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RESEARCH ARTICLE

Self-Reporting Tool On Pain in People with Intellectual Disabilities (STOP-ID!): A Usability Study

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ABSTRACT

The use of the Self-reporting Tool On Pain in people with Intellectual Disabilities (STOP-ID!), an online application developed by the authors to aid in the self-reporting of pain, was evaluated in 40 adults with Down syndrome. Comprehension of the use of the tool (the ability to recognize representations for vocabulary and pain, and to navigate the tool interface), and the use of the tool to self-report pain experience, were investigated. The use of the online tool was investigated with both a laptop and a tablet computer in a crossover design. The results provide evidence that more participants recognized representations of pain location and pain affect than representations of pain intensity and pain quality. A small percentage of participants demonstrated the ability to recognize all of the representations of vocabulary items and to navigate the tool without assistance (18% laptop, 18% tablet). Half of the participants were able to report at least one pain component of a current or remembered pain experience without assistance (50% laptop, 53% tablet). Ways to improve the design of tools for reporting pain and to improve performance are suggested.

Introduction

Due to the subjective nature of pain (Baldridge & Andrasik, 2010), self-reporting is often considered to be the preferred method of pain assessment (Herr et al., 2006). Intensity, affect, quality, and location are considered key aspects of pain to include in a self-report assessment (Jensen & Karoly, 2011). Pain *intensity* is the term used to describe the perceived somato-sensory severity of pain (Von Korff, Ormen, Keefe, & Dworkin, 1992). Pain *affect* refers to the perceived unpleasantness (Rainville, Duncan, Price, Carrier, & Bushnell, 1997), which is related to pain tolerance and suffering from pain (Scherder, Sergeant, & Swaab, 2003). Pain *quality* refers to how pain feels in subjective terms of somatosensory sensations, such as burning or stinging (Jensen et al., 2006). Pain *location* is the term used to describe the ability to perceive the location of tissue injury (Treede, Kenshalo, Gracely, & Jones, 1999).

The ability to understand such terms and to evaluate one's own pain may require a certain level of cognitive functioning, including an understanding of associated vocabulary terms. People with intellectual disabilities could have difficulties in communicating about health-related information, both in understanding what is being asked and in having a way to respond (Mastebroek, Naaldenberg, Lagro-Janssen, & van Schrojenstein Lantman de Valk, 2014). Additional factors such as fear of others' reactions and not wanting to waste others' time can result in hiding pain instead of self-reporting pain (Beacroft & Dodd, 2010; Findlay, Williams, & Scior, 2014). In

addition, the display of atypical pain behaviors such as aggression and agitation could hamper caregivers in recognizing and asking about pain (Beacroft & Dodd, 2010; Bodfish, Harper, Deacon, Deacon, & Symons, 2006; De Knegt, Pieper, et al., 2013).

The challenges in accurately assessing pain in adults with intellectual disabilities could result in under-treatment of pain (Baldridge & Andrasik, 2010; Boerlage et al., 2013; McGuire, Daly, & Smyth, 2010). This is particularly alarming: like all individuals, people with intellectual disabilities are in need of prompt medical attention in the event of illnesses and accidents. They also are at increased risk of suffering from pain due to painful physical conditions such as gastroesopha-geal reflux disease (Böhmer et al., 1999) and musculoskeletal disorders (e.g., arthritis and spasticity) (De Knegt & Scherder, 2011). Because pain could negatively influence quality of life (Walsh, Morrison, & McGuire, 2011), it is crucial that reliable and valid methods are available to help people with intellectual disabilities report their pain experience. Furthermore, techniques are needed that will allow people with intellectual disabilities to regularly report their pain experience, so that the effectiveness of interventions can be assessed over time and changes can be implemented (as needed) to obtain desired outcomes, and to prevent pain from becoming chronic. Ideally, these tools would support the independent reporting of pain so that individuals with disabilities would not be dependent upon the presence of a trained caregiver. Tools of this type are meant to provide a screening of pain; further pain assessment

should be performed by medical professionals. Such tools for self-reporting of pain also may provide individuals with intellectual disabilities with a sense of self-determination and a feeling of greater control over their lived experience. Following this line of reasoning, we argue that the development of techniques to support the self-reporting of pain might support the independent functioning of this population group.

Currently, the regular collection of information on pain from individuals with intellectual disabilities poses significant challenges for caregivers. Various behaviors are used by people with intellectual disabilities to express pain: verbal indicators, such as reporting the pain location; and non-verbal indicators, such as using sign language for "hurt," pointing to or showing the injury, touching the hurting body part, changes in facial activity, crying or moaning, and withdrawn or aggressive behavior (De Knegt, Pieper, et al., 2013). It has been stated that the majority of people with intellectual disabilities may be able to report pain by using scales corresponding to their developmental level (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). For example, people with Down syndrome may have difficulty identifying and communicating the location of pain (Hennequin, Morin, & Feine, 2000), but may be able to do so by using a picture of a human body (Benini et al., 2004). It has been found that 71% of adults with Down syndrome comprehended at least one of two scales for pain affect and pain intensity (De Knegt, Evenhuis, Lobbezoo, Schuengel, & Scherder, 2013). However, the use of scales with this population still presents many challenges. For example, adults with intellectual disabilities were unable to rate a statistically significant increase in pain on a colored analogue scale during an injection compared to baseline (LaChapelle, Hadjistavropoulos, & Craig, 1999). To date there is only limited information on the ability of individuals with Down syndrome to report comprehensive information on pain.

