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# Pain Assessment: A Relevant Concern to Increase Quality of Life in People with Intellectual Disabilities

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## Abstract

**Background:** Pain is a serious concern in people with intellectual disabilities. They may experience many painful situations because of the lack of management of common medical problems, because of their disability-related health state and because of age-related illnesses.

**Literature findings:** Validated tools are now available to assess pain with accuracy. People with mild and moderate intellectual disabilities are able to understand pain and they know coping strategies. Most treatments of pain relief, including psychological methods are appropriate.

**Conclusion:** There is still room for development in clinical training and to change attitudes to improve pain management in this population.

**Keywords:** Pain assessment; Intellectual disabilities; Pain coping

## Introduction

It is well known that pain is a complex phenomenon. Pain implies a dynamic interaction between several components from different levels. Pain is usually described in four components, adding behavioral reaction to pain to the three dimensions of pain early proposed by Ronald Melzack and Kenneth Casey [1] the sensory-discriminative or nociceptive message, the cognitive process of pain experience and the pain induced emotional state (unpleasantness). However to understand subjective pain experience, we must pay attention to the individual characteristics, the relational life, medical experiences and socio-cultural background.

Since the last decade, many works and data have improved the assessment and management of pain in general population. The pain definition of the International Association for the Study of Pain (IASP) has introduced the idea that pain could also be an unobservable damage and could be described in such damage. This was an important advance in pain assessment area but it implies that people are able to talk about their pain experiences. Vulnerable and non-communicative people remain left behind and the IASP must have added that “the inability to communicate verbally does not negate the possibility that an individual is experiencing pain” [2].

## What we know about pain in people with intellectual disabilities

Because of the communication limitations, pain is difficult to identify in people with intellectual disabilities [3]. Healthcare providers still seem to have prejudices about the relevance and efficacy of pain treatments in this population [4]. Even when the pain is acknowledged, they receive fewer analgesics than the general population or no analgesics at all [5-7].

Moreover, this population forms a heterogeneous group varying in the etiology, nature and severity of the impairment. Therefore, the prevalence of pain remains uncertain. People with intellectual disabilities experience the same range of pain as the general population. But some common medical problems can involve more pain and a health state worsening when pain is not quickly detected [8]. They also experience particular pain related to their specific condition; ill-fitting braces or wheelchair, painful procedures linked to the disability, physical therapy treatments [9]. Surgical and gastrointestinal procedures are also painful situations that are commonly experienced by people with intellectual disabilities [10,11]. Children with self-injurious behaviors show pain reactions similar to those of other children. The presence of chronic pain may be related to the location and the frequency of self-mutilation [12]. It has been suggested that self-mutilation can be a consequence of pain in people with a severe intellectual disabilities and it may be caused by their inability to communicate [13]. Pain can be detected with the non-verbal expression in adults with self-injurious behavior. This negates the idea of insensitivity to pain in this population [14].

People with intellectual disabilities have a higher risk to develop age-related illnesses including cancer because their life span is increased. But identifying cancer signs and symptoms in this group remains a challenge for relatives and health-providers. Health promotion and cancer prevention in people with intellectual disabilities are not optimal [15] when identifying signs and symptoms is a challenge to an early diagnosis. In France, between 100,000 and 400,000 people with intellectual disabilities develop cancer during their lifetime, and 7,000 new cases are expected each year. Compared to the general population, children with Down's syndrome are at high risk of leukemia although in adults with intellectual disabilities the risk of solid tumors is lower [16,17]. There is a high prevalence of stomach cancer, gastric ulcer and lymphoma in this population [18]. Pain is the most prevalent symptom experienced by children with cancer. Pain is usually rated as moderate to severe and often distressing in typical

children [19]. Cancer-related pain and treatment-related causes of pain are multi-dimensional phenomenon. A multi-disciplinary pain management is recommended and international guidelines advocate that pain should be assessed with validated tools. Child and his family should be understood in their singularity included the inter-patient variability in analgesic response. It must also be the case in people with intellectual disabilities.

### **How to assess pain?**

Research has been slow to develop specific assessment tools for people with intellectual disabilities, for a review see [20,21]. Now for assessing chronic and acute pain in children with severe disabilities validated scales are available: the Pediatric Pain Profile [22] and the Non-Communicating Children Pain Checklist-Revised (NCCPC-R) [23]. Validated versions of this tool are now available in several languages (German, Swedish, and French).

