

Craving, Creating, and Constructing Comfort: Insights and Opportunities for Technology in Hospice

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ABSTRACT

Hospice is a medical setting for patients with terminal illnesses where active treatment is withdrawn in favor of providing comfort and dignity at the end of life. Providing comfort extends beyond managing physical pain to include social, emotional, spiritual, and environmental aspects of care. We studied technology's role in achieving these multifaceted dimensions of comfort through interviews with 16 family members of past hospice patients. Comfort was an ongoing pursuit, requiring the involvement of diverse stakeholders; communication technologies were selectively chosen in service of this achievement. We provide opportunities and recommendations for technologies in hospice, including the need for varying degrees of richness and symmetry, and for support for life-affirming acts. To our knowledge, this constitutes the first study, in the CSCW and HCI literatures, of communication technology use during the final days of a person's life, with implications both for hospice and for the end of life more broadly.

Author Keywords

Comfort; hospice, palliative, and end of life care; computer-mediated communication; family communication.

ACM Classification Keywords

H.5.m [Information Interfaces and Presentation (e.g. HCI)]: Miscellaneous.

INTRODUCTION

Entrance into hospice care marks withdrawal of active medical intervention aimed at curing fatal conditions, to instead provide “a dignified, comfortable death for the terminally-ill and to care for the patient and family together” [38]. Admission into end of life care—an umbrella term encompassing hospice residences, palliative care facilities, and agencies that provide home-based care services for terminal patients—can be an exceptionally stressful time for family and friends, who seek to provide for the physical, emotional, and social well-being of a dying loved one, in addition to tending to their own needs.

Numerous studies have associated access to strong social support as an important component of quality of life for hospice care patients [16, 17, 42–44], and individuals with higher levels of social support have been found to cope better with pain [39]. Communication-centered therapeutic interventions have also been effective in later reducing grief symptoms for family members [21]. Together, this body of evidence points to the importance of communication and social support as components of high-quality end of life care.

Despite these benefits, opportunities for communication and social support may be limited. Patients will likely experience varying levels of lucidity and alertness across and within days. Family members may have competing responsibilities or geographical constraints that limit the frequency and timing of face-to-face visits. Institutions often have visiting hour limits that can further impede and complicate the task of scheduling and coordinating care. Moreover, while some patients will experience too little interaction and may feel lonely and isolated, others will experience too much and may become overwhelmed with the frequency and duration of visits. Such patients may want to limit visits from their extended social network, enabling them to focus their energy on their closest friends and family. In these cases, they may elect one or two caregivers to act as a spokesperson to their larger network. While this reduces exertion on the part of the patient, this can be an arduous task for caregivers as they are likely already overburdened with other caregiving responsibilities.

In this paper, we present findings from interviews with 16 individuals about their past experiences caring for a close family member or friend in hospice. In describing their interactions with dying relations, participants revealed the provision of comfort as a chief concern and motivating force that extended well beyond simply ensuring that their loved one was free from pain. Rather, comfort was a multi-dimensional state under constant renegotiation. In pursuing comfort, participants spoke of creating home-like spaces and of constructing life-affirming experiences such as the reliving of past memories and the sharing of small talk or a meal. Comfort was also multi-directional: participants described not only their own efforts to comfort patients, but—in describing patients' actions—revealed how the patients themselves acted to comfort caregivers. Lastly, they spoke of the need to comfort and support each other.

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Views surrounding technology and its adoption were complex. While face-to-face interaction was prized, technology was seen to provide unique benefits. Mobile phones gave patients autonomy over their social interactions, letting them choose who they wished to contact and when. Low-richness technologies such as texting enabled one participant to filter out the realities of her mother's condition and to momentarily experience pre-diagnosis-like interactions. Email and social networking sites also enabled family and friends efficient means of coordinating care and sharing information. Yet, technology also caused problems. Differing views on its ideal use led to privacy violations, and conflicts surrounding how and when information should be shared. From these findings, we suggest opportunities for design that reflect the unique constraints of the hospice setting, and that are sensitive to the value participants placed on the provision of comfort.

BACKGROUND

To set the stage for our investigation, we first briefly review the current state of research in our field concerning the end of life as a domain of inquiry. Noting that this is the first study in the literature to examine technology use during the final days of a person's life, we present an introduction to the provenance and values of hospice care. This sketch then leads us to review efforts in the nursing and medical fields on introducing technology into the hospice setting. While promising, these explorations (a) focus on introducing existing technologies rather than designing new ones, and (b) seek to improve existing methods of care rather than considering new possibilities.

HCI, CSCW, and the End of Life

The end of life has been a relatively recent, but fruitful, domain for exploring technology use and design in the HCI and CSCW communities. Key themes in this domain include materiality, identity, temporality, and ethics [25]. Massimi and Charise proposed the need for a humanistic design approach to the end of life that they termed thanatosensitive design [24]. Since then, work in the end of life has focused on a few key issues. The first is materiality and how objects and data would be potentially passed down, destroyed, or otherwise handled following a death [15, 32]. Bespoke technology heirlooms have been proposed as a way to address these issues [31]. A second strand of research has focused more on remembrance at the cultural and national levels, with efforts to create digitally-enhanced memorials of genocide [27], made possible by multi-lifespan information systems that permit the safeguarding of data [11]. A final strand has focused on social support and computer-mediated communication regarding the end of life, and highlighted issues concerning "continuing bonds" [22]—the idea that after a death the relationship is not necessarily severed, but continued in a new form [13] and that social media sites may present a space for enacting this relationship [4, 13]. Other work has investigated the features of websites that are helpful for bereavement support groups [23]. It is in this vein of social

support that our work most closely fits, but our unique contribution here is that we focus on social support and the achievement of comfort *during the process of dying*, rather than following a death. This is a space that has yet to be directly explored in the HCI and CSCW literatures.

