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SURVEY OF ASSESSING PAIN IN CLINICAL PRACTICE AND APPLICABILITY OF A NEW ASSESSMENT

by

Michelle Konz

A Thesis Submitted in
Partial Fulfillment of the
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ABSTRACT

SURVEY OF ASSESSING PAIN IN CLINICAL PRACTICE AND APPLICABILITY OF A NEW ASSESSMENT

by

Michelle Konz

The University of Wisconsin-Milwaukee, 2016
Under the Supervision of Professor Joyce Engel, PhD

Aims The purpose of this study is to identify pain assessments that are being used to measure an individual's pain experience and to discover how occupational therapists are currently assessing pain in youths who have complex communication needs with a developmental disability (DD). ***Methods*** *Phase 1:* A literature review was conducted through the use of electronic databases to research 17 different methods of pain assessment to create descriptive charts to aide in pain assessment. *Phase 2:* A 13-question survey was completed by 19 occupational therapists selected through a convenience sample, to determine how pain is currently being assessed for youths who have complex communication needs. ***Results*** *Phase 1:* Three charts were compiled of pain assessments. Each pain assessment has different aspects, but no one measure covers all pain domains and are not accessible. *Phase 2:* The results indicated that 12 out of 19 respondents do not assess pain. ***Conclusion*** In *Phase 1*, it was determined current pain assessments do not gather a holistic report of pain experiences and are not fully accessible. Survey results suggest that pain is not assessed by more than half of the OTs in this study. Creation of a new pain assessment should be completed in order to fulfill the need of an accessible self-report assessment for youths who have complex communication needs with a DD.

Keywords: Occupational therapy, pain assessment, self-report, disability, youths

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INTRODUCTION

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in such damage” (International Association for the Study of Pain (IASP), 1994, p.209). Pain assessment and pain interference on daily lives are the focus of this study. Mainly the assessment of pain with youths who have complex communication needs with a developmental disability (DD). This study began as a Master’s Thesis for an accredited OT program at the University of Wisconsin-Milwaukee in 2015. In completion of the study, a proposal was submitted and revised into a thesis format. Remnants and further evidence can be found in Appendix E, where the proposal has been provided for the readers.

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in such damage” (International Association for the Study of Pain (IASP), 1994, p.209). This study examines chronic pain, as opposed to acute pain, due to its prolonged effect on the development of youths. Chronic pain is persistent pain that no longer serves a biological purpose and involves a complex interaction of physiological, psychological, and social factors (Chambliss, Heggen, Copelan, & Peetignano, 2002). Huguet & Miro (2007) conducted an epidemiological study with 561 participants between the ages of 8-to-16 years to determine the prevalence of pediatric pain. Results of the study indicated that 37.3% of the participants reported chronic pain, thereby concluding that chronic pain is highly prevalent.

Roth-Isigkeit, Thyen, Stoven, Schwarzanberger, and Schumucker (2005) conducted a study with 751 youths between the first and twelfth grade to determine which daily activities were being restricted due to their chronic pain. The activities included absences from school, decreased socialization, loss of appetite, disturbances in sleep, and inability to pursue hobbies.

Similarly, Chambers, Huguet, King, MacDonald, McGrath, and Parker (2011) completed a systematic review consisting of 41 published papers to determine different variables that correlated with chronic pain. These variables included chronic health problems, frequent change of residence, poor performances at school, frequent television watching, fewer interactions with other children, report of missing school, withdrawal from social activities, and risk for developing internalizing symptoms. Both of these studies note that youths who are experiencing pain may have disruptions in their daily activities that are essential to their quality of life (QOL).

Furthermore, youths with a DD have a greater risk to experience pain and they may have cognitive and communication limitations that may make it difficult for them to express their pain experience (Turnquist & Engel, 1994). This may result in an increased sense of loss of control, feelings of helplessness, decreased attention span, regression in behaviors, social isolation, or depression (Barowsky, 1987). Allowing a youth who is nonverbal with an opportunity to self-report can create a greater sense of control over the youths' lived experience and self-determination and further increase their independent functioning (de Knegt, Lobbezoo, Schuengel, Evenhuis & Scherder, 2015).

Because chronic pain does have a significant prevalence and impact on daily life, it is important to continue to address the pain experiences of youths as they receive healthcare services. Understanding the impact of pain on the daily lives of youths will assist caregivers in minimizing the consequences of pain, relieving suffering, and assisting with the development of rehabilitation programs that focus on where pain is most problematic (Breau, Camfield, McGrath & Finley, 2007).

It is essential to assess pain in order to provide appropriate pain relief for youths before it may affect their development and occupational performance. IASP (2015) made a Declaration of Montreal, which stated that it is one’s right to receive pain reduction and suffering, and access to pain management is a fundamental human right. This bold statement helps to justify the importance of the consumer’s right to ongoing appropriate pain evaluation and management.

Pain must be accurately assessed to ensure adequate pain management, along with ensuring holistic healthcare. The three main methods for measuring pain include self-report, behavioral measures, and physiological measures. Self-report measures are dependent upon an individual’s cognitive development and language skills, but are found to be the most valid and optimal to accurately assess pain Self-report is also considered to be the gold-standard for assessing pain as opposed to proxy reports (Conrad, Fanurik, Harrison, Koh, & Tomerun, 1998). Proxy reports for youths are typically given by the caregiver or healthcare professional to assess pain experiences when the youth is thought to be unable to do so. It is well documented, however, that proxy respondents are not equivalent to that reported directly by the patient due to pain being a private and unique experience that is only accurately defined by the individual him or herself (Irwin et al., 2012). It should be noted, however, that verbal report of a private stimulus may be influenced by earlier conditioning (Skinner, 1964), distortion in light of an individual’s motives or self-interests such as escape from demands (Engel, 1988; Kazdin, 1980; Varni, Katz, & Dash, 1982). It is therefore important to consider behavioral measures and physiological measures to gain a holistic understanding of current pain assessment and are valuable to gaining additional knowledge of the individual’s pain experience.

Overt motor behavior or observable pain responses (e.g., pain medication intake) are commonly targeted for assessment as are well behaviors (Engel, 1988). Behavioral measures of pain include crying, guarded movements, facial expressions, body postures, and physical movements presenting discomfort (Fordyce, 2011). The assessment of pain behaviors in youths may be problematic. For example, the youth's activity level may not be an adequate indicator of pain as children experiencing mild-to-moderate intensity or chronic pain will often engage in play (Engel, 1988; Jay & Elliot, 1984).

Physiological measures that may be used to assess acute pain include heart rate, blood pressure, respiration, oxygen saturation, palmar sweating, and neuroendocrine responses (Ratnapalan, Schneewiess, & Srouji, 2010). Changes in these physiological indicators may also be seen with other subjective phenomenon such as anxiety making it difficult to detect a pattern of responses that are unique to pain. Physiological measures are not accurate for the assessmet of chronic pain due to adaptation of the sympathetic nervous system (Engel, 1988).

Both overt and physiological measures may be used by healthcare providers or caregivers to provide a proxy report of the youth's pain experience. Proxy reports or physiological measures may be useful in replace of the individual's report of pain if the youth is too young to understand pain or if severe cognitive impairments and or limited language skills affect his or her ability to report pain experiences. All three of these types of pain assessment are beneficial to be aware of as a healthcare provider.

A review of current pain assessments using all three methods would be beneficial to add to the research of pain. This review would be beneficial to provide healthcare providers with a concise overview of the current pain assessments and allow them to quickly choose which assessment may be most beneficial for use with their consumers. Currently, there are no pain assessment charts found in the literature that review accessibility features of assessments or cover the different domains of each pain assessment.

Occupational therapists (OTs) and physical therapists (PTs) work with the pediatric population. As a healthcare provider, the clinician is held accountable to provide a holistic approach towards evaluation and treatment for youths with a disability which includes assessing and managing pain. Therapists often work with youths who have complex communication needs in a variety of different healthcare settings. It is important that therapists accurately assess pain. Allowing these individuals to self-report their unique pain experiences will enhance the evaluation and treatment provided. This is essential as it is evident that pain affects a youths' participation in activities of daily living (ADLs) and may affect their QOL (Roth-Isigkeit et al., 2005; Chambers, 2011).

The research question and aim of this study was to research the current pain assessments being used in the healthcare field and to understand how occupational therapists are currently assessing pain in youths who have complex communication needs. This question was determined by the main objectives of the study and helped to steer the direction of the questions to be included in the survey. The main objectives of this study are to (a) discover which pain assessments are currently available in the field for healthcare providers to use, (b) create concise charts for healthcare providers to determine which pain assessment is most beneficial for their use, (c) determine how pain is currently being assessed by occupational therapists working with youths who have complex communication needs and how frequently this is occurring, and (d) determine how satisfied clinicians are with the way they do or do not assess pain for this population

It is hypothesized that the current pain assessments being used in healthcare are not holistic over the span of all pain domains and are not accessible for youths who have complex communication needs. Another hypothesis is that half of the occupational therapists in the survey portion of this study do not assess pain during every treatment session. Of those assessing pain, less than half of the clinicians are using self-report measures to identify pain in youths who have complex communication needs. All of the clinicians who report not assessing pain, will report not being satisfied with their current pain assessment.

METHODS

Study Design

The design of this study is organized into two phases.

Phase 1: Pain Assessment Scoping Review

A scoping review was conducted in this study to research the current pain assessments available to healthcare providers. A scoping review is defined as an "aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be taken as stand-alone projects in their own right, especially when an area is complex or has not been reviewed comprehensively before," (Mays, Roberts, & Popay, 2001, p. 194). The scoping review was conducted after the research question was identified to find relevant studies through an electronic database to explore current pain assessments available to healthcare providers. Reference lists from studies found were also used to discover new studies and evidence on the similar topic. Relevant studies were then selected and 17 methods of pain assessment were reviewed by this author.

Phase 2: Survey

A survey was used to collect data responses from 19 participants to address the research question. The inclusion criteria for this study were (a) registered occupational therapists that have experience working with youths who have complex communication needs. Exclusion criteria for this study were not being a Registered Occupational Therapist (OTR) currently working in a pediatric setting and having no experience working with youths who have complex communication needs and a DD.

Procedure

Phase 1: Pain Assessment Scoping Review

The scoping review was conducted by searching electronic databases, including PubMed, Google Scholar, and UWM Libraries. Within each search engine the following keywords were used to conduct the general search: “pain assessment,” “self-report pain assessments,” “physiological measures of pain,” “observational measures of pain,” and “behavioral pain assessments.” Specific assessments were then searched through the electronic databases to find studies conducted with each assessment. To find these studies the following keywords were used: “Wong-Baker FACES Pain Rating Scale,” “Pieces of Hurt,” “ The Oucher,” “Colored Analog Scale,” “Adolescent Pediatric Pain Tool,” “ Varni-Thompson Pediatric Pain Questionnaire,” “ Children’s Comprehensive Pain Questionnaire,” “Numeric Pain Rating Scale,” “ The Faces Legs Activity Cry Consolability Scale,” “Observational Scale of Behavioral Distress,” “ Non-communication Children’s Pain Checklist,” “Crying Requires Increased Vital Signs Expression Sleeplessness,” and “Premature Infant Pain Profile.” After the searches were conducted, the studies were reviewed and information gathered. The author reviewed the studies to find specific information regarding each assessment, including: type of pain it measures, specific impairment of focus, age range for usability, mode for administration, mode for response, reliability, validity, and accessibility of the standardized instrument. Three charts were then created to report the information found to provide a concise overview and map of the key concepts of each instrument. Each chart was split into a table based on the type of pain measure: (1) self-report measures, (2) behavioral measures, and (3) physiological measures. One last chart was then created to focus on the pain assessments currently used by the population for phase two of this study, youths who have complex communication needs with a DD. This chart used information to determine if each assessment measures each pain domain (location, frequency, duration, intensity, alleviators/aggravators, interference), and to determine if the assessment was accessible on devices. This table was formatted into a checklist to provide easy and quick review for healthcare providers. All four of the charts created were reviewed by a panel of two OT's and one Speech-Language Pathologist (SLP). The reviewers had expertise in pain assessment, accessibility, and language development respectively. Revisions were made accordingly and every assessment was referenced to their original author. The main revision included changing the highlights of table 3 (physiological measures) to focus on their correlation to pain ,rather than their validity and reliability for measuring pain, as there was found to be limited evidence in this area.

Phase 2: Survey

To begin the survey process, a questionnaire outline was created to ensure the study objectives were being clearly addressed and important demographic information was included to identify the participants involved in this study. The questions were designed and organized to make the survey flow and allow the responses to be comparable across the span of participants. A preliminary draft was created and reviewed by two OTs and one SLP to gain their expert insight on pain assessment and communication. Revisions were made as necessary and the survey was uploaded onto Qualtrics to allow participants to respond electronically. Respondents were collected at the Wisconsin Occupational Therapy Association (WOTA) conference in 2015 (n=11) and through an email database of current occupational therapists working in a pediatric setting (n=8). A cover letter was provided to introduce the respondents to the study and informed consent was gathered prior to the completion of the electronic survey.

Ethical Approval

The survey and data collection with all corresponding materials for this study have been reviewed by the University of Wisconsin-Milwaukee Institutional Review Board. The IRB granted Exempt Status under Category 2 by 45 CFR 46.101(b) on October 5, 2015 (see Appendix D).

Participants

Phase 2: Survey

The survey created in this study received twenty respondents electronically. A convenience sample was used to gather the twenty respondents. This was conducted at the Wisconsin Occupational Therapy Association (WOTA) conference in 2015 and through an email database sent to current pediatric occupational therapists. The database was obtained from current professors working at the University of Wisconsin-Milwaukee in OT department. The inclusion criteria for this study required participants to be occupational therapists that have experience working with youths who have complex communication needs. Exclusion criteria for this study were (a) not being a Registered Occupational Therapist (OTR) currently working in a pediatric setting and (b) having no experience working with youths who have complex communication needs with a DD. There was a drop-out rate of 5%, as one respondent reported they were not an OTR. The total amount of participants for this study is nineteen (n=19).

Four survey questions were used in the beginning of the survey to weed out any participants that fell under the exclusion criteria (n=1). Two survey questions were directed towards determining important demographic information including the type of setting the therapists' reported working in and the number of years of experience the clinician has working with the given population. Most participants (n=12) were school-based occupational therapists with 5-10 years of experience (n=6). Tables 5 and 6 further illustrate the other various healthcare settings and years of experience that were reported by the respondents.

Analysis of Survey Data

Phase 2: Survey

The survey conducted in this study included close-ended questions with multiple options for the participant to select. Data analysis completed manually with the use of Microsoft Excel and cross-tabulation charts. The data analyzed were quantitative in nature as the responses to the survey questions were categorized and frequency counts were obtained. The categorical data were organized by the amount of selections to obtain frequency counts and percentages for each response. The percentages were calculated based off of the total number of respondents for each individual question. This was done rather than compared to the total sample number (n=19) as participants did not complete the survey further than question #5 if they responded “no” to “currently assessing pain with your clients.” Data analysis then included cross-tabulations to discover the relationships between two or more sets of responses. A chi-squared test was also considered to further analyze the data, however, results would not be valid with this type of test as the sample numbers were too small (n=19).

