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Pain in Children with Intellectual Disabilities: A Randomized Controlled Trial Evaluating Caregiver Knowledge Measures

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Abstract

Inadequate knowledge has contributed to inaccurate pain assessment and treatment for children with intellectual disabilities (ID). **Aims**: Develop and evaluate pain knowledge measures and accompanying self-report ratings; determine their sensitivity to change. **Materials/Methods**: Young adults (n = 77; M_{age} = 18.89; SD = 2.29; 67 females) were randomly assigned to one of two ‘caring for children with ID’ training programs (pain, visual supports). Participants completed pre-post measures of pain knowledge and six self-report ratings of feasibility, confidence and perceived skill in pain assessment and treatment. **Results**: After controlling for pre-training scores, pain knowledge and self-report ratings were significantly higher following pain training versus visual support training. **Conclusions**: These measures show promise for the evaluation of pain knowledge in secondary caregivers.

Keywords: Children with Intellectual Disabilities, Caregiver Knowledge, Pain Assessment and Treatment.

Pain is common in children with intellectual disabilities (ID); these children are highly susceptible to experiencing discomfort from medical procedures, chronic pain, as well as pain in everyday life [1, 2, 3, 4, 5]. According to the American Association on Intellectual and Developmental Disabilities, children with ID show “significant limitations in both intellectual functioning and in adaptive behavior” before age 18 (AAIDD, para. 1) [6]. ID is characterized further by difficulties with effective communication and adaptive functioning (e.g., dressing and cooking) [6, 7]. Thus, even though children with ID frequently experience pain, they may have difficulty with effectively communicating the type and intensity of their pain to others [5, 7, 8, 9]. These limitations often prevent children with ID from reporting their pain, leaving the responsibility of pain assessment and treatment with these children’s caregivers.

Reliance on caregivers for pain assessment and treatment in this population of children leads to a number of challenges. For example, caregivers must acknowledge the distinction between pain experience (i.e., subjective representation of an event) and pain expression (i.e., speech or body language) [10]. Some caregivers hold misconceptions that children with ID do not perceive and/or express pain like typically developing children [1, 2, 9]. Pain assessment by caregivers is further complicated by nonverbal behavioral cues that may be unique to the child (e.g., hand clenching or rocking) as well as any co-morbid physical disability [8, 11, 12]. While some parents can interpret their child’s body language [4, 12], health care providers and other secondary caregivers should rely on pain assessment and treatment strategies based on current research evidence rather than on assumptions of how children with ID express normal or distressed behavior. Together, caregivers’ sometimes inaccurate pain knowledge, pain (mis)beliefs, and the unique behavior through which children with ID may express pain can lead to under-assessment and treatment of pain.

Although parents may be able to interpret their child’s pain expression, they are not the only individuals who care for children with ID on a daily basis; indeed, parents also seek short-term support from secondary caregivers (e.g., respite workers) in a variety of settings (e.g., family home, group home, or community programming) [13]. In these instances, secondary caregivers are responsible for pain assessment (i.e., accurate interpretation of pain cues) and treatment. In comparison to a sample of individuals with little to no experience with children with ID, respite worker secondary caregivers believed that a greater proportion of children with severe ID sensed less pain compared to typically developing children [14]. Secondary caregivers’ (mis)beliefs support the need for improved pain training to expand and update their knowledge, particularly of pain expression in children with ID [15]. Pain assessment and treatment may also be predicted by intrinsic factors other than knowledge. For example, a caregiver may have the requisite knowledge and skill to adequately lessen a child’s headache pain, but his/her level of confidence and beliefs may facilitate or inhibit administration of pain treatment [16]. Indeed, Dalton and colleagues [17] found that nurses had increased feelings of effectiveness and credibility after a pain treatment program. Thus, beyond knowledge, self-report rating scales can be beneficial to evaluate professionals’ perceptions of pain assessment and treatment, and their own abilities in these areas. The extent to which pain training teaches the pertinent information and its effectiveness can be evaluated through the use of pain knowledge measures.