Modern Hospice and End of Life Care

While caring for the dying has been practiced for many centuries and in many contexts, the modern hospice movement can be traced to the 1960s, when Dame Cicely Saunders advocated for medical professionals to view their patients as human beings with multiple needs, rather than simply as sites for treating disease. She referred to this broadened emphasis as "total pain" [6]. From the earliest days, hospice care has placed a primary focus on the concept of comfort; in fact, aspects of hospice care are sometimes referred to as "comfort care" or "palliative care" [26]. This term refers to ongoing, concerted efforts made by a care team to provide for the patient by withdrawing active treatment and instead focusing efforts on maintaining and improving the patient's quality of life [48].

From a traditional medical perspective, comfort is often synonymous with pain reduction and management [6]. In other words, comfort is the absence of physical pain associated with the disease or side effects from its treatment. In this conceptualization, comfort is then a patient state that is achieved through the administration of drugs or application of pain relief devices. Alertness is a secondary, but often present, concern. Both drugs and disease progression may result in drowsiness, sluggishness, and communication problems. Through this lens, achieving comfort is achieving the highest level of alertness possible while alleviating pain with analgesics and narcotics [33].

Hospice advocates have challenged this framing. In hospice care, patients may be encouraged to manage their pain through alternative forms of therapy such as massage or meditation [46]. In addition to an expanded set of treatments for physical pain, the hospice model of care sees patients as people who have needs for emotional and spiritual comfort as well. Emotional support may include suggestions for contacting and communicating with friends and family, or the provision of a therapist or counselor [34]. It may involve occupational therapies such as art or music therapy [8]. A patient's spiritual comfort is another important aspect of their humanity; at the end of life, patients may struggle to find solace and peace with respect to their mortality. Clergy are often present in hospices to tend to patients' spiritual needs.

While most scholarly work focuses on the comfort of the patient, there is a growing literature that addresses the comfort of medical professionals in this setting. Nurses and doctors who deal with death on a regular basis may be negatively impacted by their exposure to the accompanying existential and emotional pain, often called "compassion fatigue" [40]. Medical professionals must not only grieve

their own loss of the patient, but must confront the grief of the family and friends who may be present.

Hospice settings are also unique in their provision of support for friends and family of the patient. Many hospices will offer bereavement support groups and assist families in making arrangements after the individual passes away [10]. This is to say little of the ongoing work of managing visitors and providing updates to the family. This support, however, is generally provided informally (e.g., through bedside conversations between staff and visitors). At the same time it is worth noting that hospice has not been proven to reduce subsequent grief reactions [18]. While the loss of a loved one is clearly an important personal event and there is considerable advocacy for supporting family through this transition, the psychology, psychiatry, and medical literatures generally fail to find experimental results that indicate bereavement and its attendant grief cause long-term medically-detectable changes [3, 7].

Technology Use in Hospice Settings

Like other medical settings, stakeholders in hospice care include the patient, his/her family and friends, and the medical care team, staff, community liaisons (e.g., social workers, clergy), and professional caregivers. Each of these has different communication goals and preferences.

For the patient, communication may be impeded by health conditions or treatments that impair vocal, auditory, and motor function. Communication is of course important for sharing care preferences, but it is equally important for acts of spiritual and emotional expression. For example, terminally ill patients may create blogs to share their thoughts regarding their conditions and how they would like to die [41]. In a hospice or palliative care setting, assistive communication technologies may be used to overcome these barriers [37], but more commonly, family members are charged with making health decisions [36].

The shortened lifespan of hospice residents and hurdles to learning new technology near end of life present challenges for researchers when designing and validating technologies for hospice residents [47]. Although many online support communities exist, some evidence suggests they may be used mostly for informal emotional support and the sharing of personal experiences, rather than for formal information seeking [5].

Some patients elect to receive palliative care at home, rather than in a hospice facility. Caring for the patient usually falls to family members, although paid caregivers can sometimes be afforded. Health researchers and social workers have proposed telephone-based interventions that target family members in order to reduce stress and depression by helping caregivers develop coping skills [19].

In home-based hospice settings, telephones, videophones, and telemetric devices can be used to communicate with medical staff regarding the ongoing care of the patient [20]. A number of studies in this space have investigated the

barriers to adoption and efficacy of videophones in telehospice [33]. Others have explored the feasibility of operating home-based hospice systems and provide design recommendations for web-based hospice interventions [45]. The use of Skype as a means for geographically-distributed visitors to converse with dying patients has also been explored, with promising results [1].

With the exception of telemetric devices, communication technologies in hospice are usually off-the-shelf devices such as telephones or videophones. Though telephones and videophones provide quality synchronous communication, they offer comparatively limited asynchronous capabilities. Given the sensitivity and gravity of the issues discussed in hospice settings, and the large proportion of time that communicants may be inaccessible, technologies that target asynchronous communication may particularly improve communication for stakeholders in the hospice setting. In all of this, the achievement of comfort remains an unstated goal in the design and application of technology.

