

**DEVELOPMENT OF A DIGITAL PAIN MAPPING TOOL USING ICONOGRAPHY FOR
THE ASSESSMENT OF SENSORY PAIN**

**DEVELOPMENT OF A DIGITAL PAIN MAPPING TOOL USING ICONOGRAPHY FOR
THE ASSESSMENT OF SENSORY PAIN**

By

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ABSTRACT

The overall theme of this thesis is the study of sensory pain assessment and describes how digital pain mapping using standardized iconography can be used to help portray and understand the sensory pain experience. The research presented in this thesis is focused on the design, development, and use of a web-based sensory pain assessment tool for individuals with chronic pain called the *Pain-QuILT*. “QuILT” is an acronym describing the different parameters that are captured by the tool: pain quality, intensity, and location in a digital format that can be tracked over time.

The central hypothesis guiding this work is that users of pain assessment tools will tend to favour a digital icon-based sensory pain mapping tool (*PainQuILT*) over currently available sensory pain assessment tools. “*Pain assessment tool*” has been operationally defined as a standardized method for capturing information about an individual’s sensory pain experience. In this context, “*users*” include both individuals experiencing chronic pain and healthcare providers who seek to assess and understand pain.

Research to date has focused on phased evaluation of the *Pain-QuILT* in the context of clinical sensory pain assessment for two distinct user groups: adolescents (aged 12 to 18 years) and adults (aged 19 years and older) with chronic pain. Each stage of research has generated and been informed by user feedback, leading to iterative improvements in tool functionality. Thus, as a whole, this body of work represents an evolving effort to improve the clinical assessment of sensory pain using the approach of icon-based pain mapping in a digital and visual format.

Through the collective research presented in this thesis, we have affirmed that digital pain mapping using iconography is a viable solution to the clinical challenge of sensory pain assessment in adolescents and adults with chronic pain.

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DECLARATION OF ACADEMIC ACHIEVEMENT

In accordance with the *Guide for the Preparation of Theses at McMaster University*, the research documented herein is presented as a “Sandwich” Thesis, including both previously published and prepared material. The articles presented in Chapters 2, 3, 4, and 5 are four independent manuscripts that are connected by the overall theme of this thesis, the study of sensory pain assessment and how digital pain mapping using standardized iconography can be used to portray and understand the pain experience. Given that the manuscripts presented in this thesis have multiple authors, my contributions as first author have been described below. As of August 2014, each manuscript has been published by a peer-reviewed journal.

CHAPTER 2

Laloo C, Henry JL. Evaluation of the Iconic Pain Assessment Tool by a heterogeneous group of people in pain. *Pain Research & Management*. **16(1)**:13-18, 2011.

This work was conducted over the period of December 2008 – March 2009.

My contributions to this work included:

- Primary responsibility for obtaining approval from locally responsible Research Ethics Board
- Primary responsibility for study design, data collection, analysis, and interpretation
- Primary responsibility for the writing, preparation, and submission of the manuscript
- Equal responsibility with JLH for responding to comments from peer-reviewers

CHAPTER 3

Lalloo C, Stinson JN, Hochman JR, Adachi JD, Henry JL. Adapting the Iconic Pain Assessment Tool Version 2 (IPAT2) for adults and adolescents with arthritis pain through usability testing and refinement of pain quality icons. *Clinical Journal of Pain*. **29(3)**:253-264, 2013.

This work was conducted over the period of September 2010 – March 2011.

My contributions to this work included:

- Primary responsibility for obtaining approval from locally responsible Research Ethics Board across three sites
- Primary responsibility for study design, data collection, analysis, and interpretation
- Primary responsibility for the writing, preparation, and submission of the manuscript
- Shared responsibility with JNS, JRH, JDA, JLH for responding to comments from peer-reviewers

CHAPTER 4

Lalloo C, Stinson JN, Brown SC, Campbell F, Isaac L, Henry JL. *Pain-QUILT*: Assessing clinical feasibility of a web-based tool for the visual self-report of pain in an interdisciplinary pediatric chronic pain clinic. *Clinical Journal of Pain*. **e-pub-ahead-of-print**. 2013 Nov 28. PMID: 24300217

This work was conducted over the period of July 2011 – May 2013.

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- Primary responsibility for obtaining approval from locally responsible Research Ethics Board across two sites
- Primary responsibility for study design, data collection, analysis, and interpretation
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CHAPTER 5

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- Primary responsibility for study design, data collection, analysis, and interpretation
- Primary responsibility for the writing, preparation, and submission of the manuscript
- Shared responsibility with DK, JNS, and JLH for responding to comments from peer-reviewers

CHAPTER 1

INTRODUCTION

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1. Overview:

The overall theme of this thesis is the study of sensory pain assessment and describes how digital pain mapping using standardized iconography can be used to help portray and understand the pain experience. The research presented in this thesis focuses on the design, development, and use of a web-based visual pain assessment tool for adults and adolescents with chronic pain called the *Pain-QuILT*. “QuILT” is an acronym describing the different parameters that are captured by the tool: pain quality, intensity, and location in a digital format that can be tracked over time.

2. Background and Key Concepts:

2.1 What is pain?

The International Association for the Study of Pain has defined pain as, “*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*” [1].

Pain is a multidimensional construct comprised of sensory-discriminative, affective-motivational, and cognitive-evaluative dimensions [2]. The sensory-discriminative dimension includes components such as quality (what pain feels like), intensity (how much pain hurts), location (spatial distribution of pain), and duration (how

long pain lasts) [2]. The affective-motivational dimension describes the emotional impact of pain, such as the extent to which pain is perceived to be unpleasant or distressing [2]. The cognitive-evaluative dimension reflects an evaluation of the meaning and consequences of pain, including the degree to which pain is perceived to interfere with different aspects of life, such as physical, emotional, role, and social functioning [2].

2.2 What is chronic pain?

Chronic pain, defined as pain that persists beyond the normal time of healing (typically 3 to 6 months), is a common and debilitating health problem that is now recognized as a disease [3]. Global estimates of prevalence range from 18 to 41% [4-6]. While more common among adults, chronic pain also affects children and adolescents [7][8]. Chronic pain is known to negatively impact all aspects of health related quality of life, including physical, emotional, social, and role functioning [9][10]. In addition to the huge psychosocial burden on individuals, chronic pain also imposes a significant economic burden, with costs of medical treatment and lost productivity estimated at \$600 billion per year in the United States and \$56-60 billion per year in Canada [11].

2.3 Chronic pain assessment

The timely clinical assessment of pain is the first step in effective management [12][13]. The management of chronic pain is a long-term process that often involves numerous healthcare professionals and multiple strategies, including pharmacological, psychological, and physical therapies [14]. Ongoing and consistent assessment of pain is essential to gauge the effectiveness of different pain treatment strategies and inform

successful disease management [15]. Healthcare professionals commonly involved in the assessment and management of chronic pain include physicians, nurses, occupational therapists, physiotherapists, and psychologists [16].

2.4 Self-report of pain

Despite being a nearly universal human phenomenon, on an individual level, pain is experienced in an intensely personal and vivid way [15]. One of the biggest challenges of pain assessment is that, as a complex sensory and emotional experience, pain cannot be directly quantified [15]. Given the intimate nature of pain, patient self-report is a primary source of information during the clinical assessment of individuals who possess the cognitive and verbal ability to describe their pain [15].

Research suggests that chronological age is the best predictor of whether an individual is able to self-report pain intensity [17]. As described by von Baeyer, most individuals aged 5 years and older are able to self-report pain intensity when provided with a developmentally appropriate tool [18].

For those individuals with the cognitive and communication skills required to express their pain, self-report is the best way to learn about their private internal experiences [15]. However, self-report cannot be considered as a standalone “gold standard” for measuring pain. Unlike physiological parameters, such as the “vital signs” (i.e., pulse, temperature, respiration, blood pressure), self-report does not yield an objective index [19]. Instead, as conceptualized by Schiavento and Craig, self-reports of

pain are created as part of a social transaction between the patient and clinician [19]. This transaction is dynamic and can be influenced by many factors, such as the nature of the clinician-patient relationship, the expected consequences of the assessment, and the phrasing of questions about pain [19,20]. Thus, while self-report measures provide valuable insights to the individual pain experience, the strengths of these measures must always be tempered with knowledge of clinical context, the patient's physical and emotional state, as well as behavioural observation [19].

2.5 Development and evolution of standardized self-report tools to aid clinical assessment of sensory pain

The field of sensory pain assessment has been evolving iteratively [15][21,22]. This evolution has been driven in part by a need to develop tools that capture pain self-reports in a standardized, efficient, and user-friendly manner. From a historical perspective, available pain assessment tools have exhibited gradual increases in sophistication and detailed data capture. These iterative improvements have been informed by a dynamic interaction between research and clinical practice, wherein identified deficiencies from the clinical side are used to inform new research, which then leads to overall improvements in available pain tools.

The following sub-sections provide a brief snapshot of the historical evolution of sensory pain self-report tools for use in adult and pediatric chronic pain groups. As outlined below, the important developments in the field have been: (i) expanding from uni-dimensional to multi-component sensory tools, (ii) incorporating the concept of pain

mapping with varying degrees of sophistication, and (iii) transitioning from paper to digital modes of data capture.

2.5.1 Uni-dimensional self-report tools for sensory pain

Uni-dimensional tools are generally designed to assess pain intensity only, and often produce a single number to represent the relative magnitude of pain on a defined scale [21]. The most common tools for assessing pain intensity by self-report include:

- **Visual analogue scales**, which consist of a single vertical or horizontal line with anchors such as ‘no pain’ and ‘worst pain imaginable’ [23]. The patient is asked to place a mark on the line to show their level of pain. A numerical score, usually ranging from 0 to 100, is produced by measuring the relative position of the patient’s mark using a ruler. This type of scale is often used in patients aged 8 years and older [21].
- **Numerical rating scales**, which consist of a range of sequential numbers, such as 0-10 or 0-100 [24]. The scale is anchored by word descriptors such that a zero rating corresponds with ‘no pain’ and the highest number corresponds with a phrase such as ‘most pain possible’. The patient is asked to select the one number on the scale that best represents their pain level. The scale can be administered either verbally or on a printed sheet. This type of scale requires numeracy skills to complete, and is recommended for individuals aged 8 years and older [25-27].

- **Graphic rating scales**, which use physical objects to help patients describe their pain level. For example, the *Pieces of Hurt* tool consists of four tokens, each of which represents a different amount of pain, ranging from “a little hurt” to “the most hurt you could ever have” [28]. The patient is asked to choose the token that matches how much pain they have. The *Pieces of Hurt* tool was originally developed for individuals aged 4 to 7 years [28].

- **Verbal rating scales**, which use a combination of numbers and simple phrases to describe different magnitudes of pain [29]. Patients are asked to choose the phrase that best expresses their pain level, and their score is recorded as the corresponding number. A commonly used example is: *not at all* = 0; *a little bit* = 1; *quite a lot* = 2; and *most hurt possible* = 3 [29]. This type of scale has been used in children aged 4 to 6 years [29].

- **Faces pain scales**, which consist of a series of drawings or photographs of facial expressions that show different degrees of pain [30]. Patients are shown the sequence of faces, which range from a neutral expression (‘no pain’) to a distressed expression (high pain level), and asked to choose the one face that best represents how they feel inside. Each face on the scale has a corresponding numerical score. This type of scale can be used with individuals aged 4 years and older [30].

2.5.1.a Limitations of uni-dimensional self-report tools for sensory pain

While single-item intensity scales are simple and easy to use, by virtue of their reductive design, they are also associated with a significant loss of information. As articulated by Melzack and Torgerson, *“the word ‘pain’ refers to an endless variety of qualities that are categorized under a single linguistic label, not to a specific, single sensation that varies only in intensity. Each pain has unique qualities. To describe pain solely in terms of intensity is like specifying the visual world only in terms of light flux without regard to pattern, color, texture and the many other dimensions of visual experience”* (p. 50) [31]. Thus, by reducing the complex experience of sensory pain to a single static number, uni-dimensional scales are not designed to capture other important sensory components such as quality, spatial distribution, and duration.

2.5.2 Multi-component self-report tools for sensory pain

Multi-component tools are designed to capture sensory characteristics of the pain experience beyond intensity. As outlined below, available multi-component sensory tools for adult and pediatric groups adhere to a similar format and are designed to assess pain quality, intensity, and location.

2.5.2a Multi-component sensory self-report tools for adults

The most commonly used multi-component pain measures for adults in research and clinical practice are the *McGill Pain Questionnaire* [32] and the *Brief Pain Inventory* [33].

The *McGill Pain Questionnaire* was developed in the 1970s through a groundbreaking program of research that was focused on identifying common word descriptors for the pain experience [31,32,34]. This body of research represented the first systematic effort to standardize the language of pain quality reporting. The *McGill Pain Questionnaire* is a one-page measure with three components: (i) a list of 78 pain quality descriptors that are organized into 20 discrete subclasses according to implied intensity, (ii) a single verbal rating scale for overall pain intensity, and (iii) a body manikin with anterior and posterior views [32]. Patients are asked to review each discrete subclass of descriptors and select the one word that best describes their current pain, if applicable. They also provide a single rating of their current pain intensity, and illustrate the spatial distribution of pain by shading painful regions on the body manikin with a pencil or pen. Truncated versions of the *McGill Pain Questionnaire* have also been developed for clinical and research use [35,36]. Overall, the *McGill Pain Questionnaire* is perhaps the most well validated multi-component pain measure.

The *Brief Pain Inventory* was developed in the 1980s for use in adults with cancer pain, based on research suggesting that existing measures such as the *McGill Pain Questionnaire* were burdensome for patients to complete [33,37]. Since that time, a truncated version called the *Brief Pain Inventory Short Form* has been adopted as one of the most widely used tools for assessing chronic pain in clinical and research settings [33,37][13]. The *Brief Pain Inventory Short Form* is a one-page questionnaire with three components: (i) series of numerical rating scales to assess the level of pain interference with various aspects of life (e.g., general activity, mood), (ii) numerical rating scales to

assess current pain intensity and recalled pain over the past 24 hours, and (iii) a body manikin with anterior and posterior aspects to document pain location [33].

2.5.2b Multi-component sensory self-report tools for children and adolescents

There is a limited number of multi-component sensory self-report pain tools for children and adolescents, including the *Varni/Thompson Pediatric Pain Questionnaire* [38], *Abu-Saad Pediatric Pain Assessment Tool* [39,40], and *Adolescent Pediatric Pain Tool* [41,42]. All of these measures are modeled after the *McGill Pain Questionnaire* [32] and contain the following key components: (i) list of pain quality descriptors, (ii) visual analogue scale for pain intensity, and (iii) body manikin to show pain location. Additionally, pediatric chronic pain is often managed in an interprofessional team-based setting where clinics design their own questionnaire or semi-structured interview guide for assessing different components of sensory pain [43].

2.5.2.c Limitations of multi-component sensory self-report tools

While the multi-component tools described above are an improvement upon uni-dimensional scales in terms of breadth, they were designed in a modular fashion and thus are only able to capture information on pain quality, intensity, and location in separate, discrete categories. This lack of data *integration* may hinder the portrayal and understanding of chronic pain as a complete and complex sensory experience.

2.5.3 Pain mapping as a means of enhancing the assessment of sensory pain

The concept of “pain mapping” refers to the application of cartographical principles to the expression of pain [44]. As stated by Schott, the use of a pain map “...entails the transfer of subjectivity and symptom to objectivity and a graphic sign” (p.784) [44]. He further elaborates, “just as words can provide crucial ways of communicating the nature of a patient’s pain, so the pain map can also provide further information when symbols or colours are added to indicate subjective qualities” (p.784) [44]. The earliest known pain map appeared in the 16th century in the form of a painting by Albrecht Dürer, which was used to communicate the location of his pain to an out-of-town physician [45,46].

As summarized in the following sub-sections, the field of pain mapping has seen important advances and is characterized by increasingly complex data capture methods across different media platforms.

2.5.3.a Paper-based sensory pain mapping and its limitations

The multi-component sensory pain tools most commonly used in clinical practice (see 2.5.2) use pain mapping to a limited extent [32][33][38,39,41]. Specifically, all of these tools allow patients to record information about the spatial distribution of their pain by shading on a body manikin using a pencil or pen. In some cases, these pain maps have been used to link rudimentary drawn symbols, such as crosses and circles, to different sensory characteristics such as pain quality [47].

However, these paper-based methods of sensory pain mapping are associated with drawbacks such as: labour-intensive manual scoring, lack of standardized symbols, lack of standardization of body manikins and how they are scored, limited integration of information about pain quality, intensity, and location, as well as a limited amount of anatomical detail and viewing angles on body manikins [48]. Furthermore, paper-based pain maps cannot be easily displayed and analyzed on a computer, and must be manually stored and organized for clinicians to view changes in sensory pain over time [48].

2.5.3.b Digitized sensory pain mapping

The increasing pervasiveness of digital technologies (e.g. computers, Internet, smartphones, tablets) is providing new opportunities for innovation in the field of sensory pain mapping [49]. In particular, the use of these technologies can increase the standardization of data capture and scoring, improve the integration of information about sensory pain, increase the degree of anatomical detail on body manikins, and facilitate greater user interactivity than paper questionnaires.

Documented advantages of a digital approach to pain assessment include: minimization of errors in data transfer and transcription, ability to capture time-stamped data, ease of data sharing, increased compliance, positive patient preference, and heightened patient satisfaction [50-52][53].

There are also important drawbacks to using a digital approach to sensory pain assessment, such as high cost in comparison to paper tools (e.g. software development, maintenance, technical support, hardware), user training requirements, potential for technical malfunctions, and considerations of data privacy and security [22][54]. Furthermore, these digital tools must be kept up-to-date with rapidly changing technology trends to ensure their currency and compatibility.

2.5.3b1 Field of current digital sensory pain mapping tools

A limited number of digital sensory pain mapping tools has been developed for adult and pediatric chronic pain groups.

Wilkie and colleagues created a digital extension of the *McGill Pain Questionnaire* called *PAINReportIt* [55]. It has undergone usability and cognitive testing in adults with acute and chronic pain [55][56]. This computer-based tool adapts all components of the *McGill Pain Questionnaire* [32] for use on a touch screen platform. Instead of shading painful regions on a body manikin with a pencil, *PAINReportIt* allows patients to use their fingertip or a mouse to indicate painful body sites [55]. However, as with the original *McGill Pain Questionnaire*, information about pain quality and intensity is collected separately and there is limited integration with body location. Furthermore, while leveraging the potential of digital technology to enhance pain assessment, *PAINReportIt* requires patients to choose from a standardized list of adjectives to express pain quality [55]. This reliance on a purely word-based format may present difficulties for individuals with limited language skills and/or a preference for visual

communication [57,58]. For example, in a study involving n=25 adults with sickle cell disease, Wilkie and colleagues identified 16 different sensory pain descriptors on PAINReportIt that were not recognized or understood by participants [56].

The *MacInterview* is a computer-based tool that allows patients to visually represent different types of pain and has scales to document the relative size and amount of ‘throb’ or intensity on a virtual body manikin [59][60]. Evidence of face validity, convergent validity (compared to a word graphic rating scale and visual analogue scale), and test-retest reliability has been reported in a sample of 30 children aged 7-12 years with acute post-operative pain [60]. Importantly, the *MacInterview* is designed to be entirely visual in its depiction of pain type [60]. Applying the principles of pain mapping, patients can link images from a ‘pain palette’ with the body manikin [60]. However, the representations in the visual palette are quite basic (for example: ‘spotty or cloud-like images’ and ‘simple lines, squares or circles’) (p. 285) and also do not correspond with any standardized pain quality descriptors such as ‘burning’ or ‘sharp’ [60].

Recently, Jamison and colleagues developed and evaluated test-retest reliability of a computer-based tool for adults with chronic pain that permits 3-dimensional (3D) pain mapping [48]. This tool allows patients to identify the surface location and depth of painful sites by rotating a 3D visualization of the body, and also rate the intensity of pain at each site using a visual analogue scale [48]. While considerably more sophisticated

than the tools described thus far, this digital mapping tool does not capture any standardized information about pain quality [48].

2.5.3b2 Limitations in the field of digital sensory pain mapping

While the digital pain mapping tools described above offer advantages over paper-based questionnaires, they still rely upon either rudimentary, non-standardized symbols or lists of adjectives to describe pain quality. Furthermore, with the exception of the *MacInterview* [60], these tools provide limited integration of information about pain quality, intensity, and body location.

2.5.3.c Integration of iconography into field of digital sensory pain mapping

The *Iconic Pain Assessment Tool* is a digital mapping tool for the visual self-report of pain quality, intensity, and location [61]. It was created as part of a Master's research project at the University of Toronto [62], which explored the visualization of pain among adults with a rare type of central neuropathic pain called central post-stroke pain [61].

The *Iconic Pain Assessment Tool* builds upon the field of sensory pain mapping by using a combination of standardized icons (i.e. stylized graphic images) and word descriptors to represent various qualities of pain [61]. Each icon is designed to use a real-life object to depict a specific pain quality. The visual metaphors used in the icon library are: a matchstick for 'burning' pain, ice cube for 'freezing' pain, vice for 'squeezing' pain, knife for 'lacerating' pain, and anvil for 'aching' pain. Patients can

assign a single pain intensity score (0-10) to each pain quality category (e.g. one score for ‘burning’ pain, one score for ‘freezing’ pain, etcetera) using a series of five numerical rating scales [61].

Similar to the *MacInterview* [60], the *Iconic Pain Assessment Tool* is designed to help patients interact with the interface and create visual expressions of their current pain [61]. However, unlike the *MacInterview* [60], the *Iconic Pain Assessment Tool* provides patients with a library of five defined icons that corresponds with specific pain quality descriptors. Using a mouse, patients can drag-and-drop icons onto a simple virtual body manikin to show the location of different pain types. The hands and feet on the body manikin can be manually magnified by the user if desired. They can also manually record the time period of data entry by clicking on a single time-tab (morning, afternoon, evening, or overnight). As described by McMahon and colleagues, patient feedback from two adults with central post-stroke pain was collected through a needs assessment questionnaire and incorporated into the prototype tool [61]. The *Iconic Pain Assessment Tool* was developed in *Adobe Flash®* and is freely available online (<http://www.emiliemcmahon.ca/pain-tool.html>).

2.5.3.c1 Shortcomings of the Iconic Pain Assessment Tool

The *Iconic Pain Assessment Tool* represents a unique contribution to the field of digital sensory pain mapping by offering a standardized icon-based language for pain quality and linking these icons with a body manikin in an interactive and dynamic format

[61]. However, there are important limitations in the prototype tool as it pertains to clinical use in pediatric and adult chronic pain groups.

2.5.3.c1a Design and Testing Limitations

First, the *Iconic Pain Assessment Tool* is designed for a specialized and rare type of chronic neuropathic pain (central post-stroke pain) rather than a broad group of individuals with chronic pain. Second, patient input during tool development was limited to two adults with central post-stroke pain. Third, the pain iconography was not assessed to determine descriptiveness of sensory pain and provide evidence of content validity (i.e. degree to which the library is inclusive of different pain qualities) [63]. Fourth, the tool was not evaluated in adolescents, which is required for clinical use in this age group. Fifth, the tool was not evaluated from the perspective of clinicians who treat pain, which is important to assess its value as well as to promote future integration into clinical practice rather than solely as a research tool. Sixth, the tool was not compared with any existing method of assessing sensory pain to evaluate user preferences and convergent construct validity (i.e. degree to which the captured information is correlated with other measures of sensory pain) [63]. Seventh, clinical feasibility of the tool (i.e. ease of implementation in a clinical setting) was not evaluated [64]. Eighth, while chronic pain is a long-term disease that requires the consistent and repeated assessment of pain, the tool is not designed to support the digital tracking of pain over time.

Given these identified limitations in design and testing, the *Iconic Pain Assessment Tool* prototype has sufficient shortcomings to impede clinical uptake and use to assess sensory pain in adults and adolescents with chronic pain.

3. Thesis Aim:

The aim of this project was to iteratively develop, adapt, and extend the foundational components of the *Iconic Pain Assessment Tool* (i.e. digital sensory pain mapping using standardized iconography) in order to promote clinical uptake and use in adults and adolescents with chronic pain.

4. Thesis Objectives:

Specifically, I sought to systematically address the identified limitations in design and testing of the *Iconic Pain Assessment Tool* (see 2.5.3.c1), as follows:

1. Evaluate acceptability of the core concept and design from the perspective of individuals with different types of chronic pain.
2. Actively seek and incorporate input from individuals with different types of chronic pain by applying a user-centered design approach.
3. Evaluate and refine the library of pain quality icons to assess content validity and descriptiveness of the sensory pain experience.

4. Evaluate the tool from the perspective of adolescents with chronic pain in terms of usability and perceived value for reporting sensory pain.
5. Evaluate the tool from the perspective of clinicians who treat chronic pain in terms of perceived value and clinical usefulness for assessing sensory pain.
6. Compare the tool with common existing methods of assessing sensory pain to assess user preferences and convergent construct validity.
7. Evaluate clinical feasibility of the tool in adult and pediatric chronic pain settings.
8. Design and incorporate a method for storing and tracking pain data over time.

Nomenclature: For the purpose of this thesis and future dissemination, the tool has been re-named the *Pain-QuILT*. “QuILT” is an acronym describing the various sensory pain components that are captured: quality, intensity, and location in a digital format that can be tracked over time. For ease of reading, the tool will be referred to as the *Pain-QuILT* for the remainder of the introduction as well as the discussion chapter.

5. Hypothesis:

The central hypothesis guiding this work is that users of pain assessment tools will tend to favour a digital icon-based sensory pain mapping tool (*Pain-QuILT*) over currently available sensory pain assessment tools. “*Pain assessment tool*” has been operationally defined as a standardized method for capturing information about an individual’s sensory pain experience. In this context, “*users*” include both individuals

experiencing chronic pain and healthcare providers who seek to assess and understand pain.

6. Summary:

The overall theme of this thesis is the study of sensory pain assessment and describes how digital pain mapping using standardized iconography can be used to portray and help understand the sensory pain experience. The research presented in this thesis (see Chapters 2-5) is focused on the design, development, and use of a digital (web-based) visual pain assessment tool for individuals with chronic pain called the *Pain-QuiLT*.

Research to date has focused on phased evaluation of the *Pain-QuiLT* in the context of clinical sensory pain assessment for two distinct user groups: adolescents (aged 12 to 18 years) and adults (aged 19 years and older) with chronic pain. Each stage of research has generated and been informed by user feedback, leading to iterative refinements in tool functionality as per a user-centered design approach [65]. Thus, as a whole, this body of work represents an evolving effort to improve the clinical assessment of sensory pain using the approach of pain mapping in a digital and visual format.

The first manuscript, presented in Chapter 2 of this thesis, describes an initial evaluation of the prototype tool (*Version 1; developed by McMahon et al*) in a sample of

adults with chronic pain. Given that the prototype was originally designed for individuals with central post-stroke pain, this study represented the first step in adapting the tool for a broader group of individuals with chronic pain. Specifically, we sought to: (a) investigate user acceptance of the concept of digital icon-based sensory pain mapping, and (b) identify specific areas for prototype refinement. Using the methodology of individual semi-structured interviews, qualitative and quantitative data were collected from n=23 adults with chronic pain. Overall, the concept of icon-based sensory pain mapping was well liked by participants and the prototype tool was rated as valuable for expressing and documenting the sensory pain experience. User feedback also identified the need for three major changes to the prototype design. First, the library of pain quality icons required refinement to enhance the descriptiveness of sensory pain. Second, the tool required a design modification to allow the recording of multiple qualities and multiple intensities of pain across different body locations. Third, the addition of an electronic time stamp function was required to automatically capture the time and date of each pain report. Overall, this study provided evidence that adults with chronic pain endorsed the concept of using digital icon-based pain mapping to express and document sensory pain, and also identified specific aspects of the prototype that required refinement.

