Amélioration de l'évaluation de la douleur pédiatrique chronique : Potentiel des carnets électroniques

On déplore les lacunes méthodologiques inhérentes aux méthodes actuelles d'évaluation de la douleur chronique chez les enfants. Des approches axées sur la saisie des données en temps réel à l'aide de carnets électroniques ont été proposées comme nouvelle norme pour l'évaluation de la douleur. Toutefois, on dispose de peu de données sur le développement, la faisabilité et la validité de ces approches chez les enfants. Le présent article passe en revue les difficultés propres aux mesures actuelles, le bien-fondé des nouvelles approches pour la collecte des données en temps réel à l'aide de carnets électroniques d'évaluation de la douleur, la logistique de leur mise au point, les données actuelles sur leur accessibilité, leur faisabilité et leur validité et il propose en outre certaines pistes pour la recherche future dans ce domaine.

CURRENT METHODS FOR ASSESSING CHRONIC PAIN IN CHILDREN

Although a plethora of validated, single-item, self-report pain intensity measures exist for children with acute and chronic pain (9), only three multidimensional measures have been validated for chronic pain in children: the Pediatric Pain Questionnaire (10), the Pediatric Pain Assessment Tool (11) and the Adolescent Pediatric Pain Tool (12). These measures vary greatly in terms of their established reliability and validity, complete a diary entry. For these reasons, electronic pain diaries that use methods for RTDC have been proposed as a new standard for measurement of chronic pain because they circumvent many of these problems (5).

Although electronic diaries are becoming more prevalent, there is very little known about their use in children (8). Electronic diaries need to be comprehensively studied with children, giving particular consideration to how developmental issues (eg, age and stage of development) influence the validity of results, and the usability (intuitiveness of user interface) and feasibility (ie, compliance and acceptability) of this method in pediatric populations. The purpose of the present paper is to review current problems with assessment of chronic pain in children; discuss the rationale for and mechanics of RTDC approaches to assessing chronic pain; review the literature on electronic pain diaries for children and youth; and discuss future research directions for improving assessment of chronic pain in children using electronic pain diaries.
evidence of sensitivity (ie, ability to detect change) and responsiveness (ie, ability to detect clinically important change) and comprehensive inclusion of the dimensions of pain (9). The most notable shortcomings of these measures are that they elicit a static single index of perceived pain intensity, rely on recall (eg, averaging and summarizing ratings over the past week) and do not allow for prospective longitudinal assessment in children’s everyday environments (eg, home and school).

Single measures of pain intensity are inappropriate for chronic pain measurement because the resulting index of perceived pain is limited to one point in time. This approach fails to capture the dynamic nature of pain and its impact on all aspects of functioning. For example, reports of pain in children with arthritis appear to change over time, including during the course of a day; children often report worst pain in the morning due to joint stiffness (4). Also, a variety of environmental factors (eg, setting and person eliciting self-report) may influence pain intensity ratings obtained from children at a single point in time. Furthermore, reliance of measures on global and retrospective reports of average pain over a specified time period is problematic because single measures of recalled average or usual pain have been found to be less valid indicators of average pain than measures that incorporate a number of daily pain ratings (4,13).

Children with chronic pain are most often asked to recall their pain over protracted periods of time (eg, one week, two weeks or one month) in both clinical and research contexts. This measurement approach may lead to recall bias. The cognitive demands of indicating how much one hurts ‘now’ are less complex than the process of recalling average pain over many hours, days or weeks. Each step of the recall process has the potential to introduce significant error and distortion into recalled data (14,15). Also, the recall process may be influenced by the cognitive development of the child, as well as other physical, psychosocial and behavioural factors (15).

Furthermore, while patients’ self-reports of pain are the accepted standard in clinical and research practice, we do not fully understand what patients’ ratings mean and how they are derived. For example, we often ask children and adolescents to provide an estimate of their average or usual pain intensity over the past week. However, it is unclear how patients interpret this question. Do patients interpret this as a request for information about their pain intensity, frequency of pain, pain at rest or with activities, their ability to cope with pain, the impact of pain on aspects of everyday life (such as school) and ability to socialize with peers, or a combination of these? Several studies in adults with chronic pain have shown that patients construct their responses to these types of questions in complex and idiosyncratic ways (16,17). Thus, this seemingly simple task of asking children to recall their average pain over the past week is a deceptive, complex phenomenon.

