

Impression Management Work: How Seniors With Chronic Pain Address Disruptions in Their Interactions

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ABSTRACT

Chronic pain is an illness that affects nearly a third of senior citizens. Uncontrolled chronic pain can manifest constantly and/or intermittently, and can disrupt seniors' ability to plan or to maintain synchronous and scheduled contact with others. Such disruptions can expose seniors to stigma from others who do not understand this illness, social isolation, and a range of challenges to their social autonomy. We present results from an interview study of 27 seniors with chronic pain exploring how they mitigate and manage these disruptions in their lives. Drawing on Goffman's theory of impression management, we found that participants invested significant effort into controlling both the context of interactions and others' expectations, in order to mitigate the potential negative social consequences of disruptions. In performing this work, seniors were selective about what information they revealed to others about their chronic pain and availability. Given such efforts, seniors with chronic pain have unique needs for technologies to support their social interactions.

Author Keywords

Chronic pain, interaction, awareness, impression management, accessibility.

ACM Classification Keywords

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

INTRODUCTION

Chronic pain is a condition that affects nearly a third of senior citizens [11, 24]. In addition to causing significant discomfort, as a degenerative disease, chronic pain can constrain mobility and can cause unpredictable disruption in the everyday interactions and events that keep seniors active [20, 24] and help them avoid social isolation [30]. Seniors with chronic pain, moreover, have unique needs for communication and social coordination that are often not adequately met by current technologies, and are distinct from many existing technologies designed for seniors (e.g., [21, 25, 26]).

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CSCW'12, February 11–15, 2012, Seattle, Washington, USA.

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Chronic pain is defined as prolonged or persistent pain that lasts for 3 months or more, or pain that persists after an injury is healed [12]. As an illness, chronic pain is distinct from acute pain, which is more widely understood as a symptom of a treatable injury or disease. Estimated to affect 27-28% of non-hospitalized, non-institutionalized seniors [11, 24], chronic pain's medical consequences include depression, anxiety, sleep disorders, and progressive loss of functionality and mobility [12]. There is often no visible sign of the work people with chronic pain and their caregivers put into its management [28] and they may face barriers accessing health care and social support [9, 19].

Since chronic pain can manifest intermittently, constantly, or both, disruption of routine scheduled events and interactions can be the norm for seniors with the illness, especially during times of intense pain [24, 30]. Moreover, the disruptive nature of chronic pain can constrain availability for interaction [20] and introduce occasions where those with the illness have to take deliberate steps to avoid negative social consequences, including exposure to stigma and misunderstanding [19].

Unlike others who commonly experience disruption in social events – such as on-call medical professionals who may be summoned to an emergency at any moment – sufferers of chronic pain cannot rely on visible or role-based sources of legitimacy in extracting themselves from a social situation. Rather, their pain symptoms are invisible and may not always be perceived as legitimate (e.g., [32]). Seniors with chronic pain may desire interactions and activities with others, but frequent disruptions due to their condition can threaten their ability to remain regularly active. We know little, however, of how seniors with chronic pain are able to do this and how we might better support them in these efforts.

In this paper, we present an interview study of seniors with chronic pain, with an eye toward improving the technologies available to support the social interactions that are critical to their everyday lives, but which are under constant threat of disruption. We argue that living with chronic pain requires vigilance in impression management that has consequences for how seniors interact and live their everyday lives. Decisions about behaviors that deliberately or inadvertently reveal or conceal information related to

one's ongoing and current condition play a central role in preventing or mitigating the effects of disruptions caused by chronic pain.

BACKGROUND AND LITERATURE REVIEW

Novel technologies have substantial potential for providing support to individuals with chronic pain. Recent work, for example, has explored the use of immersive virtual reality environments which can have analgesic effects on acute pain [16], and which show promise in treating and managing chronic pain [14].

Another area for potential impact that has not been explored to a great extent is how novel communication technologies might support seniors with chronic pain in their interactions with others, which occur primarily outside of clinical settings (a similarity chronic pain shares with other chronic illnesses (e.g., [1, 7])). These interactions are important because they provide seniors with a critical connection to others, but occur under conditions that are uniquely constrained as compared with others seniors or those living with other chronic conditions.

Aging With Chronic Pain vs. Aging in Place

One point of distinction we wish to make at the outset of our discussion is that the needs of those with chronic pain are unique in many respects, and present challenges that are importantly distinct from prior work on systems for seniors aging in place. That work (e.g., [21, 25]) addresses how aging adults can retain their independence and live in familiar settings as their healthcare needs change. Many seniors do age in place with chronic pain, but our focus is on the unique needs of those with chronic pain, and the overlap is not complete. We first highlight the overlap and common experience.

