

Pain in People with Developmental Disabilities: A Scoping Review

Funding for this study was provided by the Canadian Institutes of Health Research Grant # KRS 94031.

Abstract

The expression of pain or pain behaviour is unique for each person with or without developmental disability (DD). Lack of pain assessment and management creates health disparities for people with DD. Little research has been done to support care guidelines. This scoping review was undertaken to summarize the literature about what is known about pain in people with developmental or intellectual disabilities. Studies which include people with autism have been included, recognizing that these individuals may or may not always have difficulties in verbal expression or self-injurious behaviour. Scoping reviews map the literature to clarify boundaries, identify gaps in evidence and identify areas of research priorities. This scoping review identified four main themes of research related to pain in people with DD: identifying pain; parental-caregiver report; pain measures and practice recommendations. This paper describes the method of this scoping review and the findings related to these four main themes.*

People with developmental disabilities and/or intellectual disabilities (DD/ID) are a heterogeneous group, varying considerably in the severity of their impairment (O'Hara, McCarthy, & Bouras, 2010). In order to be comprehensive, this review has included people with DD/ID, as well as those with autism, cerebral palsy, and developmental delay, since the level of mental functioning among the latter groups varies considerably. People who display self-injurious behaviours within the above populations have also been included. Since the terms DD and ID are used interchangeably in Canada, from henceforth, we refer to such disorders as DD. People with DD may express pain differently than those without DD. The underlying medical conditions related to DD may make them even more likely than other people to experience pain because of physiology related to their neurological injury. Expression of pain by people with DD can be ambiguous, and its recognition by health care providers can be highly subjective, especially considering that people with DD are sometimes non-verbal (Phan, Edwards, & Robinson, 2005). Canadian Consensus guidelines have been developed for the primary health care of adults with DD for 31 different areas of care, with 84 specific care guidelines (Sullivan et al., 2011). Randomized control

Authors

Beverley Temple,¹
Charmayne Dubé,²
Diana McMillan,¹
Loretta Secco,³
Emma Kepron,⁴
Klaus Dittberner,⁵
James Ediger,⁵
Genevieve Vipond⁵

¹ Faculty of Nursing,
University of Manitoba,
Winnipeg, MB

² New Directions for
Children, Youth,
Adults and Families,
Winnipeg, MB

³ Faculty of Nursing,
University of New
Brunswick,
Fredericton, NB

⁴ Library Services,
University of Manitoba,
Winnipeg, MB

⁵ St. Amant,
Winnipeg, MB

Correspondence

Bev.Temple@ad.umanitoba.ca

Keywords

pain,
pain assessment,
intellectual disabilities,
developmental disabilities,
scoping review

* In Canada, the terms *developmental disability* and *intellectual disability* are used in lieu of the medical term *mental retardation*. In the U.K. and some other countries, the term *learning disability* is used to denote developmental and/or intellectual disability. In this paper, the term developmental disability has been used throughout.

trials (level 1 evidence) support only four of the guidelines, while non-randomized comparison studies (level 2 evidence) support another six of the guidelines. The lack of available evidence to guide health care providers underscores the health care disparities for people with DD. The barriers that prevent people with DD from receiving the same level of care as the rest of the population must be overcome. This scoping review contributes to the knowledge base of evidence available to support the potential integration of pain assessment tools into residential, acute and or chronic care settings (Breau, MacLaren, McGrath, Camfield, & Finley, 2003c). The main research question guiding this review was, "What is known in the literature about pain in people with DD?"

Materials and Methods

Consistent with the available definitions of scoping reviews (Canadian Institutes of Health Research (CIHR), 2005; O'Malley & Croucher, 2005), this scoping review ventured to plot the extent and range of existing literature on pain in people with DD/ID. Scoping reviews should:

...map the literature to clarify boundaries and definitions in the area, and to identify gaps in evidence where primary research is necessary and would be timely. Scoping reviews are intended to help the research community and research-funding organizations identify research priorities within priority thematic areas. (CIHR, 2005, p. 34)

This scoping review was performed by four main reviewers in conjunction with two experts who advised at all stages of the process, and knowledge users who were involved at the beginning and end points of the study. The objective of this review was to include all documents that provided information about pain in people with intellectual or developmental disabilities.

Search Strategy

For the purposes of this research, the following electronic databases were searched: PsycINFO, Child Development and Adolescent Studies, PubMed, Social Sciences Citation Index (Web of Science), Mental Measurements Yearbook, Dissertations and Theses (ProQuest), CINAHL, The Cochrane Library, Academic Search

Complete, and Family and Society Studies Worldwide. Literature from 1998 to 2010, inclusive, was considered for evaluation. Searches were conducted using the appropriate subject headings for the database. Two of the team members were responsible for the initial electronic database search. Searches using keywords were then initiated using the following terms:

- (developmental disabilit* OR mental retardation OR cognitive impairment* OR learning disabilit* OR mental handicap* OR mental disorder* OR retardation) AND
- (child* OR adolescen* OR teen* OR young adult*) AND (pain OR discomfort OR nociception)
- AND (expression* OR mechanism* OR experience* OR symptom*) AND
- (measurement* OR scale* OR instrument* OR screen* OR assessment*). Further hand searches were conducted based on references from the initial articles and books retrieved.

