

Observer perceptions of pain in children with cognitive impairments: Vignette development and validation

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Genik, L. McMurtry, M. Breau, L. 2015. Observer perceptions of pain in children with cognitive impairments: Vignette development and validation. *Pain Management*.

<https://doi.org/10.2217/pmt.15.42>

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This research was funded by a faculty start up grant at the University of Guelph. All authors discussed results and commented on the manuscript. No conflicts of interest declared. The participants from this study were a subset of a sample within a larger scale study; therefore parts of their responses were utilized in analyses presented at the following conferences: Ontario Association on Developmental Disabilities Research Special Interest Group Annual Research Day (April 2013, April 2014); International Forum on Pediatric Pain (October 2013); Canadian

Pain Society (May 2014); International Association on the Study of Pain World Congress (October 2014).

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### **Abstract**

Aims: (1) develop vignettes depicting pain in children with cognitive impairments manipulating pain source and child's verbal ability, and (2) conduct initial validity analyses.

Materials/Methods: Seventy-six undergraduate students (38 female, Mage = 19.55) responded to six vignettes by rating (0-10): (1) pain intensity, (2) how difficult it was to rate pain intensity , (3) perceived need for medical attention and (4) perceived need for other attention (e.g., physical comfort). Results: Participant ratings significantly varied by pain source (e.g., a headache was rated more painful compared to injections). Verbal ability had no impact on ratings. Conclusions: These vignettes could serve as ethical and effective alternatives for gathering information from caregivers about pain in children with CI.

**Keywords:** children, cognitive impairment, vignettes, pain assessment, pain management

## Introduction

Children with cognitive impairments (CI) not only experience pain, but experience it more frequently than ‘typically developing’ peers [1; 2]. Pain also impacts the ability of children with CI to function adaptively (e.g., less ability to communicate; [3])

Pain is subjective, meaning that pain experience (i.e., how a person perceives what he/she is feeling) and pain expression (i.e., how a person communicates that he/she is in pain), can vary [4]. Many children with significant CI, particularly those who are nonverbal, are incapable of consistently and/or effectively conveying this information [5]. For example, pain behaviours could be difficult to interpret, inconsistent, or idiosyncratic. Thus, caregivers often become responsible for assessment and management of their child’s pain. Despite familiarity with the child, adequate assessment may be difficult. These challenges may be exacerbated for caregivers who are less familiar with the child. Respite care continues to grow as a service supporting families with children with disabilities [6], meaning that respite workers are common non-custodial caregivers of these children. While research has been conducted on parents and health care providers of children with CI, none has examined pain-related decisions among respite workers.

Given the heightened ethical and logistical challenges associated with research including children with CI such as need for direct participant benefit and recruitment challenges [7; 8; 9; 10], use of other research methods are often required but psychometrically strong materials are not widely available. Vignettes employ hypothetical situations to better understand participants’ knowledge/attitudes/opinions and predicted responses [11; 12; 13; 14]. Vignettes also allow researchers to collect information from larger samples, move beyond participants’ personal experience, systematically manipulate variables which may not otherwise be possible or easily

standardized, and avoid ethical issues present in other research methods [13; 15; 16; 14).

Vignette responses also correlate with actual behavior. For example, a study by Robinson and Clore [17] found that the median correlation of z scores between appraisals and emotions in online and simulated situations was .99.

Our first objective was to develop vignettes to examine pain assessment and management decisions by non-healthcare secondary caregivers of children with CI. Further understanding of these decisions is important because it can be used to both assess the need for and inform the development of pain-related interventions to improve the respite care these vulnerable children receive. Firstly, pain source was manipulated, as it should impact pain ratings [18]. Secondly, we did an exploratory manipulation of whether the child was verbal or nonverbal. While some literature has examined the impact of level of CI on pain beliefs (e.g., [19]), no previous research has investigated whether verbal ability specifically impacts pain beliefs. The second objective was to provide initial vignette validation, determining whether ratings (i.e., pain intensity, difficulty assessing intensity, need for medical attention, and need for other forms of attention) differed as a function of pain source and, secondarily, verbal ability. Vignettes depicting similar types of pain (e.g., flu shot, insulin shot) were expected to receive similar but divergent ratings from other pain sources (e.g., arthritis). While the manipulation of verbal ability was exploratory in nature, participants were expected to report more difficulty assessing pain intensity in children depicted as nonverbal. This is the first study to use vignettes based on everyday pain situations for children with CI, the first to manipulate children's verbal ability, and the first to explore ratings of respite caregivers for children with CI in pain-related situations.