Results

Phase 1: Pain Assessment

The scoping review resulted in 17 different methods of assessing pain including 8 self-report pain assessments, 3 behavioral pain assessments, and 6 physiological measures. Four tables were then created to map out current pain assessments with their key concepts and features.

Table 1 focused on the 8 self-report assessments as listed: (1) Wong-Baker FACES Pain Rating Scale (Wong, Hockenberry-Eaton, Wilson, Winkelstein, & Schwartz, 2001), (2) Pieces of Hurt (Hester, Foster, & Kristensen, 1990), (3) The Oucher (Beyer, Villarreul, & Denyes, 2009), (4) Colored Analog Scale (McGrath, Seifert, Speechley, Booth, Stitt, & Gibson, 1996), (5) Adolescent Pediatric Pain Tool (APPT; Savedra, Tesler, Holzemer, & Ward, 1992), (6) Varni-Thompson Pediatric Pain Questionnaire (VPPQ; Varni, Thompson, & Hanson, 1987), (7) Children's Comprehensive Pain Questionnaire (CCPQ; Chambliss, Heggen, Copelan, & Pettignano, 2002), and (8) Numeric Pain Rating Scale (NRS; McCafferey & Beebe, 1989). This table found clear similarities and broad differences between each of the pain assessments listed. The age range for these assessments is between the ages of 3-18 years. The majority assess chronic pain and cover a wide variety of different impairments. The accessibility column summarized different features of each instrument, and found that most instruments were accessible for youths to self-report their pain. It was determined by this author to further review these self-report assessments prior to phase two of this study.

Table 4 was created to concisely display the domains and accessibility of all the self-report measures to further review each assessment. The results show that all of the 8 assessments are accessible to youths who have complex communication needs, however, none of them cover all of the pain domains. Each assessment measures pain intensity, which for some assessments (i.e. Wong-Baker FACES, Pieces of Hurt, The Oucher, Colored Analog Scale, NRS) intensity is the only domain measured. The CCPQ measures the most domains (not pain interference) and is the only one to measure pain alleviators/aggravators, however, it is not found through evidence to be accessible or statistically valid/reliable on an r >.70 basis. The only assessment that measures pain interference is the VPPQ, but this measure also has not been found to be accessible or valid/reliable.

Table 2 included the 3 behavioral pain assessments: (1) The Faces Legs Activity Cry Consolability Scale (rFLACC; Merkel, Woelpel-Lewis, Shayevitz, & Malviya, 1997), (2) Observational Scale of Behavioral Distress (OSBD; Jay, Ozolins, Elliot, & Caldwell, 1983), and (3) Non-communication Children's Pain Checklist (NCCPC; Breau, Camfield, McGrath, Rosmus, & Finley, 2000). All of these assessments are used to measure acute pain and cover a variety of different impairments. The age range for these assessments is 2 months – 20 years, however, as indicated by the type of measure the youth is not the reporter of the pain experience. Rather, each assessment is conducted by a proxy. Each assessment has statistical evidence to support the reliability and validity of the measure, but results depend on the observers understanding of the assessment and ability to reliably report the youth's pain.

Table 3 reported 6 different physiological measures that are used to report pain: (1) blood pressure cuff, (2) manual pulse measurement, (3) respiration rate count, (4) Premature Infant Pain Profile (PIPP; Stevens & Johnston, 1996), (5) Crying Requires Increased Vital Signs Expression Sleeplessness (CRIES; Krechel & Bildner, 1995), and (6) abnormal cortisol and corticotrophin levels. Each assessment measures a different physiologic aspect (e.g. oxygen saturation, neuroendocrine responses, blood pressure, pulse, respiration levels) of the individual to determine their pain levels. These assessments can be used for all ages, with 2 assessments focusing on infants (PIPP & CRIES) and are reported to be used primarily by doctors and nurses.

Phase 2: Survey

Therapist's current assessment of pain

Results show that 7 out of the 19 participants reported they currently assess pain with the youths they treat, and 12 reported that they do not currently assess pain. Of the participants who reported assessing pain, the majority reported using self-report measures (n=6) and observation (n=6). Other means of assessment included physiological measures (n=3) and behavioral measures (n=5).

Furthermore, participants were asked questions in regards to which specific standardized pain measures they use based on the categories selected from previous questions. They were given the opportunity to "select all that apply." Based on the results for self-report assessments used by the participants (n=6), the majority reported use of the NRS (n=5). Four out of the 6 participants also selected "other" for use of self-report assessments, however, two did not state the assessment they use in the box given and two reported use of the rFLACC, which is a behavioral pain assessment. For the behavioral pain assessments, the participants mainly reported the use of the rFLACC (n=3), with the remaining reported "other" assessments, which were not identified in the space provided. The physiological measures reported to be used included respiration (n=3), heart rate (n=2), blood pressure (n=2), oxygen saturation (n=2), neuroendocrine responses (n=2), and palmar sweating (n=1).

Current purpose for the use of pain assessment

The following survey question inferred about the purpose(s) of using pain assessments. All 7 participants responded to the use of pain assessment to monitor client's pain over time. Other purposes included: planning treatment goals (n=6), track pain progress (n=6), determine therapy success (n=6), identify pain aggravators (n=6), identify pain alleviators (n=6), determine therapy success (n=6), and understand individual's pain perception (n=6).

Clinician satisfaction with current pain assessment

The remaining questions to be analyzed revolve around how satisfied clinicians were with their way of measuring pain. The majority of participants who assess pain (n=7) with clients reported feeling satisfied with their pain assessment (n=5), and the remaining reported feeling neutral (n=1) and dissatisfied (n=1).

Frequency of current pain assessment

The participants who reported they assess pain (n=7) were also asked how often they assess pain per week. The majority of participants assess pain 2-3 times per week (n=4). Others reported assessing pain 1 time per week (n=1) and 4 times per week (n=2).

Cross-tabulations comparisons

Cross-tabulations were created to find more results within the responses given. Based on a cross-tabulation of the different types of settings and which respondents assess pain, it was found that 11 out of 13 who reported not assessing pain were school-based OTs (Table 7). The years of experience reported was also cross-tabulated against which respondents assess pain. The results show that the majority of OTs with 2-4 years (n=4) and 5-10 years (n=5) of experience reported not assessing pain, which accounted for 9 out of the 12 participants who reported they do not assess pain (Table 8). A cross-tabulation of the type of settings and which type of assessments that were reported to be used, found that there were no significant findings between the two different groups, as the data were sporadic (Table 9). Another cross-tabulation was created to check the amount of satisfaction respondents had based on the type of assessment they reported using. The results show that the majority of participants who responded being satisfied (n=8) with their current pain assessment, reported the use of self-report measures (n=4) and observation methods (n=4) (Table 10).

DISCUSSION

Results from this study aim to improve the way occupational therapists assess pain in youths with a DD who have complex communication needs. Phase one of this study demonstrates there currently is not a pain assessment available that measures a holistic picture of an individual’s unique pain experience. All of the pain assessments and measures reviewed in the scoping review provide beneficial information for clinicians, however, no one measure includes all of the pain domains and is appropriate for youths who have complex communication needs. Most of these assessments are not found to be accessible, and are even impossible to use electronically. This makes them impossible to be used by those who may have a disability or impairment that prohibits them from reading or speaking to report their pain experience. All of this research has been converted into four tables which provide an easy and concise way of reviewing major pain assessments currently being used in the field. These tables make it more efficient and effective for a clinician to determine which pain assessment may be most beneficial to use with their clients.

Phase two of this study, the survey portion, has clear results that more than half of the participants (12 out of 19, 63%) do not assess pain in their current practice. This is a concerning result as it was evidenced through the literature review that pain often interferes with a youth’s daily activities and participation. The results from the survey also show that self-report was the main method of assessment. It was also noted that 2 of the 6 participants that reported use of self-report measures inaccurately stated the use of the rFLACC, which is a behavioral assessment. Further, 2 of the 6 participants from that same sample reported using “other” assessments than the ones listed, but were unable to report the name of the assessment. This is important to be note, as this can signify false representation of the accurate responses and the respondents may be unaware or unsure that the pain methods they reported were not actually self-report measures.

A prominent result from the survey was the population of participants who reported they do not currently assess pain. A total of 11 out of 13 respondents who stated they do not assess pain were school-based OTs. Also, 10 out of the 13 respondents reported having between 2-10 years of clinical experience. These results are important to discuss, as it has been proclaimed that pain assessment is a human right and can have a negative impact on occupational performance, participation, and QOL. School-based OTs have ample opportunities to assess pain in youths with disabilities and observe them in their natural environments. The OTs with years of experience reported they do not assess pain, which is a concerning factor as pain interfered with daily life. A number of factors could be limiting the assessment of pain. These factors could be that the clinicians are undereducated on the importance of assessing pain, do not have access to an accessible standardized pain instrument or do not recognize the occurrence of pain.

FUTURE IMPLICATIONS

Study results indicate that pain assessment is not being done accurately, with the use of a self-report measure and during every OT treatment session for youths who have complex communication needs. This conclusion helps prove that something needs to be changed about current pain assessments. Study findings also indicate that a new pain assessment needs to be created for youths who have complex communication needs. The next steps should be the development and testing of a new standardized pain instrument and evidence-based studies to ensure its reliability and validity. Future research should also be conducted to determine if pain assessment is being completed accurately in other client populations. The results also imply that current OTs may not be educated on this topic and should be given more opportunities to learn through continuing education on the importance of assessing pain, and the most accurate ways to complete pain assessment.

LIMITATIONS

Based on the survey results and the knowledge gained through the literature review, there are clear limitations of this study. One limitation is that this study only included 19 participants, which gives a small representation of registered occupational therapists. This restricted the author from completing more detailed statistical analysis of the results (e.g. chi-squared test). The small sample size is a limitation, however, this may be due to the refined group of participants based on the strict inclusion and exclusion criteria. Having a refined group of participants makes the study more focused and ensures the sample fits the population being discussed. A larger sample size would be beneficial to obtain to possibly gain more knowledge on this topic. Another main limitation to be aware of, is that survey results are all personal answers by the participants and trustworthiness is a factor to consider as it is impossible to determine through the survey if the participants were completely truthful with all of their given responses. This may cause a sample bias, but it cannot be assumed do to the nature of the study being anonymous.

CONCLUSION

This study helps to clarify what is currently being done to assess pain and to determine what needs to be done to help improve the way pain is assessed for youths who have complex communication needs. The study shows that clinicians are satisfied with their current approach to pain assessment, however, other areas of the study results prove that clinicians may be under-educated on this topic and may not understand the accurate ways to assess pain for youths. During the scoping review, current pain assessments were found to not cover the span of domains that are necessary to fully determine a youth's pain experience and are not accessible to all populations. This implies that there is not currently an accurate pain assessment in the field for youths who have complex communication needs with a DD to self-report their unique pain experiences. Based on the evidence-based research in the literature review and the results of the survey it can be implicated that a new pain assessment needs to be created to allow youths who have complex communication needs with a DD to self-report their pain.

DECLARATION OF INTEREST

The author reports no declaration of interest.

TABLES AND FIGURES

Table 1: Self-report pain assessments

Name of Pain Measure	**Pain Type**	**Specific Impairment**	**Age**	**Mode for Administration**	**Mode for Response**	**Reliability & Validity**	**Accessibility**	**References**
Wong-Baker FACES Pain Rating Scale	Chronic	Communication deficits/ variety	3-18 years	Paper, plastic card, key chain	Pointing and selection of corresponding face of pain intensity	Concurrent validity: Other pain measures r =.67–73 Inter-rater correlations =.26–.37 (Lindsey et al., 2008)	Allows youths who are nonverbal to individually select their pain; online PDF available	Wong, Hockenberry-Eaton, Wilson, Winkelstein, & Schwartz, P., 2001
Pieces of Hurt	Acute or Postoperative	Procedure related	4-7 years	4 red poker chips representing levels of pain	Selection of corresponding poker chip to represent their pain intensity	Inter-rater correlations r =.23–.70 Concurrent validity =.65–.94 Test-retest reliability (r=.83) (Lindsey et al., 2008)	Allows youths who are nonverbal to select a poker chip to identify their pain intensity	Hester, Foster, & Kristensen, 1990
The Oucher	Chronic	Communication deficits/ variety	3-12 years	Paper	Pointing and selection of corresponding face of pain intensity	Concurrent validity r =.62–.95 Test-retest reliability = 78% of children reported scores within ± one level after 15 min. (Lindsey et al., 2008)	Allows youths who are nonverbal to individually select their pain intensity; online PDF available	Beyer, Villarruel, & Denyes, 2009
Colored Analog Scale	Chronic	Poor cognition in an emergency setting	4-17 years	Scale on paper the size of a thermometer	Slide the marker to the spot on the scale that shows pain intensity	Strong discriminative validity ($P < .0001$), strong convergent validity ($P < .0002$); acceptable test-retest reliability (r=0.89) (Tsze, Baeyer, Bulloch, & Dayan, 2013)	Scale is not visually accessible as colors are used to represent pain intensity (green=no pain; red = worst pain); Allows youths who are nonverbal to self-report their pain.	McGrath, Seifert, Speechley, Booth, Stitt, & Gibson, 1996
Adolescent Pediatric Pain Tool	Acute	Hospitalized youths; variety of diagnoses	8-17 years	Questionnaire with a body outline, word graphic rating scale, and a pain descriptor list	Point to the body, select rating of pain intensity and descriptors	Supporting convergent validity (r = .68 to r = .97); high test-retest reliability (r=0.91);	Low accessibility for visual impairments; Difficult to understand with a cognitive impairment; requires fine motor selection skills.	Savedra, Tesler, Holzemer, & Ward, 1992

Name of Pain Measure	**Pain Type**	**Specific Impairment**	**Age**	**Mode for Administration**	**Mode for Response**	**Reliability & Validity**	**Accessibility**	**References**
Varni-Thompson Pediatric Pain Questionnaire	Chronic or recurrent	Variety	5-18 years	Self-administration paper questionnaire	The youth must select corresponding answers using pen and paper	Test-Retest reliability (r=.29–.41) Inter-rater correlations (r=.40–.85) VAS predictive of disability estimates (*p* <.05) Convergent Validity(r =.27–.68) (Lindsey et al., 2008)	Youths who are nonverbal can use this questionnaire; low accessibility for visual impairments; online PDF version available	Varni, Thompson, & Hanson, 1987
Children's Comprehensive Pain QuestionNaire	Chronic or recurrent	Variety	7-18 years	Self-administration paper questionnaire including a visual analogue scale and a facial affective scale	The youth responds using pen and paper to answers questions on the questionnaire	No evidence-based research conducted	Youths who are nonverbal can use this questionnaire; low accessibility for visual impairments; requires fine motor skills	Chambliss, Heggen, Copelan, & Pettignano, 2002
Numeric Pain Rating Scale (NPRS/ NRS)	Acute	Any, no specific inclusion criteria	6 years or older (Castarlenas, Miro, Sanchez-Rodriguez, 2013)	Use NRS horizontal line with rated numbers while asking patient how intense their pain is on a scale of 0-10.	Using NRS number line to select (point or say audibly) pain intensity	Was found to have high convergent construct validity (r=0.73-0.86), adequate discriminant validity (z=2.05-5.55), and adequate criterion-related validity (r=0.45-0.70) (Castarlenas, Miro, Sancehz-Rodriguez, 2013).	Point to a number selection indicating pain intensity. Those administering the assessment can provide different sized charts to help those with low vision, or make it portable to allow a client to point to the number line.	McCaffery & Beebe, 1989