In summary, single measures of recalled pain fail to capture the dynamic nature of pain and its influence on aspects of everyday life. More importantly, they can introduce systematic and random error into measurement results due to the effects of recall bias (5,14). Measures that include multiple prospective assessments of pain may be more sensitive than periodic single measures for assessing the subtle, day-to-day changes that would be expected following treatment intervention. Furthermore, growing interest by clinicians and researchers in moment-to-moment correlations among pain intensity and other variables give impetus for developing repeated, simple and comprehensive measures for assessing chronic pain in children using prospective RTDC diary methods.

RTDC APPROACHES

RTDC is a family of techniques that are used to collect data about an experience as it naturally unfolds in a person’s life. Individuals are asked to report how they feel at a particular moment in time. These methods differ from traditional methods of assessment in that they are based on sampling moments from peoples’ lives to more precisely capture the variability of the pain experience and reduce memory and other biases associated with recall of such experiences (5). RTDC approaches assess particular events in subjects’ lives or assess subjects at periodic intervals, often by random time sampling, using technologies ranging from written diaries and telephones, to electronic diaries and physiological sensors.

Rationale for using RTDC approaches

There are several qualities of RTDC approaches (ie, paper and electronic diaries) that make them ideally suited for the assessment of chronic pain in children. First, these approaches involve real-time data collection about momentary or near-immediate states. This feature prevents retrospective distortion of data (recall bias) and maximizes the validity of subjective reports. Researchers have shown that reports of recalled pain are influenced by a phenomenon referred to as the peak-end effect. This occurs when the most salient or intense experiences, and those that occur nearer to the time of reporting, have an especially strong influence on recalled pain. In addition, individuals tend to ignore periods of no pain, which has been referred to as duration neglect (5,18). Therefore, these and other memory processes tend to distort reports of recalled pain (18).

The second quality is that RTDC approaches allow for the investigation of within-person associations (19). RTDC typically involves sampling multiple momentary assessments per day and across days. Collecting multiple data points enables the researcher to examine changes in patient experience and the pain phenomena over time. For example, questions about pain at time 1 can be used to predict pain experiences at time 2 and so on, using time series or cross-lagged panel analyses (5). Burton et al (19) conducted a systematic review of electronic diaries as a tool for investigating associations between physical symptoms and psychological variables. They classified electronic diaries into five categories to investigate associations including experience (recording data when symptoms were present), interaction (testing relationships between variables at different levels), sequential (observing associations at different time lags), process (recording possible mediating constructs such as catastrophizing) and intervention (recording during treatment to identify trends) (19). When relations between variables are analyzed within subjects over time using RTDC approaches (paper or electronic diaries), researchers can make strong conclusions regarding study results.

The third quality is that RTDC approaches allow for higher resolution of treatment response because they enable the collection of many assessments over time. Clinical pain trials involve...
Mechanics of RTDC approaches

One of the first considerations in designing a study using a RTDC approach to assess pain is to develop a sampling scheme that adequately represents the domain of the experience being studied (14). General sampling approaches include interval-, signal- and event-contingent approaches. Interval-contingent assessment involves the completion of assessments at preselected times of the day (eg, morning, afternoon and evening) or across days (eg, end-of-day ratings). Limitations of this approach are that assessments may not be representative of the participant's day, an inflexible schedule may result in poor participant compliance and the timing of assessments can be anticipated by the participant, which may lead to certain response biases. Signal-contingent recordings involve using a prompting device (eg, pager or PDA) that emits a signal at a prespecified or random intervals to alert the respondent to make a recording about their immediate experience. However, this approach may result in important episodes being missed and frequent random prompting may increase response burden. Event-contingent assessments are those completed when a particular event occurs (eg, migraine). This method requires participant vigilance in the constant monitoring of specific events, as well as compliance with the simultaneous recording of events and participant responses. Consequently, it is often impossible to determine the validity of the report (14,23). Decisions regarding the sampling design should ultimately be based on the principles of representative sampling and nature of the pain problem being examined (eg, is the pain constant or does it fluctuate within and across days?) (23).

