

Caring for Children with Intellectual Disabilities Part 2: Detailed Analyses of Factors Involved
in Respite Workers' Reported Assessment and Care Decisions

Lara M. Genik, C. Meghan McMurtry, and Lynn M. Breau

Genik, L. McMurtry, M. Breau, L. 2017. Caring for Children with Intellectual Disabilities Part 2: Detailed Analyses of Factors Involved in Respite Workers' Reported Assessment and Care Decisions. *Research in Developmental Disabilities*. <https://doi.org/10.1016/j.ridd.2017.01.021>

Author Note

Lara M. Genik, Department of Psychology, University of Guelph; C. Meghan McMurtry, Department of Psychology, University of Guelph, Clinical Psychologist, Pediatric Chronic Pain Program, McMaster Children's Hospital, Associate Scientist, Children's Health Research Institute, Adjunct Researcher, Department of Paediatrics, Western University; Lynn M. Breau, Glenrose Rehabilitation Hospital

This research was funded by a faculty start up grant at the University of Guelph and was conducted as part of an honours thesis research project within the within the Pediatric Pain, Health and Communication (PPHC) Lab under the supervision of Dr. C. Meghan McMurtry. Participants from this study were a subset of a sample within a larger study; parts of their responses were utilized in analyses and 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); Gatlinburg Conference (April 2015); International Symposium on Pediatric Pain (June 2015).

Correspondence concerning this article should be addressed to Lara Genik, Department of Psychology, University of Guelph, Guelph, ON N1G 2W1. Email: lgenik@uoguelph.ca

Abstract

Respite workers (RW) commonly care for children with intellectual disabilities (ID), and pain is common for these children. Little is known about factors which inform RW pain assessment and management-related decisions. **Objectives:** To describe/determine the following in response to a series of pain-related scenarios (e.g., headache, falling): (1) factors considered important by RW when assessing children with ID's pain; (2) whether children's verbal ability impacts pain assessment factors considered; (3) RW assessment and management approach. **Participants:** Fifty-six RW (18-67 years, $M_{age} = 33.37$, 46 female). **Procedure/Measures:** In an online survey, participants read and responded to six vignettes manipulating child verbal ability (verbal, nonverbal) and pain source. **Results:** The factors most frequently considered when assessing pain were child behavior (range: 20-57.4%), and history (e.g., pain, general; 3.7-38.9%). Factors did not vary by child's verbal ability. RW indicated varied assessment and management-related actions (range: 1-11) for each scenario. **Discussion:** Findings suggest: a) factors informing pain assessment did not depend on whether or not the child was verbal and b) a degree of flexibility in RW response to pain across situations. While these findings are encouraging, ensuring RW have adequate pain assessment and management knowledge specific to children with ID is critical.

What This Paper Adds?

Children with intellectual disabilities (ID) are vulnerable to experiencing unmanaged pain due to increased risk of pain and difficulties in self-report. This study is the first to examine pain assessment and management-related decisions by respite workers who support children with ID. Understanding respite workers' approaches to pain in this population is critical because these

children often rely on caregivers to assess and manage their pain. Systematic vignette methodology was used to gather respite worker responses to a number of different pain-related scenarios.

Results demonstrated that respite workers are flexible in their approach to assessing pain in children with ID. The child's behavior and history were commonly considered. Respite workers also reported a number of actions they would take in response to each scenario, many of which are supported by research literature. The most commonly reported action involved using psychological pain management strategies, while the least common actions were consulting resources (children's care profiles) and reporting the incidents to caregivers. A child's ability to communicate verbally did not appear to impact respite workers' pain assessment or management.

Building from Part One of this manuscript (Genik et al., revision submitted), the current findings provide insight into the types of pain assessment and management strategies that RW are (a) aware of and (b) likely to apply across pain-related scenarios. The results can inform future intervention/educational efforts (e.g., which information may be most useful to help educate respite workers about pain in children with ID).