In terms of similarities between aging with chronic pain and aging in place, both populations face constraints on mobility and other physical activity, and may face situations where interactions with others are difficult [24, 25]. Another similarity is that both populations often live independently, but have frequent contact with others. In the case of seniors aging in place, a shared understanding of routine activities and rhythms can play a key role in communication with others, such as loved ones, caregivers [3] and senior citizen peers [25]. Daily phone calls and regular visits allow for necessary interaction, social support, and some privacy, and the disruption of these routines can serve as a signal that something may be amiss.

The case of chronic pain is unique in two key respects. First, aging is a life process that carries with it an expectation of the need for care and attention. Chronic pain, by contrast, is an illness that introduces challenges to quality of life that are above and beyond changes associated with increasing age [12, 17, 24]. Compounding such challenges is the fact that chronic pain often lacks visible symptoms that signal the need for attention, validate a senior's subjective experience, or create expectations of the

need for their care - unless the senior chooses to reveal this information and/or ask for help (e.g., [8, 20]).

Second, aging in place lends itself well to routine activities, and disruption of these routines (e.g., failing to make a daily phone call) can be a signal of major problems. The nature of chronic pain, in contrast, is less predictable. Seniors with chronic pain often desire active social lives, but their activities are often disrupted (or prevented from happening in the first place) when episodes of or consistently intense, uncontrollable pain occur.

During these periods of pain, those with chronic pain may be prevented or inhibited from communicating with others in routine or usual ways. For example, pain can temporarily introduce bodily constraints that slow down the speed at which activities or interactions can happen, restrict one's mobility [20], negatively affect one's mood [8, 12], and interrupt ongoing thoughts and physical tasks [10].

Consequences of revealing and concealing pain

These unique properties of chronic pain can mean that there are frequently times in interactions or potential interactions when seniors' behavior deliberately or inadvertently serves to reveal or conceal that they are experiencing pain. The consequences of such behaviors can be nontrivial. Evidence suggests that revealing symptoms of pain can result in possible social isolation and the stigma of negative perceptions by others (e.g., [9, 32]). One reason for this stigma is that chronic pain has only recently been recognized as an illness in and of itself, but this status is not widely recognized, including by many health care practitioners. As such, revealing pain can be met with blame or misunderstanding. At the same time, however, concealing that one is experiencing pain completely can mean the inability to discuss one's experiences with others and that others have unrealistic expectations that cannot always be met.

One key reason underlying this tension between revealing and concealing symptoms of chronic pain is the causes and symptoms of chronic pain are often not visible to others as, for example, a broken limb might be. In some cases, this invisibility – and its accompanying fear of not being believed or taken seriously – has led patients to try to hide their experience of pain or to withdraw from otherwise achievable social interactions if they feel their pain will be called into question [8] or if they fear being blamed or labeled, for example as malingerers [12]. As such, fear of not being taken seriously can lead to attempts to hide pain, sometimes simply by withdrawing from social situations, which can in turn lead to further isolation as contacts may not be aware of what is taking place. In this way, both revealing *and* concealing chronic pain can be perceived to have possible negative consequences.

In addition to possible effects on their general availability and attitude toward social interaction, seniors with chronic pain also experience conditions that can impede their ability to plan and take part in these activities even when they do

not deliberately withdraw. These conditions complicate planning and introduce further situations where decisions must be made about revealing or concealing the details of their condition.

These conditions include medical realities such as pain that does not respond to treatment, problems with irregular and unpredictable sleep patterns, and co-morbid conditions such as anxiety and depression; and also difficulties that are non-medical in nature such as lack of social or caregiving support, misunderstanding, and financial strain [12].

In addition, mobility may be restricted, so patients very often experience travel as problematic, for example because of inaccessibility issues, or physical discomfort [20]. As such, they must decide whether or not to request accommodation or make special arrangements when travel is required to participate in a scheduled activity.

These potential threats suggest there can be much at stake when symptoms of chronic pain are revealed or concealed. Of course, it is also important to note that an illness' meaning in a given social world can mediate a person's efforts of what to reveal and conceal [1]. For example, some seniors may hesitate to talk about their chronic pain if they themselves or others have the expectation that suffering because of pain is a "normal" part of aging [9]. Finding medical care can be a problem (e.g., [8, 9]), and patients in such circumstances may have to exert significant effort into making their pain "real" and credible, revealing select aspects of themselves, for example, through attention to appearance or assertiveness strategies [32].

