

Exploring the Needs of Chronic Pain Patients and Their Informal Caregivers for Diverse Pain Education Tools

**by
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Abstract

Chronic Pain is complex in most cases as it has no cause, no cure, and no biomarkers; thus, a biopsychosocial approach is suitable for researching pain. Healthcare researchers have established evidence-based information about pain education to achieve better patient care; however, patients' desires, needs, capacities, and caregivers should be considered to enhance ways for them to understand and use such complex information in their everyday lives. This study explored the needs of chronic pain patients and their caregivers for diverse pain education tools through a participatory design approach: a needs analysis was conducted, as well as explorations of education tools that vary in media forms. As a result, insights on the development of pain education tools and good practices of patient-centred care were generated, such as the preference for practical pain management in pain education, and urgency to deliver more comprehensive care for patients in healthcare.

Keywords: Patient-Centred Care; Pain Education; Chronic Pain; Caregivers; Participatory Design; Human-Computer Interaction

Dedication

To make the world a better place.

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Glossary

Caregiver	A person who helps (regularly or occasionally) with patients' daily life, day-to-day activities, etc. In health domains, 'professional caregivers' is the term that refers to those who are certified and paid by governments or non-profits.
Chronic Pain	According to the International Association for the Study of Pain (IASP) and the World Health Organization (WHO), chronic pain is defined as pain that lasts or recurs for longer than 3 months. It often “becomes the sole or predominant clinical problem in some patients” and it is “multifactorial: biological, psychological and social factors contribute to the pain syndrome”[64]. The classification contains seven main diagnostic categories, including the distinction between chronic primary pain and chronic secondary pain syndromes. It also integrates existing pain diagnoses including headaches.
Pain	“An unpleasant sensory and emotional experience associated with [...] actual or potential tissue damage” [63].

Chapter 1.

Introduction

People always say, “Pain is inevitable; suffering is optional,” but think about it in the context of chronic pain. Chronic pain patients¹ have persistent pain and face challenges in their everyday lives. Healthcare researchers dedicate their efforts to developing evidence-based information, such as pain education, for better patient care. Caregivers also deliver care by assisting patients’ life events; they can be patients’ partners, friends, neighbors, etc. Researchers from human-computer interaction assess the best way to deliver evidence-based information for chronic pain patients and their caregivers by considering the content and the context of the use of pain education and understanding the users’ desires, needs, and capacities. Together, chronic pain patients and their caregivers can use information from pain education in their everyday lives for better health outcomes and quality of life. This study aimed to examine pain education from a patient-oriented perspective to provide design implications to human-computer interaction researchers to make pain education tools from understanding patients’ and their caregivers’ desires, needs, and capacities, achieving knowledge translation from evidence-based knowledge to practical knowledge that patients and their caregivers can apply in their everyday lives.

Chronic pain impacts approximately eight million people in Canada; on average, one in five Canadians suffers from chronic pain [64]. Chronic pain patients are prone to vulnerability because their motor functions, cognitive capacity, and emotional experiences are challenged or slowly degenerate, and their mental and physical health tends to worsen over time [2]. Recently, many researchers have explored pain education and their impacts on patient outcomes; for instance, recent research about an educational tool at Stanford demonstrates how critical it is for patients to understand the complexity of chronic pain and how it is managed, leading to more positive patient outcomes that showcase clinically significant improvements in pain catastrophizing, pain intensity, pain interference [14]. However, researchers have not yet examined the potential of creating pain education tools by understanding users’ desires, needs, and

¹ I refer to people living with chronic pain as chronic pain patients in this thesis.

capacities from a patient-centered approach and involving those who care for them (caregivers) in their pain journey.

Donna Haraway's view of feminism emphasizes the standpoints below the power reveal more “adequate, sustained, objective, transforming accounts of the world”[25]. Through this lens, the feminist view is extended beyond genders and lands on all communities, which functions better as it views perspectives from the ground up, from the grounds of specific communities. This feminist lens encourages researchers to research a specific community by understanding and learning from the community. In this study, when dedicating to pain education, even though knowledge comes from evidence-based studies from the above medical system, it is essential to connect with patients and conduct patient-oriented research. That way, insights into potential solutions can genuinely benefit the communities.

Patient-oriented research oversees four dimensions of pain-centered care: patient-as-person, biopsychosocial perspective, sharing power and responsibility (with healthcare professionals), and therapeutic alliance [40]. In this study, utilizing the participatory design approach aligning with the four dimensions of patient-centred care empowered participants to contribute a form of expertise on topics related to their own experiences and communities. Participatory design is increasingly used and examined in the health and human-computer interaction domains to achieve patient-as-person and sharing power and responsibility. Moreover, as pain researchers and clinicians have recognized the biopsychosocial complexity of pain, this study aimed to communicate that biopsychosocial framework to participants, connecting their lived experiences in a widely researched framework [23]. A storytelling method using mood boards as a tool and a focus group sharing opportunity also provided participants with a safe space to achieve community bonding and work towards a therapeutic alliance [33]. There were two phases of the workshop: a needs analysis, where the participants filled out an adapted version of the McGill pain questionnaire, completed a mood board, participated in a discussion board, and a comparative analysis, where they explored three education tools and completed a questionnaire after each one, and were invited to a semi-structured interview at the end to discuss the content and usability of the tools explored, as well as anything relevant to pain education.

Pain education has been shown to be the most effective when considering pain care professionals, patients, and stakeholders [27]. It is further illustrated that patients should be the center of all clinical efforts, envisioning multiple health professionals to build a new culture of pain care [27]. This is because the complexity of chronic pain and its co-morbidities typically mean that patients (whose ability to function is already compromised) spend inordinate amounts of time seeing diverse health professionals, from pain doctors to physiotherapists, sleep specialists, pharmacists, nurses and neurologists and so on. Pain education that occurs in interprofessional education for health professionals is emphasized in research and clinical cases; however, views on caregivers as essential stakeholders in advancing the proficient care of patients with chronic pain need to be further explored, considering caregivers have been recognized as a big part of patients' lives [58]. Therefore, this study also aimed to explore the role of caregivers in pain education.

Moreover, adding to the needs analysis, this study contributed a new perspective of comparative analysis, inviting both patients and caregivers as stakeholders to effectively provide constructive feedback to human-computer interaction researchers in developing pain educational tools in areas such as content comprehension, medium functionality, design elements, and barrier of use [32, 61, 62]. Adding to the patient-centred care approach, this study invited patients' caregivers to contribute to pain education as it was closely linked to real-life settings where caregivers played a huge role in chronic pain patients' pain journey and everyday lives; little research has considered caregivers in the concept of patient-centred care. This study followed a feminist lens and the frameworks from participatory design and human-computer interaction; it also met healthcare research criteria.

Three research questions guiding this study were: 1) What information do chronic pain patients (and their caregivers) want to learn about how and why chronic pain is relevant to a biopsychosocial framework? 2) What content, functionality, design, and barrier of use should researchers consider when conveying pain education via video, interactive programs, and tangible media such as cards? 3) How can a needs analysis and a comparative analysis with chronic pain patients and their caregivers inform human-computer interaction researchers to develop a more patient-oriented pain education tool?

1.1 Contribution

I generated insights about product development and patient-centred care from twelve participants (six chronic pain patients and six caregivers) to guide researchers in human-computer interaction providing better solutions for chronic pain patients and caregivers in terms of pain education, as well as insights on developing pain education tools in varied media forms that researchers should consider when creating pain education tools for chronic pain patients and their caregivers. This study also connected the field of human-computer interaction with the area of patient-centred care in health by using a participatory design approach to explore chronic pain patients' and their caregivers' desires, needs and capacities regarding pain education from a person-centred view. Few studies include caregivers as one of the stakeholders in patient care; this study filled in the gap of involving caregivers in patients' pain journeys.

Chapter 2.

Literature Review

2.1 Chronic Pain

According to the International Association for the Study of Pain (IASP), pain is “an unpleasant sensory and emotional experience associated with [...] actual or potential tissue damage” [63]. Chronic pain, on the other hand, persists for longer than three months and often “becomes the sole or predominant clinical problem in some patients” and it is “multifactorial: biological, psychological and social factors contribute to the pain syndrome”[63]. Importantly, its prevalence is estimated to affect one in five people in Canada [64].

Pain is complex because it is associated with actual or potential tissue damage, meaning that some patients have pain triggered by tissue injuries and some patients have pain triggered by their nervous systems that is not a response to outside stimuli. Chronic pain indicates a long-lasting and degenerative pain condition; importantly, it is distinguished from acute pain by its neurobiological changes [44]. In other words, chronic pain is thought to be a dysfunction in how the central nervous system processes pain.

Neurobiological changes in the central nervous system can also alter neuronal activity, which has an impact on ongoing and stimulus-evoked pain. It is further suggested that chronic pain treatments, due to the complexity of co-morbidities involving neurobiology, should include polypharmacy with non-pharmacological therapies [17]. Multimodal interventions for chronic pain are encouraged, considering the biopsychosocial complexity of pain including the neurobiological changes impacting and impacted by chronic pain.

Chronic pain has a historical aspect emphasizing it as a clinical condition, which puts chronic pain patients at risk of opioid addiction, and downplays the complexity of it concerning biopsychosocial aspects [23, 59]. There have been non-opioid drugs approved for chronic pain conditions, indicating that more options could be explored to prevent patients from opioid abuse or addiction [8]. Moreover, recent studies that use the

current diagnostic model of the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11) show an alignment in the biopsychosocial model of chronic pain [4]. This further acknowledges the complexity of chronic pain and the need to consider the biopsychosocial aspects of chronic pain for treatment guidelines.

2.1.1 Chronic Pain Patients and Their Challenges

Chronic pain patients face challenges from aspects of the healthcare system, complex co-morbidities, and a shift of identity because of the pain conditions, relating to their hardship in seeking proper treatments, financial conditions, and maintaining daily functions, social lives, and mental health.

From the perspectives of healthcare professionals, chronic pain patients face challenges in many aspects. On a system level, healthcare professionals are limited in establishing a long-term management approach or processes for patients, especially for patients who lack a primary care doctor [42]. On a pain management level, they highlight opioid restrictions and the misuse of narcotic medications, and face limitations in how they can organize and make use of the complement of other resources for effective pain management [42]. From a provider's perspective, it is challenging to identify the "root cause" of chronic pain as pain management tends to be more effective if the pathophysiology of pain can be identified; however, there are no identifiable biomarkers [42]. There are limited guidelines and few standardized approaches for chronic pain management, there is no adequate training to understand pain and the physiological effects of both opioid and nonopioid treatments, and there are limited communications in the team of providers of a patient, especially between inpatient and outpatient providers [42]. On a patient's level, although healthcare providers are beginning to recognize the complex experience of pain and pain management, they still recommend treating pain as information to avoid injuries instead of for healing, on top of patients' hardship on the out-of-pocket costs [42]. However, few recognize how profoundly chronic pain can affect patients' abilities to function, including maintaining a job.

Chronic pain does not stand alone; it usually has co-morbidities that further affect the lives of chronic pain patients. As chronic pain patients face long-lasting pain conditions and co-morbidities from biopsychosocial aspects, they are more susceptible

to emotional and cognitive challenges, leading to psychological problems like anxiety and depression; more people then focus on instrumental coping styles, such as palliative coping and emotional preoccupation coping [19, 23]. Common co-morbidities include depression, insomnia, and obesity, affecting their abilities and capacity as they have higher risks for reduced work ability and higher absence rates, including time spent visiting physicians about their pain and its co-morbidities [46]. Specifically, patients with chronic peripheral neuropathic pain have psychiatric co-morbidities such as anxiety, depression, and sleep disturbance, as well as catastrophizing variables regarding negative pain-related cognition, such as helplessness, pessimism, and exaggeration of pain threats [43].

Moreover, chronic pain patients face identity and narrative shifts on top of the pain conditions, from getting a diagnosis to presenting their conditions and getting support. The first step is usually getting a diagnosis; however, as the complex nature of pain and medical diagnosis tends to build around the objective sense of a physical, biomechanical-like body, it is challenging for chronic pain patients to get a proper diagnosis and crave medical meaning out of it [9]. Having a medical diagnosis is important for people living with chronic pain as it gives them a label of their conditions and a new pathway for structuring and controlling their own lives. However, many are turned away and not able to obtain a proper diagnosis, which is common as pain has no biomarker. The people who obtain a diagnosis tend to go through identity and responsibility shifts where they try to understand their conditions and plan accordingly with their healthcare providers [9]. In order to support chronic pain patients more effectively and not treat their conditions as biomechanical, it is important for healthcare providers to obtain medical education in both natural sciences as well as human sciences [9].

Challenges chronic pain patients face include medical and treatment issues, finances, problems with functions and activities of daily living, social issues, sleep disturbance, and emotional distress; chronic pain patients also desire to, however, have challenges to obtain accessible, effective and acceptable care [16].

2.1.2 Caregivers and Their Roles

An “informal caregiver” is involved in helping patients with daily activities and medical tasks; they could be family members or friends who provide unpaid care to support a patient [22, 24, 50]. This differs from professionals such as nurses, doctors, allied health professionals or “in-home caregivers,” all of whom must be certified and receive compensation from governments or non-profit organizations. The term informal caregiver is regularly used to refer to the unpaid help of patients, which derives from personal relationships, such as with partners, parents, adult children, neighbors, or friends who typically help (or care for) a patient.

A caregiver’s ability to care for patients with chronic conditions impacts patients’ health outcomes; therefore, taking into account a caregiver’s needs assessment and how they can best support chronic pain patients is important to understand [13].

Caregivers are important in chronic pain patients’ lives because they support everyday activities and medical events, such as transporting and accompanying patients to multiple healthcare appointments. The relationships between patients and their caregivers have not been the focus of as much research, but given the well-known complexity of chronic pain, it is likely that patient-caregiver relationships are diverse. However, as caregivers support chronic pain patients, they also encounter physical and mental burdens, especially if they face higher patients’ pain intensity, depression, and lower self-efficacy [58]. Therefore, it is worth exploring pain education for caregivers to better support chronic pain patients in their pain journey, as well as to support caregivers, who likely face physical and mental burdens.

Caregivers usually understand the complex healthcare conditions patients experience, especially with chronic conditions that require long-term care and constant visits to hospitals or clinics. Caregivers in Spain perceive several challenges regarding the current healthcare system, such as long waits in emergency services, the lack of continuity of care, the absence of references of professionals, and the lack of understanding and emotional proximity [47]. Understanding these challenges gives caregivers a better sense of the hardship patients faces with their health conditions, especially chronic conditions requiring long-term care.

The effectiveness of caregiver intervention in helping chronic pain patients and their long-term health outcomes is rarely investigated. Low-quality evidence from a meta-analysis claimed that caregiving interventions had no benefits for psychological outcomes, fatigue, coping, or physical function in the long term for both patients and caregivers [51]. Recently, there was interest in informal caregiver training for people with chronic pain in musculoskeletal services, planning to investigate the feasibility and acceptability of a pragmatic, multicentre randomized controlled trial addressing the needs of people with chronic musculoskeletal pain and their caregivers [50]. Medical studies usually emphasize healthcare provider teams but seldom consider informal caregivers in team-based care; given this knowledge gap, it is essential to consider caregivers' education in patients' pain journeys.

2.2 Education

Education modules, in general, usually consist of the learning materials of theoretical and practical content delivered to users. Recently, they have become very reliant on technological and computational resources, and the learning environment that supports discussion spaces and collaborative work [3].

Knowledge management follows a five-step model: 1) knowledge identification, 2) knowledge creation, 3) knowledge preservation, 4) knowledge sharing, and 5) knowledge application; various factors influence knowledge management, including various learning activities, motivated activities, learning activities at different places, activities related to daily life, innovation in learning activities, the activities cooperated with the community, etc. [10]. It is also important for learners to achieve transfer of learning; thus, a conceptual framework for educators to design modules that emphasize four steps: 1) the activation of existing knowledge, 2) engagement with new information, 3) demonstration of competence, and 4) the application in real-world practice [6].

Therefore, learning theoretical information and applying the information in a real-life setting (ideally through different activities and achieving a collaborative community for learners) are viewed as two highly important elements in the development of education modules.

2.2.1 Pain Education

Pain education for chronic pain patients has been researched as it has an impact on health outcomes as well as quality of life. Aspects like basic principles of pain relief, pharmacologic interventions, and nondrug interventions for relief of pain were not only helpful for patients living with cancer pain, but also great information for family caregivers [21].

Neurophysiological pain education (NPE) focuses on cognitive-behavioral intervention, aiming to change maladaptive illness beliefs and maladaptive pain cognition by re-conceptualizing beliefs of pain in patients [55]. For patients with chronic low back pain, NPE has demonstrated a small to moderate effect on pain and disability; looking further, a verbal NPE could possibly help with both patient-specific and condition-specific questions [55]. Meanwhile, pain neuroscience education focuses on the biological and physiological processes involving pain experience and issues in anatomical structures; positive results were observed in musculoskeletal pain patients in improving pain ratings, pain knowledge, disability, pain catastrophization, fear-avoidance, attitudes and behaviors regarding pain, physical movement and healthcare utilization [35]. Another program, a 'Back School Programme' that aims to empower patients with chronic low back pain through assessment, education, and skill development using a health education method; it successfully improved the quality of life in patients compared to the groups that solely receive medical treatment independent of the health education [54].

Pain education involving multi-disciplinary interventions also demonstrates improvement in chronic pain patients' self-management practices and self-efficacy, mainly benefiting patients from physical activity, cognitive behavioral strategies, and general lifestyle changes [29]. Training sessions for caregivers are helpful in chronic diseases that could increase the perceived ability of caregivers to find helpful health information, resulting in possible relief from emotional burdens such as feelings of shame and embarrassment of the patients, holding challenging responsibilities and tasks, evoking caregivers' curiosity to learn about patients' conditions and behaviors [13]. Therefore, pain education in varied aspects for patients and caregivers has improved patients' health outcomes, quality of life, and caregivers' care of patients and sense of relief.

Parallely, pain education has been researched from the perspectives of healthcare providers, aiming to provide chronic pain patients with better care. There are two sides to the story: success includes multidimensional curricula and teaching methods, and challenges include identifying pain in the curricula, biomedical and biopsychosocial definitions of pain, perceived importance, time, resources, and staff knowledge as well as responsibility for pain education; as a result, pain education for health professionals has challenges in the practice of implementation, where deemed the design of pain education needed improvement [56]. On the other hand, the concept of 'patient-as-teacher' in deprived communities encourages medical educators to consider patients' personal experiences and knowledge of illness for pain education in health professionals, emphasizing community-based learning in health professionals' training [28]. The Pain Education and Empowerment program researched patients' and caregivers' unmet needs to improve patients' competency in the clinical path and to provide healthcare providers with communication strategies to achieve better care; during the exploratory survey, patients and caregivers indicated willingness to participate in patient education activities, preferably in a face-to-face format [57].

Therefore, pain education has the potential to positively impact chronic pain patients' health outcomes and quality of life, caregivers' care of patients and their own mental conditions, and healthcare professionals' perception of pain journeys. Moreover, as patients and caregivers have personal experiences going through pain journeys in the current healthcare system, their stories and insights are valuable for healthcare professionals to convey better care, especially in long-term care for people living with chronic conditions.

2.3 A Feminist Lens of Research

In sociological research, three main directions also challenge the "traditional notion of subjectivity," pushing the boundaries of subjectivity-objectivity dichotomy in human, non-human, and material entanglement, guiding researchers to rethink social-material relations [48]. Feminist postcolonial science and technology studies, one of the main directions, concerns Haraway's view on feminism and situated knowledge, claiming that "research will be less biased [...] bringing in more perspectives, [...] maximizing] objectivity by building upon a multitude of diverse subjectivities instead of only [...] limited perspectives and interests" [25, 48]. Therefore, in order to study a specific area,

combining insights from a diverse sample instead of treating participants as a homogenous whole, and combining as many communities as possible can bring researchers closer to objectivity and valuable research.

