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Original Article

Using Grounded Theory to Inform the Human-Centered Design of Digital Health in Geriatric Palliative Care



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Abstract

Context. Digital health offers innovative mechanisms to engage in palliative care, yet digital systems are typically designed for individual users, rather than integrating the patient's caregiving "social convoy" (i.e., family members, friends, neighbors, formal caregiving supports) to maximize benefit. As older adults with serious illness increasingly rely on the support of others, there is a need to foster effective integration of the social convoy in digitally supported palliative care.

Objectives. Conduct a qualitative study examining patient, social convoy, and health care provider perspectives on digital health for palliative care to inform the design of future digital solutions for older adults with serious illness and their social convoy.

Methods. Grounded theory approach using semi-structured interviews ($N = 81$) with interprofessional health care providers, older adults with serious illness, and their social convoy participants at home, clinic, or Zoom. Interviews were conducted using question guides relevant to the participant group and audio-recorded for verbatim transcription. Two coders lead the inductive analysis using open and axial coding.

Results. Thematic results aligned with the human-centered design framework, which is a participatory approach to the design process that incorporates multiple user stakeholders to develop health solutions. The human-centered design process and corresponding theme included the following: 1) Empathy: Patient, Caregiver, and Provider Experience reports participants' experience with managing serious illness, caregiving, social support, and technology use. 2) Define: Reactions to Evidence-Based Care Concepts and Barriers illustrates participants' perspectives on the domains of palliative care ranging from symptom management to psychosocial-spiritual care. 3) Ideation: Desired Features reports participant recommendations for designing digital health tools for palliative care domains.

Conclusion. Digital health provides an opportunity to expand the reach of geriatric palliative care interventions. This paper documents human-centered preferences of geriatric palliative care digital health to ensure technologies are relevant and meaningful to health care providers, patients, and the caregiving social convoy. *J Pain Symptom Manage* 2020;60:1181–1192. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, human-centered design, social convoy theory, older adults, family caregivers

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Key Message

This article is a qualitative study exploring patient, “social convoy” (family members, friends, neighbors, formal supports), and clinical perspectives on digital health for geriatric palliative care. Findings uncover the need for adaptable, personalized platforms for multiple users, with shared communication, tailored assessments, advanced functionalities, and alignment with current technology use.

Background

Family, loved ones, and formal caregivers provide care for nearly 1 million older adults that die each year from a serious chronic illness.¹ These older patients experience significant physical and psychological symptom burden and progressive dependence on their network of care,² referred to as a social convoy. Social Convoy Theory is a well-established framework^{3–5} for understanding the relationships of individuals in a group of people with whom they give and receive social support over the lifecycle. The convoy can include informal supports such as family members, friends, and neighbors, and formal supports such as professional caregivers that are trained and paid to provide care.

Palliative care provides an interdisciplinary and patient-family-centered approach to address the physical, psychological, emotional, and spiritual suffering for patients and their convoy.⁶ Digital health,⁷ including telehealth, wearable devices, and mobile applications (mHealth), provides modern opportunities for patients and their convoy to engage in palliative care.^{8–10} An estimated 53% of convoy members have used a technology to help with caregiving and 12% are interested in learning how to use new technologies to support the health of their loved ones.^{11,12} However, digital systems are typically designed for individual users, rather than integrating the patient’s convoy to maximize benefit. As older adults with serious illness increasingly rely on the support of others, there is a need to foster effective integration of the convoy in digitally supported palliative care.

Recently, the pandemic of the Novel Coronavirus Disease 2019 (COVID-19) shifted society’s use of digital health, specifically synchronous telehealth, to provide palliative care and support convoys’ care for older adults while maintaining social distancing.^{13,14} While reserving synchronous telehealth for specific consultations, other digital health tools such as symptom monitoring and assessment apps, wearables, and digital education may offer clinical and psychosocial supports for older adults with serious illness and those caring for them.

The aim of this study seeks to use heart failure (HF)-specific palliative care as a model to investigate the

design of digitally supported palliative care by older users and their convoy. HF is an excellent model, as it disproportionately affects older adults resulting in frequent hospitalizations and poor quality of life.^{15,16} Older adults with HF are at increased risk of COVID-19 complications and mortality,¹⁷ and there is a need for HF-specific digital health to monitor symptoms and assess palliative care needs.¹⁸ This qualitative work will inform the design of the Social Convoy Palliative Care (Convoy-Pal) digital health intervention, currently in development, by summarizing patient, convoy, and health care provider feedback. Such work also seeks to produce a human-centered designed framework useful for researchers, clinicians, and industry partners to design digitally supported palliative care solutions for both older adults and their convoy during times of COVID-19 social distancing and beyond.

Methods

A grounded theory¹⁹ methodological orientation was used to inductively describe patient, social convoy, and provider perspectives regarding digital health interventions to support palliative care needs in the setting of HF. The purpose of using a grounded approach was to develop a theoretical framework for integrating the social convoy in the design and context of digital health for older adults with serious illness. Our work was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Appendix I),²⁰ and methods were approved by the Colorado Multiple Institutional Review Board (COMIRB).

Participants and Recruitment

Study participants were identified using both purposeful and snowball methods of recruitment.¹⁹ The inclusion of patients, the patient convoy, and health care providers ensured²¹ incorporation of diverse perspectives into the design process.

