

Pain in Individuals with an Intellectual Disability: Scope of the Problem and Assessment Challenges



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Definition and prevalence of Intellectual Disability

Intellectual disability (ID) is characterized by significant limitations both in intellectual functioning (e.g. reasoning, learning, problem solving) and in adaptive behavior in a range of everyday social and practical skills. This disability originates before the age of 18 years [1]. Etiologies of ID include, but are not restricted to: cerebral palsy, Autism Spectrum Disorders (ASDs), Down syndrome, Fragile-X syndrome, Fetal Alcohol Spectrum Disorder (FASD), neurofibromatosis, and Prader–Willi syndrome. The prevalence rate of ID is around 1% and higher rates occur in low and middle-income countries [2].

The problem of pain in ID

It is recognized in the IASP definition of pain that the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. However, because pain is a subjective experience, it may be expressed in atypical or unfamiliar ways in those with significant cognitive and communicative difficulties. In some conditions, such as Down syndrome, pain may actually be experienced differently [3]. Consequently, pain may not be easily recognized and may go untreated [4]. Some reports suggest that individuals with ID are prescribed with significantly less analgesic medications compared to their cognitively intact peers [5]. There are also reports of increased, unnecessary death rates that could have been prevented if pain could be adequately monitored and treated on time [6].

Prevalence of pain in individuals with ID

A variety of factors increase the risk of both acute and chronic pain in people with an ID, including greater risk of accidental injury, reduced involvement in health decision-making, more physical comorbidities (such as musculoskeletal disorders in conditions that are associated with intellectual disability), reduced use of services for pain management, and age-related changes associated with greater life expectancy than in previous years of individuals with ID [7]. The prevalence of chronic pain in this population is difficult to estimate because the usual method of self-report may not be possible or reliable. According to caregiver reports, pain occurs in at least 13% of people with ID as in the general



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population [8].

Identifying pain in individuals with ID

Pain assessment among individuals with ID is challenging because pain assessment relies mostly on self-report as the “gold standard” and is often obtained by using rating-scales. However, individuals with ID may have difficulties in verbally expressing their pain when using rating scales and in understanding the necessary instructions. For example, adults with Down syndrome could recognize representations of pain location and pain affect, but they struggled with representations of pain intensity and pain quality [9]. The ability to comprehend and use self-report scales differs according to the type of scale and level of ID, with graphical scales (e.g., faces and pyramids) having the highest usability [10,11,12]. The use of such scales revealed that pain reports of individuals with ID were increased compared to controls following noxious events. The difficulties in self-report, especially among individuals with moderate and severe ID, necessitate the use of surrogate methods.

A number of observational assessment tools have been developed where caregivers observe and rate the presence of putative pain indicators, such as vocalizations, facial expressions, emotional expressions, and motor behaviors. These have been described in several useful review papers [13,14], with some evidence to support the use of tools such as Noncommunicating Children’s Pain Checklist [15]. Based on observational tools, individuals with ID were reported to present increased pain behavior following noxious events compared to baseline that was often greater than that of controls [11,16,17]. Studies based on quantitative sensory testing suggest that the sensitivity to pain may increase among individuals with ID, depending on the precise QST method and ID etiology [18,19]. Furthermore, endocrine responses and brain evoked potentials recorded during noxious events reveal that individuals with ID present delayed, yet increased responses, compared to controls [20,21], corroborating the behavioral findings. Thus, individuals with ID are equally as sensitive to pain as their cognitively intact peers or may even be more sensitive.

Conclusion

Pain occurs with at least the same frequency in people with ID, as in the general population. Identifying and measuring pain among individuals with ID is clearly more challenging than doing so among individuals who are cognitively intact, and may require the use of both direct and indirect methods. However, considering the risk of under-treatment of pain in this population, people with ID should be carefully and routinely monitored for any changes in their behavior and/or mood that may indicate the presence of pain, in order to institute appropriate treatment and prevent unnecessary suffering.

