

A randomized controlled trial evaluating a pain training for respite workers supporting children with disabilities part two: Training evaluations and the impact of training on knowledge application

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Abstract

Pain training may improve respite workers' (RW) knowledge and self-reported confidence and skill; however, little is known about pain training impact on skill application in respite contexts.

Objectives: Within a parallel group RCT comparing pain and control training, this paper reports:

(1) pain training impact on RW pain assessment and management approaches, and (2) training

evaluations. **Methods:** RW ($n = 158$) from fourteen organizations received pain or control training following randomization with sequentially numbered, opaque, sealed envelopes.

Researchers were blind until randomization; allocations were not shared explicitly with

organizations and participants. Immediately before either training, participants completed a

strategy use questionnaire. Evaluations were provided immediately after training. Four-to-six

weeks after either training, participants again completed the strategy use questionnaire and semi-

structured focus groups. **Results:** No differences in participant's pain approaches were noted in strategy use questionnaires. Common and unique approaches between groups emerged from qualitative focus group analyses. Both groups had similar approaches for developing a 'knowing' about pain and applied similar approaches in practice. Participants receiving the pain training also identified the importance of 'growing and strengthening' their pain knowledge. Training endorsements were favorable. **Discussion:** Findings demonstrate the value of pain training for RW and potential impact on practice.

Keywords: pain; children; intellectual and developmental disabilities; education; respite workers

Introduction

Pain is common for children with intellectual and developmental disabilities (I/DD) and may occur more frequently compared to those without I/DD (Breau, Camfield, & McGrath, 2003). The presence of cognitive and communication deficits makes pain assessment and management challenging for these vulnerable children (Carter, MacArthur, & Cunliffe, 2002; Doody & Bailey, 2017). These deficits can limit children's ability to provide self-reports of their pain (Chen-Lim, Zarnowsky, Green, Schaffer, Holtzer, & Ely, 2012) and caregivers may therefore be relied on to assist with pain assessment and management decisions. **Even this approach, however, is not without its own unique challenges as pain in these children continues to be under-recognized and under-managed (Breau et al., 2003; McGuire, Daly, & Smyth, 2010).**

Most research examining pain in children with I/DD has focused on understanding their pain expression and developing pain assessment tools to assist parents and health care providers. However, children with I/DD receive support from other caregivers in the community who would also benefit from pain-related knowledge and tools. For example, many children with I/DD receive respite care: a high in demand, critical support service which provides short-term breaks for parents raising children with disabilities (Douma & Dekker, 2006; McConkey, Kelly, & Craig, 2011). Provision of this support to family members results in several positive outcomes including stress reduction, opportunities for rest and relaxation, and a sense of relief (Robertson et al., 2011).

During respite, access to a primary caregiver who can help interpret a child's pain behavior and make pain-related decisions is not always feasible. Furthermore, respite workers: (a) may hold inaccurate beliefs about pain (████████████████████, 2017), (b) are interested in learning more about pain and related assessment and management strategies (██████████

██ 2018) and (c) are lacking in specialized pain training opportunities (████████████████████ 2018). *Let's Talk About Pain* is an empirically informed training developed to address this identified need (████████████████████ 2018). **Respite workers who completed the *Let's Talk About Pain* training as part of a pilot study demonstrated significant increases in pain-related knowledge and self-reported confidence and skill in pain assessment and management (████████████████████ 2018).**

Once past the pilot stage, there are many ways to evaluate a training's impact on its target audience more formally. Combining summative and formative evaluation approaches is commonly used in the development and evaluation of educational training programs (e.g., Watt-Watson et al., 2011). Summative evaluations represent evaluations used to demonstrate whether a program has achieved predetermined intended outcomes for a target audience, while formative evaluations gather information to further improve program implementation (Newcomer, Hatry, & Wholey, 2015).

A randomized controlled trial of the *Let's Talk About Pain* training program (ClinicalTrials.gov identifier: NCT03421795; ██████████ submitted; ██████████ ██████████ 2020a) utilized both summative and formative evaluations with results presented in two papers. The first paper on quantitative summative outcomes (Genik et al., submitted) reports the impact of the *Let's Talk About Pain* training on respite workers' pain-related knowledge and self-reported perceptions of feasibility, confidence and skill in pain assessment and management both immediately after training completion and at four to six week follow-up.