More insight is needed into the ability of people with intellectual disabilities to report different aspects of pain. It is unclear how much knowledge caregivers and medical professionals have regarding the advantages and disadvantages of each type of self-reporting scale and standard instructions for applying the scales. For example, suggestive or grammatically complex questions should be avoided (Finlay & Lyons, 2002), and, at a minimum, comprehension of the scale extremes should be tested before the scale is applied to assess pain experience (De Knegt, Evenhuis et al., 2013). In conclusion, there is a need for a method to administer various scales for self-reporting pain in people with intellectual disabilities, in which comprehension of the scale items is assessed and standardized instructions are used.

In developing a tool to support the self-reporting of pain, there are a number of important considerations. First, the tool must adequately address the needed content regarding the intensity, affect, quality, and location of the pain. Second, associated terms (and response options) must be represented in a way that is quickly understandable and usable by the person with an intellectual disability. For example, for individuals who are unable to read, instructions should be read aloud and/or represented with appropriate images (Wilkinson & Hennig, 2007). Black-and-white pictograms, already often used for communication by people with intellectual disabilities

(Fujisawa, Inoue, Yamana, & Hayashi, 2011; Kåhlin & Haglund, 2009; Renblad, 2000), could be beneficial for the visual processing of key elements, while adding an increasing red color to a numeric rating scale might enhance understanding. Third, there must be a reliable access method for the individual to select the needed vocabulary and concepts, so that the assessment can be carried out in an efficient manner both for the person with intellectual impairment and the administrator, and can be repeated over time, as necessary. It would be important that it could be used with minimal training for the administrator, due to the high level of staff turnover in the field (Hatton & Emerson, 1998). Finally, it would be important that the collection of information is efficient with respect to a caregiver's time. Professional caregivers of individuals with intellectual disabilities often have a heavy workload (Hatton et al., 1999), with 25–33% experiencing high levels of stress (Robertson et al., 2005). The development of an efficient tool would increase the likelihood that it would be used on a regular basis, and thereby serve to support the effective monitoring and reporting of pain conditions.

In developing a tool for collecting information on pain, there may be benefits to the development of a computer-based approach, which provides an easily adapted user interface, and electronic collection of standardized information. In recent decades, applications for touch screens have been developed to support the communication of people with developmental disabilities, including intellectual disabilities (for reviews see Kagohara et al., 2013; Stephenson & Limbrick, 2013). Systematic evaluation show that interventions involving touch screens are effective in this target population and it seems that many people with developmental disabilities do not have difficulty with the actual operation of the touch screen devices (Stephenson & Limbrick, 2013). Although the use of a computer mouse may require greater cognitive and motor skills than the use of a touch screen (Wehmeyer, Smith, Palmer, & Davies, 2004), other research shows that some people with intellectual disabilities are able to use a computer mouse for double clicking and dragging (Li-Tsang, Yeung, Chan, & Hui-Chan, 2005). This suggests that traditional laptop computers may also be a viable approach, especially for people with mild intellectual disabilities (Li-Tsang et al., 2005). When developing a computer application for self-reporting pain, it is thus important to determine which computer device would be most suitable to use for people with intellectual disabilities, as this is a heterogeneous population group.

As part of a larger research project on pain experience, pain assessment, and cognitive functioning in adults with Down syndrome, an online application was developed to determine whether adults with intellectual disabilities (specifically people with Down syndrome) could use a computer device that would enable them to report information about their pain. The online application, called STOP-ID! (Self-reporting Tool On Pain in people with Intellectual Disabilities) was designed to support the communication of pain information by people with intellectual disabilities. It features the use of graphic images and pictograms to represent key issues of pain location, intensity, affect, and quality, and can be used on either a laptop or a tablet device.

The purpose of the present usability study was to provide a preliminary investigation of the use of STOP-ID! with the targeted group. The following questions were addressed: (a) Can adults with Down syndrome and mild to severe intellectual disabilities demonstrate comprehension (i.e., recognize the used images and navigate the interface) of the online tool? (b) If the answer to this question is yes, what kinds of information about a current or remembered pain experience are they able to report? (c) Do they require assistance and if so, what kinds of support are needed? and (d) Do they prefer one computer device (i.e., laptop or tablet) over another?

Methods

Study Design and Procedure

The usability study was conducted with 40 adults with Down syndrome on a laptop and a tablet. A crossover design was used to control for a possible order effect: the laptop preceded the tablet in 20 participants, while the tablet preceded the laptop in the other 20 participants.

The current study consisted of a single test session, in which the use of STOP-ID! was investigated with the participants. All tests were performed in a quiet room of the facility where the participants lived or worked. During this session, caregivers were asked about the experiences of the person with intellectual disabilities with laptops, computers, tablets, and pictograms, and about the participant's ability to read. Demographic, medical, and language-related information about the participants that was previously collected in an ongoing study about pain experience in adults with Down syndrome was used for the current study, to avoid placing an additional burden on caregivers and participants. The average number of months between the initial collection of this information and the STOP-ID! testing was 14.6 months ($SD = 3.2$, range: 9–19) because time was needed to find financial support, develop the STOP-ID!, and obtain informed consent of the participants. Caregivers were asked whether changes in the medical and/or cognitive functioning of the participants had occurred in the previous year. Caregivers suspected a decline in cognitive functioning for nine participants and the development of a possible painful condition in one participant (i.e., sore throat due to reflux of gastric acid).

Ethical Approval

The Medical Ethical Committee of the university to which the first author is related approved the study and the informed consent procedure.

