Figure 1. *Plugged In* is one of several drawings made by S.M., a 47-year-old man with developmental disabilities whose case illustrates this article. This drawing is typical of those he made when he was in pain. He usually drew a central figure that he said represented himself, and when asked to show where he "hurt," he would add deep red marks around the figure's left eye. His drawings also often incorporated letters of his name and symbols of electricity, although it wasn't clear what the electricity meant to him. Drawings used with permission of the patient's family; photos courtesy of the authors.

CE **2.6** HOURS
Continuing Education

By Kathy H. Baldridge, MSN, RN, FNP-BC, and Frank Andrasik, PhD

Pain Assessment in People with Intellectual or Developmental Disabilities

Using alternate methods to assess pain when the patient can't provide a self-report.

OVERVIEW: People with intellectual or developmental disabilities suffer from the same chronic diseases and conditions as the general population but are more likely to have physical and psychological comorbidities. This places them at higher risk for experiencing pain and for having more frequent or severe pain. Self-report is the gold standard in pain assessment; but people with intellectual or developmental disabilities often cannot provide self-reports. Pain assessment in this population is therefore challenging. People with intellectual or developmental disabilities are increasingly being moved from institutions into community-based settings. Therefore, nurses in all settings need to be knowledgeable about alternate pain assessment methods. This article provides an overview of pain and pain assessment in this population, summarizes the relevant clinical research, and describes one facility's approach to pain assessment of its patients.

Keywords: pain, pain assessment, pain management, intellectual disability, developmental disability, mental retardation

S.M., a 47-year-old resident at a facility for people with intellectual or developmental disabilities, has a developmental quotient equivalent to that of a two-to-three-year-old. (This is a real case with identifying details changed.) His caregivers reported that he was exhibiting self-injurious behavior, beating his left orbital area. The psychologist completed a functional analysis but could find no tangible reason (such as attention seeking) for the behavior. S.M.'s mother and his primary care physician then referred him to the facility's pain management program for an in-depth evaluation for possible pain or discomfort. The evaluation consisted of a thorough chart review, including current and past medications and medical history; a complete physical assessment; and detailed reports from caregivers.

Reports from S.M.'s caregivers were conflicting as to the likely reason for the behavior. Some believed he was "pitching tantrums" because he wasn't allowed to have coffee or soda when he wanted. Others believed the behavior resulted from a recent decrease in his dosage of quetiapine (Seroquel). A review of S.M.'s medical history revealed diagnoses of profound mental retardation, cause unknown; and generalized tonic-clonic seizure disorder, with the last known seizure occurring 15 years earlier. The family medical history included cluster headaches (S.M.'s father and brother) and autoimmune disorders (other family members).

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The chart review revealed that S.M. had a history of injuries to his left orbital area, often severe enough to require stitches, caused by his hitting himself with his fist; there was no history of injury to his right orbital area. According to the chart notes, the injuries most often occurred between midnight and 3 AM. On several occasions S.M. was found in bed, very agitated, rocking back and forth, beating his left orbital area and yelling "Eye hurt!" His agitation would typically last for half an hour to an hour; then the behavior would resolve as suddenly as it had begun, and he would fall asleep. Left-sided rhinorrhea, tearing of the eyes, unequal pupil size (the left smaller than the right), and diaphoresis of the forehead had also been noted intermittently.

Effective pain assessment is much more difficult in a patient who cannot provide self-reports.

The assessment data, combined with the explosive nature and rapid resolution of S.M.'s self-injurious behavior, were indicative of cluster headaches. In observing and interacting with S.M. over time, the pain management program nurse noted that he had a passion for drawing and coloring. On several occasions after S.M. had exhibited self-injurious behavior, she asked him to draw what he felt like when he "hurt" his eye. Crayons in five colors (red, orange, yellow, green, and blue) were provided. (According to Wojaczyńska-Stanek and colleagues, in children's drawings the color blue commonly indicates calmness, yellow signifies happiness, and black or red indicates the presence of pain.[1]) Each time, S.M. drew a picture of a boy and then forcefully colored the area over the boy's left eye with the red crayon. Interestingly, most of S.M.'s drawings incorporated elements of electrical cords and plug-in devices or of coffee mugs. See Figures 1 and 2.

