



‘Something I Can Lean On’: A Qualitative Evaluation of a Virtual Palliative Care Counselor for Patients with Life-Limiting Illnesses

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Figure 1: Palliative Care Agent User Interface with Menu of Major Functions

ABSTRACT

Palliative care is essential for maintaining the highest quality of life for patients with life-limiting illnesses. Although the benefits of palliative care are well supported, palliative care services are often offered late in the trajectory of the patient’s disease, limiting the beneficial role these services play in mitigating patient suffering. Digital health tools represent a promising approach for expanding access to palliative care. We report findings from interviews with twenty patients who used a virtual palliative care counselor over a six-month study period and provide guidelines for developers based on these results. Through their use of the system, patients characterized how using a digital palliative care counselor that intervenes on multiple dimensions of well-being benefited their experience of illness and quality of life.

CCS CONCEPTS

• **Human-centered computing** → **User studies**; *Empirical studies in HCI*; HCI theory, concepts and models.

KEYWORDS

palliative care, life-limiting illness, serious illness, digital health tools, patient-facing

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1 INTRODUCTION

Palliative care is an interdisciplinary approach to medical treatment that offers seriously-ill patients and their families services to maintain the highest quality-of-life for the longest time possible [19, 20]. Palliative care services support patient well-being by promoting symptom and medication management [36], mindfulness [14, 30], physical activity [27, 28], psycho-social and spiritual well-being [26, 34], and assistance with end-of-life decision making [19, 20].

Although the benefits of palliative care are well supported, traditional palliative care services are often offered late in the trajectory of the patient’s disease, limiting the beneficial role these services play in mitigating patient suffering [9, 39]. Both provider reluctance to refer their patients to palliative care and palliative care provider shortages [23] represent significant barriers to patients receiving timely palliative care services. Thus, creating new innovative models for supporting, helping, and empowering patients earlier than

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currently provided is a critically important endeavor to alleviate suffering.

Digital health tools offer opportunities for addressing these challenges, presenting cost-effective ways of expanding access to palliative treatment using technology. To date, the majority of digital palliative care tools have focused on bodily health—primarily addressing symptom and medication management exclusively with the goal of complementing existing palliative care services through remote monitoring [6]. Only a handful of prior projects have addressed facets of well-being outside of bodily health [18, 25]. In addition, most digital health palliative care research has focused on patients with cancer [1], neglecting a broad range of other patients with advanced illnesses who may benefit.

We designed, developed, and implemented an embodied conversational palliative care counselor (ECA-PAL) to provide a suite of automated palliative care functions focused on multiple dimensions of well-being to patients with advanced diseases. Embodied Conversational Agents (ECAs) are virtual humans designed to simulate face-to-face conversations using speech and nonverbal behaviors (e.g., eye gaze, hand gestures, head nods, etc.) to interact with users [10]. Prior work has demonstrated the effectiveness of ECAs in delivering health counseling and promotion interventions with patients [3]. ECAs have been shown to successfully develop therapeutic relationships with their end users [5] presenting a somewhat straightforward translation from in-person services to digital interventions. The benefits of an ECA interface modality for delivering health education and counseling is twofold: 1. patients with limited health and technology literacy do not have to rely on text comprehension, but rather a universally understood format of face-to-face communication [4], and 2. when addressing sensitive health issues, in this case death and dying, ECAs are effective in building therapeutic rapport and providing empathic listening, allowing users to benefit from additional socio-emotional comfort [5]. This work takes an interdisciplinary approach to addressing patient needs by focusing on bodily, psycho-social, and spiritual well-being.

This paper reports on patient experiences using the ECA-PAL system for six months, based on semi-structured exit interviews with 20 participants. Our findings address the following research questions:

RQ1: In what ways did the ECA-PAL system benefit patients' experiences of serious illness, if at all?

RQ2: How does patient social isolation influence their perceptions of and preferences for the ECA-PAL system?

RQ3: How might future digital palliative care systems better support patients experiencing serious illnesses?

To the best of our knowledge, this work represents the first of its kind to develop a patient-facing palliative care technology for individuals with life-limiting conditions months before they would typically be referred to in-person palliative care services. Our findings highlight which components of the interdisciplinary system worked particularly well for certain patients compared to others. We contribute a set of design guidelines for future digital palliative care system designers to consider when developing these systems for patients with a broad range of diseases.