Using quantitative and qualitative approaches, this second (current) paper reports both summative and formative evaluations of the *Let's Talk About Pain* training. Specifically, the

objectives of the current paper were to explore: (a) *Let's Talk About Pain's* impact on participants' use of pain assessment and management-related approaches in practice (tertiary outcome¹; summative evaluation) and (b) participants' training evaluations (secondary outcome; formative evaluation). Participants' pain assessment and management approaches were measured in three ways: self-reported lists of strategies being used at work (questionnaire), responses to a structured vignette scenario (questionnaire), and discussion of pain-related experiences and approaches at work (semi-structured focus groups). **A priori hypotheses were** that participants who completed the pain training would report using a greater range of pain assessment and management approaches at work and in response to a structured vignette: (a) at follow-up compared to pre-training, and (b) compared to those who completed the control training. Focus groups were also used to explore similarities and differences in pain assessment and management approaches of participants in the pain and control training groups at follow-up (no a priori hypotheses specified). Finally, **an a priori hypothesis anticipated** that those who completed the *Let's Talk About Pain* training would provide favourable training evaluations.

Materials and Method

Ethics clearance was received from our research ethics board, including the presentation of direct quotes to support qualitative analyses. As previously indicated, this work is part of a larger multi-centre two-group parallel RCT. The full sample of participants represented in both the first (Genik et al., submitted) and second (current) manuscripts are identical; however, data aside from participants' age, gender and ethnicity are distinct. Only the methods relevant to the current manuscript are described here. Readers are directed to part one of this study for detail regarding overlapping methods (e.g., participant recruitment; ██████████ submitted). The full

¹ In our protocol, pain assessment and management approaches were designated as tertiary (vs. secondary) due to the exploratory nature of some hypotheses as well as concerns regarding feasibility in collecting the data.

RCT protocol is presented separately ([REDACTED] 2020b). The first author accepts full responsibility for the reliability between the methods discussed in the current paper and the published study protocol.

Eligibility, Recruitment, and Randomization

Please see part one of this manuscript for details regarding participant recruitment, eligibility, and randomization ([REDACTED] submitted).

Training Interventions

Please see part one of this manuscript and/or the full RCT study protocol for details regarding the training interventions used in this study ([REDACTED] submitted; [REDACTED] 2020b). See <https://hdl.handle.net/10214/21376> for an outline of the pain training.

Procedures

Pre-Training. Participants provided informed consent and completed the: (a) demographics questionnaire and (b) questionnaire about their use of pain assessment and management strategies in respite settings.

Training. Immediately after completing the pre-training questionnaires, participants completed the pain or control training ([REDACTED] submitted; [REDACTED] 2020b). During the training, a research assistant completed a fidelity checklist.

Post-Training. Immediately after completion of either training program, participants completed a brief training evaluation. A folder with training slides and resources, notepad/pen set, refreshments, and an opportunity to enter a \$20 gift card draw were participant incentives.

Follow-Up. Four to six weeks following the training, researchers collected follow-up data from those receiving the pain and control training. All participants were again asked to complete the pain assessment and management strategy questionnaire from the pre-training time-

point above. Finally, participants completed a 0.5 to one-hour semi-structured focus group with up to 12 other participants from their organization (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). During this focus group, participants shared their opinions about and experiences with pain assessment and management in respite settings. They also discussed their approaches to pain assessment and management on the job and any skills or concepts they remembered or applied from the training. All focus groups were facilitated by the corresponding author (see <https://hdl.handle.net/10214/21376> for complete focus group guide). An accompanying research assistant took relevant field notes which were expanded within 24 hours of each focus group (Mack et al., 2005). Focus groups were audio-recorded and later transcribed and verified. A certificate of completion, an additional opportunity to enter a \$20 gift card draw, and a \$20 cash honorarium were provided as participant incentives for completing the follow-up time point data collection. Organizations who received the control training could complete the *Let's Talk About Pain* training following completion of follow-up.

Measures

Demographics Questionnaire (pre-training). Participants provided information about their age, gender, and ethnicity.

Use of Pain Assessment and Management Strategies Questionnaire (pre-training and follow-up). This researcher-generated questionnaire was created based on results from an initial study with stakeholders aimed at informing feasible follow-up methodology for this RCT (██████████ 2020a). The questionnaire was used for two purposes. First, it gathered open-ended self-reported data about the types of pain assessment and management strategies being used at work: *Please list/describe the strategies you have used when (assessing for pain in/helping manage pain with) a child with an intellectual/developmental disability in respite care in this*

