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Pain-QuILT: A user-friendly tool for the self-report and tracking of pain

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http://app.painquilt.com

Overview

Pain-QuILT is a web-accessible and mobile-accessible tool for the visual self-report and tracking of pain symptoms. It is intended for adolescents (aged $\geq$ 12 years) and adults living with chronic pain, and the clinicians who treat them. QuILT is an acronym for the different sensory parameters associated with the pain experiences that are captured by the tool—**qu**ality, **i**ntensity, and **l**ocation—in a digital format that can be **t**racked over time. *Pain-QuILT* was developed and evaluated through PhD research[1] at McMaster University (Hamilton, Ontario, Canada) through a user-centred approach involving patients and clinicians.

Clinical use

Pain-QuILT is designed to allow patients to report different qualities and intensities of current pain across their entire body. Patients can choose relevant icons to describe their pain intensity and quality, and then map this information onto a virtual body manikin to show pain location. Pain intensity is reported using body site-specific ratings on a 0 to 10 numerical rating scale ranging from 'no pain' to 'worst pain'. Pain quality is captured through a library of simple icons to describe different types of pain, such as a 'matchstick' for burning-type pain and a 'hammer' for pounding-type pain. The virtual manikin is divided into over 100 regions, including major joints. Patients can indicate pain in more than one body region. For example, a patient could record a '3/10' dull pain in their shoulder and a '5/10' knee pain that is both 'stiff' and 'aching'. The *Pain-QuILT* app also allows patients to describe the degree of pain interference using 0 to 10 numerical rating scales for general activity, mood, walking ability, work, relationships, sleep, and enjoyment of life. On average it takes patients less than 5 minutes to enter their data on any given day. Since *Pain-QuILT* is built as an HTML5 app, it is platform-agnostic and accessible on any device (eg, computer, tablet, smartphone) that can connect to the Internet.

All information is digitally captured in time-stamped and date-stamped pain records within the app. There are tools within the app that are useful for clinical management, such as the capacity to generate simple graphs for a patient or their clinician to track their pain trends over time. Other tools allow patients' pain records to be shared with clinicians. For example, a physiotherapist who has been granted access to a patient's *Pain-QuILT* account is able to view the pain records and also download data as a comma-separated values (CSV) file for further analysis.

Development and testing

Pain-QuILT has evidence of high patient acceptability, usability, and clinical feasibility as well as emerging evidence of construct validity. In an initial study[2] involving a community-based sample (n = 23) of adults with chronic pain, participants perceived the tool as acceptable and valuable for communicating their pain. For example, one participant stated: . . . *it is a very clear, concrete way to show the doctor and helps with the memory – or lack of it*. Following improvements to the tool based on early user feedback, *Pain-QuILT* has since been evaluated in a sample (n = 30) of adolescents (aged 12 to 18 years) and adults with arthritis pain.[3] Participants took part in semi-structured interviews to evaluate the usability and content validity of the tool. Overall, it was reported to be: easy to use and understand; well liked; quick to complete; and potentially valuable for communicating arthritis pain with clinicians. All icons met a priori criteria in terms of: concreteness (object representativeness, eg, how well an icon represents a 'matchstick'); semantic distance (concept representativeness, eg, how well an icon represents 'burning-type pain'); and satisfaction for describing pain (eg, how well an icon describes their own 'burning-type pain'). Participants valued the simplicity of the tool; for example, an adult participant stated: *There's not a lot of reading. There's not a lot of mumbo jumbo there. It's all straightforward* (p. 260). Some participants also noted that using the tool may help them to more accurately report their pain; for example, an adolescent participant stated: . . . *when you're by yourself [at the computer], 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 report] to look at* (p. 261).

Subsequent studies have focused on clinical feasibility and construct validity of *Pain-QuILT* within paediatric and adult settings. In a study[4] conducted at a tertiary care paediatric chronic pain clinic, adolescent participants (n = 17) reported their pain using both *Pain-QuILT* and the clinic standard (verbal semi-structured interview) in a randomised order. Overall, 88% of adolescents preferred using *Pain-QuILT* to self-report their pain. Reasons for this preference included having a sense of ownership over creating their own pain record, ease of use, clarity of communication, and novelty. Scores on *Pain-QuILT* correlated as expected with the comparator tool, providing evidence of convergent construct validity. Focus group interviews were conducted with the clinic team (n = 9), including representatives from anaesthesiology, nursing, physiotherapy, psychology, psychiatry, and administration. The team characterised the tool as useful for triggering conversations about pain with their patients. They also reported value in empowering patients to independently enter their pain reports. For example, one clinician stated: *it might be more objective* . . . *because it's one they've plugged in. It's not from us* . . . *telling them what they said last time*. The health team also identified potential barriers to clinical implementation, including: technology requirements (internet-enabled device in clinic) and adjusting workflow to accommodate completion of *Pain-QuILT*. The clinic team characterised these barriers as surmountable.

Patients' preferences of using *Pain-QuILT* compared with the paper-based McGill Pain Questionnaire (MPQ) and Brief Pain Inventory (BPI) have been evaluated in adults with chronic pain.[5] *Pain-QuILT* was rated as significantly easier to use than the other tools. Scores on Pain-QuILT correlated well with the other tools, providing evidence of convergent construct validity.

The tool is currently being translated into French. Next steps include targeted evaluations in young children (< 12 years) and older adults (> 65 years).

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