METHOD

As noted above, hospice care means providing for the whole person and their family, extending beyond pain management. With this as our starting point, we undertook an empirical interview study to more closely examine what it is that technology might provide in pursuit of a multi-dimensional concept of care consistent with hospice values.

Participants

Over a period of 10 months (May 2012 to Feb 2013), we interviewed adult family members and friends of recently deceased individuals ($n=16^1$), asking them to describe their most recent hospice experience. Participants were recruited through advertisements distributed via partnerships with hospices across Canada, posted within the university, and advertised on several hospice and cancer-centric social networks on the web. Interviews were recorded either in person or over the phone. Participants received \$10 in compensation for their time.

Participants were between 21 and 69 years of age (mean=40, median=34). The overwhelming majority was female (14/16), which is not surprising in light of previous studies documenting how females generally assume primary responsibilities of informal caregiving [29]. Participants in our sample generally had a higher than average education, with 81% (13) having an undergraduate university degree or higher. One participant described her information and computer technology (ICT) use as “moderate”, while the rest reported “heavy” use.

Participants described hospice experiences taking place in Canada (10), the United States (5), and Pakistan (1). Their

¹ Two additional participants were interviewed, but due to equipment failure their interviews were unrecorded, and thus, are not reported here.

experiences involved 14 unique hospice patients, as in two cases we interviewed 2 different family members about the same hospice patient. All interviews took place within ten years of the patient's death. The majority (12) took place within five years, and of these 9 occurred within two years and 6 within one year. The average reported age of former hospice patients (at death) was 66 years (median = 62) of which 11 were female and 3 were male. Most of the hospice patients described in our interviews died following a cancer diagnosis (14/16); one died due to kidney problems associated with old age, and the other died from complications resulting from COPD (chronic obstructive pulmonary disease). Hospice care ranged from 2 weeks to 6 months. The reported level of ICT use during hospice care also varied across interviews with 29% (4) reporting "none", 43% (6) reporting "light use", 14% (2) reporting "moderate use", and 21% (3) reporting "heavy use". Our sample covered a variety of hospice scenarios including home-based care, residential facilities that emulate the home setting, and full institutional settings within hospitals.

Design

We chose a semi-structured approach to data collection to ensure a baseline level of consistency in the themes discussed, while also allowing participants the freedom to diverge into unanticipated topics. In addition to collecting demographic information on both the respondent and the deceased hospice patient, the interviews covered 3 main themes: (1) expectations for hospice, (2) communication during hospice, and (3) the potential role of technology. Each interview took approximately 1 hour to complete.

Data Analysis

Each interview was transcribed and later coded by two graduate student research assistants. Analysis consisted of two passes: the first to create an initial set of inductively generated codes and the second to categorize these codes into unified themes. Data was analyzed section-by-section, question-by-question, across interviews. The initial phase of coding was completed independently by each research assistant who, upon completion, worked collaboratively to develop consensus across the codes and to cluster them into overarching themes inspired by grounded theory [14].

RESULTS

In this section, we first describe our findings, organizing them into two main themes: (1) how our participants interacted and communicated with hospice patients, and (2) how caregivers coordinated and interacted with other members of the patient's social network. The provision of comfort repeatedly presented itself as a driving motivation, appearing in the way hospice settings, conversation topics, and offerings (particularly of food) were chosen. Comfort was also valued in interactions within the larger social network, with participants often noting how interpersonal strains resulted in its absence.

An additional underlying theme was the uncertainty of the hospice experience. Participants expressed having few

preconceptions of hospice care. Though many participants recalled prior experiences from childhood, these early encounters did not inform their adult experiences. As a result, participants felt they had under-anticipated the extent of the demands they would encounter, as exemplified here:

Honestly, I never thought of it. You are in high school and then university and you don't even think of something like that. For my mom, it was very sudden and for my aunt, as I said she had it [cancer] 7 years before when I [was] really young; it didn't even click that it would be something I would have to deal with. –P06

Accordingly, communication and coordination activities tended to be a reactionary response to admission. In settings where treatment and palliative care were co-located in the same institution, that distinction was even more blurred and difficult to anticipate for caregivers. The uncharted nature of hospice influenced nearly all their activities and the way they approached decision-making throughout hospice care.

Connecting with Patients: Constantly Seeking Comfort

Creating and maintaining comfort was a primary value that emerged from participants' descriptions of their hospice experiences, and extended beyond ensuring freedom from pain. Participants worked to maintain continuity between life before, during, and after hospice, and to ease difficulties they encountered in the transition from living to dying.

Recreating Normalcy inside the Hospice

Participants involved in selecting a hospice locale for their loved one sought settings that emulated home. Home-based and home-like settings helped alleviate anxiety regarding the potential for isolation:

The fact that my grandmother had her own TV in her own room [was] especially important to my mom [and] to my grandmother. Like that was something that they were really glad that my grandmother had, a TV in her room. And I think it was because it reduced a sense of isolation or socialized-relation; that it replicated what she had back home, and she would, you know, watch previous programs and the news and whatnot. –P02

Here, access to a TV and personal space, in the form of a room, was seen as extending the stability of home life into the uncertain and ambiguous context of hospice care. The consumption of media was seen as providing hospice patients with a window to the outside world, and to a source of comfort and normalcy that carried over from home life.