According to Donna Haraway's view of feminism, "feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become answerable for what we learn how to see," countering the scientific "pure" objectivity and claims to serve all but is in partial perspective [25]. Therefore, situated knowledge considers feminist objectivity through a specific lens, which is neither general nor homogenous, but from a specific community, which reflects "partial, locatable, critical knowledge" [25]. Working for a specific community does not mean being subjective, but rather the best practice of objectivity because "situated knowledges are about communities [...], the only way to find a larger vision is to be somewhere in particular" [25]. In other words, in order to create certain knowledge about a specific community to serve the community better, the learning and understanding have to start with the views of the specific community, not from the power above or any other places. In that way, knowledge, or research insights obtained would be the most applicable for learning, understanding, and serving the specific community.

Moreover, as this feminist lens is from a bottom-up perspective, instead of a top-down approach usually utilized in confirmatory scientific research, "situated knowledges require that the object of knowledge be pictured as an actor and agent"; in other words, "the agency of people studied itself transforms the entire project of producing social theory," emphasizing the importance of humans, belonging to specific communities, acting as active agents that would affect the nature and results of the studies [25]. The advantage of this feminist lens of research is to understand the people studied and utilize those insights to serve the people studied from "feminist embodiment, feminist hopes for partiality, objectivity, and situated knowledge," as a generic standpoint, or dichotomy of a spectrum, seemingly target everyone but targeting nothing, does not serve a bigger community, or any community [25]. In other words, people studied in the specific community should be treated as active agents that guide researchers to learn and think, from which way researchers and other people from the above gain the most realistic insights from the studies instead of treating the active agents as subjects that respond to researchers' presumptions.

Therefore, research using this feminist lens considers the agency of participants in the specific community studied, letting them lead researchers to learn, understand, and serve the specific community better with the perspectives from people in the community conceptualizing the research problems and goals. In that way, researchers can obtain knowledge that is most applicable to understanding and solving matters situated in the specific community, and in ways that consider the essence of situated, contextual knowledge with specific aspects of feminism. Together, these work as a lens to guide research practices.

2.3.1 The Feminist Lens Applied in Patient-Centred Care

Guidelines for patient-centred care were studied years ago, demonstrating the importance of patient perceptions in improving health outcomes. However, most research was found to be conducted from educators' or researchers' opinions or the observation of patients, although patient-oriented research should be navigated on patients' perceptions [53]. Nevertheless, some practices include guidelines for the caring of patients': 1) main reasons of visit, concerns and need for information, 2) "whole person," emotional needs, life issues, 3) problems to mutually agree on and manage, 4) prevention and health promotion, 5) continued relationships with doctors [53]. A narrative review and synthesis identified two gaps in patient-centred care: 1) the lack of ways to provide physical and emotional comforts for patients as the gap was known long ago but little effort had been put into training the healthcare team to achieve better care, and 2) the evaluation of healthcare professionals' skill sets for working with patients lacking personal qualities of politeness, good manners and being respectful [30].

"Patient" is essential in patient-centred care. Eighteen patients in the acute care medical unit were recruited to voice patient expectations and satisfaction for the quality and involvement of healthcare, generating five main themes: satisfaction with care, feeling respected, trusting and feeling trusted, communicating effectively, and patients to advise professional healthcare students [20]. More actionable feedback was also collected in 142 U.S. hospitals, indicating emotional support had the strongest relation to patients' rating of care, followed by coordination of care and physical comfort [45]. It showcases the importance of relieving patient distress for better health outcomes, providing patients with full details of their condition and treatment plan to ensure their safety, and having patients believe healthcare providers are doing everything they can. It

is emphasized that investigating family involvement and patient-centred care models in outpatient settings is also important [45].

Recently, more programs have shown efforts in addressing patient-centred care, including the effort to involve family caregivers [13, 39]. Providing caregiver-centred care education that was co-designed by multiple stakeholders including family caregivers to healthcare professionals has improved healthcare professionals' satisfaction with the education, knowledge and confidence, and their behaviors in practice with family caregivers [39]. Informal caregivers who receive multidisciplinary theoretical-practical training have shown effects in lowering caregiver burden and increasing their search for health information; however, more training on providing emotional and social support for the patients is needed from caregiver training [13]. Developing informal caregiver training has also shown an effect in improving the quality of life, for both patients and caregivers [13].

Together, patient-centred care evolves towards multidisciplinary approaches of combining theoretical and practical knowledge and education, as well as involving a diverse group of stakeholders such as healthcare professionals, caregivers, and patients. This is ideal but such approaches in healthcare are limited by what healthcare systems and health insurers will pay for.

2.3.2 Participatory Design

Patient-oriented research oversees four dimensions of pain-centered care: patient-as-person, biopsychosocial perspective, sharing power and responsibility, and therapeutic alliance [40]. Design research, aiming to tackle “the complexity of representation, sustainment of life, and complex social changes,” aligns with the value of person-centred care by highlighting local knowledge and practice in the process of learning about and engaging with marginalized communities [41].

Participatory design is a methodology more common in research than industry that steers between participants' practical knowledge and researchers' abstract and analytical knowledge, involving both users and designer-researchers in constituting and eliciting the research results [52]. Participatory design is framed beyond designing things, concerning “a way to gather together to express and address matters of concern

and care, along the way contesting and opening the subjective and temporalities of design beyond the trapping of expertise and professionalism,” and most importantly, “resisting the temptation to make designers authorities of [users’] collective futures [...]” [18]. In other words, participatory design invites users in the design research to participate in some stages of design with the design researchers, without being treated unevenly but to collectively create the best solutions for the problems in the communities.

In healthcare, multiple methods promote the improvement of person-centred care: process-focused approach, solution-focused approach, and problem-focused approach [5]. A process-focused approach is suitable when the services are offered but the delivery is inconsistent or not optimal, when the goal and the target audience are clear and changes within the process would elicit better health outcomes; a solution-focused approach is suitable when the service is new and hasn’t been tested, when a minimum viable product is available to test for at least one group of the users, address at least one key problem, and has great user experience and easy to be built and launched; a problem-focused approach is suitable when patients’ needs are not or poorly understood, then methods like human-centred design or experiment-based co-design will be valuable [5].

The early stages of design benefit the most from a problem-focused approach, where researchers can learn and understand the matter of concern and care from users in the process of participatory design, functioning like a needs analysis. Then, with a minimum viable product, users can participate in workshops following a solution-focused approach to give insights into further development of the product and the usability of the product. Finally, with continued follow-up, a process-focused approach is suitable to consider if the solution developed fits in the flow or process of the users by altering small parameters to measure the differences in outcomes. Healthcare mainly focuses on the process-focused approach to validate and slightly alter solutions as problem-focused approaches and solution-focused approaches are relatively new; however, problem-focused approaches and solution-focused approaches are valuable in conceptualizing the matter of concern and refining new models of care [5].

2.3.3 Human-Computer Interaction

Human-Computer Interaction is an interdisciplinary field concerning design for information, interaction, and communication and technology, studying methods and tools humans develop to process information and interact with, mainly referring to computer systems and interfaces [38]. Two main phases in human-computer interaction include: 1) to assess users' needs and provide insights on how to build solutions to match users' needs and 2) to provide directions in design and to consider usability and practices in the ideal solution [38].

The field of health technology is drawing on human-computer interaction concerning long-term disease management, collaboration between providers and patients, and patient involvement, self-management, and empowerment [49]. Future opportunities of research aim to support patient-provider interaction, support collaborative work among providers, develop and utilize new information and communication technology, design and utilize adaptive human-computer interactions, and move to e-health [49].

Design Thinking in Healthcare has improved treatment strategies through the process of the New Product Development Process, demonstrated in operating rooms in a hospital in Hong Kong [12]. Three steps include: 1) identifying opportunities, 2) understanding the opportunities, and 3) conceptualizing the opportunity [12]. When identifying the opportunities, researchers consider social trends, economic forces and technological advances by finding gaps through secondary research. When understanding the opportunities, researchers conduct field research such as in-depth interviews to learn about user behaviors and task analysis to consider users' interaction with the products. They also conduct value opportunity analyses to compare concepts and opportunities among different products or systems, and stakeholder analysis to interact with different key stakeholders to consider users applying the usage of products or systems within a team setting. When conceptualizing the opportunity, researchers convert the insights in the first two phases into a product or system concept that is "technically feasible and perceived as useful, usable and desirable" [12].

Drawing insights from research in human-computer interaction, healthcare domains can benefit from understanding any opportunities by considering patients' and

other stakeholders' desires, needs, and capacities through in-depth interviews. Further, conducting task analysis to observe users' interactions with different potential solutions is also valuable, in a sense that there are comparisons among different products studied. When considering solutions for users' matters of concern, presenting ideal solutions to seek concrete feedback on the usability and practices helps researchers understand the situated use case better, especially from different stakeholders and how they use the products in a team setting. Therefore, when understanding the opportunities in healthcare domains, researching the users' desires, needs, and capacities, as well as the context of users applying the usage of products in a team setting with different stakeholders, are important.

Chapter 3.

Methodology

3.1 Study Design

This study aimed to gain insights from patients and their caregivers about what desires, needs, and capacities were regarding education, such as what design of the products best suited considering the content and context of use, and what patients and their caregivers informed researchers regarding patient-centered care. The research design was from a patient-oriented perspective that included caregiver partners. Two phases of the workshop paralleled to understanding opportunities of product development in human-computer interaction: 1) a needs analysis to understand the needs and desires of chronic pain patients and their caregivers regarding pain education and 2) a comparative analysis to study how chronic pain patients and caregivers interact with products in a team setting, and what kinds of feedback they would give to the usability and practices of existing products.

With an emphasis on greater inclusion [25], I built on dimensions of patient-oriented care: patient-as-person, biopsychosocial perspective, sharing power and responsibility, and therapeutic alliance [40]. Moreover, this study aimed to communicate the biopsychosocial framework to participants beyond the study itself to better connect their lived experience to a widely researched framework [23]. Pain education has been pinpointed as the most effective when considering pain care professionals, patients, and stakeholders [27]. Further, with patients at the center of all clinical efforts and the collaborations of diverse health professionals who are building a new culture of pain care, it follows that pain education would reflect this, so I considered caregivers to be essential stakeholders [58]. Therefore, a needs analysis was best suited for creating conversations among people with lived experiences; the participatory design was examined in the health and human-computer interaction domains, achieving patient-as-person and sharing power and responsibility. A storytelling method using mood boards as a tool and a focus group sharing opportunity also provided participants with a safe space to achieve community bonding and work towards a therapeutic alliance [33]. Moreover, this study added a new perspective of comparative analysis, inviting patients

and caregivers as stakeholders to effectively provide constructive feedback to researchers in developing pain educational tools in the perspectives of content comprehension, medium functionality, design elements, and barrier of use [32, 61, 62].

With the feminist lens from Donna Haraway emphasizing situated knowledge, sharing powers and responsibilities with participants to learn about and serve the community better, this study used participatory design by inviting participants to be co-designers of solutions for their matters of concern, following guidelines for human-computer interaction: to assess users' needs and provide insights on how to build solutions to match users' needs and, to provide directions in design and to consider usability and practices in the ideal solution [25][52][38].

The two phases of the workshop were planned to answer the following research questions: 1) What information do chronic pain patients (and their caregivers) want to learn about how and why chronic pain is relevant to a biopsychosocial framework? 2) What content, functionality, design, and barrier of use should researchers consider when conveying pain education via video, interactive programs, and tangible media such as cards? 3) How can a needs analysis and a comparative analysis with chronic pain patients and their caregivers inform human-computer interaction researchers to develop a more patient-oriented pain education tool?

Twelve people participated in the research, including six patients and their caregivers. The needs analysis contained three activities: the pain diagram activity, where the data showcased the perception of patients' pain from their own perspectives, and their caregivers' perspectives; the mood board, where patients and caregivers used graphics, drawings, and writings to share what patient's pain meant to them; the discussion board, where patients and caregivers asked any questions about pain from the following categories: biology, psychology, social, treatments, support, and others. The comparative analysis contained two activities: the exploration of existing education tools, which showcase patients' and caregivers' points of view on the tools' content comprehension, medium functionality, design elements, and barrier of use, giving researchers and designers a sense of how participants viewed education tools connecting with existing products; the semi-structured interview, more was shown about participants' views on the current products, the relationships between the current tools and their desires, needs and capacities regarding pain education (see Figure 3.1).

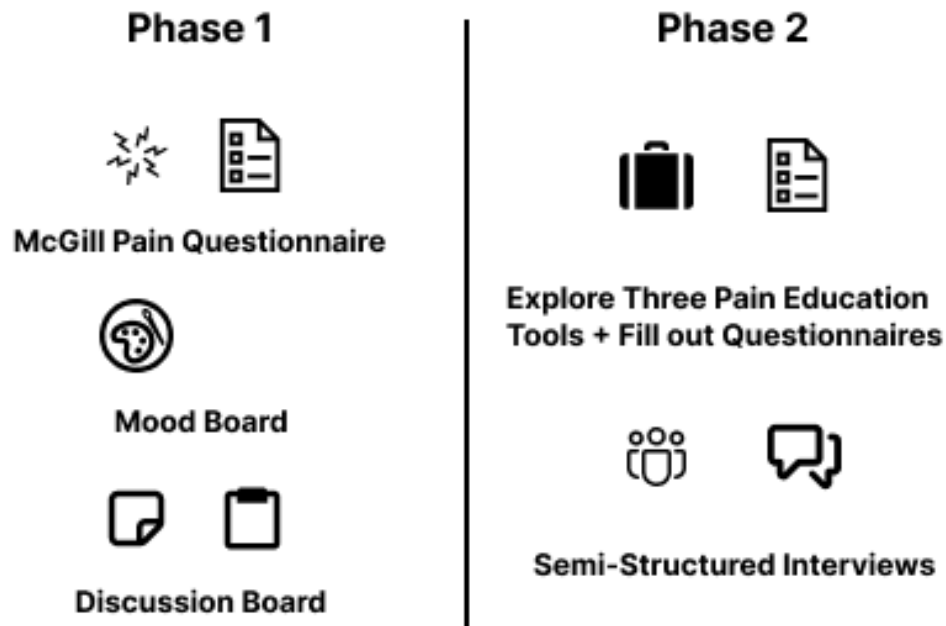


Figure 3.1: Procedures for the workshop. Each workshop lasts for around three hours.

Importantly, I designed the study to foster more input from participants to give them a sense of agency from sharing the power and responsibilities to attend to their matters of concern, educating people outside the pain communities about their conditions and voicing their desires, needs, and capacities. In this way, participants become co-designers of solutions for their challenges; they advocate for themselves, which gives them agency to change current conditions, which is very critical as they face many challenges (e.g., hardship in obtaining a proper diagnosis because of the lack of biomarker of pain, making them try to prove the pain is “real” or being turned away) in their pain journeys that have created hardship for them to gain a sense of hope. By showing their desires, needs, and capacities, and not following rigid structures of traditional top-down research approaches, participants are believed to contribute their forms of expertise that could make a difference for their own communities, showcasing the meaningfulness of patient-centred care as a guideline and participatory design as a research method.

3.2 Participants

Ethics approval was obtained through the Research Ethics Board at Simon Fraser University, with one Minimal Risk Approvals and two Amendment Approvals. This was a minimal-risk study, meaning participants did not face the risks exceeding those they face in everyday life.

Participants were recruited through Reach BC, where volunteers could sign up for health research in British Columbia and be matched with studies. Recruitment posters were also distributed through SFU Campuses. To be qualified for the study, the volunteers must: 1) be over 19 years old, 2) experience chronic pain for longer than 12 weeks, 3) have an existing medical diagnosis of chronic pain for six months or more, 4) have normal or corrected-to-normal eye vision, 5) have normal hearing, 6) be able to understand the English language and read and write in English, 7) have a caregiver presented and be willing to participate in the study (caregiver: a person who helps (regularly or occasionally) with patients' daily life, day-to-day activities, etc. (healthcare professionals, family, friends, etc.)). To qualify as caregivers, the second group of volunteers must: 1) be over 19 years old, 2) have normal or corrected-to-normal eye vision, 3) have normal hearing, 4) be able to understand the English language and read and write in English.

Every chronic pain patient and their² caregiver participated in the workshop at the same time as a pair.

3.3 Procedures

3.3.1 Informed Consent

Informed consent was distributed in print at the beginning of the workshop. After carefully reading information about the purpose of the research, participant recruitment and selection, study methods, benefits and risks, payment, withdrawal, data storage, and acceptance of the form, participants decided if they would like to participate in the study. They were also reminded that the workshop would be recorded and told they

² In this thesis, all participants are referred to using the pronoun “they/them” to avoid revealing information about their genders, especially when only one participant identified as non-binary.

could withdraw anytime during the study. To consent, they provided their name, email, date, and signature at the end of the form. All participants were anonymized and referred to by their code, for example, “patient one” as “P1”, and “caregiver one,” who was patient one’s caregiver, was referred to as “C1”.

3.3.2 The McGill Pain Questionnaire (adapted)

An adapted version of the McGill Pain Questionnaire has four parts: 1) where is your pain, inviting chronic pain patients to draw on the body diagram about areas of their pain, whether they are internal or external, and caregivers to draw their perceptions of patients’ pain; 2) what does your pain feel like, inviting patients to circle the words that can describe their pain from any words listed in 20 groups, and caregivers to circle their perception of patients’ pain; 3) how does your pain change with time, inviting patients to choose the pattern of their pain from three groups of words, as well as answering what relieve/ increase their pain, and caregivers to answer their perceptions of patients’ pain; 4) how strong is your pain, inviting patients to rate their pain in six different conditions, caregivers to answer their perceptions of patients’ pain (see Appendix A) [36].

The purpose of completing the adapted version of the McGill Pain Questionnaire in a participatory design workshop was to get participants to reflect on their pain and to remind them of the process of completing the pain questionnaire in a healthcare setting; however, in a participatory design workshop they had more freedom to represent and to talk about their pain: they could draw on a body diagram and express their pain in internal, external or both internal and external ways, they could circle more than one word in each group in the 20 groups of words describing their pain, they could also use different colors to correspond their pain diagram with different groups of words if they would like to visualize more than one area of pain, they could write down things help with their pain instead of choosing from certain categories, and they could choose to either rate or describe their levels of pain (see Figure 3.2). Moreover, patients and caregivers could leave some areas blank if that exceeded their knowledge of the patient’s pain. The purpose of having caregivers fill out the same questionnaire about patients’ pain was to assess how well they knew their patients’ conditions. The adapted McGill Pain Questionnaire also helped researchers understand each patient’s pain better, as well as the background of their conditions.

All participants completed this session in 10 minutes.

The McGill Pain Questionnaire < Sample , Not Real Data >

Part 1: Where is your pain?

Please mark on the drawing below, the areas where you feel pain. Put E if external, or I if internal, near rge areas which you mark. Put EI if both external and internal.

Part 2: What does your pain feel like?

1 Flukering Oulvering Pulsing Throbbing Beating Pounding	2 Jumping Pricking Shooting	3 Pricking Boring Drilling Stabbing Lancinating	4 Sharp Cutting Lacerating
5 Pinching Pressing Gnawing Camping Crushing	6 Tugging Pulling Wrenching	7 Hot Burning Scalding Searing	8 Tingling Itchy Smarting Stinging
9 Dull Sore Itching Aching Heavy	10 Tender Taut Ringing Splitting	11 Tiring Exhausting	12 Sickening Suffocating
13 Fearful Frightful Terrifying	14 Punishing Graeling Cruel Vicious Killing	15 Wretched Blinding	16 Annoying Irritating Miserable Intense Unbearable
17 Spreading Radiating Penetrating Piercing	18 Tight Numb Drawing Severing Tearing	19 Cool Cold Freezing	20 Nagging Nauseating Agonizing Dreadful Torturing

Part 3: How does your pain change with time?

1. Which word or words would you use to describe the pattern of your pain?

1 Continuous Steady Constant	2 Rhythmic Periodic Intermittent	3 Brief Momentary Transient
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2. What kind of things relieve your pain?

Heating Pad, Slow walk,
Hot Shower

3. What kind of things increase your pain?

Standing too long,
Walking too fast

Part 4: How strong is your pain?