2 RELATED WORK

2.1 The Landscape of Palliative Care Technologies

Reviews of information communication technologies and digital health tools leveraged by palliative care providers to manage patient care [17] have focused primarily on technologies used to mediate patient-provider communication (e.g., telehealth, e-mail, etc.) [17, 31]. To assist providers with patient monitoring, some work has explored the viability and feasibility of leveraging wearable technologies to collect patient vitals remotely and other tools to collect symptom information and medication usage. Another research team demonstrated the feasibility of a data-driven machine learning model used to predict patient palliative care status to assist providers in prioritizing patient needs [35]. Cox et. al. developed and evaluated a clinician decision support tool embedded within an intensive care unit's medical record system to refer hospitalized patients to palliative care [13]. The main purposes of these tools have been to optimize healthcare by increasing treatment responsiveness and reducing the costs associated with unnecessary hospitalizations.

Although some of these clinical decision support tools have patient-facing components (i.e., symptom reporting, medication reporting, reminders, etc. [2, 8, 24, 29]) limited work has focused on the design and evaluation of patient-facing digital health tools, where the patient is the primary user. Ferreira et. al. reported their co-design phase of a proposed mHealth tool. Although their tool was not yet developed, it is one of a small number of projects that interviewed both care providers *and* patients during the design phase [18]. In their work, participants prioritized symptom reporting, advanced care planning, group forums to mediate the exchange of social support, and a set of user details that patients could customize (e.g., whether or not the patient lives alone, the patient's religion, music preferences etc.) for providers to leverage as part of their clinical care.

While digital health tools represent a promising avenue for expanding access to palliative care, the design, development, and evaluation of patient-facing digital palliative care is still an emerging field of research. Although patients may desire tools that fulfill a broader set of needs [16, 18], most of these tools have supported physical well-being exclusively and neglected psycho-social and spiritual well-being.

3 METHOD

This work is part of a multi-year research project focused on designing and evaluating a digital palliative care counselor (ECA-PAL). Next, we describe the system design, methods, and analytic approach.

3.1 ECA-PAL System Design

The ECA-PAL system is a tablet-based ECA (Figure 1) that counsels patients on topics related to palliative care at home for six months. The agent is animated in a 3D game engine and speaks using synthetic speech driven by a hierarchical transition network-based dialogue engine. Conversational nonverbal behavior is generated

using BEAT [11], animated synchronously with speech, and includes hand gestures, posture shifts, head nods, and facial displays. User contributions to the conversation are made using a multiple-choice menu of utterances updated at each turn of the conversation.

The ECA counselled patients on various topics, including: ambulatory and non-ambulatory physical activity promotion, medications and medication adherence promotion, symptom and adverse event screening, stress management through guided meditation, and advanced care planning and establishing a healthcare proxy. A particularly novel aspect of the system was a spiritual support module. Supporting a patient’s spiritual wellness has been found to benefit patients on various health outcomes such as decreasing pain, and reducing negative emotions[37]. In this module, the ECA determined the user’s spiritual and religious beliefs and background and then provided a range of information and activities, including prayer, holiday reminders, chaplain referrals, and discussion of death and funeral preparation.

The ECA also engaged the user in daily stories (based on soap opera scripts) and referred to itself and the user by given name to build rapport and maintain engagement, and tailored all of its dialogue based on prior conversations and the length of time since the last conversation. The system also provided a web-based workstation that enabled clinicians to remotely monitor patients, view alerts generated by patient interactions with the ECA (e.g., significant symptoms or requests for palliative care services), and enabled them to view text messages from patients.

3.2 Study Overview

This study was done in collaboration with a hospital healthcare system in a United States city located in the northeast. Participants were eligible for study participation if they: were 18 years or older, English-speaking, had access to a phone, and were endorsed by their provider as having a life-limiting condition. Survey measures were collected prior to system use, including the PROMIS Social Health social isolation short form [22] and patient sociodemographics. After six months, participants were contacted to schedule a follow-up interview. The semi-structured interviews averaged 29 minutes. Prior to recruitment, the protocol was approved by the hospital’s Institutional Review Board, and patients were compensated for their participation in the overall clinical trial.

During the interviews, participants were asked for their overall impressions using the ECA-PAL system and probed to elicit their attitudes, preferences, and motivations for interacting or not interacting with the various components of the ECA-PAL system (e.g., symptom management, spiritual discussions, advanced care planning, etc.).

3.3 Data Analysis

Interviews were audio recorded, resulting in a total of 576 minutes of audio files for transcription. We conducted an inductive analysis of the semi-structured interview content [7]. We used elements of the grounded theory method, including open coding, axial and selective coding, and memo writing [38]. All transcripts were coded using NVivo 20 software, labeling concepts in the data to arrive at a codebook.