Articles selected for review were collected and organized in a dedicated RefWorks account. A standardized format was used to develop the final list of articles, paying special attention to the inclusion criteria. The inclusion criteria were: English language publication; developmental disability described; and pain, population, and pain assessment identified. Exclusion criteria included: non-English language publication, neonatal population, and participants with dementia or acquired brain injury. Non-empirical studies, theses, books, and commentaries were included to support the full range of literature regarding pain in people with developmental disabilities.

Results

Article Selection

A total of 508 abstracts (Table 1) were reviewed by two of the researchers for potential inclusion. Three hundred and forty-seven abstracts were excluded, as they did not meet the inclusion criteria. Both reviewers agreed that 102 abstracts met the inclusion criteria. To be conservative, 16 abstracts were included for which the reviewers had disagreed about inclusion

criteria, resulting in 118 full article reviews. Twelve book chapters were reviewed and 4 were excluded after full review because they were not relevant to the population, leaving 8 chapters included. A set of 58 journal documents were included after full review, with 48 identified as original studies and 10 as overview articles. The studies that were excluded were either not published in English or involved a different population (n=12). Study inclusion and data extraction forms were developed and piloted by two reviewers and then used for all subsequent reviews in order to ensure consistency in the decision-making process.

The studies were completed in seven different countries. However, four studies were of unknown origin and one had combined U.S. and Canadian origins. The majority of research studies came from Canada (n=16), followed by the U.S. (n=11) and the U.K. (n=8). Thirty-eight of the studies exclusively involved children, seven studies exclusively pertained to adults, and three used mixed age groups. The types of study designs included mixed (n=3), qualitative (n=4), and quantitative (n=41) methods. While most

studies were observational in nature, the quantitative studies mainly involved scale validation. In studies involving children, three included children with mild to moderate disability, 11 studied children with severe disability, and six studied children with severe to profound disability. Many other studies did not identify the participants' specific level of developmental disability. The studies involving adult samples often included all levels of developmental disability or did not distinguish amongst the participants.

Dominant Themes

The studies listed in Table 1 were analyzed thematically (Table 2). When summary tables were produced, a qualitative thematic approach was taken to placing studies into common themes to represent the most common areas found in the research. The themes were verified by at least two researchers (Sandelowski, & Barroso, 2007). The following four dominant themes were identified to reflect the current knowledge about pain in people with DD: 1. Identifying pain; 2. Parental-caregiver report; 3. Pain measures; and 4. Practice recommendations.

Table 1. Summary of the Number of Reviews

<i>Total # of Abstracts Reviewed</i>	<i>n = 508 (includes repeats)</i>
PsychInfo	102 included
Child Development and Adolescent Studies	347 disregarded per exclusion criteria
Academic Search Complete	13 not agreed therefore included
Family and Society Studies	
PubMed	37 included
Social Sciences Citation Index (Web of Science)	9 disregarded
Mental Measurements Yearbook	All agreed about inclusion criteria
CINAHL	
Cochrane Library	
<i>Total # of Journal Documents Included</i>	<i>n = 58</i>
Total # of Studies Included	48
Total # of Overview Journal Articles Included	10
Total # of Studies Excluded	Different Language n= 6 (pre-review) Different population n= 12 (after review)
<i>Total # of Chapters Reviewed</i>	<i>n = 12</i>
Total # of Chapters Included	8
Total # of Chapters Excluded	4 (not relevant to population)

Table 2. Summary of Relevant Articles and Themes Identified in the Review*

* The full version of the table is posted on the St. Amant website (www.stamantresearch.ca). This also is available in electronic form from the authors.

Reference

Benini et al. (2004)
Bromley, Emerson, & Caine (1998)

Breau, MacLaren, McGrath,
Camfield, & Finley (2003c)
Craig (2009)
Craig, Oberlander, & Symons (2006)
Gilbert-MacLeod, Craig, Rocha, &
Mathias (2000)

Collis, Moss, Jutley,
Cornish, & Oliver (2008)
Kay, Van Tubbergen,
Warschawsky, & Buchman (2005)
Mercer & Glenn (2004)
Messmer, Nader, & Craig (2008)

Fanurik et al. (1999)
Shinde & Symons (2007)

Breau, Camfield, McGrath,
& Finley (2003a)
Hadden & von Baeyer (2005)
Houlihan, O'Donnell, Conaway,
& Stevenson. (2004)
McKearnan, Kieckhefer, Engel,
Jensen, & Labyak (2004)
Stallard, Williams, Lenton,
& Velleman (2001)
Tervo, Symons, Stout,
& Novacheck (2006)

Breau, Camfield, Symons, et al. (2003b)
Hennequin et al. (2000)
Malviya et al. (2001)
Rojahn, Schroeder, & Hoch (2007)
Symons & Danov (2005)
Symons, Harper, McGrath,
Breau, & Bodfish (2009)
Symons (2002)

Theme 1: Identifying Pain

Gold standard of reporting pain is by self-report. Within the field of DD, self-report is more difficult to assess. However if the person with DD can reliably use typical scales or modified scales, then many established tools can be helpful.

For those unable to communicate, reliance on proxy report if available (e.g., from a caregiver or parent) is important. There is an increased risk for those who cannot report verbally to have unresolved pain due to lack of being able to identify pain cues via non-verbal behaviours especially if no baseline is established.

Facial expressions and other behavioural cues may not always be reliable in people with DD.

Attributions of pain in persons with DD by health care providers, teachers, etc., must be understood to capture beliefs that can result in inappropriate identification and treatment of pain episodes.

Increased pain is noted for individuals who are more disabled, especially physically, such as in the case of people with cerebral palsy and DD.