Previously developed pain knowledge measures show substantial discrepancies between current evidence and health care professionals’ pain knowledge and beliefs regarding children’s pain experience and expression [18, 19, 20]. For example, several researchers have evaluated the pain knowledge and attitudes of hospital-based health care professionals using surveys only to find that there is a large gap in knowledge surrounding pain assessment and treatment for children. For example, in three studies, the correct response percentage of the whole sample ranged from 40% to 56% [18, 19, 20]. These gaps in knowledge hold implications for care as inadequate pain knowledge can lead to poor pain treatment for children [22].

Much of the existing research focuses on improving pain knowledge, beliefs and care provided by health care professionals such as nurses [18, 20, 21, 22, 23, 24, 25, 26, 27, 28]. For example, Twycross and Williams' [21] pain knowledge measure (*Pediatric Pain Knowledge and Attitudes Questionnaire Revised; PPKAQ-R*) was adapted from Salanterä, Lauri, Salmi, and Helenius' [26] questionnaire, which assessed the knowledge and pain treatment practices of Finnish pediatric nurses. Twycross and Williams' [21] revised questionnaire was developed to assess nurses' knowledge and attitudes across acute, procedural, and chronic pain in children. While the *PPKAQ-R* has demonstrated validity and reliability for use with nurses, it is not designed for non-health care secondary caregivers nor is it specific to children with ID. Importantly, the needs and difficulties faced by this population are different from the needs and subsequent pain treatment strategies for children in a hospital or health care setting. Currently, there are no measures to assess pain knowledge specific to children with ID in secondary caregivers (e.g., respite workers) who support these children. These measures are integral to understanding educational needs, measuring the impact of pain training, and ultimately improving the overall quality of care for children with ID.

Objectives and Hypotheses

Objective 1. Test two measures of pain knowledge that were developed or adapted for non-health care secondary caregivers (e.g., respite workers) who care for children with ID (primary). Specifically, the sensitivity of a measure developed for this study, the *Questionnaire* *for Understanding Pain in Individuals with Intellectual Disabilities – Caregiver Report* (*QUPID-C;* available upon request to corresponding author), and an adapted version of the *Pediatric Pain Knowledge and Attitudes Questionnaire - Revised* (herein referred to as *Adapted PPKAQ-R;* available upon request to corresponding author) [21], to pain training (versus a control group) were assessed. It was hypothesized that participants' knowledge scores on the *QUPID-C* and *Adapted PPKAQ-R* [21] would be significantly higher after completing pain training; the scores of individuals who completed a non-pain related supports training were not expected to change.

Objective 2. Explore the changes in self-report ratings regarding the feasibility of and confidence and skill in pain assessment and treatment after receiving pain training (secondary). It was hypothesized that participants' scores on the self-report ratings of feasibility of and confidence and skill in both assessment and treatment would be significantly higher after completing pain training compared to the scores of those who completed a non-pain related supports training.

Objective 3. An exploratory aim was to examine the inter-relations among the pain knowledge measures as well as the feasibility, confidence, and skill ratings (tertiary). It was predicted that pain assessment confidence ratings would correlate positively with pain assessment skill and feasibility ratings across both time points, and with both knowledge measures at post (but not pre). This same pattern was hypothesized for the treatment ratings. As such, only participants' ratings of skill and feasibility were expected to significantly predict confidence ratings at the pre-time point for both assessment and treatment; pain knowledge was expected to significantly predict confidence ratings beyond feasibility and skill at the post-time point for both pain assessment and treatment.

Methodology

Study Design

The trial used a parallel groups un-blinded randomized control design with allocation determined via coin flip. A coin flip was used based on feasibility and convenience at the location of data collection. Based on an a priori power analysis using G*Power, a sample of 32 participants per group (i.e., pain training group and visual supports training group) was sufficient to detect a large effect size at power = .80, α = 0.05 for the main analyses using ANCOVA [29, 30].