4 FINDINGS

4.1 Patient Demographics

Twenty participants from the randomized control trial volunteered to participate in the exit interview. Eleven participants self-identified as Black and/or African American, four self-identified as White, two as Asian, one as more than one race, and two chose not to report. Participants’ ages ranged from 24 to 78, with an average age of 55.7. For education, seven participants reported having a high school degree, eight had some college, four had a bachelor’s degree, and one chose not to report. As part of a social isolation subanalysis, participants were categorized as having LOW-social isolation or HIGH-social isolation using an established T-score cut-off of < 42[32]. Seven participants scored as LOW-social isolation and 13 participants scored as HIGH-social isolation.

4.2 Theme 1: The Impact of a Multi-dimensional ECA-PAL system on Patients’ Experience of Illness (RQ1 & RQ2)

Participants presented examples of how interacting with the ECA impacted their experience of health and illness by 1. bringing their health and healthcare to the forefront of their minds, 2. increasing their agency, 3. creating moments for physical and emotional relief, and 4. providing emotional support.

4.2.1 Patient Activation: Bringing Matters of Health to the Forefront & Promoting Agency. Almost all participants discussed how the digital palliative care system brought their healthcare to “the forefront of their minds”. P10 shared, “when I talk to Marie now I feel good about where my health is headed...because it [ECA] makes you want to take what you’re doing more serious. It made me accountable” (“Marie” the given name of the ECA). By using some of the wellness components such as ECA-led meditations, spiritual discussions, and exercise promotion, participants explained how the system provided them with a positive outlet for prioritizing their health, “I think it [ECA-PAL]...kind of got me out of my negativity. I’m more positive towards life in general now.” (P20). Participants described how using the system created opportunities for patients to “take charge” of their health. For instance, daily check-ins with the ECA reminded some participants to engage in regular physical activity. P11 shared, “Every day when I come back on, she would ask me did I do any walking a day and how long and, and stuff like that, you know? So I felt like I was...doing what I wanted to do and, and she was interested in seeing if I did it...It motivated me to go out and take a walk everyday.” Similarly, P20 emphasized the importance of the ECA in activating her exercise routine. She stated, “without it I wouldn’t have exercised.”

Other participants found that the advanced care planning intervention promoted agency, helping them to take action. P18 emphasized the emotional relief she felt when making her end-of-life decisions with the ECA, “it felt good to do something like that, knowing that I had put these things in place [advanced care plan]...If something like that arises...I don’t have to worry...I feel less anxious.” For P18, her system use helped her make end-of-life decisions while simultaneously benefiting her emotional well-being.

Guided meditations with the ECA allowed participants to engage in a stress-reduction activity—helping center their focus and building their confidence. Participants enjoyed this component the most, stating that meditating with the character helped them feel “*more relaxed*”, “*patient*”, and “*confident*” when it came to “*handling health challenges*”. P1 shared, “*working with Marie ...gave me that feeling of, you can do this.*” Other patients echoed this finding, stating that the intervention helped them feel more capable of participating in their care and taking action to ensure they maintain the highest quality of life possible.

4.2.2 Creating Moments of Relief. Although some participants valued how the ECA brought their health to the forefront, others valued how the ECA-PAL system created moments of relief. This respite was characterized by participants as clearing one's mind, reducing physical pain, and leveraging spiritual coping. P7 explained why creating moments of emotional relief mattered to her, “*it was helpful because it cleared my mind of every other thing that I was trying to think of and everything I had to do. You're Busy, you know, you're thinking about all these things... you're managing your appointments, your medications...so it [the ECA], cleared my mind. It took me really to a nice place.*” When asked which system components provided some mental relief and relaxation, participants mentioned meditations, spiritual care, and stories.

Guided meditation with the ECA was one of the most mentioned components that participants identified as directly impacting their experience of health and illness. Participants found value in the meditations for multiple reasons. First, the ECA-led meditations were implemented as an activity to be done alongside the character, creating a sense of camaraderie. Second, some participants stated that they experienced a notable reduction in physical symptoms after meditating with the ECA.