organization. Second, a previously developed vignette was used to present a standardized and consistent scenario to all participants: “Jordan is a 10-year-old child who receives respite care. Jordan has a developmental disability and is nonverbal. While in respite care, Jordan and his/her respite worker usually go swimming or play at the park. While doing either of these activities, Jordan usually smiles and appears to be very relaxed. Today, after entering a relatively crowded pool, Jordan suddenly exits the water and becomes very restless: lifting his/her hands and holds them to his/her head. Soon after, Jordan begins to scream.” (██████████ 2015). After reading the vignette, participants responded to a series of open-ended questions: (a) ...please briefly describe the steps you would take to assess whether the child in this scenario is in pain, (b) assuming that the child in this scenario was experiencing pain, please briefly describe the steps you would take to help manage the child’s pain, and (c) please briefly describe any additional follow-up action that you would need to take if you were the respite worker in this scenario. All vignettes in the initial vignette development and evaluation study have shown evidence of convergent and divergent validity (██████████ 2015); an ambiguous scenario without a clear pain source was therefore chosen to avoid potential bias towards an assessment or management approach based on the cause of the pain.

Training Evaluation Questionnaire (post-training). Participants provided (a) self-report ratings of their agreement with different statements about the training program (e.g., effectiveness of format; 0 = *strongly disagree* to 10 = *strongly agree*), and (b) responses to open-ended questions about the training program (e.g., what component contributed most/least to learning). This questionnaire was researcher-developed and based on the training evaluation used in the *Let’s Talk About Pain* pilot study (██████████ 2018). Participants in both groups were

asked to complete the evaluations; however, results will only be presented for the pain training group.

Fidelity Checklist (training). A research assistant present at each training indicated their perceptions regarding the topics that participants were most and least interested in hearing about and what appeared to contribute most to their learning. These were analogous to select open-ended process-based questions from participants' training evaluations. As part of the larger RCT, detailed fidelity checklists were completed in both the pain and control training groups (██████████ submitted); however, results are only presented for the pain training group for the specified questions above.

Participants and Data Collection Summary

A total of fourteen organizations participated in the RCT (██████████ submitted). Each organization was randomly assigned to only one condition, and all participants were employed in only one participating organization. Thus, there were no crossovers between groups. Five of seven control training organizations opted to complete the pain training after study completion.

One-hundred and fifty-eight participants took part in the study ($n_{\text{intervention}} = 66$; $n_{\text{control}} = 92$). At follow-up, the response rate included 60.60% ($n = 40$) pain training participants and 67.39% ($n = 62$) control training participants (see Table 1), with two to fourteen staff representing each of the fourteen participating children's respite organizations. A total of fifteen focus groups were conducted (see part one of this manuscript for CONSORT flow diagram outlining the number of participants in each focus group; ██████████ submitted). All participants who attended the follow up data collection session engaged in the follow-up questionnaires and focus groups. Missing data on individual items (e.g., skipping a question) was minimal and there was no pattern observed in any data that was missing. Those who had complete data associated with a given research outcome were included in the corresponding

analysis; that is, participants were only excluded from analyses when they were missing data on the relevant variable or item. For more in-depth details of organization and participant flow regarding other RCT outcomes, see part one (██████████ submitted).

Data Analysis

Demographic data for the pain and control training groups were analyzed using frequency and descriptive analyses (for more detailed demographic information including demographic comparisons between groups, see ██████████ submitted). A pragmatic, essentialist/realist approach was used for all qualitative analyses described below.

Pain Assessment and Management Approaches (Pain and Control Training Groups)

Self-Reported Strategies at Work and Vignette Data. Coding schemes were developed to address 5 open-ended questions from the *Use of Pain Assessment and Management Strategies Questionnaire* (complete coding schemes are available at: <https://hdl.handle.net/10214/21376>). Specifically, two of these questions asked participants to list/describe the strategies they use to help (a) assess and (b) manage pain in children with disabilities when providing respite care. The remaining three questions asked participants to indicate (a) assessment, (b) management, and (c) follow-up approaches they would take in relation to the standardized vignette scenario presented. Coding schemes were developed by the primary researcher (LG) in collaboration with two additional research assistants and their research advisor (CMM) using inductive (i.e., consideration of participant responses) and deductive (i.e., consideration of evidence-based assessment and management approaches to pain; adaptations from vignette coding schemes used in ██████████ 2015) quantitative content analytic approaches with an unconstrained matrix as per the steps outlined by Elo and Kyngas (2008). Once created, each scheme included nine to thirteen coding categories with detailed definitions and examples of what types of participant responses would fit. For example, codes

within the assessment strategies coding scheme were related to self report (scale or structured activity, verbal questions, nonverbal questions/visuals), behavioural observations (formal scale or structured measure, informal, physical inspection), gathering information from other sources (review of history/documentation, asking others), environmental-based assessment and intuition. There were also codes in a broad ‘other’ category (e.g., assessment strategy unclear) to address participant responses that did not otherwise fit in the coding scheme. Each code had its own definition and examples to aid research assistants who were completing the coding. For example, ‘Self Report: Verbal Questions’, was defined as ‘response mentions asking questions verbally to ask the child if they are in pain’ and examples provided for this code were ‘Does it hurt?’ and ‘Do you have a booboo?’.

