

# UNDERSTANDING AND REDUCING ISOLATION DUE TO CHRONIC PAIN

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## ABSTRACT

As digital communications technology becomes increasingly common in households, it is vital that such technology be responsive and accessible to the needs of seniors who have chronic pain and, because of this, are often isolated. Our research goals are to understand the communication patterns and needs of these individuals and to develop technology that facilitates communication and interpersonal support for them. We report on preliminary results of a study with 20 seniors and field testing of a digital communicating picture frame prototype. Synchronous communication can pose unique challenges to people with chronic pain, which suggests new opportunities for the design of technology to combat isolation.

## INTRODUCTION & BACKGROUND

Social contact promotes health and well-being in seniors [1], yet much communication technology with the potential to facilitate contact is designed for younger people [2]. Moreover, most research concerning family connectivity does not consider the needs of families where one member is isolated because of chronic pain or loneliness [3]. Through field work and technology development, our research asks: (1) how does chronic pain and/or isolation mediate participants' communications with family and friends, and (2) how can communications technology be designed to be responsive to the needs of people with chronic pain?

Chronic pain, typically defined as pain that persists after an injury has healed or as pain that lasts longer than 6 months affects 38% seniors living in institutions and 28% of seniors living in households in Canada [4]. As a usually lifelong, systemic disorder, chronic pain is different from acute pain, which has identifiable

causes and is more commonly understood as treatable. Because chronic pain is incurable, the goal is to manage the sequelae of this degenerative dysfunction, which includes high rates of depression, anxiety, sleep disorders, and increasing loss of functionality, mobility and social contact [5]. Objectively, isolation refers to physical separation [6] and amount and frequency of social contact [7]. Subjectively, isolation refers to loneliness, a state of perceived separation and being alone that is usually negative or unwelcome [8]. Objective and subjective isolation are prominent features of the chronic pain experience [e.g., 9, 10]. This is cause for concern given isolation's association with poor health outcomes [e.g., 11].

However, social contact promotes positive health status [e.g., 1], and we want to build technology with this result in mind. Research such as the Family Window [12] and Digital Family Portraits [13] support valuable communication and peace of mind for family members, yet these projects do not consider the benefits of asynchronous communication or promote autonomy of older adults, respectively. To encourage use by family and friends, communication systems should not impose extra responsibilities [14], as many feel that they are already "too busy" to communicate or share [15]. With these considerations in mind, we aim to encourage effective communication that leads to reduced feelings of isolation in people with chronic pain.

## STUDY DESIGN

To identify existing communication patterns and needs, we conducted an interview study with 20 community-dwelling seniors aged 60 and older living in Toronto and Vancouver. Participants were recruited via fliers, snowball sampling, and a pain clinic. Interviews lasted

50-120 minutes and followed a semi-structured protocol. Data was analyzed using Grounded Theory tools [16]. Inclusion criteria was living with chronic pain (n=20) and being aged 60 or older.

In parallel, we created a digital communicating picture frame prototype and deployed it in two households (P7 in one household, P2 and P3 in another). The device consisted of a touch screen computer fitted inside of a wooden picture frame. The device displayed a picture of the frame owner's family or friends. When the frame was touched, an email was sent to those in the picture, encouraging them to log on to a web site to send a video to the frame owner. When the video arrived, the owner was notified and touched the screen to watch it. The picture frame deployment lasted for two weeks, with interviews conducted at its baseline installation and at the conclusion of the study.

## **RESULTS**

We report here on where chronic pain specifically disrupted communication routines, lowered perceived quality of social contact, and introduced barriers to face-to-face and synchronous contact. We also summarize the results from initial testing of the picture frame, including its use and reception by three participants.

### Participants

A total of 16 women and 4 men were interviewed. Average age was 73.8, and average time living with pain was 19.3 years (minimum 2 and maximum 47). Slightly less than half (9) lived alone. A variety of conditions that cause pain were reported (including osteoarthritis, neuropathic pain, fibromyalgia, diabetes, and post-surgery pain) with one participant lacking a diagnosis. Half reported feeling socially isolated.

### Limitations

Results presented here focus on isolation related to chronic pain itself and omit discussion of how other factors (e.g., death, moving residences, retirement, social stigma around chronic pain) mediated communication. Our participant set, while diverse, is not a

representative sample. Because of our reliance on interviews, the possibility exists that some participants did not adequately represent their communication habits.

### Intermittent pain and social routine

All participants with chronic pain described its intermittent variability in terms of when pain occurred, whether pain could be controlled, and in some cases what conditions caused pain. Despite pain modulation strategies (e.g., taking analgesics; regular physiotherapy, exercise, and mediation), times where pain is less controllable still occurred. For seven participants, a consequence of variable or episodic pain was disrupted ability to take part in routine, scheduled social activities. P7, a 78-year-old widow with fibromyalgia, notes:

My friends are built around activities and [the activities] are getting harder to do. I lost a whole group of people... I've felt anger, because I could no longer go on the biking trips, have them over for dinner, and I don't know why but it just fell by the wayside and that really bothers me. My contacts, when I realize they're through activities, then I have to figure out how to keep in touch with them... (P7)

Diminished ability to take part in regularly scheduled activities means losing the temporal and social scaffolding around which friendships are maintained. Two of the seven participants who had difficulty with maintaining routine unwittingly lost employment because of chronic pain and reported similar losses of social contact.