Impression management

So far we have seen that much is at stake in when and how pain is revealed to others. As chronic pain is not acute but rather is constantly and/or intermittently present, the points at which behaviors reveal or conceal symptoms of pain are not one-time happenings, but occur regularly over the course of conducting and planning interactions.

Chronic pain is subjective, and those who live without pain may not understand the degree to which it impacts the ability of people with chronic to maintain a full social, work, or volunteer schedule. Others may think that those with pain will be available on-demand or able to follow-through on plans. Still others may misunderstand or be unaware of the constraints chronic pain, for example, in terms of how it can color interactions of a patient, or in terms of the challenges seniors with chronic pain have to negotiate in order to accomplish interactions.

It therefore seems likely that seniors with chronic pain must make efforts, through behaviors that influence the expectations of others, towards managing and mitigating the ever-present possibility that disruption will be met with misunderstanding, lack of accommodation, and negative attitudes. We know little about how these efforts are currently accomplished, however, and how they could be supported via novel communication technologies.

These efforts may be understood making use of Goffman's [13] work on impression management, which offers a dramaturgical perspective on interaction. This work is underscored by a metaphor of actors operating on social stages, strategically shaping social interactions and others' impressions of themselves. Fundamentally, this is rooted in the notion of face; that is putting forward an image that is likely to be perceived in a positive light and mitigating the effects of possible threats to face [5, 31].

In the case of seniors with chronic pain, we can consider the act of revealing pain or symptoms of pain to be a potential threat to face, given the possible consequences that could cast them in a negative light. As such, theories of impression and face management tactics provide useful insight into how seniors with chronic pain reveal information and shape the context of interactions in ways that forestall or mitigate social disruption. There are two key respects in which this might be considered.

First, Goffman discusses behind-the-scenes tactics through which people shape the context and conditions of interaction in ways that are likely to reflect positively. This type of work is relevant here as it pertains to how seniors with chronic pain can use behind-the-scenes practices in advance of or during interactions to forestall or deal with the effects of disruption caused by pain and/or social factors (e.g., non-accommodative attitudes of others). Examples might include aiming to shape selection of the place, modality, and time of an interaction. Such efforts are invisible from the view of others, but may be critical to accomplishing interactions or maintaining the relationship in a positive light when disruption arises.

Second, steps may be taken to manage the expectations of others to avoid negative impressions or stigma resulting from disappointing them. Such steps may include explicit statements about the feasibility or viability of activities, or additional behind-the-scenes work to shape the context of interactions in ways that are likely to minimize disappointment.

METHOD

From the standpoint of those wishing to understand the experiences of seniors with chronic pain and design technologies to better support their day-to-day social interactions and lives, the present study aims to answer a series of questions.

First, prior work rooted in Goffman (and others) on the use of media in coordinating social interactions shows that people frequently draw on properties of their environment and the media they are using in selectively revealing information about themselves and their situation to others [2, 15]. We are interested in how seniors with chronic pain use known properties of media and of their environment to manage their impressions/social context.

Second, we are interested in how seniors make decisions about revealing and concealing aspects of their chronic

pain, the points at which they perceive these choices to occur, and their consequences.

Participants

For the present study, 27 individuals aged 60 or older were recruited from two large cities in North America. People who self-identified as having had chronic pain and who had experienced it for 3 months or more were eligible to participate. The other inclusion criterion was being able to speak and understand English.

Fliers advertising the study were posted in seniors and community centers, university alumni mailing lists, and distributed to chronic pain support groups. In addition, 10 participants were recruited by word of mouth, with help from the fourth author, from a pain clinic. The majority (21) of participants were women. Average age was 72.7 (SD = 8.2, range = 62-96). Average time living with chronic pain was 15.5 years (SD = 14.2, range = .66-47).

Data collection and analysis

Semi-structured interviews were conducted by the first author in-person (18) or over the phone (9). A standardized interview protocol was used that followed several broad topics: background and demographic information; social network structure and media use; interaction challenges; use of mass communication modalities; and the roles of loved ones and caregivers. Participants were encouraged at the outset of the interview to bring up topics not covered by the protocol that they felt they were relevant. Interviews took approximately 1 to 1.5 hours.

After the first 18 participants, the interview protocol was revised to reflect a clearer set of research questions that emerged in these first interviews. The revised protocol included questions on how chronic pain mediates synchronous communication and scheduling practices, and on when seniors decide to talk about their illness. After this revision, the first 18 participants were invited to take part in short follow-up interviews that included the new questions. Twelve participated in follow-ups; 6 did not respond or could not participate for health reasons.