Table 2: Behavioral pain assessments

Name of Pain Measure	**Pain Type**	**Specific Impairment**	**Age**	**Mode for Administration**	**Mode for Response**	**Reliability & Validity**	**Accessibility**	**References**
The Faces Legs Activity Cry Consolability Scale (FLACC)	Post-operative pain	Post-surgery; any impairment	2 months-7 years	Scoring guide (paper), chart to record	Pen/pencil or typed notes to record score of child's reactions	High interrater reliability. Validity through decreased FLACC scores after anesthesia. Criterion validity found through high correlations with objective pain scale, and nurses' global pain ratings.	Need to be able to read and rate perceived pain level of the youth;, Online PDF available. Does not allow child/patient input.	Merkel, Voelpel-Lewis, Shayevitz & Malviya, 1997
Observational Scale of Behavioral Distress (OSBD)	Acute pain due to cancer	Cancer	2-20 years	Use OSBD to rate intensity of behavior domains (Cry, scream, physical restraint, etc) observed in child.	The youth does not need to participate and will be observed by caregiver/ healthcare provider using OSBD form and pen/pencil.	Reliability: interrater r= 0.99 with total agreement-disagreement rating of 0.84. Validity of distress scores: r=0.62 (p<.001) correlation with trait anxiety, r=.76 (p<.0001) correlation with pain thermometer, r=.62 (p<.02) correlation with experienced pain. Validity of parent ratings: correlated with children's total distress (r=0.30, p<0.04).	Not readily found online. Must contact authors to receive and pay for forms.	Jay, Ozolins, Elliot & Caldwell, 1983
Noncommunication Children's Pain Checklist (NCCPC)	Post-operative (when using specific version), general pain.	Severe cognitive impairments (Breau, McGrath, Camfield & Finley, 2002)	3-18 years	2 hour observation rating pain/behaviors based on NCCPC form.	The youth does not need to participate. Parent/ healthcare provider responds for child using NCCPC with pen/pencil.	Internally consistency, consistent over time (95%), 84% sensitivity and 77% specificity. (Breau, McGrath, Camfield & Finley, 2002)	PDF format available. Does not allow for child/patient input. Observer needs to be able to understand scoring criteria and observed behaviors and relate to what is observed when watching the child.	Breau, Camfield, McGrath, Rosmus & Finley, 2000

Table 3: Physiological measures of pain assessment

Name of Measurement	**Measures**	**Age**	**Mode for Administration**	**Mode for Response**	**Correlation to Pain**	**Accessibility**	**References**
Blood Pressure Cuff	Blood Pressure	All	Blood pressure cuff placed around limb and stethoscope if needed by a health care provider; self-administration with an electronic blood pressure monitor	Patient must sit still in comfortable position and breathe normally; arm must be placed level with the heart	A study consisting of 209 children, found that there is a relation between acute pain sensitivity and blood pressure in children, and acute pain sensitivity predicts diastolic blood pressure. Further, higher acute pain ratings during childhood preceded the development of higher blood pressure 1.5 years (Drouin & McGrath, 2013)	Accessible with different size cuffs and different electronic versions to allow for self-administration if appropriate	Johns Hopkins Medicine, 2015
Manual Pulse Measurement	Pulse	All ages	Self-administration or health care professional; Firmly pressing on the arteries located close to the surface of the skin (side of neck, inside of elbow, or wrist); count pulse for 60 seconds	Patient must sit still and breath normally	A study done with 15 participants found that heart rate is important to determining the onset of acute pain. For every patient in the study, acute pain was consistently related to heart rate (Robinson, 1967)	Accessible for either self-administration, if not able than health care provider can administer at multiple locations on the body	Johns Hopkins Medicine, 2015
Respiration Rate Count	Respiration	All ages	Health care provider; Measured by counting the number of breaths for one minute by counting the amount of times the chest rises	Patient must be at rest and breathing normally	In a study done with 2,646 participants, results found that there were relationships between the acute pain score and respiratory rate, with patients reporting a pain score of 10 having a slightly higher respiratory rate (Fowler, Slater, Garza, Maani, DeSocio, Hansen, & McGhee, 2011).	Accessible as health care provider takes count, if unable to lay completely flat than count may be taken at closest laying position possible	Johns Hopkins Medicine, 2015

Table 3 Continued: Physiological pain assessments

Name of Measurement	Measures	Age	Mode for Administration	Mode for Response	Correlation to Pain	Accessibility	References
Premature Infant Pain Profile (PIPP; Stevens & Johnston, 1996)	Oxygen Saturation	Preterm and term neonates	Neonates' oxygen saturation is observed during procedure and scored.	Based on the infants observed behavior within 30 seconds, this determines if the neonate is in pain. A higher rating on the PIPP scale indicates more pain.	A change indicating there could be a painful stimulus to the infant.	The healthcare provider needs to know how to measure and understand what oxygen saturation means in terms of pain for an infant.	Srouji, Ratnapalan & Schnee-weiss, 2010
Crying Requires Increased Vital Signs Expression Sleeplessness (CRIES; Krechel & Bildner, 1995)	Oxygen Saturation	<1month	Scale used to determine if infant is in pain.	Infant is observed and their behaviors are used to determine which rating they fit in best. The higher rating indicates higher pain expression.	A decrease in oxygen saturation denotes pain.	The healthcare provider needs to know how to measure and understand what oxygen saturation means in terms of pain for an infant.	Srouji, Ratnapalan & Schnee-weiss, 2010
Abnormal Cortisol and Corticotrophin Levels	Neuroendocrine Responses in relation to severe pain	Not specified	Doctors test cortisol and corticotrophin serum levels to determine if patient then needs higher dosage of opioids to relieve severe pain	Patient must allow diagnostic testing	Study found 15 of 22 patients tested had abnormal levels, these 15 patients needed daily morphine doses >150mg. Further reliability and validity of this way to determine pain intensity has not been studied.	Patient needs to understand that they are in severe pain. Doctors need to know about neuroendocrine responses and how it relates to indicating the severity of pain.	Melville, 2012

Table 4: Self-report pain assessments checklist

Assessment Title	**Nonverbal youths**	**Measures Location**	**Measures Frequency**	**Measures Duration**	**Measures Intensity**	**Measures Alleviators/aggravators**	**Measures Interference**	**Accessible on devices**	**Reliable (r >.70)**	**Valid (r>.70)**
Wong-Baker FACES Pain Rating Scale	☒	☐	☐	☐	☒	☐	☐	☐	☐	☒
Pieces of Hurt	☒	☐	☐	☐	☒	☐	☐	☐	☒	☒
The Oucher	☒	☐	☐	☐	☒	☐	☐	☐	☒	☒
Colored Analog Scale	☒	☐	☐	☐	☒	☐	☐	☐	☒	☒
Adolescent Pediatric Pain Tool	☒	☒	☐	☐	☒	☐	☐	☐	☒	☒
Varni-Thompson Pediatric Pain Questionnaire	☒	☒	☐	☐	☒	☐	☒	☐	☐	☐
Children’s Comprehensive Pain Questionnaire	☒	☒	☒	☒	☒	☒	☐	☐	☐	☐
Numeric Pain Rating Scale (NPRS/NRS)	☒	☐	☐	☐	☒	☐	☐	☐	☒	☒

Table 5: Participant employment settings

# 2	Answer		Response	%
1	Acute Hospital		4	21%
2	Inpatient Rehabilitation		2	10%
3	Outpatient		3	15%
4	Home Health		1	5%
5	Private Practice		1	5%
6	Day or Community Program		0	0%
7	School		12	63%
8	Other		0	0%

Table 6: Participant employment history

# 4	Answer		Response	%
1	Less than 1 year		1	5%
2	1-2 years		2	11%
3	2-4 years		6	31.5%
4	5-10 years		6	31.5%
5	10+ years		4	21%
	Total		19	100%

Table 7: Type of setting vs. if they currently assess pain

	Do you currently assess pain with your clients?			
		YES	NO	TOTAL
Type of Setting	School-based (1)	1	11	n=12
	Acute Hospital (2)	3	1	n=4
	Inpatient Rehabilitation (3)	2	0	n=2
	Outpatient (4)	2	1	n=3
	Home Health (5)	1	0	n=1
	Private Practice (6)	1	0	n=1
	TOTAL	n=10	n=13	n=23

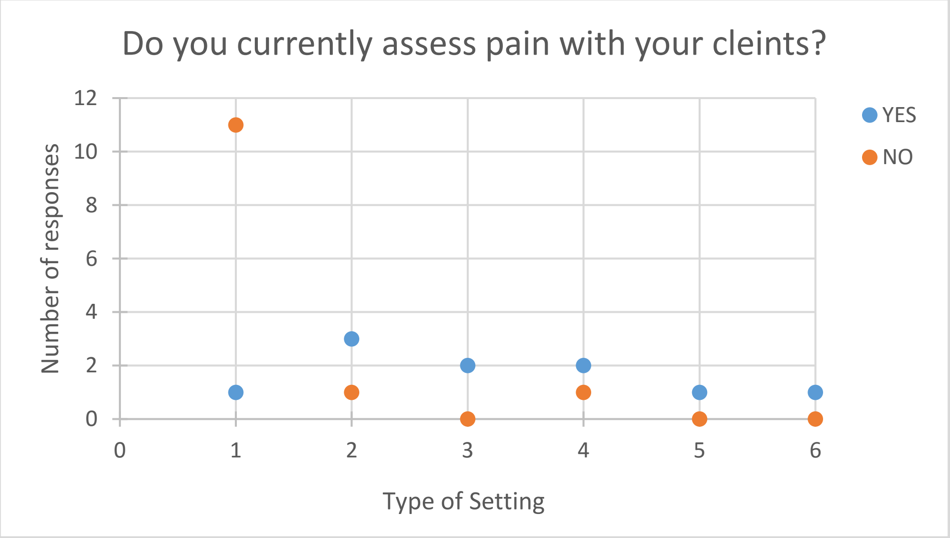

Figure 1: Type of setting vs. if participants currently assess pain

Table 8: Years of experience vs. if they currently assess pain

		Do you currently assess pain with your clients?		
		Yes	No	TOTAL
Years of Experience	Less than 1 year (1)	0	1	n=1
	1-2 years (2)	1	1	n=2
	2-4 years (3)	2	4	n=6
	5-10 years (4)	1	5	n=6
	10+ years (5)	3	1	n=4
	TOTAL	n=7	n=12	n=19

Table 9: Type of setting vs. type of pain assessment

		Type of Pain Assessment				
		Self-report	Observation	Physiological	Behavioral	TOTAL
Type of Setting	School	1	1	0	1	n=3
	Acute Hospital	2	3	2	3	n=10
	Inpatient Rehabilitation	2	2	2	2	n=8
	Outpatient	2	2	1	1	n=6
	Home Health	1	0	0	0	n=10
	Private Practice	1	1	1	1	n=4
	TOTAL	N=9	N=9	N=6	N=8	n=41

Table 10: Type of setting vs. satisfaction level

		Satisfaction Level			
		Satisfied	Neutral	Dissatisfied	TOTAL
Type of Setting	School	0	1	0	n=1
	Acute Hospital	3	0	1	n=4
	Inpatient Rehabilitation	2	0	1	n=3
	Outpatient	2	0	0	n=2
	Home Health	1	0	0	n=1
	Private Practice	1	0	0	n=1
	TOTAL	N=9	N=1	N=2	N=12

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APPENDICES

Appendix A: Pain Assessment Survey

The purpose of this survey is to gather knowledge on how registered occupational therapists (OTR) are currently assessing pain in the pediatric population and to gain expert review of a new pain assessment iPad app. Please keep in mind the clientele being discussed is youths chronologically aged 7-to-12 years old when answering the following questions. Response to this survey is voluntary and will be kept confidential. Thank you for completing this survey and we appreciate you contributing to our study.

1. Are you currently a Registered Occupational Therapist (OTR) in a pediatric setting?
   - Yes
   - No

[If response is no: end of survey]
[If response is yes: next question]

2. In what type setting(s) do you work? (Select all that apply)
   - Acute Hospital
   - Inpatient Rehabilitation
   - Outpatient
   - Home Health
   - Private Practice
   - Day or Community Program
   - School
   - Other

3. Do you have experience working with youths (ages 7-12 years chronologically) who are nonspeaking and have a developmental disability?
   - Yes
   - No

[If response is no: end of survey]
[If response is yes: next question]

4. How many years of experience do you have working with this population?
   - Less than 1 year
   - 1-2 years
   - 2-4 years
   - 5-10 years
   - 10 or more years

5. Do you currently assess pain with your clients?
   - Yes
   - No

[If response is no: go to gPad section]
[If response is yes: next question]

6. Which type of assessment do you use to assess pain? (Select all that apply)

- Self-report assessment
- Observation
- Physiological measures
- Behavioral measures
- Other

[If self-report: move question 7]
[If observation move to question 8]
[If physiological: move to question 9]
[If behavioral measures: move to question 10]
[If other: move to question 11]

7. Do you use any of the following self-report assessments? (Select all that apply)
   - Adolescent Pediatric Pain Tool (APPT)
   - Varni-Thompson Pediatric Pain Questionnaire (VPPQ)
   - Children’s Comprehensive Pain Questionnaire (CCPQ)
   - Numeric Rating Scale (NRS)
   - Other

8. Who reports pain in regards to the youth’s pain experience based on observation of behaviors? (Select all that apply)
   - Healthcare provider
   - Parent
   - Caregiver
   - Other

9. What types of physiological measures are evaluated when assessing pain in the youth’s life? (Select all that apply)
   - Heart rate
   - Blood pressure
   - Respiration
   - Oxygen saturation
   - Palmar sweating
   - Neuroendocrine responses
   - Other

10. What behavioral type of pain assessment do you use? (Select all that apply)
    - Faces, Legs, Activity, Cry, and Consolability (rFLACC)
    - Noncommunication Children’s Pain Checklist (NCCPC)
    - Other

11. How satisfied are you with the current assessment of pain used?
    - Very unsatisfied
    - Unsatisfied
    - Neutral
    - Satisfied
    - Very satisfied

12. For what purpose do you use current pain assessment? (Select all that apply)
    - Plan treatment goals
    - Monitor clients’ pain over time
    - Track pain progress
    - Identify pain aggravators
    - Identify pain alleviators
    - Determine therapy success
    - Understand individual’s pain perception
    - Other

[Have this linked to be answered with each selected mode of pain assessment in question 6]

13. How often do you assess pain with an individual client?
    - 4+ times per week
    - 2-3 times per week
    - 1 time each week

End of Survey - Thank You

Appendix B: Survey Email Sent to All Potential Participants

Hi (Potential Participant),

Alyssa Guard and I are working on our theses which involves the completion of a survey by OTs working in a pediatric setting. We spoke with Dr. Engel and she suggested contacting you to see if you have any contacts that we could reach out to via email to send them our survey. The survey takes no more than ten minutes and responses are anonymous. We are interested in contacting OTs who have experience working with children ages 7-12 years old. Our theses are focusing on how pain is currently being assessed in a clinical setting and if the iPad application we have created would be feasible for use with children who are nonverbal with a developmental disability.