Patients. Patients were identified from the health system’s electronic medical record, *Epic*. Inclusion criteria included being a patient with HF, ≥ 65 years of age, with two or more discharges for primary diagnosis of HF within the last 12 months. Patients with a diagnosis of dementia, preparing for transplant or left ventricular assist device (LVAD), and/or those unable to provide informed consent were excluded. We mailed eligible patients a letter introducing the study and requesting that patients “opt-out” by phone if they did not want to be contacted. Patients were contacted by phone, screened for eligibility, and invited to participate.

Convoys. Patient convoys were identified during patient interviews by asking patients “Could you please tell us all the people who help you with your heart condition or your daily life?”. Follow-up probes were used as needed. With the patient’s permission, potential convoy participants were contacted for an interview via phone, email, and text message. Because the average social convoy size of older adults in the U.S. is approximately three people,²² the research team aimed to interview at least two convoy members but no more than six per patient. Convoy members under the age of 15 or who were unable to provide informed consent were excluded.

Health Care Providers. Health care provider participants were identified via the palliative care consult and advanced heart failure care teams. Health care providers were recruited and consented through email. Specific recruitment efforts are documented elsewhere.²³

Data Collection

We developed three semi-structured interview guides targeting each sample group: patients, convoy, and health care providers (Appendix II). The guide was first drafted by the principle investigator (J. D. P) based on our previous qualitative work with older adults regarding digital health²⁴ and refined by geriatric, palliative care, and digital health experts (R. S. B., D. B. B., S. C., and S. B.). During the interviews, we asked participants to first reflect on their experience managing HF or treating patients with HF. We then asked participants to consider potential digital health solutions that might be helpful in a palliative care setting. We also asked participants to “think aloud” while navigating wireframes, that is, images of potential digital features and functions, and to express opinions about palliative care content.

We invited participants for 60-minute interviews to accommodate health care provider and convoy members schedules. However, the question and answer section of the interview averaged 44.6 minutes and ranged from 20 to 90 minutes. The shortest interview was due to the patient’s health and fatigue, while the longer interviews allowed for further exploration of participants’ experience and ideas. Interviews were held at a location convenient to the participant including 1) in person at the patient/family home, 2) in person at the health clinic, 3) the provider’s office, or 4) using university-supported Zoom conferencing depending. All data collection occurred during October 2018 to September 2019. Interviews were audio-recorded. Field notes and researcher memos were maintained throughout data collection to assist in data interpretation.

Analysis

All audio files were professionally transcribed verbatim before analysis. The unit of analysis (word, sentence, paragraph) was determined by the analytic team using an iterative²⁵ and inductive approach.¹⁹ We managed our data with DeDoose software (Socio-Cultural Research Consultants, LLC, 2018). Two data coders (K. L. F. and K. D.) used a combination of open and *in vivo* coding to develop an initial codebook.²⁶ The codebook included a list of initial codes, code meaning, and criteria for using the code. Over half of the transcripts were double-coded (55%) and coders met with the interview team weekly throughout the data collection process to review codes, clarify code definitions, and reconcile coding disagreements. The grounded theory approach involved a constant comparison method of analyzing data. A second cycle of focused coding, known as axial coding, collapsed initial codes into umbrella categories.²⁶ These categories were based on patterns in the data and to form themes that identify prototype design to incorporate preferred palliative care content. The research team established a coding tree, deriving themes until reaching thematic saturation.¹⁹ Our confidence in establishing saturation is based on several factors, including a sample size consistent with qualitative inquiries regarding older adults and digital health,^{27–29} initial coding during data collection, and inclusion of multiple analytic perspectives, for example, having a coder unaffiliated with the interview process and triangulation of transcript data with field notes and memos from three interviewers, to identify “new” concepts.²¹ In addition, the principle investigator established monthly meetings with palliative care and HF experts as a form of member checking.²¹

Results

Participants

We contacted 231 potential patient participants; 13.9% agreed to participate, 31.6% declined participation, and 54.5% were unable to contact. We identified 49 potential convoy participants from patients; 63.2% agreed to participate, we were unable to contact 36.7%, and only one convoy member declined participation. A total of 81 interviews were transcribed for analysis. Table 1 describes the demographics for patients ($n = 30$) and their convoy ($n = 31$). The age range varied for patients (66–91 years old) and convoys (31–80 years old). Social convoy participants were primarily adult children (28.8%) but also included spouses, siblings, grandchildren, and friends. We contacted 25 potential health care provider participants based on the health system’s palliative care and advanced heart failure care teams;

Table 1
Demographics of Patient Participants (N = 31) and Their Social Convoy (N = 30)

Demographic	Patients (n, %)		Convoy (n, %)	
Female	12	38.7	33	55.93
Member type				
Spouse			8	13.56
Child			17	28.81
Grandchild			1	1.69
Sibling			1	1.69
Friend			2	3.39
Race				
Black	3	9.7	2	6.9
White	27	87.1	27	93.1
Other	1	3.2	—	—
Hispanic	3	9.7	3	10.3
Marital status				
Single, never married	2	6.5	6	20.7
Married or domestic partnership	17	54.8	20	69.0
Widowed	7	22.6	—	—
Divorced	4	12.9	2	6.9
Chose not to answer	1	3.2	1	3.5
Education				
High school	9	29.0	2	6.9
Some college	7	22.6	5	17.2
College graduate	10	32.3	9	31.0
Postgraduate	4	12.9	12	41.4
Chose not to answer	1	3.2	1	3.5
Income				
< \$30,000	14	45.2	4	13.8
\$30,000 to \$49,999	4	12.9	8	27.6
\$50,000 to \$74,999	9	29.0	12	41.4
\$75,000	3	9.7	4	13.8
Chose not to answer	1	3.2	1	3.5

