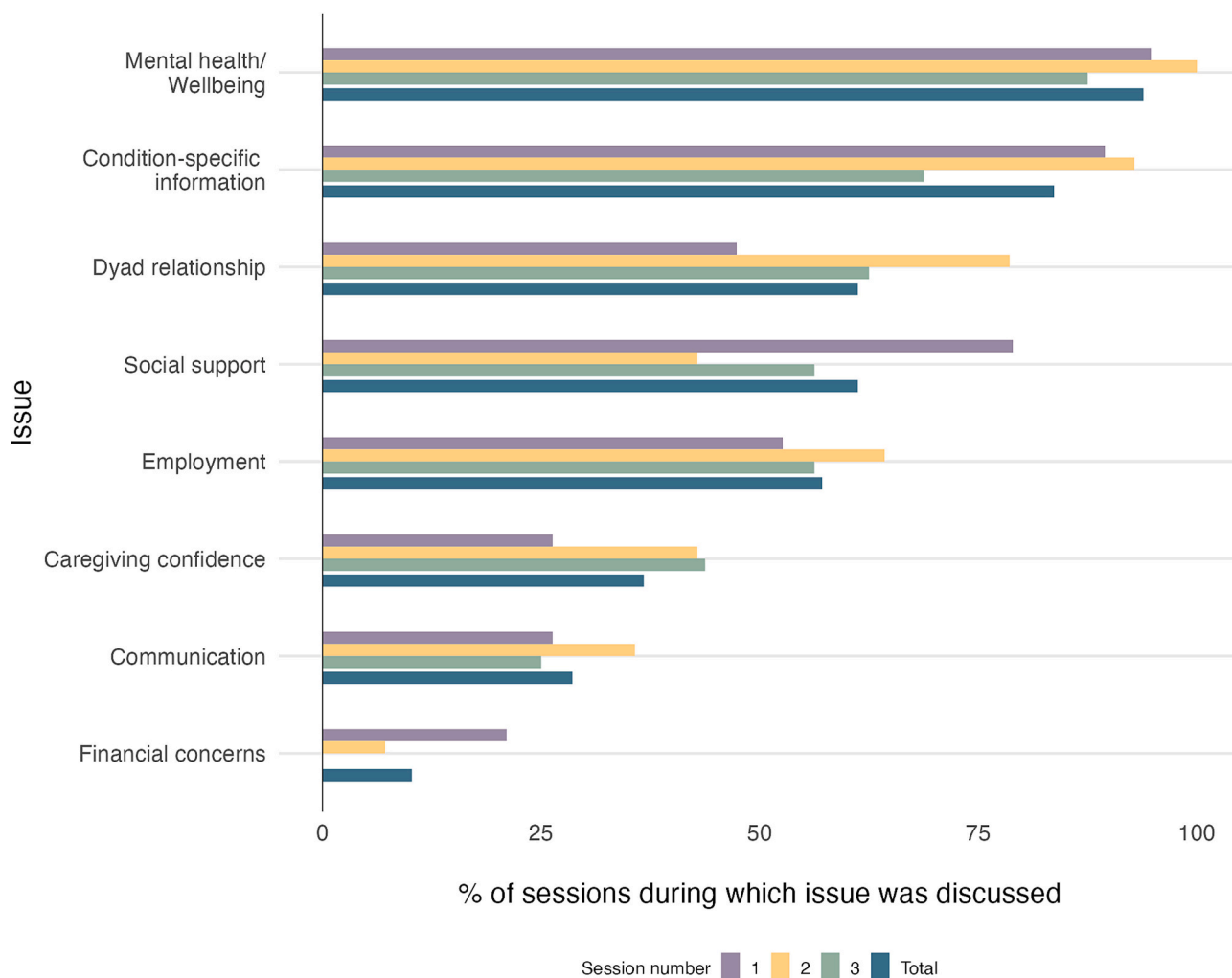


Fig. 2. Issues of parental concern discussed across three intervention sessions.

support, and communication. Competencies needing support across sessions included regulating emotions, engaging and communicating with others about needs, and co-parenting. Other clinically relevant competencies needing attention were giving care to the fetus/infant and problem solving (see Table 5). Jean and Alan used PHM™ primarily before their daughter was born. Jean viewed 100% of prenatal and the condition-specific topics, however, only viewed 47% of postnatal topic 1. Alan viewed 100% of prenatal topics 1–6 and 8% of topic 7. Following the last session, Jean's mental health deteriorated into a crisis with suicidality detected by the intervention nurse through PHM™ messaging. The nurse provided immediate support and resources, and initiated professional crisis services.