Characteristics of the Sample

Information on the intellectual disability level, possible indication of dementia, vocabulary knowledge, and medical information of the participants was available from a larger, ongoing study in which the individuals had participated. Information on intellectual disability level was obtained from the Social Functioning Scale for Intellectual Disability (i.e., SRZ or SRZ-P;

Kraijer, Kema, & de Bildt, 2004; Kraijer & Kema, 2004). The SRZ and SRZ-P can be used to assess social and cognitive abilities and activities of daily living and the SRZ-P is used with those who have been observed to demonstrate a higher level of functioning. Caregivers were asked to identify the scale they believed was most appropriate for the participant's level of functioning.[1] By using the population norms of the manual, the SRZ total score was converted into a standardized score, which was then converted into an estimated level of intellectual disability by using the *Manual of Psychodiagnostics and Limited Ability* (Kraijer & Plas, 2006). In order to be able to compare the estimated intellectual disability level of the participants, the intellectual disability levels for all participants were based on the SRZ. Participants for whom only the SRZ-P score was available were identified as having a mild level of intellectual disability according to the SRZ. To screen participants aged 40 years and older for a possible indication of dementia, scores for the SRZ or SRZ-P and the Dementia Questionnaire for Intellectual Disability (DMR; Evenhuis, Kengen, & Eurlings, 2006) were examined for two moments in time (i.e., with data from the current study, and with previously collected data from the participants' files), with at least 6 months between them to assess deterioration over time. A possible indication of dementia was considered to be present if the decrease in the total scores of the questionnaires was statistically significant according to criteria in the manuals.

Vocabulary level was estimated by using a modified version of the Vocabulary subtest of the Wechsler Preschool and Primary Scale of Intelligence – Revised (WPPSI-R) (Wechsler, 1989). Participants were asked to provide a verbal description of the meaning of words (e.g., ''knife'' and ''umbrella''), with the greatest number of points given for correct abstract descriptions according to the WPPSI-R manual (e.g., ''A knife is a weapon'' and ''An umbrella keeps the rain off you''). Afterwards, the raw score was converted into an age equivalent[2] in years and months using the Manual of Psychodiagnostics and Limited Ability (Kraijer & Plas, 2006). Medical information about the use of medication and the presence of physical conditions that may cause pain was obtained from a review of records by caregivers.

As part of the present STOP-ID! study, a caregiver was asked about the participant's ability to read, experience with pictograms in daily life, and experience with computer devices. When the caregiver of the living facility reported that the participant used a computer in the facility for work or activities, the researcher contacted the facility. When the caregiver was not aware of the participant's experience with pictograms or digital devices, the caregivers asked the participant open-ended questions in the presence of the researcher.

Participants

Forty individuals participated in the study. All belonged to a care organization for people with intellectual disabilities in a large part of the Netherlands. The following inclusion criteria were used: (a) 18 years of age or older, (b) ability to speak and understand Dutch, (c) a demonstrated willingness to participate in testing activities, and (d) a diagnosis of Down syndrome. Exclusion criteria were (a) neurological disorders

such as cerebrovascular accidents or tumors, (b) the use of antipsychotics, anticonvulsants, or antidepressants due to possible neuropsychological side effects (Handen & Gilchrist, 2006; Stein & Strickland, 1998), and (c) severe visual impairments or hearing loss. The latter exclusion criterion was based on the estimation of the caregiver whether the participant would be able to see pictures clearly and to hear clearly what was being said. Severe intellectual disability was not considered to be an exclusion criterion: adults with Down syndrome of all levels of intellectual disability could participate as long as caregivers had reported that these adults had the motor ability to press on a touch screen and use a computer mouse (i.e., move the mouse and press the button), and the cognitive ability to follow simple spoken instructions (e.g., ''Please sit down in front of this computer.''). Individuals who were and were not currently known to be experiencing pain were included in the study. The presence of painful or discomforting physical conditions according to medical information was not an exclusion criterion, because this was precisely the type of information the tool was meant to collect.

To be included in the study, participants had to provide informed consent. If there was doubt regarding their capacity to provide informed consent, informed consent was also required from parents or guardians. In total, 40 participants were included, with an average age of 43.3 years ($SD = 11.7$, range: 20–66 years) and of whom 40% were male. The median age equivalent of vocabulary abilities was 4;0 years (years; months) ($IQR = 2;0$, range: 2;1–10;1). Only three participants used pain medication (acetaminophen and/or Diclofenac) and one participant had a possible indication of dementia. Most participants (68%) were unfamiliar with both laptop and tablet devices. Table 1 provides information about other characteristics of the sample. Of the participants, 23 (58%) were able to verbally report pain. Non-verbal pain behaviors were physical changes (including to faces and posture), and emotional changes such as crying, moaning, and pointing to the painful location. Table 2 provides more information about the pain behaviors of the participants as described by caregivers.

Self-Reporting Tool On Pain in People with Intellectual Disabilities (STOP-ID!)

The concept of the online application STOP-ID! was designed by the authors and the STOP-ID! itself was developed by Stichting OOKJIJ (roughly translated as YOU TOO Foundation), a Dutch organization that has developed a website for people with intellectual disabilities to support safe use of the Internet. Participants can log in with their personal account consisting of a numeric code. After a successful login, participants see photos of themselves and hear their names spoken aloud by the device.

For the laptop condition, a Latitude E5530 laptop[TM3] was used that included Google Chrome[TM4], a mouse with two buttons and a scroll wheel, and a mouse mat. For the tablet condition, an iPad[TM5] was used that included Google Chrome, a SIM card for 3G mobile Internet, and a Smart Case[TM5] to be folded as a stand. Both devices had Internet capability. Each participant had an opportunity to complete the STOP-ID! protocol twice during the same test session: once on the laptop and once on the tablet. The STOP-ID! test itself was identical on the two devices, but the devices differed from each other in screen size (i.e., 39.62 cm of the laptop versus 24.64 cm of the tablet) and response mode (i.e., computer mouse versus touch screen) .