## **Methods**

The present article explores the development and initial convergent and divergent validity of situational vignettes about children with CI. The current work contains an exclusive/unique subset of participants from a larger study; selection of participants for the present study is described below. Only the details relevant to the present study are discussed. Ethics approval for the larger study was obtained from the university research ethics board.

### **Participants**

Seventy-six undergraduate student participants (38 female, 38 male) were selected from the larger sample of participants ( $n = 273$ ) on the basis of balancing: 1) sex and 2) vignette order presented (i.e., verbal versus nonverbal first) in a sequential approach. This sample size allowed for detection of a medium to large effect size with power of .80 and an alpha of .05 using repeated measures ANOVAs [20]. For this initial validation/examination of the vignettes, a population old enough to support children with CI outside of medical settings (e.g., through more volunteer work or paid employment at day camps), but relatively inexperienced with this population was desired. An inexperienced population was targeted to minimize the effect of biases stemming from personal experiences on participant responses to the vignettes. Thus, the vast majority of participants reported no to little involvement ( $0 = \textit{Not At All Involved}$ ,  $10 = \textit{Highly Involved}$ ) with children with CI who were nonverbal (range = 0 - 9;  $M = 1.34$ ; 72.4% of participants rated no involvement; 84.2% rated between 0 and 4).

The sample was recruited from an undergraduate university student population and ranged in age from 18 to 25 ( $M_{\text{age}} = 19.55$ ,  $SD = 1.36$ ,  $n = 76$ ). The majority of participants were European-Canadians ( $n = 59$ ; 77.6%), and remaining participants identified as: Asian-Canadian ( $n = 7$ ; 9.2%), African-Canadian ( $n = 3$ ; 3.9%), Indo-Canadian ( $n = 1$ ; 1.3%) and Other ( $N = 6$ ; 7.9%). As expected given the source of participants, seventy-three participants (96.1%) indicated

that their highest level of education was a university degree in progress [i.e., “some university (in progress)”], while three (3.9%) indicated having already completed at least one undergraduate degree. The most frequent area of academic study was developmental/behavioral social and human applied science (e.g., psychology, 35.5%,  $n = 27$ ), followed by human health related sciences (e.g., applied human nutrition, 22.4%,  $n = 17$ ), other humanities and arts programs (e.g., history, 18.4%,  $n = 14$ ), business (10.5%,  $n = 8$ ), other science programs (e.g., chemistry, 6.6%,  $n = 5$ ), and engineering (5.3%,  $n = 4$ ). One participant (1.3%) did not indicate program of study.

### **Procedure**

All study procedures were conducted online. Participants signed up for the study through an online participant pool at a mid-sized university ( $n =$  approximately 25000). After reviewing study information and providing informed consent, participants were linked to a voluntary and confidential survey. As part of the larger study, participants were asked to: (1) respond to a series of demographic questions, and (2) read and respond to questions related to six vignettes. Following submission of the survey, all participants were provided with an option to download a fact sheet about pain in children with CI and received 0.5% course credit.

### **Measures**

**Demographic Information.** Demographic information used for analyses included: age, sex, and level of involvement with children with CI who are nonverbal.

**Vignettes.** Six brief, standardized vignettes manipulating pain source and verbal ability were developed for this study, representing a number of painful experiences that children may experience in everyday settings (see Table 1).

Four of the six vignettes were adapted from Shinde and Symons ([18]; See Table 1). The settings, age and accompanying individuals were changed from Shinde and Symons' [18]

school-based vignettes for two purposes: 1) to better depict scenarios suitable for everyday pain situations that could occur while receiving care from non-custodial caregivers such as respite workers, and 2) to increase the level of consistency for non-manipulated factors (i.e., child's age and accompanying individual). In addition, Shinde and Symons' [18] vignettes were edited to ensure consistency in tense and number of words with the vignettes developed specifically for this study.

Participants were provided with a definition of respite care and what it can entail prior to completing the vignettes. All participants viewed the vignettes in the same order; however, the presentation was counterbalanced across participants so that each vignette was equally presented as containing a verbal or nonverbal character. This means that half of the participants saw the unspecified pain source vignette as verbal, headache vignette as non-verbal, flu shot vignette as verbal, and so on. The other half of the participants saw the opposite.