Based on the evaluation, S.M.'s nursing and direct support staff were taught to recognize the signs and symptoms of cluster headaches. They were also encouraged to continue asking S.M. to draw where he'd felt pain during his outbursts. The goal was to determine whether S.M. was experiencing cluster headaches so that appropriate pharmacologic treatment could begin. It took time to teach the staff to provide appropriate and adequate assessment data, and education was ongoing. Moreover, S.M.'s outbursts were cyclical, usually occurring during the spring and late fall; and staff turnover was frequent, which slowed progress. Eventually S.M. was started on a course of divalproex (Depakote) for a recurrence of seizure activity—the drug is also often prescribed for migraine and cluster headaches—and the frequency of his episodes of self-injurious behavior lessened.

PAIN: A SIGNIFICANT HEALTH ISSUE

Chronic pain is a significant public health problem in the United States. One in four adults—an estimated 76.2 million Americans—reports having had pain that lasted more than 24 hours, while one in 10 reports pain that lasted a year or longer.[2, 3] A 2006 survey by the National Center for Health Statistics found that low back pain, migraine or severe headache, and joint pain were the most common types.[3] Other conditions often associated with chronic pain include rheumatoid arthritis, osteoarthritis, gout, cancer, lupus, and fibromyalgia.[2] Moreover, pain often goes undertreated in African Americans, Hispanics, the elderly, children, and women.[2] In short, the impact of pain on everyday life in the general population is astounding. For people with intellectual or developmental disabilities, that impact may be even greater.

Research has shown that people with intellectual or developmental disabilities have markedly higher rates of both acute and chronic medical conditions than do people in the general population.[4] For example, a study by Minihan of 229 people institutionalized with "mental retardation" found that 99% had at least one chronic medical condition requiring follow-up care (for example, cardiovascular conditions, diabetes, ulcers, chronic otitis media, progressive renal failure).[5] A Swedish study found that the hospital admission rate of people with developmental disabilities was threefold that of the general population, according to Carr and Owen-DeSchryver.[4] Because people with such disabilities tend to have multiple comorbidities and often require more surgical and other medical procedures, the prevalence of pain is also likely to be higher (see Table 1).[6] Yet these individuals are often undertreated for pain—or not treated for it at all—because health care professionals either don't know how to assess their pain or don't recognize that certain nonverbal behaviors can be expressions of pain.

Terminology. The terms developmental disability and intellectual disability aren't exactly synonymous. *Developmental disability* is the broad term for "a diverse group of severe chronic conditions that are due to mental and/or physical impairments," including autism, cerebral palsy, and *intellectual disability*, according to the Centers for Disease Control and Prevention (CDC).[7] The CDC defines intellectual disability as that "characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life." (Another term for intellectual disability, *mental retardation*, is now largely obsolete.)

The International Association for the Study of Pain (IASP) has defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."[8] But the definition most clinicians will probably find more familiar and clinically applicable is the one first proposed by McCaffery in 1968 and updated in

Figure 2. *Coffee Time* is another drawing by S.M.; the small figure in the bed is probably him. Although he loved coffee, his intake was limited because staff members felt that it might be a factor in his headaches and self-injurious behavior. As in *Plugged In,* electrical cords are evident.

1989: “Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does.”[9]

Pain is a highly subjective and individualized experience; for its assessment, self-report is the gold standard. Effective pain assessment is much more difficult in a patient who has severe cognitive or communicative impairments and cannot provide self-reports.

SELECT SUMMARY OF CLINICAL RESEARCH

To find relevant clinical research, we searched the PubMed, CINAHL, and EBSCO databases using the keywords “pain,” “pain assessment,” “pain management,” “developmental disabilities,” “intellectual disabilities,” “nonverbal,” and “mental retardation.” We limited the search to articles published within the past five years. We also scanned these databases, albeit less systematically, for relevant articles published during the mid-to-late 1990s. Unfortunately, few studies have addressed the issue of pain assessment and treatment in people with intellectual or developmental disabilities. The studies reviewed in brief below are among those that did.

Behavioral indicators. Bosch and colleagues discussed the exacerbation of self-injurious behaviors (such as head banging, hitting or biting oneself, throwing oneself against hard objects) in people with severe cognitive impairment as an indication of pain.[10] Using retrospective chart review, the researchers considered 25 patients who engaged in self-injurious behavior and found that seven (28%) had previously undiagnosed medical conditions that could cause pain or discomfort; once these conditions were treated, self-injurious behavior decreased in six of the seven (86%). The findings were limited by the anecdotal nature of the evidence and by several factors not controlled for; for example, behavioral management and medical treatment occurred simultaneously, making it impossible to know which had actually reduced the self-injurious behavior. Still, the researchers concluded that “there are enough data to suggest that the role of discomfort or pain in [self-injurious behavior] deserves a more careful evaluation.”