The second manuscript, presented in Chapter 3, builds directly upon the work of Chapter 2 by incorporating the user-identified modifications into the prototype tool to create *Version 2*. Following this tool refinement, we examined content validity and usability of the *Pain-QUILT* in a sample of adolescents and adults with chronic arthritis

pain. Using the method of individual semi-structured interviews, qualitative and quantitative data were collected from n=30 participants. *A priori* criteria for content validity were used to evaluate the degree to which each icon was descriptive of the pain experience. A combination of participant feedback and investigator observation was used to evaluate usability of the interface for the self-report of current sensory pain. The tool was found to be easy to use, easy to understand, and quick to complete. All participants characterized the tool as potentially valuable for communicating the complex sensory experience of arthritis pain with healthcare providers. User-identified strengths of the tool included the ability to describe pain in a non-verbal manner, enjoyment of use, and simplicity. The major user-identified deficiency in the tool was a lack of detail on the virtual body manikin to pinpoint locations of pain. All icons met or exceeded *a priori* criteria for acceptance, providing evidence of content validity. In addition, new pain icons were designed and iterated based upon participant feedback. Overall, this study provided evidence that the *Pain-QUILT* may importantly aid the assessment and communication of sensory pain in adolescents and adults with chronic pain from arthritis.

Until this point in time, the *Pain-QUILT* existed only as a “front end” interactive interface for users to self-report sensory pain. These pain maps could be saved electronically as portable document format (PDF) images but the tool did not have a dedicated mechanism for capturing data in a quantitative format or for tracking data over time. Furthermore, as identified by study participants in Chapter 3, the virtual body manikin did not record pain location with adequate precision. To address these

shortcomings, a “back end” data capture system was incorporated into the *Pain-QuiLT* (Version 3). Specifically, the virtual body manikin was codified into 110 discrete sites to allow for greater precision in reporting of pain location. Each body site was linked to a secure online database, which was automatically populated with data as new pain records were created. This “back end” system was designed to allow data storage and simplify the process of tracking sensory pain over time.

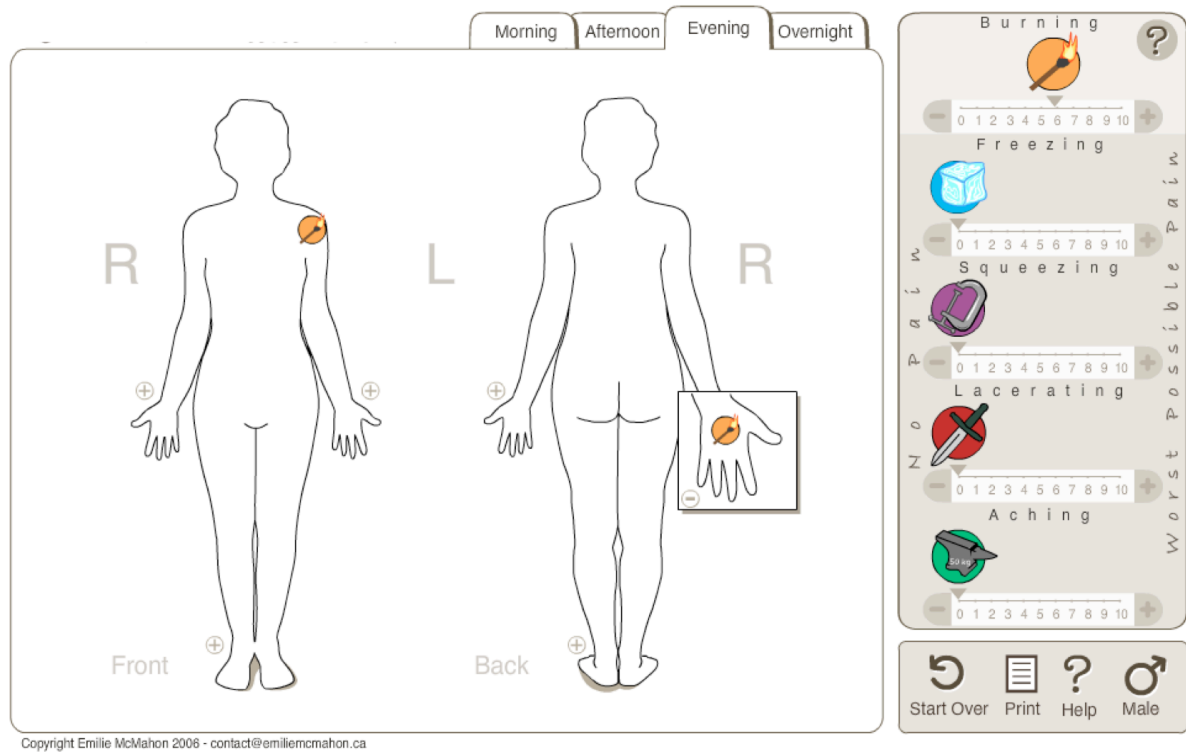
The third manuscript, presented in Chapter 4, investigates clinical feasibility of the *Pain-QuiLT* (Version 3) in the setting of an interprofessional pediatric chronic pain clinic. The standard method for assessing pain in this setting was a semi-structured verbal patient interview. The *Pain-QuiLT* was directly compared with this standard method in terms of ease of use, time to complete, user preferences, perceived clinical usefulness, and perceived barriers to implementation. Qualitative interviews were conducted with n=17 adolescents with chronic pain as well as members of their interprofessional health team (n=9) to address the study objectives. All adolescents characterized the *Pain-QuiLT* as easy to use and the majority (88%) indicated positive preference over the clinic standard. The health team characterized the *Pain-QuiLT* as a clinically useful tool for eliciting detailed self-report sensory data, and potentially increasing the efficiency of clinic appointments. Minor and surmountable barriers to implementation were also identified. Overall, this study provided evidence in support of the *Pain-QuiLT* as a clinically feasible method for assessing sensory pain in adolescents with chronic pain.

The fourth manuscript, presented in Chapter 5, builds upon the work of Chapter 4 by examining clinical feasibility of the *Pain-QuiLT* (Version 3) from the perspective of adults with chronic pain in the setting of a pain management and rehabilitation clinic. In this case, the *Pain-QuiLT* was directly compared with two of the most widely used pain assessment tools in adult clinical practice and research, the *McGill Pain Questionnaire* [32] and the *Brief Pain Inventory Short Form* [33]. Individual semi-structured interviews were completed with n=50 adults with chronic pain. The *Pain-QuiLT* was rated as significantly easier to use than both comparator tools, and was also associated with the fewest difficulties in completion. A majority of adults (58%) indicated positive preference for the *Pain-QuiLT* over the *McGill Pain Questionnaire* (16%), *Brief Pain Inventory* (14%), and other methods (12%). The *Pain-QuiLT* pain intensity scores were correlated as expected with the comparator tools, providing evidence of convergent construct validity. Overall, this study provided evidence in support of the *Pain-QuiLT* as a clinically feasible and patient preferred method for assessing sensory pain in adults with chronic pain. This study also provided early evidence in support of convergent construct validity.

For reference, screenshots of the *Pain-QuiLT* user interface (versions 1-3) are provided in section 7 of the introductory chapter.

7. SCREENSHOTS OF THE *PAIN-QUILT* USER INTERFACE (VERSIONS 1-3)

Version 1 (see Chapter 2)



Key Features:

- Library of five pain quality icons
- Single numerical rating scale (0-10) to rate the intensity of each pain quality category (i.e. one score for all 'burning' pain, one score for all 'freezing' pain, et cetera)
- Using a mouse, the user 'drags and drops' descriptive pain quality icons onto virtual body manikin to illustrate pain location
- User has option to magnify hands and feet during pain mapping process
- User is required to manually document the time period of pain reporting by selecting an appropriate time tab (i.e. morning, afternoon, evening, or overnight)
- User can print a hardcopy of their pain map or save an electronic copy as a portable document format (PDF) file

*Development described by:

McMahon E, Wilson-Pauwels L, Henry JL *et al.* The Iconic Pain Assessment Tool: Facilitating the translation of pain sensations and improving patient-physician dialogue. *J Bio Communication* 2008;**34**:E20-E24.

Version 2 (see Chapter 3)

Thursday, April 10, 2014
09:32:15

© Copyright, McMaster University
Hamilton, Ontario, Canada 2010

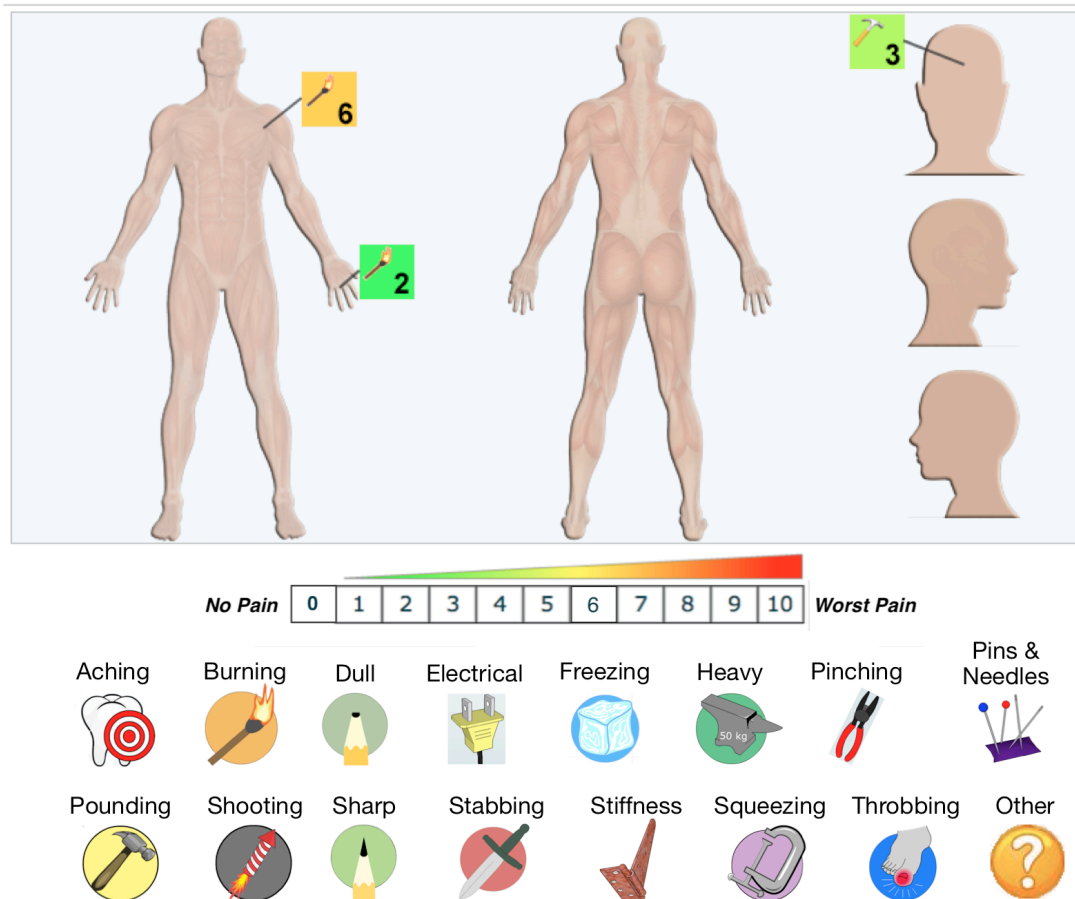
0 1 2 3 4 5 6 7 8 9 10
No Pain Worst Pain

Key Features:

- Library of twelve pain quality icons
- Centralized numerical rating scale (0-10) allows users to document multiple intensities of the same pain quality across their body. For example, the user in the map above has documented a 6/10 'burning' pain in their shoulder as well as a 2/10 'burning' pain in their hand
- Using a mouse, the user 'drags and drops' descriptive pain quality icons (with embedded intensity ratings) onto virtual body manikin to illustrate location
- The hands and feet of the body manikin are permanently magnified to reduce variability in pain mapping
- The time and date of the pain report is automatically stamped
- User can print a hardcopy of their pain map or save an electronic copy as a PDF file

Version 3 (see Chapters 4 and 5)

Thur. Apr 10, 2014. 9:33PM



Key Features:

- Library of sixteen pain quality icons
- Centralized numerical rating scale (0-10) allows users to document multiple intensities of the same pain quality across their body
- Using a mouse, the user 'drags and drops' descriptive pain quality icons (with embedded intensity ratings) onto virtual body manikin to illustrate pain location
- Body manikin is codified into 110 distinct regions. Each region is linked to a 'back end' database. As the user engages in mapping their sensory pain, information about quality and intensity is populated in the database. For example, for the map above, the database would document that the user reported a 6/10 'burning' pain in their left shoulder, a 2/10 'burning' pain in their left hand, and a 3/10 'pounding' pain in their forehead at 9:33PM on Thursday, April 10, 2014.
- User can print a hardcopy of their sensory pain map or save an electronic copy as a PDF file
- Researcher or clinician can access 'backend' database to view captured sensory pain mapping data

CHAPTER 2

Evaluation of the Iconic Pain Assessment Tool by a heterogeneous group of people in pain

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See *Declaration of Academic Achievement* for details regarding authorship.

Summary and Central Message: This study aims to evaluate the prototype digital sensory pain mapping tool from the perspective of adults with chronic pain. Given that the prototype tool was originally designed for individuals with central post-stroke pain, this study represents the first step in adapting the tool for a broader user group of individuals with chronic pain. Our data demonstrate that the concept of digital icon-based sensory pain mapping was positively endorsed by this sample of adults with chronic pain as a user-friendly method of expressing, documenting, and sharing their personal experiences with chronic pain. Specific areas for prototype refinement in terms of design and functionality were also identified by the user group.

Evaluation of the Iconic Pain Assessment Tool by a heterogeneous group of people in pain

Chitra Lalloo BHSc, James L Henry PhD

C Lalloo, JL Henry. Evaluation of the Iconic Pain Assessment Tool by a heterogeneous group of people in pain. *Pain Res Manage* 2011;16(1):13-18.

The Iconic Pain Assessment Tool (IPAT) is a novel web-based instrument for the self-report of pain quality, intensity and location in the form of a permanent diary. Originally designed for people with central poststroke pain, the tool is being adapted for a larger, more diverse patient population. The present study aimed to collect evaluative feedback on the IPAT from a heterogeneous sample of individuals with chronic pain. The specific study aims were to evaluate participant comfort with the tool including enjoyment, ease of use and comfort with the electronic medium; to assess perceived value of the tool for communicating pain quality, intensity and location; to gauge participant intent to share their pain diaries with others and use the tool on a regular basis to track their pain over time; to assess the perceived descriptiveness of current IPAT icons and the numerical rating scale; and to identify strengths and weaknesses of the tool to refine the existing prototype.

Written and verbal feedback from individuals with a variety of chronic pain conditions (n=23) were collected in the context of these objectives. Overall, the IPAT was positively endorsed by this heterogeneous sample of people in pain. The authors concluded that the IPAT is a user-friendly instrument that has the potential to help people express, document and share their personal experience with chronic pain.

Key Words: Chronic pain; Consumer driven; Pain diary; Pain self-assessment; Self-report; Web-based instrument

Tool development

The Iconic Pain Assessment Tool (IPAT) is a novel web-based instrument for the self-report of pain quality, intensity and location in the form of a permanent diary (1). The tool originated as a collaborative graduate project involving the Biomedical Communications program at the University of Toronto (Toronto, Ontario) and the Faculty of Health Sciences at McMaster University (Hamilton, Ontario). The focus of this project was an exploration of pain visualization among individuals with central poststroke pain (CPSP), a relatively rare type of central neuropathic pain (2). Specifically, Émilie McMahon-Lacharité and author JLH sought to design an interactive, web-based learning module to teach patients with CPSP about the etiology of their condition.

This module was intended to supplement the traditional flow of information from the clinician to the patient. Stemming from this idea of doctor-patient communication came the realization that the exchange of information should ideally be reciprocal because it is the patients themselves who may be viewed as 'experts' in the context of pain experience. Indeed, the importance of patient self-report of pain symptoms is widely recognized (3,4). Therefore, the CPSP educational module was expanded to include a simple instrument to facilitate the translation of patient experience into a visual record that could be rapidly interpreted by health care professionals, clinical researchers and members of the patient's social network. Specifically, the IPAT

L'appréciation de l'outil d'évaluation de la douleur par icônes par un groupe hétérogène de personnes éprouvant des douleurs

L'outil d'évaluation de la douleur par icônes (OÉDI) est un nouvel instrument Web pour autodéclarer la qualité, l'intensité et le foyer de la douleur sous forme de journal permanent. Conçu au départ pour les personnes ayant des douleurs centrales après un accident vasculaire cérébral, l'outil est adapté pour une population de patients plus large et plus diversifiée. La présente étude visait à colliger des commentaires évaluatifs sur l'OÉDI auprès d'un échantillon hétérogène de personnes éprouvant des douleurs chroniques. Les objectifs précis de l'étude consistaient à évaluer la facilité d'usage de l'outil par le participant, y compris le plaisir, la facilité et l'aisance d'utilisation de l'outil électronique, à évaluer la valeur perçue de l'outil pour communiquer la qualité, l'intensité et le foyer de la douleur, à sonder l'intention du participant de partager son journal de douleur avec d'autres et d'utiliser l'outil régulièrement afin de suivre la douleur au fil du temps, à évaluer la perception du caractère descriptif des icônes et de l'échelle d'évaluation numérique de l'OÉDI et à déterminer les forces et les faiblesses de l'outil en vue d'améliorer le prototype actuel.

Les chercheurs ont colligé les commentaires écrits et verbaux de personnes ayant divers troubles de douleur chronique (n=23), compte tenu de ces objectifs. Dans l'ensemble, cet échantillon hétérogène de personnes éprouvant des douleurs a bien accueilli l'OÉDI. Les auteurs ont conclu que l'OÉDI est un instrument convivial qui a le potentiel d'aider les personnes à exprimer, à consigner et à partager leur expérience personnelle de douleur chronique.

was designed to visually communicate what the pain feels like (quality), how severe it is (intensity) and where it hurts (location) (Figure 1).

The importance of these pain parameters has been recognized as a core domain of the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) group (5). The IPAT certainly does not exist in isolation, but rather represents a further innovation in the decades of work exploring the assessment of pain. The following paragraphs will briefly outline some existing methods of assessing pain quality, intensity and location in relation to the IPAT as well as describe the advantages associated with electronic administration of health scales. Interested readers are encouraged to consult relevant chapters of the *Handbook of Pain Assessment* for further details (3). Once this foundation has been established, we will describe our intention to expand the IPAT target audience from CPSP to a larger and more diverse pain population.

Assessment of pain quality

As eloquently described by Wagstaff et al (6), "...to communicate adequately what is perceived to another requires possession of a spontaneous vocabulary sufficient to translate feelings into words". Pioneers of pain measurement, Melzack and Torgerson (7), successfully compiled a series of adjectives to describe the various "patterns, colours, and textures" of the pain experience. The sensory component of the

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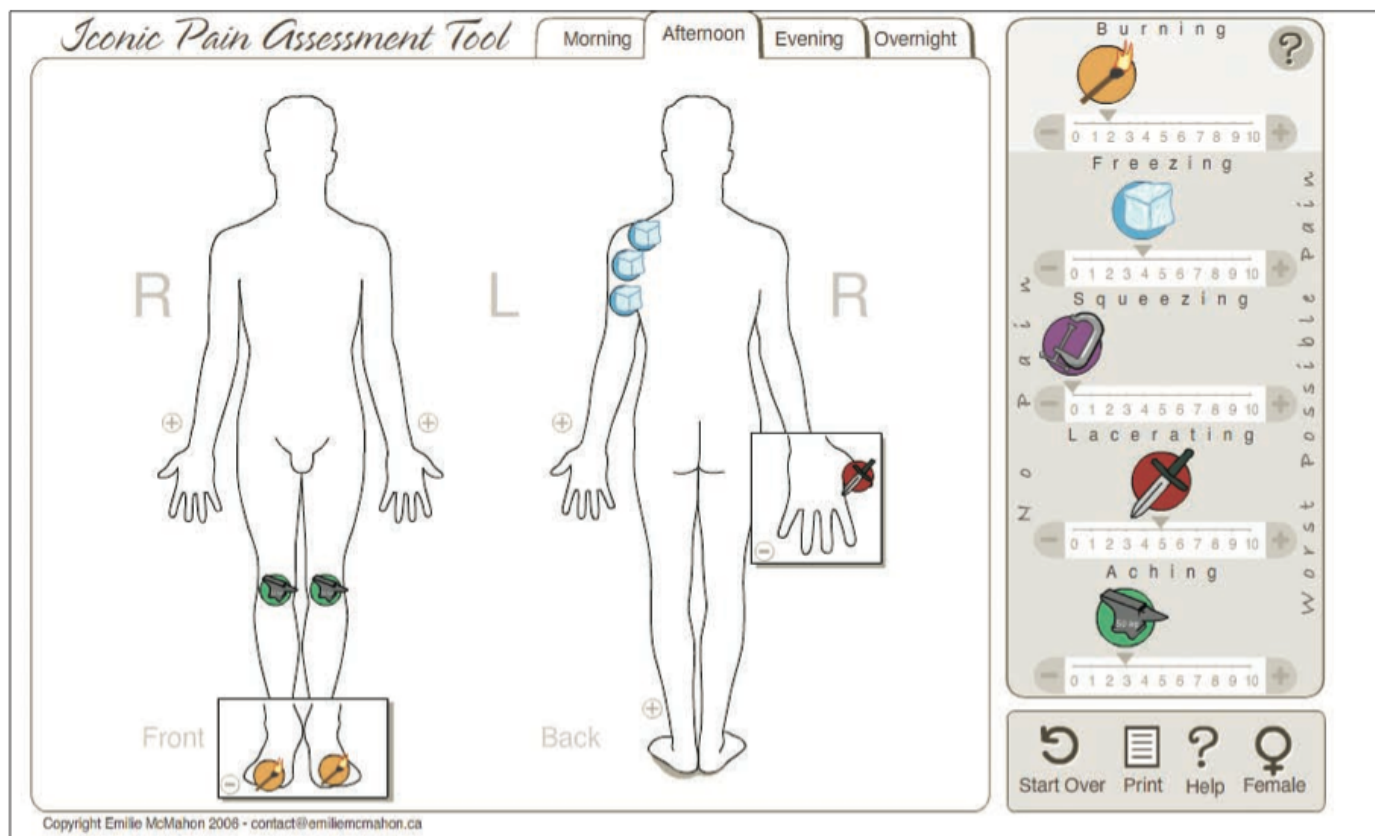


Figure 1 Current iteration of the Iconic Pain Assessment Tool (available at www.emiliemcmahon.ca/pain-tool.html). Reproduced with permission from Émilie McMahon-Lacharité

resulting McGill Pain Questionnaire (MPQ) (8) includes 54 pain adjectives organized into 20 discrete categories and ranked according to implied intensity. For example, the descriptors of the 'temporal' category, in order of increasing intensity, are the following: flickering, quivering, pulsing, throbbing, beating and pounding. Patients are asked to choose the one word from each category that best describes their pain and a total score is then calculated. The subsequently developed Short-Form MPQ (SF-MPQ) includes 11 sensory descriptors from the original scale and is useful for situations requiring a rapid symptom assessment (9). Recently, Dworkin et al (10) developed a new version of the questionnaire (SF-MPQ-2) that includes descriptors for both neuropathic and non-neuropathic pain. Although these instruments can be used to produce a comprehensive and precise explanation of what pain feels like, they also require a fairly advanced degree of literacy in the patient. Thus, the purely text-based medium presents an issue for individuals with limited written or verbal communication skills (11), or a preference for visual communication.

There are existing alternatives to a purely text-based description of pain quality. Swanson et al (12), recognizing a need for reduced reliance on the linguistic competence of patients, developed interactive computer-generated animations to represent various types of pain. This scale includes interactive animations for the qualities of pressure, burning, throbbing and piercing pain. The photographer Deborah Padfield described another interesting example of pain visualization (13). Using the technique of photomontage, Padfield worked with chronic pain patients to help them create striking and evocative visual depictions of their pain. Patients reported that this exercise helped to create an 'emotional outlet' for their suffering, and physicians stated that the resulting imagery allowed them to gain a better understanding of the nature of chronic pain.

Another viable alternative to purely text- and verbal-based protocols is the careful fusion of imagery and words. Specifically, the use of stylized graphic images (termed 'icons') can minimize native-language

and language-level barriers (14), which may help to 'level the field' in terms of description of pain.

The IPAT was designed to capitalize on these potential advantages of icon-based communication to help patients better describe their experiences. The IPAT features icons for five pain qualities (burning, freezing, squeezing, lacerating and aching) that were selected based on prevalence in the CPSP literature and consumer consultation. Émilie McMahon-Lacharité created a visual metaphor for each icon based on an image search using resources such as the Internet, magazines, television commercials and comic book depictions of pain (1). The current visual metaphors included in the IPAT are a flame on a matchstick (burning pain), an ice cube (freezing pain), a vice (squeezing pain), a knife (lacerating pain) and an anvil (aching pain). Patients choose among these icons to describe their current pain sensations. To our knowledge, the IPAT is the only web-based instrument that uses iconography in the description of pain quality.

Assessment of pain intensity

A well-known measure of pain intensity is the visual analogue scale (VAS), which consists of a horizontal or vertical line of fixed length with anchors such as 'no pain' and 'worst pain imaginable' (15). The patient is asked to place a mark along the line to directly estimate the magnitude of their pain. Originally called the 'graphic rating method' (16), the VAS has since been adapted into numerous formats and used extensively in the measurement of pain intensity (15,17). Interestingly, while the VAS appears to provide a continuous measure of pain intensity, evidence suggests that respondents tend to divide the VAS line into smaller increments of 5 or 10, essentially treating it as an 11- or 21-point scale (18).

Another form of intensity assessment is focused on the development of scales that minimize cognitive demands on the patient. For example, concrete ordinal rating scales, such as the Pieces of Hurt tool (19), use physical objects (eg, poker chips) to represent different amounts of pain. Meanwhile, the Wong-Baker Faces Pain Scale

depicts the spectrum of pain through a series of sexually and ethnically neutral hand-drawn faces (20). Patients are asked to examine each face and then select the one that best describes their current pain. This type of scale has been successfully applied to pediatric populations as well as adults with cognitive disorders (21,22).

The MPQ uses a numerical rating scale (NRS) to quantify pain intensity, in which patients are asked to rate the severity of each pain quality as 0 = none, 1 = mild, 2 = moderate or 3 = severe. The subsequently developed SF-MPQ, SF-MPQ-2 and Brief Pain Inventory (23,24) all feature an 11-point NRS ranging from 0 to 10. Indeed, the IMMPACT group recommends the use of this type of NRS to measure pain intensity (4).

The IPAT features an NRS ranging from 0 ('no pain') to 10 ('worst possible pain') below each pain quality icon. By clicking on terminal buttons, users can easily assign an intensity rating to each pain quality.

Assessment of pain location

The distribution of pain across body regions is a critical component of pain assessment. Simple diagrams of the anterior and posterior aspects of the body are commonly used in this type of assessment. In some cases, patients are instructed to shade the regions where they feel pain and then a transparent template is placed over the diagram to generate a score (25-27). Certain computer-based assessment scales allow patients to create 'dynamic pain drawings' using a mouse on a fixed body template (28).

The IPAT interface allows users to select relevant pain qualities, assign an intensity rating, and then drag and drop small circular pain icons onto a simple body map to indicate location. The user also has the option of expanding the hands and feet to more precisely document the location of pain among the digits.

Thus, the IPAT is uniquely positioned to facilitate the self-report of pain quality through a mixture of iconography and descriptors, pain intensity of each quality via NRS, and pain location by the spatial arrangement of icons on a simple body map.

Method of administration

Although the earliest pain assessment tools were necessarily paper based, there has been a recent shift toward electronic administration of pain scales (28-30). Advantages of this approach over paper-based techniques include minimization of errors in data transfer and transcription, ability to capture time-stamped data, ease of data sharing, increased compliance and heightened patient satisfaction (30-33).

The IPAT was developed in Adobe Flash (Adobe Systems Inc, USA) and is freely available online (www.emiliemcmahon.ca/pain-tool.html). Users can access the tool from any computer or mobile device with Flash capability to document their pain parameters in real time. After documenting their pain, users can print a hard copy of their pain diary or save a copy as a PDF file. Regular use of the IPAT facilitates the creation of a permanent record (collection of PDF files) of pain quality, intensity and location over time.