This desire to create a sense of normalcy extended beyond the selection of home-like spaces to using activities and visits to (re)create feelings of normal. Families in our sample described using conversation to affirm the life of their loved ones by talking about the past and about other family members. As P15 describes below, many conversations were mundane or ordinary, but these helped to extend day-to-day family life into the hospice setting:

I remember her explaining to me about gardening a lot. TV shows a bit. Francophone TV shows. We would talk about school. What plans I had for the future. –P15

Participants also described how the sharing of meals acted as a focal point for bringing families together and enabled them to be present and have meaningful interactions with their loved ones while in the hospice setting:

It was just like he was at home. Right? Up until the day before he died, he'd come out, and we'd cook him dinner, he'd sit at the dining room table. The Saturday that he died, we had a family barbecue. We had 18 people in the backyard [of the hospice] and we had a barbecue for my dad. –P17

Favorite foods were also offered as a means of providing comfort. For example, P07 would call before her visits to see if her mom wanted “any treats or sweets or anything like that.” The sharing of food was seen as a life-affirming way of maintaining quality of life, and thus great effort was expended to satisfy wants and to get participants to eat:

Whatever [she] wanted to eat we'd try to get her. She was, you know, she had a hankering all of a sudden for eggs; so whatever she wanted, we would do to keep her eating. –P05

Putting Affairs in Order

While the above actions sought to create comfort in the here and now, other actions were undertaken to plan for future comfort. Although most participants indicated that their loved ones had made funeral arrangements prior to their admission into hospice, almost all described having further conversations near the end of life. These discussions provided loved ones with an understanding of how the deceased wished to be remembered and honored. They were also a way for patients to comfort and reduce the burden on caregivers:

She really did talk about the end of her life quite a bit. She was someone who wanted to make sure every single thing was in order. I can't remember anyone having more things in order than her. Very conscious of who received what, making sure everything was very, very fair, right until the last item and penny. It was important for her to actually hand people the jewelry or the items of hers that she wanted them to have. –P05

Participants described their loved one's anxieties surrounding the handling of their estate and their fears that incomplete arrangements would be burdensome after they passed. The decision to give away one's possessions or sell one's house were emotional moments and part of the hospice patients' acknowledgement of dying.

Regulating Information and Emotion

An additional way comfort was sought was through the withholding of information. Some participants expressed feeling the need to control the flow of information to the person in their care and to change their communication style in order to support their loved one by maintaining an air of optimism and hope. Caregivers acknowledged their

own need for support during these times in order to deal with the emotional and physical impacts of caregiving:

Usually we would get very bad news so we'd try not to cry in front of [her]. That was a big part of trying to stay strong for her and at times that felt almost impossible. And at a certain point, I remember we broke down in front of her and she said "oh my God, what did they tell you?" because it was impossible to keep it in anymore. So it was just trying to calm her down, um, talk positively to her, lie to her, we did a lot of lying just to give her hope and tell her that there's still hope, that they're still doing this or there is still that option, and after this, we'd just try to joke around and talk about our everyday lives and distract her and just try to like, try to have just a little bit of the past experiences we had? And I would maybe help her eat, or force her to eat. Yeah that's pretty much how they would go. –P14

In this case, we see several ways that comfort was created. As the participant notes, she regulated her own emotional reaction to negative news to protect her loved one from worrying. She lied and distracted her with jokes and food to maintain an air of optimism. Regulating information and emotion in this way can be seen as an effort to comfort not only her loved one but also herself.

Saying Goodbye

Almost all participants expressed either the experience of—or an expectation for—meaningful conversations at the end. However, while some were able to share intimacy and emotions that they might not otherwise share in day-to-day life, others were not able to have these kinds of conversations. Positive experiences were often associated with the emotional impact of thinking of the future and the importance of loved ones sharing their hopes and dreams for after they pass:

He'd talk about his life and children; [Participant starts crying] that he was taking care of us even if he wasn't there and he would talk about my baby [crying again] because at this point, well at this point, I think dad and I really knew he wasn't going to see her. –P01

Dissatisfaction, on the other hand, was often associated with superficiality and inauthenticity, and feelings that interactions were too mundane or ordinary:

Watching the TV with your grandmother who is dying, when you really feel like you're supposed to be having, like, these profound conversations that have some kind of significant meaning, seemed far too pedestrian, far too mundane, and far too insignificant. –P02

In some cases, external supports could help to guide interaction and help broaden discussion. One participant who did report positive interactions described the role of a simple book in prompting discussions about her mother's past that they may have not otherwise thought to discuss, but that were in fact incredibly meaningful:

What the book does is, it invokes memories, for instance for my mom, it invoked memories of her childhood, her relationship with her parents. Um, special things that happened. It was an absolutely wonderful event, shall I say, of discovery for all of us. –P07

Communication Barriers

Though communication played an important role in creating comfort, communication barriers often impeded its achievement. Changes in energy levels and cognition at the end of life represented a significant communication and coordination challenge for loved ones visiting hospice patients. The impact of pain medications and the effects of declining health also had significant effects on the ability of hospice patients to participate in social interactions. Cognitive impairment due to medications made it difficult for hospice patients to carry conversations, to use devices such as the telephone, and to remember recent or past events:

It was just a chemical cocktail so that also made it difficult to focus and really understand sometimes what was going on around her and it made her extremely sensitive so even if we wanted to suggest an activity to make her feel distracted she would take it the wrong way. Her personality changed. –P14