Keywords: children, intellectual disability, respite, pain assessment, pain management

1. Introduction

Pain may be more common among children with intellectual disabilities (ID; Breau & Burkitt, 2009), and has the potential to negatively impact various aspects of these children's lives including adaptive functioning (Breau, Camfield, McGrath, & Finley, 2007). Thus, effective pain assessment and management are crucial. However, pain assessment for children with ID is particularly challenging. These children may provide inaccurate self-reports if they do not understand or have the necessary skills to participate in self-report activities (Fanurik, Koh, Harrison, Conrad, & Tomerun, 1998); thus, caregivers are often asked to assist with pain assessment. Many children with ID, particularly those who do not communicate verbally, demonstrate atypical behaviors when expressing their pain (Dubois, Capdevila, Bringuier, & Pry, 2010). Yet, it is these types of behaviors that caregivers would need to use to determine whether or not a child is in pain and in need of pain management.

There are a number of pain management strategies that have been found to effectively reduce children's pain. These may be categorized into four main domains: psychological (e.g., distraction; Birnie et al., 2015; Pillai Riddell et al., 2015; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010), physical (e.g., applying ice; Taddio et al., 2015b), pharmacological (i.e., using medication; Taddio & Oberlander, 2006) and process/procedural (e.g., providing simultaneous injections; Taddio et al., 2015b). While some research related to pharmacological pain management has been conducted (Taddio & Oberlander, 2006), much research related to non-pharmacological pain management in children appears to exclude children with ID.

There has been some investigation of pain assessment and management of children with ID in health care settings (e.g., Breau & Burkitt, 2009; Malviya et al., 2001) and with parents (e.g., Carter, McArthur, & Cunliffe, 2002; Davies, 2010). However, investigation of secondary

caregivers' pain assessment and management of these children is very limited. This is concerning, as children with ID frequently receive care from a number of different people when they are not with their parents (e.g., schools, respite care, camp). Respite care in particular is a growing service for families who have children with ID (Chan & Sigafoos, 2000). **These services allow families temporary relief from the demands of raising a child with special needs, often while also meeting the child's unique needs (e.g., social development, personal care; Neufeld, Query, & Drummond, 2001). Respite care may be provided in or out of the child's home and may take many forms (e.g., summer camps, residential treatment centres, day programs; Canadian Healthcare Association, 2012; Neufeld et al., 2001) for differing time periods (e.g., day long respite, week long respite).** When receiving respite services, the parents of a child with ID may not be available to help these secondary caregivers assess whether the child is in pain and in need of treatment.

Respite workers may hold pain-related beliefs contrary to current knowledge about pain in children with ID (Genik, McMurtry, & Breau, revision submitted). A minority of respite workers seem to receive formal pain-related training (Genik et al., revision submitted); furthermore, this training is not specific to children with ID, and often comes from health care related school programs, or other experiences outside of respite workers' employment positions. A more detailed understanding of factors (e.g., child behavior, pain history) that respite workers consider in their responses in a pain context and the impact of child functioning on these considerations is important. These factors could impact respite workers' pain assessment and management decisions, resulting behaviors, and in turn, a child's overall quality of life. For example, pain-related beliefs about children with ID's general ability to sense pain may predict individuals' likelihood of providing medical attention to a specific child with ID experiencing

pain (Genik et al., revision submitted). Similarly, understanding what actions respite workers take when a child with ID may be in pain can help us to understand how they presently care for these children. The pain assessment and management-related information described above can inform training programs and help to ensure that respite workers are aware of factors to consider and appropriate pain assessment and management strategies.

1.1 Objectives

Using a series of written vignettes, the objectives of the current study were: (1) to describe the factors (e.g., child behavior) considered by respite workers when assessing different types/sources of pain in children with ID; (2) to explore whether assessment factors vary depending on the child's verbal ability (verbal versus nonverbal); and (3) to describe the types of actions that respite workers would take (e.g., pain assessment, pain management) for children with ID in a variety of pain-related scenarios.