Participant Recruitment

An online participant pool at a mid-sized university (*n* = approximately 25000) was used to recruit students currently in a psychology course who were at least 18 years old, proficient in the English language, and who met the eligibility criteria on the pre-screening survey (see below). There were strict inclusion criteria to ensure we obtained a sample similar to secondary caregivers of children with ID. It was considered advantageous to have participants enrolled in psychology classes as they may choose to pursue a career in clinical psychology, social work, or health care, and thus would benefit from training to support children with ID.

Pre-screening. Eligible participants had to have experience working with or familiarity surrounding the care of children and youth (ages 0-18) both with and without ID. These pre-screening questions helped to ensure that participants were representative of those who may have some experience/knowledge of caring for children. Specifically, participants had to endorse at least two of the four following questions with “yes” (i.e., questions a-c) and/or a rating between 4-10, where 10 indicated the highest familiarity (i.e., question d):

(a) having experience working with children (e.g., via camps, babysitting, paid employment),

(b) having experience providing support to children with ID (e.g., personal care, behavior management),

(c) having experience providing respite care to children [for the purpose of this study, respite care was defined as "a form of short-term, temporary relief provided to parents or guardians who are caring for a child who has an intellectual disability. Respite care can take place in a variety of settings including the family home, the community, and group home settings. In addition to providing a break for the family, respite is designed to provide a positive experience for the child, often providing them with opportunities to be more involved in the community"], and

(d) familiarity with supports provided to children with ID.

Participants

A total of 77 young adults (*n* = 77, M_{age} = 18.89) comprised of 87% females (*n* = 67) and 13% males (*n* = 10) participated in the study. All participants reported having completed some university or college, and 2.38% (*n* = 2) of participants completed at least one university or college degree in its entirety. The sample was predominantly Caucasian/European (*n* = 69; 89.60%). The details of the demographic compositions for the treatment and control groups are summarized in Table 1. Comparisons using Fisher's Exact Test for categorical variables and independent samples t-tests for continuous variables indicated that the treatment group and control group were comparable ($p > .10$) on each of the reported demographic characteristics.

Intervention: Overview of Training Presentations and Case Studies

Both groups were shown a 45-minute training presentation that was either specific to pain assessment and treatment (i.e., treatment group) or to visual supports (i.e., control group). The presentations were followed by a related, interactive case study in which participants were asked to assume that they were non-health care professional secondary caregivers (e.g., respite workers) caring for a child with ID. Using the knowledge they acquired in the presentation, participants were asked to discuss with their group how they would provide the relevant support to a child with ID. The case study provided an interactive review session of the key concepts taught in the presentation before they completed the post-training questionnaires. The two researchers who facilitated the trainings each led an equal number of pain training and visual support training groups; the researchers were not blind to the purpose or hypotheses of the study, but did not complete any of the outcome measures.

Pain training. The objectives of the "Pain in Children with Intellectual Disabilities" presentation were to define pain (i.e., acute, chronic, and the biopsychosocial model), learn how children with ID express pain, and discuss effective pain assessment and treatment strategies (i.e., pharmacological, physical, and psychological). The presentation content was derived from an established body of research [3, 5, 10, 31, 32, 33, 34, 35].

Visual supports training. The "Visual Supports for Children with Intellectual Disabilities" presentation addressed the importance of using visuals (e.g., pictures, signs, objects, body language, or environmental cues) to increase comprehension of spoken language, decrease anxiety, and promote independence. The training focused on types of visual strategies, and when, where, and how to use visuals. Presentation content was adapted with permission from presentations provided by organizations specializing in mental health and developmental services as well as knowledge of the first author from working in the field.

Measures and Materials

Demographics. Data collected from participants included age, gender, ethnicity, level of education, and their experience working with and familiarity of children with ID.

