'Weather' Wearable System: A Design Exploration to Facilitate the Collaboration and Communication with Chronic Pain Patients

Xin Tong(✉), Diane Gromala, Amber Choo, Mahsoo Salimi, and Jeewon Lee

Simon Fraser University, Surrey, Canada
{tongxint, gromala, achoo, salimi}@sfu.ca, fleecy_cloud215@gmail.com

Abstract. Unpredictable spikes in pain intensity can easily interrupt the lives of chronic pain patients. The uncertainty of when these painful experiences will occur inhibits positive communications and collaborations with friends, families or co-workers in daily life. In this paper, the authors explore an affective design space for developing a wearable technology piece using real-time biofeedback monitoring capabilities. The intent of the device is to mitigate chronic pain patients' pain uncertainty in order to facilitate daily collaborations between the worker who lives with chronic pain and co-workers through social signaling. This exploratory design process, including the wearable system organization and presentation rationale, was developed in participatory design collaboration with target users: a chronic pain patient and people she works with in an academic workplace context. After three iterations, two prototypes were developed; each addresses the control of privacy and information sharing issues. In future work, appropriate evaluation methods will be explored and the iterative design prototype also will be improved based on user feedback. The long-term goal is to improve the wearable's applicability in a variety of social contexts, and applicability for other chronic conditions.

Keywords: Wearable computing system · Chronic pain · Collaboration and communication · Uncertainty mitigation

1 Introduction

Chronic Pain (CP) is a degenerative condition that can cause significant discomfort, constrain mobility and social interactions, and pose unpredictable disruptions in daily interactions [1]. Thus, living with CP often means that patients live with both "bad days and good days," [2] ranging from some days that are manageable to other days which are almost intolerable. Beyond possible negative effects on their general availability, ability and attitude toward social interactions, CP patients also experience related conditions that impede their ability to plan and take part in activities even when they do not deliberately withdraw [3]. In addition, CP patients also face considerable stigma

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from those who are unaware of the disease and its manifestations, which can cause negative and exclusionary attitudes among co-workers.

When such situations occur, CP patients need assistance to deal with communication and collaboration issues. CP patients need a tool that encourages non-patients to improve their understanding of pain uncertainties and to develop real-time approaches to coping with uncertainty, and a method that could present a patient's current condition without costing the patient too much effort to articulate.

As wearable technologies become a part of our embodied experiences as non-verbal communicators, clothing and accessories have begun to move away from an exclusive focus on style and convenience towards integrating health-related functions. It is important, however, to understand that such wearable technologies are not simply stand-alone devices devoid of context. In Susan Ryan's [4] examination of wearable technology, for example, she conceives of wearable technology as an evolving set of ideas and their contexts, always with an eye on wearable artifacts—on clothing, dresses, and the histories and social relations they represent. Current wearable systems are not specifically designed for CP patients and for collaborative purposes in the workplace, and since physical and social contexts decide how a wearable system could take effect, it is important that the needs specific to CP patients are accounted for.

Therefore, in this paper, the research question is how to design and explore a wearable system to facilitate collaboration based on a patient's experience. In this case, X (the name is coded as X), is a CP patient who heads a group of people, and experiences unpredictable pain spikes. Such increases in bodily pain, coupled with the unpredictability of when such pain spikes occur, effectively discourages collaboration with others on social and professional levels, particularly when coworkers are unaware of the CP condition.

We introduce a participatory and exploratory design of a wearable CP system. Next, three iterations are described, which led to design variations for a wearable piece titled Chronic Pain Patients' Weather System. We also present a critique on form factors and address the limitations of the system. In future work, to make this wearable system more universal and applied to generalized scenarios for chronic conditions, more patients need to be involved in the design process, diverse workplace contexts should be considered, as well as wider contexts.

2 Related Work

Although wearable technology has been widely used as a health-monitoring tool and is often applied to persons with chronic conditions, how to facilitate the communication of a long-term pain experience and to enhance efficacy of collaboration among CP patients with non-patient co-workers is still unexplored. Pain is difficult to communicate, and difficult to understand by people who do not experience it. Thus, CP patients' interaction experience during daily activities requires a longitudinal, team-based collaborative approach [5].