The STOP-ID! test consists of a number of pages (featuring graphics and/or text) that are presented to the participant on a laptop or tablet computer. All written text on a page of the test is read aloud by the computer. In completing the test, participants are first asked if they are experiencing pain on that day. In typical use, STOP-ID! automatically directs the participants without pain at the time of the assessment (i.e., individuals who are not presently experiencing pain) to the end of the test. Because of a concern that this would not have given the researchers enough opportunity to observe the use of the STOP-ID!, the procedure was modified in the current study so that it could be used with all participants (regardless of their current pain status). First, patients were asked if they were currently experiencing pain: those who were, continued. Participants without current pain were asked to think about pain that they might have experienced recently and were asked to respond to questions on that basis. As the participants answered questions, the system was navigated in one of two

Table 1. Characteristics concerning demographic and medical variables, reading, use of pictograms, and use of computer-related devices ($N = 40$).

Characteristics	n (%)
Level intellectual disability	
Mild	17 (43%)
Moderate	20 (50%)
Severe	3 (8%)
Living situation	
In care center	36 (90%)
At home with family	4 (10%)
Physical conditions that may cause pain/discomfort	22 (55%)
Ability to read according to caregivers	23 (58%)
Use of pictograms	
In total	24 (60%)
Daily	16 (40%)
Not familiar with at least one computer-related device	27 (68%)
Familiar with at least one computer-related device	13 (32%)
No use of at least one computer-related device	26 (65%)
Use of at least one computer-related device	14 (35%)

Computer-related device: laptop, tablet, regular computer, and smartphone.

Table 2. Pain behavior of participants as reported by caregivers.

Pain behavior	n (%)
Expresses pain	
Never or rarely	5 (8%)
In an exaggerated way (perseveration or overly demonstrative)	3 (5%)
Verbally	23 (37%)
Vocally (moaning)	1 (2%)
Physically (facial, posture, eating, sleeping, physiological reactions)	11 (18%)
By pointing to painful location	3 (5%)
Emotional changes (crying, mood, or behavior such as withdrawal)	7 (11%)
No pain behaviour, while pain is suspected by caregiver	2 (3%)
Expresses pain, but unclear whether pain is present	1 (2%)
High pain threshold	6 (9%)

$n =$ the number of participants displaying the pain behavior. Because some participants displayed several pain behaviors and caregivers were asked to report all pain behaviors of a participant, the number of participants exceeds 40.

ways: either the participant was automatically directed to the next page after clicking or touching an answer, or an arrow as a symbol for *CONTINUE* appeared, with the expectation that the participant would click or touch the symbol to continue.

This investigation of STOP-ID! was focused on whether it could be used as a method of supporting the self-reporting of pain by people with intellectual disability. Therefore, the testing procedures first centered on whether participants could demonstrate comprehension of the use of the tool. This was assessed by their performance on four comprehension tests that required recognition of the representations for important features of pain (i.e., location, intensity, affect, and quality) and an ability to navigate to the correct answer by using the touch screen or computer mouse. Those participants who demonstrated passing (i.e., perfect) scores on one or more of the four comprehension tests were then asked to use the tool to report a current or recent pain experience. Support (e.g., repeating the question) was only provided if participants were unable to continue independently, and was recorded by the researcher.

Answers to questions in the STOP-ID! were not provided by the researcher. Additional details are provided in the upcoming sections. All instructions and questions were provided by written text on the screen as well as recorded voice output of the computer device.

Comprehension Tests

Pain Location. To demonstrate recognition of the representation of pain location in STOP-ID! participants were shown the front and back of a human body (see Figure 1). They were then asked to locate the head, chest, belly, arms, and legs on the front side of the body; and the head, neck, back, arms, and legs on a picture of the back side of the body. A score of 10 out of 10 was required to earn a passing score.

Pain Intensity. To demonstrate recognition of the representation of pain intensity in STOP-ID! participants had to correctly indicate the larger of two numbers that were presented as numerals on the screen (e.g., when asked, *"Which is larger, two or*
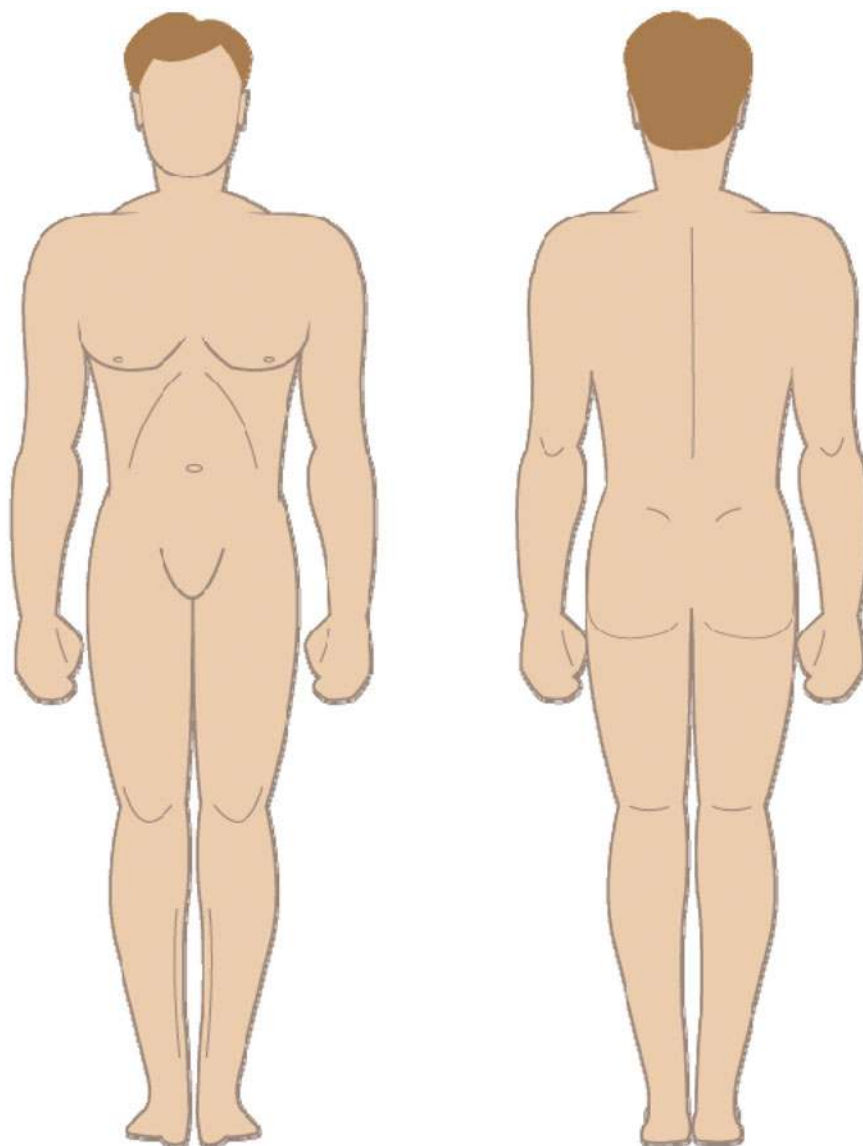

