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Pain in Adults with Down Syndrome

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Historical Overview

Understanding pain in individuals with Down syndrome is challenging and that understanding has changed over time. Families often report that an ill or injured individual with Down syndrome shows no pain or less pain than would be expected. For many years, partly due to these reports, it was believed that individuals with Down syndrome had a higher pain tolerance and/or did not perceive pain. This belief was supported by a 1999 study[1] that found that a Down syndrome mouse model had reduced responsiveness to painful stimuli. However, additional studies have changed this understanding. More recent, well-designed studies indicate individuals with Down syndrome may actually have reduced pain tolerance or increased pain perception.[2] Individuals with Down syndrome can experience acute pain and often have chronic pain.[3,4] However, while individuals with Down syndrome do experience pain, the conduction of pain signals, the central processing of pain, and the response to pain may all be slower or delayed.

Individuals with Down syndrome may also have difficulty localizing their pain.[5] However, once the pain is recognized, there can be a magnified pain response.[4] In another study, while some adults with Down syndrome did not report their painful physical conditions at all, those who did report their pain were more sensitive to pain than individuals without Down syndrome.[6] Other studies have tracked pain medications such as opioids. In studies regarding the use of opioids after heart surgery[7,8] and other surgeries[9] in children, the dosing of opioids required for pain control did not differ between those with and without Down syndrome.

Other factors that can impact pain in individuals with Down syndrome include cognitive disabilities and aging. Individuals with Down syndrome who had lower memory scores were more likely to report the presence of pain.[10] As individuals with Down syndrome age, there is a decrease in both acetylcholine and cholinergic neurons. This may increase the sensitivity to the emotional-affective component of pain, causing older individuals with Down syndrome to report more severe pain than those without Down syndrome.[4]

Clinical experience suggests that co-occurring mental and physical health problems may also contribute to increased pain perception. Depression and anxiety[11] and chronic pain itself[12] increase pain perception in individuals without Down syndrome and clinically also appear to increase pain perception in individuals with Down syndrome. It is not uncommon for those with Down syndrome to repetitively comment about their pain or their pain-related anxieties. This can lead to difficulties understanding what the individual with Down syndrome is experienc-

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ing versus what they recall or report about what they are experiencing.

Reaction time to pain can contribute to misinterpretation of pain perception. In a study evaluating responses to heat pain, parents' assessment was that children with Down syndrome were less sensitive to heat pain than their siblings without Down syndrome. However, this observation was biased by differences in reaction time. When accounting for reaction time, the children with Down syndrome were actually more sensitive. Most of the children with Down syndrome could not adequately self-report pain.[13]

Instead of providing qualitative and quantitative descriptions of their pain,[3] individuals with Down syndrome may "report" pain through emotional and social responses.[14] For example, pain symptoms are a common manifestation of rheumatological disorders which, in turn, are more common in those with Down syndrome due to increased autoimmune reactivity. However, individuals with these disorders often present with behavioral changes rather than complaints of joint pain, making diagnosis difficult. Hernias are painful and are more common in individuals with Down syndrome, but do not manifest with the same pain symptoms as expected.

Assessment and Treatment Considerations

Careful assessment of pain in individuals with Down syndrome is critical for pain management[15] and can be achieved by looking for key signs and symptoms.[4]

Facial expressions may be a good indicator of pain for people with and without cognitive impairment. Other reliable symptoms include vocal changes (moaning and crying), social changes (unwillingness to participate in normal activities or complete daily tasks), and physiological changes (shivering, becoming pale, and muscle tension). To assist adults with Down syndrome in self-reporting pain, one study found that more participants understood a facial-affective reporting scale than a numeric scale.[15]

Example of facial-affective reporting scale

In some individuals with Down syndrome, the painful condition may present with a change in behavior or a decrease in function. For example, osteoarthritis of the hip may present with decreased ability or desire to walk rather than with a complaint of pain. Pain may not only cause a change in behavior but may impair mental health, and mental and physical health problems may impact pain perception.