6. Discussion and conclusions

6.1. Discussion

Our study suggests that engaging parents during the third trimester of pregnancy and providing support and information across the perinatal period is well-timed and particularly crucial for those struggling with mental health. Moreover, this report appears to be singular in the literature describing parents' caregiving competencies and mHealth care program use before the birth of an infant with CCHD.

First, we found that most parents shared how they were mentally working on preparing to be caregivers while acknowledging the context of uncertainty. M/BPs readily brought up issues related to emotional

challenges and expressed eagerness for condition-specific information (e.g., infant diagnosis, clinical course) to shape their expectations for healthcare. CPs often contributed to partner-led narratives, perhaps favoring a socially expected role [48]. Uncertainty after a prenatal diagnosis has been well-described, with its potential to stymie hope and the connection to the fetus [13], and to threaten adaptive efforts after birth when parents focus on guarding their fragile emotional state [38,49]. Parents' emotional distress and uncertainty can be exacerbated by missed care opportunities and poor communication by healthcare providers [50,51]. Moreover, parents have reported acceptability of mental health assessments, and clinicians and researchers agree such assessments, along with education and counseling, are areas for improvement after fetal heart disease diagnosis [50-52].

Second, we observed that giving care to the fetus/infant was a well-developed caregiving competency for M/BPs, who demonstrated this care by raising numerous unaddressed questions and concerns about infant feeding. Overall, parents lacked essential, evidence-based feeding information, especially about breastfeeding and human milk. Many experiences shared with the nurse echoed a recent study about how M/BPs struggled to breastfeed their infants born with CCHD by navigating often conflicting feeding goals with healthcare providers and engaging in activities to support breastfeeding establishment (e.g., developing a milk supply) [53]. Additionally, regulating emotions required attention across sessions, and for M/BPs, co-parenting satisfaction and communication were still developing. Our findings align with a recent study describing parents' perceived unmet needs for healthcare providers to

Table 3

Top caregiving competencies identified as well developed or needing support for development as assessed by the nurse during each session (N = 49 total sessions attended by mothers/birthing persons only; N = 36 total sessions attended by caregiving partners)