Several patients found that the spiritual support also provided some emotional relief. When asked how the spiritual content impacted her experience of illness, P10 shared, “*I think to have a mix of spirituality in the other things... I think that was good. The spiritual kind of slows you down and to say it's not that serious. To get caught up and overwhelmed and...full of anxiety...you don't need that.*” Several participants reiterated that spiritual care with the ECA helped build resilience when coping with illness. These conversations also reminded participants of spiritual self-care practices, P8 explained, “*the spiritual stuff got me thinking about... a helpful scripture that I can read to kind of like ease some anxiety.*”

4.2.3 Feeling Cared For. In our social isolation subanalysis (RQ2), we found that all of the socially-isolated patients regarded the ECA as someone who “*felt like a person*” and who could provide consistent support “*whenever they needed it*”. Participants described the ECA as an entity who, while not quite human, made them feel cared for, P15 shared, “*I came to look forward to it, something I can lean on.*” These participants described how the ECA actively built a friendship with them by leveraging the engagement mechanisms our team had designed, such as storytelling. HIGH-social isolation patients often viewed the ECA's stories as opportunities to build a mutual friendship by learning about the ECA's life.

4.3 Theme 2: Digital Palliative Care Tools Can Assist Seriously-ill Patients with Socio-Emotional Processing (RQ3)

Socio-emotional processing is the act of identifying one's feelings and beliefs in order to effectively communicate and interact with others. Participants imagined using the future iterations of the ECA-PAL system to not only cope with new symptom presentations and challenges but also learn how to communicate their feelings about these health transitions more honestly to others in their lives. During the interviews, some participants explained the burden of staying positive when discussing their disease with family. P18 stated, “*You know because your family will tend to be like you shouldn't feel that way, or be a little dismissive. In other words it was like no no no it's all in your head. You're gonna be fine. But, I really didn't feel like that. And being able to say that, I don't know if I'm gonna be fine, and talking to a character, she's not gonna try to just say you'll be fine.*” For P18, the ECA-PAL system was a safe place where participants could reflect on these difficulties without the social pressure to remain positive.

Some participants stated a desire for the ECA to coach them in discussing their health more honestly with family, friends, and even co-workers and employers. P6 shared, “*You know, I'm working, and so actually one of the issues is...I'm going to be talking with the people I work with as to how much longer I will work. And I just don't know.*” Participants explained that by practicing with an ECA, these otherwise difficult conversations may become less burdensome.

4.4 Theme 3: Patients Expect Digital Palliative Care Tools to Bridge the Gap Between the Patient and their Providers (RQ3)

Most patients expressed a desire for the digital palliative care system to better facilitate and mediate patient-provider communication. Participants acknowledged that through their discussions with the ECA, the ECA collected and stored information about their symptoms and health behaviors. However, participants were unsure how their providers leveraged this information (or not), resulting in some patients discontinuing reporting their symptoms. P19 explained, “*it's not worth your time to report how crappy you're feeling if it's not gonna be used in a productive way for your own healthcare.*” In its current state, both the messaging feature (contact the study team) and ECA-administered symptom assessments had a unidirectional information flow from the patient's device to the nurses station with no patient-facing feedback. As a result, patients requested that in future versions, more information on how their treatment team would respond, especially to changes in symptoms, and how quickly to expect a response be included.

4.5 Theme 4: Patient-facing Digital Palliative Care Interventions Require Personalization When Used by a Heterogeneous Patient Population (RQ3)

While participants acknowledged that the ECA-PAL intervention was tailored, they made a case for increased personalization and adaptive tailoring. In this section, we enumerate the ways in which participants desired more personalization.

4.5.1 Medical Context. In almost every interview, participants wanted the ECA to know more about their medical history and their current diagnoses. Beyond disease-specific interventions, participants wanted the ECA to be aware of changes in their disease trajectory and respond to those changes dynamically. P1 stated, *“The hardest part was having to work with her and have surgery. Because I couldn’t walk, if she popped up on the screen she was gonna ask me. It was like me running to hide under the bed from her.”* Unfortunately, this participant avoided the ECA-PAL system because the system was unaware of her surgery and inability to walk. Participants indicated that personalizing based on the user’s medical context could help sustain future system engagement.

4.5.2 Socio-Ecological Factors. People’s illness experiences are shaped by multiple socio-ecological variables (e.g., access to health-enhancing resources, level of social isolation, employment, physical functioning, etc.). As a result, the patient experience is heterogeneous. For instance, P19 explained how her access to social support made the ECA’s stories less appealing. P19 stated, *“I have a strong family, good friends. I didn’t need it [the stories].”* Other examples included participants who had access to fitness facilities and wanted the ECA to recognize such assets. Another participant was employed during the study and wished the ECA supported them more effectively by acknowledging the strain of working while ill. Participants believed that the ECA should be aware of these factors as they invariably mediated their needs and attitudes towards the system.