Adapted Pediatric Pain Knowledge and Attitudes Questionnaire Revised (Adapted PPKAQ-R). An adapted version of Twycross and Williams' [21] questionnaire on nurses' knowledge and beliefs regarding pain in children was created and maintained the 5-point Likert scale (i.e., *Agree*, *Agree to some extent*, *Neither agree nor disagree*, *Disagree to some extent*, and *Disagree*). Changes made to the original measure included: 1) removing questions irrelevant to non-health care workers (e.g., post-operative analgesic drugs), 2) modifying items to relate more closely to secondary caregivers, and 3) removing three items that had poor reliability in Twycross and Williams' [21] initial validation study. Finally, we generated eight new Likert scale questions that pertained specifically to children with ID (e.g., "Children who have intellectual disabilities are indifferent to pain."). In total, the modified measure has 26 items to assess participants' knowledge and beliefs of pain experience and treatment in children with ID. Participants received one to five points for each question depending on their response, with a possible total score range of 26 to 130.

Questionnaire for Understanding Pain in Individuals with Intellectual Disabilities – Caregiver Report (QUPID-C). Developed by XX, XX, and XX the *QUPID-C* was designed to assess pain knowledge in non-health care secondary caregivers of individuals with ID. The questionnaire was largely based on the International Association for the Study of Pain's (IASP) core curriculum guidelines [5]. These guidelines were created by professionals as a training resource for patient care on topics which included the psychology of pain, pain assessment and treatment, and taxonomies for clinical conditions [31]. The *QUPID-C* contains 19 true/false and 16 multiple choice questions; total scores can range from 0 to 35. For example, one true/false question was: "Generally, individuals with severe ID can provide self-reports of their own pain.

(false)”. Participants were asked to assume that an “individual with ID” referred to a child with ID.

Feasibility, Confidence, and Effectiveness Ratings Questionnaire. A series of ratings gathered participants’ perceptions of the feasibility of and confidence and skill in pain assessment and treatment of pain in children with ID. Each used an 11-point (0-10) rating scale. Specifically, the three questions about pain assessment were:

1) Knowing / assessing whether a child with an intellectual disability is in pain is [0 – *Not feasible at all* to 10 – *Highly feasible*]

2) I am ____ in knowing / assessing whether a child with an intellectual disability is in pain [0 – *Not confident at all* to 10 – *Highly confident*]

3) I am ____ in knowing / assessing whether a child with an intellectual disability is in pain [0 – *Not skilled at all* to 10 – *Highly skilled*]

Three analogous questions were posed regarding pain treatment.

Procedure

The study was approved by the university’s research ethics board. First, a pilot training was conducted with seven participants in the pain intervention group to determine any logistical challenges; these data were omitted because random assignment was not used. Following the pilot, for each data collection the study ran simultaneously for the treatment group and control group in different rooms. Researchers flipped a coin to determine each participant's group assignment but this information was unknown to participants until after they had completed the consent process. All participants maintained consent upon learning their groups and were blinded to hypotheses.

Participants then completed a pre-training package of questionnaires in the following order: (1) Demographics, (2) *Adapted PPKAQ-R*, (3) *QUPID-C*, and (4) *Feasibility, Confidence, and Effectiveness Ratings Questionnaire*. Half-way through data collection (*n* = 38), the pain knowledge questionnaire order was reversed such that *QUPID-C* was completed before the *Adapted PPKAQ-R.*

Next, participants completed either the pain or visual supports presentation and case study. Following the training, participants in both groups completed the same pain knowledge measures and ratings as at pre-training with the exception of the demographics measure. The order of the knowledge measures in the post-training questionnaire packages was also reversed after running 50% (*n* = 38) of the participants. Participants received course credit and an informational fact sheet on pain in children with ID.