**Ratings:** After reviewing a given vignette, participants were first asked to rate the level of pain they believed the child felt (0 = *No Pain At All*; 10 = *Very High Pain Intensity*). Numeric rating scales were used throughout to help quantitatively standardize participant responses. Adult caregivers are commonly asked to provide global estimations of children's pain (e.g., [21; 22]). For children with CI, self-report of pain is often not possible [5]. In these cases, observational measures of behaviour (e.g., nonverbal pain expression) do play a role and serve as a good alternative [23]. Participants were then asked how difficult it was for them to rate the level of pain intensity for the given scenario (0 = *Very Easy/Not Difficult*; 10 = *Extremely Hard/Very Difficult*). This rating was included as the difficulty in assessing pain in populations with CI has been emphasized in previous literature [24]. Ratings of perceived need for medical attention (0 = *No Medical Attention Necessary*; 10 = *Emergency Medical Attention Necessary*)

and other forms of attention (e.g., physical or verbal comfort, distraction; 0 = *No Attention Necessary*, 10 = *Significant Amount of Attention Necessary*) were also collected. These two ratings served as a proxy for pain management decisions and types of strategies that may be employed.

## Analyses

### Missing Data, Analyses and Related Statistical Corrections

Missing data: across vignettes, only one rating of pain intensity (0.01%), two ratings of difficulty assessing pain intensity (0.03%), three ratings of need for medical attention (0.04%), and four ratings of need for other attention (0.05%) were missing (total missing data = 0.03%). These were dispersed throughout vignettes and were not all from the same participant, suggesting that the participants may have found the task easy to understand and complete.

- (1) Descriptive analyses for ratings of pain intensity, difficulty of assessing pain intensity, need for medical attention and need for other attention were computed.
- (2) Preliminary analyses involved a series of Pearson's  $r$  (for normally distributed data), point-biserial correlations for dichotomous data, and Spearman's  $r$  correlations (for non-normal data) were used in order to assess whether, across vignettes, participant ratings of pain intensity, difficulty of assessing pain intensity, need for medical attention and need for other forms of attention were related to participant demographics (i.e., participant age, sex, and level of involvement with children with CI who are non-verbal). If a significant correlation with demographic variables was found across more than one vignette, that variable was later accounted for as a between subjects variable in a mixed measures ANOVA on the rating for which it was significant.

(3) Main analyses utilized a series of mixed 2 (child verbal ability: verbal or nonverbal) x 6 (pain source: unclear, headache, flu shot, fall, arthritis, and insulin injection) ANOVAs to examine the construct validity of the vignettes (i.e., whether the pain source or verbal ability impacted participant ratings of pain intensity, difficulty of rating pain intensity, need for medical attention, and need for other forms of attention). A mixed measures ANOVA was also used in cases where variables from the correlational analyses were related to the participant ratings. All assumptions in the analyses output were reviewed. If Mauchly's test of sphericity was significant, Huynh-Feldt estimates were used in order to correct for this violation. T-tests with Bonferroni corrections for significance level ( $.05/15$  paired samples t-tests =  $.003$ ) were then used to look more specifically at the main effects. Consistent with the recommendations of Field [25], effect sizes ( $r$ ) were only reported for more focused paired samples t-tests which followed a significant main effect.

## Results

### Descriptives, Correlational, and Initial One-Way ANOVA Analyses

See Table 2 for descriptives of participant ratings for pain intensity, difficulty of assessing pain intensity, need for medical attention and need for other attention, respectively.

The only significant correlation between demographics and participant ratings was between sex and participants' difficulty ratings,  $r = .25$ ,  $p = .03$  (a small effect; [20]). The data suggest that females found it more difficult to rate the pain intensity of the depicted children than males. The remaining  $r$  values for the dependent variables and age, sex and level of involvement with children with CI who are non-verbal ranged from  $-.03$  to  $-.22$ . Thus, only sex was included as a between subject factor for the difficulty ratings analyses.