Respondents also described the ways in which physical changes affected the personality of their loved ones. These physical and cognitive changes were difficult for caregivers because they dramatically changed the quality of interactions they had with their loved ones. They described needing to adjust expectations and communication styles. Conversation also became increasingly one-sided and difficult as contact with the world outside of the hospice setting became increasingly foreign to the patient:

The catching up also was really kind of painful as well because it was always one-sided. I had so much going on and so much to share, and my grandmother wanted to hear about it but you can't have a natural "give and take" in a conversation because the last thing she wants to talk about is what's going on in her life, which can be frustrating. –P02

Participants perceived the lack of conversation topics, in conjunction with decreasing mental alertness, as responsible for awkward interactions with their loved one. While these barriers emerged, sometimes conversations were less important than simply being together:

I didn't really have anything to say I just came over and sat next to her and she was like, "What are you doing?" and I'm like, "I don't know, I just thought I would come over and say hi" and she started tearing up and I started tearing up. You know, we didn't have a big conversation, she just said that she was so glad I was there and I said I was glad I was there and we kind of just sat there, and held hands for 5 or 10 minutes, and kind of went on doing what we were doing. You know, those kinds of things you don't do when

everybody's fine. And you know I was glad, I wish we had done more of that. –P08

Role of Technology in Hospice Care

Not surprisingly, when asked about ICT use, participants expressed a strong preference for face-to-face contact. For example P10—though acknowledging a supplemental role for technology—emphatically declared, “*I would never want a last interaction with someone to be via some sort of text interface.*” Despite this emphasis on face-to-face interaction, participants also spoke positively about technology. The telephone was the most frequently used ICT by caregivers and hospice patients and preferred for its ease of access:

The cordless phone was a wonder. Like that was an awesome technology for her because she didn't have to get out of bed. And wireless things were like things that seemed to be really remarkable. I remember at some point in her home they got a wireless fireplace control. So that she could like turn it on or off, up or down from the bed. –P02

For this hospice patient, wireless devices enhanced her quality of life and afforded her a level of independence. With access to a cordless phone, she could seek out social interactions autonomously, and alert caregivers when needs were not being met. A fireplace remote control enabled her to independently control her environment.

Contrary to the general emphasis on face-to-face contact, participants sometimes sought less rich communication mediums. Because phones, like face-to-face interaction, carry the emotional tenor of a message, low-richness asynchronous mechanisms such as text messaging were sometimes chosen to maintain emotional distance and filter the realities of the end of life:

A lot of the conversations we had in the clinical setting was her speculating about the cause of her illness and it was really strange because there was a negativity to it... it never felt like I was talking to my mother, but then the text messages she would send me really did. There was a sweetness about them, they weren't ever really about her illness. They were about her and I. So they were kind of an equalizing, leveling, grounding gesture. –P04

In this case, mediation of communication provided a separation of context from message that allowed the participant to connect more directly with her mother and imagine the relationship in a more comforting way.

Almost no one in our sample reported the use of webcams or video chat. While participants spoke positively about the possibility of integrating web cameras into future hospice experiences, they had concerns about their unfamiliarity:

I mean by that point, my sister certainly could have grabbed a laptop with a webcam on it and stuck it in front of her, right? But on her own, the fact that she wasn't already comfortable and familiar with it would just have made it this weird new thing... –P08

Additional concerns surrounded the current symmetry of video chat, and whether it was appropriate to project a video feed of the hospice environment. Some participants expressed concerns about the visual impact of hospice on younger viewers or those who were unfamiliar or unprepared for the physical changes that accompany end of life such as changing skin color and severe weight loss:

If you were willing to take children to visit grandma in the hospital, then I guess, a FaceTime conversation would be fine. But if you didn't want the children to see grandma hooked up to an IV or on some kind of breathing machine, then you wouldn't want them to see it online either. –P07

These quotes point to the need for sensitivity to the reality of the hospice setting and the difficulty of introducing new technologies at the end of life. Relationships are unlikely to be symmetrical; designs that encourage heterogeneous ways of sharing could be valuable for respecting this asymmetry.

Coordinating Care: Comforting Each Other

The admission of a loved one into hospice was extremely disruptive to the day-to-day routines of caregivers. In this section, we shift our focus from how caregivers interacted with the hospice patients to how they interacted with each other and with extended family members. Some participants described dissatisfaction with the division of labor, particularly when they were unexpectedly and unilaterally charged with the majority of caregiving responsibilities. Many felt other potential family caregivers abandoned them, citing their own schedules and responsibilities:

Yeah it was really hard balancing commitments to school and [the] timeline I was on as well. Trying to provide support for her and be there for her because it was an intensely uncomfortable position she was in and she was alone in the city. Like my sister also lives in [the same city] but [I felt like] she was really unavailable because of her work schedule and [that she experienced difficulty] acknowledg[ing] that [our mother] had a life threatening cancer. So I felt a lot of responsibility to care for her also because her partner, my dad, just wasn't really supportive either so it was really difficult. –P04

As has been documented elsewhere [29], participants experienced stress from their multiple responsibilities as caregivers, family members, and employees. They also experienced pressure to perform these roles authentically and completely, and feared how others would judge their performance of the caregiving role:

Well obviously in real life, I found it was much more difficult. I didn't know it was going to be so, I mean of course you always assume that it's going to be sad but it was just an extreme amount of anxiety, insomnia, like just the physical toll that it takes on you; that was unexpected to me. And also, for everyone else life goes on. It's not like the world stops... and it's funny because while I was at the hospital with her, I felt nothing, I felt complete numbness. –P14