21 agreed to participate, one later declined, and four were unable to contact. The health care provider sample ($n = 20$) included palliative care physicians and cardiologists ($n = 4$), advanced practice nurses ($n = 7$; two DNs, five NPs), registered nurses ($n = 3$), spiritual providers ($n = 2$; MDiv), art/music therapists ($n = 2$), and social workers ($n = 2$). The majority of providers identified as female, identified as white, and had on average 9.78 (± 3.75) years of experience working with seriously ill older adults.

Themes

We initially used a grounded theory approach to develop new framework to inform social convoy digitally supported palliative care solutions. However, through the interview and analysis process, findings substantially aligned with design thinking,^{30,31} particularly human-centered design framework (Figure 1). Human-centered design is a participatory approach to the design process that incorporates multiple user stakeholders to develop health solutions. The model outlines a process to create digital solutions easy to use, useful, and meaningful to users by capturing the perspective of people experiencing the problem in which a solution is intended to

solve. The first steps of the process are to better understand the users and what is most important to them (Empathy) and to identify specific needs outlined by both users and scientific evidence (Define). These background phases allow for productive brainstorming around features and functions for possible tools (Ideation). Through this participatory approach, a human-centered prototype can then be developed and tested. While we did not consider human-centered design apriori, themes generated from this qualitative study highlight the first three phases of the human-centered design framework including 1) Empathy: Patient, Caregiver, and Provider Experience, 2) Define: Reactions to Evidence-Based Palliative Care Concepts and Barriers, and 3) Ideation: Desired Features for Palliative Care Digital Health.

Empathy: Patient, Caregiver, and Provider Experience

This theme captures participants' experience with managing serious illness. Participants reported experiences about their health, social support, and technology use. Table 2 illustrates exemplar quotes.

Health Experience. Patients, convoys, and providers discussed the difficulty of living with major medical conditions, function limitations, and reduced well-being and engagement in pleasurable activities. Although we targeted patients with HF, our patient participants indicated that "heart failure is the least of [their] worries." Patient participants articulated that they managed multiple chronic conditions (MCCs), including diabetes, cancer, neuropathy, among others. Patients were often more concerned about other health conditions, the decline of their health generally, and were largely content or neutral with their HF-specific care.

Social Support. Patients reported that they rely on social support and family caregivers in diverse ways. Many reported their convoy members manage the logistics of health care and daily living activities (depending on patient's function) and monitor daily HF and MCC management. Most patients and caregivers reported different and conflicting perspectives. For example, patients commonly indicated that they did not want to bother their family while the social convoy often craved more information about the patient's status. Both patients and social convoys described the complex balance between receiving care from the convoy and the need for patients to feel self-sufficient and maintain independence. Health care providers reported the importance of convoy involvement highlighting their contribution to the patient's overall health and adherence to HF care plan. They also recognized