Research assistants were then trained on each scheme over the course of two to three practice sessions. Practice sessions used contrived data and an initial 5% of randomly selected real data until a minimum of ‘substantial’ interrater reliability was met as represented by a Cohen’s Kappa > 0.60 (Cohen, 1988). All responses from pre-training and follow-up were then double coded, and discrepancies were resolved by consensus with the primary investigator. Across pre and follow-up time points, 90.5% of the codes had substantial to almost perfect interrater reliability (0.61-1.00²; Cohen, 1988). Chi-square analyses/Fischer’s exact test were used to compare coded responses between intervention and control groups at pre-training and follow-up, and within groups from pre-training to follow-up. Given the large number of chi-square analyses across codes, only values $< .001$ were considered significant to control for type I error.

² Of note, those code categories with lower than substantial reliability were all binary (present/absent) ‘other/unrelated/unspecified’ categories which had sufficient percent agreement values (75% - 97% agreement). Upon further investigation, we believe that these lower Kappa scores are likely a result of imbalances in the crosstab tables of these categories which can lead to paradoxes in binary coding (Feinstein & Cicchetti, 1990).

Focus Group Data. An inductive and essentialist/realist thematic analysis following steps outlined in thematic analysis literature (Braun & Clarke, 2006) was selected to analyze focus group data to capture more rich and detailed accounts of participants' experiences. These steps included familiarization with the data, developing initial codes, generating initial themes, reviewing themes, defining and refining themes, and compiling the report presented below. Familiarization with the data occurred via review of hard copy transcriptions; subsequently, all other steps were conducted on NVivo12 software. Through this analytic process, a series of meta- or overarching themes and corresponding sub-themes were derived. Frequency (e.g., how often a topic was raised) and topic emphasis (e.g., the length of time a topic was discussed) were taken into consideration during theme development. The researchers also considered what is known in the literature about pain assessment and management in children with I/DD, and both the primary investigator and research assistant involved in analyses had applied experience in the field. Data from the focus groups were analyzed holistically at the semantic level, with separate analyses for the intervention versus control groups. Initial analyses were conducted by the primary investigator (LG) with prior experience conducting qualitative analyses and both research and applied experience in the field. These analyses were reviewed, refined, and defined in tandem by another research assistant with applied experience in respite care. The lead researcher's supervisor (CMM) who is an established pediatric pain researcher and has experience providing training to groups of parents and support workers of children with I/DD was available for consultation as needed throughout, reviewed the final theme configuration, and made suggestions for change as relevant. Theme titles and related metaphors were developed in collaboration with two research assistants and the lead researcher's supervisor (CMM). De-

identified and anonymized quotes from the focus groups have been used in this manuscript to support the themes highlighted in the results section.

Training Evaluations (Pain Training Group) and Fidelity Checklist (Research Assistants)

Frequency and descriptive analyses were used. An analogous inductive content analytic approach to that specified above was used for the responses to open-ended questions on the training evaluations which resulted in five different coding schemes described in the results section (Elo & Kyngas, 2008). Two research assistants were trained on the five schemes in one practice session using 5% of randomly selected training evaluation data. As coders met the minimum 'substantial' interrater reliability threshold of Cohen's Kappa > .60 (Cohen, 1988), all remaining responses were then double coded. Interrater reliability measured by Cohen's Kappa ranged from 0.70 to 1.00 representing substantial to almost perfect agreement (Cohen, 1988) with one exception. Specifically, one code from the fidelity checklist related to 'fit to group needs/learning style' reached only moderate agreement (0.59; Cohen, 1988). Discrepancies were resolved by consensus.

Results

Pain Assessment and Management Approaches (Pain and Control Training Groups; Summative Evaluation)

Self-Reported Strategies at Work and Vignette Data. At the pre-training time point, no significant differences existed between the pain and control training groups for pain assessment (e.g., self report – verbal questions, informal behavioural observations, physical inspection), management (e.g., pharmacological, physical strategies, modifying the setting), or follow-up strategies (e.g., document, inform caregivers/others about the event) reported (a) as being used at work or (b) in response to a contrived vignette scenario (all p 's = .003 – 1.00; all

Cramer's V 's = .01 - .26) or follow-up (all p 's = .03 – 1.00; all Cramer's V 's = .00 - .23). There were also no significant changes in the strategies or approaches reported by those regarding (a) or (b) in the pain training group from pre-training to follow-up (all p 's = .002 – 1.00; all Cramer's V = .00 - .30).