4.5.3 Attitudes Towards ECA Personification & Fictionalization. Finally, there were varied responses to an ECA that took on human-like qualities and discussed human experiences (e.g., death, dying, overcoming challenges, etc.). For more than half of our users, this was highly effective and desired. Spiritual discussions with the ECA reminded participants to leverage their faith and spiritual communities to cope with their illness. The ECA’s simulated empathy instilled, in some, a feeling of emotional support. Stories the ECA told about her “friends” entertained some users and established a feeling of closeness with the ECA. These same users desired an even deeper interaction with the ECA, suggesting that the relationship between the ECA and the user become more casual over time (e.g., the ECA asks to be called a nickname). For other participants, the ECA’s fictionalized self was uncomfortable, unnecessary, and viewed as superfluous. P19 stated, *“you feel like if you’re talking to a robot, you’re gonna get nothing out of it...so why talk to a robot.”* For these participants, a fictionalized ECA decreased their overall satisfaction with the intervention.

5 DISCUSSION

Based on our findings, we propose a set of seven design guidelines for researchers to consider when creating patient-facing systems for palliative care. We hope that by offering these guidelines, we will ignite discussions on how to develop patient-facing palliative care technologies with the goal of expanding access.

Catalyze Patient Activation. Patient activation is a psychological process where the patient takes an active role in their medical care because they have the knowledge, skills, and confidence to do so [15, 21]. We found that the ECA-PAL system helped initiate

patient activation for some of our patients by promoting accessible and inclusive wellness activities that could positively impact their health. We invite future designers to consider how to further and more explicitly catalyze patient activation in palliative care patients using technology-based interventions.

Provide a Safe Space for Reflection. Research has demonstrated that mHealth tools can create opportunities for patients to reflect on their current situation [8]. In our work, participants echoed these findings with most participants appreciating the ability to express how they feel, free from judgement. Our results, combined with related work, demonstrate the promise that digital palliative care tools may hold as tools for reflection.

Include Features that Assist Patients in Easing Interpersonal Tensions. Participants shared how discussing their illness with others is, at times, a laborious and anxiety-producing task. As a result, they expressed a desire for tools that could help them articulate and practice discussing their thoughts and concerns with others in their lives. We encourage researchers to consider how they might build digital palliative care tools to help patients ease these interpersonal tensions. There is an opportunity for ECA researchers to investigate how conversational agents could assist patients in learning how to discuss their feelings with others through role-playing.

Set Expectations for Remote Monitoring and Communication. Our findings and related work in digital palliative care confirm that patients with advanced diseases desire technologies that facilitate patient-provider communication [8, 25]. In our work, participants expected more transparency—wanting a more fine-grained understanding of how their information would be used and reviewed and what type of response to expect. Future palliative care technology designers should examine how to address these concerns while considering provider workflows.

Personalize Content to the Individual’s Disease Profile. Our participants were referred to the trial because their provider believed they had a life-limiting medical condition. Our sample included patients with numerous serious illnesses and many with co-morbidities. As a result, our ECA-administered symptom assessment was, for some patients, less relevant and subsequently reduced system engagement. Future work should consider dynamically matching symptom assessments to the patient’s disease profile.

Consider Adaptive Content. Digital palliative care tools that incorporate multiple interventions, as ours did, should consider creating a *recommender* feature to highlight content based on the patient’s current needs, preferences, etc. Our participants described disease trajectories that were diverse and non-linear. Patients brainstormed technologies responsive to these changes and adaptive to new circumstances as they arose. Researchers outside of the palliative care space have investigated mechanisms for recommending content to their users to promote and sustain use [12]. We recommend that researchers investigate mechanisms for designing interventions that are adaptive to changes in patient functioning.

Take an Interdisciplinary Approach. Our work demonstrated how incorporating features that focus on multiple aspects of well-being (e.g., spiritual, emotional, bodily, etc.) benefited how patients thought about and navigated their disease. Patient-facing palliative care systems have focused almost exclusively on remote monitoring and bodily health [33]. Given the limited work in this area,

we recommend that future work build on our interdisciplinary approach by developing and evaluating features supporting multiple well-being dimensions.

6 CONCLUSIONS

In this work, 20 participants were interviewed about their experiences using the ECA-PAL system over six months. Participants shared how the system and its interdisciplinary components influenced their experience of illness—priming patient activation and providing relief and support. A subanalysis revealed that socially isolated participants found the provision of emotional support by the ECA more appealing and enjoyable than their low social isolation counterparts. Design guidelines for developing these systems for heterogeneous patient populations were presented. This work serves as an example of how to intervene on multiple facets of well-being using patient-facing palliative care technologies. By presenting this work, we aim to stimulate a conversation about how to expand access to palliative care using patient-facing technologies, and how to design these technologies to meet the diverse needs of those with serious life-limiting illnesses.

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