Interviews were audio recorded and fully transcribed. Data was analyzed using grounded theory tools of open coding, constant comparison, and theoretical sampling [29], but this process was guided by our initial research questions. Interview data was read and re-read, then analyzed using open coding. Emerging themes were identified based on coded data and newer data gathered through refined interview protocols and follow-up interviews. These themes were iterated on several times through discussions and exchanges of analytical notes between the authors. While it is not possible to know if we reached true theoretical saturation, towards the end of our sampling it became clear that our data was acceptably dense and varied, and that no new themes were emerging. We thus feel confident making exploratory claims about how chronic pain mediates the communication patterns of our population sample.

RESULTS

Two clear themes are important to mention at the outset of our results. First, it was clear that our participants accorded significant value to their interpersonal relationships and social activities, but that their chronic pain could make it challenging to maintain such engagements while still being sensitive to their own wellbeing and the barriers they might encounter. P22, for example, notes that she would like to take fuller advantage of programs at the art gallery and have a more active social life:

The art gallery has some wonderful things going on and I would certainly like to be able to go more frequently. But because of the, it's on many floors, because I'm restricted with the walking and pain I don't get to go as frequently as I would like to. I don't get to go out as frequently as I would like to so that I might have a social life. (P22)

Thus, an ongoing concern for our participants was how to accomplish their interactions in the face of possible disruption.

Second, disruption because of pain caused difficulties with scheduled (i.e., planned) and synchronous (i.e., in-the-moment) contact. It could be difficult to keep planned appointments and activities like volunteering, attending classes, or meeting with others. P1 notes the contrast between the fixedness of social plans now and before her chronic pain diagnosis:

I can say even I'm going to meet [my friend] tomorrow for lunch. I may get up and can hardly walk. So I'm on the phone saying, '...do you mind if we take a rain check' And [my friend with arthritis] could do the same with me. That did not happen before. You could pretty much guarantee, unless a crisis came up, that you were going to meet for lunch... So you can't plan with arthritis. (P1)

Synchronous contact, including unplanned encounters, such as having people drop by without notice, could be difficult during times of intense pain:

I really don't have any interest in people coming over and talking face-to-face. I can't be bothered because of the pain. It's really hard to concentrate on people gabbing even though it's interesting to them, if my legs are burning and my neck is aching, and that's what my brain is thinking about, it's not that I'm self-pitying, it's just that the pain is there and I can't take it away. It's hard to hold a conversation for very long. (P20)

Thus, our participants desired interaction, but also had to deal with the disruptive effects of chronic pain on synchronous and scheduled contact.

We discuss our results in terms of how impression management tactics were implicated in negotiating these

challenges, and group our participants' behaviors into three key themes: setting the stage of interaction, managing the expectations of others, and revealing and concealing pain.

Setting the stage

Participants indicated to us that engaging in regular social activities required a series of tactics that allowed them to avoid or minimize the possible negative effects of disruptions caused by their chronic pain. These tactics were both pre-emptive and reactive, and occurred at all stages of planning and executing social interactions.

The first steps people described involved attempting to set the “stage” – in terms of both the setting and timing – so the probability of disruption was minimized. We use “setting the stage” to refer to the advance or on-the-fly work that participants did to shape or respond to interaction contexts in ways that were consistent with known properties of themselves and interaction media, which we discuss in turn.

Much of this work of setting the stage may not seem like impression management, as it consists of scheduling and generally operating within a set of known constraints. We argue, however, that because much of this work is invisible to others (i.e., behind-the-scenes), the outcome is often an impression. That is, effective stage setting means that others may not even be aware of the chronic pain condition/symptoms, whereas less effective stage setting can mean stigma from both friends and the general public (i.e., strangers on public transit). As such, we present stage setting as a form of impression management behavior that takes place through careful orchestration of events within parameters known to be constrained.

Properties of the self

One key element of stage setting was reliance on self-knowledge in planning interactions. While it is natural to be aware of one's own needs and preferences when scheduling events, what is interesting here is the reliance specifically on knowledge about limitations chronic pain might place on one's energy, cognitive abilities, and physical mobility, and the times at which these are most likely to occur.