	Mothers/Birthing Persons n (%)			
	Session 1 (n = 19)	Session 2 (n = 14)	Session 3 (n = 16)	Total Across Sessions
Well-developed caregiving competencies and sub-competencies				
Knowing and relating to the fetus/infant as a person				
Expresses affection and warmth	19 (100)	14 (100)	16 (100)	49 (100)
References the fetus/infant as a person when problem solving/making decisions about care	17 (89)	13 (93)	16 (100)	46 (94)
Giving care to the fetus/infant				
Follows through on specialist care arrangements	19 (100)	14 (100)	16 (100)	49 (100)
Makes plans for feeding the baby, demonstrating understanding of potential challenges	15 (79)	–	16 (100)	42 (86)
Plans for the infant’s life by providing environmental supports/materials (e.g., crib/bedding, car seat)	–	13 (93)	16 (100)	41 (85)
Problem solving				
States criteria/reasons relevant to a decision about care for fetus/infant	16 (89)	14 (100)	16 (100)	46 (96)
Collects, uses, or integrates many types of information/criteria in assessments/decision making	16 (84)	13 (93)	–	44 (90)
Co-parenting				
Expresses a shared understanding of the diagnosis with partner	–	13 (100)	16 (100)	40 (89)
Describes agreement related to caregiving issues	–	13 (100)	–	39 (85)
Engaging and communicating with others about needs				
Informs others about changes in a timely manner (e.g., before making significant care decision)	12 (75)	–	13 (100)	36 (88)
Regulating emotions				
Verbalizes acceptance of the fetal diagnosis/situation	14 (74)	13 (93)	–	42 (86)
Caregiving competencies and sub-competencies needing support				
Being with the fetus/infant				
Verbalizes thoughts about how the fetus/infant might be experiencing life in utero/in the world	17 (89)	6 (43)	3 (19)	26 (53)
Co-parenting				
Describes division of labor in regard to caregiving	9 (69)	7 (50)	5 (33)	21 (50)
Expresses satisfaction related to caregiving	9 (69)	5 (38)	5 (31)	19 (45)
Communicates about caregiving with partner	9 (53)	5 (38)	5 (31)	19 (41)
Problem solving				
Expresses a sense of mastery over anticipated/necessary medical tasks	13 (72)	5 (42)	–	20 (43)
Anticipates surprises (unexpected events) and knows how to proceed when a surprise occurs	11 (58)	4 (29)	3 (19)	18 (37)
Regulating emotions				
Expresses emotions in ways that are personally meaningful, and promotes flexibility, growth, healing	10 (53)	5 (36)	4 (25)	19 (39)
Exhibits skills for dealing with uncertainty	–	6 (43)	4 (25)	18 (37)
Actively reflects on thoughts and feelings about the prenatal experience	–	6 (43)	4 (25)	16 (33)
Knowing and relating to the fetus/infant as a person				
Identifies traits of the baby (e.g., “he is so strong” “he kicks all night” “she is brave” “she is a fighter”)	10 (53)	4 (29)	–	15 (31)
Caregiving Partners^a				
	n (%)			
	Session 1 (n = 13)	Session 2 (n = 9)	Session 3 (n = 12)	Total Across Sessions Attended
Well-developed caregiving competencies and sub-competencies				
Giving care to the fetus/infant				
Follows through on specialist care arrangements	12 (92)	9 (100)	12 (100)	33 (97)
Plans for the infant’s life by providing environmental supports/materials (e.g., crib/bedding, car seat)	–	9 (100)	12 (100)	29 (85)
Regulating emotions				
Verbalizes acceptance of the fetal diagnosis/situation	12 (92)	9 (100)	12 (100)	33 (97)
Knowing and relating to the fetus/infant as a person				
References the fetus/infant as a person when problem solving/making decisions about care	12 (92)	8 (89)	12 (100)	32 (94)
Expresses affection and warmth	11 (85)	9 (100)	12 (100)	32 (94)

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Table 3 (continued)

	Caregiving Partners ^a			
	Session 1 (n = 13)	Session 2 (n = 9)	Session 3 (n = 12)	Total Across Sessions Attended
Co-parenting				
Expresses a shared understanding of the diagnosis with partner	10 (77)	9 (100)	12 (100)	31 (91)
Describes agreement related to caregiving issues	9 (69)	9 (100)	11 (92)	29 (85)
Engaging and communicating with others about needs				
Expresses trust and confidence in the healthcare team	11 (85)	9 (100)	–	30 (88)
Problem solving				
States criteria/reasons relevant to a decision about care for fetus/infant	9 (69)	8 (89)	11 (92)	28 (82)
Collects, uses, or integrates many types of information/criteria in assessments/decision making	9 (69)	8 (89)	11 (92)	28 (82)
Caregiving competencies and sub-competencies needing support				
Being with the fetus/infant				
Verbalizes thoughts about how the fetus/infant might be experiencing life in utero/in the world	9 (69)	5 (56)	4 (33)	18 (53)
Expresses awareness of fetal/infant movements or actions	9 (69)	5 (56)	–	15 (44)
Problem solving				
Expresses a sense of mastery over anticipated/necessary medical tasks	10 (83)	5 (63)	–	17 (53)
Demonstrates understanding of medical language/clinician communication	–	3 (33)	–	13 (38)
Giving care to the fetus/infant				
Makes plans for feeding the baby, demonstrating understanding of potential challenges	9 (69)	5 (63)	3 (25)	17 (52)
Regulating emotions				
Actively reflects on thoughts and feelings about the prenatal experience	7 (54)	4 (44)	4 (33)	15 (44)
Expresses emotions in ways that are personally meaningful, and promotes flexibility, growth, healing	–	4 (44)	5 (42)	14 (41)
Exhibits skills for dealing with uncertainty	–	3 (33)	3 (25)	12 (35)
Co-parenting				
Describes division of labor in regard to caregiving	6 (50)	4 (44)	4 (33)	14 (42)
Knowing and relating to the fetus/infant as a person				
Identifies traits of the baby (e.g., “he is so strong” “he kicks all night” “she is brave” “she is a fighter”)	8 (62)	4 (44)	–	14 (41)
Engaging and communicating with others about needs				
Negotiates a role/exhibits agency in deciding what to do concerning fetal/infant care	–	3 (33)	5 (42)	12 (35)

Note: All percentages are valid percentages. Not all competencies were applicable for every session.