Pain is less frequently assessed in people with DD. Belief of insensitivity to pain may be related to self-injurious behaviour (SIB). Some studies indicate that people with SIB are believed to not feel the pain and this has been refuted. SIB may even be considered a sign of other pain that they are unable to communicate.

Table 2. Summary of Relevant Articles and Themes Identified in the Review* (continued)

<i>Reference</i>	<i>Theme 2: Parental-Caregiver Report</i>
Carter, McArthur, & Cunliffe (2002)	Baseline involvement is imperative in the assessment of pain within this population. Health care providers frequently misunderstand individual needs and discount parental perspectives.
Abu-Saad (2000) Clarke, Thompson, Buchan, & Combes (2008) Colatarci & Nehring (2002) Fanurik et al. (1999)	Parents report that assessment should be based on knowing the person and interpreting, as opposed to an actual objective measure. However, research is indicating that when provided with a structured way or tool, observers even unfamiliar with the child with DD reliably assess pain behaviours.
Breau, MacLaren, McGrath, Camfield, & Finley (2003c)	Parents feel that health care providers do not completely understand the needs of their child, and feel that parental report is largely un-recognized by the HC field. Recommendations from parents are to include them within the discussion and assessment of pain.
<i>Reference</i>	<i>Theme 3: Pain Measures Presently Used</i>
Breau, Finley, McGrath & Camfield (2002) Breau, McGrath, Zabalía, Oberlander, & Symons (2006) Collignon & Giusiano (2001) Koh, Fanurik, Harrison, Schmitz, & Norvell (2004) Terstegen, Koot, deBoer, & Tibboel (2003)	Multidimensional pain tools are emerging, with some overlap between tools. Each tool has unique characteristics and has been studied using different subgroups of people with DD (e.g., people living in residential settings, postoperative pain).
Breau, McGrath, Camfield, Rosmus, & Finley (2000) McGrath, et al. (1998)	Non-Communicating Children Pain Checklist (NCCPC) is a validated tool with 7 categories and 31 items.
Breau, Camfield, McGrath, & Finley (2003a)	NCCPC-R (revised) is a valid pain assessment tool as pain is observable and measurable for children with DD.
Breau, Finley, McGrath, & Camfield (2002)	NCCPC-PV (post-operative version) testing of the tool indicated a high validity between caregivers and researchers.
Nader, Oberlander, Chambers, & Craig (2004)	Faces Pain Scale needs further research to understand pain & challenges to decode pain behaviour for use with people with DD.
Hunt et al. (2004)	Paediatric Pain Profile is reliable and valid

Table 2. Summary of Relevant Articles and Themes Identified in the Review* (continued)

Duivenvoorden, Tibboel, Koot, van Dijk, & Peters (2006)	This study attempted to reduce the Pain Behaviour scale checklist from 23 items to 10 items; more research is needed.
Malviya, Voepel-Lewis, Burke, Merkel, & Tait (2006)	FLACC – Face, legs, activity, cry, consolability scale for postoperative pain. Specific and unique behavioural descriptors are used with input from caregivers for non-verbal individuals are beneficial to understand pain management needs. Can be incorporated via pre-op interviews to establish baseline. Need for more research for chronic conditions.
Voepel-Lewis, Malviya, & Tait (2005)	
Voepel-Lewis, Merkel, Tait, Trzcinka, & Malviya (2002)	
Stallard, Williams, Velleman, Lenton, & McGrath. (2002a)	Pain Indicator for Communicatively Impaired Children (PICIC): must use personal caregivers to provide a baseline for the best assessment
Stallard et al. (2002b)	
Bodfish, Harper, Deacon, Deacon, & Symons (2006)	Pain and Distress Scale includes a detailed examination of clinician's beliefs and includes procedures for use of scales in practice.
Lotan, Ljunggren, Johnsen, Defrin, Pick, & Strand (2009a)	Noncommunicating Adult Pain Checklist (NCAP) is an 18 item scale within 6 categories. Only therapists and paid caregivers showed high reliability in studies, therefore requires more investigation.
Lotan, Moe-Nilssen, Ljunggren, & Strand (2009b)	
<i>Reference</i>	<i>Theme 4: Practice Recommendations</i>
Brown & Warr (2007)	There is need for a variety of methods and measures based on an understanding of the developmental level of the person.
Defrin, Lotan, & Pick (2006)	
LaChapelle, Hadjistavropoulos, & Craig (1999)	
Pivalizza & Pivalizza (2008)	
Breau, MacLaren, McGrath, Camfield, & Finley(2003a)	Training for multi-disciplines and care-providers is needed to ensure that pain and pain cues are acknowledged and interpreted to remediate pain episodes.
Oberlander (2001)	
Symons, Shinde, & Gilles (2008)	Traditional methods of pain control may be relevant for children with DD but diligence is required to ensure that staff use appropriate pain assessment scales and have the required education for use of the assessments.
Czarnecki et al. (2008)	

Discussion

Identifying Pain

Self-report is often considered the gold standard within pain assessment literature (Benini et al., 2004). Within the field of DD, this gold standard is more difficult to achieve as many individuals are non-verbal or have limited expressive language. However, findings from two studies indicate that the use of modified pain scales, based on the individual's level of developmental disability, can achieve the self-report standard (Benini et al., 2004; Bromley, Emerson, & Caine, 1998). Some of the scales suggested for this purpose used a body map to indicate pain location or a visual analog color scale to rate pain intensity, in conjunction with responses to a series of photographs of simulated pain experiences. People with DD and intact verbal abilities can reliably indicate pain location and rate pain intensity using these tools (Bromley et al., 1998).