Focus Group Data. After conducting two separate thematic analyses on data from the pain and control training groups, themes were identified both within and across groups. As such, (I) has been used to indicate themes or examples relevant to the pain training group, whereas (C) indicates themes or examples relevant to the control training group. Only themes which directly reflect the qualitative research question about similarities and differences in pain assessment and management approaches are discussed in this manuscript. A tree metaphor will be used to highlight the themes associated with participants' approaches to pain assessment and management. Of note, these themes are interactive and overlapping as they have potential to influence each other. See Table 2 for sample quotes corresponding to each sub-theme.

Meta-theme #1: Knowing and Growing Your Roots. Like the roots of a tree offering a network of stability, nutrients, and support, this meta-theme encompasses the development of a strong, effective and foundational understanding of pain in the respite context. Broadly, participants spoke about using directly available human resources as a critical approach in developing this foundation. This approach is represented in three core sub-themes or in accordance with the tree metaphor, three types of 'roots':

- Knowing the Child (I, C), which represents the need for caregivers to get to know the children for whom they care including their mannerisms, likes/dislikes, baseline behavior and history. This also includes getting to know the child through building rapport.

- Consideration of Personal Factors and First-Hand Experiences (I, C), which represents the need for caregivers to take their own ideas, beliefs and experiences on the job and elsewhere into consideration.
- Collaborating and Communicating with Others (I, C), which represents the need for caregivers to gain knowledge through collaboration and communication with others, particularly parents and peers.

Respite workers in both the pain and control training groups discussed how these approaches contribute to a better understanding of and ability to manage situations at hand as well as feeling more confident in care-based decisions. However, a handful of responses also spoke about how these approaches may have limitations or lead to ‘weaker roots’. For example, primary caregivers and respite providers may share different opinions or experiences with a child: *We were communicating with the parents...and the parent was not concerned at all... (I)*, and *So what they might do for pain management would be very different too ‘cause we are limited to what we have and what the parents have told us. (C)*.

Meta-theme #2: Using Your Trunk and Foliage. Tree trunks, branches, and foliage serve many purposes in helping a tree to function and could be likened in this context to skill application. For example, ‘nutrients’ or key information from the roots need to travel through the trunk to the branches/leaves for use in the environment. Once applied, such key information can be shared (e.g., passing on seeds) to others around. This meta-theme therefore encompasses the approaches that respite workers were aware of and their application to care for children with I/DD experiencing pain. A wide range of pain assessment and management approaches were discussed across organizations and individual participants; however, two core assessment and

three core management sub-themes were identified in participants' experiences assessing and managing pain in children with I/DD:

- Pain Assessment – Informal Behavioral Observation (I, C), which refers to observations of children's behavior without completion of formal checklists or behavioral measures specific to pain.
- Pain Assessment – Informal Self-Report (I, C), which refers to asking the child whether they are in pain without using any formal self-report measures (e.g., body diagram, pain scale). This can encompass verbal and non-verbal forms of self-report.
- Pain Management – Pharmacological Strategies (I, C), which refers to use of any form of approved oral or topical over the counter or prescribed medication to alleviate pain.
- Pain Management – Physical Strategies (I, C), which refers to use of any physical approach (e.g., massage, stretching, water therapy, hugs) to alleviate pain.
- Pain Management – Psychological Strategies (I) which refers to pain management approaches that may target psychological distress and/or muscle relaxation to alleviate pain.

As with different trees, some may have more branches or foliage than others. For example, the pain training group demonstrated this with their additional theme for psychological pain management. Unlike the control training group, pain training participants frequently discussed using a wide range of psychological strategies throughout all focus groups, with emphasis on distraction. They made direct reference to having learned many of these strategies because of the *Let's Talk About Pain* training. Additionally, the pain training group spoke of adapting and individualizing pain assessment and management approaches. These branches and

their leaves may be perceived as stronger because the strategies and knowledge can be more flexibly and creatively applied. For example:

- *I think just how to modify it to our kids. Because everything that's out there is for children that can talk or can identify that, so just the modification to the individual. I think that's what we learned from that [the Let's Talk About Pain program]. (I)*
- *It was good too to see the different assessment tools and like how we can modify them to work more for the population that we work with, and the clients that we work with and how easy it [is] to actually do them. Like we came up with solutions to that in just a couple of minutes so... (I)*

The accessibility and feasibility of the approaches themselves were central in almost all discussions of pain assessment and management in the pain and control training groups, often framed as important considerations as well as barriers. For example, regarding more formal, individualized behavioral assessment measures: *There's a lot of great ideas and people get really excited about it but then when you're actually looking at the logistics of how to do it, it's daunting to be honest. (I)*. Further, regarding pharmacological pain management approaches: *It's not like if you were in the hospital, where you could contact a doctor...but, there's usually PRNs that we can use... (C)*.