Figure 1. Graphic image showing the front and back of a human body.

eight?'', a correct response was to indicate the number eight). There were two questions of this type. Participants were also asked to correctly indicate on a 0–10 numeric scale which number would be used to represent no pain (0 or 1) and which number would be used to represent a lot of pain (9 or 10). A total of four questions were used for this concept (see Figure 2). A score of 4 out of 4 was required to earn a passing score.

Pain Affect. To demonstrate recognition of the representation of pain affect in STOP-ID! participants had to correctly indicate which of three facial pictograms would be used to represent (a) no pain (the middle face: pain affect level 0), (b) a lot of pain (the left face: pain affect level 2), and (c) a little bit of pain (the right face: pain affect level 1). A total of three questions were used for this concept (see Figure 3). A score of 3 out of 3 was required to earn a passing score.

Pain Quality. To demonstrate recognition of the representation of pain quality in STOP-ID! participants had to correctly indicate which of four pictograms represented (a) stinging pain (the first pictogram), (b) pressing pain (the second pictogram), (c) burning pain (the third pictogram), and (d) throbbing pain (the fourth pictogram). A score of 4 out of 4 was required to earn a passing score (see Figure 4).

Report of a Current or Recent Pain Experience

Those individuals who obtained passing (i.e., perfect) scores on one or more of the previous four tests of recognition and navigation also had an opportunity to provide information on a current or recent pain experience. The following instructions were provided by written text and voice output of the computer: *"Now we want to know everything about your pain"*, *"Where does it hurt?"* (showing the image of the human body to assess pain location, see Figure 1), *"Which number fits your pain?"* (showing the 0–10 scale with an increasing red color to assess pain intensity, see Figure 5), *"Which face fits your pain?"* (showing the facial pictograms to assess pain affect, see Figure 3), and *"Which picture fits your pain?"* (showing the pictograms to assess pain quality, see Figure 4).
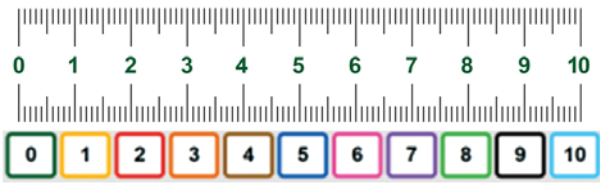

Figure 2. Pictograms and graphic images used to assess pain intensity.
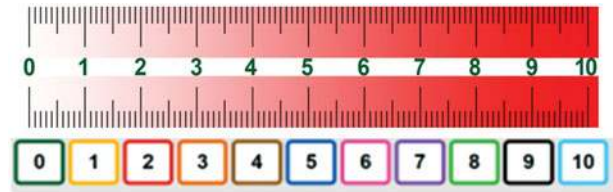

Figure 5. Scale used to self-report pain intensity.

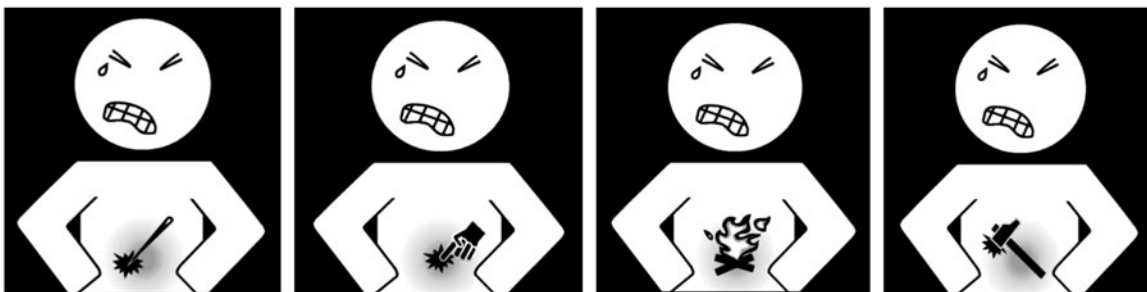Figure 3. Pictograms used to assess pain affect.

Figure 4. Pictograms used to assess pain quality.

Information on pain quality was gathered but not recorded, because pain location, affect, and intensity were deemed more clinically relevant for health care workers to determine whether further pain assessment and medical attention were necessary. The individual pain score that emerged in the database as a summary of the responses by a participant was for example "Back-side arms, 2/2, 9/10", corresponding to pain location, pain affect, and pain intensity, respectively. A key difference between the collection of information on comprehension (i.e., recognition and navigation) and the reporting of a current or recent pain experience was that it was difficult to determine response reliability. For recognition and navigation questions, the correct response was known to the researcher; for the self-reporting of pain, the correct response was known only to the participant.