2. Methods

Data for this article are from a larger study examining distinct research questions as follows. Part one of this work explored the disability and pain-related beliefs as well as broad/general pain-related care decisions held by respite workers compared to young adults with limited to no experience supporting children with ID (Genik et al., revision submitted). The present article (“part two”), examines factors which play a role in respite workers’ pain assessment and management decisions in more detail. The same group of respite workers participated in part one and part two; however, the data reported in these two publications are distinct (beyond demographics). Only the methods relevant to the present article (“part two”) are described below. A university research ethics board granted ethics approval.

2.1 Participants

Participants consisted of 56 respite workers who were over the age of 18 years and proficient in the English language (82.1% female; age range: 18-67; $M_{\text{age}} = 33.37$). The majority of participants ($n = 50$) were recruited from 31 children's respite care organizations across Ontario. A small number of participants ($n = 6$) were recruited from an undergraduate participant pool at a mid-sized university ($n = 25000$). All participants were recruited online, and reported that they provide respite care for children with ID. A total of 80.4% of participants reported that they were moderately to highly involved in the care of children with ID (e.g., providing personal care such as dressing or bathing). A large majority of participants indicated that they interact with children with ID who are nonverbal occasionally to very often (96.4%). Participants' self-reported ethnicities were as follows: European-Canadians ($n = 48$; 85.7%), Indo-Canadian ($n = 3$; 5.4%), African-Canadian ($n = 1$; 1.8%), and Other ($n = 4$; 7.1%).

2.2 Study Procedure

Participants completed all aspects of the study online, including: (1) informed consent, (2) a series of demographic questions, and (3) six pain vignettes and related questions. After completion or withdrawal from the study, all participants could download an informational fact sheet which **provided basic information** about pain in children with ID who are nonverbal (ID/NV). Respite workers recruited from the participant pool received course credit, and those recruited from respite organizations could enter a gift card draw.

2.3 Measures: Pain Vignettes

Six brief vignettes (80-81 words) depicting various sources/types of pain were presented to participants (see Genik et al., 2015 for all six vignettes). Each vignette depicted a ten year old child (sex unspecified) with ID experiencing: an unintentional injury (fall), a painful medical procedure (insulin injection, flu shot), chronic pain (arthritis, headache) and an unknown source

of pain or distress. The child's verbal ability was manipulated such that for each participant, half of the vignettes presented a child who was nonverbal and the other half presented a child who communicated verbally. This was counterbalanced across participants, ensuring that each vignette was equally presented as containing a child who communicated verbally or nonverbally.

Participants were asked to read and respond to each vignette by: (1) listing three factors they considered when making pain assessment (note: only the first factor listed was used in this study¹), and (2) describing the actions they would take if they were a respite worker in that scenario. These vignettes have been demonstrated to have preliminary convergent and divergent validity (Genik et al., 2015).

2.4 Coding

Coding Approach: In order to analyze the data, two initial coding schemes were developed using both an inductive (i.e., consideration of participant responses) and deductive [i.e., consideration of factors in Craig's (2009) Social Communication Model of Pain] content analytic approach with an unconstrained matrix as described by Elo and Kyngas (2008). These schemes could be applied to all six vignette scenarios by the primary investigators and were used to code participant responses related to: (1) the factors they considered when making pain assessment and management decisions and (2) the actions they would take for each scenario.

Practice Coding and Finalization of Coding Scheme: Following initial coding scheme development, the coders completed a series of four practice sessions. At this time, each coder independently applied the coding scheme in question to five to seven participant responses for

¹ Note: The researchers also reviewed the data for the second and third factors listed by participants when making pain assessment decisions. Given that: (1) there were often more missing data for the second and third factors of each vignette (e.g., vignette 2: factor one missing two responses, factor two missing three responses, factor three missing 9 responses) and (2) the second and third factors reported were very similar to the first factor, they were not considered further.

each of the six vignettes; of note, these responses were from a different sample of participants not included in the study analyses. Following these sessions, two additional coding categories were added to the final coding scheme (i.e., “no action/do nothing”; “consulting resources”).