Meta-theme #3: Growing and Strengthening Your Tree. While roots, trunks, and foliage are important, trees cannot remain alive and functional without continued access to resources such as sunlight and water. Without these resources, trees will fail to grow and thrive, and new trees may not be able to grow at all. Adequate resources can also allow for the foundational network of roots to grow. Like trees, we have continual professional development needs that must be met for any position we hold.

This third and final meta-theme relates to the value of pain-specific education in a respite context, which can be likened to the sunlight and water trees need to grow. All pain training groups referenced the 'Let's Talk About Pain' training and the impact of this training. For

example: “...that training literally changed the way that I thought about pain...”. They were keen to suggest the relevance of the training to other caregivers of children with I/DD (e.g., educational assistants) or the remaining staff base of their organization. For example: “*I think this training is really important and I think it’s really important for not just respite workers...there are adults that interact with these kids on a more daily basis than we do that don’t have this information like teachers and caregivers and doctors...it’s really something that could be expanded and beneficial to the general population*”. Three core sub-themes specific to this meta-theme were identified for the pain training group:

- Knowledge Development, Validation, and Confidence (I), which refers to knowledge consolidation and expansion and improved confidence that can result when new information is provided or skills already being applied are confirmed as useful.
- Improved Awareness of Pain and Nuanced Perspectives (I), which refers to the increased awareness and altered outlooks on pain in children with I/DD, such as recognizing that behavior may serve to communicate a need, or an awareness of how common pain is in this population. Participants may also report that they are more likely to consider pain as a potential explanation for behavior rather than overlook that possibility.
- New, Specific Strategies and Approaches (I), which refers specifically to novel and/or tailored methods (e.g., different language to use) gained because of educational initiatives. Participants here refer to having new approaches which they may not have been aware of for pain assessment or management prior to the training.

In contrast to the pain training group, the control training group had a theme of missed pain opportunities, such that these participants frequently recounted times when pain may have

been dismissed as attention-seeking or missed entirely. This also speaks to a need for ‘growing or strengthening your tree’. For example:

- *Well, sometimes...saying you're in pain is just a behavior...just to get attention. (C)*
- *...he broke his toe and they didn't even know his toe was broken because he would just walk on it completely fine and stuff like that and he wouldn't tell anyone... (C)*

Pain Training Evaluations (Pain Training Group) and Process Questions (Pain Training Group and Research Assistants; Formative Evaluation)

Participants rated the importance of pain training for respite workers as very high ($M = 9.55$; $range = 7-10$; $0-10$; $10 = Extremely\ Important$). Overall, they provided positive endorsements of the training (range of means: $9.22-9.63$; $0-10$ Likert scale; $10 = Strongly\ Agree$; see Table 3). In response to open-ended questions, those who wanted to learn more about pain in children with I/DD highlighted three broad training topics of interest: general pain-related information ($n = 9/52$, 17.3%), pain management ($n = 9/52$, 17.3%), and pain assessment ($n = 8/52$, 15.4%). Half of participants [$26/52$ (50.0%)] believed the training content was sufficient. Similarly, a slight majority did not want to change anything about the *Let's Talk About Pain* training ($n = 27$, 51.9%). When changes were suggested, they varied from format/delivery ($n = 7$, 13.5%), length ($n = 6$, 11.5%), aspects of the training content ($n = 5$, 9.6%), ‘other’ ($n = 5$, 9.6%), and group size ($n = 2$, 3.8%). See Table 4 for a summary of pain training participant and research assistant responses to multiple-choice and open-ended process-based training evaluation questions. There was consensus that participants were most interested in learning pain assessment and management-related information and least interested in general pain-related information; pain assessment and management were also rated by participants as the most important things they learned. The presentation/speaker was rated as contributing most to

participants' learning, followed by large group discussions. Small group discussions and videos were rated as contributing least to participants' learning. Varied explanations were proposed as to why these factors contributed the most or least to learning.