The second consideration when designing a RTDC study is the frequency and duration of self-monitoring. There is no simple answer to how many samples per day should be obtained or for how long (24). Jensen and McFarland (13) found that the most reliable and valid estimates of average weekly pain were obtained from a composite pain intensity score calculated from an average of 12 ratings across four days. Similarly, we found that 12 ratings across four days provided valid estimates of average weekly pain in youth with arthritis (4). Increasing the number of measurements per day increases the temporal resolution and statistical reliability of the data. Increasing the number of days that measurements are made may increase the generalizability of data and allow for observation of a greater range of responses. However, these advantages need to be weighed against the disadvantages of increasing participant burden and potentially reducing participant compliance (5,25). Although compliance results of electronic diaries are reportedly superior to those of paper diaries (6,20), frequent monitoring may still be burdensome for participants (25,26). Compliance is one of the most crucial components to the successful execution of RTDC methods; therefore, it is important to consider the number of daily entries and duration of recording while minimizing the response burden of children with chronic pain.

The third consideration when designing a RTDC study is the actual method used by participants to record their responses. In most RTDC studies, researchers collected data using paper diaries. Even when a 'high-tech' device (eg, wristwatch or
puterized technologies than adults (27). Generally more familiar with and confident in the use of computer for summary, review and analysis (5,23). PDA pain diaries may also provide children with a means to easily and conveniently access and, therefore, rely heavily on time-contingent schedules (ie, end-of-day reporting).

ELECTRONIC PAIN DIARIES

The development of PDA technologies offers new possibilities for the measurement of chronic pain in children. PDAs are small, portable devices that are capable of presenting text and/or graphics to subjects, recording and electronically storing subjects’ responses, and transmitting stored data to a computer to be analyzed (22). Electronic diaries have been used with patients of all ages, including children as young as six years of age and adolescents, for the measurement of a wide variety of symptoms and behaviours (8). However, to date, research studies evaluating electronic pain diaries have primarily been conducted in adults with chronic pain (5).

Advantages and disadvantages of electronic pain diaries

Advances in PDA technologies have allowed researchers to implement electronic RTDC pain protocols. Using programmable PDAs has many advantages, including built-in reminder signals and programmable alarm functions to prompt the individual at predefined intervals; reliable time and duration stamping of entries to track participant compliance; flexible question layout and response categories; design of question branches and tailor-made sequential or hierarchical strategies; concealment of previously recorded responses from subjects; prevention of backfilling or entry of invalid responses; and convenience and ease of data transfer to a stationary personal computer for summary, review and analysis (5,23). PDA pain diaries may also provide children with a means to easily and honestly express their pain. Furthermore, electronic pain diaries hold particular promise for use in children because they are generally more familiar with and confident in the use of computerized technologies than adults (27).

Despite the advantages of using PDAs or mobile telephones to implement RTDC protocols, there are also limitations. Substantial financial commitment is required to conduct RTDC studies that use the highest level of technological innovation. The price of PDAs and cell phones exceeds the cost of written methods, but is not unreasonably high in light of the flexibility of data acquisition, high technical reliability and exact timing provided by PDA technology (23). PDAs also require user training; however, children often require less training than adults because they tend to have more familiarity and competence with computerized technologies (25). Finally, RTDC methods can place a significant burden on both investigators and research participants; the programming and development are costly to implement, require high levels of technical skill and are labour-intensive. Moreover, the sheer volume of data and its complexity can pose significant logistical and analytical challenges to investigators (23,25). RTDC methods also demand significant effort and cooperation from participants, and may not be suitable for those with cognitive, sensory or motor impairments (25).

While electronic diaries have been found to outperform written diaries in terms of compliance, data accuracy and subject acceptability (5), technical malfunction is one of the main disadvantages of the PDA-based RTDC methods. Dale and Hagen (28) conducted a systematic review of nine randomized and quasi-randomized controlled trials comparing electronic and written diaries in terms of feasibility, compliance, data accuracy and acceptability. Five studies reported on feasibility, and all reported technical difficulties with PDA technology. For example, in Palermo et al’s study (20), 14% of the PDAs stopped working because of technical problems, with all data being lost and/or unusable. The authors also reported several power failures with the units and other PDA malfunctions. Furthermore, one unit was damaged, three stylus pens were broken or lost, and two of the AC adapters needed to be replaced (20). Mechanisms need to be in place to ensure regular backup of data, that batteries are adequately charged and technical problems can be resolved quickly when they occur (24 h support). For these reasons, it is crucial to undertake formal usability and feasibility testing of RTDC electronic diaries to uncover these technical difficulties before implementing them in research or clinical practice.