Final Coding: The two coders then each coded the participant responses for all six vignettes over a six week time period using the finalized coding schemes (see Tables 1 and 2). After all responses were double coded, discrepancies were resolved by consensus with a third coder (primary investigator).

3. Results

3.1 Analytic Approach

Descriptive and frequency analyses were used to analyze the data. Percent agreement and Cohen’s Kappa (using descriptors from Fleiss, 1981) were used as agreement coefficients. For factors considered in assessment (objectives one and two), percent agreement ranged from 76.0% to 96.3% (average percent agreement: 86.4%), and Cohen’s Kappa ranged from .69 (fair to good) to .95 (excellent; average Cohen’s Kappa: .81; all p ’s < .0005; lowest 95% CI = .56 - .83; highest 95% CI = .87 – 1.00) across vignettes. For actions mentioned by participants (objective three), percent agreement ranged from 87.1% to 93.2% (average percent agreement: 89.9%); Cohen’s Kappa for actions averaged across codes for each vignette was consistently in the “excellent range” (minimum average Cohen’s Kappa: .84; all p ’s < .0005²). In the following, use of italics

² The Kappa values for Objective Three in text represent averages across all individual code Kappa values for each vignette. With respect to Kappa values for individual codes across vignettes, the lowest Kappa value was 0.50 (p < .0005; 95% CI: .40 = .60) and the highest was 1.00 (p < .0005; 95% CI: 1.00 – 1.00). There were up to 11 different Kappa values for each vignette (range: 6 - 11). With respect to distribution of Kappa values for individual codes across vignettes, one Kappa value was 0.50, three were between .74 and .79 and all remaining Kappa values ranged from 0.81 to 1.00.

denotes the description of/reference to a particular coding category from the corresponding tables.

3.2 Objective 1: Factors Considered Important for Pain Assessment Decisions (Table 3)

Overall, the child's *Pain Behavior/Expression/Response* and history [*Pain History/Knowledge, General History/Knowledge, History/Knowledge (Type Unclear)*] appear to be most commonly considered (see "full" columns in Table 3). For example, across vignettes related to an unspecified pain source, headache, flu shot, arthritis and insulin injection, a range of 44.4% to 57.4% of participants indicated that they considered the child's *Pain Behavior/Expression/Response* when making a pain assessment decision. Consideration of a child's *Pain History/Knowledge* was commonly considered for the vignettes which depicted chronic pain (i.e., headache: 18.5% and arthritis: 27.8%). *General History/Knowledge* (e.g., child's age) was considered most often when the pain source was unspecified (18.5%) or when the pain source was from a medical procedure (flu shot: 14.8%; insulin injection: 14.8%). Interestingly, the surrounding *Environmental/Situational Context* was only prominently considered when the pain source was unspecified (13.0%). Respite workers were more likely to refer to a *Consideration of Specific Pain Source and/or the Severity of This (specific to vignette)* when a clear source of unintentional injury was provided (i.e., falling down: 61.1%), and to a lesser extent, when an acute and non-recurring source of procedural pain was provided (i.e., flu shot: 13.0%).

3.3 Objective 2: Whether Children Are Verbal and Factors Considered Important for Pain Assessment Decisions (Table 3)

The trend of factors considered when assessing different types of pain did not seem to vary greatly when comparing children who do and do not communicate verbally (see verbal and

nonverbal columns in Table 3). Thus, on the whole, a child's ability to use verbal language to communicate did not appear to impact the factors respite workers considered when assessing pain in children with ID. However, there were some differences observed within specific pain types. For example, for the arthritis vignette, a larger percentage of participants considered the depicted child's *Pain History/Knowledge* first when the child was nonverbal compared to when the child was presented as verbal. Similarly, for the flu shot vignette, a larger percentage of participants referred to engaging in a *Consideration of Specific Pain Source and/or the Severity of This (specific to vignette)* when the child was verbal compared to when the child was nonverbal.