Discussion

Pain assessment and management for children with I/DD is challenging, and their pain is often underdiagnosed and undertreated (e.g., Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; McGuire, Daly, & Smyth, 2010). Caregivers must be adequately equipped to monitor and address pain. *Let's Talk About Pain* appears efficacious in improving pain-related knowledge and feasibility-confidence-skill perceptions of respite workers immediately post-training with gains generally maintained at follow-up (██████████ 2018; ██████████ submitted). **Consistent with extant literature on pain training programs (e.g., Mackey & Dodd, 2010; Watt-Watson et al., 2011), this manuscript used both summative and formative evaluation approaches to describe the impact of the training on pain assessment and management approaches used in practice and participants' perspectives on and feedback for the training.**

Pain Assessment and Management Strategy Use: Integrating Quantitative and Qualitative Results

Pain assessment and management strategy use was measured with self-reported lists of strategies used at work (questionnaire), responses to open-ended questions about a structured vignette scenario (questionnaire), and discussion of pain-related experiences and approaches at work (semi-structured focus groups). Unexpectedly, there were no differences between groups on pain-related assessment, management, or follow-up reported by participants (a) as being used at work or (b) in response to the vignette; furthermore, there were no differences within the pain training group over time. Although this could raise questions about the training's effectiveness

regarding pain-related approaches in practice, triangulating this result with the demonstrated increase in knowledge post-training (██████████ submitted) and focus group data (discussed next) suggests another explanation. For example, open-ended questions and vignettes (██████████ 2015) may be efficient ways to gather information about caregivers' approaches to pain in children with I/DD but may not elicit the same depth as an interview or focus group. In listing their approaches, participants did not elaborate on the implementation details (the "how"). Indeed, participants responded using terms and approaches consistent with evidence-based practice (e.g., obtaining verbal self report where possible); but the manner in which these approaches would be applied was unclear (e.g., what language they would use, whether they would use specific assessment tools).

Focus groups addressed these challenges by gathering more in-depth information about participants' experiences and approaches. Similar themes in both groups emerged regarding two of the meta-themes. 'Knowing and Growing Your Roots' represented the approaches being used to develop a foundational understanding of a child's pain in a respite context: knowing the child, consideration of personal factors and first-hand experiences, and communication and collaboration. 'Using Your Trunk and Foliage' highlighted the pain assessment (i.e., informal behavioral observations; informal self-report) and management approaches (e.g., pharmacological, physical) applied in respite settings. These themes are consistent with: (a) extant research with parents and other professionals discussing development and acquisition of pain knowledge (Carter, Simons, Bray, & Arnott, 2016; Hunt, Mastroyannopoulos, Goldman, & Seers, 2003) and (b) evidence-based assessment and management strategies (e.g., Taddio et al., 2015). The similarities of these themes across participant groups and caregiver types in extant literature may demonstrate the need for more universal approaches to challenges associated with

pain in children with I/DD (e.g., Carter et al., 2016). For example, one common challenge reported was knowing the child being cared for and accurate interpretation of their behaviors. This uncertainty cannot be entirely alleviated (Breau et al., 2003; Brashers, 2001; Hall, 2002); yet, educational programming may help to build tolerance of uncertainty around the need to ‘know’ (Carter et al., 2016).

Unlike the other meta-themes, ‘Growing and Strengthening Your Tree’ was unique to the pain training group. Those in the pain training group provided reports of knowledge development, confidence, validation, new perspectives/awareness of pain, and new specific strategies; they attributed this growth to their participation in *Let’s Talk About Pain*. Both groups of participants had relatively strong baseline knowledge and an intuitive understanding of how to approach issues related to pain, which may help to explain the similarities in questionnaire responses discussed above; yet, those in the pain training differed in more nuanced but critical ways. For example, unique to the pain-training group in meta-theme two ‘Using Your Trunk and Foliage’ were discussions about psychological management approaches, particularly the use of distraction. Pain training participants also spoke about adaptation and individualization of strategies. Both these topics were discussed in-depth during the training, so it is possible that participants in the intervention group internalized some of these teachings and/or were given vocabulary to describe skills they were previously using. Pain training participants placed great emphasis on the training’s importance, which speaks to the educational need in these settings and training relevance.

Some differences in training results between the current study and other similar studies (e.g., Mackey & Dodd, 2010) may be related to differences in data collection and follow up approaches. For example, a component of Mackey and Dodd’s (2010) study involved follow-up

with managers rather than front line staff, and randomly checked in with select organizations for 'physical evidence' of implementation consistent with their questionnaire responses. The current study did not include management or have the means to formally support implementation within each organization which may have therefore impacted implementation of some of the more formal assessment and management approaches covered in the training.