If you have any contacts that you are willing to share with us, we would really appreciate this. Otherwise, if you are more comfortable sending the email yourself, we can give you the link to the survey and our email body that has been created and reviewed with our IRB submission.

We thank you for your time and supporting our study. Please let us know if you have any other questions.
Michelle Putzer & Alyssa Guard
BSMS 2013 OTS

Appendix C: Consent to Participate in Online Survey Research

Study Title: Pain Assessment of Nonverbal Youths with Developmental Disabilities & Survey of Assessing Pain in Clinical Practice and Applicability of a New Assessment

Person Responsible for Research: Alyssa Guard, OTS, Michelle Putzer, OTS and Joyce Engel, PhD, OT

Study Description: The purpose of this study is to determine how pediatric occupational therapists assess pain in nonverbal youth's with a developmental disability. Consequently, we will establish the clinical utility of the developed pain iPad app. Approximately 50 subjects will participate in the study. If you agree to participate, you will be asked to complete a brief written survey. This survey will ask you questions about your practice area and age of clients served, how information on a client's pain is collected and used, and feedback on the utility of demonstrated iPad application. This will take approximately 15 minutes of your time.

Risks / Benefits: Risks to participants are considered minimal. Collection of data and survey responses using the internet involves the same risks that a person would encounter in everyday use of the internet, such as breach of confidentiality. While the researchers have taken every reasonable step to protect your confidentiality, there is always the possibility of interception or hacking of the data by third parties that is not under the control of the research team.

There will be no costs for participating. There are no benefits to you other than to further research.

Limits to Confidentiality Identifying information such as your name, email address, and the Internet Protocol (IP) address of this computer will not be asked or available to the researchers. Data will be retained on the Qualtrics website server for 10 months and will be deleted by the research staff after this time. However, data may exist on backups or server logs beyond the timeframe of this research project. Data transferred from the survey site will be saved on a password protected computer for 10 months. Only Alyssa Guard, Michelle Putzer, and Joyce Engel will have access to the data collected by this study. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

Voluntary Participation: Your participation in this study is voluntary. You may choose to not answer any of the questions or withdraw from this study at any time without penalty. Your decision will not change any present or future relationship with the University of Wisconsin Milwaukee.

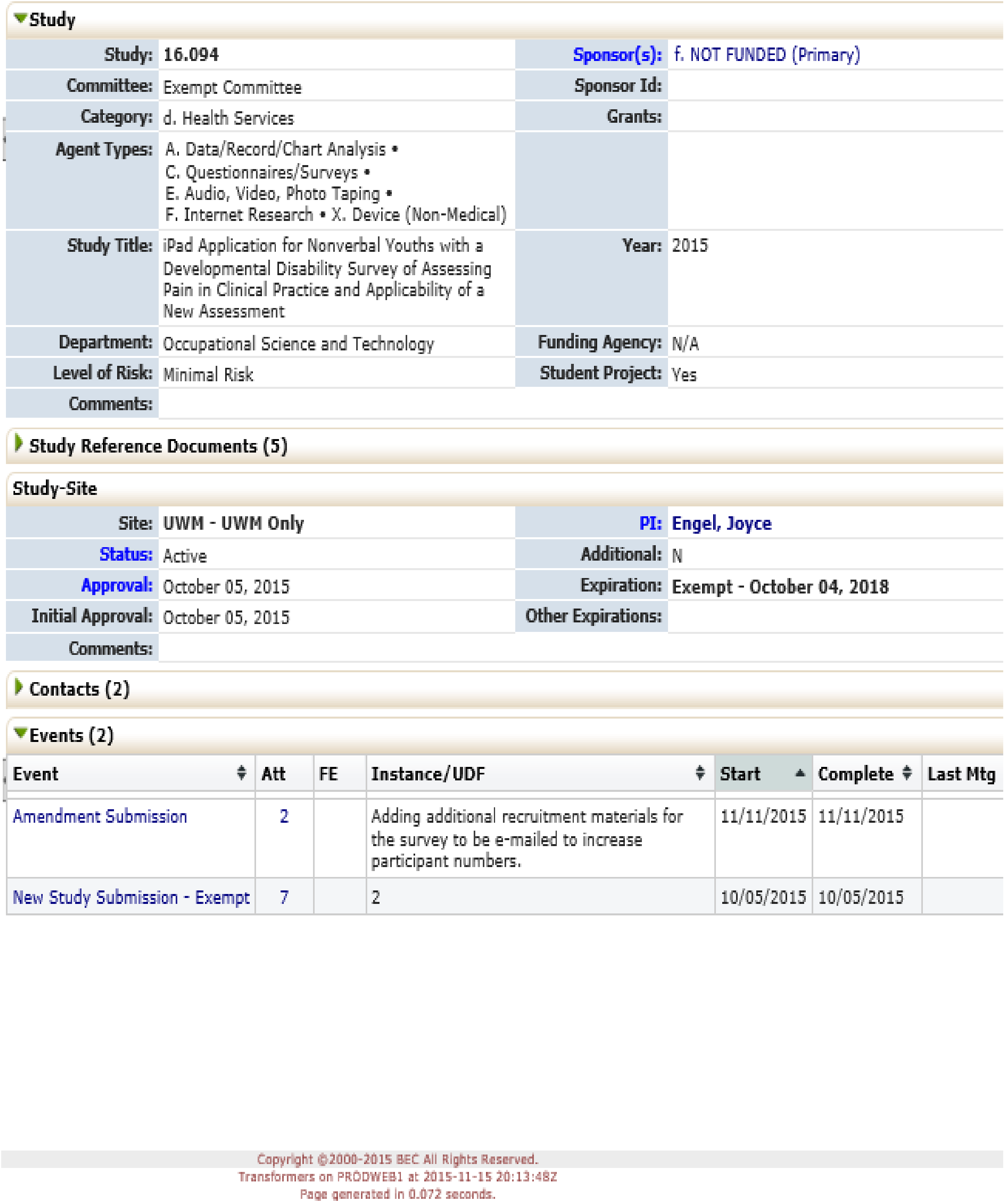
Who do I contact for questions about the study: For more information about the study or study procedures, contact Alyssa Guard (arguard@uwm.edu), Michelle Putzer (mrputzer@uwm.edu), or Joyce Engel (engel@uwm.edu).

Who do I contact for questions about my rights or complaints towards my treatment as a research subject? Contact the UWM IRB at 414-229-3173 or irbinfo@uwm.edu

Research Subject's Consent to Participate in Research:
By entering this survey, you are indicating that you have read the consent form, you are age 18 or older and that you voluntarily agree to participate in this research study.

Thank you!

Appendix D: IRB #16.094 Approval Exempt Status



▼Study

Study:	**16.094**	**Sponsor(s):**	f. NOT FUNDED (Primary)
Committee:	Exempt Committee	**Sponsor Id:**	
Category:	d. Health Services	**Grants:**	
Agent Types:	A. Data/Record/Chart Analysis • C. Questionnaires/Surveys • E. Audio, Video, Photo Taping • F. Internet Research • X. Device (Non-Medical)		
Study Title:	iPad Application for Nonverbal Youths with a Developmental Disability Survey of Assessing Pain in Clinical Practice and Applicability of a New Assessment	**Year:**	2015
Department:	Occupational Science and Technology	**Funding Agency:**	N/A
Level of Risk:	Minimal Risk	**Student Project:**	Yes
Comments:			

▶ Study Reference Documents (5)

Study-Site

Site:	**UWM - UWM Only**	**PI:**	**Engel, Joyce**
Status:	Active	**Additional:**	N
Approval:	October 05, 2015	**Expiration:**	**Exempt - October 04, 2018**
Initial Approval:	October 05, 2015	**Other Expirations:**	
Comments:			

▶ Contacts (2)

▼Events (2)

Event	Att	FE	Instance/UDF	Start	Complete	Last Mtg
Amendment Submission	2		Adding additional recruitment materials for the survey to be e-mailed to increase participant numbers.	11/11/2015	11/11/2015	
New Study Submission - Exempt	7		2	10/05/2015	10/05/2015	

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Appendix E: Thesis Proposal

PAIN ASSESSMENT OF NONVERBAL CHILDREN WITH DEVELOPMENTAL DISABILITIES

by

Alyssa Guard & Michelle Putzer

A Project Submitted in Fulfillment of the Requirements for the degree of

Master of Science

In Occupational Therapy

at

The University of Wisconsin-Milwaukee

July 2015

Abstract

PAIN ASSESSMENT OF NON VERBAL CHILDREN WITH DEVELOPMENTAL DISABILITIES

By

Alyssa Guard and Michelle Putzer

The University of Wisconsin-Milwaukee, 2016

Under the supervision of Dr. Joyce Engel

(Name of App) is an application that was designed to be a pain assessment for nonverbal children experiencing a developmental disability to self-report their pain. The app was developed by two University of Wisconsin-Milwaukee Master of Science Occupational Therapy students. The purpose of this app is to allow children to express their pain experiences in a variety of domains and give their caregivers an opportunity to understand their child's pain. Healthcare professionals working with these children will also be able to discover the way pain interferes with the child's daily life and can further work with the child to reduce pain and pain interference. Seven pain domains were used to create this app. They include pain location, frequency, duration, intensity, alleviators and aggravators of pain, and pain interference. Based on the research and current pain apps, these domains were found to be the most important and beneficial to identifying a child's pain through self-report. Moving further this app could be developed and mainstreamed into the use by nonverbal children with developmental delays experiencing pain in everyday life.

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Purpose of the Study

The purpose of this study is to design a communication board that can be used by non-verbal youths with developmental disabilities in order for therapists to understand their pain experiences. Jensen (2010) stated that “No measure of pain is perfect. No one measure assesses all pain domains, nor is any single measure useful in all settings and with all populations. Moreover, because of the imperfection of available instruments, it is theoretically possible to modify any existing measure to improve it further, or to develop new and better measures to replace existing ones,” (p.251). This statement reinforces our purpose and desire to create a new pain assessment for children that can be used in many clinical settings in order to provide client-centered care.

The communication board being designed in this study will include a variety of different domains of pain that are not included in most pediatric pain assessments. The domains of pain will include detailed locations, intensities, durations, pain interference, and activities that may aggravate or reduce the pain. The assessment will allow individuals to select different body parts they feel experience pain. As Jensen stated, “Patients often have more than one pain problem,” (p. 252) we feel it is necessary that patients are given the opportunity to report more than one pain problem. Intensity of pain will be reported in this assessment to allow patients to rate which pain problems are the most severe and also gives them the opportunity to express how much the pain affects them. The duration domain will give clinicians the sense of how long the individual’s pain is interfering in daily life and allows the client the opportunity to express if the pain occurs all day or for only periods of time. The last domain being evaluated with this assessment is profoundly important to give the patient the moment to express in which activities they experience pain the most. This will give clinicians a crucial look into which activities may be aggravating their pain and the activities that should be adapted or minimized to lessen the experience of pain. This assessment will also provide a more timely approach to save quality treatment time for more implementation of interventions, rather than lengthy evaluation.

Literature Review

Pain

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage,” (International Association for the Study of Pain, 1994). There are two basic types of pain, acute and chronic. Acute pain serves a biological purpose to alert the person that tissue irritation or damage is occurring. In contrast, chronic pain is persistent pain that is no longer serving a biological purpose (Chambliss et al., 2002). Chronic pain persists beyond the normal tissue healing time, which is usually 3 months (International Association for the Study of Pain, 2003). Chronic pain involves a complex interaction of physiologic, psychological, and social factors (Chambliss et al., 2002).

Prevalence of Pain

The prevalence of chronic pain in American youths is an important topic to address for the realization of the importance of this study. Huguet and Miro (2007) conducted an epidemiological study to provide information on the prevalence of pediatric pain. Participants included 561 children between the ages of 8 and 16 chronological years. Results of the study showed that 37.3% of the children reported having chronic pain. This study further concluded that chronic pain is highly prevalent in the youth community (Huguet & Miro). Because chronic pain does have a large prevalence, it is important to continue to address the pain experiences of youths as they go through therapy.

Zwakhalen van Dongen, Hamers, and Abu-Saad (2003) reported everyday pain in people with intellectual disabilities is common yet is rarely treated. Also, people with intellectual disability appear to have 2 to 5 times more health problems than people without intellectual disability (Zwakhalen van Dongen et al.). The limited amount of research makes it difficult to accurately determine pain prevalence in individuals with intellectual or developmental disabilities. This is important to remember as a child with a developmental disability may also have an intellectual disability, creating more communication barriers for them to express their pain. The above statements can help us to conclude that pain is prevalent in this population and should be widely recognized as an issue these individuals are experiencing.

Pain Interference

The interference of pain is important to research for this study to help us gather information as to how pain may be affecting the youths that may be using the communication board. This will also help us gather information to incorporate into our project. In a study done by Roth-Isigkeit, Thyen, Stoven, Schwarzanberger, & Schumucker (2005) examining the effects of chronic pain on daily activities, they found 68.2% of the youths responding reported having restrictions in completing daily activities due to pain. This can include absence from school, missing out on meeting up with friends, loss of appetite, disturbances in sleep, and inability to pursue hobbies. Of the youths responding, 53.6% reported to experience sleep disturbances in a range of sometimes to always as a result of their pain. Of the sample indicated, 53.3% reported that they are unable to pursue hobbies because of the experienced of pain. Absence from school was often or always occurring in 13% of students and sometimes occurring for 35.8% of students. Students with abdominal pain and headaches are more likely to miss school than those who have back pain. This same group of children with abdominal pain and headaches are also more likely to miss "hanging out" or meeting up with friends than youths who have back or limb pain. They also reported to experience a loss of appetite due to pain more than those with pain in their back or limbs. In this study, as age increased so did pain interference (Roth-Isigkeit et al.).

Similarly, Chambers, Huguet, King, MacDonald, MacNevin, McGrath, & Parker (2011) performed a systematic review of chronic recurrent pain in youths to determine individual factors related to pain. This systematic review included 41 published papers. The study found that complaints of chronic pain were significantly correlated with several variables: chronic health problems, frequent change of residence, poor performances at school, frequent television watching, and fewer interactions with other children. The children described in this study were also found to miss school, withdraw from social activities, and are at risk of developing internalizing symptoms in response to their pain (Chambers et al.). The pain prevalence study mentioned previously by Huguet et al. (2007), also discussed negative consequences that chronic pain can exert on youths. The study participants reported consequences that included reduced quality of life, missing days from school, and were more likely to use pain medication.