LITERATURE ON THE USE OF ELECTRONIC PAIN DIARIES IN CHILDREN

The use of electronic diaries for pain assessment in children is relatively new and there is little existing related research. Walker and Sorrells (29) were the first researchers to evaluate the use of an electronic diary for the assessment of daily gastrointestinal (GI) symptoms and function in children in a small pilot study. Eleven parent-child (six to 10 years of age) dyads referred to a tertiary care centre for evaluation of constipation and abdominal pain were provided with hand-held computers and modems. They completed end-of-day diary entries for a seven-day period. They were asked to respond to questions as a team regarding the level of the children’s GI symptoms and the extent to which symptoms interfered with the day’s activities. On completion of the diary use period, parents responded to a telephone interview evaluating the procedure. Parents reported that the children understood most of the questions and that the responses entered were accurate. Parents and children were enthusiastic about the data collection method. However, some technical problems arose with the units (ie, trouble logging in, modem and PDA malfunctions, dead batteries or lost units). This study provided the first evidence that this method demonstrated promise in evaluating pain in children with GI problems.

Palermo et al (20) compared the compliance, accuracy and acceptability of multidimensional electronic and paper pain

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diaries in 60 children, eight to 16 years of age, who had recurrent (ie, headaches) and chronic (ie, juvenile idiopathic arthritis [JIA]) pain. Children were randomly assigned to use either a PDA pain diary that was administered via a home visit or a paper diary that was administered during a regularly scheduled clinic visit. The diaries were designed to capture pain occurrence (ie, morning, afternoon and evening), location and intensity ratings using a faces pain scale; distress ratings (ie, emotional upset) using a five-point adjective scale; occurrence of other somatic symptoms; and activity limitations. Compliance was significantly higher in children who used the electronic diary (83%) than those who used the paper diary (47%). Age, ethnicity and baseline pain severity and frequency did not influence compliance rates, although boys were significantly more compliant with the electronic diary than the paper diary. Paper diary entries had significantly more errors and omissions than those in the electronic diaries. While only one-half of the sample completed the acceptability questionnaire, children found the electronic diary easy to use, efficient and accurate. A significant methodological limitation was that the diary protocols were markedly different and the children receiving the electronic diaries had more contact with the researchers throughout the course of the study, which may have affected their compliance and acceptability ratings.

We recently developed a multidimensional electronic pain diary using a phased approach (4,30,31). First, the prototype was developed and the usability was tested in adolescents with JIA (30). A qualitative usability testing approach with semistructured, audiotaped interviews with two iterative cycles was used. A purposive sample of 10 adolescents per cycle was drawn from a rheumatology clinic in a university-affiliated pediatric tertiary care centre. Participants were provided with a brief demonstration of the electronic diary and then asked to use the diary while ‘thinking aloud’ to record the pain they experienced when they woke up that morning, during that afternoon and from the previous evening. Adolescents were then asked a series of open-ended questions addressing ease of use of the diary. Qualitative thematic analysis was used to generate categories and emerging themes from interview data. All of the adolescents stated that the e-Ouch diary was very easy to learn, use and understand, and was satisfying to complete. Participants took less than 9 min to complete all three of the diary entries with minimal errors. The usability evaluation revealed aspects of the interface that were suboptimal (eg, VAS slider) and impeded the performance of certain tasks. Adolescents generated ideas on how the diary interface could be improved. A multifaceted usability approach provided important insight regarding the use of technology by adolescents with arthritis and, more specifically, for understanding how adolescents can more effectively use an electronic chronic pain diary (30).