Expanding the target audience for the IPAT

As described above, the IPAT was originally designed for the target population of individuals with CPSP. However, because the unique features of the tool have the potential to benefit other groups of people in pain, the decision was made to adapt the IPAT for a larger and more diverse audience. The first step in this process of adaptation was to determine whether the current iteration of the IPAT was palatable to potential future users. Therefore, the present study collected evaluative feedback on the IPAT from a heterogeneous sample of individuals with chronic pain.

Our specific aims were to evaluate participant comfort with the tool including enjoyment, ease of use and comfort with the electronic medium; to assess perceived value of the tool for communicating pain quality, intensity and location; to gauge participant intent to share their pain diaries with others and use the tool on a regular basis to

TABLE 1
Types of chronic pain reported by study participants

Arthritis (n=3)	Low back pain (n=1)
Bursitis (n=1)	Nerve damage (n=1)
Bulging disc (n=1)	Osteoarthritis (n=2)
Diverticulum (n=1)	Polymyalgia rheumatica (n=2)
Fibromyalgia (n=3)	Rheumatoid arthritis (n=3)
Herniated vertebrae (n=2)	Sciatica (n=2)
Joint trauma (n=1)	Shoulder pain (n=1)
Knee pain (n=1)	Subluxated ribs (n=1)

Some participants (n=23) reported multiple types of chronic pain

track their pain over time; to assess the perceived descriptiveness of the current IPAT icons and NRS; and to identify strengths and weaknesses of the tool to refine the existing prototype.

METHODS

This project was approved by the Hamilton Health Sciences/McMaster Health Sciences Research Ethics Board (REB #07-339), and all participants provided free and informed written consent. No personal or identifying information was collected from study participants.

From December 2008 to March 2009, an evaluation of the IPAT was conducted in a diverse group of individuals with chronic pain. The study involved 23 participants and was conducted in an informal setting.

Inclusion criteria

To be eligible for the present study, participants were required to be at least 18 years of age, exhibit stable, nondeteriorating health and be currently experiencing chronic pain of any origin. Participants also needed to be deemed capable of giving free and informed consent, and be able to read, write and speak English.

Study protocol

After informed consent was documented, each participant was given a short demonstration (approximately 5 min) of tool functionality using the investigators' laptop computer and external mouse. During this demonstration, author CL used a standard guide to explain the ability to describe different types of pain, assign an individualized intensity rating and show pain location. Subsequently, study participants used the tool to document their own pain experience. Participants were asked to 'think aloud' as they navigated the tool, providing a source of immediate, minimally filtered qualitative feedback on the IPAT. The outcome measures used by the investigators were a written questionnaire developed specifically for the present study, a discussion between participants and CL about the tool, and investigator observation of the participant as they navigated the tool. The accumulated feedback was used to address the aims of testing.

Data collected from the written questionnaire were summarized by descriptive statistics such as arithmetic means \pm SDs to describe the central tendency and data dispersion, respectively. Qualitative data in the form of written and verbal feedback are presented as direct quotations from study participants (identifiers removed).

RESULTS

Study participants

The study sample was drawn from a local chronic pain support group that meets on a voluntary, monthly basis in Burlington, Ontario, as well as through word-of-mouth recommendations within the Hamilton community. As shown in Table 1, these individuals exhibited a variety of chronic pain syndromes, providing a diverse sample in which to evaluate the IPAT.

The average severity of pain experienced by these participants on most days, according to self-report, was 5.2 on an 11-point NRS. This

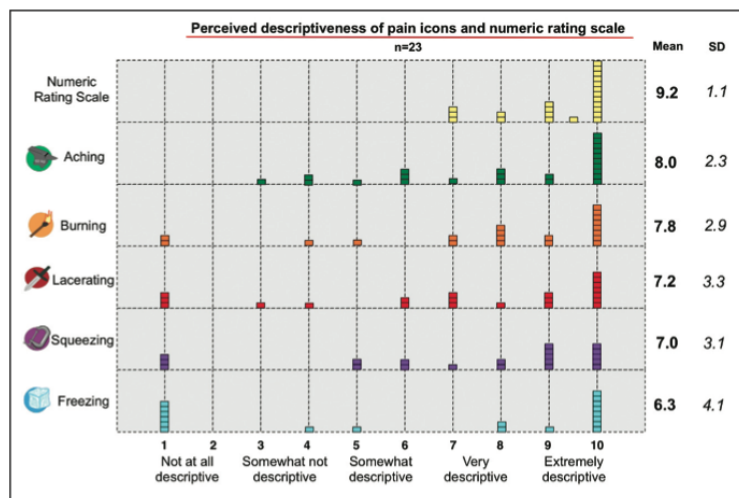


Figure 2) Perceived descriptiveness of the Iconic Pain Assessment Tool icons and numerical rating scale in relation to the quality and intensity of chronic pain, respectively. Frequency distribution of responses and arithmetic means \pm SDs are shown for 23 subjects. Note for interpretation: Each individual block represents a single participant response. For instance, a total of three participants gave the numerical rating scale a rating of 7

finding is roughly comparable to the average intensity of 6.3 reported by a national chronic pain survey involving 340 respondents (34).

Participant comfort with the IPAT

Participants were asked to rate the tool on a 10-point NRS in terms of enjoyment and ease of use, as well as their personal level of comfort with the electronic medium. The scale anchors for these items were, respectively, “didn’t like it at all/liked it very much”, “not easy at all/extremely easy” and “not comfortable at all/extremely comfortable”. Overall, participants liked using the tool (mean 8.4 ± 1.6), found it easy to navigate (mean 8.3 ± 1.9) and were comfortable with its computer-based nature (mean 7.7 ± 2.1). Overall, 21/23 participants (91%) reported that they personally had access to a computer. As well, 22/23 participants (96%) reported that “...no part of the [interface] was difficult to read or see”.

Perceived value of tool for communicating pain sensations

The literature suggests that individuals with chronic pain often feel profoundly misunderstood by people without chronic pain (35). The participants were presented with the statement, “Other people, such as friends, family and co-workers, have trouble understanding my pain experiences”. Level of agreement was assessed by an NRS ranging from 1 (‘strongly disagree’) to 10 (‘strongly agree’). On average, study participants voiced agreement (mean 7.9 ± 2.4) with this statement.

An intended function of the IPAT is to allow individuals to communicate their pain experience with others. The authors were interested in assessing how much value participants would attribute to the tool in this context. Using a 10-point NRS ranging from ‘not valuable at all’ to ‘extremely valuable’, participants gave the tool a mean rating of 8.9 ± 1.5 for value in pain communication.

Due to the novel nature of the tool, a likely audience for the pain diaries has yet to be characterized. Therefore, participants were asked to assess the value that the tool would have for “a person who they wish could understand” their chronic pain. The mean response for this item was 7.7 ± 2.5 .

Other potential audiences for the pain diaries are health care professionals and close family members. Employing a 10-point NRS ranging from “highly unlikely” to “highly likely”, participants rated the likelihood that examination of completed pain diaries would help these groups to better understand the nature of their chronic pain. The mean responses for these likelihood items were 8.4 ± 2.1 and 7.9 ± 2.4 for health care professionals and close family members, respectively.

Intent to share pain diaries with others

Closely related to the notion of pain communication is the degree to which participants are willing or likely to share their completed pain diaries with other parties. Using a 10-point NRS ranging from “highly unlikely” to “highly likely”, participants reported the likelihood that they would show their pain diaries to various individuals. Overall, participants were highly likely to show their pain diaries to a specialist (mean 9.2 ± 1.9) or family physician (mean 9.0 ± 2.1). On average, they were also likely to share this information with “a person who they wish could understand” their pain (mean 8.4 ± 2.3) and somewhat less likely to share with close family members (mean 7.8 ± 2.4).

Interestingly, participants were less likely to show their pain diaries to friends (mean 5.5 ± 2.9) or other individuals (mean 5.4 ± 3.9). On informal probing for the logic behind these responses, some individuals cited feelings of awkwardness in showing their pain diaries to a friend and a belief that no other individuals would be interested in reading their pain record. In contrast, the responses of other participants indicate that they would share their pain diaries with anyone who wished to see them, suggesting additional recipients such as government adjudicators (agents and representatives) and significant others.

Perceived value of tool for monitoring pain over time

Another use of the tool is to facilitate creation of a permanent record of pain over time in the form of accumulated PDF pain diaries. Participants were asked to assess the value of the tool for this purpose using a 10-point NRS ranging from “not valuable at all” to “extremely valuable”. The mean response for this item was 8.9 ± 1.3 . The construction of a comprehensive record of pain over time requires regular use of the tool. Given that the tool is currently available on the Internet, participants were asked to rate the likelihood that they would use the tool at least once a month, once a week and once a day. Perhaps reflecting the relatively low power of the present study, these data are inconsistent but may indicate that a diminishing proportion of participants would be willing to use the tool on a monthly (mean 8.3 ± 2.3), weekly (mean 7.1 ± 2.9) and daily (mean 6.6 ± 3.4) basis. On probing for the logic underlying the intended frequency of tool use, some individuals stated that the relatively stable nature of their pain would render weekly or daily diaries somewhat redundant. Conversely, participants who experienced frequent changes in their chronic pain seemed more amenable to daily use of the tool. Because these observations are anecdotal, future studies will aim to formally characterize use of the tool.

Evaluation of the IPAT NRS and pain quality icons

The IPAT allows users to assign a specific intensity on an NRS from 0 to 10 to each relevant pain quality. Participants were asked to rate the degree to which the IPAT NRS and icons described the intensity and quality of their chronic pain. As shown in Figure 2, the IPAT NRS was given universally high ratings, ranging from 7 (‘very descriptive’) to 10 (‘extremely descriptive’) with a mean of 9.2 ± 1.1 .

The most frequent rating for each of the five icons was 10 (extremely descriptive), and the mean ratings ranged from 6.3 to 8.0. The observed dispersion of the data may reflect the heterogeneous nature of the study sample, which reported 16 different types of chronic pain (Table 1). It is important to note that, unlike other outcome measures, wide data dispersion is a desirable characteristic for these ratings. If all icons received uniformly high ratings of descriptiveness, this would suggest that separate pain quality descriptors do not provide more information than a unifactorial intensity rating.

Direct participant feedback

In addition to the quantitative data yielded from the NRSs, the authors also wished to capture the ideas and opinions of study participants ‘in their own words’. A sample of such feedback is presented to consolidate the themes addressed earlier:

I feel that this tool will prove to be very useful, hopefully helping general practitioners to understand the degree of pain that their patients are trying to convey.

It is great to have an icon to use to describe the particular type of pain one is experiencing.

Visual, instant feedback simplified.

Pictures are a good idea, especially if dealing with someone whose first language is not English.

Again, it is a very clear, concrete way to show the doctor and helps with the memory – or lack of it.

I would like to get at this on the Internet as soon as possible.

When my hands are tight or stiff and hurting...[using the tool] would present some problems.

Because pain can come and go with different intensity it is hard to show this on the program.

[Using the tool] would make me think about my pain, but I would rather try and forget about it.

Unless you live with it, then [you can't] understand.

DISCUSSION

Participant comfort with the IPAT

On average, the tool was rated as both enjoyable and easy to use, although participants were somewhat less comfortable with its computer-based nature. The majority of current pain assessment tools are paper based, which could be contributing to the moderate comfort participants feel with the electronic nature of the IPAT.

As well, it is possible that only those individuals who felt somewhat comfortable with the computer-based nature of the tool decided to volunteer for the study. However, there is literature-based evidence that chronic pain patients are amenable to electronic information and assessment tools (30,32,36).

Perceived value of tool

The data indicate that participants view the tool in a positive light with regard to the objectives of communicating pain sensations and tracking pain over time. On probing for ways to improve the tool, participants proposed the addition of new features such as the ability to add text to the pain diaries, graph data longitudinally, store their diaries in a centralized database and control an alarm system to emit regular reminders to use the tool. These suggestions align with the existing literature on real-time data capture, a strategy to minimize recall bias and improve compliance by allowing patients to report symptoms at particular moments in time (33,37). This method has been successfully applied to electronic pain diaries for specific pain populations (38) and could potentially be adapted for the IPAT.

Because the mere availability of systematic pain assessment data is not sufficient to affect clinical decision making (39), we recognize that early clinician involvement in tool development may increase their likelihood of later uptake. Indeed, qualitative studies report that many clinicians wish to be involved in the planning of outcome assessment protocols (40). Therefore, we intend to conduct future studies to assess the perceived value of the IPAT among health care professionals. These data will also be used to determine the most appropriate method of generating a summary score for the instrument.

Intent to share pain diaries with others

Participants were most strongly inclined to share their pain diaries with health professionals, followed by individuals who they wish could understand their pain, and close family members. It is important to realize that these preliminary data are merely reflective of the participants' intended use of the pain diaries and may not necessarily be indicative of actual use. Thus, prospective studies with participant follow-up will be needed to assess individual compliance with the tool.

Descriptiveness of IPAT pain icons

The current icons illustrate five different pain qualities (burning, freezing, squeezing, lacerating and aching). Given the positive participant response to the idea of expressing pain through iconography, this icon bank will be improved and expanded to include other types of pain. This future work will examine the consistency with which patients negotiate meaning with the pain iconography and assess the need for additional icons within specific pain populations.

Potential benefit for individuals living with chronic pain

The prevalence of chronic pain ranges from 19% to 29% of the general population (34,41). The IPAT could benefit people living with chronic pain in several important ways. First, the web-based nature of the tool affords a high level of accessibility to the average consumer (42). Second, the electronic format of the pain diary facilitates rapid data storage and dissemination in the form of PDF files. Third, the use of icons to depict pain quality creates real-world points of reference and minimizes reliance on the vocabulary of patients. Lastly, and perhaps most significantly, every stage of tool development has benefited from the direct consumer feedback of individuals living with chronic pain. This patient perspective will continue to drive development of the IPAT, which, in combination with education and self-management strategies (43), should allow people living with chronic pain to better monitor and manage their condition. This patient empowerment is particularly important given that pain sufferers are likely to visit a wide range of practitioners over the course of their disease(s) and must often take responsibility for tracking their pain.

CONCLUSIONS

Overall, the IPAT was positively endorsed by this heterogeneous sample of people in pain. Our conclusion is that the IPAT, originally designed for individuals with CPSP, is a user-friendly instrument that should be further refined for a larger and more diverse pain population.

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CHAPTER 3

Adapting the Iconic Pain Assessment Tool Version 2 (IPAT2) for adults and adolescents with arthritis pain through usability testing and refinement of pain quality icons

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Summary and Central Message: This article extends the work presented in the previous chapter. First, we refined the prototype by incorporating the user-identified modifications in design and functionality. Second, we evaluated the modified tool from the perspective of adolescents (n=15) and adults (n=15) with chronic pain from arthritis. The tool was found to have high usability and the pain quality icons had evidence of content validity. Overall, this study provided evidence that the use of digital sensory pain mapping with standard iconography may importantly aid the assessment and communication of sensory pain in adolescents and adults with chronic pain from arthritis.

Adapting the Iconic Pain Assessment Tool Version 2 (IPAT2) for Adults and Adolescents With Arthritis Pain Through Usability Testing and Refinement of Pain Quality Icons

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Objectives: To evaluate usability and pain iconography of the Iconic Pain Assessment Tool Version 2 (IPAT2), a self-report instrument that combines word descriptors and representative images (icons) to assess pain quality, intensity, and location, among adults and adolescents with arthritis.

Methods: Adults with inflammatory arthritis and adolescents with juvenile idiopathic arthritis partook in a single, semistructured, audio-recorded interview to evaluate: (1) the concreteness (object representativeness) and semantic distance (pain representativeness) of the IPAT2 iconography; (2) participants' current pain; and (3) perceptions and likes/dislikes of the IPAT2. Quantitative data were summarized descriptively and a line-by-line coding analysis identified key concepts from interview transcripts. The criterion for icon acceptability was mean and median ratings ≥ 5.0 for concreteness, semantic distance, and satisfaction for describing arthritis pain.

Results: The sample was comprised of 15 adults (87% female, mean 57 y) and 15 adolescents (67% female, mean age 15 y). The IPAT2 was reported to be easy to use and understand, well liked, quick to complete, and perceived as potentially valuable for communicating arthritis pain to health care providers. The median time needed to complete a single pain record, after 5-minute demonstration, was 2.3 minutes and 1.4 minutes for the adults and adolescents, respectively. All pain quality icons met or exceeded the criterion for acceptability.

Discussion: All a priori objectives for the IPAT2 were achieved in this sample of rheumatology outpatients. With its unique blend of pain quality descriptors and representative images, the IPAT2 may importantly aid the assessment of pain in adults and adolescents with arthritis.

Key Words: arthritis pain assessment, adolescents, adults, usability testing, pain iconography

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Individuals with arthritis are 3 times more likely to report moderate to severe pain compared with people with other chronic conditions.¹ Among adolescents and adults with arthritis aged 12 to 44 years, the prevalence of chronic pain is nearly 50%.² It is well recognized that reliable and valid pain assessment is the first step toward adequate pain management and treatment.³ In view of the poor correlation between disease findings and pain experienced by people with arthritis,^{4,5} patient self-report is a primary source of information during clinical pain assessment.⁶ However, the subjective sensation of pain is notoriously difficult to communicate and measure.

Adding to the difficulty of adequate pain assessment, there is a recognized cognitive and communicative burden associated with pain self-report, which require sufficient linguistic and social skills to overcome.⁷ Furthermore, as noted by Stanford et al,⁸ the challenge of effectively verbalizing pain requires "...progressive cognitive development and acquisition of social communication skills," (p. 278). Given these potential barriers, efforts must be made to minimize the cognitive, linguistic, and time burden of self-report on people experiencing pain.^{9,10}

Available self-report scales for adults^{11–16} and adolescents^{17–20} with arthritis commonly use pain intensity as a single index of the sensory pain experience. However, the reduction of sensory components or aspects of pain to a single number fails to encompass other important characteristics, such as pain quality and location.²¹ Furthermore, while the earliest pain scales were administered on paper, recent advances in information and communication technology have permitted the development of electronic tools, such as e-diaries.²² Advantages of this electronic approach include minimization of errors in data transfer and transcription, ability to capture time-stamped data, ease of data sharing, increased compliance, and heightened patient satisfaction.^{22–24} A review of the current literature demonstrates that a limited number of paper^{25–28} and electronic^{29–31} tools have been developed that account for multiple sensory characteristics of arthritis pain. On the basis of the pioneering work of Melzack,^{32,33} all of these existing tools use word descriptors to account for the myriad of pain qualities associated with arthritis. However, standardized assessment methods that rely entirely on word descriptors may present difficulties for people with limited written or verbal communication skills³⁴ or a preference for visual communication. A viable alternative to the purely text-based description of pain quality is the fusion of imagery and words.³⁵ Indeed, there is increasing evidence that visual representations may help people to describe their pain better,³⁶ and thus gain access to more timely treatment.³⁷ However, to our knowledge, there is presently no tool available for the self-report of

arthritis pain that uses a combination of imagery and word descriptors to measure pain quality, that capitalizes on the benefits of electronic administration, and that has profited from continuous patient input during development stages.

As described below, the Iconic Pain Assessment Tool (IPAT) fills this gap by uniquely addressing the limitations of existing measures. The IPAT is an interactive web-based tool for the visual self-report of arthritis pain in the form of time-stamped pain records.^{38,39} Individuals can choose from among a collection of stylized graphical images (icons) to describe the *quality* of their arthritis pain. Each IPAT icon uses a real-life object (eg, a matchstick) to illustrate a specific type of pain (eg, burning pain). After assigning a unique rating of *intensity* (0 to 10 numerical rating scale) to each pain quality, individual icons can be “dragged-and-dropped” onto a body map to indicate pain *location*. The completed IPAT “pain record,” documenting current pain parameters, can be printed in a hardcopy and/or saved as a PDF file to track pain over time.

The IPAT has been developed and rigorously evaluated using a phased approach. As described by Lalloo and Henry,³⁹ face and content validity testing was completed through a formal evaluative study, educated consumer panel, and monthly pain support groups. These stakeholder consultations enabled creation of the IPAT version 2 (IPAT2), which includes an expanded bank of pain icons and a modified intensity rating scale that permits users to assign a unique intensity value to each pain quality *icon* and thus report multiple intensities of pain in different regions of the body. For example, a person with arthritis can communicate the simultaneous experience of “3/10” burning pain in their hand and “7/10” burning pain in their knee.

The overall purpose of the present study was 2-fold: to assess the usability of the IPAT2 in a sample of adults and adolescents with arthritis and to evaluate and refine the IPAT2 iconography to yield a bank of icons that are meaningful to people with arthritis. Usability testing is defined as any methodology “...in which users interact systematically with a product or system under controlled conditions, to perform a goal-oriented task in an applied scenario, and some behavioral data are collected” (Wichansky,⁴⁰ p. 998). In the context of usability testing, our objectives were to assess the IPAT2 for (1) ease of use, (2) ease of understanding, (3) user likes and dislikes, (4) time required to train and complete, and (5) perceived value for communicating arthritis pain. In the context of icon evaluation, our objectives were to: (1) assess the degree to which each icon is representative of the intended object (eg, matchstick) and pain type (eg, burning); (2) assess the degree to which each adjective and icon is descriptive of the participants’ arthritis pain; (3) determine the need for new pain icons to describe arthritis pain; and (4) obtain feedback on newly developed icons generated from participant input. To determine whether the IPAT2 is appropriate for use by both adults and adolescents, we also sought to compare results from the usability and iconography testing between these groups.

PATIENTS AND METHODS

Patient Selection

Adult participants aged 18 years and older were drawn from rheumatology clinics in 2 university-affiliated hospitals serving metropolitan Toronto as well as central, northern, and southwestern regions of Ontario. Adults were eligible

for this study if they had been diagnosed with inflammatory arthritis by a rheumatologist, had experienced arthritis-related pain over the past 2 weeks according to self-report, and were able to speak and read English according to their health care provider. Adults were excluded from the study if they had known major cognitive or psychiatric disorders, severe vision or hand dexterity impairments, or any other chronic pain conditions (eg, fibromyalgia, chronic headache), as determined by their rheumatologist.

Adolescent participants, aged 12 to 18 years, were drawn from a single rheumatology clinic in a university-affiliated pediatric tertiary care center serving metropolitan Toronto and central and northern Ontario. Adolescents were eligible for this study if they had been diagnosed with juvenile idiopathic arthritis,⁴¹ had experienced arthritis-related pain over the past 2 weeks according to self-report, and were able to speak and read English according to their health care provider. Adolescents were subject to the same exclusion criteria as the adult group.

Study Design and Procedure

This project received approval from the local Research Ethics Board of each participating institution. The study design adopted a variation of the “Questerview” method,⁴² which combines elements from qualitative and quantitative research methodologies. Individuals with arthritis were recruited to take part in a single, semistructured interview with a member of the research team after their scheduled rheumatology clinic visit. The same investigator conducted all interviews. A health care provider identified potential participants using an eligibility screening tool and obtained permission for individuals to be approached by a research team member. Written informed consent for participation was obtained by a study investigator.

After informed consent was documented, the participant was asked to complete a General Information Questionnaire, which collected data concerning computer proficiency, first spoken language, and current pain intensity by a 0 to 10 numeric rating scale (NRS). The participant’s health record was consulted to collect information such as age, type of arthritis, date of diagnosis, and current medications. Next, the participant was asked to evaluate various characteristics of the IPAT2 icons, as detailed below, and also to provide feedback on the usability of the tool’s interface.

Each IPAT2 icon is designed to use a real-life object to depict a specific quality of pain (eg, a matchstick is used to represent “burning” pain). These properties correspond with the concepts of “concreteness” and “semantic distance,” which are described in the body of Human Factors literature. Concreteness is defined as: “...the extent to which an icon depicts real objects, materials, or people” (Isherwood et al,⁴³ p. 466). Semantic distance is defined as, “...the closeness of relationship between the icon and the function it represents” (Isherwood et al,⁴³ p. 467).

Each participant was asked to rate the “representativeness” (0 to 10 NRS) of each IPAT2 icon, given the intended referent object (concreteness) and pain type (semantic distance). Although Isherwood et al⁴³ assessed these icon properties with a 5-point NRS, we chose to use an 11-point scale to minimize the loss in reliability associated with fewer response categories and account for the observation that respondents tend to often avoid the extreme ends of a scale (end-aversion bias).⁴⁴ To assess the relevance of each IPAT2 pain quality for arthritis, the participant was required to rate the degree (0 to 10 NRS) to

which each adjective was descriptive of their pain. For each adjective that was assigned a descriptiveness rating greater than 0, the participant was asked to rate how satisfied (0 to 10 NRS) they were with the corresponding icon for describing their own pain. Next, the participant was prompted to share any “other words” that accurately describe their arthritis pain. Lastly, the participant was asked to provide feedback on newly developed pain icons.

After this icon evaluation exercise, the participant was provided with a 5-minute demonstration of the IPAT2 features. In brief, the first interface screen required the user to select their sex (“male” or “female”), which caused the corresponding body map (anterior and posterior aspects) to appear. Next, the user had the option of choosing among the existing bank of pain quality icons to describe their current pain. The current iteration of the IPAT2 features icons for Burning, Freezing, Squeezing, Stabbing, Heavy, Electrical, Pins and Needles, Shooting, Pounding, Pinching Aching, and Stiffness pain, as illustrated in Figure 1. This sequence of icons is based upon the original IPAT and the development order of subsequent icons. After selecting a pain quality (eg, burning), a centralized NRS appears along the bottom of the interface.

The centralized NRS features a horizontal bank of pain icons, each with a unique fixed intensity rating ranging from 1 to 10. Each of these numbered icons can be independently “dragged-and-dropped” on to the body map to indicate location. This system allows a user to easily distinguish between varying intensities of the same pain quality across different body regions. For instance, a user could

visually communicate the simultaneous experience of a “6” burning pain in their leg and “1” burning pain in their hand. After documenting all “burning” pain, the user can return to the icon bank to select another relevant pain quality. After documenting all of their current pain, the user can print a hardcopy and/or save the visual pain diary as a PDF file. The IPAT2 interface features a dynamically updating text box that automatically displays the current time and date. Thus, when the user clicks “print” or saves the pain diary as a PDF, they also automatically record the time and date of entry. A screenshot of the IPAT2 user interface is shown in Figure 1.

After verbally confirming their comprehension of how to use the tool, each participant used the investigator laptop computer (MacBook Pro) with external mouse to document their current pain with the IPAT2. Investigator observation and verbal comments from the participant were used to identify any difficulties or confusion with using the IPAT2.

After the participant had gained “hands-on” experience using the prototype tool, a semistructured interview guide was used to facilitate discussion about the IPAT2. Questions were designed to assess: (1) how easy it was to learn the tool functionality; (2) features that were difficult to use or understand; (3) favorite feature of the tool; (4) least favorite feature of the tool; and (5) perceived value of the tool for communicating arthritis pain with clinicians. Participants were also asked to share any additional comments or views about the tool. Participants were compensated for their time and effort with a cinema gift card (\$10 value) and reimbursed for transportation costs.