It is evident based on the literature that youths who are experiencing pain, whether they can express it verbally or not, are experiencing disruptions in their daily activities. The importance of being able to address the pain appropriately can help reduce or eliminate pain interference ultimately allowing the child to pursue desired activities.

Importance of Assessing Pain

Jensen (2010) has written extensively on the importance of pain assessment. He stated that “valid and reliable pain assessment is essential for successful pain care,” (pp. 251). This statement supports the idea that adequate assessment is necessary to determining the need for intervention, and to understand the mechanisms of those effects. Clinicians and researchers need to be able to understand all aspects of a child’s life, including their pain intensities, in order to help them further their development and improve their quality of life. The systematic review completed by Chambers et al. (2011) demonstrated the need to assess pain because chronic pain is a serious developmental health concern that can interfere significantly with daily functioning.

It is important for clinicians and researchers to consider the issues related to pediatric pain so they can develop effective strategies to improve the possible problems.

Breau, Camfield, McGrath, & Finley (2007) completed a comparison study with 63 children and their caregivers to determine whether pain reduced the adaptive functioning of youths with severe intellectual disabilities. The authors addressed the issue that at the time of the study pain was found to interfere with functioning of typical children, but no studies had been completed with children with pre-existing intellectual disabilities. They believed that an understanding of the impact of pain on the daily lives of children will assist caregivers in minimizing the consequences of pain and assisting with development of rehabilitation programs that focus on where pain is most problematic. 64% of youths displayed their possible abilities during pain-free days and only 53% did this during days of experiencing pain. These results suggest that children displayed significantly more abilities when pain-free than when pain was present. The pain was found to impact all areas of functioning, including communication, daily living, social and motor skills. The study concluded that youth's long-term functioning could be affected because of reduced practice of skills, when faced with chronic pain from an early age (Breau et al., 2007). Ratnapalan, Schneewiess, & Srouji (2010) completed a thorough literature review that supports why it is important to assess pain. Pain in infants, children, and adolescents is often underestimated and therefore undertreated. Another topic addressed concluded that youths who experience pain in early life show long-term change in terms of pain perception and related behaviors (Ratnapalan et al.). These statements help justify that it is important for healthcare professionals to assess, address, and reduce the pain and associated anxiety as much as possible because pain interferes with the youth's daily life and long-term psychosocial development.

Overall pain is important to assess in all patients that may be experiencing pain. It is one's right to receive pain reduction and suffering. Our belief closely follows the International Association of the Study of Pain's Declaration of Montreal (IASP, 2015). The title of this declaration is the "Declaration that Access to Pain Management Is a Fundamental Human Right." One of the main objectives of this declaration is as follows:

> "The obligation of all health care professionals in a treatment relationship with a patient, within the scope of the legal limits of their professional practice and taking into account the treatment resources reasonably available, to offer to a patient in pain the management that would be offered by a reasonably careful and competent health care professional in that field of practice. Failure to offer such management is a breach of the patient's human rights," (IASP).

This bold statement helps healthcare professionals, to realize how important it is to allow youths and other patients the opportunity to express their pain, and receive pain evaluation, and receive intervention to help manage the pain itself.

How Pain is Assessed

There are three main methods for measuring pain: self-report, behavioral, and physiological measures. Self-report measures are found to be the most valid and optimal, however, they are dependent on individual's cognitive development and language skills. Conrad, Fanurik, Harrison, Koh, and Tomerun (1998) completed an exploratory study of self-report skills with 47 children with borderline-to-profound cognitive impairment between the ages of 7-8 years. This study was completed to determine the extent to which children with cognitive impairment understand a simple pain intensity scale or their skills underlying its use. The authors discussed how the "gold standard" for pain assessment is self-report, (Conrad, Fanurik, Harrison, Koh, & Tomerun). However, proxy report by a parent is often used in pediatric health care services to help determine pain a child is having when they are unable to report the information themselves. In past research, it is well documented that in both adult and children information provided by proxy respondents is not equivalent to that reported directly by the patient (Irwin, Gross, Stucky, Thissen, DeWitt, Lai, Antmann, Khastou, Varni, & DeWalt, 2012).

Behavioral measures include: assessment of crying, facial expressions, body postures, and movements. This type of measurement is most often used with neonates, infants, and younger children where communication is difficult. Physiological measures include assessment of heart rate, blood pressure, respiration, oxygen saturation, palmar sweating, and sometimes neuroendocrine responses. These methods are only valid for acute pain and differ depending on the general health and maturational age of the infant or child (Ratnapalan et al., 2010). Based on the research done, it can be concluded that self-report is the best way to approach assessment of the private experience of pain. Self-report will be the main focus of the following review of assessments as this is the method of pain assessment that is going to be used to build the communication board. The review of standardized pain instruments will begin with ones used by all children, and then will focus in on our desired population.

Type of Measure	Measures	Standardized Instruments
Self-Report	Pain intensity	Wong-Baker FACES Pain Rating Scale (Wong DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P., 2001).
		Pieces of Hurt (Poker Chip Tool) (Hester, Foster, and Kristensen, 1990).
		Colored Analog Scale (McGrath, Seifert, Speechley, Booth, Stitt, and Gibson, 1996)
Behavioral	Physical discomfort and pain intensity	The Faces Legs Activity Cry Consolability Scale (FLACC)

		(Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997)
	Pain-related distress	Observational Scale of Behavioral Distress (OSBD) (Jay, Ozolins, Elliot, & Caldwell, 1983)
Physiological	Blood Pressure	Blood pressure cuff

Table 1: Additional assessment resources for pediatric children between the ages of 7 to 12 years not mentioned in the literature of this review.

A review of pain measurements done by Ratnapalan et al. (2010), found a self-report measurement that is widely used for children experiencing pain within the chronological ages of 7-to-12-years-old. These include the Adolescent Pediatric Pain Tool (APPT; Savedra, Tesler, Holzemer, & Ward, 1992). APPT is a valid all-encompassing pain assessment tool used for individual pain assessments and measures intensity, location, and quality of pain in youths older than 8 years of age. This tool is most useful with children and adolescents who are experiencing refractory pain. It consists of a body diagram to allow youths to point to the location(s) of pain on their body and a word graphic scale to measure pain intensity (Ratnapalan et al., 2010). This assessment is important to consider in our research to see what is provided in a comprehensive self-report of pain.

Two questionnaires have been commonly used for youths to help them self-report their pain. The Varni-Thompson Pediatric Pain Questionnaire (Varni, Thompson, & Hanson, 1987) includes a visual analog scale (VAS; White & Snow, 1985) a body outline, a color coded scale for determining distress and discomfort from the pain, questions regarding family history, pain descriptors, and questions relating to socio-environmental factors to help assess chronic or recurrent pain. The VAS is a straight line with two ends that are defined as the limits of the sensation being measured. VAS is a cross-modality matching in which the length of the line is adjusted to match the strength of the perception. This self-report measure can be used for pain intensity and has been found to be reliable for children 5 years of age and older (Shields, Cohen, Harbeck-Weber, Powers, & Smith, 2003). This questionnaire has three versions allowing parents to report for children, a version for adolescent aged children to self-report and for children less than 7 years old to answer. The Children's Comprehensive Pain Questionnaire uses open-ended questions with the VAS to assess chronic and recurrent pain (Chambliss et al., 2002). It is unknown if a child with a mild cognitive impairment can reliably answer these questionnaires, and cognition should be considered and tested with the assessment we create.

To be more precise on the ways pain is assessed with our population, further research was done on pain assessments for nonverbal children with or without cognitive disability. All of these assessments do not include self-report. One way the Children's Hospital of Philadelphia has found to be beneficial in assessing pain for children with a severe or profound cognitive disability is through the revised version of the Face, Legs, Activity, Cry and Consolability (rFLACC; Merkel, Voepel-Lewis, Shayevitz & Malviya, 1997) pain assessment. This assessment was reported to have clinical practicality and allowed for parents and caregivers to enter in individualized information about the child's pain behaviors. For example, if a child was frequent to have a clenched jaw or quivering chin the child would score a 2 in the face section. A score of 1 would constitute occasional grimacing or frowning and a 0 is no particular expression. High scores of the rFLACC suggest a child is experiencing pain. This assessment takes about a minute to complete according to registered nurses testing the assessment at the hospital (Chen-Lim, Zarnowsky, Green, Shaffer, Holtzer, & Ely, 2012).

The Noncommunication Children's Pain Checklist (NCCPC; Breau, Camfield, McGrath, Rosmus & Finley, 2000) is a 30-item checklist of common pain behaviors of youths who are nonverbal. They are categorized into vocal, eating or sleeping, social or personality, facial expression of pain, activity, body or limbs, and physiologic pain behaviors. A postoperative version was created, eliminating the eating or sleeping category. Both versions of this assessment have been noted to be time consuming to complete as they require observation time.

The Individualized Numeric Rating Scale (INRS; Curley, 2003) is another form of assessing pain in a youth who is nonverbal. In this assessment caregivers are asked to rate pain behaviors as a result of the intensity of pain to the corresponding level of intensity. This instrument is used if the child is above the chronological age of 3 years and has a cognitive disability (Solodiuk & Curley, 2003). Both of these assessments have been found to have convergent validity between their total scores and ratings. The INRS ratings were higher before a pain intervention and lower after, indicating reduced pain as to be expected. This was not dependent on the type of rater, supporting the assessment’s construct validity (Solodiuk, Scott-Sutherland, Meyers, Myette, Shusterman, Karian, Harris, & Curley, 2010).

The rFLACC, NCCPC, and INRS assessments rely on observations and accuracy of the rater in the child’s presentation of each area, instead of the child self-reporting these pain behaviors and the level of severity that corresponds. The study mentioned earlier by Conrad et al. (1998) also noted that there are pain assessment scales available that have been developed and validated for children with limited verbal and comprehensions skills, such as the Faces Pain Scale (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990), the Poker Chip tool (Hester, Foster, & Kristensen, 1990), and the Oucher (Beyer, Villarruel, & Denyes, 2009). However, none of these have been studied in youths with cognitive impairments. Having all of this research on different ways that pain is currently assessed in our population, we can note that a new self-assessment would be useful because most of these assessments cannot be used with non-verbal children with developmental disabilities. This research will also help us in designing and creating a communication board to assess pain.

Project Population

We want to make a communication board for youths who are nonverbal and have a developmental disability. Both verbal and nonverbal reports require a certain level of cognitive and language development for the child to understand and give reliable responses (Ratnapalan et al., 2010). However, it should be tested as to what cognitive level our assessment would be appropriate for considering it is difficult to determine a child's cognition when they are non-verbal as well. This population has limited research, and it is mostly concerned about the intensity of pain or broad location of the pain.

An exploration study completed by Conrad et al. (1998) found that 50% of children with borderline and 35% of children with mild cognitive impairment were able to correctly use the Numeric Pain Rating Scale (NRS; McCaffery, M, Pasero, C., 1999). Half of the children with cognitive impairment demonstrated skills, such as magnitude and ordinal position, which may allow them to use simpler pain rating methods. Children with moderate to greater levels of cognitive impairment did not pass the entire self-report evaluation (Conrad et al., 1998). However, having an assessment that allows for a comprehensive self-report of their pain experiences will allow for better understanding and treatment of it by the clinician, even if the child cannot complete the assessment in its entirety. Adaption can be made to how a child responds to the questions, with a switch or head stick, or how they have the questions read to them, audibly or independently.

The Ratnapalan et al. study (201) on the review of pain assessments contributed to our narrowing of inclusion criteria. The authors stated that infants and children present a unique challenge that require consideration of their chronological age, developmental level, cognitive and communication skills, previous pain experiences, and associated beliefs. It was stated that healthcare professionals depend on self-report from school-aged children, and we agree. The authors also mentioned that children at roughly 7 to 8 years of age begin to understand the quality of pain. Children at this age are able to understand their pain and may begin to tell how it is affecting their life. Self-report, visual analogues, and numerical scales are effective in this age group. Children's capability to describe pain increases with age, experience, and changes throughout their developmental stages (Ratnapalan et al., 2010). These statements helped us decide to make a chronological age requirement of 7-12 years. An assessment with broad age limits may make it difficult for healthcare professionals to decide which pain assessment to use. Also, having an age requirement for an assessment will allow for an increase in the reliability and validity of the assessment.

One particular age group that stood out in our decision of age inclusion criteria was 6 to 10 years, or middle childhood. At this level, fine motor skills include good dexterity with small objects and precision and motor planning that is needed to use possible communicative devices, such as an iPhone or iPad. The cognitive abilities for this age range include demonstration of flexible problem solving, solving of complex problems, and abstract reasoning. These cognitive skills are important for this study because of the in-depth questions asked of the child to answer, however adaptations will be made to allow for the use of the communication device with children who may have a cognitive impairment (Case-Smith & O'Brien, 2010).

The Centers for Disease Control and Prevention (2015) define developmental disability as a "group of conditions due to impairment in physical, learning, language, or behavior areas." Based on the developmental levels mentioned above, individuals with a developmental disability may have an interference with or have limited ability to complete tasks within their expected developmental range. This is important to consider when creating our assessment for children with a developmental disability.

Current Pain Applications

When searching the Apple App Store, various pain applications are presented. Some apps are able to be downloaded for free, with options to upgrade the app for a small cost while others have a price tag of up to $42, approximately. The Web MD app allows users with a chronic pain condition to track how frequently throughout the day they are experiencing pain in relation to their diagnosis, along with triggers for their pain and a section to journal each day (WebMD, LLC, 2014). The My Pain Diary app allows a user to upload photos and print or email the tracking of their pain to share for medical purposes. It also costs $4.99 to download, with no additional cost after the initial download to use various app features (Lynn, 2013). The Chronic Pain Tracker is an app that costs $9.99 and has multiple features to allow users to track their pain history. The features include pain location mapping on a diagram of a body and allows users to have a section in which they can input information they wish to share with their doctor (Chronic Stimulation, LLC, 2014). Pain Tracker is another app that is an interface to record information about an individual’s pain and monitors the changes over time. The app is sold for $0.99 and all of the upgrades are included for free (iHealth Ventures LLC, 2012). Pain Logger is an app that gives you the option to get a lite edition for free, otherwise costs $0.99. The Pain Logger app helps users track their pain intensity levels over time and allows users to insert multiple pain locations (Astin, 2015).

All of these apps are a great way for individuals to track their pain intensity levels and location over time. However, the majority of the apps available in the Apple store are tailored more towards adults. The way the apps are presented with different charts and longer descriptions interferes with the ability for children between the ages of 7 and 12 years old to use this app. Also, the apps that use a body diagram use an adult body which is more developed and show more details than children would be able to understand.

One app that is tailored toward children ages 7 years and older is the Healing Buddies Comfort Kit^{TM}. In this application children can choose one of the 5 feelings of worried, sick, tired, pain, awake. Based on the selection, it leads the children into a definition of what they are feeling and why as well as a list of what they can do to feel better. Each of these skills is able to be spoken to the child by them hitting the speaker button. It also has additional tips and instructions for kids and a section for parents to learn how they can contribute to helping their child feel better. This app is free with no additional charges for other features inside the app (Culbert, Fitzgerald, Sullwold Ristau, & Harrington, 2012). Although it is a great tool for providing tips and tricks for alleviating a child's pain and other side effects from any medical condition it does not go as in depth to provide enough information about the child's pain as well as information a clinician can use.