People agree that the following five words represent pain of increasing intensity. They are:

1 Mild	2 Discomforting	3 Distressing	4 Horrible	5 Excruciating
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To answer each question below, write the number of the most appropriate word in the space beside the question.

- Which word describes your pain right now? B
- Which word describes it as its worst? B+t
- Which word describes it when it is least? (Never)
- Which word describes the worst toothache you ever had? C
- Which word describes the worst headache you ever had? A
- Which word describes the worst stomachache you ever had? B+t

Adapted from:
Melzack, R. (1975). *McGill Pain Questionnaire (MPQ)* [Database record]. APA PsycTests.
<https://doi.org/10.1037/104164-000>

Figure 3.2: An example of the adapted McGill Pain Questionnaire. Adapted from the McGill Pain Questionnaire [36]. Patients and caregivers can use different colors to label their pain (internal, external, or both internal and external), can circle more than one word from the 20 groups of words, and can use words to describe how their pain changes and how strong their pain is.

3.3.3 Mood Board

A total of 73 photos were chosen by four researchers in the Pain Studies Lab from the open photo source, the Open Affective Standardized Image Set (OASIS), for participants to complete their mood board (see Appendix B) [31]. Researchers chose images by considering three emotional valences: positive, negative, and neutral. Participants were invited to use the printed photos and colored pens to write or draw any thoughts relevant to the prompts (see Figure 3.3). The prompt for chronic pain patients

was “What is your pain like?” and the prompt for caregivers was “What is your partner’s³ pain like?”

All participants completed this session in 10 minutes. After that, they were invited to speak and share their mood board in a group. The audio was transcribed and analyzed.

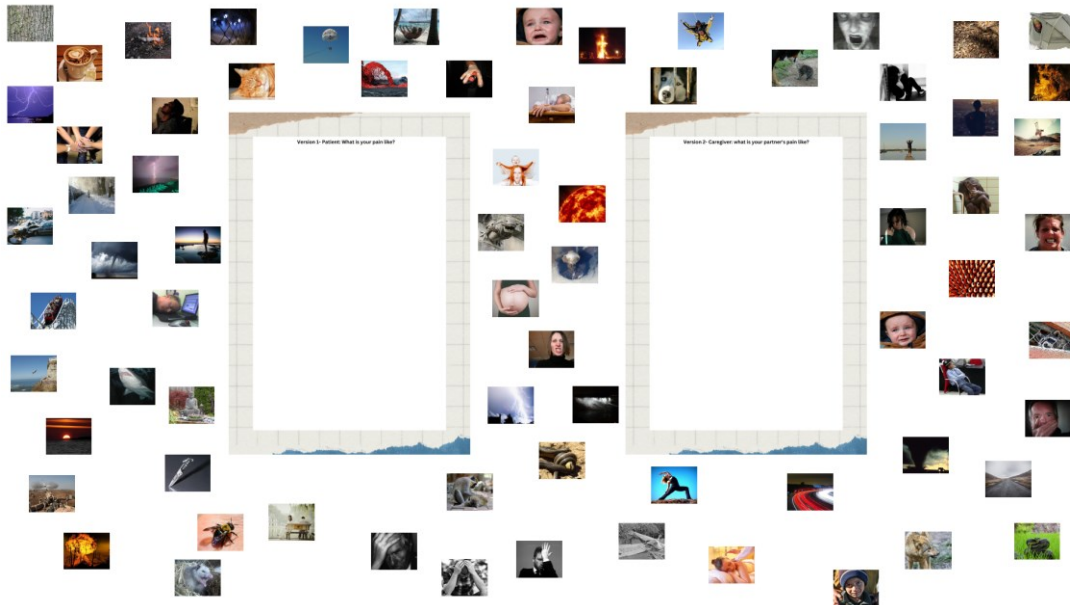


Figure 3.3: The mood boards for chronic pain patients and caregivers with images. Chronic pain patients and their caregivers used images and pens to write or draw on the mood boards. Version one, on the left, with the prompt: “What is your pain like?” was for patients; version two, on the right, with the prompt: “What is your partner’s pain like?” was for caregivers. Images were chosen from the Open Affective Standardized Image Set (OASIS) [31].

3.3.4 Discussion Board

A discussion board posted a question: “What do you wish to know about pain?” The board was separated into six sections: biology, psychology, social, treatment, support, and others (see Appendix C). Participants wrote their questions on sticky notes labeled with their codes and stuck them on the discussion board (see Figure 3.4).

³ The word “partner” was used in the workshop to refer to those who were cared for by the caregiver. Since using the word “patient” might indicate a patient-doctor relationship instead of a patient-caregiver relationship, “What is your partner’s pain like?” was written instead.

All participants completed this session in 10 minutes.

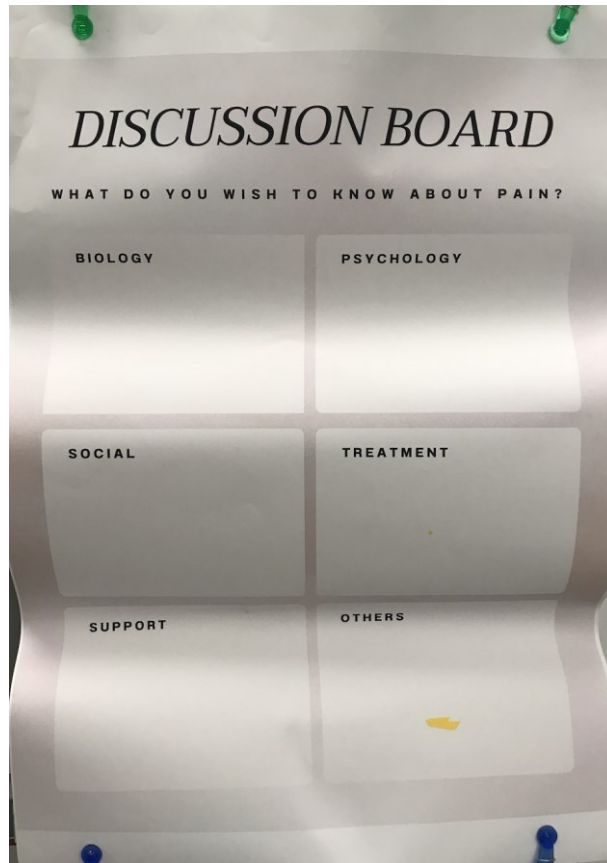


Figure 3.4: The discussion board in the Pain Studies Lab. Chronic pain patients and their caregivers were invited to write down what they wished to know about pain in six themes (biology, psychology, social, treatment, support, and others) on sticky notes and put them on the discussion board.

3.3.5 Three Education Tools

All participants were invited to explore three education tools. They watched a five-minute video from Tame the Beast⁴, named “it’s time to rethink persistent pain.” An option to rewatch was provided, but none of the four groups chose to rewatch the video [37]. After that, they were invited to fill out a questionnaire containing 43 questions about content comprehension, medium functionality, design elements, and barriers of use of the product (see Appendix D). Then, a group of participants was invited to explore

⁴ In this thesis, the five-minute video of “it’s time to rethink persistent pain” on the website of Tame the Beast is referred to as “Tame the Beast” [37].

Tinybop⁵ [1], an interactive application on an iPad from the series Tinybop that allowed participants to initiate external stimuli to affect a human body (e.g., having the bee stink the person) and the application reflected how the corresponding system work (e.g., how the nervous system respond to the action). Another group of participants explored four selected sections of Why You Hurt⁶, a set of tangible cards that teach patients about pain and elicit meaningful conversations [34].

Tame the Beast. Developed by Professor Lorimer Moseley, a pain scientist at the University of South Australia, and Dave Moen, whose team develops online treatment tools for patients and offers online treatment tools and video consultation for chronic pain patients all over the world, Tame the Beast aims to help people manage their pain [37]. It contains a five-minute video to inform the audience to “rethink persistent pain,” if anyone wishes to learn more, the website directs them to useful resources. The resources include two sections: understanding pain and moving toward recovery. In “Understanding Pain,” they offer more services like online pain treatment and clinical skills and links to more video resources like patient perspective, TED talks, podcasts, pain science, animation, and reading stories and metaphors. In “Moving Towards Recovery,” they offer video consultation for individual or group coaching, a free course in mindfulness, and an online pain management program based on Cognitive Behavioral Therapy. In the workshop, I showed participants the five-minute video “It’s time to rethink persistent pain,” in which Professor Lorimer Moseley guided users to understand nociceptive pain, which was triggered by external stimuli, and neuropathic pain, which was learned by the nervous system without the presence of external stimuli. He then proposed that the pain system can be retrained like people can tame the beast. He visualized pain as a beast sitting on patients’ shoulders and biting them (see Figure 3.5).

⁵ In this thesis, the app “Tinybop: the Human Body” is referred to as “Tinybop”[1].

⁶ In this thesis, the tangible cards from “Why You Hurt: Pain Neuroscience Education System” is referred to as “Why You Hurt” [34].

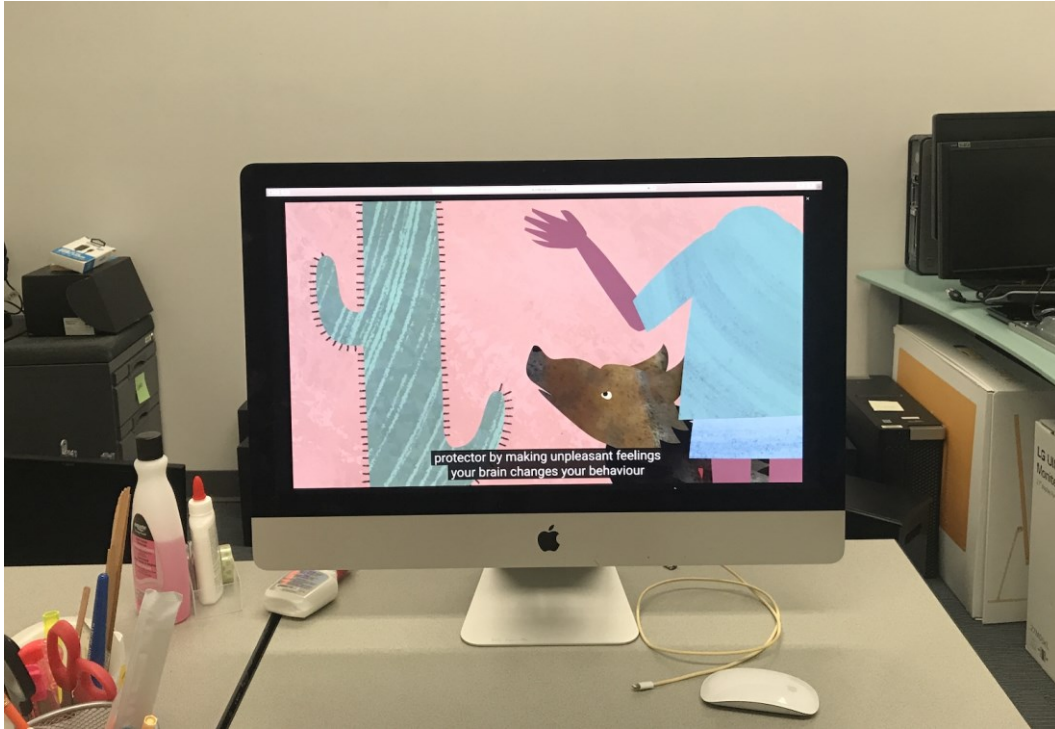


Figure 3.5: Tame the Beast being played in the Pain Studies Lab for participants. A five-minute video, “It’s time to rethink persistent pain,” introduces neuropathic pain to the audience [37].

Why You Hurt. Why You Hurt series contains textbooks, clinical tools and patient books. In this study, Why You Hurt: Pain Neuroscience Education System, participants were offered a set of physical cards to navigate. The cards developed by the Physical therapist Adriaan Louw aim to help healthcare providers engage in meaningful discussions with their patients, using easily internalized metaphors to convey complex neuroscientific knowledge [34]. For each card, visualizations are shown in the front and simple bullet points to explain the graphics are shown in the back. A digital version is available; however, it was not used in this study. Four sections were displayed for participants to navigate: the Brain’s Body Maps, Emotions and Pain, Lions and Stress, and Neurogenic Inflammation (see Figure 3.6).

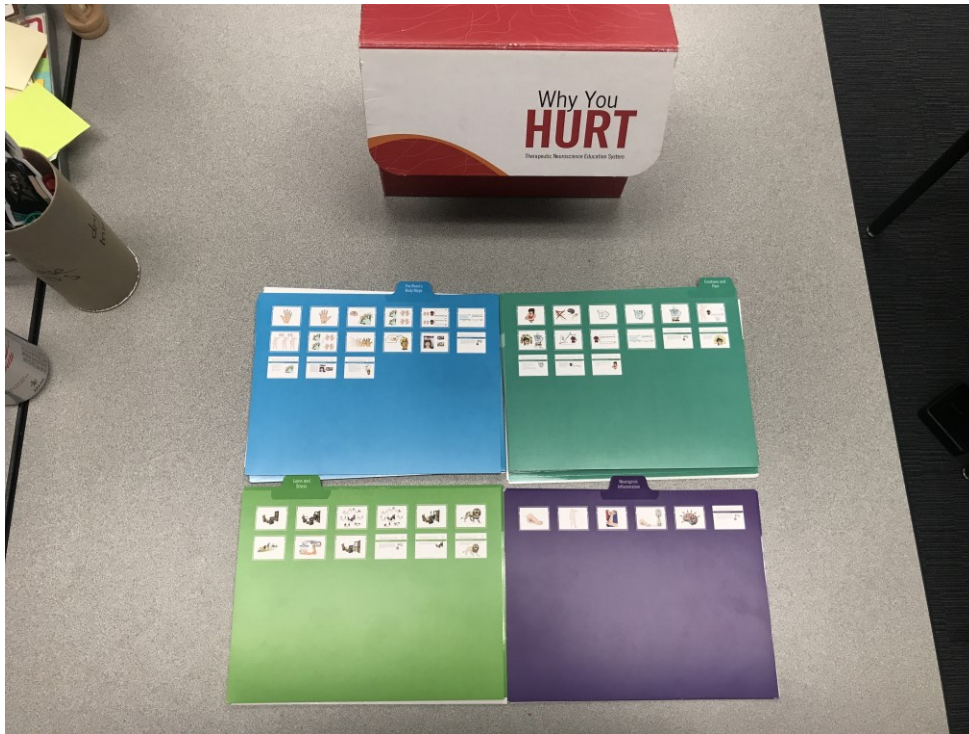


Figure 3.6: Four sections of Why You Hurt were displayed for participants in the Pain Studies Lab. Four sections from the Why You Hurt physical cards were displayed for participants to navigate: the Brain's Body Maps, Emotions and Pain, Lions and Stress, and Neurogenic Inflammation [34].

Tinybop. Tinybop: the Human Body is an app used as an interactive model, helping users navigate the skeletal, muscular, nervous, circulatory, respiratory, and digestive systems (see Figure 3.7). It was designed by Kelli Anderson, an artist who aims to discover new ways to create images and experiences (e.g., not getting queasy while drawing the vomit) so that users can learn about the human body [1]. The app is tested with kids older than four years old, as it is aimed to be a kid's learning handbook in an interactive format. When users select something, usually an external stimulus, the corresponding system responds and shows effects in animation; however, no text is available in the application. This application is not directly relevant in the context of pain. How the system responds to external stimuli can potentially deliver pain-related education.

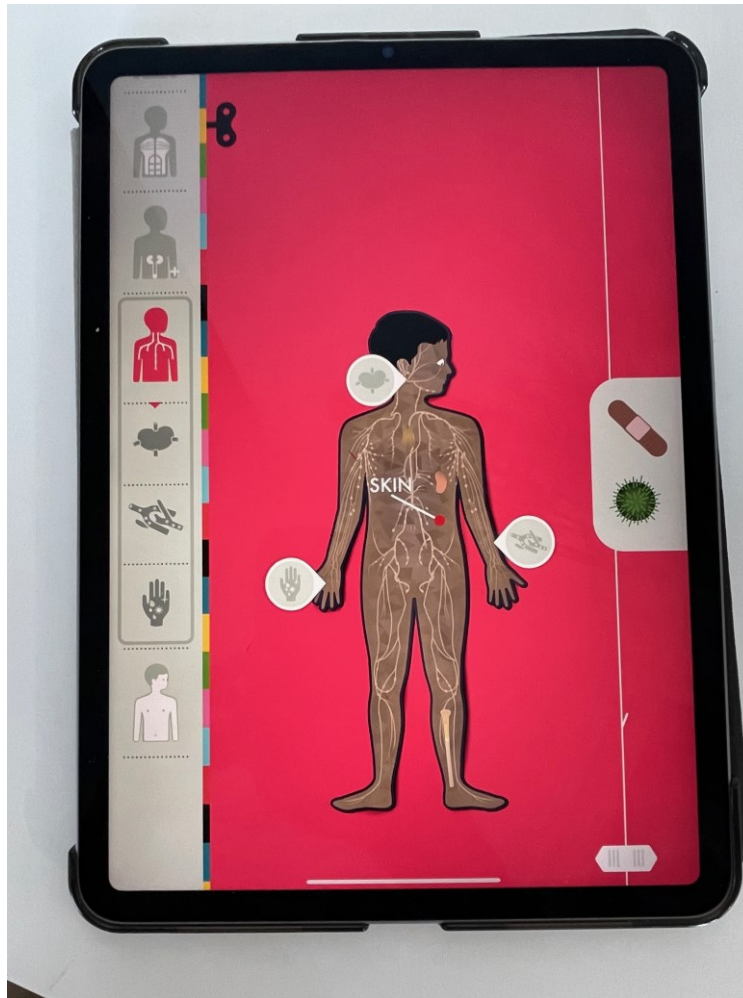


Figure 3.7: Tinybop on an iPad for participants to explore in the Pain Studies Lab.
Tinybop: the Human Body visualization from the purchased application [1].

They had 10 minutes to explore each product, after which they filled out the same questionnaire about content comprehension, medium functionality, design elements, and barrier of use of the product. Then the two pairs of participants switched to explore their third product, after which they filled out the same questionnaire again.

The questionnaire was developed by adapting multiple questionnaires on the topics of content comprehension, medium functionality, design elements, and barrier of use, such as Cognitive Load (TLX), usability scale, and other aspects discussed in other co-creation workshops on the topic of chronic pain [32, 61, 62].

3.3.6 Semi-Structured Interview

After exploring the three education tools and completing the questionnaires, participants were invited, as pairs (e.g., P1 and C1), to join me for a semi-structured interview where they could comment further on the three products and also discuss their desires, needs, and capacities regarding the use of pain education tools. The interview had five questions, and the patient was invited to speak first about issues, followed by the caregiver (see Appendix E). Patients and caregivers were interviewed in pairs because I considered that more closely connected to their dynamic in real life, they focus on patients' pain journey: they would likely use the products together at home, or when completing tasks, caregivers assisted patients in achieving the goals. There were concerns about the study design that caregivers might not speak truthfully in front of patients or would be led by patients when answering the questions; however, I still considered interviewing them as a pair valuable as it was closer to what happens in their lives, and the observation of their interactions was also valuable.

The questions include: 1) From the three pain educational tools, which helps you learn best about pain, and why? 2) From the three pain educational tools, which do you think you will constantly use in your everyday life? 3) From the three pain educational tools, which delivery methods work best for you, and why? 4) Do you have any suggestions for improvements for the three educational tools? 5) What do you wish to have learned about pain, but the three educational tools did not achieve?

3.4 Data Analysis Strategies

I collected both quantitative and qualitative data.

3.4.1 Quantitative Data

The questionnaire has 43 questions on a seven-point scale related to content comprehension, medium functionality, design elements, and barrier of use. Both patients and caregivers filled out the questionnaire three times after exploring each of the three education tools. Therefore, a factorial ANOVA was conducted to analyze the differences in participants' perspectives among the three education tools and the differences between patients and caregivers. There was also quantitative data in the McGill Pain

Questionnaire about how many words describing pain caregivers correctly predicted patients' pain and how strong the patients were. The scores were averaged to provide information from patients' and caregivers' perspectives and compare patients' and caregivers' perspectives.