First, participants said they are often able to use such awareness to carefully arrange their schedules such that disruptions are unlikely. For example, in the course of planning an outing with friends, one common strategy was consciously scheduling time for respite and self-care before and after the outing:

I always, if I know I'm going to be doing something that's going to take a lot of time or energy I will take a day before and at least a day after to do very little. And if I'm going out at night which I try not to do but sometimes I want to go to something special, same thing, I'll make sure there's a day after anyhow when I'm doing nothing. (P7)

Another behavior we observed was participants' tendency to plan interactions with others during times when they

anticipated that their chronic pain would be less intense. For example, some seniors knew what times of the day were best for them based on how they react to regularly administered medications:

It's about timing things and at times during the day when I know that my cognitive skills are good that my motor skills are good and that the pain may be less then other times. (P26)

Similarly, those who reported that their chronic pain caused difficulty sleeping through the entire night noted that they avoided making plans during the mornings.

Properties of the Environment

Another way participants relied on self-knowledge to plan interactions and prevent disruption lay in consideration of their ability to access elements of the built environment. This required the combination of self-knowledge with knowledge about elements of the environment that they might have to draw on to have an interaction. For example, P4's chronic hip pain presents in difficulties staying seated, so he says he must pay attention to how and where he sits in social gatherings.

I look after myself and conversation in a group setting happens... There's a few things I do to protect myself. Like whenever we have a gathering I'm always looking for a chair that's hard because cushiony chairs would disrupt the joint and cause me pain so that's just a piece of logic I work on but I don't mind it. (P4)

For P4, participating in social gatherings was possible if he set the stage in a way that assured his comfort sitting down.

Travel was another attribute of the environment that our participants had to consider in setting the stage. It could be very important to consider when one was traveling, and the type of transportation one used, as both factors could aggravate pain. Some participants indicated, for example, that they found certain modes of transportation difficult or impossible to use due to accessibility barriers or rush hour crowds. As P27 noted:

I have to depend on Wheel-Trans (a door-to-door accessible public bus service) or taxis which is extremely expensive. And say I want to meet somebody at Harbourfront or the art gallery. I can manage perfectly well along the street or something with a walker, which helps my back. But I can't access [standard] public transit from where I live with the walker if I want to use it [the walker]. You know the escalator or the elevator only goes to one level. I can't go over to St. Clair and Yonge. I can't do that on the streetcar with my walker because the streetcar doesn't accommodate the walker. (P27)

P27's experience highlights how a number of variables - schedules of public transportation, availability of accessible

busses, and the physical features of transport stations – had to be taken into account before traveling. Such features would deflect on her self-presentation (her ability to use a walker), autonomy and comfort level during her subsequent outing with a friend. For her, then, setting the stage means ensuring that events take place at events that she is able to access with the transportation options that are easily available to her.

In stage setting, knowledge about oneself and one's ability to travel throughout the environment could also mean forgoing the possibility of contact, as was often the case for P23 in the winter months:

My social contact [in the winter] is actually quite restricted. It's by virtue of the fact that I don't go out at night, because it's cold and that makes my pain really bad. And I don't like driving at night. (P23)

Known properties of interaction media

Another form of setting the stage entailed consideration of known properties of the media for interaction. Participants tried to anticipate and work around features of interaction media (e.g., phone, computer, face-to-face) that could potentially aggravate pain. One way this played out was in the modality participants used to communicate. For P9, interacting face-to-face was preferred if it occurred in the home as this suited her energy needs:

People do come and see me normally. It's because I think visitors is a good idea... it saves me the energy of getting to some place else so I have more energy to devote to visiting with people. And I've learned how to throw people out... (P9)

Drawing on the convenience of staying home, P17 often preferred using the phone to speak with others, such as his cousin, who lives in a suburb distant from his own home:

I get in touch with her [by phone] more often. Not just because of her chronic pain, but cause I suffer from chronic pain and I can't get out there. (P17)

Choosing a modality that required a lower-effort for the person with chronic pain was a very common behavior among our participants. This resulted both in increased comfort, and reduced the likelihood of potentially negative disruptions.

Another way of working with known properties of the environment was participants adapting communications technology to suit their unique needs. Most of our participants reported that form factor, ergonomic, or inaccessibility issues could aggravate pain or fatigue. For example, holding a phone, typing, or staying seated for long periods of time could be difficult:

[With the phone] it's the positioning. I can't hold it with this arm because of pain in my neck... I still have trouble with full range of motion, my rotator cuff feels like it's burning. I put it on speaker

phone. I first ask permission. I'll say that '[my caregiver] is in her room watching TV so I'm just going to put you on speaker phone.' (P17)

Anticipating and working around such problems – finding an appropriate seating position, a preferred position to speak from, etc. – was a way of mitigating factors that could disrupt communication.