Performance Evaluation

A scoring form was developed and used by the first author to write down qualitative observations and to evaluate the participant's performance during the laptop and tablet conditions (see Supplementary material – online only). This form contains (a) seven statements in a yes/no format (e.g., presence of distraction or impulsivity), (b) the actual time in minutes required to complete the test (i.e., without the time lost due to technical problems that were not caused by the participant), and (c) the number of times that the instructions for the different steps needed to be repeated. After participants performed both versions of the STOP-ID! they were asked which of the two tasks they liked best.

Statistical Analysis

Statistical analyses were performed using Statistical Package for the Social Sciences version 21 (IBM SPSS Statistics 21). The categories of moderate and severe intellectual disability were combined for the analyses, due to the small number of participants with severe intellectual disability, resulting in the two categories "mild" ($n = 17$) and "moderate to severe" ($n = 23$). The research questions were answered by using descriptive statistics, McNemar tests, independent-sample t-tests, a Wilcoxon signed-ranks test, and Chi-squared tests. For those questions for which it was appropriate, the level of significance was set at $\alpha = 0.05$ with rejection of the null-hypothesis when two-sided $p < 0.05$.

Results

Use of Online Application to Report Information About Pain

All participants finished the STOP-ID! in both the laptop and tablet conditions. The average performance time was 16.0 min ($SD = 8.1$) on the laptop and 14.6 min ($SD = 3.9$) on the tablet. This was timed from the starting screen up to the closing screen, including the comprehension tests and self-reporting of pain. Most participants were able to insert the account code in the laptop condition (69%) and tablet condition (85%), and all participants for whom a photo was available in the account

($n = 39$) recognized it in both conditions. It was observed by the researcher that during the study visit, some of the participants seemed at times distracted or bored (25% in laptop condition, 48% in tablet condition); and that some of the participants appeared to answer at least a few questions impulsively (30% in laptop condition, 35% in tablet condition).

Recognition and Navigation Performance. The results of the comprehension tests are presented in Table 3. The average number of comprehension tests with a perfect score per participant was 1.5 ($SD = 1.2$) in the laptop condition and 0.9 ($SD = 0.8$) in the tablet condition. In the laptop condition, the highest percentage of all participants was successful in answering questions concerning pain location and pain affect (see Table 3). In the tablet condition, the highest percentage of all participants obtained a perfect score for pain affect. These results in both conditions also applied to the participants who did not require support (see Table 3). The difference in the number of participants who were able to successfully answer questions concerning pain location with the laptop ($n = 22$ in total) than with the tablet ($n = 9$ in total) was statistically significant (McNemar test, $p = 0.007$, $Phi = 0.01$). It was observed that the small size of the displayed body parts easily resulted in touching a body part next to the target (e.g., head and neck), and that the sometimes slow Internet connection on the tablet easily resulted in touching the same body part twice (i.e., risking an incorrect answer to the subsequent question).

There appeared to be little measured difference between participants with current pain and participants with remembered pain. There was not a statistically significant difference between the two groups on their performance times with the two devices (laptop, $t (38) = 0.27$, $p = 0.79$, $r = 0.04$; tablet, $t (38) = -0.10$, $p = 0.92$, $r = 0.02$), nor on the number of comprehension tests with perfect scores on the two devices (laptop, $t (38) = 0.43$, $p = 0.67$, $r = .07$; tablet, $t (38) = 1.17$, $p = 0.25$, $r = 0.19$).

Type of Information Reported

Those individuals who had obtained perfect scores on at least one comprehension test of recognition and navigation were asked to provide information about the current or remembered pain experience. As noted earlier, the first question in the STOP-ID! was *"Are you in pain today?"* The participant reported the presence of current pain by choosing *YES* ($n = 16$ with laptop, $n = 15$ with tablet). If the participant

Table 3. Results of comprehension (recognition and navigation) tests ($N = 40$).

| | Laptop | | Tablet | |
| | n (% of 40) with perfect score | | n (% of 40) with perfect score | |
	Without support	Total	Without support	Total
Pain location	14 (35%)	22 (55%)	6 (15%)	9 (23%)
Pain intensity	3 (8%)	6 (15%)	5 (13%)	6 (15%)
Pain affect	10 (25%)	22 (55%)	17 (43%)	20 (50%)
Pain quality	8 (20%)	8 (20%)	12 (30%)	13 (33%)

"Total" equals those who received a perfect score both with and without support.

Table 4. Reported pain experience by means of the Self-reporting Tool on Pain in people with Intellectual Disabilities.

Reported information	Laptop condition n (% of 29)	Tablet condition n (% of 26)
Pain location	22 (76%)	9 (35%)
Pain intensity	6 (21%)	6 (23%)
Pain affect	22 (76%)	20 (77%)
Pain location specified		
Head (front)	1 (4% of 22)	1 (11% of 9)
Chest	3 (14% of 22)	1 (11% of 9)
Abdomen	7 (32% of 22)	2 (22% of 9)
Arms (front)	0 (0% of 22)	1 (11% of 9)
Legs (front)	1 (4% of 22)	2 (22% of 9)
Head (backside)	0 (0% of 22)	0 (0% of 9)
Neck	1 (4% of 22)	0 (0% of 9)
Back	1 (4% of 22)	1 (11% of 9)
Arms (backside)	3 (14% of 22)	1 (11% of 9)
Legs (backside)	5 (23% of 22)	0 (0% of 9)
Pain affect specified		
0	3 (14% of 22)	3 (15% of 20)
1	9 (41% of 22)	5 (25% of 20)
2	10 (45% of 22)	12 (60% of 20)

The total percentage of the three pain components exceeds 100%, because each participant could report information about several components (depending on the comprehension tests for which perfect scores were obtained).

Table 5. Number of participants who needed extra instruction, specified for the parts of the Self-reporting Tool on Pain in people with Intellectual Disabilities.