For those unable to validly communicate their pain experience, it is possible to rely on proxy report via caregiver or parent, whenever possible or use pain scales specifically developed for this population. When no baseline is established, individuals are at increased risk of experiencing unresolved pain due to an inability to identify their pain. Breau and colleagues (2003c) indicated that parental reports are more valid than using non-verbal cues to measure pain symptoms among people with DD/ID. Parents/Caregivers indicated that their children have key identifiable characteristics, especially for non-accidental pain. People with DD/ID may express pain in a different manner, often with less distressed responses, which may be due to a socio-communicative deficit (Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000). As a result, non-verbal individuals often have pain that is ignored or under-treated. When care providers must rely on proxy report for pain, it is essential to recognize that there will be a mix of interpersonal and intrapersonal determinants when evaluating another person's pain (Craig, 2009). Craig, Oberlander, and Symons (2006) developed a social communication model of pain that highlights the need to evaluate interactions between the person in pain and the care provider. An integrative approach, which considers the holistic needs of the person with DD from multiple perspectives,

is required to achieve effective pain management in this population.

Observers, without the immediate benefits of a proxy, are often influenced by facial expressions, which may lead to inappropriate responses. Children with DD may express their pain differently, with possibly fewer discrete facial expressions (Mercer & Glenn, 2004; Messmer, Nader, & Craig, 2008). Furthermore, recognition of observable pain is more difficult with children who have specific disease entities or craniofacial abnormalities (Collis, Moss, Jutley, Cornish, & Oliver, 2008; Kay, Van Tubbergen, Warschawsky, & Buchman, 2005; Mercer & Glenn, 2004). Therefore, it is important that behavioural cues be used in combination with facial expressions to evaluate pain among people with DD.

Health care providers, teachers, and others who may perform pain assessments often have their own beliefs about pain attributions, which may lead to inappropriate identification or treatment of pain episodes. Infants with DD are thought to not experience pain and this assumption may prevent health care providers from responding or intervening (Breau et al., 2006). While the level of DD may influence the types of assessments completed, this process may depend more on the experience level of the care provider, with some providers being better able to identify pain and the expression of pain in children with and without DD (Fanurik et al., 1999; Shinde & Symons, 2007).

Many researchers have identified that people with DD more often experience pain due to motor impairments and various procedures, including surgical, gastrointestinal, orthopedic, neuromuscular, and rehabilitative procedures (Breau, Camfield, McGrath, & Finley, 2003a; Hadden & von Baeyer, 2005; Houlihan, O'Donnell, Conaway, & Stevenson, 2004; McKearnan, Kieckhefer, Engel, Jensen, & Labyak, 2004; Stallard, Williams, Lenton, & Velleman, 2001; Tervo, Symons, Stout, & Novacheck, 2006). Researchers reported that the pain experienced by children with DD is more likely to be related to one of the above mentioned medical reasons rather than being related to accidental injury. Children with cerebral palsy are especially prone to painful motor impairments (Hadden & von Baeyer; McKearnan et al.; Tervo et al.).

Although the issue of self-injurious behaviour is not directly related to pain assessment, this section addresses a concern that if people with DD display self-injurious behaviour, the rest of their health care may be affected. Some care providers believe that people with DD who perform self-injurious behaviour (SIB) do not feel pain or must be insensitive to pain and, as a result, pain assessments may be performed less frequently (Malviya et al., 2001; Symons, 2002). However, this assumption is not supported by evidence in the literature. Children with SIB have pain reactions similar to those without SIB, and the presence of chronic pain may be the influencing factor for the frequency and location of SIB (Breau et al., 2003b).

It has been previously suggested that SIB may be an indication or consequence of pain in people with profound DD and may be related to their impaired communication abilities (Symons & Danov, 2005). Direct care providers using a valid pain assessment tool found that adults with SIB have pain behaviours which can be consistently detected on the basis of non-verbal expression, and this finding is not consistent with a model of pain insensitivity in people with SIB (Symons, Harper, McGrath, Breau, & Bodfish, 2009). Some of the theoretical models that have been used to describe SIB include the gate theory and stress-induced analgesia theory (Zaja & Rojahn, 2008). However, since the specifics of SIB are not well understood, further research is warranted (Symons & Danov, 2005).

Parental-Caregiver Report

Considering that the experience of pain is a highly individualized phenomenon, it is imperative to involve reliable and experienced caregivers in the baseline assessment of pain in people with DD, especially for those who have limited abilities to communicate expressively. Parents have reported uncertainty in their child's potential to experience acute and chronic pain but understand that pain assessment is a complex process. Parents have many skills and need to be included in their children's pain assessments. However, parents have reported feeling isolated in trying to manage their children's pain (Carter, McArthur, & Cunliffe, 2002). There is increasing evidence that parents assess pain based on a thorough understanding

of the individual as opposed to any objective behaviour that is measurable (Abu-Saad, 2000; Clarke, Thompson, Buchan, & Combes, 2008; Colatarci & Nehring, 2002; Fanurik et al., 1999). Checklists that help assess changes in physical behavioral signs (increased or decreased noises, change in eating habits, increased crying, etc.) may be utilized, along with an understanding of the individual's typical abilities, as potential indicators of pain by parents and health care providers. Collaboration between parents and health care providers would ensure that these more subtle, discrete indicators are connected to best practice influences from health care teams (Breau et al., 2003c).