^a Caregiving partners participated in 69% of total sessions because not all mothers/birthing persons participated in the study with their caregiving partners.

prepare them emotionally, provide information to both M/BPs and CPs, and help them manage day-to-day care including feeding difficulties for their infants with congenital heart disease [54]. The PHM™ care program could be used to provide needed support and information to parents, improving communication with healthcare providers while also offering optional mental health check-ins.

Lastly, in regard to the type and timing of PHM™, the topics of preparing for hospitalization and handling uncertainty were most frequently incorporated into sessions. All parents used PHM™ during the prenatal time, suggesting feasibility of reaching parents with mHealth and patient engagement strategies for several weeks before birth. These are important findings considering recent studies describing socioeconomic and racial inequities in prenatal care after fetal diagnosis [19], and additional care needed for parents who reside at greater distances from the clinic/hospital [50]. Thus, PHM™ has the potential for providing comprehensive and tailored care that can extend, rather than burden, the existing healthcare system.

6.1.1. Limitations

There are limitations to consider with these study findings. The nurse-reported intervention data might have been affected by interviewer or recall bias; however, we sought to confirm accuracy through review of audio recordings and analysis of transcripts. There was also potential for self-selection bias with participating parents who were emotionally stable and sufficiently resourced. In regard to delivery of

the PHM™ app content, technical error delayed postnatal content for three parents. Finally, with two recruitment sites, it is possible that parents encountered differences in healthcare.

6.2. Innovation

PHM™ represents an innovative approach that holds promise for addressing parents' psychosocial needs outside the healthcare setting. A key strength of this novel work is the well-established partnership with industry leader GetWellNetwork, Inc. No similar intervention approach for this population has been identified. These study findings are further informing our patient engagement approach by providing the right type of PHM™ content to support parents in addressing their mental health needs and bolstering their caregiving, and at the right time, when parents are eager to prepare and learn in a concentrated timeframe. Dovetailing with this approach is the opportunity to broaden access to consistent family-centered care for this parent population in ways that are intentionally inclusive. For example, ongoing care program development will include additional content improved with feedback from community partners and parents, care program content offered in languages other than English, and future nurse guides who reflect the same diversity of parents affected by a prenatal CCHD diagnosis. These next steps could be crucial for helping to reverse worse infant outcomes linked to socioeconomic and racial inequities in prenatal care after a CCHD diagnosis [19].