3.4.2 Qualitative Data

The largest set of qualitative data was the transcription of the semi-structured interviews. Thematic analysis was the main method for analyzing the transcript.

Thematic analysis is a method in qualitative data analysis, where qualitative researchers generate common themes and codes from transcripts of interviews that are relevant to research questions [7]. Although I was the lead student researcher in this study, it was best to have multiple people analyze the qualitative data via thematic analysis. I closely followed guidelines proposed by the CRICH Survey Research Unit and our team of collaborators enhanced data analysis quality as we cross-verified themes and codes, which would diminish the likelihood of themes and codes being generated because of a single researcher's perspective [15].

A codebook was developed by a team of three researchers in the Pain Studies Lab, including the lead student researcher (me), one person with lived experience of chronic pain, and a research assistant. An observer, who was another research assistant, observed the coding meetings, took notes, and provided comments when applicable. After the codebook was finalized, I went back to apply the themes and codes to relevant content and generated insights.

Other qualitative data included the drawing and selection of questions in the McGill Pain Questionnaire, which provided background information about patients' pain and caregivers' views of patients' pain. It was analyzed and compared between patient and caregiver. The mood boards themselves were analyzed, and the transcription of speaking about the mood board was analyzed by the same three researchers using thematic analysis, coming up with new themes and codes. The discussion board questions were presented, and topics were generated by me, connecting patients' conditions with their questions.

Chapter 4.

Result

A total of 14 participants expressed interest in six months, ten from Reach BC and four from recruitment posters. However, due to the schedule conflict, as well as two no-shows and two last-minute reschedulings, the workshop was broken down into four workshops, with the same procedure and materials, while two workshops had only one pair of participants, and two other workshops had two pairs of participants (see Figure 4.1). Eventually, data was collected from six pairs of participants (a total of 12 people: six chronic pain patients and six caregivers). Each workshop was completed within three hours.

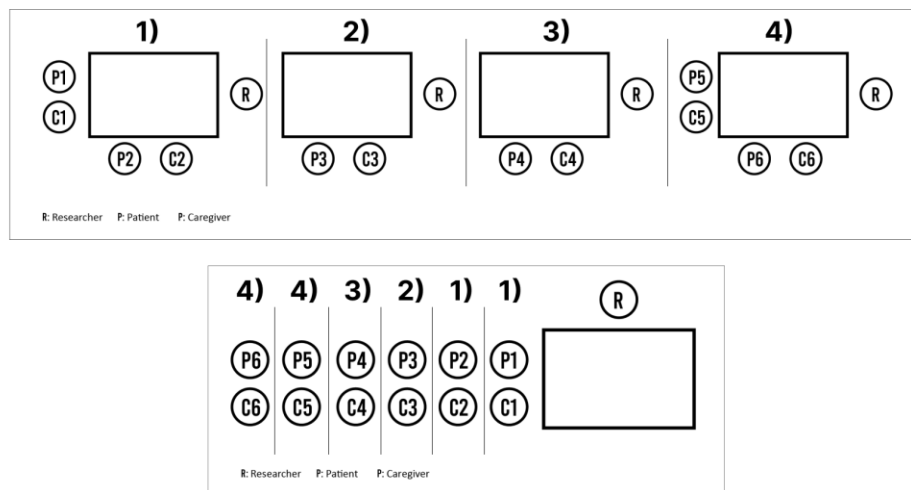


Figure 4.1: The visualization of the four workshops. The top visualization showcased participants' and researcher's positions in four different workshops on 1) November 4th, 2023, 2) February 11th, 2024, 3) February 15th, 2024, and 4) March 17th, 2024, respectively. Participants completed the adapted McGill Pain Questionnaire, the mood board, the discussion board, and watched Tame the Beast and completed the questionnaire about Tame the Beast within their designated group. The bottom visualization showcased that participants explored Why You Hurt and Tinybop and completed the Questionnaires about Why You Hurt and Tinybop only with their study partner, then joined the semi-structured interview as a pair with the researcher, away from other participants.

Among the chronic pain patients, five identified as female and one as non-binary, from age 22 to 60 ($M_{age} = 38.33$, $SD_{age} = 17.42$; $M_{years\ of\ chronic\ pain} = 16.58$, $SD_{years\ of\ chronic\ pain} = 14.53$). Among the caregivers, four identified as male and two as female, from age 24 to 82 ($M_{age} = 40.67$, $SD_{age} = 22.93$; $M_{years\ of\ being\ a\ caregiver} = 10.81$, $SD_{years\ of\ being\ a\ caregiver} = 15.92$). Three caregivers were the partners of the patients, one was the mother of the patient, one was the daughter of the patient, and one was a friend of the patient.

4.1 Adapted Version of McGill Pain Questionnaire

The areas of pain colored by patients and caregivers aligned closely, although, in two out of six instances, caregivers colored more areas than their patients, indicating that caregivers perceived more areas of pain than the patients perceived they experienced. However, the knowledge of whether the pain was internal, external or both internal and external was different between the patient and the caregiver, except for one pair of participants that matched exactly. It could indicate either patients and caregivers had different perceptions of the definitions of internal, external or both internal and external pain, or caregivers did not know whether their patients' pain was internal, external or both internal and external. Moreover, five out of six patients had more than one area of pain.

Circling the words in the 20 groups of words that describe pain, excluding false positives, caregivers had about half of the chance to predict the description of patients' pain accurately, and the success rate looked very different among all caregivers ($M = 0.42$, $SD = 0.24$). Caregivers had slightly worse success rates for the prediction of patient's pain patterns and the success rates looked very different among all caregivers ($M = 0.40$, $SD = 0.38$). Caregivers had the worst success rates for the prediction of the strength of the patient's pain under six scenarios, although the difference among all caregivers' success rates was lower ($M = 0.33$, $SD = 0.20$). However, two out of six patients use other words instead of the given words to describe their pain as one of them considers themselves to have a higher pain threshold, and the other patient does not find the given words best describe their strength of pain.

Ways patients identified to relieve their pain included a hot shower, changing position (sitting to walking or walking to sitting), heating pad, meditation, breathing, art, gardening, jokes, friends, tapping, messages, pain meds, tiger balm, distraction, going for walks, ice/ heat body, hydrotherapy, stretching, acupressure, Epson bath, few days after treatment, muscle relaxation. Ways caregivers noticed patients relieved their pain included: heating pads, meditation, friends, resting, hot and long baths, massages, art, jokes, gardening, light movements, stretches, sleep, meditation, hot/cold pads, weed, and pain killers.

Ways patients identified that could increase their pain included prolonged sitting, prolonged standing, prolonged walking, exertion, negative emotions, negative thinking, past thoughts, doing repetitive activities, severe stress, extreme heat/cold, dehydration, climbing stairs, sports, and eating hard foods. Ways caregivers noticed that increased patients' pain included walking any distance at all, getting up and sitting down and bending, being still for long periods, being very physically active, sports, and tiredness.

4.2 Mood Boards

Patients and caregivers used images, words and drawings to describe patients' pain. Then, they took turns to speak about their mood boards in a group setting.

From their mood boards, elements chosen more than three times include lightning, roller-coaster, knife, fire, trapped animals, angry animals, crying babies, the person holding their head, the person putting their head on the desk, and a person grinding their teeth.

Two caregivers also lived with chronic pain, and only they picked the lightening photos to describe patients' pain. Four out of six patients picked the lightning photos to help describe their pain.

Three researchers in the Pain Studies Lab developed codes separately on the transcription of participants sharing their mood boards, and they had three meetings to discuss codes and generate the codes into themes (see Table 4.1).

	Theme	Codes
#1	Patient History	1. Years/ Length of chronic pain; 2. Areas of pain; 3. Medical conditions
#2	Pain Management	1. Pain management strategies; 2. Long for more comprehensive care;
#3	The Impact of Chronic Pain	1. Impact on mobility/ physical conditions; 2. Impact on mentality/ mental health/ mental capacity; 3. Grief of what they were like before having chronic pain;
#4	Attitudes	1. Attitudes towards themselves; 2. Negative thoughts of future; 3. Acceptance/ effort in accepting pain
#5	Social/ Relationship	1.Social desire and support from the community 2. Support from healthcare provider; 3. Patient acknowledges the support of caregiver; 4. A feeling of loneliness
#6	Descriptions of Pain	1. Burning pain; 2. Constant/Never-ending; 3 Lighting, explosive; 4. Sudden/Unexpected; 5. Cold; 6. Instability of pain levels; 7. Debilitating; 8. Stabbing pain; 9. Shooting pain; 10. Mental pain and emotional pain; 11. Tingling pain;
#7	The Role of Caregiver	1. Forgiving the patient; 2. Caregivers' view of what patients' pain is like; 3. Caregiver's support of patient's daily life; 4. Caregiver's memory of how patients describe their pain/conditions; 5. Caregiver's description of patients' behaviors/ conditions when they are in pain

Table 4.1: Themes in the mood board activity

4.2.1 Patient History

Patients tended to introduce their patient history, such as years of chronic pain, area of pain, and related medical conditions. Two patients lived with chronic pain all their lives. Some areas of pain patients mentioned included legs and hips, knee pain, calf muscle pain, and migrates. When approaching chronic pain, patients also discussed their medical conditions, such as needing a hip replacement, being born with foot deformities, eventually developing arthritis, having the temporomandibular joints as the bone structure was not corrected, and connecting to neck pain and migraines.

4.2.2 Pain Management

One participant talked about their pain management strategies, such as doing light exercises from YouTube, which positively impacted their mobility and pain, motivating them to keep going. Meditation also kept their thoughts “pure,” where they experienced less pain. Patients also longed for more comprehensive care; they expressed that support from doctors was not enough as patients were primarily rushed

and needed a team they could rely on. One participant had to wait three months to see “a good doctor.”

4.2.3 The Impact of Chronic Pain

Participants’ mobility and physical condition could be impacted by chronic pain; one mentioned that they could not walk more than two blocks, and one mentioned that they always felt cold. They also considered chronic pain impacting their mental states as they saw themselves as a scared kitten and whiny dog, claiming that pain made them tired, scared, depressed, angry, and irritable; one patient had trouble sleeping and considered themselves unable to enjoy life fully. In caregivers’ views, two patients used to be active before chronic pain, and they felt the grief of what the patients’ lives were like before chronic pain for the patients as now they needed to take breaks often.

4.2.4 Attitudes

Patients’ attitudes towards themselves were impacted by their pain conditions, such as accusing themselves of causing their own health conditions, perceiving themselves as a burden to caregivers and healthcare teams, sick of themselves for always crying, distressing like a baby worrying about their safety. Patients also expressed negative thoughts about the future, worrying that pain might get worse. However, the same patients expressed that they had accepted that pain was not going to go away; one patient established the acceptance through meditating, letting go, forgiving, praying, and learning. However, the patient considered themselves stuck as they could not have negative thoughts of others at all, or else they would be crippled in pain.

4.2.5 Social/Relationship

Patients also mentioned their social desire and support from the community. One patient worried about not getting a life partner in the future while appreciating the support and the connections in their community they currently had. Patients also mentioned getting support from their medical team, although they perceived doctors to be frustrated, too. One patient acknowledged the support of their caregiver using an image of two people sitting in the hammock representing them and their caregiver and saying

companionship meant a lot. However, they still felt lonely regardless of being accompanied by a caregiver.

4.2.6 Descriptions of Pain

Patients' descriptions of their pain could be categorized into the following types: 1) burning pain: some patients used fire to represent their pain that it burnt, 2) constant/ never-ending: patients described their pain as constant and draining, persistent and never-ending, as they were "always in pain," 3) lighting, explosive: firing pain for migraine, 4) sudden/ unexpected: pain could come suddenly without an advance, 5) cold: pain was cold as well as their body felt cold, 6) instability of pain levels: sometimes the pain was not there at all, but very rare, and for some pain "can go from zero to whatever, in seconds," 7) debilitating: making the patients debilitating, like impacts of knife or inferno, 8) stabbing pain: stabs, pinches or poles like being wrapped in barbed wire; stabbing pain from the inner knee down to the ankles, 9) shooting pain, 10) mental and emotional pain, and 11) tingling pain.

4.2.7 The Role of Caregiver

One caregiver mentioned forgiving the patient as they were hard to deal with when in pain, but it was understandable. Caregivers also mentioned their views of what patients' pain was like: constant pain, always there, and sometimes worse, and continuous pain of feeling squeezed and suddenly a sharp pain that comes and goes. Caregivers shared their support of patients' daily lives: talked with them, helped them get out of bed, dressed, did small tasks, and massaged them. Although caregivers expressed not knowing what to do sometimes, helping the patients gives caregivers agency to do something for the patient. Caregivers also discussed their memory of how patients described their pain/condition: "pulsating and twisting," worrying about themselves could not walk in the future, "sharp, drilling pain, like somebody's putting a screw in or hit them with a pin," the type of pain like knives, like a strike. Caregivers also described patients' behaviors and conditions when they were in pain. One caregiver noticed the patient's pain got worse in the rain, and they got angry very fast and very irritable. One caregiver felt the patient "being trapped" and could not do much. One caregiver claimed that pain made the patient tired and needed to rest to recover; doing things made them depressed and took a lot of energy; they also noticed the highs and

lows of the patient from good days and bad days. More descriptions included patients grinding teeth and crying when in pain when the pain was overwhelming, the patient could not do much, being on the couch, wishing the pain could go away, and needing to lie down, especially when having done something the previous day. Sometimes, patients seemed to be like snakes, screaming and gasping for air as the pain was constricting, and they just tried to breathe in to keep themselves alive. Their body was exhausted after pain, as “everything’s come in and [they’re] just exhausted.”

4.3 Discussion Board

Patients and caregivers used sticky notes to write down anything they wished to know about pain in biology, psychology, social, treatment, support, and others. Two out of six patients did not have questions about pain; they wrote down things they wished other people living with chronic pain would know, and their responses were marked as ** (see Table 4.2).

	Patients	Caregivers
Biology	<p>What can I do to manage chronic pain? *Epson salts*</p> <p>What can I do to ease pain? *moist heating pad* *hot bath**cold compress*</p> <p>*Exact mechanism of my specific arthritis so that I have a better targeted⁷ medication plan rather than throwing things at a wall and seeing what sticks*</p> <p>Why are some triggers worse than others?</p>	<p>Why only at specific areas?</p> <p>Is there a way to manage your brain in order to force it to correctly detect pain?</p> <p>Is the problem naturally built (inherited)?</p>

⁷ The table recorded participants’ writing directly, so grammatic errors are expected.

	<p>What pain management techniques are proven to be most effective?</p> <p>How do all these body parts get connected (jaw, neck, mouth, head)?</p>	
Psychology	<p>What helps heal pain?</p> <p>*meditate**mindfulness*</p> <p>*Crying is good reliver. *</p> <p>*Body-brain connection review (controlling mental health to get better control of physical) but NOT discarding the physical pain (it's not all in your head) *</p> <p>*Reminder that this is NOT normal, other people don't just cope with pains or life better than you. You are experiencing an actual disease/ disorder*</p> <p>With a TBI, are there some areas that can cause the pain?</p> <p>Is mental escapism an okay way to take a break from pain?</p> <p>How much does pain affect a person's mood?</p>	<p>*Thinking, trying to train your mind into ignoring pain by distractions and focusing on other things to forget pain*</p> <p>What do pain meds really do?</p> <p>Best way to comfort – how to maintain positive attitude/ mood towards the treatment?</p> <p>Stress, pressure - which caused the pain?</p>
Social	<p>*Find like people* *support group*</p>	<p>How do I access disabled seating/ parking etc. when I</p>

	<p>How to describe invisible disability to strangers?</p> <p>Tips for preventing social isolation?</p> <p>How can I let people know what I'm going through without scaring them or pushing them away?</p> <p>When can I play sports again?</p> <p>In average, people with chronic pain is an introvert or extrovert?</p>	<p>have a hidden disability and feel judged?</p> <p>Pain interferes with social interaction – why is this?</p> <p>What percentage of Canadians are aware of how chronic illness effects people lives?</p> <p>What can the pain impact people socially? How can friends from social group do to help?</p>
<p>Treatment</p>	<p>*Trigger point injections*</p> <p>*Biofeedback*</p> <p>How do you get treatment for something if doctors can't explain it?</p> <p>What new pain treatments are there?</p> <p>Why is it hurting? When will it stop?</p> <p>I've been told it is my calve muscle that are causing the pain... is this true?</p> <p>Other than pain killers, any other tx can help with chronic pain?</p>	<p>*Medical supplements like collagen more than 1 type, glucosamine, MSM, turmeric, natural herbs, CoQ10, massage therapy on a weekly basis*</p> <p>*Swimming and short walks when possible. Ice packs and heating pads. Small weight lifting if weight problem is cause of pain. Positive thinking makes a difference with pain management*</p> <p>Is "natural" pain med just as effective?</p>

		<p>What does massage do to “ease” the pain?</p> <p>What is the role of new treatments for existing conditions being released to the public?</p> <p>What type of physical or mental methods?</p>
Support	<p>*Facebook friend*</p> <p>*Easier access to financial help*</p> <p>With such pain diversity – how do you get support? Someone to understand.</p> <p>How do I make sure my caregivers are supported and don’t burn out?</p> <p>What pain management resources are there?</p>	<p>How do I help my partner feel less alone?</p> <p>What resources are available for natural remedies against chronic pain?</p> <p>What can caregivers do to support them through the treatment of pain?</p> <p>Any?</p>
Others	<p>*Believe in healing [worth] 100%*</p> <p>How to get pain taken seriously by medical professionals?</p>	<p>Is there such a thing as “ghost” pain?</p>

Table 4.2: Things participants wished to know about pain

4.3.1 Biology

Themes included pain management, medication, anatomy, external stimuli, brain, nature versus nurture.

4.3.2 Psychology

Themes included mental health, mindfulness, whether traumatic brain injury could cause pain, distraction and escapism, mood, attitudes, comfort and stress, and pain medication.

4.3.3 Social

Themes included support groups and people, communication of disability to people in their lives or strangers, awareness of chronic pain in the general population, social isolation, and personality traits.

4.3.4 Treatment

Themes included injections and pain medicine, biofeedback, new/alternative treatments, doctors, the “cause” of pain, methods for relief, and physical or mental methods.

4.3.5 Support

Themes included friends, finance, support for caregivers, pain management, loneliness, resources for natural remedies, and how caregivers could support.

4.3.6 Others

Others. Themes included positive attitudes of patients, attitudes of medical professionals, and invisible pain.

4.3.7 Overall

Regardless of separating questions into different themes, participants ultimately wished to know more about the cause of pain, pain management methods, and care for patients and caregivers. Some also consider aspects of pain distraction and escapism.

4.4 Questionnaires to Evaluate the Three Education Tools

A total of 43 questions on the questionnaire measured 15 aspects of the products from both patients and caregivers: 1) demand, 2) performance, 3) ease of use (frustration R⁸), 4) need of effort, 5) usefulness (R), 6) relevancy (R), 7) trust (R), 8) customization (R), 9) satisfaction, 10) visualization, 11) learnability, 12) memorability, 13) consistency, 14) functionality, and 15) appropriation.

A factorial ANOVA was conducted for each aspect to see if there was a significant difference between the patient's view and caregiver's view on different products (main effect of patient/caregiver), among different products regardless of patient's or caregiver's view (main effect of products), and whether patient's and caregiver's view differed among different products (interaction effect).

4.4.1 Demand

Demand included physical, mental, and temporal demands, accessing the demands of products on participants' capacity. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.22, p = .646$, or in the main effect of products, $F(2, 30) = 2.31, p = .117$, or in the interaction effect, $F(2, 30) = 0.58, p = .567$.

4.4.2 Performance

Performance measured the success of participants in accomplishing the exploration of the products. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.28, p = .603$, or in the main effect of products, $F(2, 30) = 1.18, p = .321$, or the interaction effect, $F(2, 30) = 0.59, p = .563$.

⁸ "R" indicates "reverse." Multiple scales measured the key aspect in reverse, meaning the higher the score, the lower the quality of the aspect. This, however, did not affect the ANOVA test as ANOVA measured the comparison among different groups.