Pain Measures

Within the last few years, several studies have identified the issues already discussed in this review, including the issue of children with DD experiencing frequent pain, which may manifest as reduced ability to perform functional abilities (Breau, Finley, McGrath, & Camfield, 2002). Many researchers have begun the work to develop more accurate pain assessment tools (Collignon & Giusiano, 2001; Koh, Fanurik, Harrison, Schmitz, & Norvell, 2004; Terstegen, Koot, de Boer, & Tibboel, 2003). These studies have shared some common observable behaviours that could be included in assessment tools.

The heterogeneous response to pain from children with DD has limited the applicability of pain assessment tools in practice. Breau and colleagues (2003a,b,& c) comprise the most consistent group of researchers who have continued to refine pain assessment tools for children with DD. They have conducted several studies since McGrath's development of the initial pain assessment tool in 1998; this tool included a checklist with 31 items, divided into seven categories. The Non-Communicating Children Pain Checklist (NCCPC) has since been refined and expanded for use in different settings (Breau, McGrath, Camfield, Rosmus, & Finley, 2000; Breau et al., 2002; Breau et al., 2003a). These researchers have concluded that the NCCPC, NCCPC-R (revised), and NCCPC-PV (postoperative version) are valid pain assessment tools. There is evidence that even care providers unfamiliar with the individual may be able to rate pain accurately.

Researchers, such as Breau et al., often begin the development of their scales through interviews with parents or primary care providers. Stallard, et al. (2001) also used this method to develop the Pain Indicator for Communicatively Impaired Children (PICIC). They found many similarities in the expression of pain among the children, as well as in the parental reports, but there were still inconsistencies in the accuracy of pain detection using their tool (Stallard et al., 2001; Stallard, Williams, Velleman, Lenton, & McGrath, 2002a; Stallard, Williams, Velleman, Lenton, McGrath, & Taylor, 2002b).

Some scales use facial coding instruments to assess pain in children, such as The Faces Pain Scale, Pediatric Pain Profile, and the Checklist Pain Behaviour (Duivenvoorden, Tibboel, Koot, van Dijk, & Peters, 2006; Hunt et al., 2004; Nader, Oberlander, Chambers, & Craig, 2004). Nader et al. report that parents' measurement of pain in children with autism showed promise in the sensitivity and reactivity of the Faces Pain Tool. However, further research is required before the tool can be considered valid for use with this population. The Faces, Legs, Activity, Cry, Consolability Scale (FLACC) has been used to assess acute pain in pre- and post-surgical situations (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; Voepel-Lewis, Malviya, & Tait, 2005; Voepel-Lewis, Merkel, Tait, Trzcinka, & Malviya, 2002). The use of structured pain tools was found to assist parents in providing a reasonable estimate of their child's pain and to help care providers assess and understand children's pain following surgery.

Lotan et al. (2009a) have developed a modified scale for the adult population, based on the work done by Breau and colleagues. The Non-Communicating Adult Pain Checklist (NCAPC) was created to provide researchers and caregivers with a consistent assessment tool for non-communicating adults with ID. Lotan and colleagues have developed and tested an 18-item scale, with sub-categories of pain behavior, and have reported high-to-modest reliability and validity when the scale was used by health care workers (Lotan, Moe-Nilssen, Ljunggren, & Strand, 2009b). Therapists and paid caregivers demonstrated the highest reliability when using the scale and the researchers indicated that further testing is warranted.

Practice Recommendations

Since the level of the DD affects baseline measurements, there is a need for a variety of methods and measures of pain that are matched with the intellectual level of the person being assessed (Defrin, Lotan, & Pick, 2006; LaChapelle, Hadjistavropoulos, & Craig, 1999). However, when using a variety of tools, appropriate training is required to ensure accurate assessments for both children and adults. Validation of assessment must occur with objective data from consistent caregivers, whether they are the individual's parents or another caregiver (Brown & Warr, 2007; Pivalizza & Pivalizza, 2008).

Pain assessment should incorporate common sense along with consideration of developmental stage, temperament, personality, environmental factors, and previous pain experiences (Bajelidze, Belthur, Littleton, Dabney, & Miller, 2008; Hartman, Gilles, McComas, Danov, & Symons, 2008; van Dijk, Peters, Bouwmeester, & Tibboel, 2002). Assessment of people with DD must also be multidimensional and include a medical review as well as assessments of behaviour, communication needs, and functional abilities. For example, measures such as bone scans, which can identify the potential source of painful areas, or functional behavioural analysis, which can guide understanding of self-injurious behaviour, can contribute to a more thorough understanding of the potential pain sources.

Effective assessment requires a multidisciplinary approach that utilizes all of the resources to come to the correct conclusions about treatment options (Sandman, 2009; Schechter, Oberlander, & Symons, 2006). As people with DD age, more chronic pain episodes can be expected. Acute, procedural, and post-operative pain types are easier to treat and tend to have an obvious source (Schechter et al., 2006). Conversely, chronic pain is less predictable and its source is more difficult to localize (Schechter et al., 2006). Problem behaviours (e.g., rumination, pica, food refusal), will need to be considered as potential pain behaviours when they develop gradually in people with communication difficulties.