Analytic Plan

ANCOVAs were used to evaluate the sensitivity of the pain knowledge measures and self-report ratings (objectives one and two) to the training interventions. Since completing pre-training measures with pain-related terminology could have primed participants and inflated scores in the treatment condition, pre-training scores were used as the covariate to reduce error variance and improve accuracy in statistical conclusions [36].

Means and standard deviations of the raw change scores were calculated (i.e., the difference between the total post-training score and total pre-training score) and compared between groups for the *Adapted PPKAQ-R* [21], *QUPID-C,* and *Feasibility, Confidence, and Effectiveness Ratings Questionnaire* using a series of eight one-way ANCOVAs (IV: training type). Raw change scores were used as the initial pre-training score was a co-variate in the ANCOVA analyses. All ANCOVA assumptions [37] were met with the exception of two of the six self-report rating items: Assessment Confidence (i.e., unequal regression slopes) and Assessment Skill (i.e., unequal variances). Unequal variances have a negligible effect with equal or nearly equal group sizes [38]. Furthermore, the effect of heterogeneous regression slopes on the ANCOVA F test is "negligible with equal *n*'s and equal covariate means (randomized studies) and modest with unequal *n*'s" (p. 150) [38, 39][1].

Given that the data were non-normal, correlations using Spearman's rho were conducted to explore relations between all participants' knowledge scores and ratings collapsed across conditions. Two regressions were used to further explore objective three (predicting assessment confidence and treatment confidence at post)[1].

Results

Note: Raw data descriptives (*M, SD*) of participants' knowledge scores and feasibility, confidence and skill ratings for the treatment and control groups are available upon request to corresponding author.

Objective One.

Adapted PPKAQ-R. The covariate, total pre-score for the *Adapted PPKAQ-R*, significantly predicted participants' total raw change score for the *Adapted PPKAQ-R*, $F(1,66) = 7.67$, $p = .007$ (a medium effect, partial $\eta^2 = .10$). The training type had a significant impact and very large effect on the total raw change score of the *Adapted PPKAQ-R* when controlling for the covariate, $F(1,66) = 86.93$, $p < .001$, partial $\eta^2 = .57$. As illustrated in Figure 1, the pain training led to significantly higher pain knowledge raw change scores ($M = 13.56$, $SE = .82$) compared to the visual supports training ($M = 2.29$, $SE = .86$).

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[1] When assumptions were not met, bootstrapping was performed to provide a more conservative interpretation of the data [37, 38]. The pattern of the bootstrapped results were analogous to the results reported below using ANCOVAs.

QUPID-C. The covariate, total pre-score for *QUPID-C*, significantly predicted participants' total raw change score for the *QUPID-C*, $F(1,66) = 39.66$, $p < .001$, and had a very large effect size of partial $\eta^2 = .38$ [41, 42]. There was a significant large effect of training type on the *QUPID-C* raw change score after controlling for the covariate, $F(1,66) = 24.14$, $p < .001$, partial $\eta^2 = .27$. As shown in Figure 1, the pain training significantly increased pain knowledge raw change scores ($M = 4.69$, $SE = 4.69$) compared to the visual support training ($M = 1.20$, $SE = 1.20$).

Objective Two.

Feasibility, Confidence, and Effectiveness Ratings. For all ratings, with the exception of treatment feasibility ($p = .184$, partial $\eta^2 = .03$), the covariate (i.e., the pre-score total for each measure) significantly predicted raw change scores (*p's* < .001, partial $\eta^2 = .17$ to .32). Training type also had a significant impact on all raw change scores when controlling for the covariate ($p < .011$ to .001, partial $\eta^2 = .09$ to .30). See Table 2 for all *F* values, p-values, and effect sizes for the covariate impact and training type impact on all six ratings. Pain training significantly increased raw change scores compared to the visual support training for all six ratings (see Figure 2).

Objective Three.