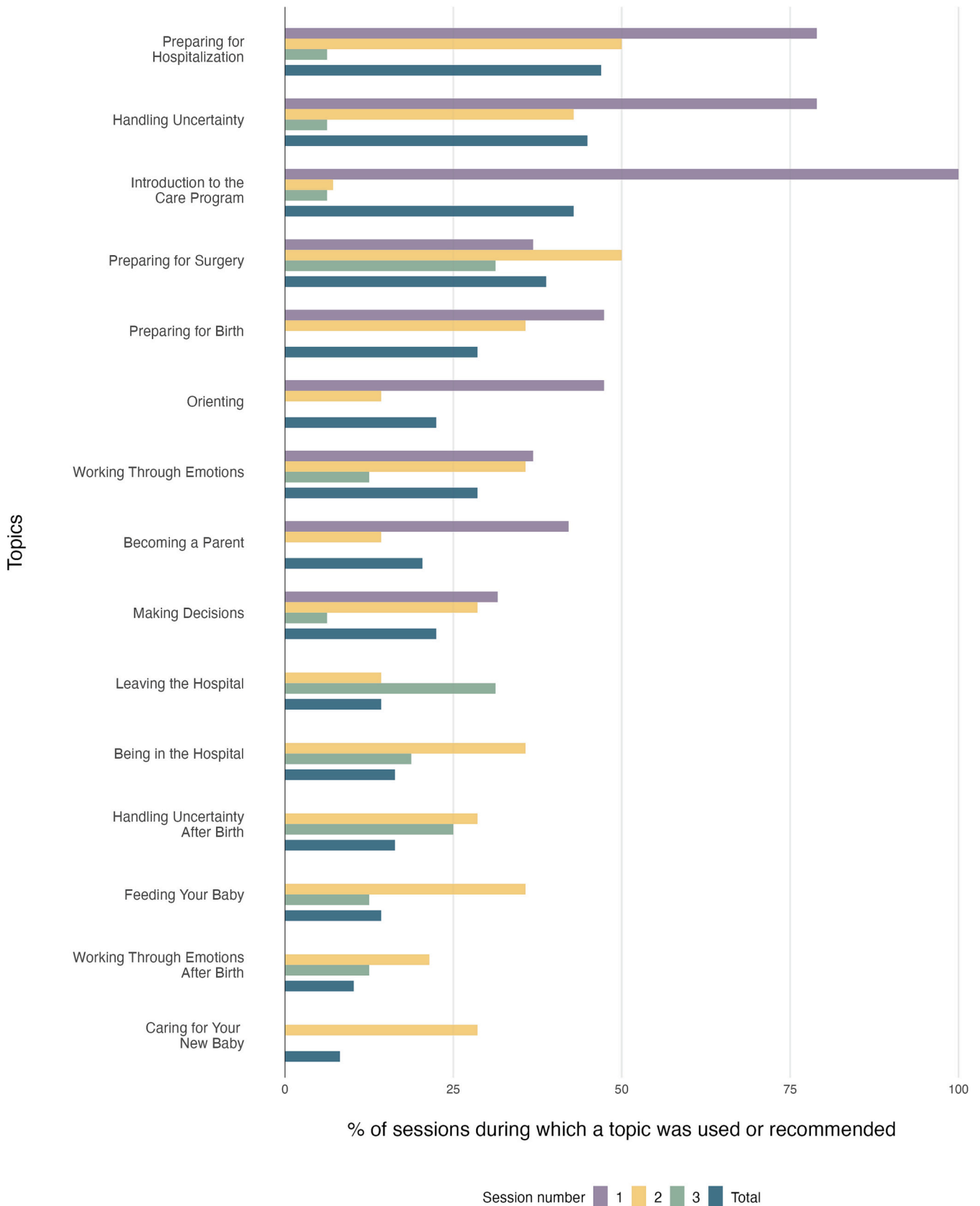


Fig. 3. PHM™ care program app topics used or recommended during the intervention sessions.

Table 4

Case 1 — Kalia and Devon: Issues of parental concern with representative quotations, caregiving competencies needing support, and PHM™ content incorporated into sessions.

Session 1

Pregnancy Week 34

Issues

Mental health/Wellbeing

My husband's a little bit more optimistic than I am. He's just like, "It'll be fine. It'll be okay. Let's not think about it." [Kalia]

I need to know everything, all the little details, so that I can prepare myself. Because I'm carrying baby, and if anything happens in the hospital, we know how to respond and not be surprised. But, you never know. Surprises come all the time. [Kalia]

I just like to know more of the important stuff that gets to the point, with as little detail possible. [Devon]

[What helps us is] talking about it some more because [expecting a baby with CCHD] is our new norm. It's a part of our life now... Talking about it, it just seems less taboo or less scary. [Kalia]

Social support

For me, connecting with other (speaking through tears), with other mothers [and] just talking ... it just seems more healing and accepting that my baby has a [heart] condition ... to just see how she [another mother] dealt with CHD too [and] hear about how she dealt with it. Then personally go through it myself ... it's not something to be ashamed of or be fearful of. It's a condition and it's normal, but just very unique. [Kalia]

Infant Feeding

I want to breastfeed. I also know that it's still a possibility, but it all depends on how baby latches and how much I produce.

I didn't even think to ask [if I could try latching baby to the breast]. Like when I am in the NICU, can I try? ... because they mentioned, we can still hold him in the NICU. He'll just have some wires around him. [Kalia]

Caregiving Competencies Needing Support

- Engaging and communicating with others about needs
- Co-parenting

PHM™ Content Incorporated

Topics used:

1. Introduction
2. Handling uncertainty
7. Preparing for birth
8. Preparing for hospitalization

Topics recommended by nurse:

2. Handling uncertainty
5. Working through emotions
6. Becoming a parent
7. Preparing for birth
8. Preparing for hospitalization