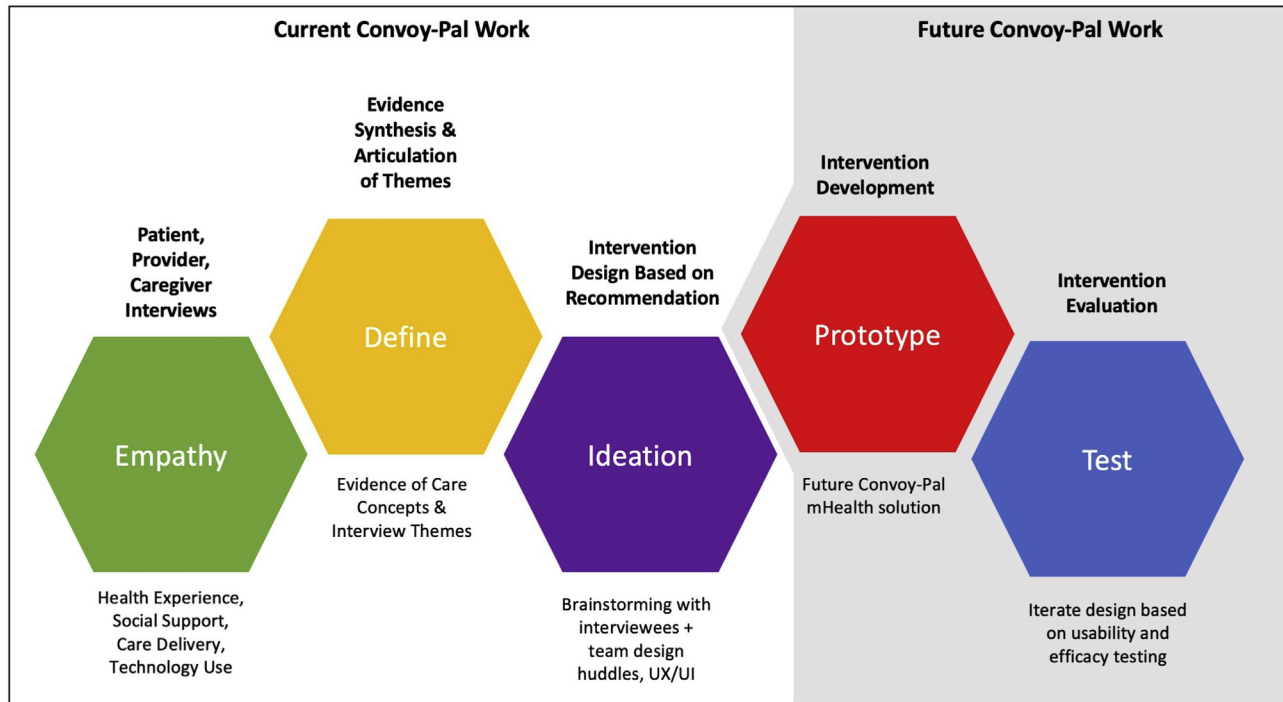


Fig. 1. Alignment of convoy-pal work with human-centered design process.

the social, environmental, and logistical challenges convoys experience in providing care for their loved ones. However, although patients and their convoys reported focusing their caregiving on daily needs such as transportation, coordinating medical appointments, and managing medications, leveraging social support to address important daily logistics was not reported as a barrier.

Technology Use. Some patients indicated a reluctance to use newer-technology, such as text or sensor-based applications, with preference for face-to-face options or more well-known technologies, such as phone calling. Most patients reported less interest in technology use, unlike convoy members and provider participants. Convoys were skeptical of their loved ones using technology. In addition, incongruence was observed across participants when probed for data-sharing access, finding providers, and convoys reported in support of data sharing, whereas patients were less enthusiastic. After probing, patients and convoys describe the value in sharing reports and app activities with each other; however, this was not universal. Patients, convoy, and provider participants all acknowledged that technology use and technology-literacy vary among patients and convoys, reflecting a generational gap in the culture of technology use and communication differences between participants.

Define: Reactions to Evidence-Based Care Concepts and Barriers to Use

Domains of palliative care generally include quality of life assessment, symptom management, family support including bereavement or grief, spiritual care, psychosocial support, decision support, value-based goal setting, and patient/family education. Participants provided feedback related to receiving and delivering these components of care via digital health. [Table 3](#) illustrates exemplar quotes from the theme. Overall, participants indicated that patients relied on their convoy for all of these palliative care domains and emphasized the need to increase patient-convoy communication. The concept of using digital tools to connect the full convoy and communicate about palliative care needs in a new way was of most interest to participants.

Symptom Monitoring. Overall, providers, patients, and convoys report the importance of having a way to self-monitor HF care. However, patients tended to be divided on their willingness to use digital tools to manage their care. Other patients mentioned they would be willing to use technology for symptom monitoring if they had additional technical support. Other patients already use or are interested in using a variety of technology to track their HF, ranging from activity trackers, patient portals, to sophisticated monitoring equipment. Providers reported interest in ways to

Table 2
Empathy: Subthemes and Exemplar Quotes

Subtheme	Quote
Health experience	It's very discouraging, very disappointing that I'm not able to do what I'd like to do or what I should be doing by myself. I need to have help with it or hire somebody or have one of the kids come over and do it for me. It's just very discouraging. — 2183
Social support	It's kind of like walking a tight rope. You got to keep your feet going a certain way or you're going to fall off. And it's the same with a heart issue. If I don't do everything to take care of it, it's going to come back on me. — 2081 Well, my wife's been a good influence on me. She's been a big help and the kids also. Before I had the heart transplant, they would come over to the house and help me do things that I couldn't do because of my weak state. And so, the whole family's been—and I have some great friends at church and they've been a big help, and some of my coworkers, so I've had a lot of support. —2183 You got to find somebody that you trust and you're comfortable with. — 2077 My wife sits there and clubs me. We've been together 48 years. She's just a hoot. She says hey you know you're looking kind of bright red. Oh OK I'll sit down and drink a little juice or something. I got a basket for pills, it used to be an Easter basket. I don't even know what half the pills I take do. I used to know but I don't, I just take them. — 2023 It's been an experience [care giving], I can tell you that. It is challenging. It is frustrating. Sometimes there are so many hands in the pot, that you can't get the answer that you need and then you have my father who's recovering and sometimes difficult to work with. — 2110_1 It can be scary. It is difficult to know when you can't see or monitor them yourself, not knowing what their heart is doing, not knowing if it's a good day or a bad day. I call my mom and one day she's perfectly fine and a couple of days later, she's in the ER because of a problem with her heart. It can be a rollercoaster ride, really. — 2081_1 The things that are feeling more valuable—is the connection with the convoy and less about the prescriptions. — 1015 (provider)
Technology use	Well my wife does because we write them [appointments] all down or she does. We don't do it electronically. I'm electronically challenged. My tech support is an 11-year-old. — 2023 But technology today, we need to be using it more. We need to embrace it more. It can really be a tool for us. And this is in the right direction because I mean, it's just like the portal. It manages a lot of things. — 2130 A lot of people don't cope with it. They're like me. I'm not ignorant, you know, I got an education. I can read and write. But at this—the technology, I don't care for it. That's my opinion. — 2211 I mean, they're constantly, even though they're not tech savvy, they constantly say, "Can you order this on Amazon? Can you show us this? Can you look at this?" So they use technology through me, but they don't use it themselves. — 2113_1

encourage patient-reported outcomes and remote patient monitoring and however still questioned their clinical significance with vast amounts of real-time data.