Chronic pain did not unequivocally disrupt social routines. All but one reported having established calling schedules to interact with friends and family members. Eight reported they were able to do scheduled activities that were less physically-intensive (e.g., attending lectures or seniors' centres). Two maintained restorative routines (e.g., of mindfulness meditation, yoga, or physiotherapy) designed to manage chronic pain. It appears that social activity type, impairment related to pain, and individual circumstance played a role in how and whether participants maintained social routines.

### Chronic pain and perceived quality of contact

Half of participants reported that chronic pain mediated perceived quality and satisfaction of communication. Thus, on “bad” days, low mood, and difficulties understanding content, saying “no” to contact, or having long interactions could arise. Of this group, five said they were reluctant to see people face-to-face, other than their spouse or caregiver, for similar reasons.

By contrast, 10 felt pain did not affect quality of contact over the phone, email, or face-to-face. This suggests that for some, satisfying interactions were a function of quality of relationships. It may also reflect the fact that, since most participants had had pain long enough for it to become a “normal” feature of their life, their ability to cope with pain was such that pain did not affect perceived quality of contact.

### Challenges of synchronous contact

Decreased mobility can be a consequence of aging, but chronic pain introduced additional challenges to having synchronous contact. For slightly less than half of participants (8), limited mobility due to impairment, difficulty staying seated, or lowered energy meant both having visitors and travel for the purposes of face-to-face contact was becoming more difficult.

While some participants (3) who experienced decreased ability to leave the house reported an increased reliance on the phone since the onset of chronic pain, eight said their use had remained constant. Obvious circumstances for use included times where face-to-face contact was impossible (e.g., because of decreased mobility) or when a contact did not own a computer. Use of the phone was seen as particularly valuable for tasks that had an urgent temporal dimension. For a minority of participants (3), form factor and the synchronous nature of the phone was a barrier to sustaining longer conversations or answering the phone during times of severe pain.

### Digital Communicating Picture Frame

For the initial testing, participants used the frame to receive videos from their family members. P2 and P3 used the frame to

complement phone conversations during which videos would be discussed. P7 developed a routine around the frame where she would touch the frame in the morning and wait for messages by the end of the day. She felt comfortable doing this because there was no expectation for there to be an immediate response; that is, her relatives could respond on their own time and she could get messages when she returned home in the afternoon.

The limitations of the device did not take away from the overall experience of using the frame. For example, volume was an issue for P2 because she was hard of hearing, but seeing the videos was still satisfying. Despite its limited functionality, participants appreciated the frame’s ease of use. As P3 explains:

The best thing because instead of Skype, you just have this small thing that you press and there you go... For somebody like me who’s very lazy to do all kinds of things on the computer or Skype or whatever, this is for me. (P3)

Overall, response was positive, and pilot participants were vocal about potential frame features and contexts of use.

## **DISCUSSION**

The challenges intermittent and episodic pain could pose to maintaining synchronous and regular contact suggest new opportunities for design. Preliminary results from interviews and field testing with the frame suggest that communication methods that afford for asynchronous contact may be suitable in situations where an individual desires limited contact but is unable to meet face-to-face, over the phone, or on Skype. As an asynchronous tool, the frame lent itself to limited interaction on the owner side. Family members also found this useful, because they were able to respond to a request from the frame in a manner that was not time-sensitive.

While we think an asynchronous tool could be sensitive to the needs of people experiencing isolation and chronic pain, we also note some potential drawbacks of this approach. Such a device could discourage both mobility and synchronous connection by family and friends. Greater device accessibility, ease

of use, and frequency of communication will not necessarily lend itself to reduced isolation [8]; nor will it “cure” the social barriers and stigmas people with chronic pain must negotiate [17].

### **FUTURE WORK**

The results from the interview study and the frame’s deployment are being used to assist in designing the second version of the picture frame. One new feature will be the customization of the message being sent by the frame owner as well as who the message is being sent to; that is, if the owner touches the picture of their son, a message is only sent to him instead of everyone [18]. The web site will also be updated, adding new affordances for friends and family members to send back content.

Further studies will be conducted in institutional settings (hospitals and nursing homes), with those living alone, and with caregivers. We will complement interviews with a diary study where patients can record their communication habits as they happen. We also want to assess which members of participants’ social networks are most involved with using the frame, whether there are improvements in health for the frame owner, and how family and friends are affected.

### **CONCLUSION**

Chronic pain brings about unique communication challenges that can lead to social isolation. Our research suggests an accessibly designed, asynchronous tool will be useful to seniors with chronic pain who face communication barriers. We envision such a device playing an important role in bridging geographical, social, and technological distance and in enhancing well-being.

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