What all of these behind-the-scenes behaviors bring into relief is the extent to which seniors with chronic pain must carefully manage interaction contexts in order to accomplish their interactions with others.

Managing the expectations of others

When one is experiencing periods of intense chronic pain, for example times of "breakthrough pain" where pain is uncontrollable, some disruption is often inevitable even after care has been taken in setting the stage. Mitigating the potentially negative and impression-threatening effects of these disruptions was a second clear theme in our findings. In managing the expectations of others, our participants had to be selective about what information was revealed or concealed about their condition. This selectivity played out in the use of both pre-emptive statements that helped prevent their contacts from holding unrealistic expectations, as well as plausible explanations or accounts for their behavior during times of disruption.

One tactic through which the expectations of others could be managed was making pre-emptive statements that sketched feasible boundaries for possible interactions. Such statements influenced others because they aimed to create reasonable expectations in others for an upcoming interaction. Such statements were common in events being planned with contacts who were aware of their chronic pain condition. These statements delineated what was or was not possible, as P7 describes here:

I do talk about what I need to go with them. They know I walk very slowly, they know I don't walk that far. They know I don't like to go out that much at night. Stuff like that. So they have accommodated me many times. Particularly 2 or 3 of them. (P7)

This example reflects a common strategy of letting others know about one's constraints (e.g., around mobility) in order to seek accommodation.

Another tactic for managing the expectations of others was to warn in advance that social plans could be disrupted in the event of significant pain. As P25 notes:

Put it this way. All my friends know... if I'm going out somewhere, they know if I call and say, "look, I just can't make it", they understand. So it doesn't become a problem in the sense that the next week they'll say, 'How you feeling now [P25], a bit better? Well let's do it now then.' (P25)

This strategy was used while making plans, and drew on the fact that P25's friends knew and were understanding of his chronic pain.

Importantly, however, the feasibility of these strategies depended on the social and relational context. Some participants did not feel the same level of trust with their contacts. P5, for example, indicated that she sometimes used deceptive excuses, especially if it was suspected that others might not believe her:

So I usually tell people I'm having a bad few days sometimes you think they don't believe you - but it doesn't matter it's your life. So yeah, some days you just can't face calling anybody or you just say you might even lie, 'I'm busy I just need time out.' (P5)

P5's strategy is interesting because it explicitly communicates boundaries – being busy and needing time out – but this boundary does not draw on and is not explained by the participant's pain status. Rather, it deliberately avoids revealing this information because it is not felt to be believable.

In other cases, participants shaped the expectations of others more implicitly, such as when unavailability for activities was communicated by delaying or avoiding communication with the affected individuals. As P9 describes:

If it's at all possible I avoid other people. So whereas if I'm having a really bad day and I had nothing particular planned to do – I wasn't going out or anything like that – but I had thought of making some phone calls, the phone calls just don't get made. (P9)

Not answering the phone or delaying contact were common strategies used when social interaction was untenable. It should be noted, however, that such tactics could result in negative consequences for the senior with chronic pain. In the case of P24, who stated she lives with constant pain, putting off engagements with her friends damaged those friendships:

I'm not as open and as free with cause I always think, well, the pain is there and it's pretty bad. I want to get off, I want to get off the phone... Now there's another thing, you lose friends by because they keep asking to come, you keep saying, 'yes, I will, I will, so I will' and you don't. I will phone and try and make some or send them little notes, which my husband mails them for me. Because you know they send cookies and stuff so I have to write notes to thank them. But otherwise I would be out visiting them all and you know doing things together. It makes it very difficult. (P24)

This quote from P24 illustrates how a tension between signaling boundaries and maintaining contacts could play

out in a loss of friends. P24 created expectations that were possibly unrealistic by promising contact later. Such statements had isolating consequences in that they fostered the expectation that she would be able to follow-through.

Revealing and concealing chronic pain

A third theme running through many of the issues discussed so far has been the conditions in which revealing and concealing information related to chronic pain occur.

Pressure to remain silent

An important observation we want to underscore is that our participants often described an impetus to keep silent about the chronic pain that was an ongoing feature of their lives. This means that in many circumstances that spanned both setting the stage and controlling the expectations of others, preserving face and maintaining positive impressions involved concealing their experience of pain. One reason for not revealing this aspect of their life was the expectation on the part of participants that others do not want to hear about chronic pain.

