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**Formal and Informal Messages: Early  
Reflections on How Context and Content  
Influence ICT Use at the End-Of-Life**

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**Abstract**

For dying individuals, communication with friends and family is an urgent need; however, little is known about

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how technology is used in this situation. Family and friends of former hospice residents were interviewed to develop a better understanding of ICT use in hospice, palliative, and end-of-life home care settings, and of how ICT can improve presence, communication, and quality-of-life experienced by hospice residents and their caregivers. In this paper, we provide a preliminary reflection on how participants define particular forms of information as formal or informal, and how this influences their (non)use of ICTs while managing care.

**Author Keywords**

Hospice, palliative care, end-of-life, formal and informal communication, communication technology, Internet use, mediated communication, family communication

**ACM Classification Keywords**

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

**General Terms**

Design, Human Factors.

**Introduction**

Entrance into hospice care marks withdrawal of active medical intervention aimed at curing potentially fatal medical conditions, to instead “provide a dignified, comfortable death for the terminally-ill and to care for the patient and family together” [5]. Admission into end-of-life care—an umbrella term encompassing hospice residences, palliative care facilities, and agencies that provide home-based care services for

### **Kinds of ICTs Available**

*"Ah, in the hospital? I'm going to take a wild guess and say none? I don't think... I mean she would go up there with her laptop but there was no access to the Internet in the ward, or the hospital. [...] There was telephone in the [chemo] ward and it was always on her lap. She practically owned it. As far as upstairs in the palliative unit, there was one in her room but I don't know if they actually paid for service because everyone had a cellphone."*

*- P12 (low availability)*

*"I believe she had her laptop with her just for just personal use. And I know they had, previous to the isolation [for an antibiotic resistant staph infection], she had access to a computer during the experimental therapy when she was an inpatient. They had a computer lab on the floor and emails she would send me and look things up, stuff like that. But her personal computer while in isolation, [I] don't think she had access to WIFI."*

*- P04 (high availability)*

terminal patients—can be an exceptionally stressful time for caregiving family and friends, who seek to provide for the physical, emotional, and social well-being of an ill loved-one, in addition to their own needs.

Questions about when and how to best implement ICTs into the directed and self-care of hospice residents are unresolved in the current literature. Research has focused on better understanding the current needs and capabilities of key stakeholders in end-of-life care, with a primary emphasis on telehealth, or in this case *telehospice*, technologies (for an overview, see [4]).

Meta-analysis of Internet use by hospice families has highlighted many of the difficulties evaluating and validating use in this setting. The short lifespan of hospice residents and hurdles to learning new technology near end-of-life underscore the challenges ICT researchers face when designing and validating technologies for hospice residents [6]. Buis explored the use of a free online support community by hospice caregivers and found it was mostly used for informal emotional support and sharing personal experiences, rather than formal information seeking [3].

More recently studies have begun to report on the use of Skype in hospice and palliative care settings for the purpose of connecting residents with family and loved ones [1, 2]. While these case reports largely exult the many benefits and opportunities offered by video to support diverse communication needs, concerns persist surrounding privacy and technology access. A broader understanding of the challenges and benefits of ICT use

in this domain would help clarify where development effort would be best placed.

In this paper, we present preliminary findings from 12 in-depth interviews with the family and friends of former hospice residents. Participants were recruited through word of mouth, partnerships with Canadian hospice organizations, and flyers in the Montreal area. They were asked about the strengths and challenges they experienced using information communication technologies (ICT), including personal computers, smartphones, and the Internet, to manage care and enhance the quality-of-life of their late loved-ones.

The primary intentions of this paper are 1) to reflect on the current availability of ICTs in end-of-life care settings in our sample; and 2) to examine accounts of how the formality of message content changes based on context; particularly when considering geographic proximity, effort, and the quantity of people in close contact within a hospice resident's given extended social network. In the left sidebars of this paper, we present a small selection of representative quotes to help set the context of this work.

### **Emerging Themes**

#### *Low In-House Accessibility of Most ICTs*

We found that many family members and friends described their loved-ones as technologically savvy prior to their admission into end-of-life care, yet ICTs, and especially Internet-enabled ones, were not readily available in the majority of their hospice and palliative care settings.