Session 2

Pregnancy Week 37

Issues

Mental health/Wellbeing

We're both just kind of waiting until he comes. I think that's the hard part because I'm the one carrying baby, so I feel the most connected. And then Devon is supportive and there, but it is different. So I don't think it's going to hit him yet until [our baby] is here. [Kalia]

I'm just anxious because, like I said, I'm a planner. There are so many things I have to do. [Kalia]

I really like the [PHM™] care tips and questions. They really help me process. Some of these things I feel like I've already processed more internally, and not written down. I've done a lot of screenshots because I want to remember, like, "how do you feel?" or "what are your thoughts about this?" I really like the questions because they help me to feel OK. [Kalia]

Condition-specific information

[After talking with] the doctors. Then we had an idea of how delivery would look ... this is how much time you have with baby. But then right when baby comes, we're going to want to make sure that he's doing OK or he's breathing on his own. And then bringing him to NICU pretty shortly after because they want to just monitor him. [Kalia]

Dyad relationship

I've already given him some warnings like, I might be a little irritated if I'm in pain [during labor/postpartum] ... I have to do some research to figure out what my husband can do as a partner ... I'm interested in how that's going to look like after delivery too because he's going to be the one with [our baby] ... he can be in the NICU.

There's not really much that I wanted to say that I'm in charge of. I'm pretty much open to whatever [our baby] needs ... I don't need to go to every appointment. [Devon]

Devon can't go to all of my appointments. So I'd be like, "Do you feel like you're in the loop?" ... I'll try to send him updates and be like, "[our baby] passed his test, he was breathing! And he's this big now" ... that's the best way, at least for myself right now, that I can get him to be a part of my appointments. [Kalia]

Devon is very get straight to the point, give me the info that I need and we're good ... we process it differently. [Kalia]

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Table 4 (continued)

Caregiving Competencies Needing Support

- Regulating emotions
- Co-parenting

PHM™ Content Incorporated

Topics used:	Topics recommended by nurse:
4. Making decision	6. Becoming a parent
5. Working through emotions	9. Preparing for surgery
9. Preparing for surgery	

Session 3^a

Infant Age 4 Weeks

IssuesMental health/Wellbeing

I really, really wanted to breastfeed and that was the thing I had to mentally accept that it might not happen. [Then] we made the decision, “Okay, as much as I want to breastfeed, that’s my goal. It’s not about me, it’s about [our baby].” What’s important is that [baby] is being fed. And too mentally, I’m OK with it. And I’m still able to provide [breast milk] for him. [Kalia]

They [doctors] put it into words that his heart was failing. But [before] it was always, “he has a heart condition.” ... never, “he’s going to have a failing heart.” So Devon and I were like, “What? He is?!” That just really hit me ... what’s going to happen? My first thought was, oh my gosh, his heart’s going to stop, it’s going to stop in an instant. And I had to tell myself like, “Okay, we’re in the NICU right now, we’re getting discharged, let’s stay positive.” [Kalia]

Condition-specific information

I guess I never asked “why can’t it [surgery] happen after six months?” ... To me, that [timing of surgery] is an indication that it’s important, and it’s high risk. [Kalia]

Dyad relationship

And then they took him [baby to the NICU], and I was like, “Can you [Devon] just stay here please?” I also needed that moral support, and it worked out. I wanted Devon to go with [our baby] at first, but I changed my mind right then. Thankfully he did [stay] because I really needed him. [Kalia]

I’ll check in on how Devon is doing. Like, “How are you? Are you OK? Are you getting sleep?” And he’s been very selfless where he’ll tell me to rest first because he knows I’m the one who’s up a lot longer than he is in the middle of the night. So that’s been super helpful. I think we’ve been on the same page. [Kalia]

Infant Feeding

The NICU doctor had previously mentioned, “just so you know, latching is not going to be a priority for [your baby].” ... I still wanted to [breastfeed] and I still tried and everything. [Kalia]

They [doctors and nurses] did mention that we don’t want him to overwork his heart. And every time I would try breastfeeding, he was really sucking. And I was like, “I feel like he’s working way too hard for just like 10 mls of breast milk when it could just be ready.” [Kalia]

I’ve never even thought about having a goal [of pumping for 6 or 12 months]. I just wanted to provide milk for [baby]. And so maybe that’ll help with just setting a goal. [Kalia]

It is a lot. It’s a lot of time [to pump and feed the baby] ... how am I going to tackle this? But, we’ll figure it out. [Baby] and I will come up with a schedule and we’ll make it work. [Kalia]

Caregiving Competencies Needing Support

- Problem solving
- Co-parenting

PHM™ Content Incorporated

Topics used:	Topics recommended by nurse:
9. Preparing for surgery	9. Preparing for surgery
11. Feeding your baby	14. Leaving the hospital
14. Leaving the hospital	

^a Caregiving partner did not participate in session 3.