Examining Inter-Relations Between Knowledge Measures and Caregiver Ratings. As hypothesized, participants' ratings of assessment confidence correlated positively at both time points with their perceptions of assessment feasibility (pre: $r = .34$, $p < .01$; post: $r = .38$, $p < .01$) and their own assessment skill (pre: $r = .83$, $p < .001$; post: $r = .35$, $p < .01$), and at post with scores on both knowledge measures (*QUPID-C:* $r = .39$, $p < .01$; *Adapted PPKAQ-R*: $r = .39$, $p < .01$). Similarly, participants' ratings of treatment confidence correlated positively at both time points with their perceptions of treatment feasibility (pre: $r = .24$, $p < .05$; post: $r = .34$, $p < .01$) and their own treatment skill (pre: $r = .78$, $p < .001$; post: $r = .56$, $p < .001$), and at post with scores on both knowledge measures (*QUPID-C*: $r = .33$, $p < .01$; *Adapted PPKAQ-R*: $r = .32$, $p < .01$).

Predicting Participants' Pre-Assessment/Treatment Confidence Ratings. In the regression predicting pre-assessment confidence ratings, pre-assessment feasibility ratings were in the first block, followed by pre-assessment skill (block two), and total pre-knowledge scores from the *QUPID-C* and the *Adapted PPKAQ-R* (block three). All three models in the regression predicted pre-assessment confidence significantly better than the mean alone; block three: $F(4, 60) = 19.24$, $p < .001$ (see Table 3); however, these models were predominantly driven by participants' perceptions of their own skill. Participants' pre ratings of assessment feasibility (block one) only significantly contributed to the model in the first block. Participants' total knowledge scores from the *QUPID-C* and the *Adapted PPKAQ-R* did not significantly contribute to the model. The same results trend was found for the second regression which predicted treatment confidence at the pre time point; block three: $F(4, 59) = 27.71$, $p < .001$ (see Table 4). Here, pre-treatment feasibility ratings were in the first block, followed by pre-treatment skill (block two), and total pre-knowledge scores from the *QUPID-C* and the *Adapted PPKAQ-R* (block three). With respect to the third block of both regressions, participants' knowledge scores on either *QUPID-C* or the *Adapted PPKAQ-R* at pre did not significantly contribute to the model.

Predicting Participants' Post-Assessment/Treatment Confidence Ratings. After controlling for participants' pre-assessment confidence ratings in the first block, participants' post ratings of assessment feasibility (block two), assessment skill (block three), and their total knowledge scores from the *QUPID-C* and the *Adapted PPKAQ-R* (block four) were all significant individual contributors to the model. Similarly, all four models in the regression predicted post-assessment confidence significantly better than the mean alone; block four: $F(5, 61) = 32.53$, $p < .001$ (see Table 5). The same results trend was found for the second regression which predicted treatment confidence at the post time point; block four: $F(5, 61) = 83.82$, $p < .001$ (see Table 6). Here, pre-treatment confidence ratings were in the first block, followed by treatment feasibility (block two), treatment skill (block three), and total knowledge scores from the *QUPID-C* and the *Adapted PPKAQ-R* (block four). With respect to the fourth block of both regressions, participants' knowledge scores on the *QUPID-C* at post significantly contributed to the model prediction above and beyond the variance explained by skill and feasibility ratings. In both regressions, participants' confidence ratings appear to be predominantly driven by their perceptions of their own skill.

Discussion

Pain is common in children with ID; however, there is a lack of pain training and pain knowledge measures for non-health care secondary caregivers who are often responsible for pain assessment and treatment of this population [15, 43, 44]. Accurate pain knowledge measures have been used to help identify and determine exactly where knowledge deficiencies exist in health care professionals [21, 18, 19, 20]. Analogous measures are also required for non-health care secondary caregivers, as respite workers may underestimate the level of pain that children with severe ID sense compared to typically developing children [14]. This could lead to inadequate pain assessment and treatment; as a result, the well-being of children with ID could be jeopardized. Developing sensitive pain knowledge measures to evaluate pain training interventions for secondary caregivers is important and was the objective of the current study.