Psychosocial Support. Many patients and convoys reported being positive and optimistic about their psychosocial well-being. However, some disclosed challenges around mental illness, social isolation, anxiety, and depression. There were mixed reviews on how to incorporate psychosocial support using technology. Some participants reported negative reactions to virtual assessments while others reported it as a useful way to check-in on patients or caregivers. Many patients expressed this support “wasn't for me” but might be useful for patients or caregivers “like me.”

Decision Support. Most patients and convoys described their experience throughout the patient's disease trajectory, describing confusion and difficulties dealing with the unknown. Many participants reported how individualistic their care plan was due to multiple chronic conditions and highlighted how technology must account for personalization. Providers reported critical to include tools for prognosis and advanced care planning. Most caregivers remained optimistic about their choices and decisions; however, reported

in hindsight, it would have been useful to obtain more guidance around clinical and palliative care decisions.

Social Convoy Support. Many convoys were surprised when asked about their own well-being. Most patients reported wanting resources to support their convoy's health, as many of the convoys were also suffering from illness or poor physical and emotional health. Patients and convoys acknowledged the severity of HF and participants were open to resources for anticipatory grief and bereavement. Most providers agreed resources for convoy support must be carefully communicated using technology, as it is a sensitive and emotional topic.

Spiritual Care. While spiritual well-being remains an important aspect of palliative care in the literature, patients and convoys reported mixed feelings about incorporating this domain into digital tools. Some patients expressed interest in virtual connection with a congregation or reminders for religious practices, while others were unable to draw the connection with spirituality and HF care. Spiritual care providers reported interest in this feature and however presented similar reservations about unobtrusive design of spirituality digital tools.

Table 3
Define: Palliative Care Domains and Exemplar Quotes

Subtheme	Quote
Symptom monitoring	I'm a diabetic. I mean I take more drugs now than I did in the 60s. It's just I can tell. I know if I get high, I know if I get low. That I do monitor. Stab your fingers. I got I forgot where we were going. When you get so many health issues going on at once, where do you focus. Or do you just roll with the punches. I just roll with the punches. — 2023 The more I know, the more it is easier for me to keep an eye on her entire health because she has many comorbidities. If I can keep track of those two heart issues and the basics—the things like the weight, the breathing issues, the oxygen levels, things like that, I can kind of—that gives me a little picture, too, of where she's at in general. So that helps me all the way around. — 2081_1
Psychosocial support	Yeah. You know, I haven't really had that problem but if need be, I think it would be helpful. — 2096 You can't go through it without feeling that way [sad and isolated]. But, I always tried to stay positive as I could. Live each day to the fullest. You never knew when it was going to be the last. — 2109
Decision support	It's difficult to live with because you never know from day to day what's going to happen with it. One day you may feel fine, the next day you may feel like somebody smacked you a good one in the chest and you just can't function. And on those days, you've got to figure out cause there you really need to go in or if you don't. And if you really need to go in and do it. My biggest concern up until recently has been generally I'm here alone and so if something's going on with me I've got to take care of it. Nobody else is here to do it. — 2081
Family support	I think that would be great. I mean, I don't—like in—mom's doing so well on her own, but I know there are people who were—it's a very big burden to take care of their loved ones with heart failure. And it would be great to have something that checks in with the caregiver. — 2199_1 Yeah, but it hasn't been easy. We're getting through it and he always try to keep positive about it. But there's just some days where you just want to strangle somebody. Not necessarily my father, but somebody. — 2110_1 I mean, talk about—we don't have great support for patients. We have even less support for caregivers, right? — 1018 (provider)
Spiritual care	Probably for some people, that would help. I don't know. For me, I don't think so. — 2050 As long as that spiritual support included a nice bottle of beer or a drink of whiskey. — 2077 You know illness isn't just about what's happening physically but it impacts the whole life. And you talked about the caregivers and family; it also impacts people's spirit and their sense of themselves and their role in the world and their sense of what the future is going to be like; hopes and worries. — 1012 (provider)
Goal setting	If you set physical goals and then dietary goals, because I know that's another thing that he pushes back on, is just taking care of his health from a dietary perspective. I mean, I know he tries to push himself physically by walking the dogs or even checking out to my boys' soccer games and everything else. Like, I know that's a lot of work for him, a lot of physical work. But I think yeah, setting goals, daily goals, hourly goals, or whatever is appropriate. Not only physically but maybe also in regards to diet and then also maybe mental goals, you know. — 2023_2 With palliative care some things we talk to people about are identifying their goals or their hopes. And not goals of treatment in terms of like I want to get this medication or whatever; I want to qualify for this device; but the reasons they would want the device for; the reasons they would want to get stronger. You know, to be able to work in the garage again; be able to spend time with my grandkids. And if there could be ways to really personalize something like this with someone's goals; so that 1) to keep that central so we don't get lost in is my leg swelling getting worse or is it getting better? Because the goal of getting the legs down is that I'm able to do things I want to do and live the life I want to live. And if there are ways to have that stuff and be able to celebrate the things that are going well and track the good days, and also look and see I haven't been able to do the stuff that I really want in a really long time and what does that mean? Do I have to adjust my expectations; do I have to rethink the treatment or what? — 1012 (provider)
Education resources	Oh my wife did a lot of research, on using the Internet, just finding out different things. Plus we had a lot of our conversation with the doctors in terms of understanding the situation. The doctors that I had were very, very good in terms of explaining and listening, and so as a result, the technology was supplemental to actual interface with the medical staff. That was available. — 2019