More recently, Carr and Owen-DeSchryver studied 11 people with intellectual or developmental disabilities and determined that serious problem behaviors, including but not limited to self-injurious behaviors, were more evident on days when the patients were ill than on days when they were well.[4] Sick days were associated with higher levels of pain or discomfort, and higher levels of pain or discomfort were associated with more frequent or more intense problem behaviors. Behavior patterns that might indicate pain—including not only self-injurious behavior but also aggression toward others, stereotypic movement disorders, and tantrums, among others—can also be a significant barrier to effective pain management.

Several experts have described the challenges of differential diagnosis in people who are intellectually or developmentally disabled and have other comorbidities, particularly psychiatric disorders.[11-14] Indeed, people with intellectual and developmental disabilities are at increased risk for mental health problems, with some reviewers reporting a prevalence that's three to five times higher than in the general population—yet as with pain, assessment is difficult because these individuals often cannot verbally communicate their thoughts and feelings.[13, 15] There are many reasons why a person with intellectual or developmental disabilities might engage in a challenging or "problem" behavior.[11] It might be a way of seeking attention, avoiding undesired activities or situations, or dealing with illness. And as Zwakhalen and colleagues noted, people can have different reactions to the same stimulus, and the same person might react differently in different situations or at different times.[16] McGrath and colleagues observed that behaviors typically associated with pain in "normal" people might be hard to interpret in people with intellectual or developmental disabilities and that their behavioral limitations may actually mask the expression of pain.[17]

Clinicians and family members should be educated on possible alternative indicators of pain.

Proxy reports and behavioral pain assessment tools. Caregivers are often relied upon for essential information about people with intellectual or developmental disabilities who are unable to communicate, especially during physician or ED visits. But caregivers often have different perceptions about why a person is exhibiting certain behaviors. A caregiver who's familiar with the person will likely recognize the ways she or he expresses pain or discomfort; but one who's less familiar might not, or might harbor misconceptions about the person's ability to feel and express pain. Behavioral pain assessment methods involving primary caregivers—family members or professionals—have been the subject of some studies.

Fanurik and colleagues interviewed the parents of 145 children with varying levels of cognitive impairment to learn more about parents' perceptions of their children's pain experience.[18] About two-thirds of parents felt that their children experienced pain differently than "normal" children did—for example, they had a lower sensitivity to or a higher tolerance for pain. The researchers advised interpreting this finding with caution, noting that severe cognitive impairment is often accompanied by severe motor impairment, limiting a child's ability to display behavioral cues. Almost half of the parents reported feeling unable to adequately assess their child's pain, and nearly one-third felt the pain was treated "differently" by professionals. Many reported that clinicians also had difficulty accurately assessing their child's pain and that consequently such pain was under- or overtreated.

Voepel-Lewis and colleagues evaluated the accuracy of parents' pain reports on children with cognitive impairment.[19] Parents observed their children and rated their pain using the Faces, Legs, Activity, Cry, and Consolability (FLACC) scale and the 0-to-10 Numbers Scale; nurses simultaneously completed the FLACC. The researchers concluded that parents provided "reasonable estimates of their child's pain, particularly when using a structured pain tool."

In 1997 McGrath and colleagues interviewed the primary caregivers of 20 children with cognitive impairment in order to create a checklist of indicative pain behaviors.[17] They identified 31 specific behaviors in seven categories (vocal, eating–sleeping, social–personality, facial expression of pain, activity, body and limbs, and physiological). The final checklist was then used to assess the 20 children for pain. Some of the items on the checklist, such as crying and moaning, were used by almost all the caregivers to detect pain. But most of the items were used by fewer than half, an indication that pain responses are highly individual; the researchers stated that "there may not be a single set of items that can be reliably used to discriminate pain in this population." Despite the study's limitations, the checklist was found to have good reliability and excellent content validity.