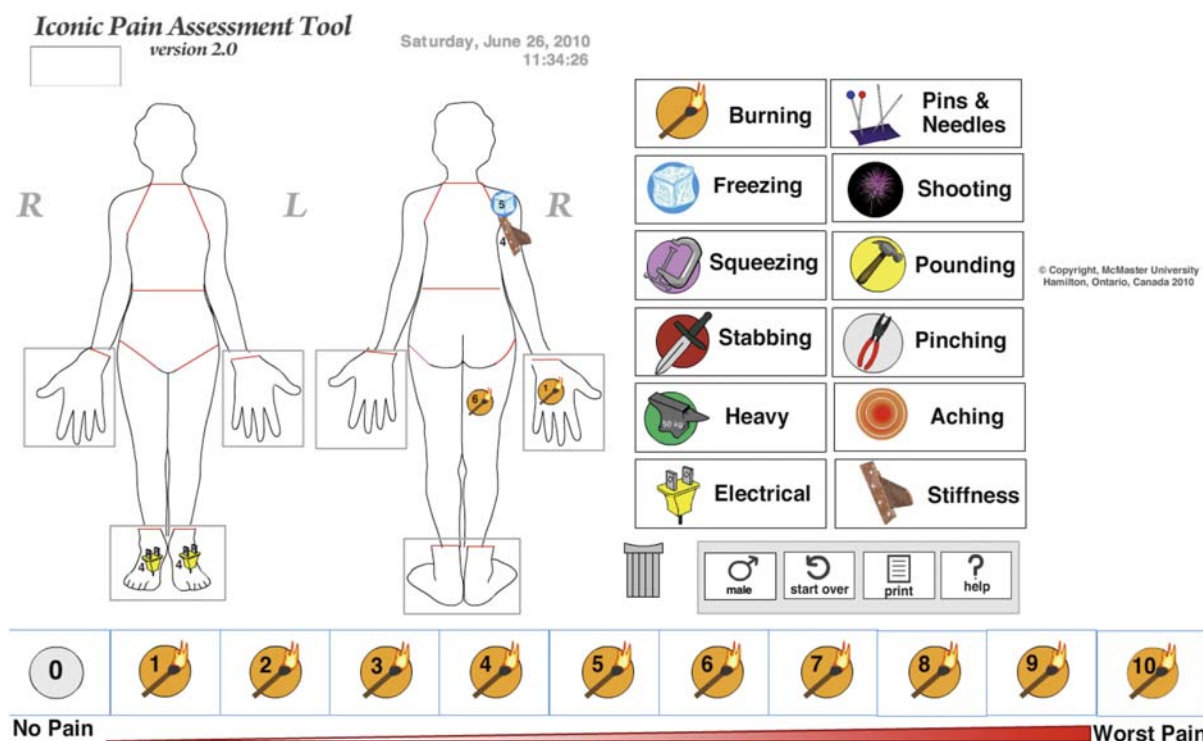


FIGURE 1. The Iconic Pain Assessment Tool Version 2 is an Adobe Flash-based program for the self-report of pain quality, intensity, and location. A series of stylized graphical images (icons) have been created to depict various qualities of pain. Using a mouse, patients can assign a rating of intensity (0 to 10) and then “drag-and-drop” individual icons onto the body map to indicate pain location. The resulting time-stamped “pain diary” can be printed in a hardcopy or saved as a PDF file for patient records. Copyright McMaster University. Used with permission. All permission requests for this image should be made to the copyright holder.

Analysis

Each interview session was audio recorded, transcribed verbatim, converted to text files, and imported into the qualitative software program, HyperRESEARCH.⁴⁵ A line-by-line coding analysis was used to identify key emerging themes from the interview transcript and field notes. Concepts addressed during the semistructured interview were used to thematically code and organize participant responses.⁴⁶

Quantitative data from the General Information Questionnaire, Health Record Questionnaire, and Icon Evaluation Questionnaire were coded, scored, and entered into a Statistical Package for the Social Sciences (SPSS) database.⁴⁷ All of these data were analyzed to assess measures of central tendency (mean, median) and dispersion (SD, interquartile range). Data were also evaluated to ensure that they met the assumptions of parametric statistical analysis (ie, the normal distribution). When these assumptions were not met, the nonparametric equivalent test was used.

Icon data were summarized in the order in which participants evaluated them. An icon was considered “acceptable” if mean and median ratings of concreteness, semantic distance, and satisfaction for describing arthritis pain were 5.0 or higher. The completed IPAT2 pain diaries were saved as PDF files and data concerning selected pain quality were manually entered into SPSS. The time needed for each participant to complete the IPAT2 pain diary was obtained by referring to the interview audio recording. Independent *t* tests (parametric distribution) or Wilcoxon rank-sum tests (nonparametric distribution) were conducted to determine whether there were any differences between the adult and adolescent groups on demographic and disease-related variables and on ratings of the IPAT2 icons and time to complete a pain diary. The Fisher exact test was used to identify any differences between the groups in terms of categorical frequency characteristics such as sex, computer access, and Internet access. This statistical test was used instead of χ^2 because the expected frequency of 1 or more cells in each 2×2 contingency table was < 5 .⁴⁸ The Fisher exact test was also performed to test the null hypothesis that the proportion of adults who used each IPAT2 icon to describe their current pain is the same as the proportion of

adolescents who applied each icon to describe their pain. The level of significance was set at $P < 0.05$ for all tests.

RESULTS

Sample Selection

Participant recruitment for the adults and adolescents is summarized in Figure 2.

Participant Characteristics

Participant characteristics for the study sample are summarized in Table 1. Sixty-seven percent of adults stated that they were “comfortable” or “very comfortable” with computers. Ninety-three percent of adolescents were “very comfortable” with computers. There were no significant differences between the adults recruited from site 1 versus site 2 in terms of age ($P = 0.15$), sex ($P = 0.20$), computer access ($P = 1.0$), or Internet access ($P = 0.47$). There were also no significant differences between the adults and adolescents in terms of sex ($P = 0.39$), computer access ($P = 1.0$), or Internet access ($P = 0.48$).

Illness Characteristics

Illness characteristics among the adults and adolescents are outlined in Table 1.

Adults

The majority of adult participants were diagnosed with rheumatoid arthritis (12/15; 80%), whereas a minority experienced osteoarthritis with an inflammatory component (2/15; 13%) and ankylosing spondylitis (1/15; 7.0%). Arthritis-specific medication use ranged from 1 to 5 medications per adult, with an average of 3. The most commonly used class of arthritis medication was disease-modifying antirheumatic drugs (67%), followed by nonsteroidal anti-inflammatory drugs (33%), steroids (7.0%), and analgesics (ie, acetaminophen with codeine) (7.0%).

Adults recruited from site 1 had a significantly shorter median (minimum, maximum) duration of illness compared with adults recruited from site 2 at 2.8 years (0.020, 6.5)

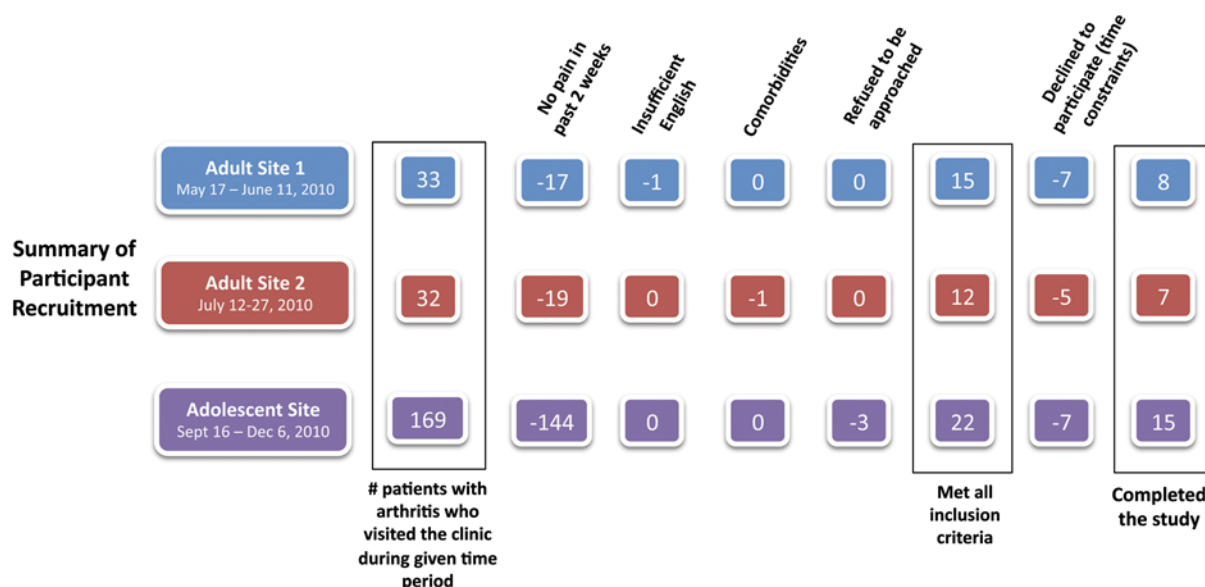


FIGURE 2. Flow chart summary of the participant recruitment process across 3 sites.

TABLE 1. Sample Characteristics

Characteristics	Parameters	Adult Site 1 (n = 8)	Adult Site 1 (n = 7)	All Adults (n = 15)	Adolescents (n = 15)
Age (y)	Median (IQR)	64 (50, 68)	51 (44, 58)	58 (48, 65)	15 (14, 17)
Male	n (%)	0	2 (29)	2 (13)	5 (33)
Female	n (%)	8 (100)	5 (71)	13 (87)	10 (67)
Computer at home	n (%)	7 (88)	7 (100)	14 (93)	15 (100)
Internet access	n (%)	6 (75)	7 (100)	13 (87)	15 (100)
Pain intensity (0-10 NRS)	Median (IQR)	5.0 (4.3, 8.0)*	3.0 (1.0, 3.0)	4.0 (3.0, 5.8)	4.0 (3.0, 6.0)
Years since arthritis diagnosis	Median (IQR)	2.8 (0.66, 4.9)†	13 (3.0, 21)	4.6 (1.0, 13)	3.1 (1.0, 8.0)

*Pain intensity, Adult site 1 versus site 2, Wilcoxon rank-sum test ($t = 21$, $P = 0.0010$).

†Years since arthritis diagnosis, Adult site 1 versus site 2, Wilcoxon rank-sum test ($t = 46$, $P = 0.040$).

IQR indicates interquartile range; NRS, numerical rating scale.

versus 13 years (0.77, 37), $P = 0.040$. Adults from site 1 also reported a greater median (minimum, maximum) NRS pain intensity of 5.0 (4.0, 10) compared with adults from site 2 at 3.0 (1.0, 3.0), $P = 0.0010$.

Adolescents

The most common juvenile idiopathic arthritis onset subtypes were oligoarthritis (4/15; 27%) and rheumatoid factor-negative polyarthritis (3/15; 20%), followed by psoriatic arthritis (2/15; 13%), systemic arthritis (2/15; 13%), rheumatoid factor-positive polyarthritis (2/15; 13%), enthesitis-related arthritis (1/15; 7.0%), and “other” (1/15; 7.0%). Arthritis-specific medication use ranged from 0 to 3 medications per adolescent, with an average of 1. The most commonly used class of arthritis medication was disease-modifying antirheumatic drugs (80%), followed by non-steroidal anti-inflammatory drugs (47%), and steroids (7.0%). The median (minimum, maximum) duration of arthritis among the adolescents was 3.1 years (0, 15), and the median NRS pain intensity was 4.0 (1.0, 7.0).

Group Comparison of Illness Characteristics

There was no significant difference between the adult and adolescent groups in terms of median (minimum, maxi-

mum) duration of arthritis at 4.6 years (0.020, 36) and 3.1 years (0, 15), respectively, $P = 0.54$. There was also no significant difference between the groups in terms of median (minimum, maximum) NRS pain intensity at 4.0 (1.0, 10) for the adults and 4.0 (1.0, 7.0) for the adolescents, $P = 0.95$.

Relative Frequency of Pain Quality Icons in Participant IPAT2 Diaries

Each participant created a single IPAT2 record to document his or her current arthritis pain. Table 2 summarizes the relative percentage of participants who used or did not use each pain quality icon (eg, burning, freezing) to describe their pain. The proportion of adolescents who used the “stiffness” icon to describe their current arthritis pain was significantly greater than the proportion of adults who chose this icon to describe their pain. Specifically, all adolescent participants (100%) employed the “stiffness” icon in their pain diary compared with only 9/15 (60%) adult participants ($P = 0.017$). There were no other significant differences between adults and adolescents in terms of pain icon utilization. Across all 30 participant diaries, the most commonly used pain quality icons were “stiffness” and “aching.” The least commonly used pain icons were

TABLE 2. Relative Use of Pain Quality Icons Among IPAT2 Records Documenting Current Arthritis Pain

Pain Quality	Adults (n = 15)		Adolescents (n = 15)		Overall (N = 30)	
	Absent (%)	Present (%)	Absent (%)	Present (%)	Absent (%)	Present (%)
Burning	73	27	67	33	70	30
Freezing	100	0	93	7.0	97	3.0
Squeezing	87	13	80	20	83	17
Stabbing	60	40	60	40	60	40
Heavy	80	20	73	27	77	23
Electrical	100	0	93	7.0	97	3.0
Pins/needles	67	33	60	40	63	37
Shooting	73	27	87	13	80	20
Pounding	93	7.0	60	40	77	23
Pinching	100	0	87	13	93	7.0
Aching	27	73	20	80	23	77
Stiffness	40	60	0	100*	20	80

*Fisher exact test, $P = 0.017$ (The proportion of adolescents who used the “stiffness” icon to describe their current arthritis pain was significantly greater than the proportion of adults who chose this icon to describe their pain.)

IPAT2 indicates Iconic Pain Assessment Tool Version 2.

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“freezing,” “electrical,” and “pinching.” The icon endorsement frequency did not appear to be influenced by the order of presentation on the IPAT2 interface (Fig. 1). For instance, the endorsement frequencies for burning (30%) and pins/needles (37%), which appear atop the interface, were lower than those for icons with less prominent positions such as stabbing (40%), aching (77%), and stiffness (80%). However, the potential effect of icon order was not specifically assessed.

Evaluation of the IPAT2 Pain Quality Icons for Concreteness and Semantic Distance

Concreteness and semantic distance ratings for each icon are summarized in Table 3. Because of the nonparametric distribution of the data, the Wilcoxon rank-sum test was used to compare the groups. There were no significant differences between the adults and adolescents in terms of these icon ratings.













Overall, all icons received a mean concreteness rating of at least 8.2, with the exception of the iconic depiction of a “target” (aching pain), which had a mean rating of 6.1 (SD 3.4). Similarly, all icons received a median concreteness rating of 10, apart from the “aching” icon (median 7.0).

Overall, all icons received a mean semantic distance rating of at least 7.4, with the exception of the icons for “shooting” and “aching” pain, with mean ratings of 6.9 (SD 3.0) and 6.0 (SD 3.7), respectively. The median semantic distance ratings ranged between 8.5 and 10 for all icons except for “shooting” (median 7.5) and “aching” (median 7.0).

Descriptiveness of IPAT2 Adjectives and Satisfaction with Icons for Describing Arthritis Pain













Adjective descriptiveness ratings are summarized in Table 4. There were no significant differences between adults and adolescents in terms of these ratings. Adjectives

TABLE 3. Evaluative Ratings of the IPAT2 Pain Quality Icons by Study Participants

Icon	Intended Object	Icon Concreteness Representation of Intended Object (0-10 NRS)			Intended Pain Quality	Icon Semantic Distance Representation of Intended Pain (0-10 NRS)		
		<i>M</i> (SD)	Mdn	IQR		<i>M</i> (SD)	Mdn	IQR
A 	Matchstick	8.7 (2.2)	10	8.0, 10	Burning	9.1 (1.7)	10	8.4, 10
B 	Ice cube	8.2 (3.2)	10	7.8, 10	Freezing	8.2 (3.1)	9.8	7.9, 9.8
C 	Vice/clamp	8.5 (2.3)	10	7.0, 10	Squeezing	8.6 (1.8)	9.0	7.0, 9.0
D 	Knife	9.6 (0.77)	10	9.0, 10	Stabbing	9.5 (0.75)	10	9.0, 10
E 	Anvil/weight	8.5 (2.5)	10	7.8, 10	Heavy	8.5 (2.6)	10	7.8, 10
F 	Electrical plug	8.8 (2.5)	10	9.5, 10	Electrical	8.5 (2.2)	9.5	7.4, 9.5
G 	Pins and needles	9.2 (1.5)	10	9.0, 10	Pins/needles	9.0 (1.8)	10	8.8, 10
H 	Fireworks	8.9 (2.6)	10	9.0, 10	Shooting	6.9 (3.0)	7.5	5.0, 7.5
I 	Hammer	9.5 (1.6)	10	10, 10	Pounding	8.9 (1.7)	10	8.0, 10
J 	Pliers/pincers	9.0 (1.8)	10	8.0, 10	Pinching	8.3 (2.4)	9.0	7.8, 9.0
K 	Rusted hinge	8.5 (2.3)	10	7.0, 10	Stiffness	7.4 (2.9)	8.5	5.4, 8.5
L 	Target	6.1 (3.4)	7.0	3.0, 7.0	Aching	6.0 (3.7)	7.0	2.8, 7.0

There were no significant differences between the adults and adolescents in terms of icon ratings for concreteness or semantic distance (Wilcoxon rank-sum test). IPAT2 indicates Iconic Pain Assessment Tool Version 2; IQR, interquartile range; *M*, mean; Mdn, median; NRS, numerical rating scale. Copyright McMaster University. Used with permission. All permission requests for this table should be made to the copyright holder.

TABLE 4. Descriptiveness and Satisfaction Ratings of IPAT2 Adjectives and Icons

Icon	Pain Quality	Reported Descriptiveness of Adjective for Arthritis Pain (0-10 NRS)			Satisfaction With Icon for Describing Arthritis Pain (0-10 NRS)			
		<i>M</i> (SD)	Mdn	IQR	# Responses (%)	<i>M</i> (SD)	Mdn	IQR
A 	Burning	4.3 (3.4)	4.5	0, 7.5	20 (67)	8.2 (1.9)	8.0	7.0, 10.0
B 	Freezing	1.9 (2.7)	0	0, 4.0	10 (33)	6.6 (2.9)	7.0	5.0, 8.5
C 	Squeezing	4.2 (3.2)	4.0	0, 7.3	20 (67)	6.7 (2.3)	6.8	4.3, 9.5
D 	Stabbing	6.7 (3.4)	7.5	3.9, 10.0	27 (90)	8.5 (2.1)	9.0	7.0, 10.0
E 	Heavy	5.1 (3.4)	6.0	1.5, 8.0	22 (73)	7.3 (2.7)	7.5	5.8, 10.0
F 	Electrical	3.2 (3.7)	1.0	0, 7.0	16 (53)	6.3 (3.0)	6.0	4.3, 9.8
G 	Pins/needles	5.9 (3.9)	7.0	2.1, 9.3	24 (80)	8.2 (2.0)	9.0	7.1, 10.0
H 	Shooting	6.1 (3.4)	6.8	4.1, 9.0	25 (83)	6.9 (3.1)	8.0	4.8, 10.0
I 	Pounding	5.3 (3.9)	5.5	0, 9.3	22 (73)	8.0 (2.1)	8.0	6.9, 10.0
J 	Pinching	4.6 (3.3)	5.0	0.75, 7.0	19 (63)	7.0 (2.3)	7.0	5.0, 10.0
K 	Stiffness	8.9 (2.3)	10.0	9.0, 10.0	28 (93)	7.5 (3.2)	8.5	6.0, 10.0
L 	Aching	8.5 (2.2)	10.0	7.0, 10.0	30 (100)	5.7 (4.0)	7.3	1.0, 10.0

There were no significant differences between the adult and adolescent groups in terms of descriptiveness and satisfaction ratings. For the satisfaction items, number of respondents is shown because participants were given a nonresponse option of "I do not experience this type of pain."

IPAT2 indicates Iconic Pain Assessment Tool Version 2.

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that received the highest overall ratings for descriptiveness of arthritis pain were "stiffness" (median 10) and "aching" (median 10). Adjectives that received the lowest overall ratings for descriptiveness of arthritis pain were "freezing" (median 0) and "electrical" (median 1.0).

There were no significant differences between adults and adolescents in terms of ratings for icon satisfaction (Table 4). Iconic depictions that received the highest median ratings of satisfaction for describing arthritis pain were: "knife" for "stabbing pain" (9.0), "pins and needles" for "pins and needles pain" (9.0), and "hinge" for "painful stiffness" (8.5). Icons that received the lowest median ratings of satisfaction were the "electrical plug" for "electrical pain" (6.0) and the "vice" for "squeezing pain" (6.8).

Spontaneously Generated Descriptors for Arthritis Pain and New Pain Icon Designs

During the semistructured interview, participants were asked to share any "other words" that accurately described their arthritis pain. Participants were also asked to provide suggestions for imagery to accompany their arthritis pain quality descriptors. On the basis of participants' sugges-











tions, new icons were designed to depict: "throbbing pain" (stubbed toe), "bone-cracking pain" (broken bone), "sharp pain" (sharpened pencil or shard of glass), and "dull pain" (dull pencil tip).

In addition, alternative icons were designed for "shooting pain" (bow and arrow; lightning instead of fireworks) and "stiffness" (a metallic arm rather than the rusted hinge). Participant ratings of these new and alternative icons, alongside the corresponding ratings of adjective descriptiveness, are outlined in Table 5.

Time to Complete a Pain Diary and IPAT2 Ease of Use

The time required for adult completion of a single pain diary (median 2.3 min, minimum 1.0, maximum 5.9) was significantly longer than that for adolescents (median 1.4 min, minimum 0.33, maximum 3.2), $P = 0.041$. All of the participants described the IPAT2 as "easy" or "very easy" to use. One adult participant, who rated themselves as "not at all comfortable" with computers, stated: "It was very easy. If I can learn, who does not like computers, I think it's very easy to learn."

TABLE 5. Evaluation of New and Alternative Pain Quality Icons

		Adjective Descriptiveness of Arthritis Pain (0-10 NRS)				Semantic Distance (0-10 NRS)				Icon Satisfaction (0-10 NRS)			
Icon	Pain Quality	n (%)	M (SD)	Mdn	IQR	n (%)	M (SD)	Mdn	IQR	n (%)	M (SD)	Mdn	IQR
Current and alternative icon designs													
	Shooting (current)	30 (100)	6.1 (3.4)	6.8	4.1, 9.0	30 (100)	6.9 (3.0)	7.5	5.0, 10	25 (83)	6.9 (3.1)	8.0	4.8, 10
	Shooting (alt #1)					25 (83)	7.1 (3.1)	8.0	5.0, 10	25 (83)	6.3 (3.7)	8.0	3.0, 10
	Shooting (alt #2)					13 (43)	6.4 (2.4)	7.0	4.3, 8.8	12 (40)	5.8 (2.9)	5.5	4.0, 8.0
	Stiffness (current)	30 (100)	8.9 (2.3)	10	9.0, 10	30 (100)	7.4 (2.9)	8.5	5.4, 10	28 (93)	7.5 (3.2)	8.5	6.0, 10
	Stiffness (alt #1)					22 (73)	6.6 (2.9)	7.0	5.0, 9.0	22 (73)	6.0 (3.0)	7.0	4.0, 8.0
New icon designs													
	Throbbing	22 (73)	7.3 (2.9)	8.0	5.8, 10	22 (73)	9.0 (1.2)	9.8	8.0, 10	21 (70)	8.6 (1.7)	9.0	7.8, 10
	Bone cracking		3.3 (3.3)	3.5*	0, 6.0		8.4 (2.4)	10	7.3, 10	13 (43)	7.9 (2.3)	9.0	6.5, 10
	Sharp (#1)		5.4 (3.5)	6.5	2.8, 8.3		7.4 (2.8)	7.8	5.0, 10	18 (60)	7.3 (2.7)	8.0	5.0, 10
	Sharp (#2)		5.4 (3.5)	6.5	2.8, 8.3		3.9 (3.1)	4.0†	0.25, 6.8	18 (60)	3.6 (3.2)	3.5‡	0, 6.3
	Dull		3.5 (3.7)	2.5	0, 7.3		7.1 (2.9)	7.0	5.4, 10	14 (47)	6.8 (1.8)	6.3	5.0, 8.3

There were no significant differences between the adult and adolescent groups for ratings of descriptiveness, semantic distance, or satisfaction with the following exceptions:

*Adolescents (Mdn 5.0) gave a significantly higher descriptiveness rating to "bone cracking" than adults (Mdn 0) (Wilcoxon rank-sum test, $P = 0.0030$).

†Adolescents (Mdn 5.0) gave a significantly higher semantic distance rating to the "sharp glass" icon than adults (Mdn 0) (Wilcoxon rank-sum test, $P = 0.0060$).

‡Adolescents (Mdn 6.0) gave a significantly higher satisfaction rating to the "sharp glass" icon than adults (Mdn 0) (Wilcoxon rank-sum test, $P = 0.0010$).

Alt indicates alternative; IQR, interquartile range; M, mean; Mdn, median; NRS, numerical rating scale.

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Participant Likes and Dislikes With the IPAT2

A commonly cited favorite feature of the IPAT2 was the ability to describe the nature of pain in a nonverbal manner. For instance, 1 adult participant stated: "I suppose it's expressing yourself when you can't describe [your pain]. A lot of people don't know how to put it into words." Several adolescent participants also described the tool as enjoyable to use. In the words of 1 adolescent: "Like, for the kids, it's more fun for them because there are pic-

tures and this kind of thing. You can actually drag it and stuff, so it's kind of like a game for them. And so I'd say it would entertain them instead of doing how they have now with just answering those questions." Other valued aspects of the tool were its simplicity (Adult: "There's not a lot of reading. There's not a lot of mumbo jumbo there. It's all straight-forward."), the drag-and-drop feature (Adolescent: "That you could put [the icons] anywhere, like on the certain part that it hurts. So you could see like where it hurts.

When you keep track of it you can tell which parts of the body you have trouble with.”), and clarity (Adult: “Everything’s very clear...once you start doing it, it can be quick.”).

The cited “least favorite” features of the IPAT2 experience were: nervousness with using the computer, unfamiliarity with the tool, orienting themselves on the body map (Adult: you had to think for a minute in terms of which one is the front one and which was the back one. It took me a while.”), selecting appropriate intensity ratings (Adult: “I find it really difficult to rate pain or anything by 1 to 10.”), irrelevant pain icons (Adult: “Not all the pains really related to me but I understand [the need] because everybody has different feelings and sensations.”), the necessity of thinking about pain, and the large size of icons relative to the body map. Overall, 6 (40%) adults and 11 (73%) adolescents stated that they did not have a “least favorite” feature of the tool.

Perceived Value of the IPAT2

All participants agreed that the IPAT2 could be valuable for helping to communicate pain with their health care provider. For instance, an adult participant stated, “That would be great if you could do that ahead and then email it to the doctor or something so that they have it ahead of time.” The tool was also considered to be valuable for keeping track of trends in arthritis pain over time. In the words of an adult participant: “...when I come in [to the doctor] on Monday it’s just after the weekend and I’m not doing as much work, so maybe I’m not having as much pain. So they ask me how it’s been over the last few days, well it’s not been bad. But last week was horrible. So I think that’s nice that you could [fill in the diary] more than once.” Similarly, an adolescent participant stated, “I like that it’s online, because a lot of people go on the computer in my age group, so it would be easier instead of writing it down. And it’s easy on the computer, and it’s like neater.”

Several participants also noted that using the IPAT2 could cause them to document details about their pain that they otherwise may not have disclosed to their health care provider. In the words of an adult participant, “...when you come into the doctor you always say ‘[I’m] not bad’, because that’s the way you’re used to dealing with it. So if you actually have to fill out a thing...[they] can at least see what you’re saying.” In the words of an adolescent, “...when you’re by yourself ... you actually tell the truth. But like when you have doctors around you, you kind of get scared, like what they would say, so they would have this [my pain diary] to look at.”