In the next phase, the e-Ouch multidimensional electronic pain diary was pilot tested in terms of compliance and acceptability in adolescents with arthritis (31). Two iterative phases in a descriptive study design were used. A purposive sample of 13 adolescents with mild to severe pain and disability was drawn from a large rheumatology clinic in a university-affiliated pediatric tertiary care centre in Canada over a four-week period in December 2004. Participants were signalled with an alarm to use the diary three times per day for a two-week period. Adolescents also completed an electronic diary acceptability questionnaire. Overall mean compliance for phases 1 and 2 was 72.9% and 70.5%, respectively. Compliance was affected by the timing of data collection and technical difficulties. Children rated the diary as highly acceptable and easy to use. Phase 1 testing revealed aspects of the software program that affected compliance, which were subsequently altered and tested in phase 2. No further changes were made following phase 2 testing. Pilot testing was the crucial first step in facilitating the future evaluation of the construct validity and feasibility of this measure in children with chronic arthritis (31).

We then conducted two descriptive studies to evaluate the construct validity and feasibility of the e-Ouch electronic pain diary in adolescents with JIA (4). Participants were drawn from a large metropolitan rheumatology clinic in a university-affiliated pediatric tertiary care centre. In study 1, 76 adolescents with active arthritis recorded their pain three times a day for two weeks using the e-Ouch. In study 2, 36 adolescents recorded their pain three times a day for one week before and two weeks after joint injections. Adolescents in both studies completed multiple measures to determine the construct validity and feasibility of the e-Ouch. Adolescents reported mild levels of pain intensity, unpleasantness and interference, as well as stiffness and mild to moderate levels of fatigue. e-Ouch average weekly pain unpleasantness and interference scores were higher in adolescents with higher pain intensity scores. Correlations among average weekly pain ratings on the e-Ouch and scores from recalled least, average and worst weekly pain; health-related quality of life and pain coping; and disease activity were as predicted. Pain ratings were significantly lower following joint injections, with effect sizes in the low to moderate and moderate to high ranges at the first and second week postinjection, respectively. To our knowledge, this was the first study to evaluate the construct validity of an electronic pain diary in adolescents with JIA (4).

**FUTURE RESEARCH**

While holding great promise, there are many challenges with RTDC approaches that need to be addressed before their potential is fully recognized. Future research is needed to determine the optimal number of items (eg, five to 20 questions) and the time to complete electronic diary entries (eg, brief; taking less than 5 min to complete), schedule for use with children and youth to avoid interference with school (eg, preset times tailored to participants’ schedules), modes of data entry (VAS, versus word-based entry, graphic icons for word descriptors, or body outlines where patients can shade percentage body area in pain or rate pain intensity in various painful body locations) and amount of training and support required to enhance acceptability and compliance with this measurement approach. Research is also needed to explore the issue of reactivity with RTDC electronic diaries in children. Finally, electronic pain diaries using RTDC approaches need to be tested to determine their usability, feasibility and psychometric properties in children and youth.

Future research is also warranted to explore how we can meld RTDC electronic diary approaches with proactive advice. An example of this would be incorporating decision-making
support systems into the diaries and/or integrating them into electronic health interventions (eg, a patient would receive a prompt on a PDA or cell phone to take some therapeutic actions if pain exceeded some predetermined threshold). Sorbi et al (32) recently reported on a mobile Web-based monitoring and coaching program for adults with migraines. Adults were asked to record their pain on electronic handheld pain diaries and received Internet-based coaching and health information on managing migraines. Clearly, this is a burgeoning area of research that extends beyond electronic diaries to include other electronic health technologies, such as the Internet and cell phones (for short message service and/or text messaging). These are the types of interventions that need to be further explored to see whether they can assist youth with chronic pain in being engaged in self-care during the difficult period of adolescence and transition to adulthood.

REFERENCES


CONCLUSION

RTDC methods hold significant promise for clinical practice and research on chronic pain in children due to the primary importance of self-report methods of pain assessment and the inherent limitations of retrospective self-report. Moreover, there are numerous limitations for using the traditional methods of questionnaires and paper diaries to obtain RTDC data. For these reasons, PDA technologies for facilitating RTDC make electronic methods increasingly powerful and practical for research and clinical care in children. Future research in this area will enable clinicians and researchers to better understand the chronic pain experience of children, and more optimally treat it.

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