### Vignette Validation Analyses

**Pain intensity ratings.** Participant ratings of perceived level of pain intensity varied with pain source,  $F(4.01, 292.45) = 16.21, p < .001$  (see Table 2). Further analyses using paired samples t-tests revealed that an acute, recurrent source of pain (insulin injection) was rated as significantly less painful than an unspecified pain source, acute accidental pain (falling), and pain that was recurrent or chronic in nature (headaches and arthritis). Similarly, pain intensity ratings for an acute procedural pain source (flu shot) were rated as significantly less painful than recurrent or chronic pain types (headaches and arthritis). Supporting the convergent and discriminant validity of the vignettes, in all cases, the acute procedural pain scenarios (flu shot and insulin injection) fell, on average, closer to the mild range of pain intensity, whereas other sources represented more moderate pain intensity (see Table 2). Effect sizes ranged from  $r = 0.48$  to  $r = 0.66$ , medium to large effects [20]. There was no significant main effect of child's verbal ability,  $F(1, 73) = .69, p = .409$  on pain intensity ratings. No significant interaction was found between pain source and verbal ability,  $F(4.01, 292.45) = 1.38, p = .240$ .

**Difficulty of Assessing Pain Intensity Ratings.** A mixed measures ANOVA was conducted with participant sex and vignette character's verbal ability as between-subjects variables, and pain source as the within subjects variable. The main effect of participant sex was close to reaching significance<sup>1</sup>,  $F(1,70) = 3.92, p = .052$ . Participants' level of difficulty assigning pain intensity ratings varied with pain source,  $F(4.73, 330.78) = 15.54, p < .001$  (see Table 2). Participants found it more difficult to rate pain intensity for unspecified and chronic pain (headaches and arthritis) than an acute, recurrent source of procedural pain (insulin

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<sup>1</sup> Further examination detected an outlier in the first vignette (unspecified pain source) that was more than two standard deviations below the mean. Removal of this outlier led to a significant main effect of sex,  $F(1, 69) = 5.07, p = .027$ , such that females ( $M = 6.43$ ) had significantly higher difficulty ratings than males ( $M = 4.61$ ),  $r = 0.26$ , a small effect [20]).

injection). Further, participants reported it was less difficult to rate pain intensity for an acute procedural pain source (flu shot) and an accidental pain source (falling down) than an unspecified source of pain. Participants found the unspecified pain source vignette to be the most difficult for rating pain intensity; the needle scenarios were reported as the least difficult. Effect sizes ranged from  $r = 0.23$  to  $r = 0.29$ , representing small effects [20]. There was no significant main effect of the vignette child's verbal ability on participants' ratings of difficulty of assessing pain intensity,  $F(1, 70) = .64, p = .426$ . No significant interaction effects were found between pain source, verbal ability, and participant sex (all  $p$ 's  $> .229$ ).

**Need for Medical Attention Ratings.** Participant ratings of perceived need for medical attention varied with pain source,  $F(4.05, 287.34) = 29.09, p < .001$  (see Table 2). Both an acute, recurrent source of pain (insulin injection) and an acute procedural pain source (flu shot) were rated as requiring significantly less direct medical attention than an unspecified pain source, acute accidental pain (falling), and recurrent or chronic pain (headaches and arthritis). Effect sizes ranged from  $r = 0.58$  to  $r = 0.73$ , representing medium to large effects [20]. Children's verbal ability had no significant impact on participant ratings of need for medical attention,  $F(1, 71) = .44, p = .512$ . No significant interaction was found between pain source and verbal ability,  $F(4.05, 287.34) = .63, p = .643$ .

**Need for Other Attention Ratings.** A main effect of pain source on need for other attention ratings was found,  $F(4.03, 282.14) = 51.34, p < .001$  (see Table 2). Both an unspecified pain source and recurrent source of pain (headache) were rated as requiring significantly more forms of other attention than those of all other pain sources in the study (flu shot, falling down, arthritis and insulin injection). The unspecified pain source had the highest need for other attention rating compared to all other vignettes. Need for other attention ratings for the flu shot

and falling down vignettes were also rated significantly higher than an acute, recurrent source of pain (insulin injection). Effect sizes ranged from  $r = 0.46$  to  $r = 0.83$ , representing medium to large effects [20]. Children's verbal ability did not significantly impact participant ratings of perceived need for other attention,  $F(1, 70) = .584, p = .447$ . No significant interaction was found between pain source and verbal ability,  $F(4.03, 282.14) = .87, p = .481$ .

## Discussion

The aim of this research was to develop a series of vignettes to examine pain assessment and management decisions of caregivers for children with CI.