DISCUSSION

To our knowledge, this is the first study to evaluate the usability of a web-based tool for the visual self-report of pain quality (icons and word descriptors), intensity (0 to 10 NRS), and location (body map) among adults and adolescents experiencing arthritis pain. Our findings indicate that the IPAT2 was easy to use, easy to understand, well liked, quick to complete, and perceived as potentially valuable for communicating the nature of arthritis pain to health care providers. The median time needed to complete a single pain diary after minimal training was 2.3 and 1.4 minutes for the adults and adolescents, respectively. These average times compare favorably with other electronic pain assessment tools, such as the e-Ouch³⁰ (average

of <9 min to complete 3 daily entries among adolescents), as well as clinician-administered paper questionnaires such as the McGill Pain Questionnaire (5 to 10 min) and Short Form-McGill Pain Questionnaire (2 to 5 min).⁴⁹

To our knowledge, there are no reference values for determining the acceptability of iconography provided in the literature. For this study, we chose the criterion of requiring all icons to achieve mean and median ratings of 5.0 or greater on a 0 to 10 NRS for the parameters of concreteness, semantic distance, and satisfaction. All IPAT2 icons met or exceeded this criterion within this sample of adults and adolescents with arthritis pain. In terms of concreteness, only the icon depicting “aching” pain received a median rating <10. This icon was particularly challenging to design because “aching” is an abstract sensation with no obvious counterpart in a real-life object. On the basis of early pilot testing of the IPAT2 at chronic pain support groups and public forums, as well as investigator opinion, an image was created consisting of concentric diffuse rings. This image was given the referent label “target.” All study participants were asked to think about other possible representations of “aching pain,” however, no alternative images emerged. As described in Table 5, alternative icons for “shooting” and “stiffness” pain were designed based on early participant suggestions, but ultimately received similar ratings to the original icons. It is important to note that although all icons achieved the criterion for acceptability, we recognize that further validation of the IPAT2 is needed in a clinical setting to confirm that the current icon designs are appropriate for assessing arthritis pain.

In addition to its use of iconography, the IPAT2 capitalizes on existing web-based technology to enable the creation of visual, time-stamped pain records. The IPAT2 offers many novel advantages over existing self-report tools for arthritis pain. First, its web-based nature affords a high level of accessibility to consumers⁴ and is associated with advantages such as rapid data storage, increased compliance, and heightened consumer satisfaction.^{22–24} Second, the unique mixture of icons and word descriptors to illustrate pain quality creates real-world points of reference and minimizes reliance on the vocabulary of people living with arthritis pain.^{38,39} Third, the IPAT2 allows consumers to visually express and document different intensities of arthritis pain occurring in their entire body. Fourth, every stage of tool development has been driven by the feedback of people living with pain through public forums, pain support groups, educated consumer panels, and evaluative studies of participant preferences.^{38,39}

A few potential limitations of this study must be addressed. First, this study had a relatively small sample size of 30 participants, which may influence the generalizability of our results. However, there is literature-based evidence that this number of participants is sufficient for the purpose of usability testing.^{50,51} The study results are also limited to adults and adolescents with arthritis pain. Earlier study by our group has indicated that the IPAT is acceptable to people with other forms of chronic pain.^{38,39} Thus, the present study design could easily be adapted to refine the iconography for other pain groups. Second, recall bias may have influenced findings when participants were asked to rate the descriptiveness of each word for their arthritis pain. However, we minimized this bias by including only people who had experienced pain in the last 2 weeks. Furthermore, all participants had arthritis pain at the time of the study, and the recalled word ratings corresponded well with the pattern of icon selection in the diaries that documented

current pain. Third, volunteer bias may have influenced the study's results by virtue of the potential differences between individuals who did and did not choose to participate. Overall, 3/52 (6.0%) individuals who were eligible for the study refused to be approached by the research team, whereas 19/49 (39%) people who were approached chose not to participate due to time constraints. As the inconvenience associated with the study was the only reason given for nonparticipation, future studies may notify eligible individuals before their scheduled clinic appointment so that they can arrange to extend their visit, if necessary. Fourth, participants were not specifically characterized according to factors such as educational level or cultural background. Future study will take into consideration how these user characteristics may influence both ease of use of the tool and interpretation of icon meaning. Fifth, this study did not incorporate the health care provider perspective, which will be critical to the successful implementation of the IPAT2 as a clinical tool. This issue is being addressed in a subsequent study. Lastly, from this study sample, we do not know how the tool will perform among people who are not English speaking or who have cognitive difficulties. A major aim of this study was to assess the proposed relationship between "icon," "depicted object," and "pain descriptor" through a semistructured interview that required all participants be able to communicate fluently in English and be free of cognitive difficulties. Future study will examine the consistency with which various populations negotiate meaning with the pain iconography. Further validation is also needed to evaluate IPAT2 *clinical feasibility* (ease of application in the clinical setting) and *clinical utility* (meaningful application of tool results) as well as comparison with standard pain assessment tools.⁵²

In this study, "stiffness" and "aching" were the most descriptive words and icons among all participants, whereas "freezing," "electrical," and "pinching" were the least descriptive words for arthritis pain. A focus group study conducted by Hochman et al⁵³ suggests that the unprompted use of certain pain descriptors by people with osteoarthritis could be used to identify individuals with possible neuropathic pain. A future study involving a mixed patient sample will seek to determine whether the relative use of IPAT2 pain icons could be used to distinguish between individuals with different underlying pain mechanisms. This subsequent study will also take into consideration possible order effects related to the presentation of icons on the interface.

By virtue of the IPAT2 design, the precision of documenting pain location is limited by the size of each icon relative to the surface area of the body manikin. Furthermore, the manikin does not presently have a standard coding scheme to quantify "dropped" icons.⁵⁴ Thus, error might arise in the interpretation of pain quality location in smaller body regions such as radial versus ulnar digits of the hand. To address these issues, an expanded version of the tool with a codified body manikin after the IASP Classification of Chronic Pain⁵⁵ and allowing greater precision in reporting pain location is currently under development. This expanded version of the tool will also be linked to a secure database, which will automatically be populated with data as new pain records are created. This "back-end" system will facilitate long-term data storage and simplify the process of tracking pain parameters over time within discrete body locations.

In terms of dissemination, the IPAT2 will be made freely available online for clinical use. Version 1 of the tool, described in references, 38–39 is currently available at

<http://www.emiliemcmahon.ca/pain-tool.html>. A link to the IPAT2 will be added to this website once it is "live" on the Internet. A direct user feedback mechanism will also be incorporated into the website to identify any difficulties with usability or icon interpretation among the nonvolunteer group of users who will access the tool online.

In conclusion, this study has uniquely evaluated the IPAT2 user interface and iconography for adults and adolescents with arthritis pain. The tool was reported to be easy to use and understand, liked by users, quick to complete, and perceived as valuable for communicating arthritis pain. All pain quality icons met or exceeded the criterion for acceptability, and the icon bank has been refined to reflect participant preferences. The findings indicate that the IPAT2 represents an innovative contribution to the field of arthritis pain assessment, which should allow people living with arthritis to better express and document their sensory pain.

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CHAPTER 4

Pain-QuILT: Assessing clinical feasibility of a web-based tool for the visual self-report of pain in an interdisciplinary pediatric chronic pain clinic

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Summary and Central Message: This article further builds upon the work presented in Chapter 3. First, we incorporated the patient-suggested pain quality icons into the interface. Second, we codified the virtual body manikin into 110 distinct regions to allow greater precision in reporting pain location. Third, we created a dedicated mechanism for capturing pain data in a back-end database. Fourth, we carried out clinical feasibility testing of the *Pain-QuILT* in the setting of an interdisciplinary pediatric chronic pain clinic compared to a semi-structured interview method. Overall, this study provided evidence in support of the *Pain-QuILT* as a clinically feasible tool for assessing sensory pain in adolescents with chronic pain. It also provided early evidence of convergent construct validity by directly comparing the *Pain-QuILT* with a common clinical method of assessing sensory pain.

TITLE:

Pain-QuILT™: Assessing clinical feasibility of a web-based tool for the visual self-report of pain in an interdisciplinary pediatric chronic pain clinic

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RUNNING TITLE: Clinical feasibility of *Pain-QuILT™*

KEYWORDS: *adolescents; chronic pain; interdisciplinary; pain assessment; clinical feasibility; e-health*

Pain-QuILT

Assessing Clinical Feasibility of a Web-based Tool for the Visual Self-Report of Pain in an Interdisciplinary Pediatric Chronic Pain Clinic

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Key Words: adolescents, chronic pain, interdisciplinary, pain assessment, clinical feasibility, e-health

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Objectives: To evaluate clinical feasibility of the *Pain-QuILT* (previously known as the *Iconic Pain Assessment Tool*) from the perspective of adolescents with chronic pain and members of their interdisciplinary health team. The *Pain-QuILT* (*PQ*), a web-based tool that records the visual self-report of sensory pain in the form of time-stamped records, was directly compared with standard interview questions that were transformed to a paper-based tool.

Methods: Qualitative, semi-structured interviews were used to refine the *PQ*. Adolescents with chronic pain aged 12 to 18 years used the *PQ* and comparator tool (randomized order) to self-report pain before a scheduled clinic appointment, and then took part in a semi-structured interview. The health team used these pain reports (*PQ* and comparator) during patient appointments, and later participated in focus group interviews. Interview audio recordings were transcribed verbatim and underwent a simple line-by-line content analysis to identify key concepts.

Results: A total of 17 adolescents and 9 health team members completed the study. All adolescents felt that the *PQ* was easy to use and understand. The median time required for completion of the *PQ* and comparator tool was 3.3 and 3.6 minutes, respectively. Overall, 15/17 (88%) of adolescents preferred the *PQ* to self-report their pain versus the comparator. The health team indicated that the *PQ* was a clinically useful tool and identified minor barriers to implementation.

Discussion: Consultations with adolescents and their health team indicate that the *PQ* is a clinically feasible tool for eliciting detailed self-report records of the sensory experience of chronic pain.

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Chronic pain is common among adolescents, with prevalence rates ranging from 20% to 35%.^{1–4} Interdisciplinary pain teams comprised of health professionals who are specialized in the diagnosis and management of pediatric chronic pain are considered the standard of care for treating adolescents with chronic pain.^{5–7} One important component of chronic pain assessment is an evaluation of sensory features such as pain intensity, quality, and location.² Given the inherently subjective nature of pain, self-report measures are regarded as a primary source of clinical information, complementing observation and knowledge of clinical context.^{8–11} Within the field of pediatric pain, there is a high availability of single-item measures of sensory pain intensity.^{12–17} The psychometric properties, interpretability, and feasibility of these measures have been comprehensively reviewed elsewhere.^{8,18,19} For older children and adolescents, the visual analogue scale, adjective descriptor scales, and numeric rating scale (NRS) are recommended.^{18,20} These single-item intensity scales are simple to use and their validity has been demonstrated in situations requiring unidimensional measurements of current pain. However, these scales are not suitable to elicit a detailed account of the complex sensory experience of pain, including pain quality and location.²¹ A limited number of pediatric pain scales have been developed to meet this need such as the Varni/Thompson Pediatric Pain Questionnaire,²² Adolescent Pediatric Pain Tool,²³ and Abu-Saad Pediatric Pain Assessment Tool.^{24,25} These paper-based tools are designed to measure pain intensity using the visual analogue scale, pain location by drawn body manikins, and pain quality through lists of word descriptors. Another common way of assessing sensory pain in clinical practice is for interdisciplinary teams to develop their own pain questionnaire or interview protocol. However, these methods do not allow patients to easily report the complex experience of varying intensities and qualities of pain across different body locations. Furthermore, methods of self-report that rely entirely upon verbal-based and word-based descriptions of pain may present difficulties for individuals with limited written or verbal communication skills,²⁶ or a preference for visual communication.^{27–31} Recent advances in technology have facilitated the development of new methods for assessing pain, such as e-diaries.^{32–34,35} This electronic approach

offers multiple advantages over pencil-and-paper questionnaires, such as minimization of errors in data transfer and transcription, ability to capture time-stamped data, ease of data sharing, increased patient compliance, and heightened patient satisfaction.^{32–34,35} Electronic tools can also facilitate real-time data collection of “pain right now,” which minimizes the documented shortcomings of retrospective pain ratings, such as data distortion from recall bias.^{36–39}

The *Pain-QuILT (PQ)* (previously known as the *Iconic Pain Assessment Tool*) is a web-based tool designed to allow patients to visually self-report the nature of their current sensory pain (*quality, intensity, location*) in the form of time-stamped pain records.^{40–42} To our knowledge, the *PQ* is the first tool that combines the benefits of electronic administration, real-time data collection, and illustration of pain through a mixture of icons and word descriptors on a detailed virtual body-map. Specifically, patients can choose from a library of stylized images (icons) to describe the quality of their pain, such as a flame for burning pain. After giving a rating of intensity (0 to 10 NRS), each individual icon can be “dragged-and-dropped” onto a detailed virtual body-map to show pain location. The *PQ* has been iteratively developed and evaluated using a phased approach.^{40–42} In brief, the original version of the tool (available at: <http://www.emiliemcmahon.ca/pain-tool.html>) was created for adults with central poststroke pain⁴⁰ and was subsequently adapted for adults with chronic pain⁴¹ as well as adults (aged older than 18) and adolescents (aged 12 to 18) with arthritis (available at: <http://www.painquilt.mcmaster.ca>).⁴² As described in previous publications, the tool has undergone content validation through icon evaluation and refinement as well as usability testing in several different chronic pain populations.^{40–42} However, it has never been used in a clinical setting alongside the current protocol for assessing sensory pain in a clinical feasibility trial.⁴³

METHODS

The aim of the present study was to assess the clinical feasibility of the *PQ* from the perspective of adolescents with chronic pain and members of their interdisciplinary pediatric health team in the context of a follow-up chronic pain clinic appointment. As a clinical feasibility test, the specific objectives of this study were to assess the *PQ* for (1) ease of use; (2) time required to train and complete; (3) user preferences; (4) perceived clinical usefulness; and (5) perceived barriers to implementation. This project received approval from the local Research Ethics Boards and all participants provided free and informed written consent.

Study Setting

This study was conducted at a single chronic pain clinic in a university-affiliated pediatric tertiary care center serving metropolitan Toronto and central and northern Ontario. It was staffed by an interdisciplinary health team consisting of anesthesiologists, advanced practice nurses, a psychologist, a psychiatrist, physiotherapists, and a clinic administrative coordinator. During a typical follow-up clinic appointment, the patient met with the entire health team and took part in a comprehensive assessment, including history of the pain problem, pain-related disability (eg, impact on sleep, mood, school), and current pain management strategies (eg, physical, psychological, pharmacological). The team utilized a semi-structured

verbal interview format to assess sensory aspects of pain, including quality, intensity, and location (see section Clinic comparator tool). After the assessment, the patient and health team worked together to generate a comprehensive pain management plan.

Patient Selection

Adolescent participants aged 12 to 18 years were consecutively scheduled follow-up patients at the participating chronic pain clinic. Because of the high burden of multiple clinical assessments completed by new admissions, only follow-up patients were invited to take part in the study. Adolescents were eligible for this study if they were currently receiving treatment for chronic pain, were able to speak and read English according to their health care provider, and had self-reported pain in the previous 12 hours. Adolescents were excluded from the study if they had known major cognitive or psychiatric disorders that could preclude interview discussion as per their health care provider. Individuals were also excluded if they had severe vision or hand dexterity impairments that could prevent independent use of a computer and mouse.

Chronic Pain Health Team Selection

Members of the chronic pain team were eligible for this study if they were involved in the care of at least 1 adolescent participant and/or provided administrative support at the clinic. Visitors to the clinic and trainees were excluded.

Study Design, Consent Procedure, and Demographic Questionnaires

Iterative cycles of semi-structured individual (adolescent patients) and focus group interviews (health team), incorporating both qualitative and quantitative approaches,⁴⁴ were used to evaluate the clinical feasibility of the *PQ*. We chose to conduct focus groups rather than individual interviews with the health team to capitalize on shared communication and interaction between professional colleagues (eg, building ideas through discussion and communication of personal experiences).⁴⁵ A health care provider known to patients identified eligible adolescents by screening the patient lists of consecutively scheduled follow-up clinic appointments. Informed consent for study participation was obtained by the investigator before the adolescent met with the health team for their appointment. The participant completed a General Information Questionnaire, which collected data concerning current grade, computer comfort, and weekly computer use. The participant's health record was consulted to collect information on sex, year of birth, type(s) of chronic pain, and date of pain symptom onset.

Pain Tool Comparison

Before meeting with the health team for their scheduled appointment, the adolescent self-reported their pain using both the *PQ* and the clinic comparator tool in a quiet study room within the clinic. The order of these 2 assessments was randomized for each participant using a random numbers table to control for potential order effects.

The Pain-QuILT (Previously Known as the Iconic Pain Assessment Tool)

Participants were taught how to use the *PQ* using a standard 3-minute demonstration. Each participant used the investigator laptop computer (MacBook Pro) with

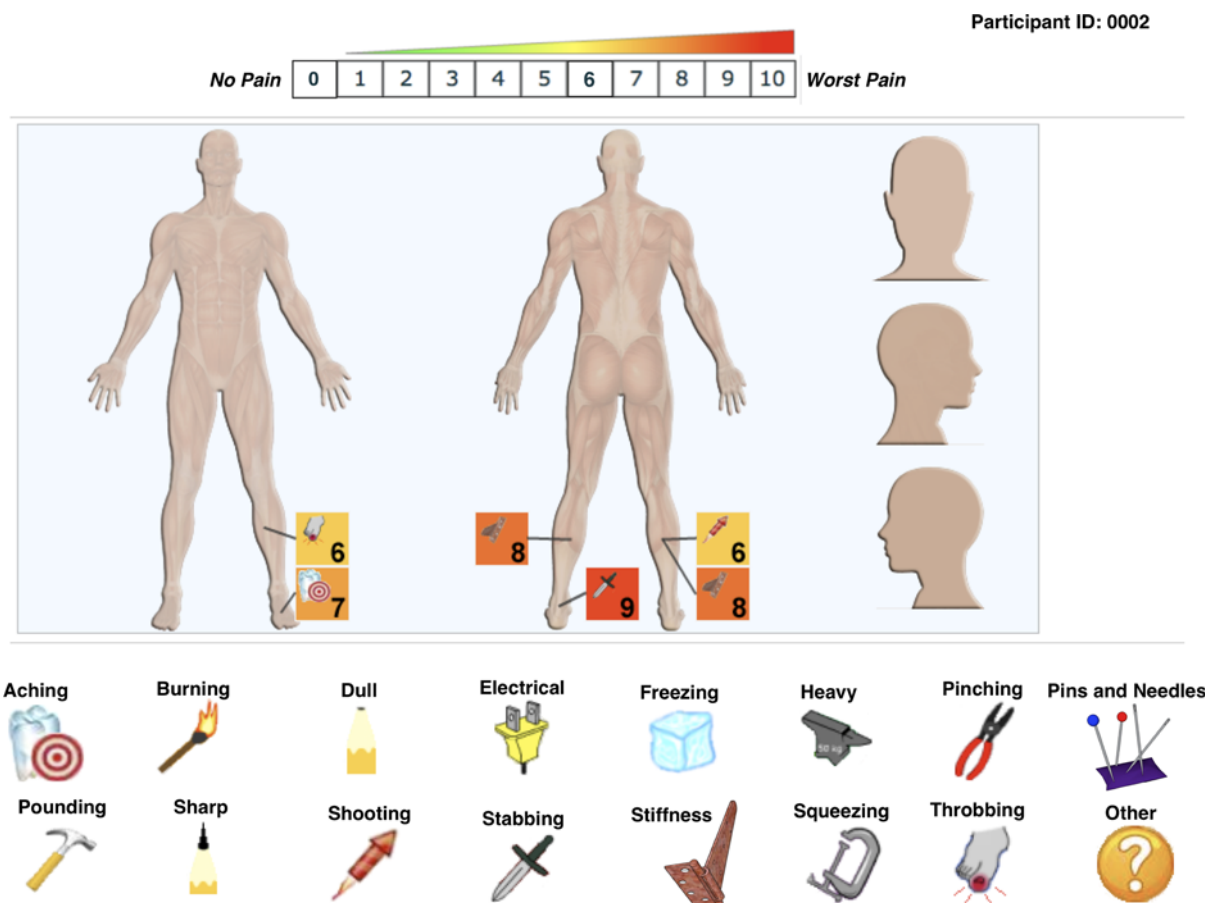


FIGURE 1. Example of completed pain record from the Pain-QUILT (PQ). The Pain-QUILT (previously known as the Iconic Pain Assessment Tool) is a web-based program for the visual self-report of pain quality (library of icons), intensity (0 to 10 numerical rating scale), and location (drag-and-drop descriptive icons onto virtual body-map) in the form of time-stamped records. In this study, adolescents with chronic pain used the PQ to document their current pain before a scheduled clinic appointment. This is an example of one participant's completed pain record. Copyright McMaster University. Used with permission. All permission requests for this image should be made to the copyright holder.

external mouse to “create a picture” of their current pain, as illustrated in Figure 1. First, they chose from the library of labeled pain quality icons to describe what their pain felt like, such as a “matchstick” icon for “burning” pain. Second, they used the mouse to “drag-and-drop” this descriptive icon onto the virtual body-map to show pain location. The body-map was codified into 110 distinct regions and each region became highlighted as the computer mouse hovered over it. Third, after “dropping” the icon onto the appropriate body region, the user assigned a rating of intensity for this pain by using a 0 to 10 NRS ranging from “no pain” to “worst pain imaginable.” After the user had chosen an intensity value, the pain icon appeared on the body-map along with the numerical rating. Users continued to “drag-and-drop” icons onto the body-map until all of their current pain had been recorded. As seen in Figure 1, the tool allowed users to visually express different qualities and different intensities of pain across their body (eg, foot pain that is both “electrical” and “burning”; abdominal pain that is “dull” and “aching”).

Clinic Comparator Tool

The standard method of assessing sensory pain in the participating clinic was a semi-structured verbal interview,

administered during the patient appointment. As it was not practical from an ethical standpoint for the study investigator to be present during each patient's private appointment with the health team, these interview questions were transformed to a paper-based questionnaire that could be administered by the investigator in the study room. See Figure 2 for comparator tool.

Investigator observation and participant comments were used to identify any difficulties or confusion with using the PQ and clinic comparator tool. The results from both tools (color print-out from PQ; written comparator tool) were given to the health team for review, and then the patient joined the team for their scheduled private clinic appointment. Adolescents were also given a copy of their completed PQ record and comparator questionnaire, and were encouraged to use the tools to help explain their pain while meeting with the team.

Adolescent Semi-structured Interview and Chronic Pain Team Focus Group

Following their private clinic appointment, the adolescent returned to the study room and took part in a 15- to 25-minute semi-structured interview with the investigator to discuss their experience using the PQ and comparator tool

To be verbally administered by the study investigator.

1. Can you tell me **where** your pain is today? Starting with the **most bothersome** and ending with the **least bothersome**, please list all parts of your body where you have pain:

2. What does your pain **feel like** right now? (Choose all the words that apply to you and indicate pain location)

Pain Word Descriptors	Applicable (X)	Pain Location
Aching		
Burning		
Cold		
Cutting		
Dull		
Hot		
Pounding		
Stinging		
Throbbing		
Tingling		
Other:		

3. On a scale of 0 to 10, where 0 is no pain and 10 is the worst pain you can imagine, how much does your pain hurt **right now**? _____

4. Now, I'd like you to tell me about your pain in the **past week (7 days)**.

- a) On a scale of 0-10, how much did your pain hurt **on average** during this time? _____
- b) On a scale of 0-10, how much did your pain hurt **at its worst (highest number)** during this time? _____
- c) On a scale of 0-10, how much did your pain hurt **at its least (lowest number)** during this time? _____

FIGURE 2. Comparator tool: the standard method of assessing pain in the participating clinic was to verbally ask a series of questions to the patient during their appointment. These standard interview questions were transformed to a paper-based questionnaire that could be administered by the investigator in the study room. Adolescents were asked to describe the location of their current pain using word descriptors, rank their current pains in order from most bothersome to least bothersome, choose from a list of adjectives to describe the quality of their pain, and also rate their current, worst, least, and average pain intensity over the past week using the 0 to 10 numerical rating scale.

with the health team as well as their preferences for self-reporting pain. The investigator was experienced in conducting interviews with adolescents and used techniques to minimize the power differential between the interviewer and participant (eg, established rapport, used developmentally appropriate language, engaged in active listening, used relaxed body language).⁴⁵ The investigator also stressed that the research team wished to ensure that the *PQ* addressed the needs of adolescents with chronic pain, and thus encouraged participants to freely express opinions about good and bad aspects of the tool. Adolescent interview questions were designed to assess the *PQ* in terms of: (1) how easy it was to learn the functionality; (2) features that were difficult to use or understand; (3) favorite feature; (4) least favorite feature; (5) perceived value for communicating pain with clinicians; and (6) comparison of the *PQ* and clinic comparator. Participants were also asked to share any additional comments or views about both tools. Each interview was audio-recorded and was conducted by the same investigator. A focus group was conducted with the entire chronic pain team after the first cycle of n = 8

adolescents completed the study. Semi-structured questions for the health care professionals were designed to assess: (1) ease of interpreting the *PQ* record; (2) perceived value for patients; (3) clinical usefulness; (4) how well the *PQ* fit into clinic workflow; (5) perceived barriers to implementation; and (6) comparison of the *PQ* and clinic comparator tool. Focus groups were moderated by the same investigator (C.L.) who conducted the adolescent interviews. After completion of the first testing cycle (8 adolescent interviews; health team focus group), the *PQ* prototype was refined based on adolescent and provider feedback, and then another cycle was initiated. Testing continued until no new issues with the prototype were identified.

Analysis

Each interview session was audio-recorded, transcribed verbatim by an experienced transcriptionist, converted to text files with identifiers removed, and imported into the qualitative software program, HyperRESEARCH.⁴⁶ This software was used to facilitate a simple content analysis of the data.⁴⁷ Field notes were also transcribed and imported

into the HyperRESEARCH database and included in the content analysis. A line-by-line coding analysis was used to identify key concepts from the interview transcripts and field notes. Concepts addressed during the semi-structured interviews and focus groups were used to thematically code and organize participant responses.⁴⁷ Participant quotations were selected to illustrate each key interview concept with the aim of representing the balance of opinion among the adolescents and health team. The identified interview themes and participant quotations were also reviewed with representatives from the health team focus groups for consensus (member checking).

Quantitative data from the General Information Questionnaire, Health Record Questionnaire, *PQ*, and clinic comparator tool were coded, scored, and entered into a Statistical Package for the Social Sciences (SPSS) database.⁴⁸ All data were analyzed to assess measures of central tendency (mean, median) and dispersion (SD, interquartile range [IQR]). Data were also evaluated to ensure that they met the assumptions of parametric statistical analysis (ie, the normal distribution). When these assumptions were not met, the nonparametric equivalent test was used. Pain-related data from *PQ* were extracted from the backend database and entered into SPSS for descriptive analysis. Data from the comparator tool were manually entered into SPSS. The time needed for participants to complete each tool was extracted from the interview audio recording. Paired *t* tests (parametric distribution) or Wilcoxon Related-Samples Signed Rank Tests (nonparametric distribution) were used to determine whether there were any differences between the *PQ* and comparator tool in terms of: number of reported pain locations, number of reported pain quality descriptors, current pain intensity ratings, and time needed to complete. The Fisher exact test was used to identify differences between the cycles 1 and 2 adolescents in terms of categorical frequency characteristics such as sex. This statistical test was used instead of χ^2 because the expected frequency of one or more cells in each 2×2 contingency table was < 5 .⁴⁹ Independent *t* tests (parametric) or Wilcoxon Rank Sum tests (nonparametric) were used to identify differences between the cycles in terms of age and pain duration. The level of significance was set at $P < 0.05$ for all tests.

RESULTS

Overview of Testing Cycles

Two iterative testing cycles were completed over a period of 2 months. On the basis of feedback from adolescent and health team participants in cycle 1, minor changes were made to the study process in cycle 2. The specific changes were: (1) copies of completed *PQ* and comparator questionnaires were given to the health team for review approximately 3 to 5 minutes before they met with the patient; (2) a technical “bug” related to dropping pain icons in the white space around the virtual body-map was resolved.

Participant Characteristics

Adolescents

A total of 17 adolescents completed the study (8 in the first cycle and 9 in the second cycle). Sample characteristics are summarized in Table 1. There was no significant difference between the adolescents from cycles 1 to 2 in terms

of age ($t(15) = -1.28$, $P = 0.22$), sex (Fisher exact test, $P = 0.47$), or pain duration ($U = 25.0$, $Z = -1.06$, $P = 0.29$). All adolescents (17; 100%) had a computer at home with Internet access. Ninety-four percent of adolescents reported being “comfortable” or “very comfortable” with using computers and the Internet. The self-reported frequency of computer use among participants was: once per week (1; 6%), twice per week (1; 6%), 6 times per week (1; 6%), every day (14; 82%).