Table 5

Case 2 — Jean and Alan: Issues of parental concern with representative quotations, caregiving competencies needing support, and PHM™ content incorporated into sessions.

Session 1

Pregnancy Week 28

IssuesMental health/Wellbeing

You see sad stories on there [Facebook group], too. So then it makes you think like, “What if something bad does happen?” You just never know. Just kind of take it day by day. [Jean]
And then you just start thinking ahead, and it’s going to be tough on a newborn. And surgery ... hers is like way more serious. So I know it’s like she’s working basically with half a heart.
It’s going to be tough on her. [Alan]

It’s scary. I probably just have to deal with it. I’d have to get through it. I try not to think about the things that can go wrong, but then surgery and the first six months is the most critical time. Brings up mortality, and I can’t help but think of that because I know it’s really serious. I just kind of think stay positive, but still ... I tend to overthink things a little bit. [Alan]

[The doctors] said there is a possibility that she could need a heart [transplant]. Just to have that out there—it’s kind of like tough to think about. Hopefully, that’s not the case. [Alan]

Condition-specific information

Then COVID, too. She’s probably going to be more susceptible, like most infants and newborns ... There’s a lot of things where you want to be super cautious, but you don’t want to be too cautious, but I guess you do, and you just kind of want to be normal. So there’s all these variables. [Alan]

[After baby is born] she won’t be able to eat. Which is scary, too. They [doctors] said, they’re not going to force feed her. So I’m like trying to understand if she eats at all before the surgery, or not, or how that works. [Jean]

Dyad relationship

I don’t want to get sick because, you know, if I get the COVID now and then I can still get it again before I go to the hospital. It’s like, I just don’t want to be around people ... Alan likes to go out still sometimes, so that bothers me, I get mad at him. [Jean]

Caregiving Competencies Needing Support

- Regulating emotions
- Giving care to the infant
- Engaging and communicating with others about needs
- Problem solving

PHM™ Content Incorporated

Topics used:	Topics recommended by nurse:
1. Introduction	2. Handling uncertainty

Session 2

Pregnancy Week 32

IssuesMental health/Wellbeing

We don’t have any more heart appointments or echos or anything, but we have the stress of ultrasounds every week now ... Every time I have an appointment, it’s like the next day I’m just dead. Just all night, I think about it. And then, it’s tough. [Jean]

I just started to get stressed out over COVID, and like everything. It’s not going to do her [Jean] any good, [so] I keep telling her we’re going to be fine. We’re going to just take it easy and take it one day at a time. And that’s pretty much it. And it’s not that we’re not communicating about it. [Alan]

A lot of the [PHM™ care program] stories are like, “I can relate to that.” There’s one about somebody feeling alone sometimes. And I think any parent going through this, especially the pregnant one, just feels like they’re doing it by themselves. [Jean]

Dyad relationship

We don’t really talk a lot about it [plans after birth] at all actually, I mean sometimes. [Jean]

I yelled at him [Alan] the other day. I called and his phone was on silent, and he was sleeping. I was like, “What are you going to do if I go into labor?!” [Jean]

We’re just kind of rolling with the punches right now. I mean, she [Jean] hasn’t killed me yet. [Alan]

Caregiving Competencies Needing Support

- Regulating emotions
- Engaging and communicating with others about needs
- Co-parenting

PHM™ Content Incorporated

Topics used:	Topics recommended by nurse:
2. Handling uncertainty	7. Preparing for birth
5. Working through emotions	8. Preparing for hospitalization
6. Becoming a parent	9. Preparing for surgery

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Table 5 (continued)

Session 3
Infant Age 6 Weeks

Issues
Mental health/Wellbeing
I feel alright. It was a little rough, she [Jean] was getting stir crazy once I went back to work. Because they [the doctors] wanted someone to be there for her [baby] at all times. I think just being in the hospital was the most stress. Now that we're home, it's good. [Alan]