Goal Setting. When prompted about goal setting, all participants reported enthusiasm for the ability to create tailored, value-based goals for patients and convoys. For example, some patients hope to take the trash out each week, while healthier patients expressed interest in monitoring their symptoms more robustly. Providers reiterated the importance of creating realistic goals for both patients and caregivers. Many patients reported health-specific goals such as eating better or exercising more, while others emphasized increasing time with friend and family or travel. Most convoys reported wanting to monitor the patient's goals for social support and accountability.

Education Resources. Nearly all participants expressed interest in a resource library offering consolidated information about disease trajectory, personalized goals,

and end-of-life planning. Many patients and convoys reported the challenges of obtaining educational resources online (via Google). Most providers suggested the resources be accessible, evidence-based, and easy to read and interpret.

Ideation: Recommendations and Desired Features

Participants were asked to brainstorm ideas on the palliative care domains and offer recommendations for future technology with older adults, caregivers, and palliative care. Suggestions are outlined in Table 4.

Both patients and convoys recommended similar desired features related to content and technology interface, stressing the importance of tailoring and personalization. They reported interest in syncing palliative care tools to patient portals, and the

Table 4
Ideation: Recommendations and Desired Features Exemplar Quotes

Domain	Suggestions	Quote
Symptom monitoring	<ul style="list-style-type: none"> • Syncing to patient portal • Interoperable with current technologies • Medication reminders • Goal setting features 	<p>This is in the portal. If all this stuff was in together, but see, with my pharmacy, they—it's all on automatic so I mean, I wouldn't—because this wouldn't be a big deal to me. And I use something else. — 2130</p> <p>I have a machine that does it but I do put it in my journal. My daily records of it. I do my weight, my oxygen level, my blood pressure. I can tell you my blood pressure for the last 30 years. — 2001</p> <p>I think people with heart failure sometimes feel that they don't have control over it so giving them any sense of empowerment or ability to manage anything on their own I think it big. Especially if you look at the average age person diagnosed with heart failure, they are generally speaking are going to be older. Having kids telling them what to do. — 1000 (provider)</p> <p>Because I'm a nurse practitioner in symptom management, I want to know if they're short of breath, if weight's going up, if weight's going down, fatigue, all the symptoms would be of what would be most in my domain. But knowing how they're doing, good day, bad day, in general is really helpful too. And then the other things that they're struggling—psych, social, financially, that's good for me to know so that I can refer it on. But maybe to kind of give a little bit of a protection of the providers maybe all of this information would download to kind of a networking central person or team that would then go, okay, [NAME] needs to know that [NAME] is suffering shortness of breath so I'll send that message on to her. So that way I know I'm getting pertinent information, I'm not wasting a lot of time in my day chasing false alarms when I should be addressing the real ones. — 1005 (provider)</p>
Psychosocial support	<ul style="list-style-type: none"> • Photo reminders of loved ones or memories • Encouraging text messages • Syncing to music apps 	<p>I think it's a good idea for the other guy. Not a good idea for me. — 2198</p> <p>I think maybe a fun feature would be, you know, "Your doctor wants to get to know you better. Pick two favorite pictures that somebody in your family or a pet or something that you could share your doctor with." You come into the coming visit, that's [] kind of selfish. But you know, I always love to see pictures of grandkids and dogs and vacations photos. — 2199_1</p> <p>I'd be really curious to know how honest my dad would be if he were to be asked these [psychosocial support] questions because—how hard is it to admit that you're not okay? That's extremely difficult. — 2023_2</p> <p>And so if people are having a really difficult time there's reminders of the resources they have in their life; reminders of things that have worked well for them. — 1012 (provider)</p> <p>Maybe that part of it would be on there and then psychosocial, I guess, if you had like so many sad or down days in a row, is that triggered? Maybe you do need a referral to a social work or palliative care for evaluation. — 1011 (Provider)</p>
Decision support	<ul style="list-style-type: none"> • Check lists for specific situations 	<p>If you could go into the app and maybe have a list of things you need to take with you. Because in the process of it, you don't think straight. — 2081</p> <p>An app would be fine because that would save me Googling stuff. Because a lot of times you can't get that information from the doctor. — 2002_2</p> <p>People may want information on those things [LVAD options], too. A little could be just down in sort of the education but as you progress heart failure stuff that happens there's like chronic daily decisions, chronic daily management with these big sort of decisions as you go. And I don't know if this is the place to incorporate that but it's something like the rest of the months ago. — 1015 (provider)</p> <p>[viewing trends in disease state] So if I can step back and look over six months' period of time and I can see that they're doing this slow downward trajectory, then I better be getting on the game with end of life discussions or making sure things are—that they're along with me in this perception of the way things are going. — 1005 (provider)</p>
Family support	<ul style="list-style-type: none"> • Syncing to family organization apps (calendars, shared lists) • Resources 	<p>We put a man on the moon. They have a hotel now that's underwater. You can't make two systems talk each other. That's insane. — 2023</p> <p>I think even for family members and social—the educational pieces are really good. There are a lot of families who are deep in denial and want to downplay that this person's as sick as they are. So it</p>