2.1 Communication and Collaboration Between Chronic Pain Patients and Non-patients in Daily Activities

The complex challenges of chronic pain and its effects on collaborations between CP patients and non-patient co-workers requires a multi-faceted approach, in contrast to verbal communication alone, in order to deal with uncontrolled pain [6]. One of the challenges is that chronic pain is "invisible" — that is, it typically lacks observable physiological responses, visible signals or absences of behaviors, making it difficult for co-workers or others to get a sense of the variability of the CP patient's general state in the ways in which, for instance, we assess someone's mood. Moreover, the ways in which CP patients cope with "bad days" and the disruptions they may create may vary considerably from patient to patient, or according to the tasks at hand. For example, as Benjamin et al.'s research discovered [3], a CP patient currently experiencing a really 'bad day' or spike in perceived pain may not want to be interrupted while conversely, another may really want a distraction. In Wells et al.'s study [6], they found that nonverbal methods of assessment provide useful information, and that self-reports of pain are the most accurate. Therefore, in health care contexts, it is recognized that certain interventions are essential to allow communication among patients, clinicians or others about the current status of the patient's pain and their responses to the plan of care [6]. Therefore, we adopted a similar approach: the goal of our intervention is to enhance communication, especially during disruptive spikes in pain, in a manner that takes into account a patient's self-reports in a non-verbal manner.

Because of widespread stigma, revealing that one has CP in a workplace context is a choice that may result in negative attitudes that worsen over time. Obviously, any technological intervention cannot in itself change widespread misinformation and social attitudes. However, it was determined that if a CP patient finds that information about their states may improve communication among co-workers, that information may potentially work best when it can remain in an ambient form, much like the weather. One may look out of the window to see that it is raining and respond by taking their umbrella, but much of the time, what is outside of the window is simply background information.

As previously described, a CP patient's "bad days" and spikes in pain introduce uncertainty both for the CP patient as well as for co-workers. In order for any proposed system to work, it must not only clearly communicate the state of the CP patient, but the patient's co-workers must also feel that they know how to respond appropriately. For example, certain collaborations in workplaces, such as informal meetings with coworkers or non-urgent questions from them, might bring unnecessary physical and mental fatigue for the CP patient during "bad days." As our initial participatory design meetings revealed, co-workers' responses to information about a CP patient's state varied because they were uncertain about how they should respond. Some interpreted indications of a "bad day" as a signal to avoid *any* social interaction with the CP patient at all. Others interpreted it to mean that more attention was desired, which the patient found inappropriate. Both responses are common responses that contribute to increasing social isolation that many CP patients experience. The CP patient simply wanted to mitigate uncertainty to better manage work and does not desire more attention, which was interpreted as pity. Therefore, we found that knowing what are and are not appropriate responses to the information were critical to the design of the system.

2.2 Wearable Systems as Communication and Collaboration Tools

In recent years, there has been increasing interest in wearable health monitoring devices that have been developed for sports conditioning and weight management areas, both in industrial and academic fields [14]. Despite medical and health monitoring uses, many wearable systems are also developed to foster social interaction and collaboration. As proposed by Ryan [4], wearable technologies comprise a pragmatics (being utilized and understood in certain circumstances or contexts) of enhanced communication in a social landscape. Wearable systems embedded into daily activities embody the wearers' information so that they inspire motivation and more collaborations and communication [11, 12]. The popularity of wearable bracelets like some forms of Fitbit and Nike FuelBand, are just two examples of how health monitoring (including heart rate, sleep patterns, activity levels and so on) has been adopted by non-medical users. They are worn like a watch, and data from them is uploaded to a personal computer or website where users can see visualizations of their data. Other examples, such as Nuria and Fernando's [7] Health-Gear, are real-time wearable systems for monitoring, visualizing and analyzing physiological signals that are wirelessly connected through Bluetooth to cell phones that monitor users' blood oxygen levels and pulse rates while sleeping.

Several researchers also demonstrated how wearable systems are used collaboratively, how they influenced interactions among users and how they could enrich the building of a collaborative network. Light Perfume [8], for instance, is an interactive wearable system designed to help wearers better communicate with each other by mirroring their partners. In this design, the output of Light Perfume is based on input from the user's environment, such as noise levels and body gestures; these synchronize the blinking speed and the color of LEDs. The user study showed that all participants enhanced their sociability dimension of impression towards their partners, and that they also felt closer and more familiar with each other. Kate Hartman's [9] idea about wearable systems is that the body per se can be designed as interfaces and platforms for promoting physically expressive engagement, which could process, transmit and receive data with outside world – including both people and environment. In her Inflatable Heart and Glacier Embracing Suit, she employed wearable electronics to explore how people communicate with self and the outside world, allowing new modes of expression and communication.