In the general population, the emotional experience of pain is influenced by factors such as culture, family role models, cognitive-emotional characteristics, and past experiences with pain.[20] But people with intellectual or developmental disabilities may not have developed this aspect of pain perception, and thus might seem indifferent or insensitive to pain. Using third-party reports, Biersdorff explored the incidence and effects of pain insensitivity or indifference in 123 people in a large rehabilitation facility for people with intellectual or developmental disabilities.[21] Although about half (52%) showed typical pain responsiveness and 11% were hyperresponsive, 37% were found to be hyporesponsive, demonstrating a high pain threshold, a slow reaction time, or unusual pain behaviors. Biersdorff warned that staff members "may miss signs of illness or injury because they are looking for the more obvious pain signals." Breau and colleagues looked at how pain affected the daily functioning of 63 children with severe intellectual disabilities.[22] Caregivers completed an observational pain checklist and kept up to seven one-week diaries over the 87 weeks of the study. The researchers found that if pain expression was lacking or atypical, a child's pain could remain unrelieved, and this in turn could adversely affect functioning in the four areas studied: communication, daily living skills, socialization, and motor skills.

Such findings indicate the need to educate clinicians and family members on the possible alternative indicators of pain in people with intellectual or developmental disabilities.

PAIN ASSESSMENT

Self-report should always be attempted first, as it's the most reliable report of pain.[23] That said, for clinicians, the challenge lies in how to obtain a valid and reliable assessment of pain from a person who's unable to provide a self-report. In our experience, people with intellectual or developmental disabilities who are living with conditions known to be painful are often assessed for pain less frequently, have their pain levels underestimated, and are given less pain medication than are people in the general population. Similar observations have been alluded to in other studies of people with cognitive impairment.[18, 21] This is probably directly related to the difficulties in assessing pain in this population. There are currently no ideal tools available for assessing pain; the few that are available have reportedly only been psychometrically tested in children with cognitive or developmental disabilities or in adults with dementia.[16, 24]

However, there are behavioral pain assessment tools available for use in other populations who are unable to self-report. In 2006 the American Society for Pain Management Nursing (ASPMN) issued "Pain Assessment in the Nonverbal Patient: Position Statement with Clinical Practice Recommendations." It describes numerous tools used to assess pain in nonverbal populations, including adults with advanced dementia, infants and preverbal toddlers, and patients who are intubated or unconscious.[23] Although many

Table 1. Common Pains Experienced by Persons with Developmental Disabilities

Developmental disability	Painful comorbid conditions	Location/type of pains experienced as a result of painful conditions
Down syndrome	Cancer (leukemia)	Disease process Diagnostic procedures Treatment
	Oral health—diseases	Periodontal General dental Temporomandibular
	Drug toxicity	Mucositis Infection Peripheral neuropathy
	Congenital health defect	General locations: • Ear, nose, throat • Leg, abdomen, head, neck, and back
Autism	Epilepsy	Postseizure
	Gastrointestinal disorder	Gastroesophageal reflux Reflux esophagitis Abdominal
Cerebral palsy	Gastrointestinal	Gastroesophageal reflux Constipation
	Musculoskeletal (including hip and back pain)	Muscle spasms Dislocated hips Joint problems Position/posture changes Spontaneous pain
All	Pain experienced more commonly than the general population	Medical procedure–related pain Daily living Infection Gastrointestinal discomfort

From Bottos S, Chambers CT. The epidemiology of pain in developmental disabilities. In: Oberlander TF, Symons FJ, editors. *Pain in children and adults with developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co., Inc.; 2006; p. 74. Reprinted with permission.

of these tools haven't been tested for reliability and validity in people with intellectual or developmental impairments—and none have been subject to rigorous psychometric evaluation in this population—some may be useful. Each has distinct advantages and disadvantages, and clinicians will need to weigh these in making a selection; the ASPMN cautions that no single behavioral scale has been shown to be superior in all cases and populations. For instance, some tools may be easier or less time-consuming to use than others, but might not be sufficiently comprehensive; others might be more comprehensive but require more time. Some tools may yield more false-positives than others. For more information about specific tools, see the ASPMN's paper, available free online at http://bit.ly/btw25S.

According to the ASPMN, pain assessment in nonverbal people should also include a search for pathologic conditions or other problems or procedures known to cause pain; the observation of behaviors that might indicate pain; and the use of proxy reports (also called surrogate reports) by people who know the person best, whether family caregivers or professionals.[23] These recommendations are useful for people with intellectual or developmental disabilities as well. Documentation of an individual's "baseline" or usual, characteristic behaviors and of any past history of problematic or challenging behaviors and their situational causes (if known) can be helpful in identifying the presence of pain through behavioral indicators. The ASPMN states that in the absence of self-reports, behavioral observations provide a valid method of pain assessment; and proxy reports provided by those caregivers who know the person best are usually credible with regard to the presence of pain.[23]

For more on pain assessment in people with intellectual or developmental disabilities, see *One Facility's Approach*.[9, 19, 23, 25-29]