(Continued)

Table 4
Continued

Domain	Suggestions	Quote
		might actually improve, you know, breaking through that denial. — 1020 (provider)
		Facilitating the networks so that you encourage community and family in a way that—not only encouraging it, but you’re triggering it for key times. — 1018 (provider)
		Well I’m just thinking—you have to come out with a team approach. Like recipe suggestions, you know, just for the whole family again, not just for the person who has the label of heart failure. — 1006 (provider)
Spiritual care	<ul style="list-style-type: none"> • Connection with current church Facebook groups • Journal prompts as push notifications or texts 	I think you also could do it [spiritual assessment question] as a more nuanced; To make it more complex, you could acknowledge that care for someone with a serious illness can impact many areas of life. And have you found—or in what ways has your life been impacted or changed, or have you had to adjust? It could open it up to things like relationships. It could open it up to a caregiver’s sense of themselves or their ability to do things that they enjoy or have found meaningful beyond work and school. — 1012 (provider)
Goal setting	<ul style="list-style-type: none"> • In-app goal setting and monitoring 	I think if you’re looking at the psychosocial part of that, you want to help them do an activity that they would succeed in, not tell them to do something that they can’t. — 1011 (provider)
Educational resources	<ul style="list-style-type: none"> • Resource library with credible links on palliative care topics • Algorithms to send resources based on assessments 	A: “Yeah. I think maybe if there was like a tab about maybe end of life or questions that people have that people are afraid to ask. That can just be like a frequently asked questions, for lay out kind of what people could expect “—2198
		For caregivers, I would say that explanation of the disease. What they can do to help you balance it and keep it in check. — 2081
		No. My only concern is what can I do? I just need to find out more information on how I take care of myself. Knowledge is power. — 2003
General suggestions	<ul style="list-style-type: none"> • Physical activity reminders • Features to improve communication between patient and convoy • Video/virtual family visits with care team • In-app games related to care or medication 	Yeah. I mean, if the case where that someone was bad at taking his medications, a text message reminder, even to family members or whomever is the one responsible for helping that family member takes their medication could be helpful. — 2198
		I think it’s tough because too many people helping can kind of become frustrating probably for my dad. So there becomes a point where too much help is hurting more than helping. 2198_2
		I said this before but I’ll say it again, I just think older people have a hard time with too much information. Keeping it all meat and no gravy with him and [] to the left or the right, always the center is important. — 2113_1
		The simpler you can keep it the better people will use it. Because if it starts to become too complicated, they’re gonna get halfway through there and say “Oh, forget it. I don’t want it. It’s bugging me, I don’t want to bother with it anymore.” But if you can just ... (ptoo!) quick easy references, great. — 2001_1
		If you kind of did it like an onion peel, this is really a simple app and then you could do some deep things and as part of the research, it would be to see what deep things people use. — 1015 (provider)
		I really like the convoy concept and the connecting, and having apps that speak to each other to the caregiver. I think that could be really cool and applied to lots of things. — 1015 (provider)

importance of an easy-to-use interface with large fonts and accessibility. For example, many participants recommended the technology be available for individuals using voice-to-text features for hearing or visual impairments. Balancing privacy and confidentiality was a preference for all participants, highlighting the varying levels of access to data when sharing reports. Providers stressed the importance of access to credible, evidence-based resources,

rather than obtaining information via “Dr. Google” or WebMD. Providers reported a need for thoughtfulness to language, context, and delivery when assessing care needs, particularly to collect what you can intervene on. Most patients and caregivers agreed with recommendations to not overburden end-users with assessments, and reminders (text messages or push notifications) should be often, however not too many.

Discussion

The aim of this study was to investigate patients, convoys, and health care providers' perspectives regarding palliative care digital health to inform the design of future digital interventions. While we initially intended to generate a grounded theory framework specific to geriatric palliative care, our results aligned with human-centered design approaches. These participatory approaches allow for the generation of meaningful, valued, and evidence-based design of digital health solutions.^{30,31} The documentation of participants' experiences, opinions about palliative care domains, and desired features can be used to design digitally supported palliative care interventions for both older adults and their convoy. Digital health strategies are needed more than ever during COVID-19 pandemic to provide palliative care interventions, monitor patients, support convoys, and promote caregiving across the social convoy.

Participants highlight the challenge of developing digital health tools in the setting of serious illness and also the need for tools incorporating MCC. Many digital palliative care interventions address specific diseases.³² Disease-specific interventions have the advantage of targeting and tailoring information and resources. However, this specificity may not be as meaningful to older adults and convoys that are managing MCC. Developing tools for conditions that commonly co-occur, providing tool settings to personalize targeted illnesses, or syncing interventions across multiple conditions may be helpful for this population.³³

Results suggest that patients and convoys have conflicting perspectives about using and adopting specific technologies, the amount of information and tools needed, and personal health information sharing. Differences in patient and caregiver needs and expectations are well documented, and incongruence in health management is associated with poorer health outcomes among patients and caregivers.^{34–38} Patients often wanted less tools and information, suggesting that too many tools would burden their convoy. In opposition, caregivers were eager for supportive tools. Introduction materials for digital interventions that include clear rationales for how each tool is useful to convoys, rather than burdensome, may be helpful for concerned patients.