Pain Squad is another app that is geared toward children between the ages of 8 and 18 that allows them to track their pain within a 12 hour span. The app has a police theme to help the kids "put pain where it belongs…behind bars". Mainly the app is meant for children with cancer to track their pain each day during treatment, and has an option to set up reminders so they do not forget to track. Besides providing a body map and intensity scale, it also includes a section to select pain descriptors and a chart of their pain intensity over time (The Hospital for Sick Children, 2015).

Researching all of these current applications has given us a good understanding on features our app should include. Our pain app will need to be easier to comprehend and not include charts that can be confusing to understand with no verbal or audible explanation. It will also include how the pain is interfering in the youth's day, as this is going to be helpful for clinicians and children to understand how their pain is hindering their daily life.

App Title	Location	Frequency	Duration	Intensity	Alleviate/aggravators	Interference
Web MD Pain Coach	☐	☒	☐	☒	☒	☐
My Pain Diary	☒	☒	☐	☒	☒	☐
Pain Diary & Community-CatchMyPain	☒	☒	☐	☒	☐	☐
Chronic Pain Tracker	☒	☐	☒	☒	☒	☐
Pain Tracker	☐	☒	☐	☒	☒	☐
Healing Buddies Comfort Kit TM	☐	☐	☐	☐	☒	☐
Pain Logger	☒	☐	☐	☒	☐	☐
Pain Squad	☒	☐	☐	☒	☐	☐

Table 2: Current pain applications available for individuals to track various pain domains.

Need for New Assessment

Every child's perception of pain is going to vary, even if they all are exposed to the same noxious stimulus. This further supports the need for self-report of pain experiences of the child, which as stated earlier is the current "gold standard" for pediatric pain assessment. Forms of self-report can include interviews, questionnaires, pain rating scales, and pain diaries recording events causing pain onset, intensity, and duration (Chambliss et al., 2002).

Every assessment is different and allows for variability in understanding pain for certain individuals. However, many assessments available today for nonverbal children with developmental disabilities do not provide a subjective view the youth's private experience of pain. A new universally designed assessment, including a variety of pain dimensions, will allow clinicians to give their pediatric patients a subjective client-centered approach towards improving their daily activities and quality of life. The pain dimensions added into the communication board are important in understanding the whole person and will give clinicians more detailed information about their patients' pain experiences. These dimensions are important because past research has found that “pain is a multidimensional experience that includes a number of measurable qualities” (Jensen, 2010).

Methods

Design

An extensive review of the pain assessments currently available for youths has been completed in order to develop a new pain assessment. Each assessment that promotes self-report of the child’s pain experience and has been studied to have strong psychometric properties will be considered in the development of a more universal and comprehensive pain assessment. Each assessment used to help in the development of the pain assessment app is listed in Appendices 2, 3, and 4.

Procedures

To ensure that the developed iPad application and assessment have content validity, expert reviewers will complete a survey and provide feedback on the utility and ease of the assessment in clinical practice in addition to the content. These expert reviewers will not be contributing to the initial development; instead the supporting advisor and committee members of the project will be providing feedback on the app. Then, the expert reviewers can provide information on how practical they feel the use of the app would be in the clinic and if the app covers topics they find most important to assess.

Development of the app is made possible through the use of Prototyping on Paper, an iPad app that will take a picture of the hand drawn page and allow the user to create links to other pages creating the feel of an app (WOOMOO, Inc., 2014). This will be useful in creating our own prototype to see if this is feasible in the population we hope to use this assessment with after its development. In order to keep some similarity with pictures for the youths taking the assessment, Boardmaker symbols will be used when applicable (Tobii Dynavox, 2015). Many of the youths who may be taking the pain assessment, may also have their own communication board and be familiar with these symbols. Universal design concepts, such as voice over, high contrast, and Boardmaker symbols are being used during this entire process. The Apple iPad has many great features that allows for creating a universally designed app that will not limit which children will be able to use the pain assessment app once developed.

A decision tree (Appendix 1) has been written out and developed before creating each page of the app on Prototyping on Paper's app and website. Following the decision tree, drawings and symbols will be put together on grid paper following the dimensions of the app. Every sheet will then be scanned onto the iPad using the Prototyping on Paper's app. Setting up direct links will make new locations for the app to go to based off what the user selects and for order of questions within the app being developed. Once this process is completed, then expert review and suggestions will be considered to cover any errors or possible improvements that could be made to the completed app.

In Appendix 2 the Numeric pain rating scale is depicted. The Numeric Pain Rating Scale has shown to have adequate test-retest reliability when using one assessment to test the pain intensity each week for two weeks, and excellent test-retest reliability when testing two or more days during the first week compared to testing the pain level two or more days during the second week. This was with a population experiencing chronic pain (Jensen and McFarland, 1993). Content validity, when studied with people who acquired a spinal cord injury, was voted by participants as being used first over the visual analogue scale, and was voted to be a valid measure to be a part of a minimum data set (Bryce, 2007). This is what the intensity rating will be based on in the app development.

Appendix 3 contains the Varni-Thompson Pediatric Pain Questionnaire. This includes a body chart for children to mark and color code pain areas. The psychometrics for this assessment, along with its parent and physician questionnaire counterparts, has good test-retest reliability when testing at intervals of 1 week, 3 weeks, and 6 months. This assessment has also been used to assess children with chronic pain, beside the original intended populations of juvenile rheumatoid arthritis and sickle cell disease. The shows the utility and generalization that is possible across pediatric populations (Cohen, Lemanek, Blount, Dahlquist, Lim, Palermo, McKenna, and Weiss, 2008). This assessment is aiding in the body mapping for pain locations.

In Appendix 4 the Adolescent Pediatric Pain Tool is displayed. This assessment is shown to have adequate content, construct, and criterion validity, test-retest reliability, alternate forms reliability, inter-rater reliability, and internal consistency reliability. Sensitivity to reduction in pain was also found with this assessment over five days postoperatively. The psychometric properties of the APPT indicate that it is adequate for children between the ages of 8 to 17 years old. Boys and girls are both also found to be appropriate for this assessment, as well as individuals from diverse cultural groups (Jacob, Mack, Savedra, Van Cleve, & Wilkie, 2014). This assessment will aid in providing different ideas for domains to be considered with the new app and the body map also will help with implementing a body into the app to determine the location of the child's pain.

The part of the pain app that includes the rating of the interference of pain on daily activities was pulled from the assessment in Appendix 5. This assessment was developed with previous students being supervised under Dr. Engel.

Participants

The intended population for this application is for youth's ages 7-12 years old that have a developmental disability and are non-verbal to use as a way to express their pain experience to a therapist or caregiver. Until further research has been conducted children who are younger than this developmental age group should not be considered to use this app effectively. Also, it should only be used on an iPad.

Materials

The main materials of this study are a pen, pencil, colored pencils, sharpie markers, tape, scissors, paper, and iPad. To make the assessment the pen, pencil, colored pencils, and paper are going to be needed to draw up the various screens for the app. The tape and scissors will serve the purpose to cut Boardmaker symbols to the correct size and tape them onto assigned grid papers to fit the Prototyping on Paper's layout. Then the iPad is needed to take pictures of the pages and upload them to the Prototyping on Paper account.

Limitations

One limit to this study is that this pain assessment will be entirely designed on an iPad. This hinders the use of the pain assessment for individuals who cannot afford an iPad or do not have access to an iPad. Children who do have access to an iPad, this app will contribute in giving them the opportunity to express their experiences with pain to their caregiver and therapist in a manner that allows for potential insight into new ways to decrease the amount of pain experienced daily. Overall, this will increase the individual's amount of occupations they can participate in and quality of daily life. Another limitation to this study is that individuals may not be technologically savvy, resulting in inability to use this app based on a technology device. This can extend to not understanding how to set up voice over, or connect a switch or scanning method for selecting buttons on the app. Not having enough adaptations available may be another limitation for individuals who may be visually impaired or illiterate. This limitation can be address by the accessibility given by the iPad product, which includes adaptations for the visually impaired and illiterate individuals.

Future Implications

The next step that should be taken for this pain assessment is conducting evidence-based research on this app. The research should include completing a survey to mail out to expert reviewers, which could be health care professionals working with children with developmental disabilities. The healthcare professionals could be occupational therapist, physical therapists, speech language pathologists, or professionals specializing in assistive technology devices. The step after completing the survey would be to take the results and implicate them into the development of the full app to be accessible in the iTunes store for Apple products. Further research could then be done using the app in clinical trials to ensure the reliability and validity of this pain assessment. Future research should also be conducted to determine if the pain app is improving healthcare professional's ability to better understand nonverbal children's pain and help alleviate pain and pain interference of daily life.

Discussion

The medium in which this app is developed on can be both an asset and setback to the administration of a pain assessment. Apple has many universal design features that allow for children with a variety of abilities to use the app successfully. However, until the app is fully developed beyond the prototype it is difficult to use all of the universal design features on the iPad. Based on the input from the expert reviewers…

Appendix 1

Pain Assessment

Pg. 1: “Name of Assessment” “start’

Location

Pg. 2: Front of body picture “Pick your worst pain location”

Pg. 3: dependent on selection made on page 2

- Head and neck: “Pick the exact location of your pain”
  - → Close up of head and neck
    - → possible selections: ears, eyes, nose, mouth, teeth, forehead, chin, cheeks
    - → Side of head and neck
    - → Back of head and neck
- Torso: “Pick the exact location of your pain”
  - → Side of torso
  - → Back of torso
- Arm: “Pick the exact location of your pain”
  - → possible selections: fingers, hand, forearm, elbow, upper arm, shoulder
- Leg: “Pick the exact location of your pain”
  - → possible selections: toes, foot, ankle, shin, calf, knee, thigh, hip

Frequency

Pg. 4: “How often do you have this pain?” “Everyday” “weekly” “monthly” “constant”

Pg. 5: dependent on selection made on page 4

- Weekly possible selections: 1 time per week, 2-3 times per week, 3-4 times per week, 4-5 times per week, and 5 or more times per week
- Monthly possible selections: 1-2 times per month, 2-3 times per month, 3-4
- times per month, 4-5 times per month, and 5 or more times per month

Duration

Pg. 6: “How long does this pain last?”

- Possible selections: 1 minute, 5 minutes, 10 minutes, 30 minutes, 60 minutes, 1-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, and 21-23 hours; Constant

Intensity

Pg. 7: “On a scale of 0(no pain)-10(worst pain possible), how much does this pain hurt?”

- Possible selections: 0,1,2,3,4,5,6,7,8,9,10

Helps pain

Pg. 8: “What helps your pain?”

- Possible selections: “nothing” “exercise/movement” “concentrating/relaxing” “medication” “changing thoughts” “heat” “cold” “stretching”

Aggravators of Pain

Pg. 9: “What makes your pain worse?”

- Possible selections: “nothing” “exercise/movement” “stress” “depression” “walking” “sitting” “laying down” “heat” “cold”

<u>Interference of Pain</u>

Pg. 10: “On a scale of 0 (no pain)-10 (worst pain possible), how much does your pain interfere with the following activities?”

- Pg. 11: “General Activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 12: “Mood” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 13: “Ability to get around” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 14: “School work and participation” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 15: “Socializing” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 16: “Sleep” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 17: “Playing recreational activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 18: “Self-cares” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 19: “Communication with others” “0 1 2 3 4 5 6 7 8 9 10”

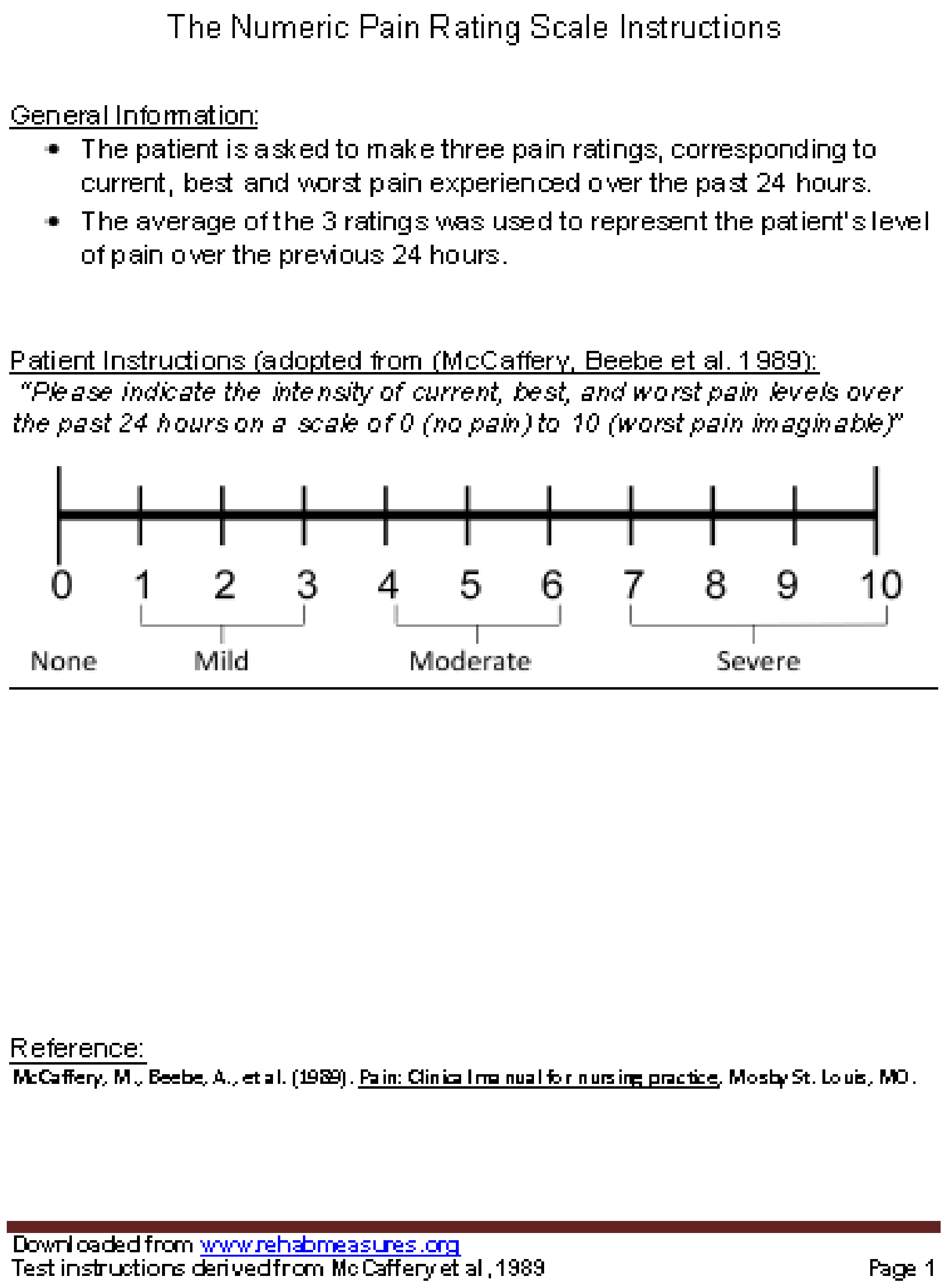
Pg. 20: “Do you have any other pain locations?”