NURSING IMPLICATIONS AND FURTHER RESEARCH

Currently there's a push to integrate people with intellectual or developmental disabilities into community-based settings rather than to separate or isolate them

One Facility's Approach

Pinecrest Supports and Services Center, an intermediate care facility for people with intellectual or developmental disabilities in Pineville, Louisiana, established a pain management program in 2001. (Both of us were involved in this program: KHB helped to develop and then coordinated it from 2001 until April of this year; FA served as a consultant from 2002 through 2009.) Its goals were twofold: to improve pain assessment by educating staff on the ways pain can manifest in this population; and to provide appropriate, effective treatment of pain to improve patients' quality of life. The facility provides services to about 500 people; approximately 87% have been assessed as having severe or profound intellectual deficits.[28] The majority have one or more chronic comorbidities, yet few can provide accurate self-reports of pain. This has presented a significant barrier to meeting the program's pain management goal.

The facility's clinicians have incorporated a variety of other methods to assess a person's pain and evaluate her or his response to treatment. These include a complete physical examination and review of the medical history, a review of any prior pain experiences and responses, and consideration of proxy reports, as well as completion of the most appropriate pain assessment tool. At Pinecrest, clinicians have used or adapted for use various pain assessment tools, including the Wong-Baker Faces Pain Rating Scale,[29] the Poker Chip Tool,[26] the Eland Color Scale,[9] and the Faces, Legs, Activity, Cry, and Consolability (FLACC) scale.[19, 27] In some cases, patients have also been asked to draw pictures that reflect their pain experience.

The FLACC scale is the pain assessment tool most commonly used at this facility. The interdisciplinary team, which typically includes the primary care provider, a psychologist, a physical therapist, an occupational therapist, RNs, and direct caregivers, individualizes the FLACC scale for each patient.[25] The team goes through each section of the tool and describes what the person looks like when she or he is comfortable and when she or he is not. Even subtle indicators of discomfort, such as a furrowed brow during abdominal palpation, as well as any changes in the person's usual facial or bodily appearance, habits, or movements, are noted. This, in conjunction with the other steps of the pain assessment process, gives the team an improved awareness of pain, and its intensity, in that person.

When pain is suspected, a search for possible causes is conducted. Patients with chronic illnesses and conditions known to cause pain are treated for pain, even if they don't display any identifiable signs of pain. When a patient engages in self-injurious or other challenging behaviors, the treatment team works together to determine whether pain might be the cause and to exclude other possible factors. When the team isn't sure pain is present but has reason to suspect it might be, then pain is assumed to be present and an analgesic trial is initiated. As the American Society for Pain Management Nursing guidelines state, if behavioral improvement is noted after a reasonable analgesic trial, then one can reasonably assume that pain was the cause of the behavior.[23]

Although the program's effectiveness hasn't been formally studied, it's our belief that pain assessment and management have improved considerably at Pinecrest. Direct care staff have learned that behaviors that have no clear psychological basis can indicate the presence of discomfort or pain, and they are better able to recognize such instances. Collaboration and teamwork have also improved: clinicians consult the pain management team more often, and interdisciplinary teams often use the pain assessment tools on their own in cases of suspected pain, leading to earlier intervention.

in institutions. This has been the case even for people with significant cognitive and developmental disabilities.[28] As a result, it's becoming more common for nurses and other health care professionals in a variety of settings to encounter these patients. To ensure effective pain management, nurses need to be knowledgeable about pain assessment in this population.

Because there's no standard pain assessment tool for people with intellectual or developmental disabilities, assessment methods vary greatly. Many of the tools mentioned above and in the ASPMN position statement and guidelines can be adapted for use in this population, but additional research is needed to establish their reliability and validity.

Studies are also needed to better describe the phenomenon of pain insensitivity or indifference in this population, explore the behavioral aspects of pain communication, and examine the functions of self-injurious and other challenging behaviors. In order to obtain the most meaningful results, it's vital that research efforts be interdisciplinary.