Your family don't want to hear it. They know you're in pain, and they don't want to hear it... I ran into somebody yesterday and we had a discussion about this. It's perceived as being very negative. Every time you talk to someone and they ask you how you feel. If you really tell them how you do feel, then you're being perceived as being very negative. So you don't do it. (P22)

Another explanation for not showing pain was the idea that chronic pain was a "banal" feature of aging:

I don't tell [my elderly friends] very much about my problems. Not unless I fall. But I try not to complain. And that's maybe why [my friend who also has chronic pain] irritates me. I mean so many of us at this age have so many aches and pains it just gets rather boring. (P13)

P13 says she would not notify a friend unless an injury occurs that is, as it were, out of the ordinary (e.g., a fall). These quotes may reflect an expectation of others among many of our participants that pain is an obvious or "normal" feature of aging; if this is the case, staying silent may belie the work that goes into sustaining interactions, setting the stage and controlling the expectations of others.

Context matters

Clearly, though, the stakes of revealing chronic pain were different in different arenas. On one hand, a social context might, such as a workplace, not be supportive of revealing illness. For example, at P23's workplace, she felt the need to conceal her pain because she thought her coworkers would perceive her in a negative light:

[When you work] during the day you can sort of 'muff it' and pretend that you don't have pain, you don't dare tell work colleagues that you have some form of a disability that's pain because that's immediately a downer. (P23)

On the other hand, in supportive contexts, the perceived stakes of revealing pain could be much lower. P2 related that her daughters and granddaughters grew up knowing about her illness; her diabetes and diabetes-related chronic pain was a frequent topic of conversation. For instance, P2 said that and she felt that she could talk about her health in interactions with her granddaughter, who worked as a physician:

[My granddaughter] tells me from her experience, what I should take, and usually whatever medication she gives me agrees with me... maybe it's psychological, but when this favorite granddaughter of mine talks to me I feel good... as soon as she learned about Neurontin [a drug that can relieve neuropathic pain] she sent me medical samples, she said "Grandma, this is something new you take for your chronic pain." She is always ahead of the time. As soon as she learns something new about chronic pain she calls me right away. (P2)

P2's granddaughter, with whom she had a close and understanding relationship, could be a source of support and information on chronic pain, so this aspect of P2's life was openly discussed.

One benefit of supportive contexts was that when a disruption occurred in a senior's activity or interaction, communicating a need for withdrawal could draw openly on one's chronic pain. This as the case for P3, who plays ping-pong regularly with friends at a local seniors' center, but often must stop during the course of a game:

Well like every Thursday, I go for lunch and we play ping-pong for at least 2 hours. We're in a group, and instead of playing, as soon as I start feeling the pain, I sit down. I tell them: 'I cannot continue playing, I have this pain.' And then somebody else takes over. So the group knows. (P3)

Likewise P26, who attends a chronic pain support group, noted that withdrawing from its meetings involved a straightforward email:

I will e-mail the other people in the [chronic pain support] group and I will say, 'I can't make the meeting tonight, I am in too much pain.' (P26)

Both of these quotes illustrate cases where participants disclosed that their chronic pain was causing a disruption in their ability to interact or perform an activity, and where it was possible to disclose this due to the perceived supportiveness of the context.

DISCUSSION

Our study has several implications for understanding and supporting the communication needs of seniors with chronic pain. Our results make it clear that participants value their autonomy and ability to interact regularly with

others, but accomplishing these interactions can require substantial effort. This effort stems not just from the disruptive impacts of pain itself, but also on the potentially negative consequences of revealing symptoms of one's pain to others.

The first implication is that fostering a sense of social support and connectedness for those who live with chronic pain is not as simple as increasing opportunities for social interaction. This aligns with research that has established that increased frequency of contact will not necessarily reduce feelings of isolation or increase perceived quality of contact or support [6], as well as studies that identify social barriers, such as stigma and misunderstanding, as uniquely challenging to people with chronic pain (e.g., [9, 12, 32]). Further, while systems intended to support seniors aging in place often aim to support regular and recurring interactions with family and loved ones in new ways [18, 22], chronic pain complicates this scenario somewhat. Pain may cause unanticipated disruption of interactions or potential interactions, a fact that our participants were constantly aware of as they set the stage for their interactions and activities.

Two factors played heavily into participants' efforts in this regard: reducing the likely effects of pain on their interactions, and managing the release of information about their pain. Each of these has implications for how systems might support not only frequency of contact but also the perceived quality, responsiveness, and appropriateness of communications technology.