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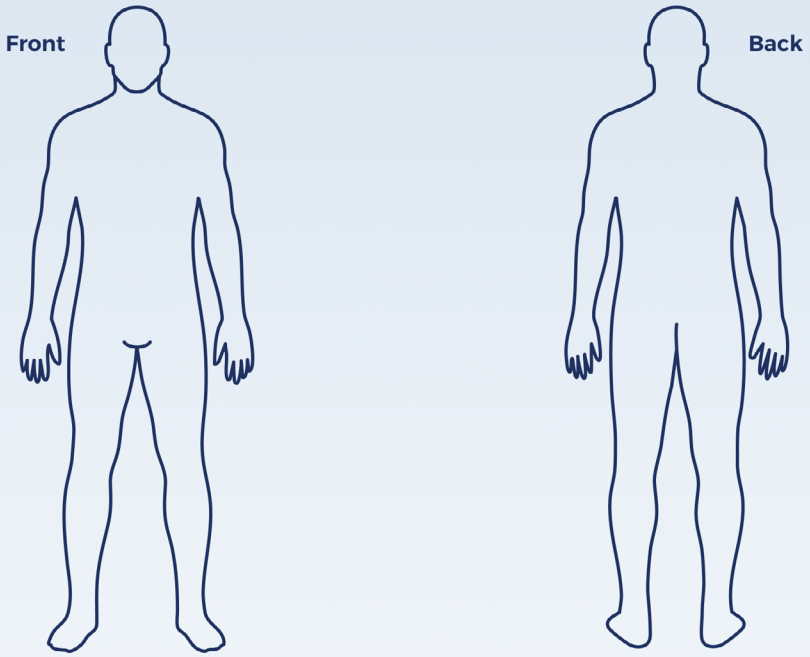
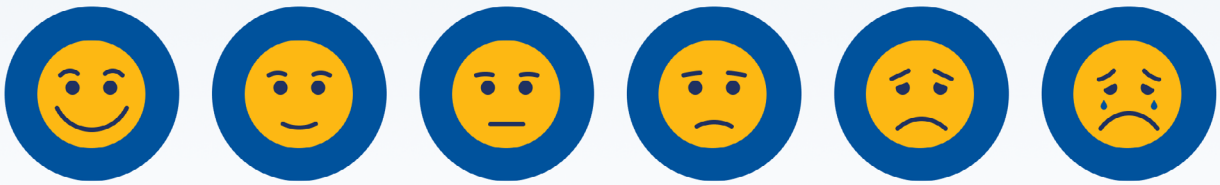
Self-Advocacy at Medical Appointments

Where are my symptoms?



How much pain?



0	2	4	6	8	10
No Pain	Hurts a Little Bit	Hurts a Little More	Hurts Even More	Hurts a lot	Worst Pain

It is important to account for co-occurring conditions and their potential impact on pain management.[16] For example, obstructive sleep apnea and chronic upper airway obstruction are more common in individuals with Down syndrome. In children with Down syndrome who were post-operative for congenital heart surgery, respiratory complications and infections were more frequent, and sensitivity to opioids in those with obstructive sleep apnea was a contributing factor.[17,18]

There are limited data regarding pain management in individuals with Down syndrome. For musculoskeletal pain, physical and occupational therapy can be valuable parts of the treatment plan. One case study described physical therapy as a successful treatment for a man with Down syndrome with chronic back pain.[19] As noted above, the dosing need for morphine, at least in children, has been shown to be similar between individuals with and without Down syndrome. However, the potential for complications, such as infections at the same dose as noted above, is greater in children with Down syndrome.

In summary, careful consideration of co-occurring conditions, reporting biases, psychological manifestations, and behavioral changes is key to assessing pain and recommending appropriate pain management in individuals with Down syndrome.

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