3.4 Objective 3: Approach to Various Pain-Related Scenarios (Table 4)

Similar to the factors considered when assessing pain, respite workers indicated a variety of actions that they would take when dealing with the pain-related scenarios described in the vignettes (Table 4). Varying by vignette and by individual respite worker, between one and eleven different actions was/were listed in a participant's approach to each scenario. The majority of these actions related directly to assessment and management. In particular, the pursuit of various forms of *Assessment* were indicated for the scenarios related to an unspecified pain source, headache, falling down and arthritis (21.5% to 36.1%), whereas *Assessment* was indicated much less often for acute procedural pain scenarios (flu shot: 6.1%; insulin injection: 4.5%). Across vignettes, participants were most likely to report they would engage in *General* assessment approaches or *Asking Child/Self-Report* in comparison to *Asking Others* to assess the child's pain.

With respect to pain management, *Pharmacological*, *Physical* and *Psychological* strategies were mentioned by participants but frequency varied with pain source. *Psychological*

strategies were the most common management strategy endorsed by participants (range across vignettes: 14.3% to 68.1%), being used most often in the flu shot (62.6%) and insulin injection (68.1%) scenarios. *Pharmacological* strategies were most likely to be mentioned for the headache scenario compared to other vignettes. Participants did not mention using *Pharmacological* strategies for the unspecified pain source, falling down and insulin injection scenarios. *Physical* strategies were not frequently listed as an intervention strategy, but when indicated, were most likely to be used in the falling down scenario (14.9%). Some participants indicated that they would engage in *Modification of Setting/Environmental Factors* when approaching the situation at hand. This appeared most prevalent for the scenario with the unspecified pain source (18.6%). Participants appeared most likely to engage in *Reporting - Inform Caregiver of the Event* if it involved an unintentional injury (i.e., falling down; 11.9%). Across all vignettes, participants very rarely indicated that *Consulting Resources* would be needed.

4. Discussion

Respite care is a growing service for children with ID (Chan & Sigafos, 2000), but formal training on pain assessment and management is rarely required or provided (Genik et al., revision submitted). Understanding the decision making process and actions taken by respite caregivers in pain-related scenarios with children with ID is important given the impact that these decisions can have on these children's quality of life.

4.1 Factors Considered for Pain Assessment Decisions

Objectives one and two of this study were to learn more about factors respite workers consider when making pain assessment decisions for children with ID, and whether they vary depending on whether or not a child with ID communicates verbally. Given that (1) caregivers'

beliefs about pain in children with ID may not align with current knowledge (Genik et al., revision submitted) and (2) formal pain training for respite workers does not seem to be common (Genik et al., revision submitted), it is important to ensure that respite workers are knowledgeable about aspects unique to pain assessment among children with ID. For example, children with ID who are unable to communicate their pain verbally may communicate their pain differently or in an atypical way (Dubois et al., 2010).

A number of different factors were considered by participants when assessing the child's pain in a given scenario. The variability in the factors considered speaks to the complexity of pain assessment with children with ID. When reviewing the results overall, it seems that many of the factors indicated by participants (e.g., consideration of a child's behavior and history) were in line with what one would expect someone to consider when assessing pain in a child with ID. Indeed, a number of pain assessment tools developed for use with children with ID in clinical settings incorporate behavioral observations and/or knowledge about the child's pain history [e.g., Breau, McGrath, Camfield, Rosmus & Finley's (2000) Non-Communicating Children's Pain Checklist – Revised; Hunt et al.'s (2004) Pediatric Pain Profile]. The focus on these two areas is also similar to an older but related body of literature suggesting that nurses working with children in general were often influenced by behaviors such as vocal expressions and a child's medical diagnosis when assessing pain (Hamers, Abu-Saad, van den Hout, Halfens, & Kester, 1996; Hamers, Abu-Saad, Halfens, & Schumacher, 1994).