- Possible selections: “yes” “no”

Pg. 21: dependent on answer to page 20

- Yes: start back at page 2 and repeat the entire process for a new pain location
- No: “ End of Assessment” “Thank you”

Appendix 2



The Numeric Pain Rating Scale Instructions

General Information:

- The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours.
- The average of the 3 ratings was used to represent the patient's level of pain over the previous 24 hours.

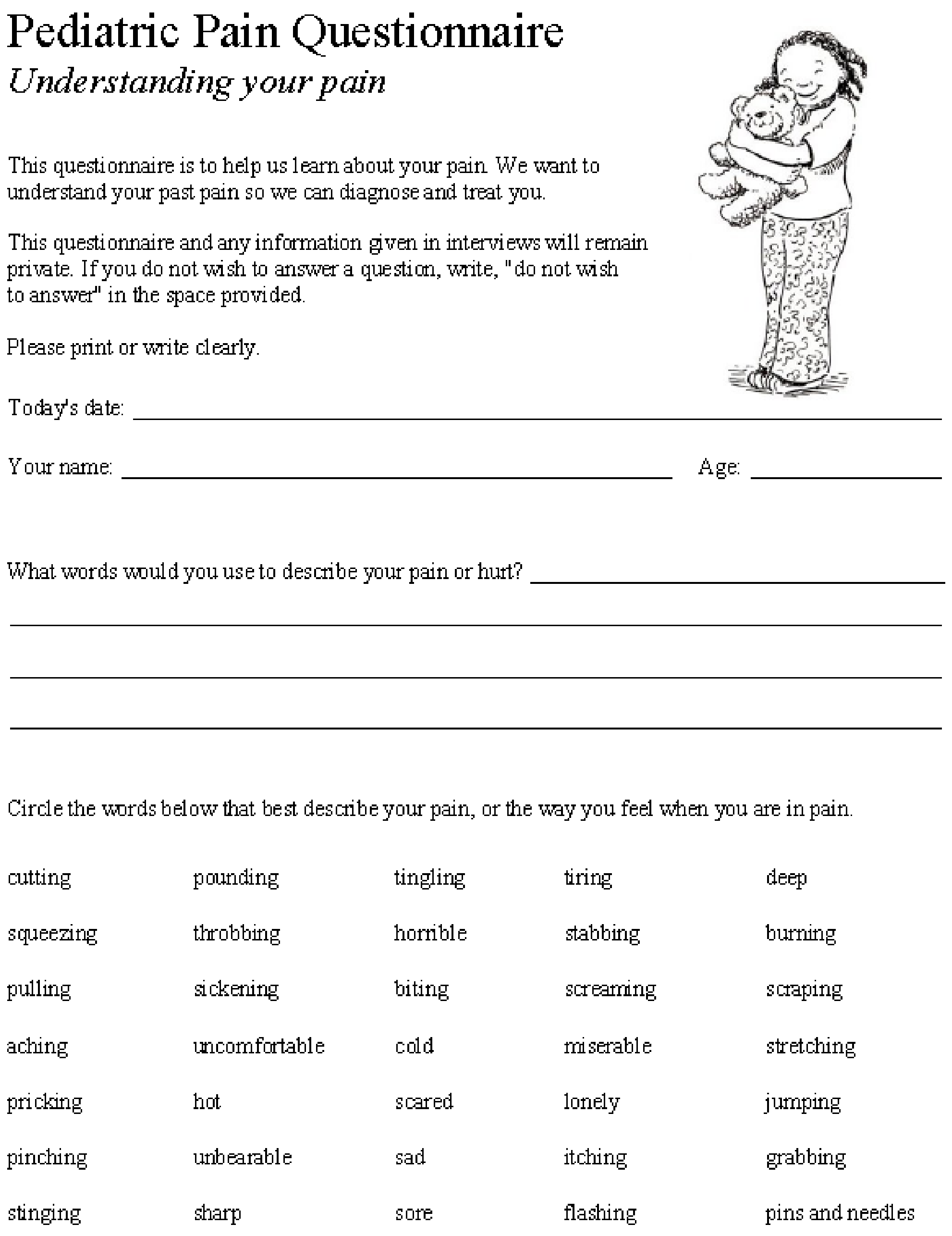
Patient Instructions (adopted from (McCaffery, Beebe et al. 1989):

"Please indicate the intensity of current, best, and worst pain levels over the past 24 hours on a scale of 0 (no pain) to 10 (worst pain imaginable)"

Reference:

McCaffery, M., Beebe, A., et al. (1989). Pain: Clinical manual for nursing practice, Mosby St. Louis, MO.

Appendix 3



Pediatric Pain Questionnaire

Understanding your pain

This questionnaire is to help us learn about your pain. We want to understand your past pain so we can diagnose and treat you.

This questionnaire and any information given in interviews will remain private. If you do not wish to answer a question, write, "do not wish to answer" in the space provided.

Please print or write clearly.

Today's date: ______________________________

Your name: ______________________________ Age: __________

What words would you use to describe your pain or hurt? ______________________________

____

____

____

Circle the words below that best describe your pain, or the way you feel when you are in pain.

cutting
squeezing
pulling
aching
pricking
pinching
stinging
pounding
throbbing
sickening
uncomfortable
hot
unbearable
sharp
tingling
horrible
biting
cold
scared
sad
sore
tiring
stabbing
screaming
miserable
lonely
itching
flashing
deep
burning
scraping
stretching
jumping
grabbing
pins and needles

Appendix 3

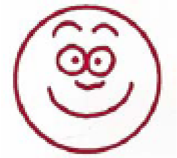
From the words you wrote or circled, which three words best describe the pain you are feeling right now?

____

____

____

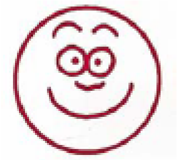
Rate **how you feel now**. If you have no pain put a mark at the end of the line by the happy face. If you have some pain, put a mark near the middle of the line. If you have a lot of pain, put a mark by the sad face.



Not hurting
No discomfort ____ Very uncomfortable
No pain

Hurting a whole lot
Severe pain

Rate **the worst pain you had this week**. If you had no pain this week, put a mark at the end of the line by the happy face. If the pain you had was some hurting, put a mark by the middle of the line. If the worst pain you had was a whole lot of pain, put a mark by the sad face.



Not hurting
No discomfort ____ Very uncomfortable
No pain

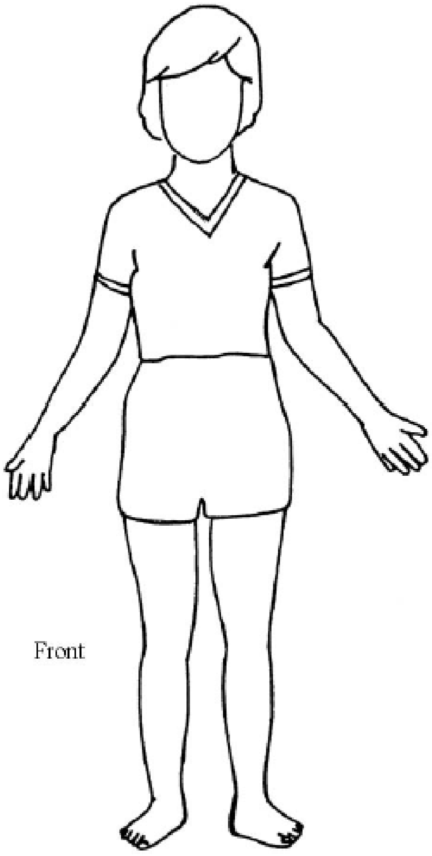
Hurting a whole lot
Severe pain

From Hockenberry MJ, Wilson D, Winkelstein ML: Wong Essentials of Pediatric Nursing, ed. 7, St. Louis, 2005, p. 1259. Used with permission. Copyright Mosby.

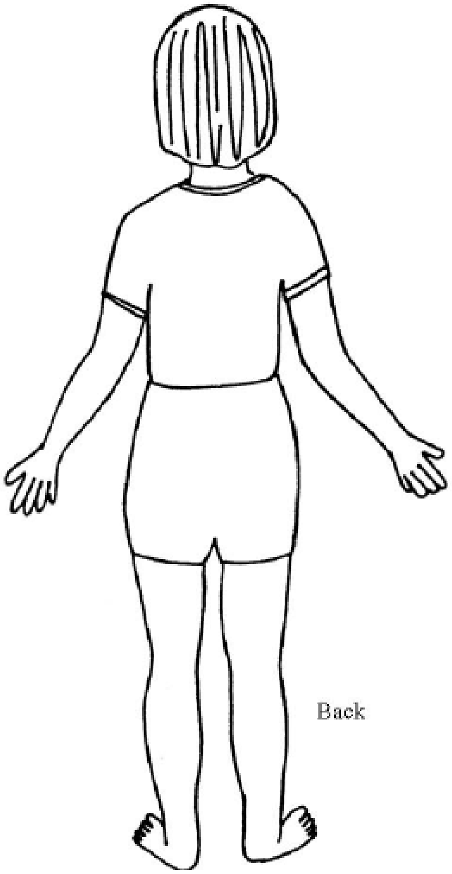
Appendix 3

Pick colors that mean **no hurt**, **a little hurt**, **more hurt**, and **a lot of hurt** to you and color in the boxes.
Now, using those colors, color in the body to show how you feel.

No pain No hurt	Mild pain A little hurt	Moderate pain More hurt	Severe pain A lot of hurt
☐	☐	☐	☐



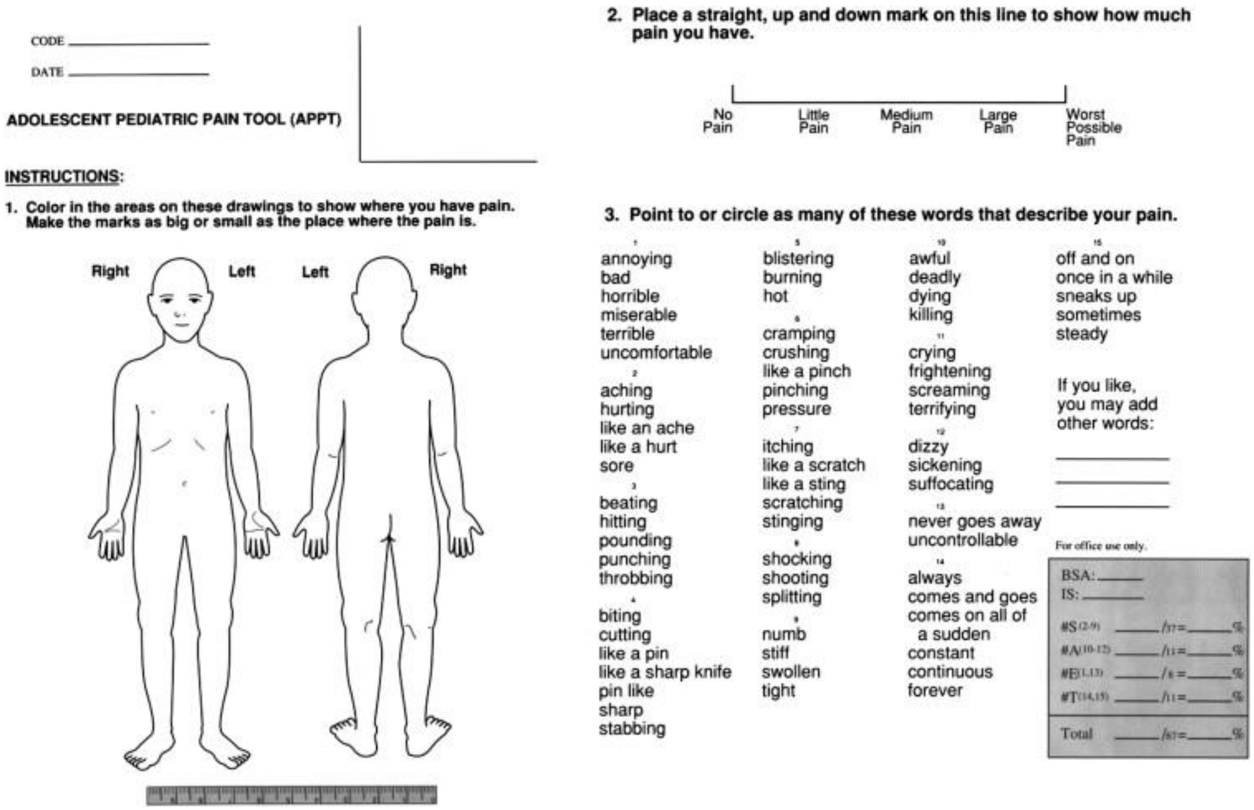
Front



Back

Children's
Hospital & Regional Medical Center

4800 Sand Point Way NE, PO Box 5371, M/S 9G-1
Seattle, WA 98105-0371
Phone 206-987-2704
Fax: 206-987-3935



CODE ________________

DATE ________________

ADOLESCENT PEDIATRIC PAIN TOOL (APPT)

INSTRUCTIONS:

1. **Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.**

2. **Place a straight, up and down mark on this line to show how much pain you have.**

3. **Point to or circle as many of these words that describe your pain.**

1
- annoying
- bad
- horrible
- miserable
- terrible
- uncomfortable

2
- aching
- hurting
- like an ache
- like a hurt
- sore

3
- beating
- hitting
- pounding
- punching
- throbbing

4
- biting
- cutting
- like a pin
- like a sharp knife
- pin like
- sharp
- stabbing

5
- blistering
- burning
- hot

6
- cramping
- crushing
- like a pinch
- pinching
- pressure

7
- itching
- like a scratch
- like a sting
- scratching
- stinging

8
- shocking
- shooting
- splitting

9
- numb
- stiff
- swollen
- tight

10
- awful
- deadly
- dying
- killing

11
- crying
- frightening
- screaming
- terrifying

12
- dizzy
- sickening
- suffocating

13
- never goes away
- uncontrollable

14
- always
- comes and goes
- comes on all of a sudden
- constant
- continuous
- forever

15
- off and on
- once in a while
- sneaks up
- sometimes
- steady

If you like, you may add other words:

____

____

____

For office use only.