4.4.3 Ease of Use

Frustration (R), the reverse of frustration, measured the reverse of how insecure, stressed, and annoyed the participants were while they used the products. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.00, p = 1.00$, or in the main effect of products, $F(2, 30) = 1.62, p = .215$, or the interaction effect, $F(2, 30) = 0.81, p = .453$.

4.4.4 Need of Effort

Need of effort measured the effort participants had to put in to accomplish the exploration of tasks and their performance. There was a significant difference in products, showing a main effect of products, $F(2, 30) = 4.24, p = .024$. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.0070, p = .934$, or in the interaction effect, $F(2, 30) = 1.03, p = .369$.

4.4.5 Usefulness (R)

Usefulness measured the helpfulness of the product for participants regarding the education content. The reverse of usefulness was measured, the higher the number, the less useful the product from the participants' perspective. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.046, p = .832$, or in the main effect of products, $F(2, 30) = 1.57, p = .226$, or the interaction effect, $F(2, 30) = 0.027, p = .973$.

4.4.6 Relevancy (R)

Relevancy measured the product's relatedness level in participants' opinions regarding their desires. The reverse of relevancy was measured; the higher the number, the less relevant the product was from the participants' perspective. There was a significant difference in products, showing a main effect of products, $F(2, 30) = 3.51, p = .043$. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 1.36, p = .252$, or in the interaction effect, $F(2, 30) = 0.20, p = .819$.

4.4.7 Trust (R)

Trust measured the level of trust participants felt towards the products. The reverse of trust was measured; the higher the number, the less trust participants felt towards the products. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 4.03, p = .054$, or in the main effect of products, $F(2, 30) = 1.20, p = .315$, or the interaction effect, $F(2, 30) = 0.17, p = .843$.

4.4.8 Customization (R)

Customization measured participants' perspectives in the room for customization of the products. The reverse of customization was measured; the higher the number, the less room for customization participants felt toward the products. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.014, p = .907$, or in the main effect of products, $F(2, 30) = 0.31, p = .739$, or the interaction effect, $F(2, 30) = 0.15, p = .858$.

4.4.9 Satisfaction

Satisfaction measured the level of satisfaction participants felt towards the products. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.44, p = .514$, or in the main effect of products, $F(2, 30) = 0.84, p = .444$, or the interaction effect, $F(2, 30) = 0.14, p = .868$.

4.4.10 Visualization

Visualization measured the quality of visualization in each product. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.084, p = .774$, or in the main effect of products, $F(2, 30) = 0.81, p = .453$, or the interaction effect, $F(2, 30) = 1.73, p = .195$.

4.4.11 Learnability

Learnability measured the easiness participants could learn about using the products for the first time. There was no significant difference in the main effect of

patient/caregiver, $F(1, 30) = 1.62, p = .213$, or in the main effect of products, $F(2, 30) = 0.44, p = .647$, or the interaction effect, $F(2, 30) = 0.16, p = .853$.

4.4.12 Memorability

Memorability measured the perceived ease of participants recalling the steps of using the products after a period of time. There was no significant difference in the main effect of patient/ caregiver, $F(1, 30) = 0.75, p = .393$, or in the main effect of products, $F(2, 30) = 1.37, p = .269$, or the interaction effect, $F(2, 30) = 1.45, p = .251$.

4.4.13 Consistency

Consistency measured the consistency of the products from participants' perspectives, including the consistency of design elements and the system's consistency. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.20, p = .660$, or in the main effect of products, $F(2, 30) = 0.086, p = .918$, or the interaction effect, $F(2, 30) = 0.60, p = .553$.

4.4.14 Functionality

Functionality measured whether the functions in the products were well-integrated from participants' perspectives. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.70, p = .407$, or in the main effect of products, $F(2, 30) = 0.69, p = .511$, or the interaction effect, $F(2, 30) = 0.18, p = .834$.

4.4.15 Appropriation

Appropriation measured whether the design elements of the products were suitable to deliver pain-related content. There was no significant difference in the main effect of patient/caregiver, $F(1, 30) = 0.0062, p = .938$, or in the main effect of products, $F(2, 30) = 0.30, p = .741$, or the interaction effect, $F(2, 30) = 0.82, p = .448$.

4.5 Semi-Structured Interviews

Thirteen themes were identified from the transcriptions of the semi-structured interviews, with seven themes relevant to pain education tools (theme #1 to theme #7) and six themes relevant to users (theme #8 to theme #13) (see Table 4.3).

	Theme	Code
#1	Trust	1. Professionalism and credits from legitimate research 2. List of references
#2	Accessibility	1. Physical weight and easy to "carry around"; 2. Steps to get to the information; 3. Target audience 4. How people know the products exist; 5. Technological devices
#3	Specificity	1. Deeper and more detailed knowledge; 2. Specific to self: personalization/customization; 3. Relevancy of pain;
#4	Pace	1. Preference of own pace; 2. Fast/ slow pace catering to patients' cognitive capacity
#5	Info Design	1. Toolbox; 2. Combining visualization and text; 3. Instruction and onboarding; 4. Interactivity/Gamification;
#6	Content	1. Appropriateness of animation; 2. Realism of illustration/metaphor; 3. Holistic view; 4. The importance of new information; 5. Specific scenarios and explaining; 6. Evoke users' curiosity
#7	Delivery	1. The tone/ voice of information; 2. Short videos; 3. Combining different media for same information
#8	Capacity	1. Pain fog, cognitive; 2. Fatigue;
#9	Healthcare Attitudes	1. Patients turned away by healthcare providers; 2. Patients long for more comprehensive care; 3. HCPs to not overlook the seriousness of pain based on how the patient expresses it; 4. Inadequacy of the healthcare system
#10	Mind-Body Connection	1. Divert the brain pathways; 2. The neuropathic pain; 3. The connection of physical and mental health
#11	Agency	1. Being an advocate for self; 2. Positive attitudes and resilience; 3. Having the control to actively learn materials
#12	Practicality	1. Pain management action items; 2. Lists of resources; 3. Do's and don'ts for caregivers
#13	Social	1. Support groups for both patients and caregivers; 2. Patient-doctor teamwork; 3. How the environment affects one's condition

Table 4.3: Themes in semi-structured interviews

4.5.1 Trust

Professionalism and credits from legitimate research. Participants tended to trust materials from legitimate research teams or materials recommended or mentioned by their healthcare team. One participant trusted Tame the Beast as their doctors had

mentioned their pain was conditioned and their body was reliving the pain centric in the brain (they called it a “new science”), aligning with values in Tame the Beast, making it “serious, real tangible and believable.” Another participant preferred learning about the same materials from someone else’s interpretation; things had been shown by their psychologists. Another participant mentioned they would like a book or a paper written by somebody where they knew the information was accurate. In the same theme but with a different perspective, a caregiver considered Tame the Beast less serious, “making fun of somebody’s pain, more cartoonish than anything,” and lacking professionalism. A participant mentioned longing for more professional wording and detailed descriptions in Why You Hurt. All of the above showed that participants trusted materials that seemed professional and were scientific or presented legitimately.

List of references. One patient liked Why You Hurt because they could look up the references in the tools, knew the pain education tool was from research, and could point them to more directions if they needed to explore more.

4.5.2 Accessibility

Physical weight and easy to “carry around.” Two participants claimed they preferred materials available on technical devices because when they were outside and had an issue, they could pull out their phones and look at them; it was easy and accessible. Similarly, two other participants mentioned people carrying their laptops around or accessing online videos more conveniently, but possibly not physical cards.

Steps to get to the information. Several participants preferred YouTube because they could turn on YouTube and watch, not having to log into an app, and they could watch videos and do other things at the same time. Steps varied from person to person; another participant liked physical cards they could go to repeatedly without logging into an account from a computer or a laptop.

Target Audience. Some participants considered Tame the Beast able to connect with everybody in any age group to make them understand more about pain in chronic pain patients. Some thought Tame the Beast could be for younger users as they were easy to understand and visually appealing; others thought it was also not too childish for older users to understand. Tinybop could be for 15 or 16 years old. Language of Why

You Hurt was in the middle; it could be for younger and older users or tailored to fit a group. One participant considered older users to prefer paper and to pick up a box of information more often than younger users. One participant considered Tinybop mentally demanding for people who were not biology majors. Moreover, several participants thought Tame the Beast was ideal for someone new to chronic pain and “could just be an informational video for anyone to learn from.” Tinybop could also be tailored for “non-professional caregivers”; when clicking something, something happens.

How people know the products exist. One participant said they “have never thought of downloading an app to learn about pain.” It was harder for users to know there was an app for particular usage, like managing chronic pain, than putting the materials on already existing platforms, like YouTube or TikTok, as they suggested. Alternatively, the same participant thought the doctors could suggest the patients download the app to help them manage their pain.

Technological device. Some people did not have technical devices or tended not to like using them. A participant said they were “not a tech person [and didn’t] like using tablets at all.” Two other participants considered this a technological era in which materials should be made in something that people could download onto their tablet or laptop. Moreover, Tinybop worked well on an iPad, and a participant was concerned that they predominantly used their phone and wondered if the app would work as well on a phone since the interaction seemed to need a bigger screen to carry out the information nicely.

4.5.3 Specificity

Deeper and more detailed knowledge. Participants preferred deeper and more detailed knowledge. One participant described the Tinybop as “a child’s play toy” that did not offer any information they did not already know, and more depth and layers could be added to Tame the Beast to make the video longer. While interested in Tame the Beast, the same participant asked, “Is there more happening?” Another participant considered themselves getting everything out of Tame the Beast upon the first watch.

Specific to self: personalization/ customization. A participant wanted to “customize a set of cards that [was] relevant to them based on what [they] want[ed] to

learn, which would be “more advanced [in the point of view] of pain learning materials.” Their caregiver agreed that it would be great “customizing [it] to [their] particular issues.” Another participant considered all materials as “informative introduction tool,” but for specific issues, they still probably would go and talk to their health professional and discuss about what they’re feeling and where they’re feeling it and what it feels like. Another participant was disappointed that the materials were not directed toward one person and their specific pain.

Relevancy of pain and pain management. One participant thought Tinybop was “missing the connection between chronic pain and how your different bodily systems work[ed].” Many also found Tinybop less relevant to pain: “It didn’t tell anything about the pain. It just told us the body and how it worked.” On the contrary, Why You Hurt was specifically relevant to pain: “It talk[ed] about how you [could] minimize your pain, that lion story one, it really specifically [told] you how this method [could] help you reduce your pain.” One participant thought pain reduction was more important than learning about the human body and its relevancy to pain as they “basically have the idea of all the sensory [... but] what [they are] interested in was about how to kill the pain.”

4.5.4 Pace

Preference of own pace. One participant preferred the delivery of Why You Hurt physical cards because they liked to “sit and go over it a little bit of a time together.” another participant resonated: “I can go at my own pace, which is pretty good as well. I’m a fast reader.”

Pace catering to patients’ cognitive capacity. Two participants considered Tame the Beast too quick to go from one thing to the next and a little fast-paced. However, another participant considered it very straightforward, not too fast, and not too slow (and kept them interested).

4.5.5 Information Design

Toolbox. Participants expressed a desire to have information about pain management ready in the format of a toolbox. One patient would like specific distraction tips so that when they are in crisis, they can be reminded of those things that worked.

One caregiver would like the toolbox to work as “a reference and a diagnostic tool” to know whether to take the patient to the doctor or ask them to take a Tylenol three and go to work. One patient considered making Tinybop a first aid tool for pain, and they could search for pain management strategies when needed.

Combining visualization and text. Participants said visualization in Tame the Beast was informative and that people sometimes learned the best from it. One participant thought Tame the Beast had a great amount of visualization and text. However, another participant thought Tame the Beast needed a better combination of visualization and text. Tinybop showed that visualization was still important, but without any text or speech, it made it a bit confusing or not direct enough to describe pain. Several participants thought one could not “look at a picture and be like that’s what we’re talking about” and claimed that they were guessing what Tinybop was trying to explain; more text was needed to guide users through exploring Tinybop and explaining what the body parts were about. For Why You Hurt, they claimed a good combination of visualization and text; even though the description seemed minimal, it was enough to convey the content. However, several participants thought it was hard to read as the visual was on one side and the text was on the other, which they had to flip through. They thought about working in a classroom where the teacher showed the students the image while reading the text. Still, for participants using it at home, it would be more beneficial to have the visualization and text on the same page or maybe organized like a book on two different pages but could be shown simultaneously.

Instruction and onboarding. Almost all participants recognized that Tinybop lacked instructions in this context of use, which prevented them from confidently exploring the tool. One participant said they would delete the app if it were not for this study that they were navigating it at home. Onboarding messages either showed up as tips or in a separate document as simple as screenshots and slides to explain what each button could do and what was expected to happen if conveying specific actions would be helpful, as considered by multiple participants. One participant thought Tinybop was ideal for teens to learn pain but also needed assistance navigating and learning.

Interactivity/ Gamification. Two participants were enthusiastic about the interactivity in Tinybop. They saw the potential of turning it into a game, like completing a task, getting points, and leveling up, with clear rules and deliveries. Another participant

thought Tinybop was visually interactive, and inserting videos like someone speaking could make it more interactive and engaging in the context of pain education.

4.5.6 Content

Appropriateness of animation. One participant considered Why You Hurt representing their experience on cards in a “childlike manner”; the lion in Why You Hurt seemed too cute to represent pain. Another participant did not resonate with the animal biting in Tame the Beast, considering it “unreal” and a misconception to represent pain. Their caregiver further considered Tame the Beast “making fun of somebody’s pain, more cartoonish than anything, and lacking professionalism.” However, sometimes cartoons might be better for some people. A participant considered one graphic unfolding the brain too biological and too real (“weird amalgamation”). It would be better to represent it in a more cartoon style or bars representing statistics.

Realism of illustration/ metaphor. One participant considered metaphors helpful in helping them understand the content. Another participant considered the metaphor in Tame the Beast appropriate, seeing pain as a beast to be tamed.

Holistic views. Although participants preferred to learn about pain management strategies rather than general pain education, some still thought understanding bodily function also helped with understanding pain, so they considered Tinybop not necessarily unrelated to pain and had the potential to give answers for pain or for different areas of the body and causes. However, a participant thought Tinybop missed some body parts, like the legs and the ankles, and they thought it was important to include all body parts. One participant would like the animation in Tinybop to show the effect of an action in the entire body in a continuous manner, like “for example, the digestive system instead of just clicking each of the intestines maybe go from the mouth, have a full animation harvest down the road,” and showing the reaction from the entire body.

The importance of new information. Several participants thought they had explored all health supplements and different ways of managing pain, and they would like to learn about new information in pain education and pain management, especially

new technology treatments that they did not know at the moment. One participant claimed they learned new information from Why You Hurt and were excited to try it.

Specific scenario and explaining. Several participants saw the potential to turn Tinybop into a demonstration of specific scenarios with explanations of those scenarios. Specific scenarios like what happens to the body when the bee stings, with someone explaining on the side, talking about what happens for allergy and how it affects the brain and the body. Tinybop can also show someone new to chronic pain that this is how their body usually works, and then have another diagram that this is how pain affects their body, showing medication effects and how it impacts some parts of the body, showing a burn physically on their skin and how it directs to the nerves and go to the pain. One participant also saw the potential in Why You Hurt, showing how the body parts look like in pain, how to connect to the nerves and brain, and eventually how to control that thinking of the pain.

Evoked users' curiosity. Several participants thought Tame the Beast introduced pain management in a way that made them want to find out more and could be used as good information "out there for people to see and learn about maybe an ad campaign," especially for people who lacked knowledge of chronic pain. Some thought the information was not enough, but the start of understanding pain was good, and it was a good hook, making them want to know more.

4.5.7 Delivery

Tone and Voice of information. Several participants considered Tinybop to have no sound and no information, and they needed someone to talk to and text to explain all functions. One participant had concerns about the tone of delivery in Tame, the Beast, making patients feel belittled while emphasizing the mental aspects rather than making them feel like they had more control, but at the same time, less trying in their non-ideal situations. However, another participant liked that someone was talking to them, especially in how the researcher presented the information in Tame the Beast. Another participant preferred short-form visuals and listening to the things, especially because it did not come off as clinical, with subtitles. For Tinybop, more words or something presenting was needed for a better delivery in the context of pain education. One

participant liked the wording in Why You Hurt, claiming it was straightforward, step-by-step, not too much information at once, and had easy-to-understand terminologies.

Short videos. Several participants wished Tame the Beast had a bunch of short videos for specifics or to make it longer and have joint points to indicate the content. Some participants wanted Tame the Beast to have more videos on social media platforms, such as TikTok and YouTube shorts, to show short videos of subcategories about pain.

Combining different deliveries for the same information. One participant would like “a combination of cards and apps.” And it might be interesting to have the cards as “apps, like flash cards.” Another participant had similar ideas and would like an app to show an animation of the body users could interact with; cards were also available for more information about certain body parts. One participant considered combining the video and the app, where the app interaction would also show some videos that deliver the content.

4.5.8 Capacity

Pain fog, cognitive capacity. A participant needed a refresher of knowledge when they got lost in their pain. Another participant tended to prefer short-form visuals with audio (that “doesn’t come off as clinical”) and subtitles because their focus level was affected by pain. At worst times, they could not read.

Fatigue. A caregiver considered themselves “very tired at the end of the day, after a lot of physical activity, and to just sit down and not do anything except just watch a video would be really simple and easy for [them].”

4.5.9 Healthcare Attitudes

Patients turned away by healthcare providers. Many expressed experiences of being turned away by healthcare providers as healthcare providers did not know how to treat the pain, they did not think the pain was major, or they ignored the pain of one patient, eventually turning out to be a massive tumor.

Patients long for more comprehensive care. Patients would like more comprehensive care from their healthcare providers so that they could spend more time at the appointments and not be too burnt out to “go for the easy answer for everything.”

Healthcare providers to not overlook the seriousness of pain based on how the patient expresses it. Some patients expressed that as they had dealt with pain their whole lives, they knew when they needed special care instead of just having another bad day. One participant was not taken seriously when expressing the need to get a referral to rehabilitation, physiotherapy, or a specialist, and the doctor told them to “rest use ice and a heating pad but that [they had] already tried and nothing worked.” Another participant expressed that doctors did not “take people with chronic pain seriously, if [patients were] in the ER, [they] could be in more pain than the person beside [them] [...just] because [they were] better at dealing with pain.” There was also a controversy over rating pain levels, especially with numbers. One participant struggled to use a numerical value to represent their pain level as they were very uncomfortable and looking for help at the clinics.

Inadequacy of the healthcare system. Some participants considered the healthcare issues more than just healthcare providers but related to the whole healthcare system, claiming that “the medical system needs to be generous [than] just rushing people off”. One participant considered that the connection between physical and mental health and the healthcare system could be better by incorporating them for patient care.

4.5.10 Mind-Body Connection

Divert the brain pathways. As further emphasized in Tame the Beast about the mind-body connection, participants were interested in knowledge of diverting the brain pathways to make the pain go away. One participant considered “deconditioning” as the goal of their pain management as they had a history of abuse, and they thought that connected to their chronic pain. They wondered if it was achievable through hypnosis. Another patient got confused and started to rethink the existence of their pain (“According to the video, pain is something that your body is tricking you into thinking that you may or may not have. So, like, do I actually have the pain? Or is it like happening because somebody’s ringing the bell [Pavlov reference] in front of me?”). Two

more participants had heard about the mind-body connection. Still, they would like to further pursue the exact methods they could use to “retrain the brain,” or “divert [their] focus” when they were in pain.

The neuropathic pain. One participant considered themselves ostracized by Tame the Beast as they emphasized biological and mental connection, but in a way indicating pain was in their head. They were triggered by the emphasis on “neuropathic,” considering that downplayed their medical condition. Another participant thought acknowledging the neuropathic pain would be helpful to improve their day-to-day function. If there were a “root cause,” it would be further helpful as they still believed there should be a “root cause,” an external stimulus, for their pain, seeing it as nociceptive. One caregiver thought the cause of the pain was important, and Tinybop could showcase it interactively. However, their patient let them know that not every patient with chronic pain had a diagnosis or even related symptoms.

