



FACT SHEET No. 11

Pain in Cognitive Impairment, not Dementia-Related: management

Individuals with intellectual disability often display pain in unusual ways. Subtle changes in behavior and appearance may be indicators of pain, as expressions of pain may be variable and idiosyncratic [8]. Depending on the cause of intellectual disability and various areas of the brain involved, the motivational-affective, cognitive-evaluative, and autonomic responses to pain can be affected [4]. This creates a misconception that people with intellectual disability are a homogenous group who are less sensitive to pain and have a higher pain threshold [1].

Pain recognition in cognitive impaired

People with intellectual disability may express pain differently, making its recognition highly subjective due to nonverbal indicators, which are not easily recognized given the subtlety or individuality of pain behaviors. As pain is a highly individualized and subjective phenomenon, potential indicators of pain include changes in physical and/or behavioral signs together with an understanding of the individual's typical abilities [13]. However, varied responses due to verbal and cognitive skills have limited the applicability of pain assessment tools in practice [31]. Therefore, there is a need for a variety of methods and measures of pain that are matched with the ability of the person being assessed. Within this process, baseline recordings should be part of each individual's annual health assessment where pain responses can be documented and reviewed for the benefit of unfamiliar healthcare professionals [14]. What needs to be considered is that pain needs to be assessed using a recognized and appropriate pain scale using a variety of modalities including: self-report, behavioral observation, and physiological measures depending on the individual and their communication abilities. In addition, atypical reactions to pain, such as laughing or making the same sounds whether excited, happy or in pain need to be considered [22]. Examples of available pain assessment instruments validated for children with intellectual disability include: the relatively simple and easy to use Individualized Numeric Rating Scale - INRS [27], Revised Face, Legs, Activity, Cry, Consolability - r-FLACC [32] and the more complex Paediatric Pain Profile - PPP [15].

For adults with intellectual disability, validated pain assessment instruments include: NonCommunicating



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Adult Pain Checklist – NCAPC [19], Pain and Discomfort Scale – PADS [2], Checklist of Nonverbal Pain Indicators – CNPI [7] and the Disability Distress Assessment Tool - Dis-Dat [26]. Interrater reliability of most pain assessment instruments is adequate, and construct validity estimated by correlating the outcomes of a new scale with those of an existing scale is sufficient [15,20,28]. While numerous pain assessment tools exist, however, what is essential is that an assessment is conducted in light of the ability to assess the person with intellectual disability on all aspects of the tool and that baseline observations have been recorded. This process ideally involves input from those who know the individual at baseline and when in pain. Determining individualized physical, physiological, behavioral and atypical reactions/observations are essential if pain is to be recognized and treatment delivered [25].

Pain management in cognitive impaired

In order to manage pain, an effective pain assessment and evaluation of pain sources is necessary. Conditions that cause nociceptive (acute) pain, for example fractures and dental problems, should be evaluated [10]. Gastroesophageal reflux disease is a major cause of pain in intellectual disability [9] and may be associated with vomiting, pneumonia, and dental problems. All of which are potentially painful [5]. Validated tools are available to quantify symptom frequency and severity of gastroesophageal reflux [3] and early detection and early treatment of gastroesophageal reflux is key to preventing pain and other symptoms. Besides nociceptive pain, neuropathic pain should be considered as a cause as well.

Neuropathic pain is a clinical description of chronic or recurrent pain caused by a lesion of the somatosensory nervous system. Symptoms could include pain resulting from non-painful stimulation with pain being described as a burning and electrical-like sensation. Neuropathic pain can also be more difficult to treat, and might respond better to other analgesics such as gabapentinoids and tricyclic antidepressants [11,12]. Some people with intellectual disability exhibit self-injurious behavior such as head banging or self-biting, and pain could be a causative factor (i.e. a way of expressing pain). The incidence of self-injurious behavior in children with autism can be as high as 50%, but only in a small percentage was a nociceptive pain source identified as a cause [23]. However, it has suggested that neuropathic pain is a trigger for self-injurious behaviors [24,29].

After pain assessment and recognition, the next step is prescribing adequate analgesic agents with appropriate dosing instructions. Pain management according to the World Health Organization [33] analgesic pain ladder can be followed. Pain is often difficult to treat and frequently requires ongoing assessment, review and titration and/or trial of drugs before a satisfactory outcome can be achieved [30]. Generally, people with intellectual disability receive less pain relief and two retrospective studies [17,18] identified that children with intellectual disability received lower doses of intraoperative opioids compared with controls. Malviya et al., [21] also reports 89% of physicians tend to prescribe subtherapeutic doses of analgesics to children with intellectual disability.