Chronic Pain Health Team

All members of the chronic pain team, which consisted of 8 health care professionals, took part in the focus groups for cycles 1 and 2. The cycle 1 focus group also included the clinic administrative coordinator and thus had 9 participants. The average age of team participants was 46.7 years (SD 9.6) and a majority (67%) was female. Participant professions were: administrative coordinator (1; 11%), anesthesiologist (4; 44%), advanced practice nurse (1; 11%), physiotherapist (1; 11%), psychologist (1; 11%), and psychiatrist (1; 11%). They had a mean of 21.8 years (SD 12.6) of health care professional experience, and a mean of 7.5 years (SD 7.7) experience working in pediatric chronic pain.

Self-reported Pain Using *PQ* and Clinic Comparator Tool

The administration order among all participants was: *PQ* first (47%); comparator first (53%). Tables 2 and 3 summarize the self-reported pain data from the *PQ* and comparator, respectively.

A Related-Samples Wilcoxon Signed Rank Test indicated that adolescents reported significantly more unique locations of pain when using the *PQ* (median of 5 different locations) versus the comparator tool (median of 3 different locations), $Z = 16.5$, $P = 0.013$.

There was no significant difference in the number of pain quality descriptors chosen by adolescents to communicate their pain using the *PQ* (median of 5 pain qualities) and comparator tool (median of 4 pain qualities), $Z = 28.5$, $P = 0.394$.

TABLE 1. Demographic Characteristics of Adolescent Participants (n=17)

Characteristics	n (%)
Age (mean [SD]) (y)	15.4 (1.7)
Sex	
Male	1 (6)
Female	16 (94)
Current grade	
Grade 6 to 8	3 (18)
Grade 9	3 (18)
Grade 10	5 (29)
Grade 11	3 (18)
Grade 12	3 (18)
Chronic pain type	
Abdominal	2 (12)
Back	2 (12)
Complex regional pain syndrome type 1	2 (12)
Limb	2 (12)
Neuropathic	3 (18)
Musculoskeletal	2 (12)
Otagia (ear pain)	1 (6)
Widespread	3 (18)
Chronic pain duration (mean [SD]) (mo)	12.1 (9.6)

TABLE 2. Summary of Adolescent-generated Pain-QuLLT Records for Current Pain

Participants	# Unique Pain Locations Reported on Codified Body-Map	# Different Pain Quality Descriptors Reported by Icon Selection	Lowest Reported Current Pain Intensity* (0-10 NRS)	Highest Reported Current Pain Intensity* (0-10 NRS)	Mean Pain Intensity Score† for Current Pain (0-10 NRS)
1	10	6	4.0	7.0	5.5
2	5	5	6.0	9.0	7.3
3	15	4	5.0	8.0	6.6
4	4	3	4.0	6.0	5.0
5	4	3	3.0	7.0	5.4
6	2	6	1.0	7.0	4.7
7	2	6	1.0	4.0	2.3
8	2	3	4.0	5.0	4.3
9	19	9	4.0	8.0	5.9
10	4	5	3.0	8.0	5.6
11	14	6	5.0	8.0	6.4
12	1	2	3.0	6.0	4.5
13	1	5	1.0	9.0	5.0
14	5	3	3.0	7.0	5.2
15	13	3	3.0	7.0	5.5
16	11	11	2.0	8.0	5.8
17	15	8	3.0	9.0	6.4
Mean	7.5	5.2	3.2	7.2	5.4
SD	5.9	2.4	1.4	1.4	1.1
Median	5.0	5.0	3.0	7.0	5.5
Interquartile range	2.0, 13.5	3.0, 6.0	2.5, 4.0	6.5, 8.0	4.9, 6.2
Minimum	1.0	2.0	1.0	4.0	2.3
Maximum	19.0	11.0	6.0	9.0	7.3

*Among all icons “dropped” on the Pain-QuLLT body-map.

†The average of all individual intensity ratings on a single Pain-QuLLT record. For example, if a participant reported a 2/10 burning pain and a 5/10 stabbing pain, their mean pain intensity score would be $([2 + 5]/2) = 3.5/10$.
NRS indicates numeric rating scale.

A paired sample *t* test indicated that there was no significant difference in 0 to 10 NRS ratings for current pain intensity between the PQ (mean 5.4, SD 1.1) and comparator tool (mean 6.0, SD 1.7), $t_{16} = -2.09$, $P = 0.053$. The Pearson correlation coefficient between the PQ intensity score (cumulative score across all body sites) and comparator (single NRS rating) was $r = 0.61$.

PQ Ease of Use by Adolescents and Health Team

All adolescent participants described the experience of using the PQ to self-report their pain as “easy” or “very easy.” For example, one adolescent stated, *I found it easy to use and really helpful...because sometimes it's hard to think of the word that you're looking for to describe the pain.*

Members of the health team provided feedback on the ease of interpreting the adolescent-generated PQ pain records. For example, *It gives a very concise picture of...the quality and the quantity of pain...in a quick snapshot. Because trying to get all of this information from the patient takes quite some time...so it's a really nice way to have a nice visual overall...which I think would be useful just for efficiency plus for managing over the longer term.*

When asked to contrast the PQ with the comparator tool, the team recognized strengths and limitations of both approaches. In describing the PQ, one team member stated, *It's just much more pleasing to the eye and more immediate. When I see it, 9 times out of 10, it's pretty clear what their problems are and how significant they are. It requires less processing than this [the comparator], for me.* Perceived strengths of the comparator were the items related to pain

trajectory and pain affect (ie., asking patients to recall their average, worst, and least pain intensity from the past week as well as listing all current pains in order from most bothersome to least bothersome). For instance, 1 team member stated, *you really have to understand trajectory over time, how much it bothers you. But, in terms of just getting a quick visual, the [PQ] is better. I couldn't say that one is better than the other...they're complementary.*

In terms of adding affective components to the PQ, such as an NRS related to the degree of “bothersomeness” associated with each pain icon, the team stated that it could compromise ease of use. For example, *I think if you were to add anything else [to PQ], you're going to compromise its utility [because] it would become too busy and there would be too much on it. There are always other questions, but they're on our list to explore....so it's a starting point.*

Time to Complete PQ and Comparator

There was no significant difference in the time required for adolescents to complete a single PQ pain record (median 3.3 min; IQR 2.1, 5.0) versus the investigator-administered comparator tool (median 3.6 min; IQR 2.5, 4.3), $Z = 37.5$, $P = 0.346$.

Preferred Method for Self-reporting Pain in Clinic

Given a choice of methods for communicating their pain in the clinic, 15 (88%) adolescents preferred the PQ, 1 (6%) individual preferred the comparator tool, and 1 (6%) person felt that the 2 methods were equivalent. When

TABLE 3. Summary of Adolescent Pain Self-Report Using Clinic Comparator Tool

Participants	# Unique Pain Locations Verbally Reported	# Pain Quality Descriptors Reported by Word Selection	Recalled Average Pain in Past Week (0-10 NRS)	Recalled Worst Pain in Past Week (0-10 NRS)	Recalled Least Pain in Past Week (0-10 NRS)	Current Pain Intensity (0-10 NRS)
1	6	6	4.0	10	2.5	5.5
2	4	6	6.0	10	1.0	7.0
3	9	4	7.0	9.0	2.0	6.0
4	3	4	7.0	9.0	3.0	6.0
5	2	2	7.5	9.0	5.0	6.5
6	4	4	7.5	9.0	4.5	7.0
7	3	5	5.0	8.0	2.0	3.5
8	2	4	6.0	8.0	2.0	4.0
9	9	12	8.0	10	4.5	7.5
10	3	4	7.0	9.0	5.0	7.0
11	3	3	7.5	9.0	6.0	7.5
12	1	2	4.0	10	0	2.0
13	3	6	3.0	9.0	0	7.0
14	3	3	5.0	7.0	3.0	5.0
15	4	3	7.0	7.0	6.0	6.5
16	9	6	8.5	9.3	8.5	8.8
17	10	7	6.0	9.0	4.0	6.0
Mean	4.6	4.8	6.2	8.9	3.5	6.0
SD	2.9	2.4	1.6	0.93	2.3	1.7
Median	3.0	4.0	7.0	9.0	3.0	6.5
Interquartile range	3.0, 7.5	3.0, 6.0	5.0, 7.5	8.5, 9.6	2.0, 5.0	5.3, 7.0
Minimum	1.0	2.0	3.0	7.0	0	2.0
Maximum	10	12	8.5	10	8.5	8.8

NRS indicates numeric rating scale.

asked to elaborate on their reasons for choosing the *PQ* over the comparator tool, 4 adolescents (24%) referred to a sense of ownership and control over creating their own pain record. For instance, 1 adolescent shared, “*Because this [the PQ], it’s like I’m doing it. I know that there’s not going to be a problem...someone might write something and it’s either not completely accurate or it’s not what I meant to say.*” Other reasons for choosing the *PQ* included the ability to create a pain picture (*it was easier for me to target my pain with visuals*), ease of use, clarity of communication (*it is a quick way to show what pain it is...and the exact area it’s coming from*), and novelty (*I pick the computer because I’ve done the paper a million times*).

The adolescent who chose the comparator tool for self-reporting pain explained, “*because it’s simpler to read it and answer it.*” The participant who did not have a specific tool preference shared the view that, “*at the moment, they’re both equally good.*”

Clinical Usefulness from Perspective of Adolescents and Health Team

Adolescents characterized the *PQ* as useful for initiating and promoting clear communication with the health team. For instance, 1 adolescent shared: “*Yeah, I definitely did [find it helpful] because at first I was like, ‘I’m going in there and how am I just going to start off?’*” Similarly, another participant said, “*[it was helpful], especially when I was explaining where on my back it hurts. They asked where it is the most painful. Instead of me turning around, pointing out where it is and trying to explain that...it was easier to explain [with the PQ]. I thought that was pretty cool instead of them having to read a huge paragraph or...try to figure out another doctor’s notes, or their own, from months and months*

ago.” Adolescents also felt that reading the *PQ* records could help the team to gain a more complete understanding of their pain experience: “*I think it would be much easier for them to understand and comprehend where the pain is coming from, how much it’s hurting, and what type of pain it is.*” In the words of another adolescent, “*they can actually see it instead of me trying to remember it. It would be better.*”

In discussing the experience of using *PQ* records during appointments, the team described the tool as a useful trigger for conversation: “*One patient...said, ‘I have a pain in the back,’ and then we were able to say, ‘we notice here that you’ve also described some pain in your shoulder. So, it gave us another tool to...help, because the patients are often anxious...and don’t always remember, or just get a bit overwhelmed...so, it allows us to...prompt them a little bit.’*”

The team also commented on the value of allowing patients to independently enter their pain report: “*...because [the PQ] gives all of the words at once and fairly equally, it is a lot less biased...for them to choose a word descriptor. Whereas if we tell them, then the order of how we say it matters and the emphasis that we may inadvertently put on a word matters. So, I think that is also important for the truth of the information that we get.*” Another person shared, “*it [PQ] might be more objective...because it’s one they’ve plugged in. It’s not from us telling them what they said last time.*”

In discussing their experience with reading complex pain records, the team agreed that the *PQ* provided different information than the comparator tool. For instance, “*It gives you insight that they have a wide range of pains everywhere. Even if I’m not looking at each individual pain score...I just have an idea of how to approach that patient. I can prepare myself...[to] expect...a whole range of pain complaints...affecting a wide range of anatomical areas.*”

1 Clinical Implementation of PQ

3 Perceived Barriers and Solutions

5 The health care team identified the following potential
7 barriers to permanent clinical implementation of the PQ:
9 technology requirements (Internet-connected computer;
11 printer if hardcopies are desired), adjusting workflow to
13 accommodate patient completion and team interpretation
15 of the PQ, and ensuring patient privacy as they completed
17 the tool. The team also commented on the transferability of
the PQ software across different web platforms. Currently,
the tool can be used on any web-enabled computer that is
compatible with Adobe Flash Player. The team also gener-
ated potential solutions to identified issues such as pri-
vacy screens for the computer, using private rooms in the
clinic for the PQ assessment, and asking patients to arrive
at the clinic a few minutes early.

19 As an alternative to requiring patients to complete the
21 PQ at the clinic before their appointment, the team also
23 suggested: “[They] could either e-mail it or print it out. The
possibilities are endless...I think it might somewhat empower
these people to have this physical picture of how they’re
doing.”

25 Incorporation of the PQ into Clinic Workflow

27 In describing how the current clinic workflow could
29 accommodate the PQ, a member of the health team shared,
31 “As we’re dishing up each other’s paperwork, this is there.
33 We can have a quick look...to see...where their major pains
35 are, and we can hone in. I think it fits quite well at the
37 beginning of the clinic. It certainly doesn’t impede anything or
39 delay anything unless we’re waiting for them before.” The
41 team also suggested that the PQ could potentially increase
43 efficiency of the pain assessment portion of clinic appoint-
ments. For example, “It wouldn’t replace the conversation
[with patients], but I think it might supplement [it] by
speeding it up, especially if we gave them an extra five
minutes...to fill it out and think about it beforehand.” When
asked about whether their opinion of the PQ had changed
over the 2-month period that it was used in the clinic, 1
team member stated, “Unlike some things we do, I’ve become
more enamoured with it the longer I use it...I’ve grown
fonder of it over time not neutral or negative.”

45 DISCUSSION

47 To our knowledge, the PQ is the only tool that allows
49 patients to visually self-report sensory pain using a mixture
51 of graphics and word descriptors on a detailed virtual body-
53 map. Previous work has established the acceptability, usa-
55 bility, and content validity of the PQ in samples of adults
with central poststroke pain,⁴⁰ adults with chronic pain,⁴¹
as well as adults and adolescents with arthritis.⁴² This is the
first study to examine PQ clinical feasibility in the context
of an interdisciplinary pediatric chronic pain clinic
appointment.

57 Adolescent participants described significantly more
59 unique locations of pain when using the PQ (“dragging-
61 and-dropping” icons onto a virtual body-map) versus the
63 comparator tool (verbally stating painful body regions).
65 One reason for this difference could be that adolescents
found it easier to report a variety of pain sites when pre-
sented with a visual body image, rather than being required
to spontaneously generate their own list of body locations.
It is also likely that the coded regions of the PQ body-map
allowed adolescents to be more specific in pinpointing the

precise location of their pain (eg, selecting 3 different areas
of the spine on the *Pain-QuILT*, compared with verbally
stating “back pain”). In contrast, there was no significant
difference in the number of different pain qualities reported
by adolescents when using the PQ and the comparator.
This finding may reflect the similar approach used by these
tools, both of which require adolescents to select from
libraries of pain qualities. The major difference between the
tools in this regard is that the PQ offers visual icons
matched with word descriptors, whereas the comparator
tool offers word descriptors alone. The PQ pain qualities
also correspond with defined regions on the body-map.

In terms of pain intensity, the PQ data are captured
and recorded in a layered format, wherein each NRS
intensity score is nested within a specific pain quality icon,
which is also nested within a specific body-map site. Thus, a
completed pain record could contain multiple NRS scores
across different painful body sites. Given this complexity, it
is important to consider whether intensity should be
reported (i) separately for each site; (ii) as an average across
all sites; or (iii) only for the site of greatest concern.⁵⁰ As
described by von Baeyer, each reporting method has its
own advantages and limitations.⁵⁰ While reporting intensity
for each site would be comprehensive, it would also pro-
duce an overwhelming amount of data as the PQ body-map
is codified into over 100 sites. Calculating the average of all
NRS scores on the body-map provides a convenient indi-
cator of the central tendency of data, but also results in a
significant loss of information. Thus, while a mean intensity
score can provide a mathematical summary of reported
pain, we suggest that *clinical interpretation* of a PQ record
requires consideration of this single number in the context
of the entire visual record, as well as quantifiable variables
such as the number of unique pain sites, and the lowest and
highest NRS scores (Table 2).

The median time needed to complete the PQ and
comparator tool was 3.3 (IQR 2.1, 5.0) minutes and 3.6
(IQR 2.5, 4.3) minutes, respectively. These average times
are comparable with other available electronic pain
assessment tools, such as the e-Ouch⁵¹ (average of <9 min
to complete 3 daily entries among adolescents), as well as
clinician-administered paper questionnaires such as the
Adolescent Pediatric Pain Tool (3.2 to 6.4 min),²³ McGill
Pain Questionnaire (5 to 10 min), and Short Form-McGill
Pain Questionnaire (2 to 5 min).⁵² As indicated by the
health team, PQ implementation did not have a major
impact on clinic workflow, particularly because it is patient
driven (ie, adolescents are able to input their data without
clinician supervision). In this regard, the PQ may also
empower patients to assume greater responsibility for
expressing their pain to their health team. Recently,
Dell’Api et al⁵³ sought to understand how interactions with
multiple health care professionals shaped the experiences of
youth with chronic pain aged 10 to 17 years. Qualitative
interviews indicated that interactions with health care
professionals had a great influence on youths’ perceptions
and chronic pain experiences. These authors concluded,
“... it is essential that healthcare professionals provide chil-
dren with the opportunity to communicate their unique
experiences with pain.”⁵³ The literature indicates that the
mere availability of systematic pain assessment data may
not be sufficient to affect clinical decision making.⁵⁴ Fur-
thermore, qualitative studies report that many clinicians
wish to be involved in planning outcome assessment pro-
tocols.⁵⁵ This study purposefully sought input from a

variety of pediatric pain clinicians to evaluate usefulness of the *PQ* and to determine the best route for future implementation. We anticipate that this early involvement of clinicians could increase the likelihood of subsequent uptake by the larger clinical and research communities. The *PQ* will be licensed for clinical use and studies through the McMaster Industry Liaison Office.

A few potential limitations of this study must be addressed. First, the study had a small sample (17 adolescents; 9 health care professionals) that was drawn from a single multidisciplinary pain treatment facility (MPTF), primarily serving metropolitan Toronto and central and northern Ontario. It is important to note that the purpose of this study was to conduct a *PQ* feasibility trial in the context of this specific pediatric MPTF, rather than to generalize to other centers. A recent survey of Canadian pediatric MPTFs demonstrated that all existing centers treat chronic pain “from an interdisciplinary, multimodal, rehabilitation perspective.” (p.990)⁶ Thus, the organization and treatment model of the participating site is similar to other MPTFs in Canada. However, recognizing that every treatment facility has a unique culture and “way of doing things,” we suggest that the present methodology could be applied to establish the best way of incorporating the *PQ* into the workflow of other clinics. Although every effort was made to recruit all consecutively scheduled follow-up patients, our convenience sample included only 1 male adolescent. Furthermore, as our study only included follow-up patients, we are unable to conclude about the preferences for self-report among new admissions coming to the clinic for an initial evaluation. Second, from this study sample, we do not know how the tool will perform among people who are not English speaking or who have major cognitive difficulties. As this study required adolescents to take part in a semi-structured interview, it was necessary for all participants to be able to communicate fluently in English. The study sample included 1 adolescent who had minor cognitive impairment but was judged to have sufficient capacity to participate according to their health care professional. This individual had encountered no difficulties with navigating the *PQ* interface or completing the comparator tool. Future work will be required to fully examine the usability and feasibility of the *PQ* in non-English and/or cognitively impaired populations. Another future direction will be to test the *PQ* as a measure of changes in pain over time. Third, although the identified themes were reviewed by the health team, we were not able to perform similar “member checking” with adolescent participants. Finally, the comparator tool was created through adaptation of the health team’s typical interview questions into a questionnaire that could be administered by the study investigator. It is important to note that the health team is comprised of 8 different individuals, each of whom may have their own style of asking patients about pain (eg, using open-ended questions versus prompts). The literature suggests that multiple contextual factors, such as variations in question phrasing, modifications of top scale anchors (eg, “worst possible pain” vs. “very much pain”), and social desirability, can influence collected pain data.^{20,56} Thus, the comparator tool, which was always administered by the same person in a quiet interview room, may have yielded somewhat different data from an interview between the team and patient.

This study has evaluated *PQ* clinical feasibility in the context of an interdisciplinary pediatric chronic pain clinic.

Results indicate that the *PQ* is: (1) easy to use and understand; (2) quick to complete; (3) preferred by a majority of adolescents; (4) perceived as clinically useful for visually capturing pain and promoting patient-provider communication; and (5) limited by minor barriers to clinical implementation. We conclude that the *PQ* may offer unique advantages over traditional methods of pain assessment by empowering patients and health care providers to visually communicate sensory pain in a web-based format.

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CHAPTER 5

Pain-QUILT: Clinical feasibility of a web-based visual pain assessment tool in adults with chronic pain

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See *Declaration of Academic Achievement* for details regarding authorship.

Summary and Central Message: This article extends the work of Chapter 4 by evaluating clinical feasibility of the *Pain-QUILT* in the setting of an adult pain management and rehabilitation clinic. The *Pain-QUILT* was directly compared with the *McGill Pain Questionnaire* and *Brief Pain Inventory Short Form*, which are two of the most commonly used tools in adult clinical practice. Overall, this study provided evidence in support of the *Pain-QUILT* as a clinically feasible and patient preferred method for assessing sensory pain in adults with chronic pain. It also provided early evidence in support of convergent construct validity by directly comparing the *Pain-QUILT* with well-validated measures of sensory pain.

Original Paper

Pain-QuILT: Clinical Feasibility of a Web-Based Visual Pain Assessment Tool in Adults With Chronic Pain

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Abstract

Background: Chronic pain is a prevalent and debilitating problem. Accurate and timely pain assessment is critical to pain management. In particular, pain needs to be consistently tracked over time in order to gauge the effectiveness of different treatments. In current clinical practice, paper-based questionnaires are the norm for pain assessment. However, these methods are not conducive to capturing or tracking the complex sensations of chronic pain. Pain-QuILT (previously called the Iconic Pain Assessment Tool) is a Web-based tool for the visual self-report and tracking of pain (quality, intensity, location, tracker) in the form of time-stamped records. It has been iteratively developed and evaluated in adolescents and adults with chronic pain, including usability testing and content validation. Clinical feasibility is an important stepping-stone toward widespread implementation of a new tool. Our group has demonstrated Pain-QuILT clinical feasibility in the context of a pediatric chronic pain clinic. We sought to extend these findings by evaluating Pain-QuILT clinical feasibility from the perspective of adults with chronic pain, in comparison with standard paper-based methods (McGill Pain Questionnaire [MPQ] and Brief Pain Inventory [BPI]).

Objective: The goal of our study was to assess Pain-QuILT for (1) ease of use, (2) time for completion, (3) patient preferences, and (4) to explore the patterns of self-reported pain across the Pain-QuILT, MPQ, and BPI.

Methods: Participants were recruited during a scheduled follow-up visit at a hospital-affiliated pain management and physical rehabilitation clinic in southwestern Ontario. Participants self-reported their current pain using the Pain-QuILT, MPQ, and BPI (randomized order). A semistructured interview format was used to capture participant preferences for pain self-report.

Results: The sample consisted of 50 adults (54% female, 27/50) with a mean age of 50 years. Pain-QuILT was rated as significantly easier to use than both the MPQ and BPI ($P < .01$) and was also associated with the fewest difficulties in completion. On average, the time to complete each tool was less than 5 minutes. A majority of participants (58%, 29/50) preferred Pain-QuILT for reporting their pain over alternate methods (16%, 8/50 for MPQ; 14%, 7/50 for BPI; 12%, 6/50 for “other”). The most commonly chosen pain descriptors on MPQ were matched with Pain-QuILT across 91% of categories. There was a moderate-to-high correlation between Pain-QuILT and BPI scores for pain intensity ($r = .70$, $P < .01$).

Conclusions: The results of this clinical feasibility study in adults with chronic pain are consistent with our previously published pediatric findings. Specifically, data indicate that Pain-QuILT is (1) easy to use, (2) quick to complete, (3) preferred by a majority of patients, and (4) correlated as expected with validated pain measures. As a digital, patient-friendly method of assessing and

tracking pain, we conclude that Pain-QuILT has potential to add significant value as one standard component of chronic pain management.

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KEYWORDS

chronic pain; assessment tool; Internet; clinical feasibility

Introduction

Chronic pain, defined as pain that persists beyond normal time of healing, is a prevalent and debilitating problem that is now recognized as a disease [1-3]. Common types of chronic pain include low back, headache, abdominal, musculoskeletal, and neuropathic pain [4]. Pain is a complex sensory and emotional phenomenon that, while intensely experienced, is often difficult to communicate [5].

Accurate and timely pain assessment is critical to developing and monitoring a pain management plan [6]. Given that there is no medical test to directly measure pain, health care providers rely primarily on patient self-report, including pain quality (what it feels like), intensity (how much it hurts), location (spatial distribution), and temporal nature (how it changes over time) [6]. Assessment of pain quality and location is particularly important because this information can be used to distinguish between different diagnostic subgroups (eg, neuropathic versus non-neuropathic pain) [7,8].

Chronic pain management often takes place across multiple settings (eg, hospitals, clinics) and involves numerous health care providers, including physicians, nurses, physiotherapists, chiropractors, and psychologists [9-11]. Pain outcomes need to be consistently tracked over time in order to gauge the effectiveness of different management strategies, including physical, psychological, and pharmacological approaches. However, there is often a lack of consistency in the assessment of pain across these different settings and providers. One reason for this lack of consistency is the standard use of paper-based assessment tools, which are not conducive to tracking pain over time. Commonly used paper-based tools include the McGill Pain Questionnaire (MPQ) [12] and the Brief Pain Inventory (BPI) [13]. However, there is limited research on the serial use of these measures in clinical pain assessment.

The emergence of Internet and mobile technology has created opportunities for innovation in the field of pain assessment and management. For example, electronic pain diaries offer advantages such as ease of data tracking, improved patient compliance, and capture of real-time pain reports without memory bias [14-20].

Pain-QuILT is a Web-based tool for the visual self-report and tracking of pain (quality, intensity, location, tracker) in the form of time-stamped records [21-24]. Pain quality is expressed by choosing from a validated library of labeled pain icons, such as a matchstick for “burning pain”. Pain intensity is quantified using a 0-10 numerical rating scale (NRS) ranging from “no pain” to “worst pain imaginable”. Pain location is illustrated by “dragging-and-dropping” pain icons onto a detailed virtual body-map that is codified into over 100 regions.

To our knowledge, Pain-QuILT is the only tool that captures the complex sensations of chronic pain by allowing patients to self-report different qualities and intensities of pain across their entire body. For example, they can record the simultaneous experience of a “3/10” burning pain in their shoulder as well as a “5/10” pain in their foot that is both “burning” and “sharp”. All reported data are digitally captured and then populated into a database, which can be used to track changes in pain quality and intensity across different body regions over time.

Health care professionals can use this information to monitor the effectiveness of any pain management practices. Patients can keep track of their pain to help inform self-management in the home setting. By standardizing the assessment of pain outcomes in a digitized format, Pain-QuILT may also improve the coordination of pain management across multiple health care providers.

Pain-QuILT has been iteratively developed and evaluated in adolescents and adults with chronic pain, including usability testing and content validation. Before widespread implementation of Pain-QuILT, it is critical to evaluate clinical feasibility (ie, the ease with which it can be applied in a real-world setting), compared with standard methods of pain assessment. Recently, our group established clinical feasibility in an interdisciplinary pediatric chronic pain clinic that used a semistructured interview method to assess pain [24]. In comparison with this standard method, Pain-QuILT was preferred by a majority of adolescent patients and was perceived to be clinically useful for visually capturing pain and promoting better communication between patients and health providers.

Given that the MPQ and BPI are the standard tools used in adults, the purpose of this study was to extend the findings from our pediatric work to evaluate clinical feasibility of Pain-QuILT among adults with chronic pain in comparison with the MPQ and BPI. In the context of this clinical feasibility study, our primary aims were to assess Pain-QuILT for (1) ease of use, (2) time for completion, and (3) patient preferences. Our secondary aim was to explore the patterns of self-reported pain across the comparator methods of Pain-QuILT, MPQ, and BPI.