The connection between physical and mental aspects of pain. One patient described part of their pain as “emotional pain, mental pain” when they did not have pain in their body but thought they were in pain. A participant recognized the psychological aspects and expressed the need for “a two-pronged intervention with mental and physical care.” Another participant, however, had an alternative perspective that some healthcare providers emphasized the mental aspects of pain and wrote patients off as okay and perceived they could deal with the pain themselves instead of having any medical intervention for them until the condition got to a certain point. Another participant acknowledged mental health but did not consider cognitive-behavioral therapy working for everyone but considered counseling in general very important because treating patients’ medical conditions as well as mental health was important, especially for those that “have some sort of underlying trauma that either caused it or has just made [them] more susceptible to chronic pain.” Combining physical and mental health, one participant emphasized biofeedback and urged the medical system to tighten the connection between physical and mental interventions.

4.5.11 Agency

Being an advocate for self. Two patients in pain their whole lives claimed to have learned and experienced all relevant to pain. One other patient had a severe medical

condition that half of the people could not walk, but they distracted their mind from experiencing pain and believed they could do better, and walked, even running some distance. One patient even took the initiative to train their doctors: “I have a chronic lifelong medical condition. I don’t get brushed aside. I want you to listen to what I’m telling you. And I want you to see if there’s a way that we can make it better. And he’s learning. He’s learning that patients are people that we don’t have complaints.” They fought the imbalanced doctor-patient relationships and stigma of “complaining.” Another patient also fought stigma within their own thinking, claiming that they used mindfulness as the first stage to “de-monster” their pain. One caregiver also cared about working with doctors and would like to learn more about what doctors could provide for the patients and how to work with doctors more efficiently.

Positive attitude and resilience. A patient thought 95% of healing was attitude, 5% was medical, claiming that they had this major pain, but life went on. Another patient had the mindset that they were not handicapped and not handicapped by the pain either.

Having the control to actively learn materials. Patients tended to learn and research their pain such as “look[ing] at books or look[ing] [things] up online and [spending] many hours to look at [them]. One patient learned about “what [they] can take, what side effects, what causes pain, what doesn’t, what takes the pain away,” and they found calcium to have an interaction with the medications they were taking. One caregiver also actively learned and wondered about pain medication, evoking more thinking after watching Tame the Beast, wondering if the pain was something good for the people, why would doctors and the patients themselves took pain medication to make the pain go away (“How safe is that? Sorry, this is what’s coming out for me from all this. Man, I never think about that for quite a while. I’ll be researching this on my own.”). One caregiver also mentioned that using Tinybop, a mobile application, made them feel the agency of learning as they actively explored and gained information instead of people reading it to them in a video format.

4.5.12 Practicality

Pain management action items. Actionable items were considered more important than pain education, and participants were more interested in what they could do to manage or reduce their pain. They would like tips for pain management, new ones,

and also be reminded of what they might have already known. They would like more options and solutions for dealing with pain, and one caregiver was interested in natural options. Actionable items were important, as one patient voiced: “I don’t even know if it will be helpful, because I like, sure, they gave us like a great idea, but they didn’t tell us how it’s going to be executed.” The participant that emphasized mind-body connection would like to learn about “how daily, [they] can work on changing [their] thoughts, [...] how to move forward out of [their] past of this pain”. One participant wondered how to avoid being in more pain. And one other participant would like to know how to maintain day-to-day functions.

Lists of resources. As participants were interested in knowing their pain management options, they also wanted to know how and where they could get those proper treatments. One caregiver was interested in a list of extra sources they could seek help from or gain information on how to support their patients.

Do’s and don’ts for caregivers. One caregiver was interested in knowing what they could and should not do around the patients to support them better.

4.5.13 Social

Support groups for both patients and caregivers. One patient would like to be in a support group where chronic pain patients could share their experiences, and people could learn from other people’s experiences. One caregiver considered caregivers as a group and would like support and community. Another patient was interested in knowing if there was any community around them that they could attend to and gain support or if any volunteers could help. Ultimately, one patient said they wished to “make sure patients, as well as their caregivers, are being taken care of.”

Patient-doctor teamwork. Patients expressed interest in working with doctors for their pain management journey, even having doctors as friends to pick their brains for answers.

How the environment affects one’s condition. One patient wondered if the environment in one’s life could affect their pain.

Chapter 5. Discussion

5.1 Insights into Pain Education Materials

From the participatory study to explore the needs of chronic pain patients and their caregivers for diverse pain education tools, patients and caregivers shared their desires. They also reflected on their needs and capacity degrees and evaluated existing products to give more constructive insights into product development. Insights were generated from the discussion board of things participants wished to know about pain, questionnaires to assess three existing education tools, and semi-structured interviews about the products and their further thoughts on pain education.

5.1.1 Participants' Interests of Pain Education

In the discussion board, chronic pain patients and their caregivers shared things they wished to know about pain. Although topics covered biology, psychology, social, treatment, support, and others, patients mainly wished to know about treatment options for pain management and the connection between the brain and the cause of pain. Caregivers were also interested in learning about treatment options and the connection between the brain and the cause of pain. The caregivers were also interested in how they could support patients in their pain journey.

From the semi-structured interviews, participants longed for more actionable practices of pain management, ideally specific to their pain. At the same time, many of them desired to learn about their bodily parts (brain and areas of pain) holistically, through which they perceived they would know themselves and their pain better.

This is important because it reveals that participants rely on habits of thinking reflecting biomechanical medicine. For example, believing there is always a cause of pain, treating chronic pain as acute pain, and looking for pain distraction. Pain education is evolutionary, and learning chronic pain sometimes involves “learning about,” like pain management strategies, and “learning to recognize,” like chronic pain, differs from acute pain in that there could be no cause. Therefore, while being interested in practical knowledge like pain management strategies, education about chronic pain with complex biopsychosocial aspects holistically is necessary for participants.

5.1.2 Need of Effort and Relevancy

From the questionnaires assessing content, functionality, design, and barriers of use for the three existing education tools, the main effects in products were observed in Need of Effort and Relevancy.

Need of Effort measured the effort participants had to put in to accomplish the exploration of tasks and their performance. Relevancy measured the product's relatedness level in participants' opinions regarding their desires. The results indicated that in the three existing education tools, participants, regardless of being patients or caregivers, noticed some tools required more effort to navigate and accomplish their learning tasks than others, and they noticed that some tools were more relevant to their needs than others.

The results did not indicate that they preferred one product to another; rather, the participants articulated the differences in how much effort was required and how relevant the education content and medium were to their own needs and context of use. Moreover, all participants' opinions about the three education tools were situated in the context of the use of pain education tools that they could use in a non-clinical setting; therefore, those opinions do not work as any evaluation for the three tools as they have different contexts of use (as I introduced in Chapter 3.3.5) than in this study.

5.1.3 Trust

Participants preferred trustworthy materials; they referred to trustworthiness as showcasing professionalism and credibility from research, most likely created by healthcare professionals. They showcased more trust toward *Tame the Beast* and *Why You Hurt*, created by healthcare professionals. They also appreciated the list of references provided to enable them to further learn about pain education in their area of interest, knowing that the information is scientific and legitimate.

The result indicated that participants preferred pain education tools that showcased trustworthiness, including research and information from healthcare professionals that showed credibility and trust in medical fields. Evidence-based is important.

5.1.4 Accessibility

Participants preferred products that were easy to carry around and did not require too many steps to log in. Participants also recognized the potential of making the products cater to different user groups, such as younger users, older users, people new to chronic pain, non-professional caregivers, etc.

Having people know the products exist is also a critical accessibility issue, so participants are concerned about ad campaigns and introducing videos on existing social media platforms like YouTube and TikTok. In that way, more patients and caregivers will know about the tool, and the introductory information will also provide the general public with information about chronic pain and an opportunity to fight social stigma. They also suggested that healthcare providers could introduce tools to help them learn about their pain during their health appointments.

Accessibility to certain technical devices was also mentioned. Making an interactive application that has the best use case on tablets might also have accessibility challenges; maybe people use their phone for the same application because they don't own a tablet, and the user experience will be different as the screen size changes and people having different habits navigating apps on phones versus tablets.

5.1.5 Specificity

Participants preferred pain education to be specific, with deeper and more detailed knowledge ready for them to review, and with content specific to their medical conditions and area(s) of pain, and content relevant to pain, and many cases, most relevant to pain management.

5.1.6 Pace

Participants preferred to review pain education tools at their own pace or have paced products that cater to their cognitive capacity.

5.1.7 Information Design

Participants longed for a pain education tool in the “a toolbox” format, where they could easily access tips for chronic pain management or diagnoses with actionable items. The information design also indicates that patients and caregivers long for pain education that can be used more than once, requiring more depth of knowledge and references they can look up.

Participants preferred the tools with visualization and text and the right balance of the two elements working well together. *Why You Hurt* was designed for healthcare providers to use with their patients by facing the images of patients and reading the text from behind; therefore, visualization and text were on different sides. During the exploration, none of the patients and caregivers used the tool together, and it was to my surprise. Therefore, I drew two insights: 1) consider the tools primarily used by one user when designing pain education tools for chronic pain patients and caregivers, or 2) have instructions to let them know the context to use the tools, if they were designed to be used together, have instructions to guide patients and caregivers to use them together.

Participants preferred tools to be interactive, making them engage while learning about pain, and they suggested making the information into a game-like form tool that motivates them to complete tasks and level up. However, the gamification aspect should be considered with care, and other research regarding chronic pain made it clear that “having relief from pain” was not equivalent to “having fun” in a gamified setting [11]. In this case, gamification might denigrate the seriousness of pain, as patients are likely experiencing pain while playing games that could affect their attitudes to the game, pain, and themselves.

5.1.8 Content

Participants paid attention to the visualization and animation of the pain education tools, and their perceived appropriateness of the animation impacted their views of the products. Some preferred more “real” illustrations to show professionalism, while some preferred cartoon illustrations to ease the tension of biological graphics being too real. The realism of metaphor also mattered; some participants resonated with some metaphors of pain, but others felt strongly against them. More research should be

conducted on this topic to generate patterns not found in this study; the result indicated the importance of these two elements but did not find any patterns of what was and what was not appropriate.

Participants were also interested in having a holistic view of the pain information, for example, connecting their brain and areas of pain with pain management strategies. This was interesting on top of participants interested in knowledge catered explicitly to their pain and actionable items. Some information to guide them in understanding their physical and mental states was also perceived to be valuable in a pain education tool.

Participants were interested in learning new information about pain as some had been in chronic pain for a long time and had learned about everything from their perspectives. However, they seemed to be open to learning about new methods or anything unconventional that would challenge their views of pain; some were interested in natural options for pain management. They were open-minded and willing to try different pain management strategies to see if they worked, although two participants considered that they knew everything about pain. This might be relevant to the medical journey of chronic pain patients. Research has shown that many people with chronic pain might have seen multiple physicians and undergone numerous laboratory tests to get a proper diagnosis, try many things to manage their pain, although pain resisted, and not being understood by people around them and worse, labeled as symptom magnifiers [23]. Given such a long-term “pain odyssey,” one might expect that chronic pain patients and their caregivers might also experience burnout and frustration continuously trying new things. This appears to reinforce the observations that patients would necessarily have different degrees of motivation to try a new pain education tool, and primarily, such a tool should have varied levels that patients and caregivers should continue to use.

Participants reported that they wished the pain education tools to showcase specific scenarios and explain those scenarios. For example, if the cause of pain is known, how does it impact the specific parts of the body, how does it impact or is impacted by the nervous system, and what would be the further impact on those parts of the body or overall health? After, if any pain management strategies were found to work, participants wanted to know the impacts on the parts of the body and the nervous system. Some were also interested in the effects and side effects of certain pain medications and the illustration of how they would work, including how they might impact their physical and mental health.

Participants recognized some content would evoke their interests and make them want to learn more. For example, a brief introduction to neuropathic pain could educate those new to chronic pain or those who do not live with chronic pain. It serves as an excellent introduction to motivate users to learn about chronic pain or as a good ad campaign that educates those with limited knowledge.

5.1.9 Delivery

Participants cared about the tone and voice of the information. They preferred having a voice instead of making them have to guess what was happening. They preferred the tone of researchers or anyone professional to convey the information. Conveying evidence-based information to the users was not a wrong practice. Sometimes, it was also important to see things from patients' perspectives to adjust information to a tone that worked for them.

Some people preferred less clinical terms, and some also liked content to be straightforward, step-by-step, has not too much information at once, and in easy-to-understand terminologies. Therefore, a tone and voice that seems professional to convey scientific information is preferred; however, given that patients and caregivers are likely not healthcare professionals, it is also important to convey the information straightforwardly. The balance between having a professional tone and voice while remaining a lay-person language should be further investigated.

Participants liked the format of short videos to show multiple subcategories of pain, especially if they were on social media platforms like TikTok and YouTube shorts. In that case, they could easily access the short videos and only watch the videos relevant to them or their interests.

Regarding delivery methods of information, some participants liked to combine different deliveries for the same information, such as combining apps and cards to make cards interactive or combining videos and apps so that users could actively choose what to watch or read as they navigate an app.

5.2 Insights about Patient-Centred Care

From the participatory study to explore the needs of chronic pain patients and their caregivers for diverse pain education tools, patients and caregivers shared their desires and reflected their needs and capacity, which were valuable to inform patient-centred care. Insights from the adapted McGill Pain Questionnaires, Mood Board and Pain Stories of participants, and semi-structured interviews about the products and their further thoughts on pain education were helpful for creating guidelines for patient-centred care.

5.2.1 Patients' Relationships with Their Caregivers

After collecting information about years of being caregivers from the participants, I recognized that some caregivers had closer relationships with the patients than others. That also depended on their relationships with each other, such as partners, spouses, children-parents, and friends. The closeness of their relationships was also reflected on the adapted McGill Pain Questionnaire, where caregivers filled out their perspectives of patients' pain. Overall, all caregivers had knowledge of patients' pain conditions, especially their areas of pain. The large number of standard deviations meant that caregivers' knowledge levels varied from participant to participant, further indicating that caregivers' knowledge of patients' pain conditions varied from person to person.

The adapted McGill Pain Questionnaire was more qualitative and exploratory as it also collected the patients' pain management and what would worsen their pain. The result further indicated that patients, as well as caregivers, had knowledge of pain management and had knowledge of their own pain conditions. Comparing all the fields of pain conditions, caregivers had the most knowledge of patients' areas of pain, and the least knowledge of how patients' pain felt, and the intensity of patients' pain under certain conditions.

The adapted McGill Pain Questionnaire offered freedom for patients and caregivers to choose more than one word in each category of the description of pain, asked qualitative questions about what relieves and what increases patients' pain, and allowed participants to leave certain areas blank if necessary (e.g., when caregivers do not know the intensity of pain patients feel about their worse stomach-ache). Participants

expressed curiosity, especially patients, saying they had not filled out a McGill Pain Questionnaire in that way before. This made a step forward in bridging the distance between the people-oriented manner of participatory design and the strictly medical evidence-based studies in clinical settings.

5.2.2 Patients' Pain Stories

Patients made mood boards to share information about their pain, and caregivers to share their perception of patients' pain; after that, they further shared the group their elements on the mood board with each other. Using the help of existing images, patients described their pain as burning, constant, explosive, sudden, cold, stabbing, shooting, and tingling. After that, they also discussed that their pain was not stable, and the pain was deliberating and affected the mental and emotional aspects of the patients. This helps researchers and caregivers learn about pain from patients' perspectives and gives patients the voice to share and describe their pain.

As a discussion session, many other topics came up besides describing pain. Patients shared their history, including years of chronic pain, areas of pain, and medical conditions. They also shared pain management strategies and their hope for more comprehensive care from healthcare providers, the impact of chronic pain in mobility/physical conditions, and mental conditions. They shared their attitudes towards themselves and negative thoughts of the future while trying their best to accept their pain conditions. They shared their social desire, sense of loneliness, and support from the community, healthcare providers, and caregivers. Caregivers also shared their attitudes towards the patient, how they saw patients' pain, their support of their everyday life, their memories of how patients described their conditions, and their views of patients' behaviors and conditions when they were in pain.

After the pain story section, I learned the importance of patients' and caregivers' mental health as they were both in a trying situation. Even though the prompt only asked about the patient's pain, participants shared all aspects related to the patient's medical conditions, physical and mental health impacts, pain management, and the importance of support from the community, healthcare providers, and caregivers. Caregivers also shared how supporting the patients changed their daily lives and their views of pain. This activity indicated that pain affects patients' lives in many aspects, and patient care

should not be limited to medical intervention. Patient-centred care should work in multiple facets to accompany the pain journey of patients and their caregivers.

5.2.3 Capacity

Multiple patients mentioned their cognitive capacity being limited while they were experiencing pain; one patient called it “pain fog.” At that time, they might be less capable of navigating information, such as reading actively, but needed visual and audio elements to feed the information to them. Especially if creating a toolbox for chronic pain patients and having them access it during their pain, having visual and audio elements of the pain education tool is ideal because they will be in an emergency when they are in pain, and their capacities might be limited. Caregivers did not go through “pain fog,” but one expressed their capacity after work was also limited due to fatigue. During those times, they preferred passively receiving information, such as watching short videos.

Therefore, when designing pain education tools, one needs to consider the times of use for the actual users according to the use case. More in-depth user interviews are encouraged to assess the degree of capacity and how information could be best conveyed during those times.

5.2.4 Healthcare Attitudes

Participants mentioned the importance of the attitudes of healthcare professionals. Patients shared experiences of being turned away by healthcare providers, resulting in physical and mental trauma. Patients expressed the desire for more comprehensive care from healthcare providers instead of being rushed out the door and feeling like they were “just paychecks to the doctors.” Patients also expressed being overlooked by healthcare providers because they were better dealing with pain (with higher pain tolerance, in their words) and not being taken seriously while they were in pain. Lastly, both patients and caregivers urged the healthcare system to convey better care, as well as strengthen the system connection between access to physical and mental healthcare for people living with chronic pain.

Although patients and caregivers did not articulate the specific kinds of healthcare professionals the patients were seeing, it seemed that they were not in an

interdisciplinary program created to treat chronic pain. Based on participants' feedback, it seemed that either the awareness of enrolling in an interdisciplinary program that concerned the biopsychosocial aspects of managing chronic pain needed to be raised among chronic pain patients or caregivers, or those interdisciplinary programs were rare or not accessible. Nevertheless, patients should learn about and manage their chronic pain in settings that concern biopsychosocial aspects of their care journey, and further research should propose feasible solutions to assist patients in enrolling in an interdisciplinary program for better care in their pain journey.

5.2.5 Mind-Body Connection

Recognizing the biopsychosocial aspects of pain, participants discussed the topic of mind-body connection. Participants expressed interest in diverting the brain pathways to achieve pain management, especially after viewing the education tools. One participant expressed that their pain came from medical conditions. It was not all in the head, and emphasizing the psychological aspects of pain could influence the biological aspects of pain being emphasized by healthcare providers. This also connects to the tone and voice of delivering pain information through pain education tools that consider the information received from the users' side important.

Some caregivers also had limited knowledge of chronic pain regarding neuropathic pain, perceiving if the medical conditions could be treated by navigating the "root" of pain like nociceptive pain, the patients would be better. Both views could harm patients living with chronic pain by not recognizing the complex biopsychosocial aspects of pain. Fortunately, the connection between mental and physical health, and patients and caregivers should take care of both, was also widely mentioned, potentially making healthcare more well-rounded. Therefore, an interdisciplinary program is needed for patients and caregivers to learn about chronic pain. Also, due to the complexity of chronic pain, pain education tools that are used more than once and contain references and resources for patients and caregivers to look up also cater to their needs.

5.2.6 Agency

Patients were advocates for themselves when it came to pain self-management by actively looking up information, communicating with their healthcare team to achieve

an equal doctor-patient relationship, and fighting the stigma associated with chronic pain. Many patients maintained a positive attitude toward life and were resilient enough to care for their medical conditions. Patients and caregivers also mentioned the desire to have control and actively learn materials by navigating the area of interest regarding pain information and thinking deeply about relevant questions that would help them know more about pain.