The use of wearable technology for monitoring health in clinical contexts has been addressed as well. Paolo Bonato [10] examined wearable technology and its medical applications on a theoretical level. He concluded that a great deal of progress in the field patient monitoring has benefited from the wearable sensors and systems which provide tools for the prevention of chronic conditions, and the ability to promptly respond to emergency situations. He also demonstrated that wearable technologies could work as informatics systems that promote improved care for medical purposes, especially in regards to chronic illnesses.

3 Methodologies and Design Principles

To better clarify users’ needs and the contexts in which this wearable would be utilized, single-case exploratory design and participatory design were adopted. A focus group was set up, consisting of eight members, including X and seven of her coworkers.

3.1 First Interview: Analyzing Contexts in the Exploratory Design

Since few studies can be referred to, and few wearable technologies have been designed specifically for CP patients’ collaboration purposes, the goal of this exploratory sequential design (also known as exploratory design) focused on gaining insights into and familiarity with the design problem for further investigation. Because the problem was in a preliminary stage of investigation, this exploratory design first utilized a focus group comprised of the stakeholders — X and her colleagues — which enabled us to gain background information. Two interviews were conducted, each lasting one hour. Questions that were asked concerned: (1) the seven coworkers’ experience collaborating with X, and if, how and how often the uncertainty of her condition affected their ability to work effectively; (2) if they felt the information about X’s pain state might enhance communication; (3) what kind of information would be most valuable; (4) how to display and present the information.

Although her CP condition is invisible, it can impact X’s collaborations, particularly with those of her colleagues who were employed as her assistants. Table 1 is a summary of her self-reported regular pain level and its correspondent consequences on her collaborations from the interview. The pain scales were also provided by her to better illustrate where the boundary of pain influences over her daily collaborations seems to be. For example, she sometimes must miss meetings. While all can adapt by Skype or by rescheduling, the matter of uncertainty emerged as the primary concern. To conclude X’s case, higher levels of pain distracts her because it takes additional effort to manage the pain, making concentration more challenging, especially when it involves communicating with others.

Table 1. A Use Case of X: pain weather and possible solutions to maintain a better collaboration

Weather	Pain Level (0-10)	Collaboration Condition with Others
Good Day & Fatigue Day	< 3	Pain is not too bad but fatigue becomes the problem – can work
Pain Day	3-5	Talk and action in the lab is welcome and energizing
Worse Pain Day & Bad Day	> 5	Moves more slowly, has intermittent cognition disruption from pain, finds interruptions difficult

In the interview with X, her opinion showed that this wearable design might help her to deal with pain distractions in the following way: for instance, when X is experiencing a ‘Worse Pain Day,’ the wearable will act as a display and will generate a sign of her current state. The needs of non-patient coworkers who are involved in the same activities are also significant: as the signal's receiver, they would respond by modulating their communication with her. Since these responses may significantly influence the collaboration process, we investigated the attitudes of non-patient coworkers as well.

During the interviews with the whole team, they all agreed that they would like to have such a wearable piece, not for inferring mood but for better understanding the pain condition so that they could arrange their work activities efficiently.

3.2 Second Interview: Analyzing Target Users, Tasks and Goals

After making sure that such a wearable has value and a design space in the first interview, the following, more concrete questions were answered in the second phase: (1) Who will be the targeted users, exactly, and what is the context? (2) What is the task of this wearable design? (3) What is the goal, or specifically what characteristics would you like to have in this wearable design? Specific scenarios were conducted to more specifically determine how visible the wearable should be, under what conditions, and how could privacy be maintained?

Here are some responses from the group. When asking about what this wearable could be like, one participant proposed this idea: *I think it could be a small simple thing that you could just take it off. So it is obtrusive enough that I could know, and unobtrusive enough so it doesn't bother you or me.* As for what special things will be taken into consideration when designing this wearable, here is the opinion we found regarding the privacy issues: *If I were you, I would like to have the control over my privacy. For example, I do not want to show it to the public. I want to show it inside the group members.*

Therefore we arrived at the following conclusions: (1) Targeted Users: The system was designed for CP patients who might constantly be interrupted by their uncertain CP and distracted from daily communication and collaboration with others, especially in workplace. The disruptive nature of CP can constrain availability for interaction [13] and introduce occasions where those with the illness have to take deliberate steps to avoid negative social consequences [1]. However, the unpredictable pain cannot easily be understood by their colleagues or communicated by the patient (2) Task: The task is to communicate hard to understand pain via a wearable system that falls into the category of clothing or an accessory. In reference to the wearable's real-time conditions, the audience (colleagues, friends or family) should be able to make quick decisions about appropriate strategies, plans or schedules upon changes detected by the system; (3) Goal: The goal of the design of this wearable system is to facilitate communication and collaboration between CP patients and non-patients in a workplace through nonverbal, unintrusive methods.