Pain training led to significantly larger raw change scores on both knowledge measures over time compared to the visual supports training. The *Adapted PPKAQ-R* [21] was sensitive to the pain training intervention, suggesting that the researchers' modifications to the questionnaire were relevant to the targeted secondary caregivers. Twycross and Williams [21] alluded to the fact that continued use of the *Pediatric Pain Knowledge and Attitudes Questionnaire* (*PPKAQ*) and its variations has allowed for instrumental feedback and adaptions for use in clinical settings over the last fifteen years [20, 22, 24, 25, 45]. These adaptions have contributed to improved evaluation of pain knowledge of health care and non-health care professionals who work in the pediatric field. Of course, the larger difference between pre-training and post-training pain knowledge scores for participants who completed pain training also speaks to the effectiveness of the intervention. This is perhaps not surprising given that the intervention was created according to the IASP guidelines [5] and pain-related content was incorporated into the pain knowledge measures.

The *QUPID-C* was also sensitive to pain knowledge acquired from the training intervention. Similar to the *Adapted PPKAQ-R*, future research should examine the validity and reliability of the *QUPID-C* for use in non-health care secondary caregivers. These professionals have an important responsibility to understand the complexity of children with ID before assessing and managing their pain. It is necessary to clarify misconceptions and (mis)beliefs regarding pain in children with ID through the use of effective pain training interventions.

Following pain training, participants: (1) believed that pain assessment and treatment for children with ID was more feasible, (2) felt more confident in their own ability to assess and manage pain, and (3) perceived themselves to be more skilled in assessing and managing pain for children with ID. There was a substantial difference between the raw change values in assessment confidence (i.e., $M_{\text{differencepain}} = 2.48$; $M_{\text{differencevisual}} = .91$) and treatment confidence (i.e., $M_{\text{differencepain}} = 2.08$; $M_{\text{differencevisual}} = .27$) between the pain training and visual training groups. While promising on first consideration, this may also indicate that participants were *overconfident* in helping a child with ID to manage pain following the pain training, as they only completed a one-hour pain training intervention. Similarly, it is important to acknowledge that social desirability may have also contributed to the changes in these ratings.

Results from the regression analyses suggest participants' perceptions of confidence in assessing and managing pain in children with ID is largely driven by perceived skill. However, depending on the type of knowledge measure used (explored further below), knowledge gained through pain-related training further predicted participants' confidence at the post time point. Perhaps caregivers may be more likely to engage in pain assessment and management strategies if they are confident in their ability to use them. These regression results suggest the importance of training provision not only to increase topic-specific knowledge, but also as a means to impact participants' confidence in providing relevant care to children with ID. After acquiring knowledge, participants may be able to use this to inform their perceptions of their confidence in a given skill area.

Only one pain-related knowledge measure (*QUPID-C*) significantly contributed to the regression model predicting participants' post-training confidence ratings. Upon review of the two measures, the format of the *QUPID-C* and the *Adapted PPKAQ-R* are quite different in that the *QUPID-C* is structured as a mastery-based test with one specific right or wrong answer per question, while the *Adapted PPKAQ-R* seems to be more beliefs-based with potentially more than one correct response (arguably, one's response on particular items as 'agree' or 'strongly agree' could technically be correct). Perhaps participants' ability to more clearly decipher whether they know the answer to a question or not has a greater impact on their confidence overall. Thus, consideration of formatting and structure of knowledge measures and their intended purpose may be important.

Strengths, Limitations, and Future Directions

To our knowledge, this is the first study to consider non-health care secondary caregivers' pain-related knowledge of children with ID. The study design controlled for extraneous variables to help ensure accuracy in study results. For example, individual differences were minimized through pre-screening and random assignment; order effects were minimized by reversing order of questionnaire packages for 50% of participants; use of ANCOVA controlling for pre-scores minimized potential for inflation of post-scores and error variance [36]; partial eta squared was used, which is a more conservative estimate of effect size [37].