Epilepsy is a very common comorbidity in intellectual disability and many people with intellectual disability will therefore need lifelong treatment with antiepileptic drugs (i.e. phenytoin, phenobarbital, carbamazepine) which may cause drug–drug interactions, since they are potent inducers of multiple cytochrome P450 enzymes. A pain management regime needs to be comprehensive, integrative, and involve all relevant persons. Attention should be given to multimodal interventions, which includes



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pharmacological and non-pharmacological treatments. Such interventions may include pharmacological, physical, social, psychological and spiritual approaches to address pain management at molecular, functional, behavioral, cognitive and affective levels [6]. Thereby, pain management interventions will vary according to pain etiology, patient characteristics and preferences, and in keeping with best practice guidelines. A structured approach incorporating an effective assessment of pain, identification of the source and type of pain, and accurate documentation is essential.

Given the complexity of pain in the intellectual disability population, effective pain management requires a multidimensional approach and continuous reassessment to ensure a focus on quality of life indicators and not just reduction of pain. In addition, relevant individuals such as family/caregivers and the individual with intellectual disability themselves should be included in the assessment, management, and evaluation [6]. Consideration needs to be given to the lack of education and knowledge of intellectual disability, which are considered primary barriers to effective pain management.

Keypoints

- 1) The management of pain in people with intellectual disability involves many considerations in view of pain assessment difficulties, the high incidence of comorbidities, and the use of co-medication.
- 2) Adequate pain assessment is the cornerstone of pain management, and pain in people with intellectual disability benefits from use of validated pain assessment tools appropriate to the individual's level of ability.
- 3) Prescribers must be aware of the potential alterations in pharmacokinetics and pharmacodynamics of analgesics in people with intellectual disability, such as drug–drug interactions with antiepileptic drugs.

REFERENCES

- [1] Beacroft M. and Dodd K. (2010) I feel pain - audit of communication skills and understanding of pain and health needs with people with learning disabilities. *British Journal of Learning Disabilities*. 39: 139–147.
- [2] Bodfish J., Harper V., Deacon J. and Symonds F. (2001) Identifying and measuring pain in persons with developmental disabilities: A manual for the Pain and Discomfort Scale (PADS). Available from Western Carolina Center Research Reports, 300 Enola Rd. Morganton NC 28655.
- [3] Deal L., Gold B.D., Gremse D.A., Winter H.S., Peters S.B., Fraga P.D., Mack M.E., Gaylord S.M., Tolia V. and Fitzgerald J.F. (2005) Age-specific questionnaires distinguish GERD symptom frequency and severity in infants and young children: development and initial validation. *Journal of Pediatric Gastroenterology and Nutrition*. 41(2):178–185.
- [4] de Knecht N. and Scherder E. (2011) Pain in adults with intellectual disabilities. *Pain*.152(5):971–4.
- [5] de Veer A.J., Bos J.T., Niezen-de Boer R.C., Bohmer C.J. and Francke A.L. (2008) Symptoms of gastroesophageal reflux disease in severely mentally retarded people: a systematic review. *BMC Gastroenterol*. 8:23.
- [6] Doody O. and Bailey M.E. (2017) Interventions in pain management for persons with an intellectual disability. *Journal of*



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Intellectual Disabilities, <https://doi.org/10.1177/1744629517708679>