I feel pretty stuck, not going to lie. When he [Alan] gets home, I go outside or I'll go to the store quick or something. And I feel a little bit better after that. I always tell him, "you're so lucky you get to go to work." You know, I'm okay [quietly] ... I love being home with her [baby], but it would just be nice to be able to go for a walk at least or something. You know, feel safe going to the grocery store with her. [Jean]

Being at home is hard, but obviously, one of us has to be at home. And I think that maybe I could work nights, but then I would be too tired to take care of her too, and I need to be alert. [Jean]

Condition-specific information
I googled everything. Especially when she threw them [medications] up the other day. I'm like, "Oh God, what does this do?" And then I learned that, you know, most of them are long lasting, so they build up over time. [Jean]

I just kinda look. I can tell if she's having trouble breathing or something is off. I'm always watching. I mean ... she's got dark circles and you can see a little bit of discoloring around her mouth – not too much. Like they [healthcare providers] said that if she gets really blue or something like that, but I'd just be able to tell from how she was acting. [Alan]

Dyad relationship
We're kind of following the doctor's recommendations. You know, people who want to see her need to quarantine [due to COVID-19 pandemic], obviously besides from work. So, I want to make sure she stays healthy ... And obviously, we want people to meet her ... [but] we don't want her to get sick because the doctors keep saying how high risk she is, if she does get sick and she hasn't had her vaccinations, yet. [Jean]

We've been going back and forth a lot about it [how to protect infant from COVID-19 exposure] ... So when Alan says, "Well, it [socializing in public places or going on vacation] is the same is going to work." I'm like, "No, it's not the same." [Jean]

Communication
The [home care] nurse usually comes and just weighs her. Coming home, [the hospital nurses said] "Oh, here's a scale." They didn't really say when to weigh her. But she has her first appointment tomorrow. So maybe I'll get more info from her doctor. I don't know. They didn't even tell me to send anything in or anything. So I'm like, just give her her meds. So until they ask, you know, it's like, it's a lot of work being at home by yourself. [Jean]

In the hospital, we had so many restrictions. She can only have this much [for a feeding]. And now we're home, and [the home care nurse says], "Oh, she's still hungry – feed her." And we're like, OK, at the hospital you had to always ask, "can she have her bottle early because she's screaming her brains out?" [Jean]

The nurse said we can give her extra food as long as she handles it. I try not to give her too much, but, you know, she can go that extra hour I figure if she's had the extra. [Alan]

Caregiving Competencies Needing Support

- Regulating emotions
- Engaging and communicating with others about needs
- Co-parenting

PHM™ Content Incorporated

Topics used:	Topics recommended by nurse:
14. Leaving the hospital	14. Leaving the hospital

6.3. Conclusion

Considering the mental health challenges for parents and threats to growth and development that their infants with CCHD encounter, innovative and effective approaches to providing support and information are needed. This study identified parents' top issues of managing mental health/wellbeing and needing condition-specific information, and their capacities for caregiving development—particularly for infant feeding. Parents used and discussed app content with the nurse guide, especially during the prenatal timeframe. Future directions specifically include added content on feeding and adaptation of the PHM™ care program for an updated app platform in English and Spanish for testing with a larger heterogeneous sample.

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Confidentiality statement

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

CRedit authorship contribution statement

Anne Chevalier McKechnie: Conceptualization, Funding acquisition, Project administration, Supervision, Methodology, Formal analysis, Writing – original draft. **Kristin M. Elgersma:** Investigation, Project administration, Data curation, Software, Formal analysis, Visualization, Writing – review & editing. **Taylor Iwaszko Wagner:** Investigation, Writing – review & editing. **Anna Trebilcock:** Investigation,

Writing – review & editing. **Jenna Damico:** Formal analysis, Validation, Writing – review & editing. **Alejandra Sosa:** Formal analysis, Validation, Writing – review & editing. **Matthew B. Ambrose:** Funding acquisition, Investigation, Resources, Writing – review & editing. **Kavisha Shah:** Resources, Writing – review & editing. **Aura A. Sanchez Mejia:** Investigation, Resources, Writing – review & editing. **Karen F. Pridham:** Conceptualization, Methodology, Validation, Resources, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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