Training programs for care providers and multi-disciplinary professionals are of utmost importance to ensure that pain and associated pain cues are acknowledged and interpreted to remediate pain episodes. Training must also occur across multidisciplinary groups to facilitate approaches that will ensure ongoing pain assessment and management and, ultimately, improve the quality of life of people with DD (Bodfish, Harper, Deacon, Deacon, & Symons, 2006; Breau et al., 2006a; Breau, McGrath, Zabalia, Oberlander, & Symons, 2006; Oberlander, 2001; Symons, Shinde, & Gilles, 2008). In addition, checklists can assist caregivers to provide more accurate descriptions of previous pain and, when these are used in conjunction with assessment of other behaviours, a greater understanding from multi-disciplinary groups can result in improved assessments of the complex needs of people with DD. The development of practice guidelines that apply to a broader range of professional groups would facilitate this approach to pain assessment and management among people with DD (Breau et al., 2006a; Oberlander, 2001; Symons et al., 2008).

Pain assessment and management must be considered important for people with DD, especially since the significance of their disability sometimes might be translated to increased pain during daily activities (Czarnecki et al., 2008). In addition, means of pain management applied to other groups of individuals should not be dismissed for people with DD, including methods such as nurse assisted Patient Controlled Analgesia (Czarnecki et al., 2008) when some means of pain assessment has been developed for an individual with DD. The treatment must be monitored to determine its effectiveness, as there is the potential for reduced efficacy of pharmacological management as well as interaction between multiple drugs (Sandman, 2009).

Future Directions

This study has several limitations to note. As noted in the introductory section, the populations studied in the research reviewed often are mixed, and the abilities of the individuals are not always presented. However, most of the comments in this review are relevant to people with communication difficulties. The assessment of each individual with an intellectual disability

is dependent upon many factors, but some progress has been made in recognizing differences in common behaviours, which should be useful to practitioners in their practice with people with DD. People with DD are considered a vulnerable population and are less likely to be included in "trial" research which leads to fewer studies, demonstrating that much more evidence is needed to support standards of care. If, however, practitioners caring for and supporting people with DD consider pain assessment more consistently, their care and access to appropriate health care will be improved.

Conclusions

In conclusion, research into pain assessment for people with DD has increased over the last few years, but many of the scales have not been used in clinical or community settings. In addition, very few scales have been adapted for use in practical scenarios, beyond experimental settings, especially for adults with DD. Providing consistent education and a context of support for care providers are the next steps required to improve pain assessment and management within multidisciplinary teams.

Acknowledgements

We would like to acknowledge Dr. C. T. Yu for his assistance with grant development and review of this paper. The paper was also reviewed by Angie Miller prior to submission and her assistance is appreciated.

Key Messages From This Article

People with disabilities: You deserve to have pain treated as part of your health care.

Professionals: Providing competent health care for people with disabilities requires use of consistent pain assessment tools to assess and document their pain and will have an impact on actions taken to treat that pain.

Policymakers: Policies should include education about use of pain assessment tools for multidisciplinary teams to ensure people with disabilities have pain assessed and treated consistently.

References

- Abu-Saad, H. H. (2000). Challenge of pain in the cognitively impaired. *Lancet*, 356, 1867-1868.
- Bajelidze, G., Belthur, M. V., Littleton, A. G., Dabney, K. W., & Miller, F. (2008). Diagnostic evaluation using whole-body technetium bonescan in children with cerebral palsy and pain. *Journal of Pediatric Orthopedics*, 28(1), 112-117.
- Benini, F., Trapanotto, M., Gobber, D., Agosto, C., Carli, G., Drigo, P. et al. (2004). Evaluating pain induced by venipuncture in pediatric patients with developmental delay. *The Clinical Journal of Pain*, 20(3), 156-163.
- Bodfish, J., Harper, V., Deacon, J. M., Deacon, J. R., & Symons, F. (2006). Issues in pain assessment for adults with severe to profound mental retardation: From research to practice. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 173-192). Baltimore: Paul H. Brookes Publishing.
- Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2003a). The incidence of pain in children with severe cognitive impairments. *Archives of Pediatrics and Adolescent Medicine*, 157(12), 1219-1226.
- Breau, L. M., Camfield, C. S., Symons, F. J., Bodfish, J. W., Mackay, A., Finley, G. A. et al. (2003b). Relation between pain and self-injurious behavior in nonverbal children with severe cognitive impairments. *Journal of Pediatrics*, 142(5), 498-503.
- Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the non-communicating children's pain checklist-postoperative version. *Anesthesiology*, 96(3), 528-535.
- Breau, L., MacLaren, J., McGrath, P. J., Camfield, C. S., & Finley, G. A. (2003c). Caregivers' beliefs regarding pain in children with cognitive impairment: Relation between pain sensation and reaction increases with severity of impairment. *The Clinical Journal of Pain*, 19, 335-344.
- Breau, L. M., McGrath, P. J., Camfield, C. S., 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.
- Breau, L., McGrath, P. J., Zabalia, M., Oberlander, T., & Symons, F. J. (2006). Assessing pediatric pain and developmental disabilities. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 149-172). Baltimore: Paul H. Brookes Publishing.
- Bromley, J., Emerson, E., & Caine, A. (1998). The development of a self-report measure to assess the location and intensity of pain in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 42, 72-80.
- Brown, E., & Warr, B. (2007). *Supporting the child and the family in paediatric palliative care*. London: Jessica Kingsley Publishers.
- Canadian Institutes of Health Research (CIHR). (2005). *Knowledge translation: Synthesis - scoping reviews: Research call*. Retrieved from <http://www.cihr-irsc.gc.ca/e/41382.html>
- 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.
- Clarke, Z. J., Thompson, A. R., Buchan, L., & Combes, H. (2008). Parents' experiences of pain and discomfort in people with learning disabilities. *British Journal of Learning Disabilities*, 36(2), 84-90.
- Colatarci, S., & Nehring, W. (2002). Recognizing and tracking pain in children with developmental disabilities. *Exceptional Parent*, 32(11), 69.
- Collignon, P., & Giusiano, B. (2001). Validation of a pain evaluation scale for patients with severe cerebral palsy. *European Journal of Pain*, 5(4), 433-442.
- Collis, L., Moss, J., Jutley, J., Cornish, K., & Oliver, C. (2008). Facial expression of affect in children with Cornelia de Lange syndrome. *Journal of Intellectual Disability Research*, 52(3), 207-215.
- Craig, K. (2009). The social communication model of pain. *Canadian Psychology*, 50(1), 22-32.