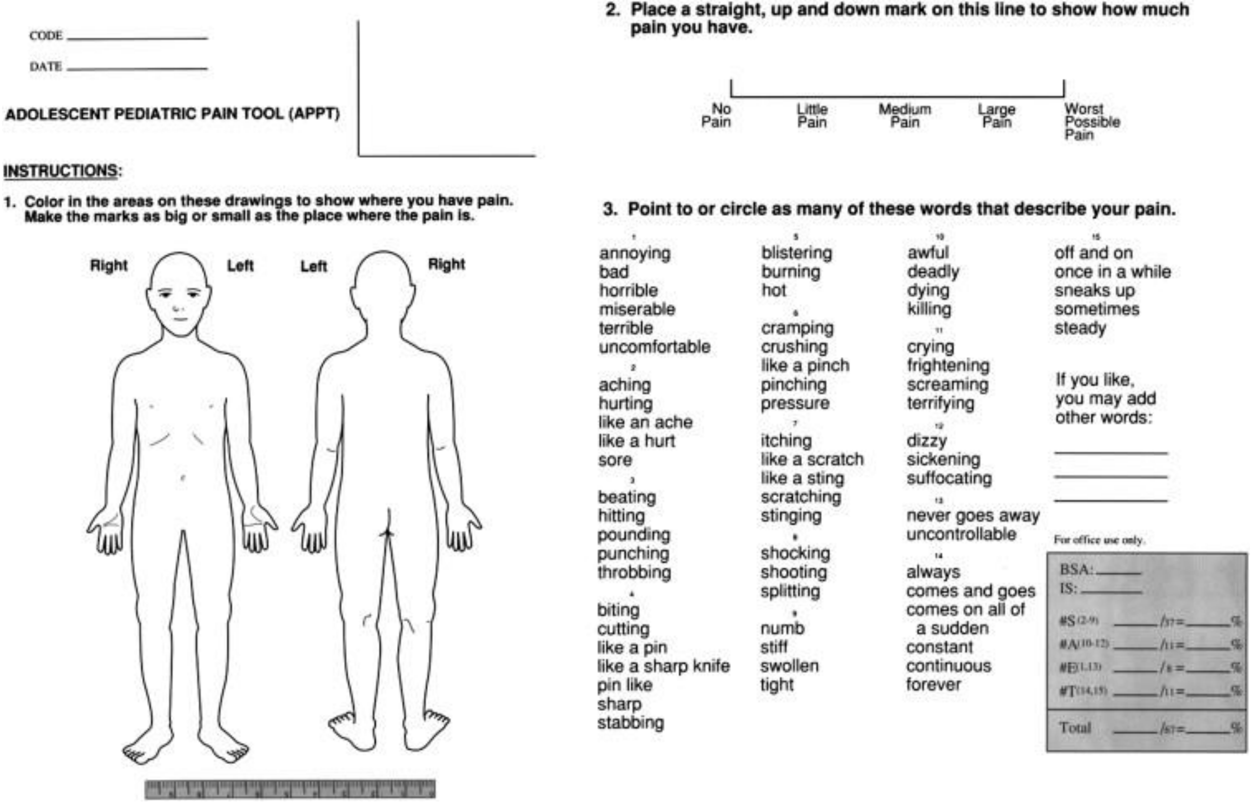
BSA: ______

IS: ______

#S (2-9) ______ /37 = ______ %
#A (10-12) ______ /11 = ______ %
#E (1,13) ______ /8 = ______ %
#T (14,15) ______ /11 = ______ %

Total ______ /67 = ______ %

Appendix 4



CODE ______________

DATE ______________

ADOLESCENT PEDIATRIC PAIN TOOL (APPT)

INSTRUCTIONS:

1. Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.

2. Place a straight, up and down mark on this line to show how much pain you have.

No Pain — Little Pain — Medium Pain — Large Pain — Worst Possible Pain

3. Point to or circle as many of these words that describe your pain.

1
annoying
bad
horrible
miserable
terrible
uncomfortable

2
aching
hurting
like an ache
like a hurt
sore

3
beating
hitting
pounding
punching
throbbing

4
biting
cutting
like a pin
like a sharp knife
pin like
sharp
stabbing

5
blistering
burning
hot

6
cramping
crushing
like a pinch
pinching
pressure

7
itching
like a scratch
like a sting
scratching
stinging

8
shocking
shooting
splitting

9
numb
stiff
swollen
tight

10
awful
deadly
dying
killing

11
crying
frightening
screaming
terrifying

12
dizzy
sickening
suffocating

13
never goes away
uncontrollable

14
always
comes and goes
comes on all of a sudden
constant
continuous
forever

15
off and on
once in a while
sneaks up
sometimes
steady

If you like, you may add other words:

____

____

____

For office use only.

BSA: ______
IS: ______

#S(2-9) ______ /37= ______ %
#A(10-12) ______ /11= ______ %
#E(1,13) ______ /8 = ______ %
#T(14,15) ______ /11= ______ %

Total ______ /67= ______ %

(Jacob, Mack, Savedra, Van Cleve, & Wilkie, 2014)

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Appendix F: Text Descriptions

Table 1:
Brief Description Table of self-report pain assessments to summarize the current assessments available.
Summary Description This table contains 8 self-report assessments that are reviewed for the purpose of providing the research area of pain with a concise review of the assessments. Each assessment was reviewed to find information regarding: pain type, specific impairments, age range, mode for administration, mode for response, reliability, validity, and accessibility. The main authors for each assessment are listed in the references column.
Detailed Description The heading row of this table reads as follows: name of pain measure, pain type, specific impairment, age, mode for administration, mode for response, reliability & validity, and accessibility. Headers in the first row has one column which is divided into 8 boxes for the responses to be inserted and separated. The name of pain measure column contains the: Wong-Baker FACES Pain Rating Scale, Pieces of Hurt, The Oucher, Colored Analog Scale, Adolescent Pediatric Pain Tool, Varni-Thompson Pediatric Pain Questionnaire, Children's Comprehensive Pain Questionnaire, and Numeric Pain Rating Scale. Each of these assessments are separated by the individual rows with the information obtained from the review by this author in each of the 8 sections headed by the first row.

Table 2:
Brief Description Table of behavioral pain assessments to summarize the current assessments available.
Summary Description This table contains 3 behavioral pain assessments that are reviewed for the purpose of providing the research area of pain with a concise review of the assessments. Each assessment was reviewed to find information regarding: pain type, specific impairments, age range, mode for administration, mode for response, reliability, validity, and accessibility. The main authors for each assessment are listed in the references column.
Detailed Description The heading row of this table reads as follows: name of pain measure, pain type, specific impairment, age, mode for administration, mode for response, reliability & validity, and accessibility. Headers in the first row has one column which is divided into 8 boxes for the responses to be inserted and separated. The name of pain of measure column contains: the Faces Legs Activity Cry Consolability Scale (FLACC), Observational Scale of Behavioral Distress (OSBD), and Non-communication Children's Pain Checklist (NCCPC). Each of these assessments are separated by the individual rows with the information obtained from the review by this author in each of the 8 sections headed by the first row.

Table 3:
Brief Description Table of physiological pain measures to summarize the current assessments available.
Summary Description This table contains 6 physiological measures for assessing pain which were reviewed for the purpose of providing the research area of pain with a concise review of the assessments. Each assessment was reviewed and summarized for the following information: name of measurement, what it measures, age range, mode for administration, mode for response, correlation to pain, and accessibility.

Detailed Description This table is an 8x3 table with 6 different physiological measures. The heading row contains: name of measurement, measures, age, mode for administration, mode for response, correlation to pain, accessibility, and references. The measurements being reviewed includes: blood pressure cuff, manual pain measurement, respiration rate count, Premature Infant Pain Profile (PIPP), Crying Requires Increased Vital Signs Expression Sleeplessness (CRIES), and abnormal cortisol and corticotrophin levels. Each measure is described in the individual rows which are divided by the header columns. The main authors of each measure or evidence used to complete the chart are listed in the reference column.

Table 4:

Brief Description Checklist of self-report pain assessment to determine pain domains and accessibility.

Summary Description This checklist contains 8 self-report pain assessments which were reviewed to obtain concise information about each one. The information is presented in checklist format, and each pain assessment has their own row with 10 boxes, which are either checked or not checked depending if the assessment fits the headers. The headers being considered are if each assessment: can be used by nonverbal youths, measures location, measures frequency, measures pain duration, measures pain intensity, measures pain alleviators/aggravators, measures pain interference, are accessible on devices and is found to be reliable/valid on a basis of r>.70.

Detailed Description This table is an 11x9 chart that has 11 headers and 8 different self-report pain assessments that were reviewed to decide if each assessment fit the categories. In the header row they are listed as: assessment title, nonverbal youths, measures location, measures frequency, measures duration, measures intensity, measures alleviators/aggravators, measures interference, accessible on devices, reliable (r>.70), and valid (r>.70). The assessment titles are listed in the first column and each one has an individual row of 10 boxes, which are checked or un-checked dependent on if the assessments fit the category. All assessments are checked for use with nonverbal youths and for measuring pain intensity.

Table 5:

Brief Description Table of the participant employment settings from survey results.

Summary Description This table lays out the results of the second question on the survey used in phase two of this study. The 7 different settings participants could select from were as follows: school-based, acute, inpatient, outpatient, home health, private practice, and day program. The response rates and percentages were also listed in this table to help lay out the portion of the participants each setting displayed. The majority of participants (n=12) were school-based occupational therapists.

Detailed Description This table has four different columns, each headed with different titles in row one. The first column was headed as answer, with the 7 different setting types listed below. The second column was a bar graph to show a clear lay out of the representations of each setting. The third column was the number of responses, ranging from 0-12. The last and fourth column list the percentages of the total amount each setting took up, the highest being school-based with 70% of the participant sample.

Table 6:

Brief Description Table of the participant years of experience from the survey results.
Summary Description This table lays out the results of the fourth question on the survey used in phase two of this study. The five different ranges of years of experience included: <1 year, 1-2 years, 2-4 years, 5-10 years, and 10+years. The majority of participants ranged from having 2-10 years of experience.
Detailed Description This table has four different columns, each headed with different titles in row one. The first column was headed as answer, with the 5 different ranges of years of experience listed below. The second column was a bar graph to show a clear lay out of the representations of each range. The third column was the number of responses, ranging from 1-7. The last and fourth column list the percentages of the total amount each range represented, the most being 2-4 years and 5-10 years with 31.5% each.

Table 7:
Brief Description Cross-tabulation of the type of setting participants work in compared to if they currently assess pain.
Summary Description The cross-tabulation between the type of setting participants reported they work in compared to if they currently assess pain was created to determine which setting assesses pain the least within these participants. This was done by taking the 7 different settings and placing them down in a column and taking yes and no as the header for the first row, while plugging in the responses for each survey. The results of this chart found that 11 out of 12 school-based OTs reported not currently assessing pain, and those 11 were the majority for the whole sample of 19 participants. The other settings only consisted of 2 other no's, 1 from acute and 1 from outpatient setting.
Detailed Description To create this cross-tabulation, one question was placed on the y-axis or first column, and the other was placed on the top row or x-axis. The type of settings went in the vertical column, while yes and no responses to if the participants report pain went in the top horizontal row. The responses for each survey were plugged into the overlapping boxes based on the setting type and either yes or no. The total numbers for each section were computed. This table allowed the results to be clear that school-based OTs reported the highest rate for not assessing pain.

Table 8:
Brief Description Cross-tabulation of the years of experience participants have compared to if they currently assess pain.
Summary Description This cross-tabulation was created to compare the results of how many years the participants had experience and if they assess pain with their clients. This was done by putting the 5 different ranges of experience in the first vertical column of the chart and putting the yes and no selections on the top horizontal row. The response rates were then plugged into the overlapping boxes in the chart and totals were computed. The results of this cross-tabulation showed that the years of experience the participants reported having were sporadic with whether or not they assessed pain.
Detailed Description In the top row of this table yes and no are displayed at the head of two separate columns of 5 boxes. The 5 different ranges of experience are located in the first column, in the column next to the yes column. The response rates are presented in the overlapping boxes between the two variable responses being compared. The totals are displayed to represent how many responses were reported for each overlapping group.

Table 9:

Brief Description Chart comparing the type of settings participants reported working in and the type of pain assessment they us.

Summary Description The cross-tabulation was created to compare the results of which settings the participants work in and what assessments they report using. The majority of results in this chart show that the comparison is sporadic and the types of setting does not seem to influence the type of assessment used. It is apparent that the OTs working in an acute setting reported mainly using observational and behavioral assessments, but they also reported use of self-report and physiological assessments. This implies that the cross-tabulation is not significant and no results can be concluded.

Detailed Description The 6x4 chart is head by a horizontal row with the four main types of assessing pain, including self-report, observation, physiological, and behavioral. The first vertical column lists the type of settings that were reported, including school, acute, inpatient, outpatient, home health, and private practice. The amount of responses reported were entered into the 24 boxes to be compared against the two groups. The numbers are sporadic, ranging from 0-3. Participants were given the opportunity to select multiple answers for both of the corresponding questions. Due to this factor and the numbers being sporadic, no significant results can be concluded with this chart.

Table 10:

Brief Description Cross-tabulation chart comparing the type of setting the participants reported working in and the satisfaction level of their current pain assessment.

Summary Description The cross-tabulation chart was created to compare two groups and analyze the results. The two groups being compared are the type of settings participants reported working in and how satisfied they were with their current pain assessment. The results from this chart show that the majority of participants were satisfied with their current measure of pain. There were only 3 other responses, 1 in the neutral column and 2 in the dissatisfied column. This makes it clear the participants are satisfied, however, the results are sporadic when compared to the type of setting the participants work in. The cross-tabulation makes it evident that the type of setting does not have an impact on who is satisfied.

Detailed Description The 6x3 chart was headed by a horizontal row with the level of satisfaction listed in each box, including satisfied, neutral, and dissatisfied. The type of settings are listed in the first vertical column, including school, acute, inpatient, outpatient, home health, and private practice. The number of responses for each variable were listed in the 18 boxes in the middle of the chart to compare the results. The majority of numbers were listed in the satisfied column, with all other boxes except three containing a 0 to signify no responses. This cross-tabulation helps to clarify that the majority of participants were satisfied with their current assessment of pain, but their responses do not correlate with the type of settings they work in.

Figure 1:

Brief Description Bivariate scatterplot depicting the results from table 7 as to whether participants currently assess pain compares with the type of setting they work in.

Summary Description This scatterplot was created to clearly show the results from the cross-tabulation completed in table 7. The two variables being compared are whether participants assess pain and what type of setting they work in. As seen in the scatterplot, the majority of settings have a higher response of “yes” than “no”, except for school-based setting. The school-based setting has a total of 11 “no’s,” which is higher than any other setting. This figure helps represent the results that the majority of participants who responded no were school-based OTs, and that there is a concerning amount of school-based OTs reporting not assessing pain.

Detailed Description The title of this scatterplot is “do you currently assess pain with your clients?” The y-axis is titled “number of responses” and the x-axis is titled “type of setting” with a legend of the right depicting the colors for the yes or no responses. The numbers on the x-axis signify which setting the participants work in: (1) school, (2) acute, (3) inpatient, (4) outpatient, (5) home health, and (6) private practice. The two colored dots listed for each setting depict if the participants assess pain; red for no and blue for yes. The y-axis contains even numbers ranging from 0-12 to signify the number of responses each setting had for the corresponding answer, either yes or no. The dots for the responses are placed in their according position to represent the amount of yes responses and no responses to be easily compared by the readers.