- [7] Feldt K S. (2000) The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing*. 1(1): 13-21.
- [8] Findlay L., Williams A.C.D.C., Baum S. and Scior K. (2015) Caregiver experiences of supporting adults with intellectual disabilities in pain. *Journal of Applied Research in Intellectual Disability* 28: 111–120.
- [9] Gossler A., Schalamon J., Huber-Zeyringer A. and Hollwarth M.E. (2007) Gastroesophageal reflux and behavior in neurologically impaired children. *Journal of Pediatric Surgery*. 42(9):1486–1490.
- [10] Hauer J. and Houtrow A.J. (2017) Pain assessment and treatment in children with significant impairment of the Central Nervous System. *Pediatrics*. 139(6): e20171002.
- [11] Hauer J.M. and Solodiuk J.C. (2015) Gabapentin for management of recurrent pain in 22 nonverbal children with severe neurological impairment: a retrospective analysis. *Journal of Palliative Medicine*. 18(5): 453-456.
- [12] Hauer J.M., Wical B.S. and Charnas L. (2007) Gabapentin successfully manages chronic unexplained irritability in children with severe neurologic impairment. *Pediatrics*, 119(2): e519-e522.
- [13] Herr K., Coyne P.J., McCaffery M., Manworren R. and Merkel S. (2011) Pain assessment in the patient unable to self-report, position statement with clinical practice recommendations. *Pain Management Nursing* 12: 230–250.
- [14] Hoghton M., Martin G. and Chauhan U. (2012) Annual health checks for people with intellectual disabilities. *British Medical Journal*. 345, e7589.
- [15] Hunt A., Goldman A., Seers K., Crichton N., Mastroyannopoulou K., Moffat V., Oulton
- [16] K. and Brady M. (2004) Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology*. 46(1):9-18.
- [17] Koh J.L., Fanurik D., Harrison R.D., Schmitz M.L. and Norvell D. (2004) Analgesia following surgery in children with and without cognitive impairment. *Pain* 111: 239–244.
- [18] Long L.S., Ved S. and Koh J.L. (2009) Intraoperative opioid dosing in children with and without cerebral palsy. *Paediatric Anaesthesia*. 19: 513–20.
- [19] Lotan M., Ljunggren A.E., Johnsen T.B., Defrin R., Pick C.G. and Strand L.I. (2009) A modified version of the NonCommunicating Children Pain Checklist-Revised (NCCPC-R), adapted to adults with intellectual and developmental disabilities. Sensitivity to pain and internal consistency. *Journal of Pain*. 10(4): 398-407.
- [20] Malviya S., Voepel-Lewis T., Burke C., Merkel S. and 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):258-65.
- [21] Malviya S., Voepel-Lewis T., Merkel S. and Tait A. (2005) Difficult pain assessment and lack of clinician knowledge are ongoing barriers to effective pain management in children with cognitive impairment. *Acute Pain*. 1(7):27–32.
- [22] Masterson M. (2011) Understanding pain in patients with intellectual disabilities. *American Nurse Today*. 6: 1–6.
- [23] Minshawi N.F., Hurwitz S., Morriss D. and McDougale C.J. (2015) Multidisciplinary assessment and treatment of selfinjurious behavior in autism spectrum disorder and intellectual disability: integration of psychological and biological theory and approach. *Journal of Autism and Developmental Disorders*. 45(6):1541–68.
- [24] Peebles K.A. and Price T.J. (2012) Self-injurious behaviour in intellectual disability syndromes: evidence for aberrant pain



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signalling as a contributing factor. *Journal of Intellectual Disability Research*. 56(5): 441-452.

[25] Rattaz C., Dubois A., Michelon C., Viellard M., Poinso F. and Baghdadli A. (2013) How do children with autism spectrum disorders express pain? A comparison with developmentally delayed and typically developing children. *Pain*, 154, 2007–2013.

[26] Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication difficulties, Developing and assessing the disability distress assessment tool (DisDAT). *Journal of Intellectual Disability Research*. 51(4): 277-292.

[27] Solodiuk J. and Curley M.A.Q. (2003) Evidence based practice, Pain assessment in nonverbal children with severe cognitive impairments - The Individualized Numeric Rating Scale (INRS). *Journal of Pediatric Nursing*. 18:(4), 295-299.

[28] Solodiuk J.C., Scott-Sutherland J., Meyers M., Myette B., Shusterman C., Karian V.E., Harris S.K. and Curley M.A. (2010) Validation of the Individualized Numeric Rating Scale (INRS): a pain assessment tool for nonverbal children with intellectual disability. *Pain*. 150(2):231-6.

[29] Symons FJ. (2011) Self-injurious behavior in neurodevelopmental disorders: relevance of nociceptive and immune mechanisms. *Neuroscience and Biobehavioral Reviews*. 2011; 35(5):1266-1274.

[30] Taverner T. (2014) Neuropathic pain: an overview. *British Journal of Neuroscience Nursing*. 10: 116–123.

[31] Temple B., Dube´ C., McMillan D., Secco L., Kepron E., Dittberner K., Ediger J. and Vipond G. (2012) Pain in people with developmental disabilities: a scoping review. *Journal of Developmental Disabilities* 18: 73–86.

[32] Voepel-Lewis T., Malviya S. and Tait A.R. (2005) Validity of parent ratings as proxy measures of pain in children with cognitive impairment. *Pain Management Nursing*. 6(4): 168–174.

[33] World Health Organization (1996) *Treatment of Cancer Pain*. Geneva: World Health Organization.

AUTHOR

Owen Doody, PhD, MSc, BSc, RNID
Department of Nursing and Midwifery
University of Limerick,
Limerick, Ireland

Abraham J. Valkenburg, MD, PhD
Department of Anesthesiology
Erasmus University Medical Center
Rotterdam, the Netherlands



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