### Pain Intensity Ratings

Mean pain intensity ratings were in the mild to moderate range. While the needle-related scenarios were rated similarly, their intensities generally differed from the other pain sources. This suggests a general and understandable discrimination between views of pain intensity from needle-related procedures versus other sources. Participants' lower pain intensity ratings for the acute pain-related vignettes in comparison to more chronic pain sources demonstrates their understanding of the former's typically time-limited and likely less severe nature. This is also consistent with the descriptions of the children in these vignettes as returning to baseline activity/normal behavior. The unspecified pain source received pain intensity ratings between acute and chronic pain sources. Given that the child's reaction was observable (e.g., child screaming), participants may have been more likely to rate the pain as higher than mild. This was also consistent with findings from Breau et al. [19].

Interestingly, participants' mean pain intensity ratings for the 10 year old characters undergoing needle procedures in the vignettes were higher than self-reports for same age

typically developing children undergoing venepunctures [26]. It is well documented that in typical populations, proxy ratings by parents and nurses are related to but do not wholly overlap with children's self-reports of pain [27]. Another study of children with spina bifida found a discrepancy between parent-child pain ratings 47% of the time (19% underestimated, 28% overestimated; [28]). That said, research with children with high functioning autism found no significant difference between mean pain ratings of these children and their parents [29]. Further research could investigate agreement of pain intensity ratings between caregivers and children with CI who can self-report, and the impact of caregiver type (e.g., parents vs. support workers).

### **Difficulty Ratings**

The variability of difficulty ratings across vignettes also supports the discriminate and convergent validity of the vignettes. In the absence of other information, participants may have relied on the pain stimulus to guide their pain intensity decisions; thus when the pain source and related signs were clear, they found the task easier to complete. For example, the fall scenario provided description of physical signs which could be used to help determine severity (i.e., redness/some bruising; no swelling/bleeding). The arthritis and headache scenarios may have been more difficult to rate given the lack of visible clues. The scenario in which the pain source was unclear was most difficult for participants to rate, perhaps due to the lack of information available in general.

Participant/observer sex may impact perceived level of difficulty in evaluating pain intensity of a child with CI. Specifically, females found it more difficult to rate children's level of pain intensity than males. It is unclear as to why this was the case. Sex of both the child and parent may relate to parent ratings of their child's pain (e.g., in Moon et al. [30], child sex impacted father's pain intensity ratings; fathers seemed to more accurately rate their children's

pain than mothers). Consistent with the social communication model of pain, future research could consider observer sex and whether the accuracy of pain ratings is related to an individual's perceived level of difficulty in rating pain intensity [31].

### **Ratings of Perceived Need for Medical and Other Attention**

Paralleling the pain intensity ratings, ratings of perceived need for medical attention also suggested that both needle procedures were seen as requiring less medical attention compared to other pain sources. Seeking medical attention was not rated as critical in any scenario (i.e., while ratings varied from 0-10, average ratings on any vignette did not exceed). That said, the scenarios described in the vignettes may not have warranted as much medical attention in comparison to other forms of attention. Despite this, a pattern in participant ratings was noted, such that need for medical care was rated highest for those vignette scenarios in which there were unknown consequences: headache (e.g., could indicate a shunt problem), fall including a blow to the head, and unknown source. In contrast, the arthritis and procedural pain vignettes likely depicted children already involved with medical personnel to some extent resulting in reduced perceived need of medical attention.

With respect to participant ratings of perceived need for other forms of attention, the unspecified and headache sources were reliably differentiated from all other scenarios. This suggests that the highest utility for future use of these vignettes may be related to assessing participants' views regarding need to provide attention to children with CI following a painful event. It is important to further investigate whether these ratings for need for medical and other forms of attention have real world implications for the likelihood of provision of medical or other forms of care.

### **Participant Ratings by Verbal Ability**

Whether a child was verbal or nonverbal did not influence participant ratings of difficulty in assessing pain severity, pain intensity and need for medical or other attention. The investigation of verbal ability on caregiver decisions is an important contribution to the literature. Although previous research (e.g., [19; 32; 33]) has investigated the impact of level of CI on different aspects of pain (e.g., perceptions, expression) the specific exploration of verbal ability is novel. These vignettes were useful in separating out the effects of verbal ability from CI. This would be more difficult to study in actual clinical populations, as increased level of CI is generally associated with decreased verbal ability. This new finding suggests that for observers without substantial experience with CI, the verbal skills of a child may not impact observer opinions related to pain assessment and care decisions. Further research should be conducted to investigate whether verbal ability impacts opinions related to pain assessment and care decisions of caregivers who have personal experience with children with CI. The implications of these findings on caregiver decisions may be important given the increased need for reliance on behavioral observation by others, challenges associated with pain assessment, and the under-treatment of pain in this population [34]; [35].

