

43

Pain Issues in Individuals with Limited Ability to Communicate Due to Cognitive Impairment

I. General

Understand the full range of conditions (e.g., dementia, developmental disabilities, severe head injury, stroke, and autism) that can lead to limitations in ability to communicate due to cognitive impairment (Kolb and Wishaw 1996; Hadjistavropoulos et al. 2001; Breau et al. 2004a; Nader et al. 2004).

Recognize that individuals may have multiple impairments that can affect motor, cognitive, language, and social/emotional capabilities to communicate pain and distress.

Know about the pain conditions and sources of pain that are frequently encountered in individuals with cognitive impairments and limitations in ability to communicate (Miller et al. 1997; Stallard et al. 2001; Breau et al. 2003a; Jansen et al. 2004).

A. Pain sources

1. Recognize that pain is a frequent complication of motor impairment in certain populations with cognitive and neurological impairments (e.g., cerebral palsy).
2. Recognize that individuals with cognitive and motor impairments have multiple potential sources of pain.
3. Be aware that people with cognitive impairments are not immune from the everyday pains suffered by non-impaired individuals, e.g. headaches, menstrual pains, toothache, and earache.
4. Be aware of the other pains that are commonly reported in patients with cognitive impairments, e.g., musculoskeletal pain, pain from reflux esophagitis, constipation, and spasticity (Gilbert-Macleod et al. 2000).

B. Know the effects that many neurological disorders associated with limited ability to communicate have on the experience of pain (Farrell et al. 1996; Benedetti et al. 1999; Oberlander et al. 1999; Gibson et al. 2001; Hadjistavropoulos et al. 2001).

C. Understand the risk factors that may increase the prevalence of pain in these individuals because of:

1. Comorbidities that increase risk for pain e.g. central damage, gastroesophageal reflux, contractures (Hennequin et al. 2000; Breau et al. 2004a).
2. The increased number of medical procedures (especially, but not only, in neonates and children) that these individuals may experience (Stevens et al. 2003).
3. Increased risk of accidental injury (Leland et al. 1994; Hsieh et al. 2001; Braden et al. 2003) and intentional injury (Homer and Gilleard 1990; Sullivan and Knutson 1998; Goldson 2001).
4. Likelihood of difficulties in communication.
5. Devaluing of these individuals by society.
6. Poor services for these populations (Ziring et al. 1999).
7. Limited lobbying on behalf of these populations.

D. Know that the level of physical disability does not necessarily reflect the level of intellectual disability. (Smith and Phillips 1992).

E. Know the developmental abilities that children of differing mental ages would display and how these may be affected by their level of physical disability (Smith and Phillips 1992).

- F. Know the neurological factors that could affect pain sensation, processing, or expression, and know that this effect could lead to a lesser or greater pain experience.
 - G. Know the medical conditions that could affect pain sensation, processing, or expression, and know that this effect could lead to a lesser or greater pain experience.
 - H. Know the pharmacological treatments that may be given to people with intellectual or physical disabilities for associated medical conditions; know that these could affect pain sensation, processing, or expression, and know that this effect could lead to a lesser or greater pain experience.
 - I. Be aware that pain sensitization (being more sensitive to stimuli) can result from repeated pain and that many people with physical or intellectual disabilities are subjected to repeated painful procedures or have long-term recurrent or chronic painful conditions.
 - J. Know the medical conditions that may lead to true pain insensitivity and be aware of the rarity of these conditions (Oberlander et al. 1999, 2000; Oberlander 2001; Shorer et al. 2001).
 - K. Know that the presence of self-injury does not necessarily mean that a person is insensitive or indifferent to pain (Breau et al. 2001b).
 - L. Know the short- and long term impact of pain on children's and adults' functioning (Houlihan et al. 2004).
- II. Assessment and treatment
- A. General
 - 1. Recognize that pain is often underestimated and undertreated in these populations.
 - 2. Be aware of the reasons for underestimation and undertreatment of pain in these populations, i.e., attitudes and misconceptions of health care professionals. Be aware of the legal consequences of the underestimation and undertreatment of pain.
 - B. Assessment
 - 1. Be aware of the assessment procedures suitable for specific populations with cognitive impairments (Hadjistavropoulos et al. 1998, 2000, 2001; McGrath et al. 1998; LaChapelle et al. 1999; Breau et al. 2000, 2001a,b, 2002a; Feldt 2000; Hunt et al. 2003; Abbey et al. 2004; Fuchs-Lacelle and Hadjistavropoulos 2004; Hunt et al. 2004; Stolee et al. 2005) and understand how measures intended for other populations may be modified (Breau et al. 2002a,b; Stallard et al. 2002; Boldingh et al. 2004).
 - 2. Be familiar with possible applications of certain self-report tools among subsamples of persons with cognitive impairments (Fanurik et al. 1998; Hadjistavropoulos et al. 1998, 2001; Chibnall and Tait 2001; Benini et al. 2004). Be aware that pain assessment/measurement methods that are not specifically designed for this population may lead to underestimation of their pain (Defrin et al. 2004).
 - 3. Ensure that individuals with limitations in ability to communicate are assessed for pain on a regular basis.
 - 4. Be familiar with the literature concerning the undertreatment of pain among certain populations with cognitive impairment and the negative implications of undertreatment (Biersdorff 1991; Marzinski 1991; Kaasalainen et al. 1998; Koh et al. 2004).
 - 5. Be familiar with environmental, situational, and emotional factors that can affect an individual's response to pain.
 - 6. Be familiar with psychosocial interventions that could be adapted to treat the negative psychological consequences of pain among persons with cognitive impairments (Teri and Gallagher-Thompson 1991).
 - 7. Be aware of the most frequent causes of pain in this group and the relation of risk for these pain causes to child factors (Hunt and Burne 1995; Breau et al. 2000a,b).