In general, the factors that respite workers considered when assessing pain in children with ID did not seem to vary greatly depending on whether or not the child was verbal. This finding is consistent with related quantitative studies using vignette methodology. For example, Shinde and Symons (2007) found that the ratings of pain intensity by educators were not

impacted by information about the child's level of functioning. Another empirical study using the same vignettes in this article (Genik et al., 2015) also found that whether or not a child with ID was verbal did not impact undergraduate students' ratings of perceived pain intensity of children with ID. Despite this, however, some differences within specific vignettes for individual factors did emerge. This finding could have positive or negative effects on the care that respite workers provide. For example, in the arthritis scenario, respite workers were more likely to consider a child's pain history if the child was nonverbal. It is possible that there are logical explanations for differences like these. For example, this increased reliance on pain history for children with ID who are nonverbal may be a result of the increased complexity and barriers associated with pain assessment for children who cannot communicate verbally. However, understanding an individual's pain history would be important for a child who was either verbal or nonverbal, and may help us to better understand their pain and how to help. Ensuring respite workers have adequate information about pain assessment and management, particularly when a child cannot verbally communicate pain, is important.

4.2 Respite Worker's Approach to Pain-Related Scenarios

The final objective was to describe the types of actions that respite workers indicated they would take in a given pain-related situation with a child with ID. Respite workers reported a number of actions they would take in each scenario, many of which are supported by research literature (e.g., pain assessment for children with ID: Quinn, Seibold, & Hayman, 2015; procedural pain management strategies: Taddio et al., 2015a, Taddio, 2013). From the data presented, it seems that pharmacological and physical management strategies were mentioned less often as potential actions than psychological strategies. Limitations in respite settings (e.g., no permission to administer medication) may lead respite workers to be less likely to engage in

these types of management strategies. Finally, respite workers seemed less likely to consult resources or report incidences to parents. Respite workers may be lacking resources in this area and/or may not have clear guidelines for reporting less serious or unintentional painful incidents to parents. Beyond understanding respite worker knowledge, the types of resources (e.g., availability of pain assessment and management related information) and policies (e.g., use of pharmacological management strategies) in respite organizations for pain in children with ID is also an important area for future research. For example, do respite workers know about the limitations in using self-report measures for pain assessment with children with ID (e.g., Chen-Lim, Zamowsky, Green, Shaffer, Holtzer, & Ely, 2012)? How exactly are they approaching pain assessment when they indicate that they will ask the child? Do they understand how to properly use some of the pain management strategies mentioned? It was also unclear whether they would approach these situations in a logical manner versus more haphazardly (e.g., using what they know works for the child first versus choosing the first strategy that comes to mind).

4.3 Strengths, Limitations, and Future Directions

This is the first study to more closely examine the decisions that respite workers (report they) make when children they support experience different types of pain. Understanding how respite workers approach these situations is important because children with ID are often unable to provide self-reports of their pain, and may rely on caregivers to make pain-related decisions. This research study was well designed in that its use of vignette methodology contributes to high internal validity of the constructs being measured. Using open-ended response options allowed respite workers to generate and express their own ideas that may be unique from how researchers may have predicted they would respond. Further, it allowed participants space to provide rich data. A rigorous content analytic approach was used in order to analyze and interpret the data.

The sampling method utilized for participant recruitment and online methodology allowed for potential access to respite workers with differing experiences from locations across Ontario. This may have also excluded participants who did not have access to the study online, however.