3.3 Privacy

An information sharing mechanism like the wearable weather system might give rise to potential concerns of privacy because it displays personal physical conditions.

Interview questions concerning privacy were asked of the patient during our exploratory design. Users responded that a human-control button should be added to this wearable so that the CP patients would be able to show their data in smaller, known contexts, like in the workplace. Also, they do not need to worry about their private information since the design outlook of the wearable itself has a context, and would only be used in this context. For instance, the LED's off and on status' indication would only be understood within the wearers' pre-determined context.

3.4 Chronic Pain Patients' Weather Framework

Presentation Rationale: As described in Table 1, the extent of pain varies from no pain at all to disabling pain. Five categories were offered by X to describe these pain states. Also, from the interviews with her coworkers, 3 levels (regular day, painful, and extreme pain) of pain displayed in the same wearable were considered enough for their collaboration and decision-making purposes. Therefore, a scaled measurement of pain level was used to better communicate the pain, allowing the coworkers to respond appropriately and to figure out efficient solutions according to different pain levels.

System Framework Design: The wearable was composed of three main parts: the input, which monitors the pain state and transmits the data to the wearable system; a control switch, that allows users to maintain their privacy and sustain information sharing in certain groups; output, to display pain data to coworkers for purposes of enhancing communication by changes in the displayed state of this wearable. Biofeedback sensors (GSR and heart rate variability will be investigated in future phases of development, as that data provides a way to make good inferences about anxiety, which accompanies periods of greater pain; for now, what is implemented is the pulse sensor) can capture CP patients' real-time physiological data, reflecting the user's comparative physiological stress level directly, and pain level indirectly. Under the control and wish of the user, certain contents can be displayed in this wearable weather system based on contexts. Like watching a 'weather' broadcast, both the patient and co-workers observe changes and develop feasible collaborative solutions. For one thing, it could facilitate communication and enhance collaboration efficacy. For another, CP patients may detect a positive change in coworkers' ability to ascertain and respond to the uncertainty of CP, which in turn may mitigate a patient's anxiety about the negative effect their uncertainty has on coworkers, and affording them to better manage times of greater pain.

Technical Implementation: During the implementation, we chose the pulse sensor to gather biofeedback data from patients, an Arduino LilyPad as the main electronic board to process and then present the display data, a switch for the user to control the device and the LEDs as the pain level indicators. In Fig. 1, we summarized the composition of the wearable system in terms of users, hardware and software. Based on the interviews with the CP patient and people she works with (described in the Method section), three signals will be displayed for communication purposes: the blinking of the LED stands for data from the biofeedback sensor (pulse sensor). White color means it is a normal day; red color means it is a painful day; and a constant red (because red is associated with the danger or failure in achievement contexts and evokes avoidance motivation [15]) represents the highly painful experience. What, when and where to show the signal depends on the patients and his/her control.

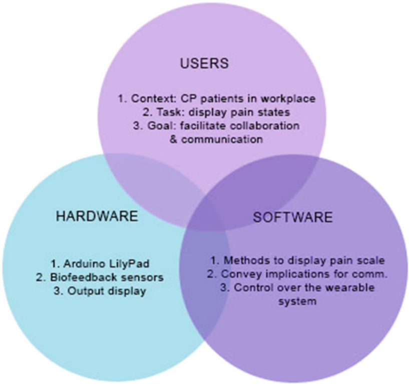

Fig. 1. Wearable weather system compositions

4 Design Exploration and Evolution

This wearable was named "weather" system because it could imply different conditions of CP patients' unpredictable pain. In this section, an overview of the system design is described. Design iterations and evolutions were demonstrated together with the patient in this participatory design, from the initial sketches to prototype design, and later, final implementations.

4.1 Evolutions and Iterations

As we sewed the electronic components into the fabric, we noticed that some cloth has patterns which can be fitted with electronic components (Fig. 2). This correlation inspired us to integrate electronics into the patterns, because such connection between displayed location and way and the cloth would enable the appearances of the wearable piece with more wearability and functionality.