Training Evaluations

Consistent with the pilot (██████████ 2018), participants provided favourable ratings of the *Let's Talk About Pain* training. These evaluations combined with findings of increased knowledge and feasibility-confidence-skill perceptions (██████████ submitted) support the training's relevance for a broad range of children's respite workers. Participants' primary interests in learning about pain assessment and management were also consistent with data gathered during training development (██████████ 2018). Participants indicated that they were least interested in hearing about general pain-related information. However, understanding how to assess and manage pain likely requires foundational pain-related knowledge, just as sunlight on its own is not enough for a tree to grow. Parents and health care professionals supporting children with severe to profound impairments have reported similar viewpoints, suggesting that knowing the science of pain is critical for optimal pain assessment and management (Hunt et al., 2003).

The preference for active learning was less obvious in the current training endorsements compared to during the training's development (██████████ 2018). Participants reported that the presentation/speaker was the most important contributor to learning whereas a more active component of small group discussions was reported as least important. Although active learning is efficacious in educational literature (e.g., interprofessional education; Hammick, Freeth,

Koppel, Reeves, & Barr, 2007), a balance of passive and active learning styles may be beneficial to meet a range of learning styles. Beyond *what* learning approaches are being used, consideration of *how* they are implemented is important to ensure audience-relevant content and interactive activities (Braun & Clarke, 2006). Here, factors contributing least to learning were most commonly seen as not fitting with the group's learning needs. Respite organizations can vary substantially in their programming; this suggests that a train-the-trainer approach and/or more tailored, interactive activities may increase relevance to different support services. For example, case scenarios could be designed to represent a wide range of children with varied needs and the most appropriate ones could be used in each training rather than using standardized vignettes.

Strengths, Limitations, and Future Directions

To our knowledge, this was the first RCT to explore the impact of a specialized pain training for respite workers supporting children with I/DD on their approaches to pain assessment and management in practice. The follow-up methodology and approaches were developed based on stakeholder feedback (██████████ 2020a), enabling application in varied respite organizations, regardless of organization-specific policies and staff constraints. A balance of descriptive quantitative and qualitative feedback about the training and its impact enabled a nuanced understanding of the training's outcomes. We present novel, rich data on how trained and untrained respite workers assess and manage pain in children with I/DD; a close inspection yielded critical insights following pain training which can guide future research efforts and knowledge translation.

However, using self-report approaches as a primary means of data collection can lead to bias and potential overestimation or reporting as self-reported and actual responses to a given

situation are may differ. Although the vignette allowed exploration of participant responses to a standardized scenario, it was not real. Further, although researchers were able to probe further about participants' responses in pain-related scenarios during focus groups, these were time limited and not all participants may have been fully forthcoming or comfortable sharing in this context. Future research should consider feasible approaches to incorporate observational or other forms of data collection to better understand participants' approaches to pain in the respite context (e.g., 'case-study' methodology may lend itself better to this observational approach).

As study participants were not given an opportunity to review the themes generated from their focus group data, it is unclear whether they would fully agree with the themes and outcomes. Given the difficulties with response rate at follow-up, important perspectives may have been lost. It is impossible to know whether those absent from the focus groups had different experiences than those attending. Although many strategies for participant retention were used (e.g., gift card draws, honorariums), future work should also consider more flexible data collection approaches (e.g., phone interviews, questionnaires for those who cannot attend focus groups).

Conclusions

The current study described the impact of the *Let's Talk About Pain* training on pain assessment and management strategy use in practice (summative evaluations), as well as participants' perspectives of and feedback on the training (formative evaluations). **Of note, while there were no significant differences between intervention and control participants' responses to open-ended and vignette-based questions regarding pain assessment, management, and follow up approaches, important similarities and differences between participant groups were indicated within participant focus group responses.** Both groups had similar approaches for developing a

‘knowing’ about pain (roots) and applied similar strategies (making use of their trunk and foliage). However, an additional theme for the pain training group was identified which related to ‘growing and strengthening’ their pain knowledge ‘tree’. These participants seemed to have a broader knowledge/strategy base, more confidence in themselves, and a greater awareness of pain. Consistent with the pilot (██████████ 2018), participants provided very positive endorsements of the training program. *Let’s Talk About Pain* may be an effective and positively regarded strategy to provide respite workers with pain-related knowledge and approaches that are relevant to a respite setting, ultimately increasing caregivers’ awareness of, sensitivity to, and ability to address pain in children with I/DD.

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