	Laptop n (% of 40)	Tablet n (% of 40)
Use of device		
Mouse	15 (38%)	–
Touch screen	–	17 (43%)
Use of arrow (CONTINUE)	31 (78%)	29 (73%)
Presence of pain	24 (58%)	15 (38%)
Comprehension		
Pain location	17 (43%)	17 (43%)
Pain intensity	26 (65%)	18 (45%)
Pain affect	10 (25%)	7 (18%)
Pain quality	8 (20%)	7 (18%)
Self-report of pain		
Pain location	7 (18%)	1 (3%)
Pain intensity	1 (3%)	1 (3%)
Pain affect	3 (8%)	5 (13%)
Pain quality	0 (0%)	2 (5%)

answered NO, then the researcher asked "Were you recently in pain?" Some of the participants answered in the affirmative ($n = 14$ with laptop, $n = 7$ with tablet). Participants who had not reported current or recent pain were asked to think about pain that they might have experienced in the past ($n = 10$ in laptop condition, $n = 18$ in tablet condition).

It was not within the scope of the present study to examine whether the reported pain was accurate (i.e., truly represented the experience of the participant). A McNemar test showed that the association between the self-reported presence of pain in the tablet and laptop conditions was statistically significant ($p < 0.001$), in which a Phi coefficient of 0.59 suggested a moderate to large test-retest reliability. In total, 32 of the 40 participants reported the presence of pain in a similar manner in the laptop and tablet conditions, while eight of the 40 reported the presence of pain differently in the two conditions.

Table 4 shows the available information about the self-reported pain experience. A participant would only carry on and answer questions about a particular component of his/her personal pain experience if the participant had previously obtained a perfect score for that particular component on the comprehension test. In total, 29 participants (73%) in the laptop condition reported information about at least one pain component; 20 of these individuals were able to make this report without assistance. In the tablet condition, 26 participants (65%) reported information about at least one pain component; 21 of these individuals were able to make this report without assistance. In both tablet and laptop conditions, participants most frequently chose the highest level of pain affect, with the abdomen the most frequently reported pain location (see Table 4). The average pain intensity on the 0–10 scale was moderate to severe, with $M = 6.7$ ($SD = 2.9$) in the laptop condition and $M = 7.8$ ($SD = 3.1$) in the tablet condition, but this was based on only the six participants who passed the comprehension test. Pain quality was not used to report pain experience because pain location, affect, and intensity were deemed more clinically relevant information for health care workers to determine whether further pain assessment is necessary.

Need for Assistance

Participants varied in the level of required support. Some participants were able to use the tool independently ($n = 7$ laptop, $n = 7$ tablet). The other participants needed assistance at least once. A Wilcoxon signed-ranks test showed that the larger number of times that assistance was provided during the laptop condition than during the tablet condition was statistically significant, $z = -2.39$, $p = 0.017$, $r = -0.38$, $Mdn_{laptop} = 6$, $Mdn_{tablet} = 5$. A few participants needed assistance only with the use of the device ($n = 0$ laptop, $n = 4$ tablet), some needed assistance only with the questions about the comprehension tests and/or self-report of pain ($n = 18$ laptop, $n = 16$ tablet), and others needed assistance with both the use of the device and the questions ($n = 15$ laptop, $n = 13$ tablet). Verbal and/or non-verbal requests of assistance were made by 68% of the participants in the laptop condition and by 70% of the participants in the tablet condition.

Table 5 provides information on those parts of the assessment activities for which the participants requested additional explanation. In both conditions, most participants required assistance to use an arrow as a symbol for CONTINUE. The question regarding pain intensity (as part of the comprehension test) was the test item that required the most assistance in both conditions. Interestingly, a relatively high number of participants needed assistance with the question about the presence of pain (58% in the laptop condition and 38% in the tablet condition).

Preference

The preference for the type of computer to perform the STOP-ID! was almost equally distributed: 53% ($n = 20$) for the laptop and 47% ($n = 18$) for the tablet. Two participants did not have a

preference. There was no statistically significant difference for preference, χ^2 (1, $n = 38$) $= 0.11$, $p = 0.75$. The reasons that most participants gave for their preference could be categorized into "easier to use" (40% for laptop, 25% for tablet) and "more attractive" (10% for laptop, 18% for tablet). Having a mild level of cognitive impairment was related to preference for the laptop (71%) and having a moderate to severe level was related to preference for the tablet (62%), χ^2(1, $n = 38$) $= 3.98$, $p = 0.046$, $Phi = 0.32$.

Discussion

The results provide evidence that the use of tools such as STOP-ID! appear to be a promising approach for the reporting of pain information by some adults with Down syndrome in the presence of a trained caregiver. The moderately high percentage of participants who demonstrated the ability to report information by using STOP-ID! (73% with laptop, 65% with tablet) suggests that the online application has potential for self-reporting pain, especially as most participants (68%) had never used a laptop or tablet before. However, the finding that only seven participants (18%) were able to perform the entire test session without assistance indicates that the value of the STOP-ID! is tentatively limited in terms of increasing individual capabilities for independent self-reporting of pain and reducing the workload of caregivers.

Although 58% of the sample expressed pain verbally in typical pain situations, the use of the STOP-ID! might facilitate the communication about more pain components than simply the presence of pain. To optimize the potential, the application may benefit from additional changes. For example, it may be of benefit to clarify the question about the presence of pain by using the word "now" instead of the word "today": the use of explicit terms might help to reduce underreporting of pain. In addition, assistance was often required when using the arrow as a symbol for *CONTINUE*: it may be preferable that participants automatically continue to the next page after the text is read aloud (introduction) or an answer is selected. Displaying a larger human figure may reduce the risk of erroneously selecting the adjacent body part: it has been previously found that people with Down syndrome benefit from a human figure with enlarged body parts to report their pain location (Benini et al., 2004). Additional work is also needed to address challenging issues related to representation. Our results show that comprehending a numeric pain scale is more difficult than comprehending a facial pain scale, and that comprehending quality-of-pain pictograms is difficult, possibly because pain quality is an abstract concept. A numeric rating scale has been identified as appropriate for individuals with a developmental level of 8 years because comprehension of the quantitative significance of numbers is developed over time (Von Baeyer, 2006). Quantity of pain can be represented in more simplified ways than numbers, such as cubes of increasing size (Benini et al., 2004) or the number of poker chips (Von Baeyer, 2006).