8. Be aware of the characteristics of pain due to specific causes (location, duration, intensity, etc.) (Stallard et al. 2001, Breau et al. 2003a; Hunt et al. 2003).
9. Know behaviors associated with pain in this group, including the importance of facial expression. Learn to attend to and be vigilant for behavioral pain cues. Recognize that behavioral cues of pain can be similar to other populations and/or idiosyncratic (Coffman et al. 1997; Fanurik et al. 1999a; Benini et al. 2004).
10. Be aware that observational procedures for assessing pain that only include a small number of items may be failing to identify important, idiosyncratic pain behaviors that can be characteristic of many persons with severe cognitive and neurological impairments.
11. Know the limitations of self-report by persons with intellectual disabilities (Fanurik et al. 1998).
12. Know about factors that may affect people's expression of pain, such as intellectual functioning, physical disabilities, and autistic features (Fanurik et al. 1999a; Nader et al. 2004).
13. Learn to attend to the reports of caregivers. Be aware of the importance of context in assessing pain in people who are cognitively impaired. Respect the judgements of those who know the individual well.
14. Recognize that many persons with cognitive impairment may have the capacity to self-report pain and may be familiar with pain assessment tools that can facilitate self-report of pain (Closs et al. 2004).
15. Take into account diagnostic and results of medical tests, where possible, when assessing for the presence of pain in persons with cognitive impairment.
16. Be aware of personal and societal beliefs or attitudes that may affect judgments of pain (Breau et al. 2003b, 2004b).

C. Treatment

1. Be familiar with various treatment modalities that either are suitable for persons with cognitive impairments, or could be modified for such individuals (Ferrell 1995).
2. Understand the significant issues regarding pharmacological and other interventions with this population, including difficulties in using cognitive or behavioral methods.
 - a. Note that there is limited literature on pharmacological treatment in this population. Koh et al. (2004), on finding that children with cognitive impairment received lower opioid doses in the perioperative (but not postoperative) period than children without cognitive impairment, suggested there may be a belief that children with cognitive impairment are more sensitive to side effects of opioids, but there is no research to substantiate this assertion. Malviya et al. (2001) found that children with cognitive impairment undergoing surgery received smaller opioid doses than children without impairment.
3. Given the wide variety of pain manifestations among people with severe neurological impairments (McGrath et al. 1998), be prepared to match intervention and assessment procedures to the needs and abilities of each patient (Hadjistavropoulos et al. 2000).
4. Ensure that qualified health professionals are responsible for prescribing and administering pain medications.
5. Recognize the importance of multidisciplinary intervention in the pain management of individuals with limitations in ability to communicate.
6. Be knowledgeable about methods of institutionalizing programmes (e.g., CARES 2005) to meet the needs of individuals with limited ability to communicate due to cognitive impairment.
7. Know the most validated pain management techniques available for the painful conditions most likely to affect this group (e.g., gastrointestinal pain, orthopedic pain, and pain due to respiratory infections) (Oberlander 2001).
8. Be aware of common medical conditions that could affect pain management (e.g. seizure disorders, motor disorders) and how to adapt pain control to manage these conditions.
9. Be aware that mental age may differ from chronological age and that pain management should take this factor into account.

10. Be aware of pain management techniques commonly used by caregivers, or in self-management, as appropriate (Breau et al. 2001a, 2003a).
11. Be familiar with the treatments for the most commonly occurring pains, e.g. nonsteroidal anti-inflammatories, muscle relaxants, anticonvulsants, proton pump inhibitors, and treatments for neuropathic pain.
12. Be aware that surgical interventions may be necessary but can have reduced effectiveness in people who are severely neurologically impaired.
13. Be prepared to refer patients to specialists in the management of painful conditions.

III. Caregivers and social context

- A. Recognize the importance of the social context and social support when attempting to understand the pain experience of persons with limited ability to communicate.
- B. Know about the role of caregivers in assessing pain among persons with limitations in ability to communicate (McGrath et al. 1998; Feldt 2000; Breau et al. 2003b).
- C. Be familiar with issues related to stress and burden experienced by caregivers of patients with severe limitations in ability to communicate, because high levels of caregiver burden can lead to difficulties in ability to provide care (Zarit et al. 1985). Accordingly, be familiar with necessary community resources aimed at assisting caregivers to help the patient.
- D. Be familiar with family system management approaches suitable for families of individuals with severe neurological impairments and limitations in ability to communicate (Gwyther and Blazer 1984).
- E. Be aware of societal attitudes toward children and adults with impairments and understand how these attitudes could influence assessment and treatment of pain (Savage 1998; Fanurik et al. 1999a,b; MacLaren et al. 2001; Malviya et al. 2001; Breau et al. 2002a, 2004b).
- F. Be aware of personal beliefs that could affect your assessment or treatment of pain in a child or adult with physical or intellectual disabilities.

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ADDITIONAL RESOURCE LIST

SPASTICITY

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