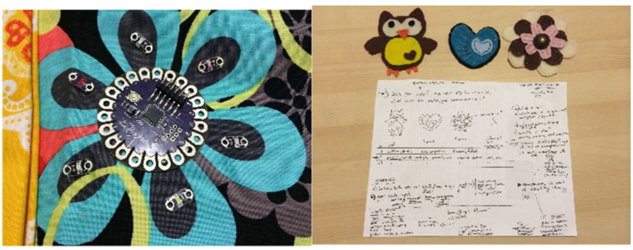

Fig. 2. Initial implementation; First iteration

However, after the first implementation, when the patient wore the prototype, she reported that it was not flexible enough for her when the wearable is in her clothing. Since it would be expensive to fit every garment with the wearable system, she expressed the preference for a small accessories, such as brooches, jewelry or badges, which would be more easily attached or detached from her clothes. As for the material, the patient also mentioned that ligthtweight fabric might be too thin to hold the electronics when the wearable was designed as an accessory. So in the second iteration, felt was chosen since it was thicker than regular shirt fabric.

After the first iteration, we made a quick test with the patient and used the first prototype to check its functionality. Then the patient came up with critical design questions regarding the outfits and metaphors of this wearable system: (1) the electronic can be an identifiable factor for others to know it's a wearable in a more public context, but it will also bring out the electronic aesthetic beauty of the front of the design. For the electronic components, whether should we try to mirror it and visualize them in front of the wearable accessories instead of hiding it? (2) What will be the differences that outfits could generate?

Therefore, we put the electronics in front side of the wearable and then tested it with patient wearing it (Fig. 2). Then we designed a poppy flower that already has the metaphor of pain as well as an abstraction image, which use small size of medicine bottles to indicate pain data and the outfit cannot tell anything to other people (Fig. 3).

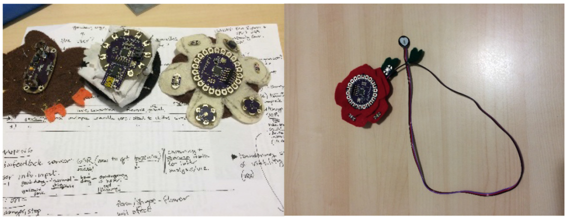

Fig. 3. Implementation of the first iteration (left); Implementation of the final design (right)

5 Discussion

5.1 Chronic Pain Patients' Weather Wearable System Design Critique

In the era of communication and device proliferation, it is important to think about how CP patients can improve their workplace collaborations even when they are in pain. Chronic Pain Patients' Weather System measures CP patients' physical index and returns biofeedback data real-time, then mapping the body condition into three types of presentation methods (regular day, painful day, and worst painful day). Based on the displayed information, coworkers can understand the pain information by observation when needed and they could make decisions of how to collaborate with the patient (for instance, either to leave her in a quite environment or to reschedule activities).

This wearable piece can affect decisions as how non-patients and CP patients' communication and collaboration with others from two sides. For one thing, it reflects

CP patients' temporal pain condition and allows others to make a judgment to better cope with uncertainties. For another, patients are able to focus more on managing their pain without worrying about misunderstanding, or social stigma due to the interruption from constantly uncontrolled pain during their work time. Their collaboration with colleagues is also taken care of by others. The responses from others towards the interaction process transmits the signal of careful interaction that could change CP patients experience about collaborating with others from a frustrated social process into an acceptably encouraging one.

5.2 Limitations and Future Work

In the design process, X is the only patient who got involved in the participatory design process. More CP patients from different backgrounds should join the design process to better evaluate the prototype. Second, in the current wearable system, it is a one-way projection from patients to coworkers, not a two-way interaction. Coworkers' response towards the patient are also valuable for communication and collaboration purposes. How to design the mechanism of presenting both of the patients' and non-patients' responsiveness to each other and how to encode it in a nature way under certain context still needs to be studied. However, the most significant issue is that we neither designed for nor considered remote conditions in our research. There is a large possibility that the patient could not even go out from their home, so we need to figure out how this wearable could work remotely (such as sync data with mobile devices and send messages).

Therefore, in the future work, we probably give a sample of each current design to patients from various backgrounds in different contexts. Besides, we will try to fix the remote condition problem by connecting the wearable to mobile phones and sending information to the coworkers so that the wearable can still be functional when the patients are too sick to work.

6 Conclusion

Living with chronic pain means that patients often need to deal with pain distractions, with uncertain occurrence. Such uncertainty inhibits positive communications and collaborations with friends, families or co-workers in daily life. Therefore, based on X's personal experience and needs to enhance efficacy of communication and collaboration in her daily life, Chronic Pain Patients' Weather System is designed and developed for CP patients to better collaborate and communicate with non-patients in their daily activities. This wearable contributed in exploring design space for CP patients' health care which is a new health realm besides information monitoring: (1) the design space was explored under the case of X and her research team; (2) it could imply different conditions of CP patients' unpredictable pain, since there is an uncertainty of 'good days' and 'bad days' for them, and this weather could bring distraction for them during collaboration and communication process.

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