First, participants put substantial effort into setting the stage for interactions to maximize the probability of success. They were careful to work within their personal limits and constraints imposed by such external factors as transportation schedules or options, and the built environment. As such, one design implication that emerges from these results is to not just help seniors with chronic pain interact, but to *help them set the stage for their interactions* as well. Possible ways to act on this include the development of systems to support seniors that take into account properties of themselves and the environment as they plan interactions. Systems that identify accessible spaces and routes, map transit schedules to one's own calendar, provide mechanisms to support the scheduling of respite time, and possibly even communicate such information to trusted contacts could be useful.

At the same time, seniors were also concerned about how to mitigate the effects of disruption when it did occur. Where disruption for seniors aging in place could be a sign of emergency and a need for immediate attention (e.g., via devices that alert others during a crisis, etc. [21]), disruption for our participants was a sign of temporary withdrawal and a need for an explanation that did not draw negative attention. Thus, a second design implication following from our results would be to *help seniors with chronic pain explain their limitations or disruptions to others*.

This may include systems that selectively reveal details to others, possibly using different explanations for different individuals. Thus, “one status fits all” systems that might indicate seniors’ availability for interaction with others (see, e.g., [27]) should allow for different settings for different people or groups of people; and possibly allow for others to “approach” or check availability before starting an interaction (as in [4], for example). As seniors with chronic pain frequently encounter a tension between managing their illness on one hand, and maintaining contact on the other, customizable explanations on the part of the senior with pain, so that this tension might play out more positively, will be important. Systems that support selective revealing would be especially valuable in more ambiguous scenarios, such as where a senior cancels meeting a friend outside the home, but at the same time desires social support, such as having that friend visit them.

Calendar systems could also frame scheduling more flexibly to reflect the possibility of disruption, and give seniors an easy way to opt out of certain activities known to be strenuous. Rather than have event slots appear as “scheduled” or “empty”, there could be certain activities that the user knows to be in a “if I feel up to it” category, and the system could send a reminder asking “Do you feel you’re up to Activity X?” beforehand, and allow them to easily send a notification to other participants if they are not.

Given the extra work seniors with chronic pain must invest into setting the stage and managing the expectations of others, alongside their own pain and illness management work [8], systems that support seniors foster a sense of participation and contact with others while maintaining necessary personal boundaries could prove very helpful.

Limitations

Our study relied on a limited sample of seniors who self-identified as having chronic pain. This focus enabled us to look at general ways that chronic pain mediated our participants’ interactions, and we believe we have presented a range of experiences to that end.

At the same time, it is important to recognize that our participants had diverse health issues that caused them chronic pain, including rheumatoid and osteoarthritis; diabetes; neuropathic pain; post-cancer pain; pain that persisted after injury, and unexplained pain. We acknowledge that these conditions may affect communication in specific ways, and that further studies might be needed to draw out such details. There are at least two implications of this to consider. Firstly, from an impression management perspective, a range of social (and potentially stigmatizing) meanings come with these conditions and may also affect the self-presentation of seniors in specific ways. Secondly, from a design perspective, the range of conditions that are known to lead to chronic pain could motivate illness-specific designs. While it was beyond the scope of the present exploratory

study to address such issues, we think that significant value could be gained from a more systematic analysis that uses stratification to target participants with a range of conditions.

Another limitation is that our data were derived solely from interviews with seniors. Their perspectives and accounts of their interaction behaviors provided the basis for our study, but accounts from others are missing. The domestic space is a centre of collaborative work, where multiple stakeholders (people with chronic pain, their loved ones and/or caregivers, health care providers, etc.) are implicated in the management of this illness [1]. Future studies might take this into consideration, and include sampling from broader social networks, or employ ethnographic methods to examine communication patterns in-context.

Future Work

There are many opportunities for future work in supporting seniors with chronic pain. Additional studies with seniors themselves – including possible observation, message log studies, or participatory design endeavors – would deepen our understanding of their day to day lives, concerns, and interaction patterns. Attention to how communication during times of pain is impacted by device accessibility, usability, and form factor, as well as possible cognitive and motor changes that can arise from pain and/or due to aging [23] will be necessary. In addition, field studies of the deployment of novel systems would enable us to understand how specific design choices could help us better support specific scenarios.

CONCLUSION

Chronic pain is a complex illness, but it is clear that where communication is concerned, seniors with chronic pain invest significant work into controlling both the context of interactions and others’ expectations so that they may participate in social interactions and minimize disruptions in their lives. Systems that support such efforts could prove to be one component of broader strategies that address the biological, psychological, and social dimensions [12] of chronic pain.

ACKNOWLEDGMENTS

We would like to thank our participants, the O’Neill Long-Term Care Centre, and Dr. Pamela Squire. We are grateful for grant support from NSERC, GRAND NCE, and from Google Research.

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