Primary caregivers were not always alone in wanting better coordination support. Some secondary caregivers described wanting to provide support but experiencing difficulty in doing so effectively:

It was really about helping [the primary caregiver]. I'm trying to think, it was very challenging. Challenging in that sense because there were times perhaps when she needed help and for whatever reason we weren't there, or couldn't be there, or you know, those were challenges. That was probably the biggest challenge of the whole thing, because it was hard, it was hard for her. I mean it wasn't hard for her. She did a great job, don't get me wrong. It was an emotional... it was a really emotional, straining journey for her. So in that respect, um, I have to say, that was a challenge. Because you wanted to be there to help as much as you could and you couldn't always be there to help. –P05

Communication and Coordination Technology

A desire for better ways of coordinating support also emerged when we asked participants to imagine how technology could have helped. Here, participants described the emotional drain of having to independently call large numbers of individuals and envisioned some sort of management system that would allow caregivers to automate the transmission of repeated information. Emotionally sensitive and time-critical messages were described by interview participants as requiring personalization, thoughtfulness, and the ability to respond to the emotional needs of the receiver. At the same time, the requirement to personalize and respond to the emotional impact of messages added an additional level of challenge that participants saw as amenable to technological support:

It was very difficult to make all those phone calls. If there is a way of having something that is in-between a mass email and individual phone calls for a million people, I don't know what that would look like but something that balances the competing needs of not making it seem like a mass-message impersonal thing but also saving the emotional sanity of the family member because with each new person you tell, they're shocked and they're upset and you're going through it every time with each person. –P08

Participants did make use of email and social networking sites such as Facebook to aid in these tasks, but with mixed success. Email was valued for its ability to transmit documents across distance, communicate across time zones, and accommodate thorough updates and accounts:

Email for me, that's tops. For [the patient] she preferred the telephone I think because she worked online, so it's, you know... For everybody else, I can't really speak, I think probably email was the preferred because a lot of these are distant, you know, they're busy. –P12

Email is for thorough communication, like our emails are very long, like this happened and that happened and then, you know. Oh and we'd scan and send reports. –P06

Technology was also used as an emotional buffer and a means of easing communication when relations were tense:

I don't think [my half-brother is] totally comfortable with me, so texting just kind of made it easier... Well I mean he didn't say much, but I think talking to him would have made it a lot harder for him even to say whatever he had to say. I also didn't want him to hear me on the phone, because I was a bit of a wreck... And if he didn't want to answer, he could just ignore it or leave it for a little bit. And I wasn't necessarily interrupting anything... –P16

Although asynchronous text-based communications were used extensively, some participants expressed concern about overreliance on them. The lag time between sending and receiving messages made these mediums less useful for time sensitive content. They were considered too cold and impersonal for the emotional, sensitive nature of some messages (i.e., the passing of the hospice patient).

Differences in their adoption among concerned parties also limited their usefulness; not everyone who needed to be reached could be reached in the same way. For example, generational differences were pronounced when it came to the use of social networking sites like Facebook. In some cases, the ability to reach a large number of people with relative ease infringed on the agency of the hospice patient and his ability to control the flow of information:

My brother posted on Facebook that my dad was ill and all these people started coming out of the woodwork to visit my dad. People that my dad really didn't want to see. –P17

In other cases, the posting of private information within Facebook's relatively public and general-purpose space caused discomfort for extended family members who received upsetting news at an unexpected place and time:

When my father-in-law passed, all my nephews and nieces on that side of my family, there's a ton of them, and everybody's on Facebook and one of them actually said, "Rest in peace, Grandpa." All of them hadn't been told yet and it created a horrible, horrible family fight. –P07

This is not to say that all social networking experiences were negative. In some cases, they were successfully harnessed to support feelings of connectedness:

Like a year ago I set up like a Facebook group for our family, and this is us putting status updates, and then letting us comment on each other/them. It's increased the amount of communication my family has 10 fold. This Facebook group with my family has recreated intimacy... it's a space I have where I actually can perform the role of [a] "brother", "son", "brother-in-law", "uncle", effectively. And I can only imagine that had my grandmother had access to this, or had she been participating in this, that [it] would have had a different kind of impact... –P02

DISCUSSION: REVISITING COMFORT

As our results suggest, participants were continually in pursuit of comfort in the hospice setting, but this notion of comfort is far more than merely the reduction of pain for the patient. While the hospice setting highlights the pursuit of multiple types of comfort, we must bear in mind that comfort is something that we are always in pursuit of in all social situations. In almost all everyday encounters, we seek to avoid conflicts and pain; the hospice setting provides a unique, instructive lens onto these issues. With this in mind, we remark on how comfort might be more productively unpacked and reconsidered in the context of designing interactive systems.

First, comfort is multidimensional and continually produced. While we often talk about “giving comfort” to others as if it is a commodity that can exchange hands, our work suggests that comfort is better understood as a state that is actively produced and pursued by all involved in the hospice setting. It is not a thing, but a repeated set of actions. Comforting acts are undertaken again and again—medication is given, a meal is shared, a favorite TV show is watched, a mother consoles a crying daughter with gentle words, a hand is held—but none of these actions alone are equivalent to the lived experience of comfort. There are endless forms of such compassionate or pain-reducing acts that one may perform, and they are contributors to comfort, but it is the concerted and continual undertaking of these actions that gives rise to a larger, more effable sense of comfort in the hospice environment. It is in this spirit that we must consider technologies for hospice care, where the technologies allow new or varied actions to take place, but bearing in mind that these technology-mediated actions must be subsumed into a more holistic and sustained effort in order to be eventually recognized as comfort.