For the adult population, a modified scale based on the NCCPC was introduced by Lotan and colleagues [24]. The Non-Communicating Adults Pain Checklist (NCAPC) is an 18-item scale with sub-categories of pain behavior. However studies on the assessment of pain in people with mild to moderate intellectual disability are still rare. The self-report of pain still remains the best way to assess pain when people are able to communicate. But it implies that health-provider or relatives have access to current knowledge about the pain expression skills in this population to provide self-assessment when required. Children and adolescents with mild to moderate intellectual disabilities are able to assess self-reported pain or the pain experienced by a character in colored pictures [25]. They can use validated tools, Visual Analog Scale and Faces Pain Scale-Revised [26] and children with Down's syndrome use the FPS-R with the same accuracy than children with typical development [27]. In these studies, children with mild to moderate intellectual disabilities were able to describe pain with 6 or more words according to the situation (fall, burn and injection). Their verbal skills were equal to the skills of typical children when matched to the mental age. But we must take into account that their cognitive function and regulation abilities could be reduced when they actually experience pain [28,29]. We must keep in mind that the main objective is not to get an accurate description of their painful experience. We need sufficiently stable and relevant information to make decisions about treatment. Although all aspects of painful phenomena are important to assess, the parameter most commonly used is the pain intensity, as indicated by the recommendations of the Ped-IMMPACT (Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials Consensus Group) [30]. In most clinical settings, the distinction between no pain, mild pain and moderate to severe pain is good enough for daily practice.

### **What can we do to manage pain and promote coping?**

Most experts in the area suggest that almost all treatments available for pain relief can be used with people with intellectual disabilities, provided that the treatment is compatible with their mental and physical conditions [5,6]. Multi-disciplinary care is highly recommended to increase the synergistic effects of several treatment options (pharmacological and non-pharmacological). Behavioral approaches of psychological pain management techniques are often used with young children because they require different cognitive levels. Relaxation or breathing techniques could be appropriate for people with intellectual disabilities as they have been used with typical developed children as young as 5 or 6 years. Distraction is usually used

to manage procedural pain in children and it is more effective with younger [31,32]. It could be useful for people with intellectual disabilities but it is more helpful when the person is performing an activity (eg. playing with a toy, blowing bubbles). The capacity of children and adolescents with mild intellectual disability to benefit from hypno-analgesia protocols was investigated in one study [33]. Most techniques used with 6- to 12-year-old children (think of a favorite place, think of a hobby, listen to a story) involve mental imagery and autobiographical memory. Results of this study indicated that adolescents were able to generate mental images when listen a story. Auto-biographical memory can be used for evoking specific personal events. Then, hypno-analgesia should be considered accessible to people with intellectual disabilities who have a mental age >4 years, as it is in young typically developing children. In children, self-hypnosis can reduce abdominal pain [34,35] and headache [36,37]. Guided imagery has been used for post-operative pain in typically developing children over the age of 7 years [38], and recurrent abdominal pain over the age of 5 years [39]. Training is necessary for children with intellectual disabilities; however, those with only mild levels of disability may be able to learn scripts that they could use independently afterward [40]. In a semi-structured interview, 28 adolescents aged 13 to 17 years with mild to moderate intellectual disabilities (IQ from 45 through 70, mental age from 4 through 12 years-old) discussed their knowledge about pain coping strategies [41]. Results indicate that adolescents with intellectual disabilities expressed pain and reported coping strategies appropriately. The strategies presented were mainly focused on the problem (Problem-solving and Seeking Social Support). The use of social-support strategy may be an appropriate response because individuals with intellectual disabilities cannot deal with the pain on their own. These problem-focused strategies are likely to reduce anxiety when the situation is controllable, but may amplify it otherwise. Overall, adolescents with intellectual disabilities put into words appropriately their need to be with a person capable of controlling the situation.

Emotion-focused strategies are rarely expressed because they involve cognitive processes (cognitive self-instruction), or emotional regulation control (distraction). These strategies reduce the anxiety caused by pain when the event is uncontrollable [42]. But if adolescents with intellectual disabilities rarely use this strategy, it may have important implications for iatrogenic pain. Procedural pains are uncontrollable painful events for the patient. Individual resources of children and adolescents with intellectual disabilities are probably not sufficient to raise a distraction strategy on their own for example. The presence of a relative seems necessary for an appropriate guidance.

### **Conclusion**

After being a long-time excluded from works about pain assessment and pain management, people with intellectual disabilities are now recognized as sensitive to pain when pain management is considered as a fundamental right. Their abilities were under-estimated because of our wrong representations. Now health-providers and caregivers should undergo training in pain assessment and pain management protocols to reduce misconceptions and ensure that pain will not remain an obstacle to the development and well-being of these people.

## Compliance with Ethical Standards

### Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent: Informed consent was obtained from all individual participants included in studies cited.

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