- Craig, K., Oberlander, T., & Symons, F. (2006). The construct and definition of pain in developmental disability. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 7-18). Baltimore: Paul H. Brookes Publishing.
- Czarnecki, M. L., Ferrise, A. S., Jastrowski Mano, K. E., Garwood, M. M., Sharp, M., Davies, H. et al. (2008). Parent/nurse-controlled analgesia for children with developmental delay. *The Clinical Journal of Pain*, 24(9), 817-824.
- Defrin, R., Lotan, M., & Pick, C. G. (2006). The evaluation of acute pain in individuals with cognitive impairment: A differential effect of the level of impairment. *Pain*, 124(3), 312-320.
- Duivenvoorden, H. J., Tibboel, D., Koot, H. M., van Dijk, M., & Peters, J. W. B. (2006). Pain assessment in profound cognitive impaired children using the checklist pain behavior; is item reduction valid? *Pain*, 126(1-3), 147-154.
- Fanurik, D., Koh, J. L., Schmitz, M. L., Harrison, R. D., Roberson, P. K., & Killebrew, P. (1999). Pain assessment and treatment in children with cognitive impairment: A survey of nurses' and physicians' beliefs. *The Clinical Journal of Pain*, 15(4), 304-312.
- Gilbert-MacLeod, C. A., Craig, K. D., Rocha, E. M., & Mathias, M. D. (2000). Everyday pain responses in children with and without developmental delays. *Journal of Pediatric Psychology*, 25(5), 301-308.
- Hadden, K. L., & von Baeyer, C. L. (2005). Global and specific behavioral measures of pain in children with cerebral palsy. *Clinical Journal of Pain*, 21(2), 140-146.
- Hartman, E. C., Gilles, E., McComas, J. J., Danov, S. E., & Symons, F. J. (2008). Clinical observation of self-injurious behavior correlated with changes in scalp morphology in a child with congenital hydrocephalus. *Journal of Child Neurology*, 23(9), 1062-1065.
- Hennequin, M., Morin, C., & Feine, J. (2000). Pain expression and stimulus localisation in individuals with Down's syndrome. *Lancet*, 356(9245), 1882-1887.
- Houlihan, C. M., O'Donnell, M., Conaway, M., & Stevenson, R. (2004). Bodily pain and health-related quality of life in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 46(5), 305-310.
- Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V. et al. (2004). Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology*, 46(1), 9-18.
- Kay, J. B., Van Tubbergen, M., Warschausky, S., & Buchman, S. R. (2005). Social response in children with severe cognitive impairments: Factors in craniofacial surgery decision-making. *Plastic and Reconstructive Surgery*, 116(2), 408-418.
- Koh, J. L., Fanurik, D., Harrison, R. D., Schmitz, M. L., & Norvell, D. (2004). Analgesia following surgery in children with and without cognitive impairment. *Pain*, 111(3), 239-244.
- LaChapelle, D., Hadjistavropoulos, T., & Craig, K. (1999). Pain measurement in persons with intellectual disability. *Clinical Journal of Pain*, 15, 13-23.
- Lotan, M., Ljunggren, E., Johnsen, T., Defrin, R., Pick, C., & Strand, L. (2009a). A modified version of the non-communicating children pain checklist-revised, adapted to adults with intellectual disabilities: Sensitivity to pain and internal consistency. *The Journal of Pain: Official Journal of the American Pain Society*, 10(4), 398-407.
- Lotan, M., Moe-Nilssen, R., Ljunggren, A., & Strand, L. (2009b). Reliability of the Non-Communicating Adult Pain Checklist (NCAPC), assessed by different groups of health workers. *Research in Developmental Disabilities*, 30(4), 735-745.
- Malviya, S., Voepel-Lewis, T., Burke, C., Merkel, S., & Tait, A. R. (2006). The revised FLACC observational pain tool: Improved reliability and validity for pain assessment in children with cognitive impairment. *Paediatric Anaesthesia*, 16(3), 258-265.
- Malviya, S., Voepel-Lewis, T., Tait, A. R., Merkel, S., Lauer, A., Munro, H. et al. (2001). Pain management in children with and without cognitive impairment following spine fusion surgery. *Paediatric Anaesthesia*, 11(4), 453-458.