As participant responses were completed anonymously and online, researchers could not follow up on responses that were too vague or unclear to code. In the future, it may be helpful to ask these questions in person so that the researchers can clarify responses as necessary. When indicating factors they would consider when assessing pain, it is also important to note that participants were somewhat primed with information (e.g., having just read a vignette mentioning a history of headaches). It is unknown whether respite workers would consider the same factors in a more spontaneous scenario when supporting a child with ID (e.g., would they automatically think that the child may be in pain and consider their pain history?). With respect to the actions they would take in each situation, participants were not asked to list the actions they would take in each scenario in the order in which they would take them. This means that while researchers have a better understanding of the types of actions they might take, it is unclear whether they would be conducted in a logical order (e.g., assessment followed by a management strategy). To address external validity issues when using vignettes, future research should further investigate the areas addressed in this study in real life situations to find out whether this differs at all from the hypothetical scenarios presented here. Finally, this was an exploratory study with a small sample size, so additional research with a larger and more diverse sample should be conducted.

4.4 Conclusions and Clinical Implications

This research study provided unique insight into the types of factors respite workers consider and actions they may take when supporting children with ID in a variety of pain-related

scenarios. Ensuring that respite workers have adequate knowledge and information specific to pain in children with ID is critical to ensure accurate pain assessment and more effective pain management. The current results suggest that respite workers do have knowledge of some pain assessment and management strategies, and are capable of applying them in hypothetical scenarios. However, pain-related education and resources may still be warranted to help facilitate the use of these strategies in practice and ensure that they are being used effectively. Consistent with this idea, we are working to develop a caregiver pain resource that could be shared between parents and respite workers, as well as a pain training program designed for respite workers.

References

- Birnie, K.A., Chambers, C.T., Taddio, A., McMurtry, C.M., Noel, M., Pillai Riddell, R., Shah, V., & HELPinKids&Adults Team (2015). Psychological interventions for vaccine injections in children and adolescents: Systematic review of randomized and quasi-randomized controlled trials. *Clinical Journal of Pain, 31(10S)*, 72-89.
- Breau, L.M., & Burkitt, C. (2009). Assessing pain in children with intellectual disabilities. *Pain Research and Management, 14(2)*, 116-120.
- Breau, L.M., Camfield, C.S., McGrath, P.J., & Finley, G.A. (2007). Pain's impact on adaptive functioning. *Journal of Intellectual Disability Research, 51(2)*, 125-134.
- Breau, L.M., McGrath, P.J., Camfield, C., Rosmus, C., Finley, G.A. (2000). Preliminary validation of an observational pain checklist for persons with cognitive impairments and inability to communicate verbally. *Developmental Medicine and Child Neurology, 42(9)*, 609-616.
- Canadian Healthcare Association. (2012). *Respite care in Canada*. Ottawa: Canadian Healthcare Association.
- Carter, B., McArthur, E., & Cunliffe, M. (2002). Dealing with uncertainty: parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing, 38(5)*, 449-457.
- Chan, J.B., & Sigafos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child & Youth Care Forum, 29(1)*, 27-37.

Chem-Lim, M.L., Zarnowsky, C., Green, R., Shaffer, S., Holtzer, B., & Ely, E. (2012).

Optimizing the assessment of pain in children who are cognitively impaired through the quality improvement process. *Journal of Pediatric Nursing*, 27(6), 750-759.

Craig, K.D. (2009). The social communication model of pain. *Canadian Psychology/Psychologie canadienne*, 50(1), 22-32.

Davies, R.B. (2010). Pain in children with Down syndrome: Assessment and intervention by parents. *Pain Management Nursing*, 11(4), 259-267.

Dubois, A., Capdevila, X., Bringuier, S., & Pry, R. (2009). Pain expression in children with an intellectual disability. *European Journal of Pain*, 14(6), 654-660.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115.

Fanurik, D., Koh, J.L., Harrison, R.D., Conrad, T.M., & Tomerun, C. (1998). Pain assessment in children with cognitive impairment: An exploration of self-report skills. *Clinical Nursing Research*, 7(103), 103-119.