This study also has a few limitations. First, new training interventions (i.e., pain and visual supports presentations) and new measures (i.e., *QUPID-C* and *Adapted PPKAQ-R*) not yet used in previous research were used to teach and assess participants' pain knowledge. Second, the sample had an underrepresentation of men (13%) and ethnicities besides Caucasian/European (90%). Historically, the university at which the study took place has maintained a significantly larger proportion of women to men and Caucasian students; thus, the gender and ethnic representation was limited due to the population from which the researchers recruited participants. Future research should examine the knowledge measures specifically in a respite context and also collect data through long term follow-up to further examine the performance of these measures across time. In the context of pain-related education for caregivers, these measures could be used to ensure a baseline of minimum caregiver knowledge when introducing them to validated pain assessment measures and management approaches. Similarly, if an adequate length of time between pain trainings could be established, a program with suggested follow up training dates could be developed to ensure that quality of pain-related care for children with ID is maintained over time. Finally, future research should examine the impact that child factors (e.g., severity of ID) may have on caregivers’ knowledge.

Conclusion

This study yielded evidence supporting the sensitivity of both (1) new and (1) adapted pain knowledge measures for use in secondary caregivers (e.g., respite workers) for children with ID. The contribution is of importance to the clinical field, as such knowledge measures have yet to exist for the specific population of non-health care secondary caregivers. Using these knowledge measures, accurate assessment of pain knowledge can lead to (1) obtaining a quantifiable baseline for pain knowledge of secondary caregivers, (2) identifying discrepancies in pain knowledge and beliefs with existing research, (3) determining whether pain training improves pain knowledge and beliefs, and subsequently, (4) using newly-acquired knowledge to provide appropriate pain assessment and treatment to children with ID. In conclusion, the development and continued use of evidence-based pain knowledge measures may contribute to the increased well-being of a vulnerable population that has often been misunderstood in terms of communication, pain experience, and pain expression.

Summary Points

- Pain is common in children with ID, despite misconceptions about this population not perceiving pain like typical-developing children.
- Inadequate pain assessment and treatment is likely due to ineffective communication of pain from children with ID and caregivers' inaccurate pain knowledge and beliefs.
- There are no pain knowledge measures for secondary caregivers (i.e. respite workers) who care for children with ID.
- Participants showed higher pain knowledge scores on both the *Adapted PPKAQ-R* questionnaire [21] and newly-developed *QUPID-C* questionnaire following pain training (vs. control group).
- Significantly higher ratings of *Feasibility, Confidence, and Effectiveness* (6) showed that participants viewed pain assessment and treatment with more feasibility, confidence, and skill after pain training.
- Knowledge measures of pain in children with ID can be used to obtain a quantifiable baseline of pain knowledge and identify discrepancies in knowledge and beliefs in secondary caregivers.
- Utilizing accurate, evidence-based pain knowledge measures and pain training interventions over time may contribute to the provision of appropriate pain assessment and treatment for children with ID.
- Caregivers' confidence in pain assessment and management for children with ID is largely driven by perceived skill; however, pain-related education can additionally contribute to an increase in caregivers' pain assessment and management confidence.

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Annotated References

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Twycross and Williams created the PPKAQ-R questionnaire, from which the researchers of the current study created an adapted version to use as one of two primary knowledge measures.

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The complexity of nonverbal pain expression is one of the primary forms of communications that is overlooked by caregivers and contributes to undermanaged pain.

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This study explores the attitudes of respite workers, which is part of our population of interest (i.e., secondary caregivers) for the current study, and finds that respite workers underestimate the pain experienced by children with cognitive impairments.

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Breau and colleagues discuss the various risks and future implications that children with ID face when their pain experience is undermanaged.