REFERENCES

- [1] <http://aaid.org/intellectual-disability/definition>. Accessed 31 October, 2018.
- [2] Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: A meta-analysis of population-based studies. *Res Dev Disabil*. 2011 Mar-Apr;32(2):419-36. doi: 10.1016/j.ridd.2010.12.018.
- [3] McGuire BE, Defrin R. Pain perception in people with Down syndrome: A synthesis of clinical and experimental research.



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Front Behav Neurosci 2015; 9:194.

- [4] McGuire BE, Daly P, Smyth F. Chronic pain among people with an intellectual disability: Under-recognised and under-treated? *J Intellect Disabil Res* 2010;54:240-245.
- [5] Boerlage AA, Valkenburg AJ, Scherder EJ, Steenhof G, Effing P, Tibboel D, van Dijk M. Prevalence of pain in institutionalized adults with intellectual disabilities: a cross-sectional approach. *Res Dev Disabil* 2013;34:2399–406.
- [6] Mencap. *Death by indifference*. London: Mencap; 2013.
- [7] McGuire BE, Kennedy S. Pain in people with an intellectual disability. *Curr Opin Psych* 2013;26:270-275.
- [8] Walsh M, Morrison TM, McGuire BE. Chronic pain in adults with an intellectual disability: Prevalence, impact and health service utilization based on caregiver report. *Pain* 2011;152:1951-1957.
- [9] de Knecht NC, Lobbezoo F, Schuengel C, Evenhuis HM, Scherder EJA. Self-Reporting Tool On Pain in People with Intellectual Disabilities (STOP-ID!): A usability study, *Augment Alternat Communic*. 2016;32:1-11.
- [10] Defrin R, Lotan M, Pick CG. The evaluation of acute pain in individuals with cognitive impairment: A differential effect of the level of impairment. *Pain* 2006;124:312–20.
- [11] Benromano T, Pick CG, Merick R, Defrin R. Physiological and behavioral responses to calibrated noxious stimuli among individuals with cerebral palsy and intellectual disability. *Pain Med*. 2017;18:441-453.
- [12] de Knecht NC, Lobbezoo F, Schuengel C, Evenhuis HM, Scherder EJA. Self-reported presence and experience of pain in adults with Down Syndrome. *Pain Med* 2017;18:1247-1263.
- [13] Herr K, Coyne PJ, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: Position Statement with Clinical Practice Recommendations. *Pain Manage Nurs* 2011;12:230-250.
- [14] De Knecht NC, Pieper MJC, Lobbezoo F, Schuengel C, Evenhuis HM, Passchier J, Scherder EJA. Behavioural pain indicators in people with intellectual disabilities: A systematic review. *J. Pain*. 2013;14:885–896.
- [15] Breau LM, McGrath PJ, Camfield C, Rosmus C, Finley GA. Preliminary validation of an observational pain checklist for persons with cognitive impairments and inability to communicate verbally. *Devel Med Child Neurol* 2000;42:609–616.
- [16] Breau LM, Burkitt C. Assessing pain in children with intellectual disabilities. *Pain Res Manag* 2009;14:116-20.
- [17] Shinde SK, Danov S, Chen CC, Clary J, Harper V, Bodfish JW, Symons FJ. Convergent validity evidence for the Pain and Discomfort Scale (Pads) for pain assessment among adults with intellectual disability. *Clin J Pain* 2014;30:536-43.
- [18] Defrin R, Pick CG, Peretz C, Carmeli E. A quantitative somatosensory testing of pain threshold in individuals with mental retardation. *Pain* 2004;108:58–66.
- [19] Valkenburg AJ, Tibboel D, van Dijk M. Pain sensitivity of children with Down syndrome and their siblings: quantitative sensory testing versus parental reports. *Develop Med Child Neurol* 2015;57:1049-55.
- [20] Aguilar Cordero MJ, Mur Villar N, García García I. Evaluation of pain in healthy newborns and in newborns with developmental problems (down syndrome). *Pain Manag Nurs* 2015;16:267-72.
- [21] Benromano T, Pick CG, Granovsky Y, Defrin R. Increased evoked potentials and behavioral indices in response to pain among individuals with intellectual disability. *Pain Med* 2017;18:1715-1730.

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