Agency is important for patients and caregivers to care for themselves and each other (i.e., to be in the “driver’s seat”). This is important as chronic pain is a complex medical condition that has no identifiable biomarkers and no cure. Moreover, social stigma and the opioid crisis exacerbate how hopeless chronic pain patients may feel [23]. Therefore, it is important that patients are in control of battling their own health conditions. However, it also indicates that patients and caregivers need resources that would aid patients’ pain management and assist them in maintaining their daily lives to navigate through this complex pain journey.

5.2.7 Practicality

Patients and caregivers longed to learn practical information relevant to pain. Patients expressed interest in learning pain management actionable items, showing a willingness to try methods that could work. More importantly, it was also desired to have lists of resources to show available services and direct them to possible next steps. Lastly, caregivers asked for a list of “do’s and don’ts” to better care for patients, preventing triggering or making situations worse.

When it comes to patient-centred care, being able to execute partial information is essential. It would save patients’ and caregivers’ time and energy to actively search for what to do next. Providing them with what could be helpful, with resources and guidance, helps achieve better patient care.

5.2.8 Social

Patients and caregivers recognized the importance of social support. Support groups for patients and caregivers were desired to share similar experiences. Patients and caregivers also mentioned that patient-doctor teamwork is needed for better care.

One caregiver, who also lived with chronic pain, also wanted to learn how the environment around the patient could have an impact on their pain. The desire to learn about how the environment around the patient could have an impact on their pain was interesting as it was rarely mentioned in current research, and it also showcased the agency of participants wanting to learn more about their pain in the context of environmental factors, showing their desire to see pain education holistically.

Patient-centred care focuses on health and the social environment around the patient, including but not limited to their communities, caregivers, healthcare team, and other nonhuman environmental factors.

5.2.9 Caregivers

Caregivers were included in this study to explore their roles in patients' lives and their needs for pain education to support the patients better and take care of themselves. This study successfully navigated caregivers' and their patients' knowledge of pain. Caregivers seemed to have limited knowledge of some aspects of chronic pain, such as neuropathic pain. Caregivers had some knowledge of the pain conditions of those they cared for, especially in patients' areas of pain; however, as the relationships between patients and caregivers were diverse, the differences in knowledge of patients' pain conditions were also observed.

Caregivers reported similar interests in pain information with patients, adding on how they could best support patients. Like patients, they were also interested in learning about pain management, the complexity of pain regarding the connection between the body and the mind, and resources that could support patients and caregivers themselves to go through the pain journey. For their needs, it seemed that they would need more biopsychosocial information about pain, such as information about neuropathic pain. They also appreciated learning about pain from patients' perspectives and how it impacted their functionality, mental health, social lives, etc. Therefore, to better support those they care for, caregivers need to learn about the complexity of pain and how that complexity affects patients' lives in multiple facets. Given that some caregivers are close to patients and participate in their everyday lives, they experience those facets; however, hearing patients voice those challenges and learning about them as global issues all chronic pain patients go through is important. In the future, more

effort could be put into navigating caregivers as person-centred in the research as this study lacked depth to investigate how caregivers' desires differed from patients' as they seemed to echo patients' desires while patients were present.

5.3 Contributions

5.3.1 Main Findings

In terms of pain education, chronic pain patients and their caregivers both reported that they desired to learn about pain management strategies that had depth and were ideally specific to patients' pain. Some patients were interested in learning about their pain conditions holistically, for example, what caused the pain, what happened to the designated body parts, how these connect to the brain, how to manage the pain, what medications could help, and what would be some side effects, what were some resources they could seek that help them take care of themselves and their caregivers, how would the environments around them affect their pain conditions, etc. Caregivers also expressed interest in the questions patients had about pain, primarily how to support chronic pain patients in their daily lives or when they had pain breakouts. In other aspects, patients expressed their desire to receive more comprehensive care and understanding from healthcare providers and more resources from healthcare systems.

Chronic pain patients and caregivers in this study seemed to have different degrees of knowledge regarding chronic pain. Chronic pain patients had more pain knowledge than caregivers, and caregivers expressed that they learned a lot about pain from the workshops, tools, and things patients shared. Therefore, caregivers need to receive more pain information, especially about the biopsychosocial aspects of pain, such as the differences between neuropathic pain and nociceptive pain. Caregivers also expressed that introducing the complexity of chronic pain to the public would be valuable; as people understood more about chronic pain and its complexity, there might be less social stigma around patients. Patients, however, expressed gaps in connecting their care for mental health and their care for physical health. Therefore, the need for interdisciplinary programs for patients is prominent because of the complexity of the biopsychosocial aspects of pain. As patients in this study seemed to not be in the programs, there might be gaps in the availability or accessibility of those programs.

Patients and caregivers expressed the desire to learn more, such as looking up references and other resources or asking for multiple sections of videos about pain information; this reflected that pain education tools should be designed for constant learning with multiple layers of information about pain, not a one-time education tool. Patients and caregivers in this study trusted tools created by healthcare professionals. They considered acquiring pain education tools from healthcare providers as one of the ways to access information, reflecting that healthcare providers are ideal for delivering pain information to patients and caregivers. Therefore, when designing pain education tools, researchers in human-computer interaction should consider collaborating with healthcare professionals to establish accurate information and credits from evidence-based research.

Chronic pain patients and caregivers in the study also identified that the need of effort in exploring different education tools could differ. Patients had limited capacities, especially when they experienced pain. One caregiver also expressed their limited capacities after work. Therefore, pain education tools should have instructions that allow users to navigate, and ideally, the information could have multiple delivery forms as some like more interactive components that they have agencies in exploring, and others like just to listen while doing other tasks. Patients and caregivers also identified short videos as the best delivery format for information, especially on platforms that can be easily accessed. Capacities are also concerned with technological capacities in this study. As people have different technical skills and levels of access to technical devices, it would be best if pain education tools could be in multiple media forms. Most participants would like information accessible through their phones, while some still liked to have physical products.

More insights towards creating pain education tools were also mentioned, such as having a pace that could cater to users or follow users' pace, the importance of assessing the appropriateness and ideal degree of realism of the animation, having both visualization and text in a tool, inserting game elements with cautious in interactive tools, and having appropriate tones and voices in delivering information in the tools.

5.3.2 The Bridge of Human-Computer Interaction and Patient-Oriented Care

This study connected topics in human-computer interaction and patient-oriented care. As both areas value conducting research following a person-centred approach, this study connected them to provide a more realistic sense of working collaboratively to create user-centred products to achieve patient-centred care. As a result, this study drew insights about product development and patient-centred care, both relevant to informing human-computer interaction researchers work with healthcare researchers to understand users' desires, needs, and capacity and provide solutions truly benefiting the specific users.

In this study, the use of the adapted McGill Pain Questionnaire established an alternative usage of a questionnaire for medical use, making a strict, grading, quantitative assessment more creative and flexible for patients to describe their conditions. As pain is complex, so might other medical conditions, there might be instances that they do not fit precisely in the words or numbers provided in the survey. The creative approach of using the adapted McGill Pain Questionnaire in the study gave patients and caregivers more freedom in expressing their opinions. It was a good start to the participatory design workshop. Although the assessment did not strictly reflect their medical conditions in pain and would not be used in any medical settings, it provided chronic pain patients and caregivers an alternative way of communicating their knowledge of patients' pain conditions.

5.3.3 The Consideration of Caregivers

This study considered patient-centred care in a multi-disciplinary setting; unlike most studies that consider healthcare professional teams, this study filled in the gap of involving caregivers in patients' pain journey. As a result, caregivers were found to have prominent roles in patients' lives and would benefit from pain education in the biopsychosocial framework.

The dynamic of having chronic pain patients and their caregivers participate in the study reflected that there are diverse relationships between patients and those who care for them daily. Although directly observing their interactions was not an aim of the study, from speculation by thesis reviewers, caregivers seem to respect patients'

thoughts and knowledge about pain and try to think from their shoes; this could relate to empathy. However, the needs and capacities of patients and their caregivers for using pain education seemed to differ — as much as caregivers would like to imagine themselves from patients' perspectives, they are not the patients, and most do not live with chronic pain. In this way, their dynamic also showcased the importance of using a participatory design approach, where users are invited as co-designers of solutions to the matters of concern, instead of a broad user-centred approach, where designers emphasize users to create solutions, mainly for communities they do not belong to.

When designing a pain education tool for patients, researchers from human-computer interaction should consider patients' desires, needs, and capacities, and when designing for caregivers, their desires, needs, and capacities. However, if considering a pain education tool used by both patients and caregivers and letting patients be in the dominant role of their pain journey, the tool should consider the content and the context of use from further exploring the dynamic of chronic pain patient and their informal caregiver, which could play a big role in patients' care journey, including patients' health outcomes and both patients' and caregivers' qualities of lives.

5.3.4 The “Toolbox”

This study contributed to the field of Human-Computer Interaction and the area of Patient-Centred Care in Healthcare by providing insights about product development and patient-centred care, informing researchers from varied disciplines to engage in understanding users' desires, needs, and capacity and provide solutions truly benefiting the specific communities. In this case, this study provided aspects of desire, needs, and capacity of both chronic pain patients and caregivers regarding pain education in patients' journey of chronic pain, as well as insights on developing pain education tools in varied media forms that researchers should consider when creating pain education tools for chronic pain patients and their caregivers. Moreover, this study also pointed human-computer interaction researchers to the importance of involving healthcare providers in designing pain education tools, as patients and caregivers desire trustworthy products with the effort of healthcare researchers and also trust them as the medium to learn about existing pain education tools. This echoes the importance of having a multi-disciplinary team to provide the best care for people with chronic pain. In my opinion, these insights are not exceptionally novel, but having them together in this

thesis seems like a “toolbox,” which is an information design that several participants desired their learning tool to be like. In the future, should researchers need insights for pain education from both the needs assessment of users and concrete themes in content and usability for product development without a minimal viable product, they can refer to this “toolbox.”

5.4 Limitations

There are a few limitations in this study. The sample size of the study and the sample size of participants in each workshop were not ideal due to the recruitment challenges. Therefore, the quantitative data served better as a reference to future research and provided insights to researchers in terms of areas of content, functionality, design, and barrier of use in video, interactive programs, and tangible cards instead of providing meaningful statistics on the differences of perspectives between patients and caregivers, among the three education tools. In this study, qualitative data was more insightful than quantitative data for the following reasons: 1) participants were allowed to leave the scale blank if they perceived the questions not making sense, and they were encouraged to leave comments instead of numbers, although it was not required, 2) most insights in this study came from interview transcriptions and activities before the interview had the purpose of getting participants into the mindset of reflecting their pain conditions to evaluate education tools and consider pain education, 3) the sample size of this study was not adequate to draw a confident conclusion of differences between patients and caregivers, or among the three education tools, it seemed rather like a pilot study.

Secondly, the study design involved patients and their caregivers participating as a pair in every activity to mimic the real-life settings of how they might interact with the products and assuming they complete day-to-day activities together. However, the relationships between the patient and the caregiver varied from pair to pair, and their years of being caregivers also varied. In activities and interviews, patients tended to be in a more prominent role, and caregivers tended to go with patients' view, although it was expected that regarding the topic of pain, patients should be in the primary position and caregivers should accompany them. However, this is a complicated factor because caregivers' views might be biased when answering the same questions in the same room with patients, and caregivers might conceal some points they would like to express

in front of a group of strangers and those they care for. Therefore, to truly investigate pain education for caregivers specifically, it is more beneficial to have a section for caregivers only instead of hosting it with patients.

Thirdly, this study was more exploratory and tended to rely on methods in inductive approaches. Although research questions were answered and the goal was completed, there is a need to narrow down the topic to a more focused, explanatory, and deductive approach that aligns with evidence-based research in health research, clinical care, and health technology domains. It is also worth noting that while the health and technology sectors differ, they both rely primarily on scientific methods. However, the rigor required for health research exceeds typical standards for technology fields. Although this research study is limited, it explored a growing area of concerns, pain education, and a gap in patient-centred care that should include caregivers' desires and needs for pain education.

5.5 Future Directions

Future studies can navigate pain education tools for chronic pain patients and their non-professional caregivers separately. It will be more meaningful to recruit participants with one specific type of pain and caregivers in the same role (e.g., spouse) to draw more specific insights that can be applied. Moreover, the ideal situation is to have all participants in one workshop so the confounding variables from having multiple workshops on different days can be limited, and the sense of community built for chronic pain patients and their caregivers will be more prominent.

This exploratory study explored whether participatory design was a suitable methodology to draw insights for evidence-based topics like patient-oriented research for people living with chronic pain. All elements used in the study were modified under the guideline of patient-centred care, as well as user-centred design. Products that were suitable for the goal of the study were chosen from existing ones in the market. However, if at least a minimally viable product can be presented to participants and invite them to co-create or provide feedback for the product, then launching the product and asking participants to test it would be a more insightful study for building pain education tools for chronic pain patients and/or their caregivers. Whether this approach is feasible, given how much time and effort would be required, is questionable, but it

would likely require a longer commitment from users (patients and caregivers). Such long-term engagement is possible, and such patients are termed “patient partners,” For instance, they were involved in co-creating with health and technology collaborators [60]. When such long-term commitments are not possible, researchers should strive for short-term research such as the kind in this thesis, focusing on recruiting a number of participants that is close to enough to obtain statistical validity. Generally, the number of participants required is expensive, time-consuming, and exceeds what is possible for a master’s study. Nevertheless, research that addresses a notable gap traditionally begins with small studies that focus on qualitative methods; their usefulness is in providing researchers with an example from which issues and problems begin to be articulated and acted upon by subsequent researchers. For an example, refer to early case studies about immersive virtual reality’s usefulness for acute pain distraction [26].

Chapter 6. Conclusion

The purpose of the study was to explore the needs of chronic pain patients and caregivers for diverse pain education tools, by assessing their desires, needs, and capacities to draw insights for human-computer interaction researchers to develop user-centred pain education and patient-centred care.

Twelve participants, including six chronic pain patients and those who care for them (in this thesis as in clinical practice, referred to as 'caregivers'⁹ that are usually untrained), participated in a needs analysis and a comparative analysis; both followed a participatory design approach. After filling out an adapted version of the McGill Pain Questionnaire, completing a mood board, and posting questions on a discussion board, chronic pain patients and caregivers explored three existing education tools. They filled out the same questionnaire after each section. Chronic pain patients and their caregivers joined me for a semi-structured interview to provide feedback on the content and usability of the existing tools and more suggestions for creating a pain education tool from a person-centered perspective.

In terms of desires, chronic pain patients and their caregivers desired to learn about pain management strategies that had depth and were ideally specific to patients' pain. Besides, caregivers wanted to learn to deliver better care for chronic pain patients in their daily lives, and patients also longed to receive more comprehensive care and understanding from healthcare providers and more resources from healthcare systems.

In terms of needs, chronic pain patients had more pain knowledge than caregivers, and caregivers needed to receive more pain information, especially about the biopsychosocial aspects of pain. The need for interdisciplinary programs for patients is prominent because of the complexity of the biopsychosocial aspects of pain, targeting physical health, mental health and more. Also, pain education tools need to aid chronic pain patients and caregivers to learn about pain information constantly, instead of being

⁹ Unless they work in the healthcare field, these caregivers are typically untrained. However, because of their personal, on-going relationship with a patient these caregivers may play an important role in how well patients learn to manage their persistent pain.

a one-time tool. Moreover, researchers in human-computer interaction should collaborate with healthcare researchers to establish products that contain accurate information and have credits from evidence-based research.

Pain education tools should have instructions allowing users to navigate and explore at their own pace because patients have limited capacity, especially when in pain. Several participants expressed interest in having a toolbox of practical pain management practices for them, especially when they are in pain. In that case, more research is needed to investigate what kind of delivery works best within their limited capacity in those times. Patients and caregivers also identified short videos as the best delivery format for information. However, having the pain education tool in multiple media forms is ideal, but most participants access information through their phones.

Supporting chronic pain patients and caregivers using evidence-based materials is a complex topic that requires the effort of researchers from different disciplines. More research is needed to navigate the dynamic of patients and caregivers and how they may impact patient-centred care in chronic conditions. It is meaningful to conduct further research to investigate the gaps in evidence-based medical education in a non-clinical setting for people who lack advanced medical knowledge and how healthcare providers can play a role in patient's care journey, to explore how to use technologies to aid and streamline the delivery of pain education for chronic pain patients and their caregivers. The quickly growing inclusion of technology in healthcare is changing traditional notions of patient care. Researchers in human-computer interaction should work with healthcare professionals to create user-centred pain education tools that meet the desires, needs, and capacities of chronic pain patients and their caregivers, aiding one in five people who live with chronic pain and several more people involved in their lives to understand the complexity of pain and battle the pain during their care journeys in the long term.

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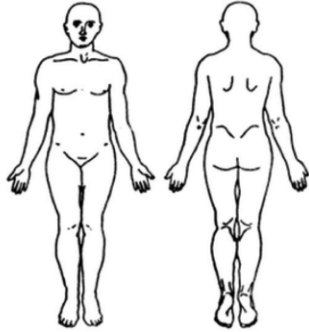
Appendix A.

The Adapted Version of McGill Pain Questionnaire

The McGill Pain Questionnaire

Part 1: Where is your pain?

Please mark on the drawing below, the areas where you feel pain. Put E if external, or I if internal, near the areas which you mark. Put EI if both external and internal.



Part 2: What does your pain feel like?

1 Flickering Quivering Pulsing Throbbing Beating Pounding	2 Jumping Flashing Shooting	3 Pricking Boring Drilling Stabbing Lancinating	4 Sharp Cutting Lacerating
5 Pinching Pressing Gnawing Cramping Crushing	6 Tugging Pulling Wrenching	7 Hot Burning Scalding Searing	8 Tingling Itchy Smarting Stinging
9 Dull Sore Hurting Aching Heavy	10 Tender Taut Rasping Splitting	11 Tiring Exhausting	12 Sickening Suffocating
13 Fearful Frightful Terrifying	14 Punishing Gruelling Cruel Vicious Killing	15 Wretched Blinding	16 Annoying Troublesome Miserable Intense Unbearable
17 Spreading Radiating Penetrating Piercing	18 Tight Numb Drawing Squeezing Tearing	19 Cool Cold Freezing	20 Nagging Nauseating Agonizing Dreadful Torturing

Part 3: How does your pain change with time?

1. Which word or words would you use to describe the pattern of your pain?

1 Continuous	2 Rhythmic	3 Brief
Steady	Periodic	Momentary
Constant	Intermittent	Transient

2. What kind of things relieve your pain?

3. What kind of things increase your pain?

Part 4: How strong is your pain?