More instructional prompts were needed in the laptop condition ($Mdn = 6$) than in the tablet condition ($Mdn = 5$). Many participants required assistance in maneuvering the mouse, clicking without moving the cursor, and using only the left mouse button. The task of mastering these motor skills and the ability to remember them makes the use of a computer mouse more complex than the use of a touch screen, as has been described in the literature (Wehmeyer et al., 2004). The participants' own preferences also confirmed the difficulty of using a laptop: most of the participants with mild intellectual disabilities preferred the laptop, whereas the majority of those with moderate to severe intellectual disabilities preferred the tablet. Still, some difficulties with using the tablet were also observed by participants (e.g., pressing too long). In particular, it was observed that the participants with severe intellectual disabilities had difficulties using both computer devices and comprehending the questions.

It took participants an average of 14.6 min to complete the STOP-ID! in the tablet condition and 16.0 min in the laptop condition. The observed distraction, impulsivity, and relatively long performance time may be explained by the difficulty of the questions, the observed difficulty with using a computer mouse (sometimes also with using a touch screen), and the slow Internet connection of the tablet. All of these factors indicate the need to closely examine the number of questions and the representations used for the answers, which may increase the usability of the STOP-ID! Reducing the length of the STOP-ID! will strengthen its practical use as a screening tool for pain. Using a 4G Internet connection and offering a short basic training session on using a computer mouse may further facilitate the use of the STOP-ID!

Our usability study was an essential first step towards developing a novel solution for technology-aided pain assessment aimed at reducing the under-treatment of pain in people with intellectual disabilities. Future research should also explore whether individuals can be taught to use the STOP-ID! on a regular basis, and examine whether autonomous use of this tool increases over time. It is important to determine whether this is possible, because it would signify that frequent, autonomous use is an attainable goal and that tools such as STOP-ID! are suitable for broad implementation in clinical practice to complement pain diagnostics through its inclusion, among other things, in the care plans of care facilities.

Another important area for further research is the concurrent validity of the STOP-ID! as a screening tool for pain assessment. For example, the computer-based version of the tool could be compared with the same self-reporting pain scale assessed person-to-person. Comparisons could also be made with other self-reporting pain scales assessed person-to-person (e.g., Coloured Analogue Scale or Facial Affective Scale: McGrath et al., 1996), and/or with proxy ratings of pain intensity (e.g., NRS: Boerlage et al., 2013). Careful evaluation is required to determine whether regular use of the STOP-ID! improves pain assessment and management in clinical practice.

Limitations

The findings reported here should be interpreted with caution, as they represent the initial investigation of an innovative tool for the assessment of a challenging topic (i.e., pain) by people with intellectual disabilities. Participants without current pain were asked to think about pain that they might have

experienced recently, so that use of all parts of the STOP-ID! could be evaluated in each participant. However, questions about recent pain appeal more to memory than questions about current pain and can, therefore, be more difficult to answer (Scherder et al., 2001). Although our currently available results suggest that the two groups were similar (i.e., performance time and the number of perfectly scored comprehension tests were comparable), the reported information about remembered pain should be interpreted cautiously, as there is no information on the concurrent validity of this tool (i.e., would the same information have been collected if it were collected in other formats, for example, by verbal report?). Although it was not the aim of the current study, it was not possible to verify if the self-reported pain reflected the actual experience of the participants. More research is also needed on the test-retest reliability of the STOP-ID! because eight participants reported inconsistently the presence of their pain in the two conditions.

In addition, the use of qualitative observations of only one rater may have biased the results, due to the lack of inter-rater agreement data. Furthermore, the exclusion criterion of severe visual impairments and hearing loss was checked only by asking the caregiver during the selection procedure, in order to estimate whether the participant was able to see pictures clearly and to hear clearly what was being said. Finally, the tablet was more susceptible to poor performance in the presence of weak wireless signals and was, consequently, sometimes slower than the laptop. This could have influenced the preference of participants for the laptop.

Conclusion

The two objectives for developing the STOP-ID! were (a) to enable people with intellectual disabilities to self-report pain, and (b) to provide a standardized information-gathering tool that covers multiple aspects of pain experience. As a result of the study we can conclude that, if modified, the STOP-ID! might accomplish these objectives; however, more research is needed to establish reliability and to validate the tool by comparing it with other means of pain assessment. The presence of a trained caregiver is recommended for the current version. Modifications to the length of the tool, the graphic images used, and the phrasing of questions are needed to improve the autonomous use of the STOP-ID! and hence its additional value for clinical practice as a screening tool for pain.

Notes

1. The scores for the intellectual level for the participants should be interpreted with caution, as there is evidence that for at least two of the participants, the use of the SRZ-P instead of the SRZ appeared incorrect according to guidelines in the manuals.
2. The scores for language level should be interpreted with caution, as they are based on adaptations made by the current research team in creating a modified Dutch version of the WPPSI-R Vocabulary test, which may have resulted in a slight over-estimation of their language ability (as reported using age-equivalent scores).
3. A Latitude E5530 laptop is a product of Dell Inc., Round Rock, TX, USA.
4. Google Chrome is a product of Google Inc., Mountain View, CA, USA.

5. The iPad 2 and Smart Case are products of Apple Computers Inc., Cupertino, CA, USA.

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Declaration of interest

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