Second, the achievement of comfort involves multiple, and non-obvious, stakeholders. Returning to the phrase “giving comfort,” we often think of the dying patient as the recipient of this gift and the healthy as benefactors. Our work suggests that patients are much more active and vital to the production of comfort than traditional medical models might suggest. For example, the patient may selectively hide potentially damaging information, or lie about the severity of pain, to make the young and healthy feel less uncomfortable. Family members may be complicit in this act; we may have a child talk to their grandparent on the phone to spare them the pallor and frailty that a face-to-face visit would reveal. While first steps to improve a sense of comfort in hospice might involve technologies that are designed for caregivers to provide for their dying loved ones, it may also be helpful to consider technologies for use by the patient that could enable them to more fully comfort those around them. Further to this point, comfort is something that is sought after by an extended network of family and friends. Family members might comfort one another, or a caregiver might try to comfort herself. While providing comfort to the patient will always be a central

concern of stakeholders in this setting, some technologies for producing comfort in hospice may actually have little to do with the patient, but instead focus on the experiences of friends and family.

Finally, achieving comfort is not a process that is limited to the people in the hospice room at a given time; people work to produce comfort in the future, and to produce comfort in places beyond the hospice. Patients would often speak about post-mortem arrangements, ensuring their estates were cleanly divided, that funeral costs were covered, and so on. In this sense these patients are attempting to temper future financial or emotional pain for their loved ones. Because a death is painful but unavoidable, patients exerted control and asserted their personhood by exercising their abilities to minimize avoidable pain. This was not simply on the part of the patient, however. Family members remarked on how some of the most uncomfortable conversations—those ridden with conflict, or those that touched on mortality and death—were the ones that ultimately produced the greatest comfort down the road. Thus, there is no simple path to comfort. Actions causing ephemeral discomfort may be undertaken at one point in time, to create more durable forms of comfort later on. This again ties back to the multi-dimensional nature of comfort: some forms may be mutually exclusive, and not all discomfort can or should be avoided. As we also saw, participants sought to provide comfort to those who were not physically present in addition to those who were. Family members who had demanding work schedules and children were seen to be important stakeholders, but because their commitments or maturity did not permit them to be present, the process of creating comfort had to extend out to them and meet them on their own terms wherever possible. Comfort, therefore, is not simply a property of objects or an environment (e.g., as in a comfortable bed, or a comfortable temperature). Rather, *comfort is a mutually, continually produced state that arises out of a wide variety of actions performed by multiple stakeholders over a long period of time and despite distance*. The upshot of this argument suggests that technology can play a vital role in the production of comfort in hospice, given its unique capabilities to connect human actors across time and space.

OPPORTUNITIES FOR DESIGN

Building on this discussion, we now provide more grounded and succinct design recommendations that are derived from our findings. We anticipate that these recommendations would be helpful not only for designers targeting hospice environments, but additionally for those designing for end of life circumstances more generally.

Information seeking and communication: Because participants felt that admittance into hospice occurred suddenly, they had little idea of what to expect. Participants expressed the desire for better education regarding the dying process in general and administrative procedures governing their loved one's admission into hospice: a role

they attributed to the professionals responsible for their loved one's prior treatment and hospice organizations that received their loved ones after the cessation of treatment. Thus, it is unlikely that prospective caregivers would seek out ICTs designed for end-of-life settings independently and preemptively.

Hospice is not the time to introduce new interaction paradigms: Hospice patients typically experience a reduction in their cognitive and physical abilities that would impede the learning and use of unfamiliar technologies. Moreover, learning a new technology is unlikely to be a top priority for hospice patients. This is not to say that new technologies cannot be designed for this setting or that they cannot be innovative; however, the success of a technological intervention will likely hinge on its ability to leverage familiar metaphors and known technologies to control new interactions.

For inspiration in this regard, we can turn to existing design work, such as that done by Blythe et al. [2] to support ludic engagement in residential care settings. In this work designs were introduced to encourage engagement and interaction among residents and across generations, but none of these designs required computer literacy on the part of older users. Similarly, the Photostroller [12] demonstrates how technology can be designed to spark engagement and interaction with a computational system with minimal demands on the user. As a final example, Petrelli et al. [35] used an old fashioned radio as an interaction paradigm for browsing sonic mementos from family vacations. One could imagine adopting a similar metaphor to enable hospice patients to access relevant audio streams, such a pre-recorded messages from loved ones.

Designs could also strive to take advantage of the blurred line between treatment and hospice care to introduce technologies as early as possible, thereby enabling them to leverage earlier learning while slowly adapting to the evolving needs of the patient.

Life-affirming technologies can help provide emotional support: Novel ICTs designed for end-of-life care settings need to be life affirming while at the same time guiding caregivers through the dying process of a loved one. By life affirming, we refer to technologies that focus on the patient's capabilities and opportunities for continued interaction. For example, designing technologies that allow people to achieve their own sense of comfort (thinking here of the cordless phone or fireplace remote control) may be particularly effective. Leveraging existing modes of producing comfort, such as shared meals, conversations, TV/radio shows, favorite activities, and connections to home may also be fruitful. Support for sharing provides a rich space for design to explore, and as our participants revealed, the items shared are often of less significance than the simple act of sharing itself. Technologies along these lines can also look at supporting emotional needs. Our participants described experiences that went beyond

conversation to feelings of just being together, and technologies could enable these experiences for those who cannot do so face-to-face.