Patients, convoy, and health care providers alike were excited about the opportunity to communicate about palliative care needs in a new, digitally supported way. While several digital palliative care interventions currently target symptom monitoring and assessment^{32,39} and participants recognized the importance of these domains, they were less enthusiastic about these specific tools. Rather, participants were

eager to use tools regarding decision support, convoy support, goal setting, and educational resources. There is increased interest in developing digital decision aids, caregiver interventions, and mobile goal monitoring for older adults. Integrating these tools in combination with symptom monitoring and assessment features to tailor educational resources may provide a more comprehensive digital palliative care experience for patients and their convoy. Comprehensive digital solutions may allow patients and convoys to better self-manage and identify individualized palliative care needs, reserving synchronous palliative-telehealth for more complicated and intensive cases, particularly during the COVID-19 pandemic.

The COVID-19 pandemic highlights the need for digital solutions to address spirituality, anticipatory grief, and bereavement needs.⁴⁰ While our participants had some difficulty connecting spiritual needs with their HF care, owing to social distancing measures, many people are staying connected with their spiritual and religious communities via discussion boards, social medical, and streaming services. Best practices for integrating these supports after social distancing will likely benefit older adults who are unable to participate in-person in the future. Owing to the high hospitalization and fatality rates of COVID-19 particularly among older adults with MCC,¹⁷ anticipatory grief and bereavement tools may be most needed at this time. While there are few nonsynchronous bereavement options, less is available for anticipatory grief.³²

Based on these findings, we are currently developing the Convoy-Pal digital health intervention. The human-centered design model was a useful method to merge both scientific evidence and user feedback. Some key considerations we are incorporating in our design include the following: using a mobile platform for multiple users that includes patients and several caregivers; incorporating assessments on patients and convoy to tailor resources; increasing interoperability with technologies currently used by participants (wearables, calendars, videoconferencing); comprehensive tools that range from symptom monitoring to psycho-social-spiritual supports; and facilitating shared patient-convoy health decision-making. Our next steps include iterative usability testing and a feasibility trial.

While this study documents perspectives from a large, multi-stakeholder qualitative sample, there are limitations to our work. First, our sample lacked the desired diversity in race and ethnicity but included a broad age-range among patients and convoys. Many of our sickest patients had a difficult time participating and providing detailed feedback. Therefore, our findings are likely biased toward a slightly healthier sample. Some patients were unable to identify

convoy members, while for others, we were able to recruit multiple convoy participants. Convoy participants were also primarily adult children. Perspectives of less-involved convoys may be missing from the described experiences and recommendations. Although we member-checked our results with clinical experts, we did not review findings with patient and convoy participants.

In conclusion, digital health provides an opportunity to expand the reach of geriatric palliative care interventions. This paper documents human-centered preferences of geriatric palliative care digital health to ensure technologies are relevant and meaningful to all engaged stakeholders.

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Appendix

Appendix II

Example Interview Guide Questions by Participant Group

Group	Interview Structure		
	Experience	Potential of Digital Health	Wireframe “Think Aloud”
Patient	<ul style="list-style-type: none"> • Can you tell me about your experience with HF and other serious illnesses? • What are some of the challenges you experience? • Do you have any concerns about your health? • Do you have family/friends to help you? 	<ul style="list-style-type: none"> • What do you think would help you manage your health? • Do you use any technology to help you with this specific (caregiving) concern? • Would a digital tool be helpful in addressing this concern? 	<ul style="list-style-type: none"> • Reviewing this (example tool): • Would you use a tool like this? • Would you prefer to type in your answer? Voice response? Use sensors? • Would you want to share this information?
Social convoy	<ul style="list-style-type: none"> • Can you tell me what it is like to help care for someone with HF and other serious illness? • What are some of the challenges you have in helping your loved one? • Do you have family or friends to support you and your loved-one in providing care? 	<ul style="list-style-type: none"> • What do you think would help you better manage caring for your loved-one? • Do you use any technology to support your own self-care? • How do you make sure you are also taking care of yourself? • Do you have any suggestions of how the tool could be supportive to you in achieving your own health and well-being goals? 	<ul style="list-style-type: none"> • Reviewing this example tool: • Are there particular aspects of this tool that you find helpful? • How would you want to use this tool? • How often would you access this tool? • How could we improve this tool for you? • Would you want to share this tool with others?
Health care provider	<ul style="list-style-type: none"> • How long have you been working with patients with serious illness? • How often do you work with patients with HF? • What role do you play in supporting the health of the patient and caregivers? 	<ul style="list-style-type: none"> • What kinds of digital tools do you think would be most helpful? • Are there palliative care tools you think would be particularly helpful for patients and caregivers? • Is there anything else you would like to include on a mobile tool? 	<ul style="list-style-type: none"> • As you look at this (example) tool, what do you think? • Do you think patients and caregivers would use this tool? • What information from this tool would be particularly helpful in your clinical practice?