People agree that the following five words represent pain of increasing intensity. They are:

1 Mild	2 Discomforting	3 Distressing	4 Horrible	5 Excruciating
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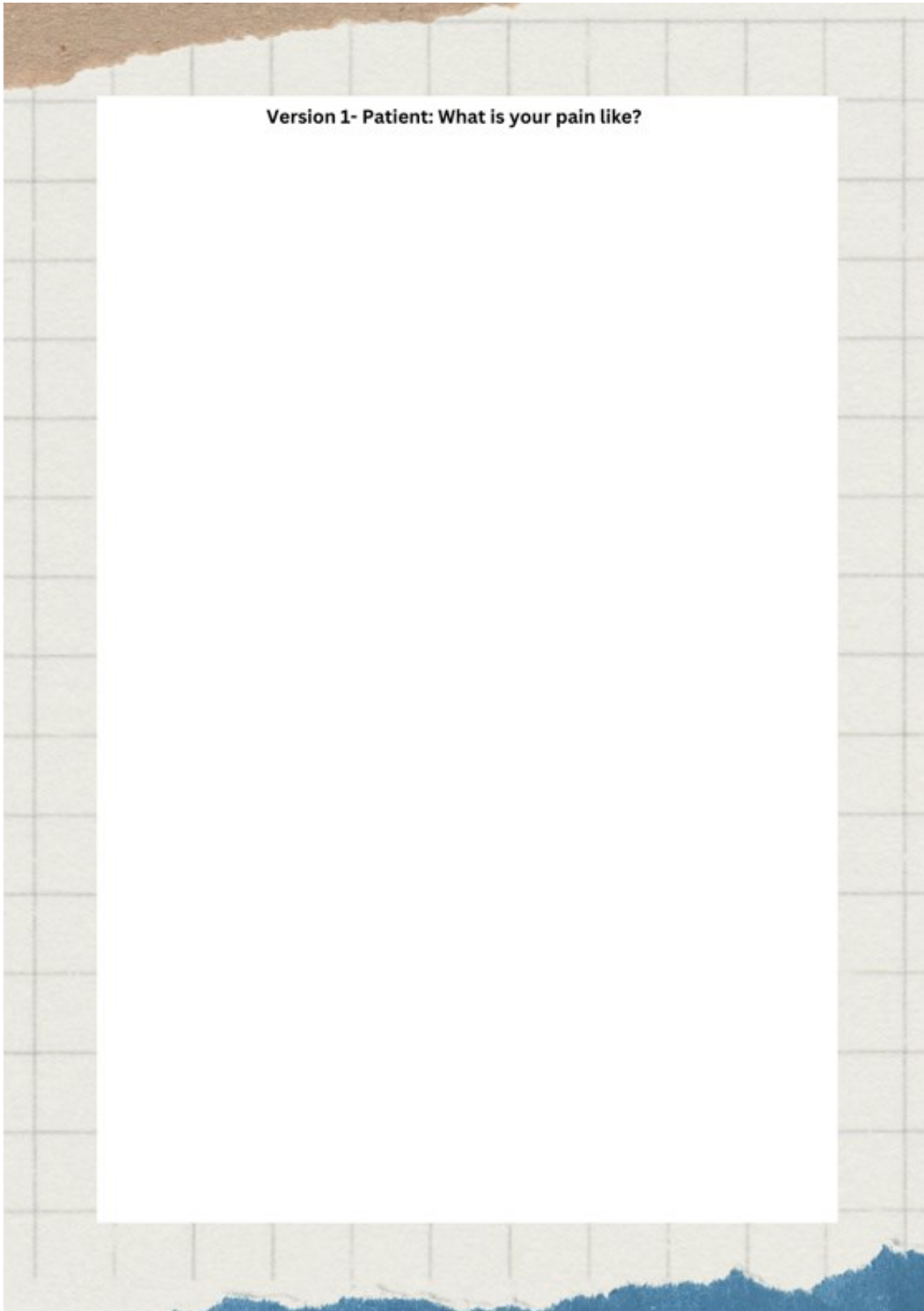
To answer each question below, write the number of the most appropriate word in the space beside the question.

- Which word describes your pain right now? ()
- Which word describes it as its worst? ()
- Which word describes it when it is least? ()
- Which word describes the worst toothache you ever had? ()
- Which word describes the worst headache you ever had? ()
- Which word describes the worst stomachache you ever had? ()

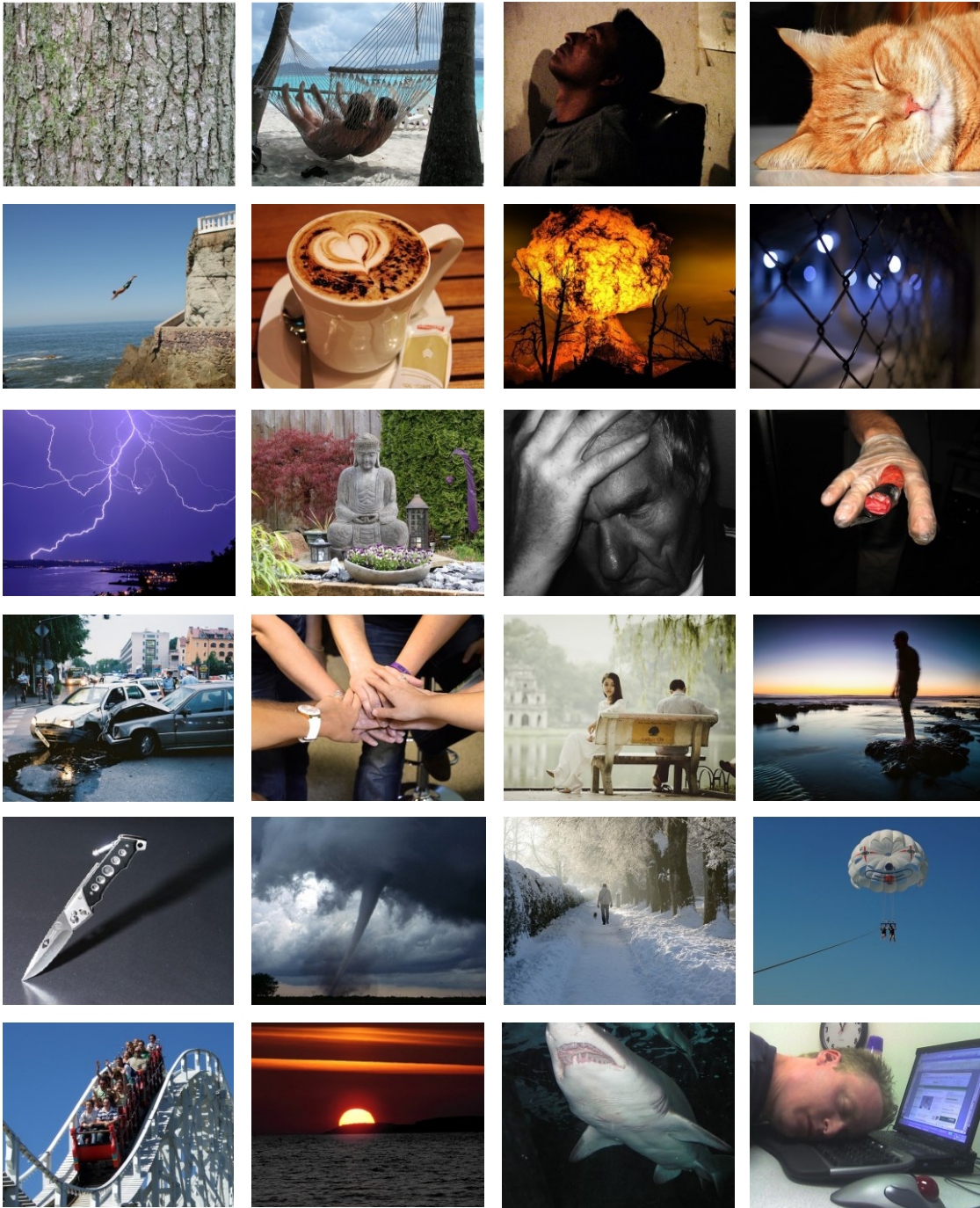
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<https://doi.org/10.1037/t04164-000>

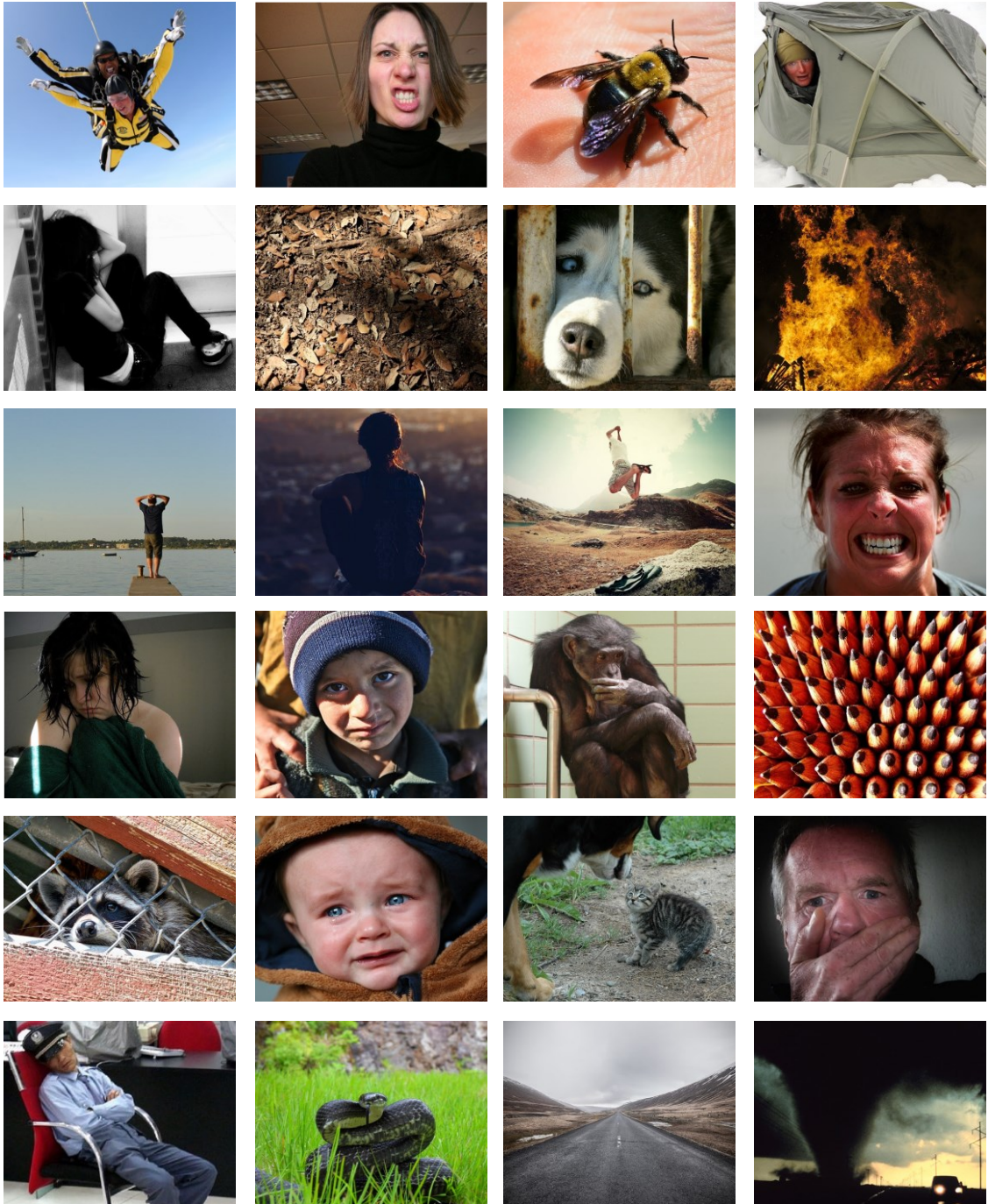
Appendix B.

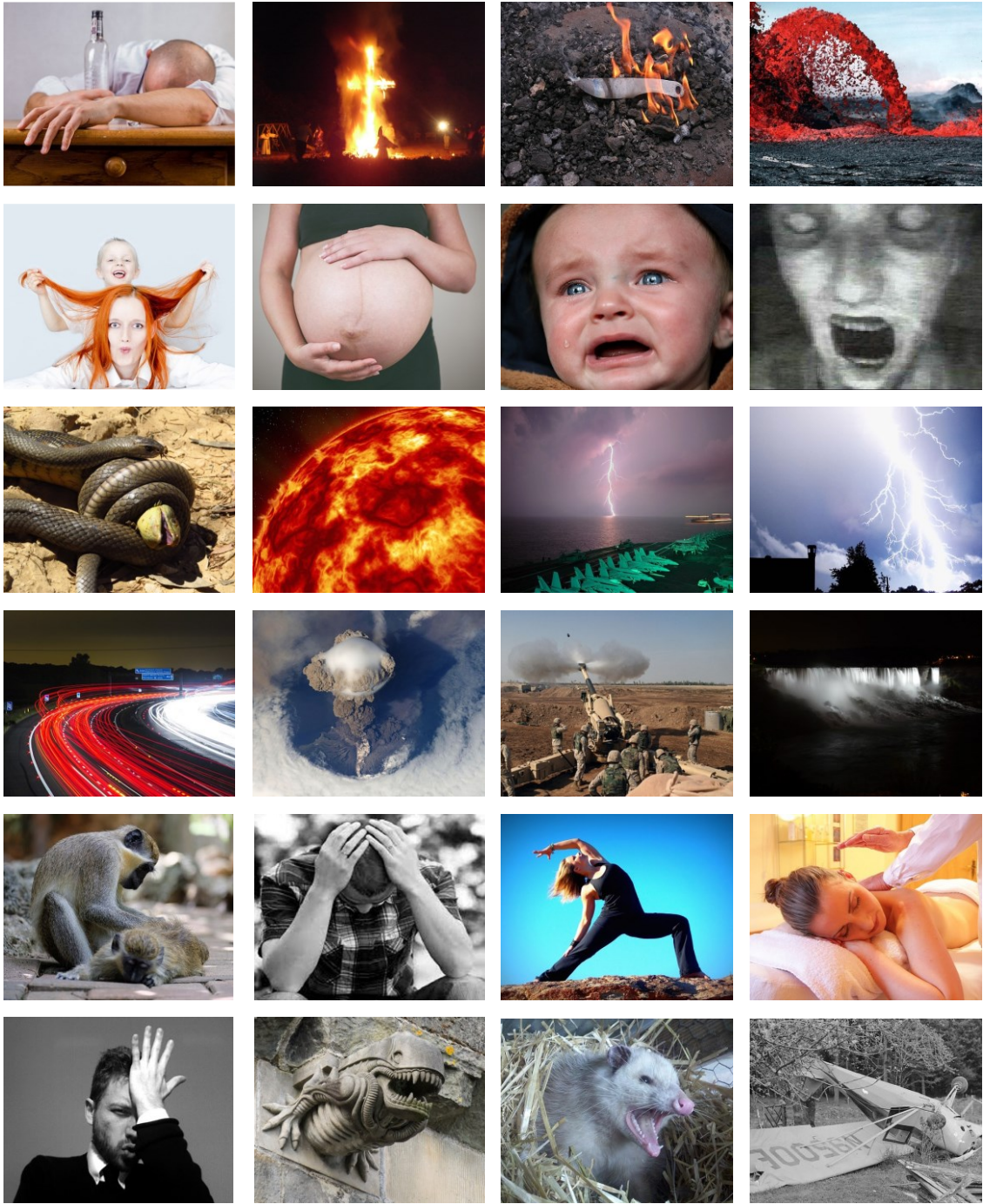
Mood Boards and Images from OASIS



Version 2- Caregiver: what is your partner's pain like?









Appendix C.

Discussion Board

DISCUSSION BOARD

WHAT DO YOU WISH TO KNOW ABOUT PAIN?

BIOLOGY	PSYCHOLOGY
SOCIAL	TREATMENT
SUPPORT	OTHERS

The image shows a discussion board form with a light beige background. At the top, the title "DISCUSSION BOARD" is written in a large, italicized, black serif font. Below the title, the question "WHAT DO YOU WISH TO KNOW ABOUT PAIN?" is written in a smaller, black, all-caps sans-serif font. The form is divided into six rounded rectangular boxes arranged in a 3x2 grid. Each box has a thin black border and contains a category name in a bold, black, all-caps sans-serif font. The categories are: "BIOLOGY" (top-left), "PSYCHOLOGY" (top-right), "SOCIAL" (middle-left), "TREATMENT" (middle-right), "SUPPORT" (bottom-left), and "OTHERS" (bottom-right). The boxes are currently empty, intended for handwritten or typed responses.

Appendix D.

Questionnaire



SIMON FRASER UNIVERSITY
ENGAGING THE WORLD

Ethics application #30001924
Version: 2.0

Title of Study: Exploring the delivery of pain education packages for chronic pain patients and their caregivers.

Department, School or Faculty: School of Interactive Arts & Technology, SFU

QUESTIONNAIRE

Content Comprehension

<i>Not demanding at all</i>	1	2	3	4	5	6	7	<i>Very demanding</i>	
		1. How <u>mentally demanding</u> is the content							
<i>Not demanding at all</i>	1	2	3	4	5	6	7	<i>Very demanding</i>	
		2. How <u>physically demanding</u> is to complete reading the content							
<i>Not rushed at all</i>	1	2	3	4	5	6	7	<i>Very rushed</i>	
		3. How <u>rushed</u> is the pace of the content delivery							
<i>Not successful at all</i>	1	2	3	4	5	6	7	<i>Very successful</i>	
		4. How <u>successful</u> do you think you are in understanding the educational content							
<i>Not hard at all</i>	1	2	3	4	5	6	7	<i>Very hard</i>	
		5. How <u>hard</u> do you work in finishing reading the educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>	
		6. Overall, understanding the educational content was <u>frustrating</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>	
		7. The educational content seems <u>trustworthy</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>	
		8. The educational content seems <u>professional</u>							



	9. The tone of voice seems caring							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	10. I see myself <u>applying</u> the educational content in everyday life							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	11. I <u>relate</u> to the educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	12. I see myself <u>developing awareness</u> after learning the educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	13. I see <u>biological</u> benefits in this educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	14. I see <u>psychological</u> benefits in this educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	15. I see <u>social benefits</u> in this educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	16. The educational content delivery is <u>factual</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	17. The educational content delivery is <u>metaphorical</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	18. This educational content featured <u>social support from peers</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	19. I think it is helpful to have more content about social support from peers							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>



	20. This educational content featured <u>social support from professionals</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	21. I think it is helpful to have more content about social support from professionals							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	22. Overall, I <u>learned a lot about pain</u> from the educational content							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

Medium Functionality

	1. I think I can use this educational tool <u>every day</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	2. I see this educational tool <u>merging</u> in my everyday life							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	3. I can <u>easily access</u> the tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	4. I want to <u>use the tool every day</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	5. I <u>am always able to find</u> what I want to learn in the tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	6. I see room for making the tool <u>more customizable</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>



		7. I see room for developing a function to <u>track my process</u> within the tool						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		8. I see room for developing a <u>reward system</u> within the tool						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		9. I see room for <u>connecting with peers</u> within the tool						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		10. I see room for <u>connecting with professionals</u> within the tool						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

Design Elements

		1. I think the <u>amount</u> of visualization is ideal						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		2. I think the <u>frequency</u> of visualization is ideal						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		3. I find the visualization too <u>complex</u>						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		4. I find the visualization too <u>serious</u>						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
		5. I find the visualization too playful						
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>



	6. I think the design of the educational tool is <u>suitable to deliver pain-related content</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	7. I think the design elements are <u>consistent</u> through the educational tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

Barriers of Use

	1. I think I would like to use this tool <u>frequently</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	2. I find this tool <u>unnecessarily complex</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	3. I think this tool is <u>easy to navigate</u>							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	4. I think I <u>need the support</u> from another person to use this tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	5. I think the <u>functions</u> in this tool are well integrated							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	6. I find too much <u>inconsistency</u> in this tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

	7. I imagine many people learning to use this tool quickly							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>



	8. I find this tool <u>cumbersome</u> to use							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	9. I feel <u>confident</u> using this tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	10. I need to <u>learn a lot of things</u> before navigating this tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	11. I can <u>easily recall</u> what knowledge I obtain from this educational tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>
	12. Overall, my <u>learning experience</u> is							
<i>Negative</i>	1	2	3	4	5	6	7	<i>Positive</i>
	13. Overall, I would <u>rate</u> this tool							
<i>Negative</i>	1	2	3	4	5	6	7	<i>Positive</i>
	14. Overall, I think I can <u>learn about my pain</u> from this educational tool							
<i>Strongly agree</i>	1	2	3	4	5	6	7	<i>Strongly disagree</i>

Appendix E.

Semi-Structured Interview Questions



SIMON FRASER UNIVERSITY
ENGAGING THE WORLD

Ethics application #30001924
Version: 1.0

Title of Study: Exploring the delivery of pain education packages for chronic pain patients and their caregivers.

Department, School or Faculty: School of Interactive Arts & Technology, SFU

SEMI-STRUCTURED INTERVIEW QUESTIONS

Question 1

From the three pain educational packages, which helps you learn best about pain, and why?

Question 2

From the three pain educational packages, which do you think you will constantly use in your everyday life?

Question 3

From the three pain educational packages, which delivery methods do you think work best for you, and why?

Question 4

Do you have any suggestions for improvements for the three educational packages?

Question 5

What do you wish to have learned about pain but the three educational packages did not achieve?