### **Most convenient types of communication technology**

*"I'll tell you by medium? Maybe that it will easier. So in [SMS] text, it is very day-to-day, like "right now, the doctor is coming" or "wait two hours, doctor will be here" and then we know what it happening. So it is very out by the hour. Um, phone is... usually we just called when it is an emergency because in the hospital, you can't really talk freely. You know, because it is all silence and there are all these other people. You have to go out if you want to talk-talk. Um, and of course in front of the patient as well, we think it is really rude to be on the phone so it would just be easier to be texting, you wouldn't even really notice compared to the phone. So no phone was unless there was some serious emergency. And email is for thorough communication. Like, our emails are very long, like "this happened and then that happened". Oh and we'd scan and send [medical] reports."*

- P06

Only 3 out of our 12 participants recalled Internet and public computers being available to hospice residents. However, two of these participants were exceptional in other ways as well: one received end-of-life care in a non-typical setting as part of a cancer drug clinical trial (see quote from P04, pg. 2), while the other received care in a daughter's home.

The low availability of ICTs for patients and family in hospice meant that many participants had little opportunity to use ICTs in situ but many did use their own technology when possible. However, over time accessibility became an additional obstacle. Participants recalled how their loved ones made use of personal laptops and cellphones in the hospice setting for a time but as they entered into later phases of the dying process, physical and cognitive limitations resulting from their conditions and/or medication became significant barriers to the continued use of ICTs.

#### *Face-to-Face or Mediated?*

Family and friends in caregiving roles reported their own steady use of ICTs to mediate and coordinate the dissemination of updates on their loved-one's health and coordination of visits within extended social networks of family and friends. Consistently, family and friends preferred face-to-face interactions with loved-ones in hospice over mediated forms of communication. For most participants, ICT cannot replace the physical presence and directness of being face-to-face. One participant described how simply holding her mother's hand while watching television communicated more than any conversation they had prior to her passing.

Furthermore, many participants travelled great geographical distances for the opportunity to spend face time and talk with their loved ones. Yet another preferred the mediation of SMS-texting: for her, the limited richness helped mask the effects of her mother's illness allowing her to briefly feel like she had her mother back (see quote from P04, pg.4).

#### *Formalizing and Informalizing Communication*

Use of ICT was preferred for coordinating care and overcoming temporal and geographical obstacles within extended social networks. Participants positively evaluated the use of email and text messages for sharing announcements and updates *en masse*. They viewed such announcements as quick, easy, and of high quality. Email formalizes communication within social networks and allows updates to be delivered more frequently and/or completely compared to other ICTs. Formalization enables social networks to communicate frequently and mobilize people and resources.

Information that was seen as emotionally sensitive, such as the death of their loved one, was most often delivered using the telephone. The phone was seen as immediate and personal. The formality—or significance—of announcing a passing warranted the time and effort required to reach people individually and directly. However, the location of the conversation partner within a given social network affected whether the delivery of this news was formalized or not. The task of calling persons located peripherally within a family network (i.e. extended relatives, past friends, etc) was often delegated to persons located more peripherally within

**Most convenient types of communication technology (cont.)**

*"If there was something everyone needed to know, it would be email because you could tell everyone in a one message, both because we're large and spread out... there are some things [you] don't want to deliver by an email message but even then, if it was something everyone needed to know right away, that was the fastest way to do it because there was five kids."*

- P08

*"A lot of the conversations we had in the clinical setting were about her speculating about the cause of her illness... it never felt like I was talking to my mother but then the text message she would send me really did... they weren't ever really about her illness; they were just about her and I."*

- P04

their social network after core members of the network were reached. Participants preferred to contact close family members and persons highly involved in the end-of-life care directly, either by telephone or in person in order to break the news and provide emotional support.

*Imagining an Ideal ICT for End-of-Life Care*

Participants made several suggestions of how current and emerging ICTs can further support these communicative functions. The integration of video in cellphone and computing devices was seen as positive, allowing participants the potential to monitor their loved ones remotely or enable family and friends to communicate across large geographic distances. Several participants also expressed concerns that the end-of-life is not an ideal time to learn how to use a new technology for both hospice residents and persons within extended social networks. Acquiring and learning a new technology was perceived as adding expense and stress to an already difficult experience.

**Conclusion and Next Steps**

Our current data highlights how the content of messages and the amount of effort required to communicate that message affects caregivers' decision to use any particular ICT. Most importantly, our current data underscores the importance of context when considering ICT use, in which the low availability of the Internet in hospice limits participants' opportunities to integrate ICTs into their loved ones' last moments.

The preliminary reflections cannot be generalized without caution due to the small sample sizes and some

atypical care settings reported. Our next steps will be chiefly directed at collecting sufficient data to help untangle the complex interactions between context and content to better understand how they influence ICT use. At present, we have interviewed 12 participants, 40% of our qualitative target sample (of 30 participants). In addition to extending our interview sample, we are currently developing an online web-survey. This web survey will supplement our small qualitative sample size and provide baseline figures for how families use ICTs near the end-of-life. Our long-term goal is to use the findings from this work to develop novel communications technologies to support the unique needs of this environment.

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