### **Strengths, Limitations and Future Directions**

The creation of vignettes depicting pain in children with CI is important to inform theory and drive future research efforts. Vignettes were carefully constructed to maximize face validity by using common sources of pain in situations that could easily occur in non-custodial care of children with CI. Use of the vignettes allowed both a high degree of internal validity over some situational aspects (e.g., consistent age, sex not specified) and the systematic manipulation of variables of interest (i.e., pain source, verbal ability). In a naturalistic study, this would not be possible. In combination with a balanced sex ratio of participants, a rigorous statistical approach

was employed with the effects of various demographic variables taken into account in analyses. The pattern of results supports the discriminant and convergent validity of the pain source manipulation.

Given the versatility, cost efficiency, convenience and ease of administration of vignettes, replication and novel studies could easily be conducted. Use of these vignettes with various caregiver populations (e.g., respite workers, teachers, personal support workers) would provide valuable information on the knowledge, attitudes, and opinions regarding pain in children with CI held by these caregivers and training needs. These vignettes could also be used as an outcome measure in intervention trials (e.g., pain training for respite workers). This line of research could improve understanding of pain assessment and management both between and within caregivers.

Future research should investigate whether observer ratings vary according to characteristics of individuals (e.g., sex, disability -related beliefs) or of children portrayed in the vignettes (e.g., age). Verbal ability of the child presented in a given vignette was counterbalanced; however, given constraints with the survey program, all vignettes were presented in the same order, thus we did not control for order effects. That said, the pattern of results for pain source is logical.

The external validity of participants' responses may be questionable. Undergraduate students with little experience with children with CI may not have been able to accurately extrapolate ratings to an unfamiliar population of children. Although it cannot be assumed that the responses endorsed by participants accurately represent behaviour in real situations, previous appraisal research has demonstrated high correlations between vignette and real-life responses to situations [17]. This study's unbiased sample without prior experiences with children with CI in pain allowed us to ensure that the vignettes could be completed and distinguished from each

other. The differences found with this homogenous sample also suggest that the vignettes should be able to detect differences with other more variable groups of participants. Our subsequent research on pain assessment and management decisions will utilize these vignettes with respite caregivers who have more experience with (and perhaps biases about) children with CI, further increasing the utility of the vignettes to distinguish patterns of responses due to observer, child, or pain characteristics.

### **Conclusions**

Pain sources impacted participant ratings of pain intensity, difficulty of rating pain intensity, and perceived need for medical and other forms of attention for a hypothetical child with CI. Observers' sex may play a role in how difficult they find rating a child's pain intensity. In this sample, verbal ability of the child did not impact participant ratings. Demonstrating preliminary convergent and divergent validity, these vignettes could serve as an ethical and effective alternative research methodology to examine assessment and care decisions for children with CI.

### **Summary Points**

- When placed in hypothetical situations, participants' pain intensity ratings vary depending on the type of pain a child with CI is experiencing.
- The type of pain in a given scenario and observers' sex may play a role in how difficult they find it to rate a child with CI's pain intensity.
- Observers' ratings of their perceptions of need for medical and other forms of attention for children with CI may depend on the type of pain experienced by a child.

- For observers with little to no experience with children with CI, the child's verbal ability (i.e., verbal versus nonverbal) does not seem to impact ratings associated with pain intensity, difficult to rate pain intensity, or perceived need for medical or other forms of attention.
- The situational vignettes developed in this study demonstrate convergent and divergent validity, and may therefore be a promising method for gathering information about pain assessment and management decisions related to children with CI.
- Vignettes are an ethical and effective method for gathering information from caregivers of children with cognitive impairments about pain assessment and management decisions.

### **Future Perspective**

It is speculated that ten years from now, we will better understand the needs of secondary caregivers such as respite workers related to pain assessment and management in children with CI. In turn, respite workers (and other secondary caregivers) will have more resources available to them so that they can gain more knowledge, skill and confidence in pain assessment and management, ultimately improving the quality of care they can provide to children with CI.

### Financial Disclosure/Acknowledgements

This research was funded by a faculty start up grant. The researchers would like to thank Dr. Scott Colwell for his statistical consultations.

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