As nurses gain a heightened awareness of how pain can manifest in people with intellectual or developmental disabilities, and learn how to assess pain in this population, the likelihood that such pain will go untreated will lessen. Pain management is as much art as it is science, and it must be pursued with fervor—as one expert said, "as though a life depended on it. Certainly the quality of life does."[30] ▼

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REFERENCES

1. Wojaczyńska-Stanek K, et al. Headache in children's drawings. *J Child Neurol* 2008;23(2):184-91.
2. American Pain Foundation. *Pain facts and figures*. 2009. http://www.painfoundation.org/newsroom/reporter-resources/pain-facts-figures.html.
3. National Center for Health Statistics. New report finds pain affects millions of Americans [press release]. *NCHS press room* 2006 Nov 15. http://www.cdc.gov/nchs/pressroom/06facts/hus06.htm.
4. Carr EG, Owen-DeSchryver JS. Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *J Autism Dev Disord* 2007;37(3):413-24.
5. Minihan P. Planning for community physician services prior to deinstitutionalization of mentally retarded persons. *Am J Public Health* 1986;76(10):1202-6.
6. Bottos S, Chambers CT. The epidemiology of pain in developmental disabilities. In: Oberlander TF, Symons FJ, editors. *Pain in children and adults with developmental disabilities*. Baltimore, MD: Paul H. Brookes Pub.; 2006. p. 67-87.
7. Centers for Disease Control and Prevention. *Developmental disabilities* 2004. http://www.cdc.gov/ncbddd/dd/default.htm.
8. Merskey H, Bogduk N, editors. *Classification of chronic pain: descriptions of chronic pain syndromes and definitions of pain terms*. 2nd ed. Seattle: International Association for the Study of Pain; 1994.
9. McCaffery M, Beebe A. *Pain: clinical manual for nursing practice*. 1st ed. St. Louis: Mosby; 1989.
10. Bosch J, et al. Role of medical conditions in the exacerbation of self-injurious behavior: an exploratory study. *Ment Retard* 1997;35(2):124-30.
11. Barnhill LJ. The diagnosis and treatment of individuals with mental illness and developmental disabilities: an overview. *Psychiatr Q* 2008;79(3):157-70.
12. Davis E, et al. Treatment models for treating patients with combined mental illness and developmental disability. *Psychiatr Q* 2008;79(3):205-23.
13. Ferrell RB, et al. Neuropsychiatric syndromes in adults with intellectual disability: issues in assessment and treatment. *Curr Psychiatry Rep* 2004;6(5):380-90.
14. Fuller CG, Sabatino DA. Diagnosis and treatment considerations with comorbid developmentally disabled populations. *J Clin Psychol* 1998;54(1):1-10.
15. Rush KS, et al. Assessing psychopathology in individuals with developmental disabilities. *Behav Modif* 2004;28(5):621-37.
16. Zwakhalen SM, et al. Pain assessment in intellectually disabled people: non-verbal indicators. *J Adv Nurs* 2004;45(3):236-45.
17. McGrath PJ, et al. Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals. *Dev Med Child Neurol* 1998;40(5):340-3.
18. Fanurik D, et al. Children with cognitive impairment: parent report of pain and coping. *J Dev Behav Pediatr* 1999;20(4):228-34.
19. Voepel-Lewis T, et al. Validity of parent ratings as proxy measures of pain in children with cognitive impairment. *Pain Manag Nurs* 2005;6(4):168-74.
20. Monina E, et al. Behavioural evaluation in patients affected by chronic pain: a preliminary study. *J Headache Pain* 2006;7(6):395-402.
21. Biersdorff KK. Incidence of significantly altered pain experience among individuals with developmental disabilities. *Am J Ment Retard* 1994;98(5):619-31.
22. Breau LM, et al. Pain's impact on adaptive functioning. *J Intellect Disabil Res* 2007;51(Pt 2):125-34.
23. Herr K, et al. Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. *Pain Manag Nurs* 2006;7(2):44-52.
24. Hatfield CF, et al. Diagnostic tools for dementia. *Maturitas* 2009;63(3):181-5.
25. Andrasik F, Rime C. Pain assessment. In: Matson JL, et al., editors. *Assessing childhood psychopathology and developmental disabilities*. New York City: Springer; 2009. p. 445-70.
26. Hester NO, et al. Measurement of pain in children: generalizability and validity of the Pain Ladder and Poker Chip Tool. *Adv Pain Res Ther* 1990;15:79-84.
27. Merkel S, et al. Pain assessment in infants and young children: the FLACC scale. *Am J Nurs* 2002;102(10):55-8.
28. Thorn SH, et al. Increasing community integration and inclusion for people with intellectual disabilities. *Res Dev Disabil* 2009;30(5):891-901.
29. Wong DL, Baker CM. Pain in children: comparison of assessment scales. *Pediatr Nurs* 1988;14(1):9-17.
30. Spross JA. Cancer pain and suffering: clinical lessons from life, literature and legend. *Oncol Nurs Forum* 1985;12(4):23-31.