Methods

Study Setting

This study was conducted at a hospital-affiliated pain management and physical medicine and rehabilitation outpatient clinic in southwestern Ontario. It was staffed by an interdisciplinary team of health care professionals, consisting of a physiatrist, physical therapist, and kinesiologist. Patients who are referred to this outpatient clinic receive a thorough medical evaluation, including assessment of pain, and are then informed of the management plan including pharmacological,

injection, and physical therapies. They may also be referred for psychological therapy (eg, group counseling, cognitive behavioral therapy) if needed. All patients are reassessed at timely intervals and treatments are adjusted according to clinical need.

Recruitment

Informed written consent was obtained from all participants, and the study was approved by the locally responsible Research Ethics Boards. A health care provider known to patients identified eligible individuals by screening the patient lists of consecutively scheduled clinic appointments. Individuals were eligible to participate if they were (1) aged 18 years or older, (2) able to speak and read English, and (3) currently experiencing pain of any intensity according to self-report. Individuals were excluded if they had severe cognitive impairment or major comorbid medical or psychiatric illness that could preclude their ability to self-report pain or take part in a verbal interview, according to their health care provider. Individuals were also excluded if they had severe vision or hand dexterity impairments that could prevent independent use of a computer and mouse.

Demographic and Health-Related Data

Following consent, each participant completed a Demographic and Health Questionnaire, which collected data on age, sex, computer comfort, weekly computer use, language proficiencies, education level, and date of pain problem onset.

Interview Protocol

All participants took part in an individual semistructured interview (20-30 minutes) with a trained investigator (author CL). The investigator was experienced in conducting qualitative interviews and used techniques to minimize the power differential between the interviewer and participant (eg, established rapport, engaged in active listening, used relaxed body language) [25]. The investigator also stressed that the research team wished to ensure that Pain-QuILT addressed the needs of adults with chronic pain and thus encouraged participants to freely express opinions about good and bad aspects of the tool. As a first step, participants self-reported their pain using the Pain-QuILT, MPQ, and BPI (described in detail below). These tools were administered in a randomized order for each participant, in order to minimize potential order effects. Investigator observation and participant comments were used to identify any difficulties or confusion with using each tool; these were recorded as field notes. The time required to complete each tool was recorded. Next, a semistructured interview format was used to discuss participant preferences for pain self-report. A 0-10 NRS ranging from “not easy at all” to “very easy” was used to appraise each tool. Qualitative written feedback on the ease of using each tool was also collected. Finally, participants were asked to indicate their preference of methods for self-reporting pain and explain the reason for their choice. All interviews were conducted by the same investigator in a quiet room within the clinic.

Pain Tool Comparison

McGill Pain Questionnaire

This paper-based questionnaire was developed in the 1970s through groundbreaking research that was focused on identifying common word descriptors for the pain experience [12,26,27]. At the time, there was no available tool that accounted for the multidimensional nature of pain. The MPQ is composed of 20 subclasses that correspond to sensory, affective, evaluative, and miscellaneous pain. Each subclass consists of a clustered list of 2-6 word descriptors. For example, the first subclass of word descriptors is “sensory-temporal” and is made up of the descriptors: “flickering; quivering; pulsing; throbbing; beating; pounding”. There is a total of 78 descriptors on the MPQ. Participants were instructed to review each discrete cluster of words and then select the one word that best described their current pain. If none of the words within a cluster were descriptive of their pain, then no word was selected. The MPQ is one page in length and was administered by the study investigator.

Brief Pain Inventory Short Form

This paper-based questionnaire was developed in the 1980s for patients with cancer pain, based on research suggesting that existing measures such as the MPQ were burdensome for patients to complete [13,28]. Since its initial development, the BPI has subsequently become one of the most widely used tools for assessing all types of pain in both clinical and research settings [29]. It is designed to assess pain location and severity as well as level of interference with daily life. In the present study, participants used a pen to shade painful areas on a body-manikin diagram. The body-manikin consisted of anterior and posterior aspects and included no regional demarcations. Next, participants were required to rate the intensity of their “pain right now” as well as their “worst”, “least”, and “average” pain from the past 24 hours using separate 0-10 NRS items ranging from “no pain” to “pain as bad as you can imagine”. Finally, participants were asked to rate the extent to which pain had interfered with different parts of their life in the past 24 hours. Each quality of life domain was rated on a separate NRS ranging from 0 (“does not interfere”) to 10 (“completely interferes”). The BPI is one page in length and was administered by the study investigator.

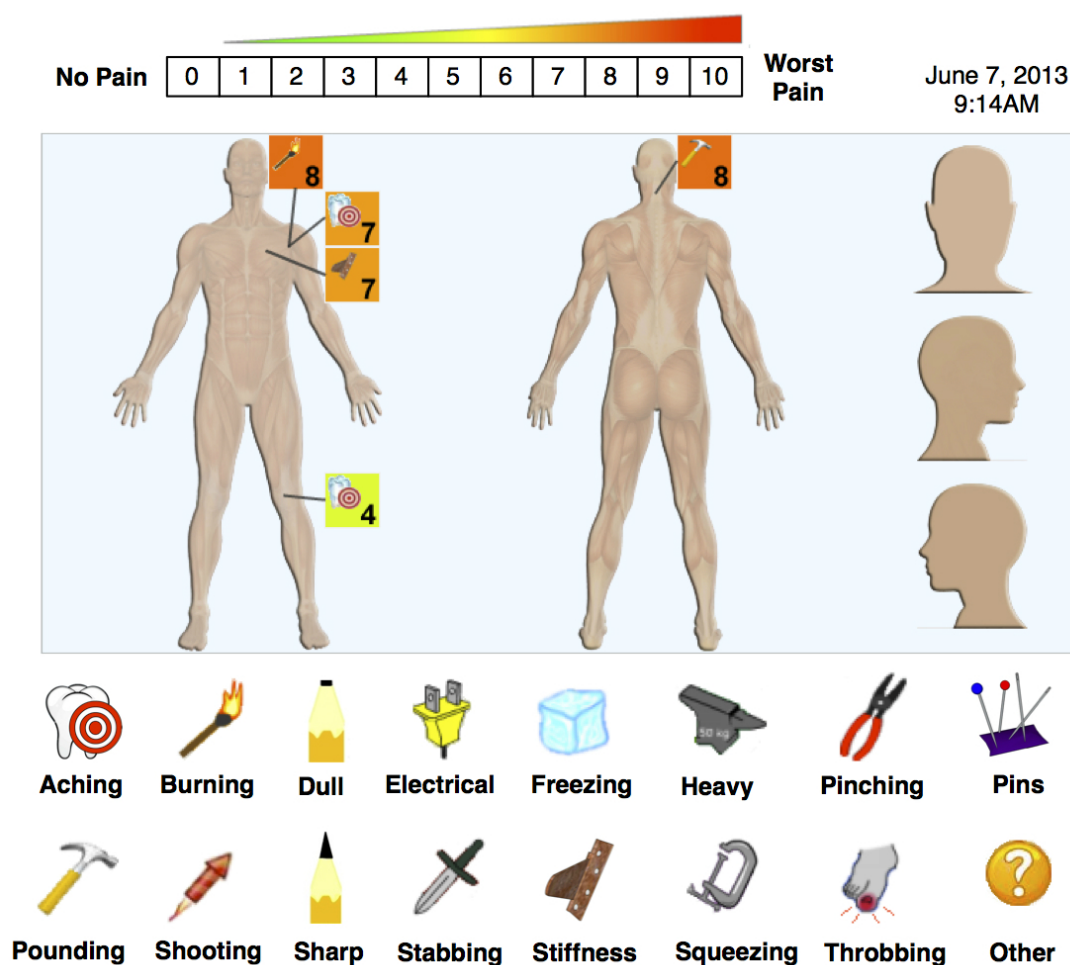
Pain-QuILT

Participants were taught how to use Pain-QuILT via a standard 3-minute demonstration. Following confirmation of understanding, each participant was instructed to use the investigator laptop computer (MacBook Pro) with external mouse to “create a picture” of their current pain, as illustrated in Figure 1. First, they chose from the library of labeled pain quality icons to describe what their pain felt like. The Pain-QuILT library consisted of 16 icons to represent aching, burning, dull, electrical, freezing, heavy, pinching, pins & needles, pounding, shooting, sharp, stabbing, stiffness, squeezing, throbbing, and “other” pain. They then used the mouse to “drag-and-drop” a miniature copy of this descriptive icon onto a virtual body-map to show pain location. The entire body-map was displayed on a single screen and was made up

of anterior and posterior aspects, as well as magnified views of the head (anterior, posterior, side-view). The body-map was codified into 110 distinct regions, and each region became highlighted in blue as the computer mouse hovered over it. Next, after “dropping” the icon onto the appropriate body region, the user assigned a rating of intensity for this pain by using a “pop-up” 0-10 NRS ranging from “no pain” to “worst pain imaginable”. The 0-10 NRS also corresponded with a color scale ranging from green (lower intensity) to red (higher intensity). After the user had chosen an intensity value, the pain icon was added to the body-map, along with the numerical rating. The dropped icon-number pair was enclosed within a

square box whose fill color corresponded to the intensity rating (eg, dark green fill for a rating of 1/10). Users continued to “drag-and-drop” numbered icons onto the virtual body-map until all of their current pain or pains had been recorded. Figure 1 shows a patient reporting multiple pains across their body of different qualities and intensities, specifically, shoulder pain that is both “burning” and “aching”, a painful stiffness in their chest, an “aching” knee pain, and a “pounding” pain in the back of their neck. All user-entered pain data (quality, intensity, location), as well as information on time and date of entry, were automatically uploaded to a back-end database that was accessible to the research team.

Figure 1. Screenshot of Pain-QuILT user interface for self-reporting the quality, intensity, and location of current pain. Copyright McMaster University. Used with permission. All permission requests for this image should be made to the copyright holder (McMaster Industry Liaison Office).



Data Analysis

Qualitative written data and field notes from the semistructured interview were transcribed verbatim and imported into the qualitative software program, HyperRESEARCH [30]. This software was used to facilitate a simple content analysis of the data [31]. A line-by-line coding analysis was used to identify key concepts from the interview transcripts and field notes. Concepts addressed during the semistructured interviews were used to thematically code and organize participant responses [31]. Participant quotations were selected to illustrate each key

interview concept with the aim of representing the balance of opinion among participants.

Quantitative data from the Demographic and Health Questionnaire, MPQ, BPI, and Pain-QuILT were coded, scored, and entered into a Statistical Package for the Social Sciences database [32]. As described by Lalloo and colleagues, the extracted parameters from each Pain-QuILT report were the number of unique painful sites (range 0 to 110) and number of different pain quality descriptors (range 0 to 16) used to express current pain [24]. Additionally, a cumulative mean pain intensity score was calculated across all painful body sites. While this

cumulative score provided a convenient indicator of the central tendency of data, it was also sensitive to outliers. Thus, we also extracted the lowest and highest single NRS intensity score to provide an indicator of data dispersion. For example, if a participant reported a 5/10 burning pain in their foot, a 3/10 burning pain in their hand, and a 3/10 stabbing pain in their back, then the number of unique painful sites would be recorded as 3, the number of unique pain quality descriptors would be 2, the cumulative intensity score would be calculated as $[(5+3+3)/3]=3.7$, the lowest reported NRS score would be 3, and the highest reported NRS score would be 5.

All data were analyzed descriptively to assess measures of central tendency (mean, median) and dispersion [standard deviation, interquartile range]. Data were also evaluated to ensure that they met the assumptions of parametric statistical analysis (ie, the normal distribution). When these assumptions were not met, the non-parametric equivalent test was used. Repeated measure analysis of variance (ANOVA) was used to determine whether there were any differences between Pain-QuILT, MPQ, and BPI in terms of time to complete or ease of use ratings. Pearson correlations were used to examine the association between pain intensity scores on Pain-QuILT

and BPI. The *a priori* criterion for evidence of convergent validity was a moderate correlation of $r=.5$ between Pain-QuILT and BPI scores for current pain intensity. Using the guidelines from Streiner and Norman pertaining to sample size for correlation coefficients, assuming $\alpha=.05$ and $\beta=.05$, the required sample size was $N=50$ [33]. The level of significance was set at $P<.05$ for all tests.

Results

Participant Characteristics

A total of 50 adults completed the study over a 5-month period in 2013. Sample characteristics are summarized in Table 1. Nearly all participants (48/50, 96%) had a computer at home as well as Internet access (45/50, 90%). Of the 50 participants, 84% (42/50) reported being “comfortable” or “very comfortable” with using computers, while 10% (5/50) were “a little comfortable” and 6% (3/50) were “not at all comfortable”. The self-reported frequency of computer use among participants was none (3/50, 6%), once per week (3/50, 6%), twice per week (2/50, 4%), three times per week (4/50, 8%), five times per week (1/50, 2%), and every day (37/50, 74%).

Table 1. Characteristics of study participants (N=50).

Characteristics	n
Age in years, mean (SD) (range)	50 (14) (18-76)
Gender, n (%)	
Male	23 (46)
Female	27 (54)
Language, n (%)	
English as first spoken language	39 (78)
Spoke English only	31 (62)
Spoke English and another language	19 (38)
Total years education, mean (SD) (range)	13.8 (3.8) (0-21)
Chronic pain duration in years, mean (SD) (range)	8.3 (8.9) (1-33)
Current pain treatment modalities, n (%)	
Pharmacological	43 (86)
Physical therapy	19 (38)
Massage therapy	9 (18)
Alternative or complementary	5 (10)
Chiropractic therapy	2 (4)
Acupuncture	2 (4)
Pain interference in past 24 hours, mean (SD)	
Normal work	7.2 (2.5)
Enjoyment of life	7.0 (2.9)
Sleep	6.8 (2.6)
General activity	6.7 (2.5)
Mood	6.2 (2.9)
Walking ability	5.6 (3.1)
Relations with other people	5.0 (2.9)

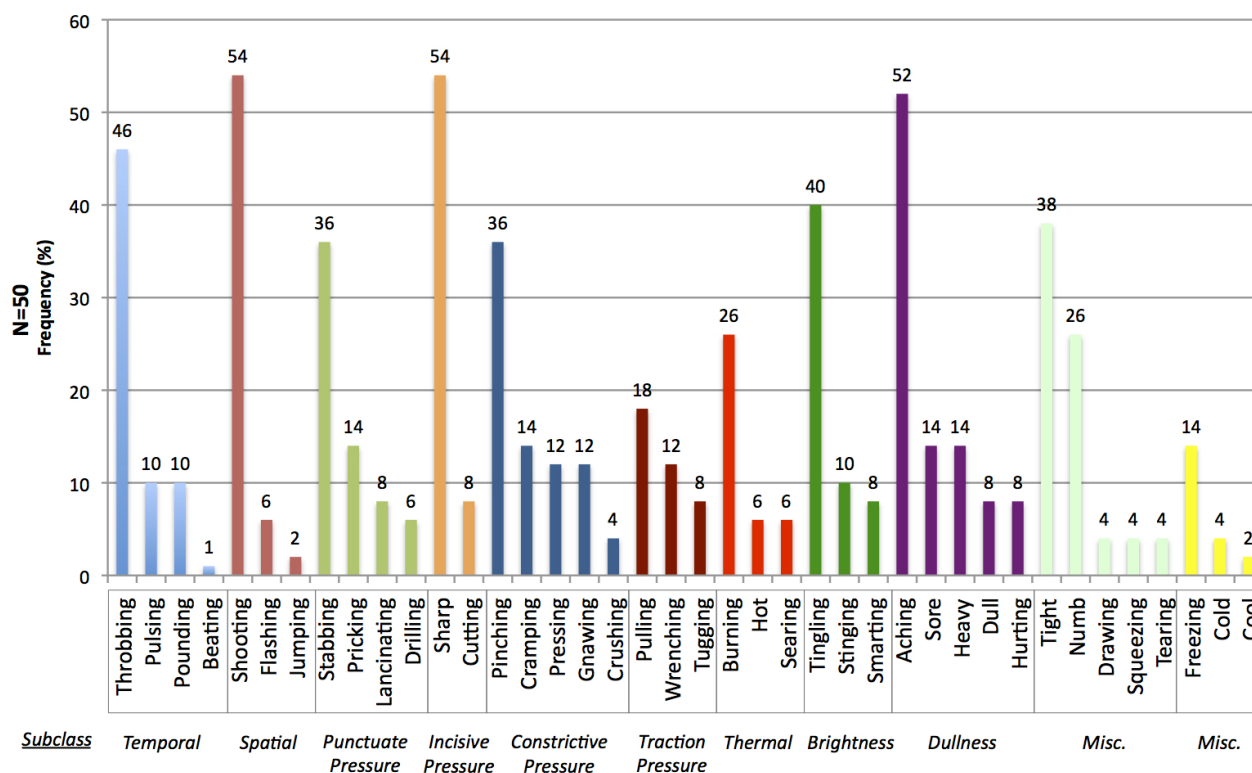
Self-Reported Pain

McGill Pain Questionnaire

The relative endorsement of MPQ pain quality descriptors between and within subclasses is illustrated in Figure 2. The most commonly chosen MPQ words to express current pain

were matched with a descriptor in the Pain-QuILT library across all subclasses, except for “miscellaneous”. This pattern was consistent regardless of whether the MPQ was administered before Pain-QuILT (29/50, 58%), or Pain-QuILT was administered before the MPQ (21/50, 42%).

Figure 2. Relative frequency of words chosen by participants on the McGill Pain Questionnaire to describe their current pain.



Brief Pain Inventory

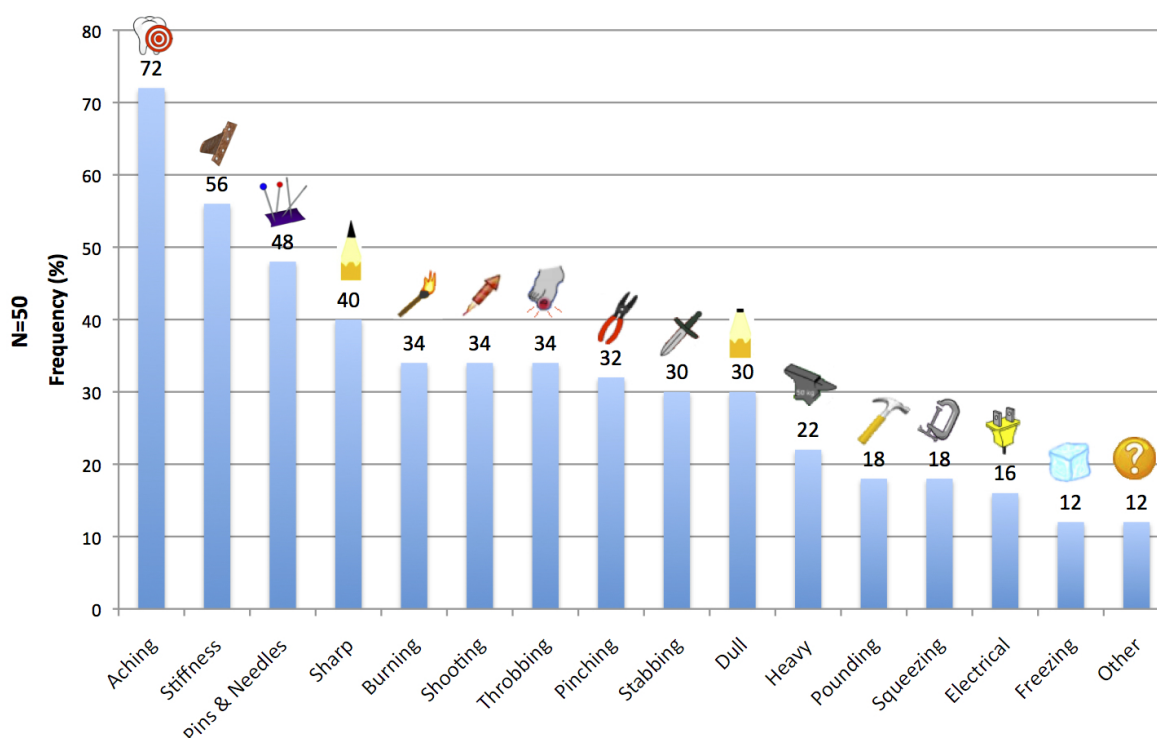
The mean score for current reported pain intensity was 6.6 (SD 2.1). The mean scores for recalled pain in the past 24 hours were 7.9 (SD 1.4) for “worst” pain, and 4.4 (SD 2.2) for “least” pain, respectively.

Pain-QuILT

The mean number of unique painful sites reported was 6.5 (SD 4.0, range 1-22). The mean number of different pain qualities used to describe current pain was 5.0 (SD 2.4, range 1-10). The relative endorsement of *Pain-QuILT* icons across all participants is illustrated in Figure 3. The mean reported intensity for current

pain (ie, the cumulative calculated score across all body sites) was 6.2 (SD 2.0). The mean lowest reported pain intensity score was 4.8 (SD 2.1), and the mean highest reported pain intensity score was 7.4 (SD 2.1).

The Pearson correlation coefficient between the *Pain-QuILT* score for current pain (calculated across all body sites) and BPI score for current pain (single NRS rating) was $r=.70$. The Pearson correlation coefficient between the highest reported intensity score on Pain-QuILT and the BPI score for current pain was $r=.76$. The Pearson correlation coefficient between the lowest reported intensity score on Pain-QuILT and the BPI score for current pain was $r=.55$.

Figure 3. Relative frequency of Pain-QuILT icons chosen by participants to describe their current pain.

Ease of Use

All participants reported the relative ease of using each tool for self-reporting pain. The mean ratings were 5.9 (SD 2.6) for the MPQ, 7.0 (SD 2.6) for the BPI, and 8.3 (SD 2.0) for Pain-QuILT. Overall, there was a significant difference between the tools in terms of perceived ease of use, $F_{2,96}=20.6$, $P<.001$. Pairwise comparisons also indicated significant differences between the MPQ and BPI ($P=.009$), MPQ and Pain-QuILT ($P<.001$), as well as BPI and Pain-QuILT ($P=.002$).

Participant-Reported Difficulties With Using Each Pain Tool

Overall, 46% (23/50) of participants indicated that they had difficulties in completing the MPQ, while 22% (11/50) reported difficulties with the BPI and 16% (8/50) specified difficulties with Pain-QuILT.

The most commonly reported issue with the MPQ was trouble with understanding the qualitative word descriptors (10/23, 43%) due to language barriers (eg, English as second language) or uncommon vocabulary, such as “taut” and “smarting”. Participants (7/23, 30%) also reported that the available pain words “...weren’t very good to describe [pain]” (ie, lack of descriptiveness). Other participants (7/23, 30%) noted that it was difficult to select the right words to express their pain due to ambiguity (“what is difference between cool, cold, freezing?”), the number of available options (“too many choices”), and the presence of more than one relevant word from certain subclasses. Last, participants (2/23, 9%) expressed concern about potentially misrepresenting their pain to their health care providers: “more fear of not describing your pain properly with this test”.

The most commonly reported issues with the BPI were communicating pain location using the body-manikin (2/11, 18%; “hard to pull out meaning”) and choosing intensity ratings to describe pain (2/11, 18%; “hard time with pain numbers”). Other reported difficulties included recalling pain over the last 24 hours (“hard to simplify pain”), reporting pain from multiple sites (“varying intensities of pain from different injuries”), and questionnaire design (“cumbersome to complete, too general”). One participant also indicated a “fear of not explaining properly what is happening”.

The most commonly reported issues with Pain-QuILT were related to the virtual body-map (3/8, 37.5%). Specifically, participants identified a need for orientation labels (left, right) and to make it easier to isolate specific painful body areas (“hard to find specific regions on [the] back versus a ‘paint’ tool, because some pain radiates”). In addition, participants (2/8, 25%) indicated difficulty in choosing pain quality icons due to “too many choices...sometimes it aches, sometimes it burns”, and a dislike of using descriptors because “pain just hurts”. Other participants (3/8, 37.5%) identified a “bug” in the software related to an inability to remove icons that were mistakenly added to the body-map.

Time to Complete

The mean time required by participants to complete a single pain report using each tool was 4.2 minutes (SD 1.5) for the MPQ, 4.0 minutes (SD 1.4) for the BPI, and 4.1 minutes (SD 2.2) for Pain-QuILT. There was no significant difference between the tools in terms of time to complete, $F_{1,44.8}=0.13$, $P=.81$.

Participant Preferences for Self-Reporting Pain

Overall, 16% (8/50) participants chose the MPQ as their preferred method for self-reporting pain, while 14% (7/50) chose the BPI, and 58% (29/50) chose Pain-QuILT. Four of the 50 participants (8%) indicated that they preferred the “other” method of verbally explaining pain to their health care provider. Finally, one participant (1/50, 2%) indicated an equal preference between the BPI and Pain-QuILT.

Reasons for selecting the MPQ included a preference for paper versus electronic pain reporting and greater perceived precision in describing pain, for example, “[it has] words that exactly indicate what is happening to [my] leg—bang on”.

Reasons for choosing the BPI included familiarity, the ability to describe how pain changes over time, and ease of choosing ratings on a set scale, for example, “[it] seems more easy to answer personally. Fits the way that I speak”.

Explanations for choosing Pain-QuILT included greater ease of use, ability to pinpoint different locations and types of pain, preference for computer versus paper-based pain reporting, as well as the visual language to express pain, for example, “[I would] feel more confident being treated by a doctor if they used this tool because [they] would know exactly what you are feeling”.

Discussion

Previous Findings

Our previous work has established the acceptability, usability, and content validity of Pain-QuILT in samples of adults with central post-stroke pain [21], adults in the community with a range of different types of chronic pain [22], as well as adults and adolescents with arthritis pain [34]. Clinical feasibility testing, the focus of the present study, is an important stepping-stone toward widespread implementation of a new assessment tool [35]. Our group has recently demonstrated clinical feasibility of Pain-QuILT in the context of an interdisciplinary pediatric chronic pain clinic among adolescents aged 12-18 years [24]. The present study sought to extend these findings by evaluating clinical feasibility of Pain-QuILT from the perspective of adults attending an outpatient pain clinic for treatment of chronic pain. This study included a comparison of Pain-QuILT with standard methods of pain assessment.

Principal Results

As a tool for self-reporting pain, Pain-QuILT was rated as significantly easier to use than the MPQ and BPI, which are two of the most commonly used pain assessment tools in research and clinical practice. Almost half (46%) of participants reported difficulties in using the MPQ. Most of these difficulties related to understanding the pain descriptors and finding accurate words to express pain from a large number of options. These findings of the present study are consistent with a meta-analysis of 51 studies involving 3624 patients, which found that most MPQ words (75%) are rarely endorsed by patients to describe their pain [36]. Although the BPI was associated with fewer reported difficulties, participants indicated that its design was not conducive to reporting different

intensities of pain in different body sites. Numerous studies have demonstrated that chronic pain is rarely confined to a single body region [37-39]. For instance, in a study involving 2445 patients, Carnes and colleagues found that 73% experienced pain across multiple body sites [37]. Among patients with low back pain, only 13% experienced regionally isolated pain. In terms of implications for pain assessment and management, these authors concluded, “self-reported measures of multi-site pain are problematic with pain measures that are site-specific. Pain in other areas may render them less reliable and responsive. Future intervention studies should consider recording other pain sites to identify predictors of response to treatment” (p. 1170) [37]. Overall, Pain-QuILT was associated with the fewest reported difficulties among participants. Most of the identified issues (75%) will be resolved in the next iteration of Pain-QuILT software (eg, adding orientation labels to body map, fixing “bug” related to deleting unwanted icons). Participant concerns related to the changing nature of pain (“sometimes it aches, sometimes it burns”) will be addressed in future longitudinal studies, which will allow patients to use Pain-QuILT as a diary to document symptoms as they occur. A major identified strength of Pain-QuILT was the ability to record multiple sites, types, and intensities of pain.

The average time required to complete each assessment tool was less than 5 minutes. While there was no significant time difference between the tools, it is important to note that patients can enter Pain-QuILT data independently, while the MPQ and BPI are usually administered by a health care provider in the context of a clinic appointment. Moreover, Pain-QuILT data are generated and stored in a digital format, while information from MPQ and BPI must be manually transcribed into a spreadsheet (paper or computer-based) in order to facilitate tracking over time. Thus, Pain-QuILT has the potential to increase efficiency of clinic appointments by (1) empowering patients to self-report pain on their own time (eg, at home and/or in the clinic waiting room), (2) providing health care providers with digital summaries of tracked pain data to evaluate and inform their management plan, and (3) standardizing the assessment of pain outcomes for use across multiple providers.