Fleiss, J.L. (1981). *Statistical methods for rates and proportions*. (2nd ed.) University of California: Wiley.

Genik, L. M., McMurtry, C. M., & Breau, L. M. (2015). Observer perceptions of pain in children with cognitive impairments: Vignette development and validation. *Pain Management*, 5(6), 425-434.

Genik, L.M., McMurtry, C.M., & Breau, L.M. (revision submitted). Caring for children with Intellectual disabilities part 1: Experience with the population, pain-related beliefs, and care decisions. *Research in Developmental Disabilities*.

- Hamers, J.P.H., Abu-Saad, H.H., Halfens, R.J.G., & Schumacher, J.N.M. (1994). Factors influencing nurses' pain assessment and interventions in children. *Journal of Advanced Nursing*, 20(5), 853-860.
- Hamers, J.P., Abu-Saad, H.H., van den Hout, M.A., Halfens, R.J., Kester, A.D. (1996). The influence of children's vocal expressions, age, medical diagnosis and information obtained from parents on nurses' pain assessments and decisions regarding interventions. *Pain*, 65(1), 53-61.
- Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V., Oulton, K., & Brady, M. (2004). Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology*, 46(1), 9-18.
- Malviya, S., Voepel-Lewis, T., Tait, A. R., Merkel, S., Lauer, A., Munro, H., & Farley, F. (2001). Pain management in children with and without cognitive impairment following spine fusion surgery. *Pediatric Anesthesia*, 11(4), 453-458.
- Neufeld, S.M., Query, B., & Drummond, J.E. (2001). Respite care users who have children with chronic conditions: Are they getting a break? *Journal of Pediatric Nursing*, 16(4), 234-244.
- Palermo, T. M., Eccleston, C., Lewandowski, A. S., Williams, A. C. D. C., & Morley, S. (2010). Randomized controlled trials of psychological therapies for management of chronic pain in children and adolescents: an updated meta-analytic review. *Pain*, 148(3), 387-397.
- Pillai Riddell, R., Taddio, A., McMurtry, C.M., Chambers, C.T., Shah, V., Noel, M., & HELPinKids&Adults Team (2015). Psychological interventions for vaccine injections in young children 0 to 3 Years: systematic review of randomized controlled trials and quasi-randomized controlled trials. *Clinical Journal of Pain*, 31(10S), 64-71.

- Quinn, B. L., Seibold, E., & Hayman, L. (2015). Pain assessment in children with special Needs: A review of the literature. *Exceptional Children*, 82(1), 44 - 57.
- Shinde, S.K., & Symons, F. (2007). Educator perceptions and ratings of pain in school-age children with mental retardation and developmental disabilities. *Education and Training in Developmental Disabilities*, 42(2), 224-229.
- Taddio, A. Needle procedures. In McGrath, P.J., Stevens, B.J., Walker, S.M., & Zempsky, W.T. (Eds.). (2013). Oxford textbook of paediatric pain. Oxford (UK); Oxford University Press, 184 - 193.
- Taddio, A., McMurtry, C. M., Shah, V., Riddell, R. P., Chambers, C. T., Noel, M., ... & Bleeker, E. V. (2015a). Reducing pain during vaccine injections: Clinical practice guideline. *Canadian Medical Association Journal*, 187(13), 975-982.
- Taddio, A., & Oberlander, T. F. (2006). Pharmacological management of pain in children and youth with significant neurological impairments. In *Pain in Children and Adults with Developmental Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co, 193-211.
- Taddio, A., Shah, V., McMurtry, C.M., MacDonald, N., Ipp, M., Riddell, R., Noel, M., Chambers, C.T. & HELPinKids&Adults Team (2015b). Procedural and physical interventions for vaccine injections: Systematic review of randomized controlled trials and quasi-randomized controlled trials. *Clinical Journal of Pain*, 31(10S), 20-37.