Returning to the family radio example above, one could imagine linking homes such that a hospice patient could enjoy the sound of familiar routines (e.g., the start of the coffee maker, the running of the shower, the morning news over breakfast), while family members receive a reassuring soundscape of activity from the hospice. Privacy concerns would of course need to be addressed, but techniques such as audio distortion could be employed to provide a sense of connection without revealing unnecessary detail. CSCW research on long-distance couples has revealed openness to this sort of sharing within intimate relationships [30].

Supporting conversation: Designers might consider conversation in two ways: the ability to have one, and the topics that might be discussed. Because alertness and cognizance decline over time, technologies should accommodate changing levels of activity on the part of the patient. Similarly, asymmetry in media richness and availability is a resource for design; hiding the sensual aspects of being in hospice might allow family members to re-experience their loved one as they once were, or allow children who are deigned too young to visit, an opportunity to talk to their loved one. Technologies that help support or guide individuals through interaction (thinking here of the book of questions used by P07) could be potentially helpful for encouraging conversations of the type that family members expect. Alternatively, technologies could focus on bringing in aspects of the outside world to spur conversation or could capture and maintain elements of each visit upon which subsequent visitors could build.

In this vein, we may also consider technologies to connect larger conversation groups. Rather than envisioning video calling as a one-to-one connection between the hospice patient and a remote loved-one, it may be fruitful to explore it as a means for bringing a larger group of remote and co-located visitors together in the hospice room. Used in this way, the patient him or herself need not be capable of managing the technology, and the technology could support communication by reducing (1) the pressure on each individual visitor to sustain conversation topics, (2) the pressure on the patient to participate in conversation when s/he may only have the energy to listen, and (3) the awkwardness of one-sided conversation by offering a more dynamic multi-way interaction.

Coordination support: Technologies should be employed selectively and delicately in spreading news and coordinating care. For example, email was valuable for its asynchrony and ability to target specific people. Social networking sites offer many features that could be helpful, but existing ones might not be the right setting for the types of conversations that hospice entails. In particular, conflict seemed to arise from the sharing of sensitive and private end-of-life information on public and blithe forums such as

Facebook. Dedicated systems do exist. For example CaringBridge provides a suite of tools for sharing information, coordinating care, and connecting with others, but no one in our sample used (or seemed to have any awareness of) such tools. This suggests an interesting tension: whereas individuals are unlikely to appropriate new technologies during the disruptive transition to hospice care, end-of-life interactions seem to require a dedicated private space.

Coordination of care has been explored in related domains. For example, Consolvo et al. [9] developed CareNet an ambient display to help the members of an elder's care network coordinate day-to-day care. This display enabled individuals to quickly assess the elder's condition and to monitor events (such as medications, meals, activities, mood, falls, and calendar) to determine whether or not assistance was needed. Similarly, the Digital Family Portraits project sought to enable individuals to remotely monitor the status of an elderly individual [28]. Future research could examine the ability of such systems to meet the needs of individuals in hospice care.

LIMITATIONS

There are a number of limitations to this study that should be noted. Firstly, our participants provided retrospective accounts based on past experiences; in some cases these experiences were quite distant (up to 10 years). Recruiting individuals willing to revisit this period of their life proved difficult, requiring us to be flexible in our inclusion criteria; however, the span of our sample does mean that some details may have been forgotten or modified over time. Encouragingly, caring for a dying loved one appeared particularly salient for our participants; only seldom did a participant indicate forgetting a detail. Secondly, our participants tended to have somewhat above average education levels. This can be at least partially attributed to our recruiting process (which relied heavily on snowball sampling, and also included postings on a university campus). Thus, our results may not fully capture the range of experiences that exist in the population at large. Thirdly, of our 16 interviewees, 10 reported little or no technology use in the hospice. While this is a true representation of our participants' experiences, it may be interesting to contrast our findings with a more technologically-oriented sample. Finally, our interviews captured almost exclusively the point of view of primary caregivers. We felt this was a good starting place for the research; however, additional perspectives are needed to build a holistic picture of the technology use in this setting. Future work could enhance our understanding with accounts from hospice workers, and terminally ill individuals themselves, as well as with more detailed accounts from secondary and tertiary caregivers.

CONCLUSION

We have discussed here the ways in which family members of patients in hospice care view their activities in the hospice setting, and found that the pursuit of comfort was a

consistent theme. In achieving comfort, participants remarked on the barriers that they faced, such as difficulty coordinating visits, declining levels of participation on the part of the patient, and the emotional challenges associated with the dying process. While technology was seen as somewhat alien to this process, participants described evocative scenarios where selectively-chosen ICTs allowed them to provide and coordinate support, and reflect on relationships with their loved ones. Our findings suggest that technologies that are designed for hospice should support conversation, coordination, remembrance, and life-affirming activities. At the same time, the hospice is a challenging setting to introduce new technologies, and focusing on well-established interaction paradigms may be effective in early system designs. Our future work will entail a series of design sketches that address some of these needs, with long-term work to include a potential deployment and evaluation of our designs. This work highlights the opportunities for technology to aid families in their pursuit of comfort before, during, and after their encounters with the hospice setting.

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