Given the inherently personal nature of pain, it is important to consider patient preferences regarding the most effective way of expressing symptoms. The majority of participants (58%) indicated positive preference for Pain-QuILT over alternate methods. It is well recognized that patient engagement is a critical factor in the successful management of chronic disease [40]. In particular, effective doctor-patient communication is known to enhance the health outcomes of pain management [41]. The interactive and dynamic format of Pain-QuILT may also help patients forge a stronger emotional connection to the tool as a means for portraying and conveying their pain experience, compared to static questionnaires. Moreover, there is a growing body of literature documenting the rise of “self-tracking” among people living with chronic illness. A recent Pew Research Center report found that 40% of adults with 1 chronic condition and 62% of adults with 2 chronic conditions currently self-track their symptoms [42]. In terms of patient benefits, respondents indicated that self-tracking influenced their overall approach to maintaining health (56%),

prompted them to ask their doctor new questions (53%), or influenced a treatment decision (45%) [42]. Thus, by providing a user-friendly method for communicating with health care providers and self-tracking painful symptoms, Pain-QuILT may encourage greater patient involvement in the long-term management of their own disease.

There is a growing number of patient-oriented mobile applications (apps) designed to aid the self-tracking of pain. In 2011, Rosser and Eccleston identified 111 pain management apps, of which 24% included a self-monitoring function [43]. A more recent scoping review, conducted in 2013, identified 224 pain apps, of which 14% allowed users to self-track their symptoms [44]. Unfortunately, both studies identified major limitations in the current field of pain apps, including a lack of formal evaluation and limited involvement of health care professionals and patients in their development. Pain-QuILT has been iteratively evaluated and refined through consultation with patients as well as health care professionals and thus has potential to address these identified gaps in the field, as one component of chronic pain management.

Given that participants were asked to self-report their current pain using three different methods, we expected to observe consistency in reported pain. Using the MPQ, participants were presented with a choice of 46 qualitative descriptors across 11 subclasses. Interestingly, the most frequently chosen MPQ words were consistent with the icon descriptors on Pain-QuILT. This relationship was independent of the order of tool assessment. Pain-QuILT icons and word descriptors have been iteratively refined based on patient interviews to ensure that they are representative of the pain experience. The observation that the icons correspond with the most frequently endorsed MPQ descriptors provides further evidence of validity. In terms of pain intensity scores, we examined correlations between Pain-QuILT (body site-specific pain scores) and the BPI (single global score for current pain). There were high correlations ($r \geq .70$) observed between BPI score and (1) the calculated average pain score across all body sites, and (2) the single highest reported pain score across all body sites. There was also a moderate correlation ($r = .55$) observed between BPI score and the single lowest reported pain score across all body sites. Along with our previous pediatric study, which compared Pain-QuILT scores with a verbal NRS ($r = .61$), the current data provides

further evidence of convergent validity. Importantly, in terms of clinical usefulness, we suggest that the greater level of detail elicited by Pain-QuILT may help inform pain management strategies (eg, observing how treatment affects pain quality and intensity scores within specific body sites) more than a single global intensity score.

Limitations and Future Directions

The present clinical feasibility study was conducted at a single interdisciplinary pain management and rehabilitation clinic in Southwestern Ontario. Although the organization and treatment model of this site was consistent with other Canadian multidisciplinary pain treatment facilities [45], we acknowledge that future work is needed to evaluate clinical feasibility of Pain-QuILT in other settings. Further, given the interview component of this study, it was necessary for all participants to be able to speak and read English. Although 38% of participants spoke multiple languages, future work is needed to formally evaluate Pain-QuILT in non-English speaking groups. Given the visual nature of Pain-QuILT reporting, it could prove to enhance pain communication for individuals with limited verbal or cognitive skills.

Participants in this study completed only a single Pain-QuILT report. Future work will evaluate whether patient perceptions regarding ease of use and preferences, as well as time to complete, are affected by repeated usage.

Conclusions

The results of this clinical feasibility study in adults with chronic pain are consistent with our previously published pediatric findings [24]. Specifically, data indicate that Pain-QuILT is (1) easy to use, (2) quick to complete, (3) preferred by a majority of adults with chronic pain, and (4) correlated as expected with validated pain measures. As a digital, patient-friendly method of assessing and tracking pain, we conclude that Pain-QuILT has potential to add significant value as one standard component of chronic pain management.

The tool will be licensed for clinical use and research studies through the McMaster Industry Liaison Office [46,47]. Updated information on availability will be provided on the author website [47] and Twitter account (@PainQuILT).

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Authors' Contributions

All authors contributed substantially to (1) study conception, design, and data interpretation, (2) drafting the manuscript or revising it critically for important intellectual content, and (3) final approval of the version to be published. Participant interviews were conducted by author CL.

Conflicts of Interest

None declared.

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Abbreviations

BPI: Brief Pain Inventory
MPQ: McGill Pain Questionnaire
NRS: Numerical Rating Scale
SD: standard deviation

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CHAPTER 6

DISCUSSION

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6.1 Overview

The intent of this concluding chapter is to draw together the main findings of the completed research, revisit the hypothesis, identify limitations, describe implications for clinical practice, and discuss prospective future research pathways in the evolution of digital sensory pain mapping tools.

6.2 What did the *Pain-QUILT* testing reveal?

6.2.1 Key findings in the context of thesis objectives

(1): Evaluated acceptability of the core concept by individuals with different types of chronic pain.

The concept of using digital icon-based pain mapping as a means of communicating sensory pain was well accepted by the community-based sample of adults with chronic pain (see Chapter 2). This positive endorsement provided a framework to develop and iterate on the *Pain-QUILT*, originally envisioned for individuals with central post-stroke pain, for relevance and application to a broader group of people with chronic pain. The concept was also well accepted by clinic-based samples, including adults and adolescents with arthritis pain (Chapter 3), adolescents with chronic pain (Chapter 4), and adults with chronic pain (Chapter 5).

(2): Iteratively refined Pain-QulLT design and functionality by applying a user-centered design approach.

The process of actively seeking input from individuals with different types of chronic pain revealed the need to expand the *Pain-QulLT* in several important ways (see Chapter 2).

First, the results of the initial acceptability study indicated that participants wished to express varying intensities of the same pain quality across multiple body sites (e.g., 2/10 foot pain that is both ‘burning’ and ‘sharp’ in quality, as well as 4/10 wrist pain that is ‘burning’ in quality). These findings are consistent with evidence from the literature, which indicates that individuals with chronic pain commonly report multiple sites of pain [66-68]. For instance, in a study involving N=2,445 chronic pain patients, Carnes and colleagues found that 73% of individuals experienced pain across multiple regions [66]. To match this identified user experience, the *Pain-QulLT* was redesigned to enable users to document multiple qualities and multiple intensities of pain across different body locations.

Second, investigator observation during user navigation of the Version 1 prototype revealed that the majority of users failed to manually document temporal information about their pain recording (i.e. morning, afternoon, evening, or overnight). In order to remove this limitation as well as to increase the precision of capturing temporal information, an automatic time and date stamp was added to the *Pain-QulLT*. This added functionality also served to minimize the risk of users “back-filling” their pain

reports, which is a known potential bias of self-report tools [50].

Third, observation of users as they recorded painful sites on the body manikin revealed inconsistency in use of the magnification feature for the hands and feet (Chapter 2). In order to remove this potential source of mapping variability, the body manikin was modified such that the hands and feet are permanently magnified.

(3): Evaluated and refined library of pain quality icons for chronic pain to assess content validity and descriptiveness of sensory pain.

As stated by Jensen and colleagues, *“to ensure that a measure of pain quality is most useful, it should assess all of the pain qualities most commonly experienced by individuals with chronic pain; that is, it should have content validity”* (p. 2722)[69].

As highlighted in the Introduction (see 2.5.3b1), the combination of standardized pain quality iconography and word descriptors is a unique feature of the *Pain-QUILT* in the field of digital sensory pain mapping tools. While the original group of five sensory icons was designed to be descriptive of central post-stroke pain, the icon library was systematically evaluated and expanded to generate a more comprehensive visual language for chronic pain. Specifically, as described in Chapters 2 and 3, the icon library was iteratively developed by consulting adolescents and adults with chronic pain from community-based and clinical settings.

Each individual icon was evaluated in terms of concreteness (degree to which it

is representative of a real-world object), semantic distance (degree to which it is representative of a specific pain quality), and satisfaction for describing pain [70]. All icons met or exceeded *a priori* criteria for these characteristics, providing evidence of content validity. In addition, new icons were designed and evaluated for ‘sharp’, ‘dull’, and ‘throbbing’ pain.

This process of iterative refinement has resulted in a *Pain-QUILT* library comprised of sixteen different sensory pain qualities: ‘aching’, ‘burning’, ‘dull’, ‘electrical’, ‘freezing’, ‘heavy’, ‘pinching’, ‘pins and needles’, ‘pounding’, ‘sharp’, ‘shooting’, ‘stabbing’, ‘squeezing’, ‘stiffness’, ‘throbbing’, and ‘other’. All of these sensory pain quality icons are included in Version 3 of the *Pain-QUILT*, which has undergone clinical feasibility testing (see Chapters 4 and 5).

Adolescent and adult participants in the clinical feasibility studies indicated that these sixteen icons are appropriate for expressing the sensory component of their chronic pain (i.e. no pain descriptors were perceived to be ‘missing’ from the library).

While commonly used multi-component sensory self-report tools include a larger number of different pain adjectives (e.g. 54 sensory words in the *McGill Pain Questionnaire* [32]), fewer sensory pain qualities may be commonly experienced by individuals with chronic pain [35,36].

Recently, Jensen and colleagues published two studies that sought to identify the

most common words used to describe chronic pain by adults with spinal cord injury or multiple sclerosis (study 1), and adults with low back pain, fibromyalgia, or headaches (study 2) [69,71]. Telephone interviews were conducted with n=213 individuals in study 1 [71], and n=302 individuals in study 2 [69].

Across both studies, there was a high level of overlap in identified pain descriptors (fourteen words in study 1; fifteen words in study 2). Similar to our findings, these authors concluded that, “...*although as many as...78 descriptors have been included in pain quality measures, much fewer pain quality domains appear to be needed to describe the experience associated with chronic pain*” (p. 2726) [69].

(4): Evaluated the Pain-QUILT in adolescents with chronic pain to assess usability and perceived value for reporting sensory pain.

A large proportion of youth with chronic pain will continue to experience pain that persists into adulthood [72]. As these young individuals transition from pediatric to adult-based healthcare, it is important that they have the ability to effectively communicate their disease experience with clinicians, including sensory pain [73].

To align with the aim of refining the tool to increase usability across the lifespan, the work described in Chapters 3 and 4 evaluated the *Pain-QUILT* from the perspective of adolescents (aged 12-18 years) with chronic pain. Findings indicate that the concept of digital sensory pain mapping using iconography is well accepted by this age group. For example, all adolescent participants characterized the *Pain-QUILT* as easy to use,

easy to understand, and valuable for initiating and promoting clear communication about sensory pain with their healthcare provider.

Dell’Api and colleagues have qualitatively explored the experiences of children and adolescents with chronic pain in relation to their interactions with multiple healthcare professionals [74]. In a study involving semi-structured interviews with youth aged 10 to 17 years, one of the major identified themes was *‘seeing is believing’*. A subtheme in this category was, *‘if they can’t see it, it’s not there’*. Specifically, the authors report that, *“all the children...noted that the invisible and sporadic nature of their pain complicated their interactions with health care professionals. Children believed that since healthcare providers were unable to see their pain, they could not confirm that it existed”* (p. 275) [74].

The use of sensory pain mapping, which *“...entails the transfer of subjectivity and symptom to objectivity and a graphic sign”* (p.784) has potential to overcome this identified barrier in the communication of pain during clinical interactions [44]. Indeed, adolescent participants (Chapters 3 and 4) reported that the visual nature of the *Pain-QUILT* could help their health team to gain a more complete understanding of their sensory pain experience, including details about multiple pain sites. Furthermore, adolescents indicated that using the *Pain-QUILT* helped them to document details about their pain experience that they otherwise may not have shared with their health team.

(5): Evaluated the Pain-QUILT from the perspective of pain clinicians in terms of perceived value and clinical usefulness for assessing sensory pain.

For a new assessment tool to be adopted in practice, it is important to involve clinician end-users in the process of tool development [75]. To align with this element of usability, as described in Chapter 4, the *Pain-QUILT* was evaluated from the perspective of an interprofessional pain team, including representatives from medicine (anesthesiology and psychiatry), nursing, physiotherapy, and psychology. The team characterized the *Pain-QUILT* as clinically valuable for efficiently capturing detailed sensory information about pain in a visual format. They also described the tool as clinically useful for triggering and guiding conversations with their patients about pain in the context of clinic appointments. Overall, the pain team characterized the *Pain-QUILT* as providing important information about sensory pain within the larger context of interprofessional chronic pain assessment and multimodal management [76,77].

(6): Compared the Pain-QUILT with existing methods of assessing sensory pain to evaluate user preferences and convergent construct validity.

In order to position the *Pain-QUILT* as a clinically useful tool, it was important that it be directly compared with commonly used methods of assessing sensory pain in pediatric and adult chronic pain groups (see Chapters 4 and 5).

In the setting of an interprofessional pediatric chronic pain clinic, which used a standard verbal interview method to assess sensory pain, a majority of adolescents (88%) preferred the *Pain-QUILT* to self-report pain. A commonly articulated reason for

this preference was that the *Pain-QuILT* provided adolescents with a greater sense of ownership and control over communicating their pain. Other reasons cited by adolescents for preferring the *Pain-QuILT* included the ability to visually communicate pain rather than relying on words, ease of use, and the novelty of using a digital tool to express pain. Moderate correlations were found between reported pain intensity scores on the *Pain-QuILT* (calculated average across all painful body sites) and the comparator method (single verbal numerical rating scale), providing evidence of convergent validity.

In the setting of an adult pain management and rehabilitation clinic, the *Pain-QuILT* was directly compared with the *McGill Pain Questionnaire* [32] and *Brief Pain Inventory Short Form* [33]. The *Pain-QuILT* was rated as significantly easier to use than both comparators and was associated with the fewest reported difficulties in completion. In agreement with the pediatric findings, a majority of adult users preferred the *Pain-QuILT* (58%) for self-reporting pain compared with alternative methods such as the *McGill Pain Questionnaire* (16%), *Brief Pain Inventory* (14%), or verbal communication (12%). High levels of agreement were found between the pain quality words chosen on the *McGill Pain Questionnaire* and the icons in the *Pain-QuILT* library, providing further evidence of validity. Moderate-to-high correlations in pain intensity scores were found between the *Pain-QuILT* (calculated average across all painful body sites) and the *Brief Pain Inventory* (single numerical rating scale), providing support for convergent validity.

These direct comparisons of the *Pain-QuILT* with currently used verbal and paper-based methods of sensory pain assessment were pivotal for evaluating user

preferences related to adoption of a digital sensory pain mapping tool, and for demonstrating early evidence of validity.

(7): *Evaluated clinical feasibility in adult and pediatric chronic pain settings.*

Clinical feasibility testing of the *Pain-QUILT* was carried out in pediatric (see Chapter 4) and adult (see Chapter 5) chronic pain settings. Data indicated that, on average, the *Pain-QUILT* can be completed in less than 5 minutes by both adolescents and adults. Health team participants indicated that using the *Pain-QUILT* could potentially improve the efficiency of the pain assessment portion of clinic appointments by capturing a detailed visual summary of sensory pain. In addition, minor and surmountable barriers to implementation were identified, such as technology requirements, providing a private space for patients to complete the tool, and adjusting clinic workflow to accommodate use of the *Pain-QUILT*.

(8): *Designed and incorporated a method for storing and tracking pain data.*

Since the management of chronic pain is a long-term process that requires the consistent and repeated assessment of pain, it was essential to include a ‘back-end’ storage and tracking mechanism in the *Pain-QUILT*. Unlike paper questionnaires or verbal interview methods, which are often administered by a clinician and must be manually transcribed into a computer, the *Pain-QUILT* data are entered directly by the patient in a digital format. As pain data are entered into the ‘front-end’ interface, they are automatically time-stamped and populated to an online database. The database is accessible to the research team with a username and password, and can be used to

monitor pain quality and intensity parameters across different body locations over time.

6.3 Revisiting the hypothesis

The research project reported in this thesis was designed to investigate the usefulness of an icon-based digital mapping approach to sensory pain assessment, to iteratively develop a prototype mapping tool to promote usability, to evaluate various stages in this digital development process, to compare a refined digital tool, the *Pain-QUILT*, with current standard tools used in clinical practice, and to provide emerging evidence of psychometric properties (content and convergent validity).

Research to date supports the hypothesis that users of pain assessment tools will tend to favour a digital icon-based sensory pain mapping tool (*'Pain-QUILT'*) over currently available sensory pain assessment tools.

6.4 Reflections on completed research

This project has benefited immensely from the involvement of users (people with pain, healthcare professionals) in all stages of developing, evaluating, and refining the *Pain-QUILT* [65]. The research process included a community-based group of adults with chronic pain as well as clinical groups of adults and adolescents under treatment for chronic pain. Results were consistent between these groups in terms of the high usability and perceived value of the tool for expressing and documenting sensory pain.

Iterative user feedback has been used to inform progressive development of the

Pain-QuILT in terms of both design and functionality (see version screenshots in Chapter 1, Section 7). New developments in technology were also leveraged to enhance the *Pain-QuILT* based on identified user needs, such as a codified body manikin linked to an online database.

A similar user-centered design approach has been used successfully in the development of other digital health tools, such as the “*Bant*” diabetes self-management smartphone application [78].

6.5 Limitations of completed research

As a digital pain mapping tool, the *Pain-QuILT* is designed to assess multiple components of the sensory pain experience (i.e. quality, intensity, location). However, pain is a multidimensional construct that also includes affective-motivational and cognitive-evaluative dimensions [2]. Therefore, a comprehensive clinical assessment of chronic pain requires a consideration of sensory pain in the context of other important factors, such as the impact of pain on physical, emotional, role, and social functioning; exacerbating and alleviating factors; and pain-related disability [79]. Given that the scope of the *Pain-QuILT* is restricted to the assessment of sensory pain, it must necessarily be considered as just one component of a complete clinical assessment.

Studies to date have evaluated the *Pain-QuILT* as a single point-of-care assessment of sensory pain in pediatric and adult clinic settings. As a digital tool with a backend database to store and track captured data, the *Pain-QuILT* has the capacity to

be used by clinicians to help monitor changes in sensory pain over the trajectory of disease management. However, given that a longitudinal study has not been conducted, the enduring clinical performance of the tool in terms of factors such as number of completed administrations over multiple appointments, reasons for non-administration, and user preferences over time is not known.

To date, the *Pain-QUILT* has been directly compared with some of the most common methods used for clinical pain assessment, which are designed for paper or verbal administration. However, the *Pain-QUILT* has not yet been directly compared with an existing digital pain assessment tool.

Both clinical feasibility studies (see Chapters 4 and 5) were completed at single pain management centres for adults and adolescents, respectively. The *Pain-QUILT* was administered in the context of research studies, and therefore was only exposed to patients who chose to participate in the studies. Adoption of the *Pain-QUILT* into routine assessment protocol is needed to determine its usefulness across the complete roster of clinic patients. Furthermore, while the workflow structure of many chronic pain clinics may be similar, we recognize that uptake of the *Pain-QUILT* beyond the sites where it has already been evaluated will require consideration of centre-specific needs.

Related to the idea of clinical implementation, the current iteration of the *Pain-QUILT* (Version 3) is a distinct web-based application, built on an *Adobe Flex®* platform. It is not integrated with any existing electronic health record system. However, given

that the sensory pain data collected by the *Pain-QuILT* needs to be considered in the context of other clinical health information, it is likely that such integration would be needed to promote uptake of the tool.

Research to date has provided emerging evidence in support of the psychometric properties of the *Pain-QuILT*. Specifically, studies have evaluated face and content validity, convergent construct validity, and clinical feasibility. However, the completed work has not evaluated responsiveness (i.e. ability to detect clinically meaningful change over time) [80] or reliability (i.e. reproducibility over different occasions while minimizing sources of measurement error) [81] of the information captured by the *Pain-QuILT*.

6.6 Implications for clinical practice and research

Chronic pain is best treated within the context of a biopsychosocial model that encompasses biological, environmental, and cognitive-behavioural components [14,82]. Within this larger disease management framework, it is envisioned that the *Pain-QuILT* has potential to: (1) empower adults and adolescents with chronic pain to clearly communicate the nature of their sensory pain with health care providers, and (2) provide clinicians with detailed sensory pain data.

By contributing information about sensory pain to the structure of a complete pain assessment, the *Pain-QuILT* may help to inform the clinical management of chronic pain. For example, clinicians could use the *Pain-QuILT* to determine whether their

patients perceive certain pain qualities to be more or less distressing, or whether particular pain locations are associated with a greater impact on function. This information may be used to guide specific pain management strategies, including physical, pharmacological, and psychological approaches; and to potentially evaluate their effectiveness over time [14].

The web-based and user-friendly design of the *Pain-QuiLT* may also provide a valuable addition to clinical research studies that seek to evaluate sensory pain in adolescent and adult groups.

6.7 Knowledge translation and the completed research

While the prototype tool (Version 1) was published on the author's personal website [83] and described in a peer-reviewed publication [61], it was not otherwise disseminated to promote uptake by the research and clinical communities. In order to address this gap in dissemination, we have used multiple strategies to promote awareness and uptake of the *Pain-QuiLT*.

To reach the scientific community, in addition to four peer-reviewed publications, the *Pain-QuiLT* research has been presented at seven national and five international pain-related conferences. Studies to date have also been conducted in large multidisciplinary pain treatment centres, which has exposed the *Pain-QuiLT* to a variety of pain clinicians. It is anticipated that this early engagement of clinicians in the process of developing and testing the *Pain-QuiLT* may promote later uptake. Engagement of

potential users has also been promoted by participating in ‘pitch competitions’, such as “*LiON’s LAIR*” [84], and the “*Synapse Life Science Competition*” [85].

Engagement of lay community members who live with chronic pain has also been sought by presenting at public education forums, chronic pain support groups, and events such as the university-wide “*3-Minute Thesis*” competition [86]. A website (<http://painquilt.mcmaster.ca>) and Twitter account (@PainQuILT) has been launched to publicly share the tool.

6.8 Future research pathways

There are great possibilities for a future research program built around the *Pain-QuILT* platform:

First, while the work to date has focused on English-speaking groups, the visual design and minimal text associated with the tool may offer a valuable template for translation into multiple languages. Such translations would also offer opportunities to formally assess how individuals from different language groups negotiate meaning with the pain iconography, and could potentially result in the development of a commonly accepted visual language for sensory pain.

Second, given that the *Pain-QuILT* allows users to express their sensory pain in a non-verbal manner, the tool may be evaluated in individuals with impaired verbal communication abilities, in concert with the existing battery of available observational

and behavioural pain assessment tools [87].

Third, while body manikins comprise one component of existing pediatric multi-component pain tools (see 2.5.2b), to our knowledge, the concept of digital sensory pain mapping using iconography has not been tested in individuals under the age of 12. It is anticipated that iterative evaluation of the tool in these younger individuals may dictate the need for a simplification of the pain iconography, pain intensity scale, and/or the digital body manikin based on developmental level of the user.

Fourth, given that pain maps have been used successfully to help older adults communicate their pain [88], the icon-based approach of the *Pain-QUILT* should also be evaluated for usefulness and patterns of use [89] in this group. The assessment of sensory pain in older adults is particularly important given that the prevalence of chronic pain increases substantially with advancing age [90].

Fifth, it would be valuable to directly compare the *Pain-QUILT* with other digital methods of pain mapping, such as the *MacInterview* [60], *PAINReportIt* [55], and 3D pain mapping tool [48]. For instance, the *MacInterview* [60] includes a dynamic ‘throb’ scale, where selected pain symbols visually pulse at different rates. This use of animation could be compared with the ‘drag-and-drop’ functionality of the *Pain-QUILT* in terms of user preference and clinical value. The *PAINReportIt* is administered on a touch screen device, which may be contrasted with the computer and mouse-based administration of the *Pain-QUILT* [55]. The 3D pain mapping tool of Jamison and

colleagues permits users to document information about the depth of their pain, which could be compared with the regionalized 2D mapping of the *Pain-QUILT* [48].

There is also a growing number of smartphone-based pain diary applications ('apps'), which could be tested alongside the *Pain-QUILT* [91,92]. A 2014 review of commercially available apps in the *Apple*®, *Android*®, *Windows*®, and *BlackBerry*® online stores identified 31 apps with a pain diary component [93]. While most of these apps include a digital body manikin to document pain location, not one app uses an icon-based approach to pain mapping. Additionally, no available app allows users to document multiple qualities and intensities of pain across multiple body locations. To date, these available pain apps have also not been evaluated for usefulness in a clinical setting to assess chronic pain.

Overall, these side-by-side comparisons would provide evidence to inform the potential refinement of *Pain-QUILT* features, while maintaining high levels of usability and clinical usefulness. This comparative work could also help to tease out the influence of technology on patient preferences for methods of expressing their pain, and further improve the functionality offered by the *Pain-QUILT* or other digital approach.

Sixth, while the web-based design of the *Pain-QUILT* offers high accessibility and potential for use as an electronic pain diary, studies to date have not evaluated the tool in this context. Electronic pain diaries have been used successfully in adult [52] and pediatric [94][95] chronic pain groups. However, the performance and usefulness of the

Pain-QuILT as an e-diary are unknown.

Seventh, while research to date has focused on a broad group of adolescents and adults with chronic pain, the tool could also be adapted for individuals with acute pain conditions, such as a measure for monitoring the trajectory of post-surgical pain [96][97]. Given that pain is one of the most common presenting symptoms in emergency departments [98], the *Pain-QuILT* could also be used as one component of patient assessment in this setting.

Eighth, although the current iteration of the *Pain-QuILT* is designed to comprehensively capture information about the sensory dimension of pain, the platform could potentially be expanded to assess affective and evaluative dimensions of pain. A particular challenge with this endeavour would be to maintain the visual and intuitive interface design while incorporating additional parameters into the tool.

Ninth, the *Pain-QuILT* software is *Adobe Flash*®-based. While appropriate for use on a computer, this software is incompatible with the majority of mobile (smartphone, tablet) devices. To meet this technical need, an HTML-5 version of the *Pain-QuILT* is being developed that will be optimized for use across all smartphone (e.g. *iPhone*®, *Android*®) and tablet (e.g. *iPad*®) devices, as well as web-based platforms. It is anticipated that this beta ‘app’ will be useful for long-term patient monitoring, as well as to correlate *Pain-QuILT* data on sensory pain with specific functional outcomes.

6.9 Concluding Remarks

Within the rich historical context of clinical sensory pain assessment, our research has positioned the *Pain-QUILT* as an important evolutionary step in the field of digital sensory pain mapping. Collectively, through the individual studies presented in this thesis, we have affirmed that digital icon-based pain mapping is a viable solution to the clinical challenge of sensory pain assessment in adolescents and adults with chronic pain. Looking forward, we believe that the *Pain-QUILT* shows great promise as a means of improving our portrayal and understanding of sensory pain, and has potential to be included as a standard element in the process of chronic pain management.

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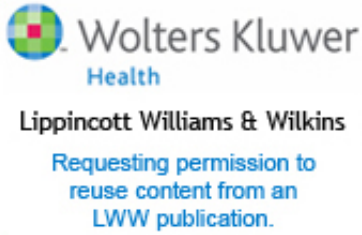
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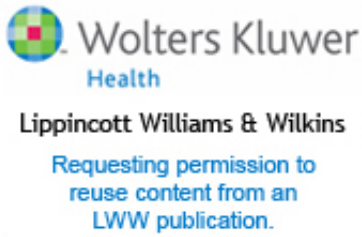
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