- McGrath, P., Rosmus, C., Canfield, C., Campbell, M., Hennigar, A. (1998). Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals. *Developmental Medicine & Child Neurology*, 40(5), 340–343.
- McKearnan, K., Kieckhefer, G., Engel, J., Jensen, M., & Labyak, S. (2004). Pain in children with cerebral palsy: A review. *Journal of Neuroscience Nursing*; 36(5), 252–259.
- Mercer, K., & Glenn, S. (2004). The expression of pain in infants with developmental delays. *Child: Care, Health and Development*, 30(4), 353–360.
- Messmer, R., Nader, R., & Craig, K. (2008). Brief report: Judging pain intensity in children with autism undergoing venipuncture: The influence of facial activity. *Journal of Autism and Developmental Disorders*, 38(7), 1391–1394.
- Nader, R., Oberlander, T. F., Chambers, C. T., & Craig, K. D. (2004). Expression of pain in children with autism. *The Clinical Journal of Pain*, 20(2), 88–97.
- Oberlander, T. (2001). Pain assessment and management in infants and young children with developmental disabilities. *Infants and Young Children*, 14, 33–47.
- O'Hara, J., McCarthy, J., & Bouras, N. (Eds.). (2010). *Intellectual disability and ill health*. Cambridge, UK: Cambridge University Press.
- O'Malley, L., & Croucher, K. (2005). Housing and dementia care: A scoping review of the literature. *Health and Social Care in the Community*, 13(6), 570–577.
- Phan, A., Edwards, C., & Robinson, E. (2005). The assessment of pain and discomfort in individuals with mental retardation. *Research in Developmental Disabilities*, 26, 433–439.
- Pivalizza, P. J., & Pivalizza, E. G. (2008). Pain assessment tools for children with cognitive impairment. *Paediatric Anaesthesia*, 18(12), 1233.
- Rojahn, J., Schroeder, S., & Hoch, T. (Eds.). (2007). *Self-injurious behavior in Intellectual Disabilities*. (2nd ed.) Amsterdam: Elsevier.
- Sandelowski, M., & Barroso, J. (2007). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.
- Sandman, C. (2009). Psychopharmacologic treatment of nonsuicidal self-injury. In M. K. Nock (Ed.), *Understanding nonsuicidal self-injury: Origins, assessment, and treatment* (pp. 291–322). Washington, DC: American Psychological Association.
- Schechter, N., Oberlander, T., & Symons, F. (2006). Pain in developmental disabilities: Lessons learned. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 215–226). Baltimore: Paul H. Brookes Publishing.
- 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.
- Stallard, P., Williams, L., Lenton, S., & Velleman, R. (2001). Pain in cognitively impaired, non-communicating children. *Archives of Disease in Childhood*, 85(6), 460–462.
- Stallard, P., Williams, L., Velleman, R., Lenton, S., & McGrath, P. (2002a). Brief report: Behaviors identified by caregivers to detect pain in noncommunicating children. *Journal of Pediatric Psychology*. 27(2), 209–214.
- Stallard, P., Williams, L., Velleman, R., Lenton, S., McGrath, P. J., & Taylor, G. (2002b). The development and evaluation of the pain indicator for communicatively impaired children (PICIC). *Pain*, 98(1–2), 145–149.
- Sullivan, W., Berg, J., Bradley, E., Cheetham, T., Denton, R., Heng, J., Hennen, B., et al. (2011). Primary care of adults with developmental disabilities. Canadian consensus guidelines. *Canadian Family Physician*, 57(5), 541–553.
- Symons, F. J. (2002). Pain and self-injury: Mechanisms and models. In Schroeder, S., Thompson, T., & Oster-Granite, M. (Eds.), *Self-injurious behavior: Genes, brain and behavior* (pp. 223–234). Washington: American Psychological Association.
- Symons, F. J., & Danov, S. (2005). A prospective clinical analysis of pain behavior and self-injurious behavior. *Pain*, 117(3), 473–477.
- Symons, F. J., Harper, V. N., McGrath, P. J., Breau, L. M., & Bodfish, J. W. (2009). Evidence of increased non-verbal behavioral signs of pain in adults with neurodevelopmental disorders and chronic self-injury. *Research in Developmental Disabilities*, 30(3), 521–528.

- Symons, F. J., Shinde, S. K., & Gilles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research, 52*, 275-286.
- Terstegen, C., Koot, H. M., de Boer, J. B., & Tibboel, D. (2003). Measuring pain in children with cognitive impairment: Pain response to surgical procedures. *Pain, 103*(1-2), 187-198.
- Tervo, R., Symons, F., Stout, J., & Novacheck, T. (2006). Parental report of pain and associated limitations in ambulatory children with cerebral palsy. *Archives of Physical Medicine & Rehabilitation, 87*(7), 928-934.
- van Dijk, M., Peters, J. W., Bouwmeester, N. J., & Tibboel, D. (2002). Are postoperative pain instruments useful for specific groups of vulnerable infants? *Clinics in Perinatology, 29*(3), 469-491.
- Voepel-Lewis, T., Malviya, S., & Tait, A. R. (2005). Validity of parent ratings as proxy measures of pain in children with cognitive impairment. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 6*(4), 168-174.
- Voepel-Lewis, T., Merkel, S., Tait, A. R., Trzcinka, A., & Malviya, S. (2002). The reliability and validity of the face, legs, activity, cry, consolability observational tool as a measure of pain in children with cognitive impairment. *Anesthesia and Analgesia, 95*(5), 1224-1229.
- Zaja, R., & Rojahn, J. (2008). Facial emotion recognition in intellectual disabilities. *Current Opinion in Psychiatry, 21*(5), 441-444.