



The Pain Experienced by Children and Adolescents with Osteogenesis Imperfecta



Hôpitaux Shriners
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Introduction

Shriners Hospitals for Children houses cutting-edge research and state-of-the-art treatments for orthopaedic disorders, such as Osteogenesis Imperfecta. Our diverse team of experts is dedicated to improve the lives of children by providing outstanding care and support to patients and their families. Our current research efforts target, among other aspects, the pain experienced by children and adolescents with OI.

What is pain?

Pain is a complex multidimensional subjective concept that researchers have organized into three main dimensions:

(1) sensory, (2) affective, and (3) cognitive.

These dimensions are linked and allow patients and researchers to understand pain as experienced by OI patients.

Pain can be described in terms of **duration**:

Acute pain can be viewed as a warning sign to your body to notify it of actual tissue damage. The pain is only endured for a limited time.

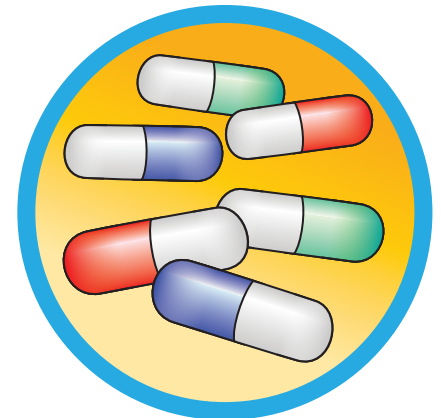
Chronic pain may arise in the absence of injury or disease and persists beyond 3 months after healing.



Pain is present and problematic



Issues with pain assessment



Issues with pain management

What Have We Found?

Our research team has analyzed the findings of 19 studies that have examined at least one dimension of the pain experienced by children and adolescents with OI.

There is a lack of comprehensive, multidimensional pain assessments.

The majority of the studies we have reviewed assess only one – at most two – dimension of pain. There is a preference for examining sensory or cognitive pain dimensions. This means that there is a lack of literature on the affective dimension of pain in the OI population and it needs more attention.

There is no standard method for assessing pain.

There are no clinical guidelines outlining how to carry out a pain assessment in the OI population. Furthermore, in the case of children with OI, parents are often the ones reporting on the pain experienced by their children. Many different tools and types of interviews were used across studies to assess pain. There is also an inconsistency in the different times when pain is assessed (pre- versus post-treatment).

There are many difficulties in assessing pain in younger children.

In several studies, parents reported having trouble in completing pain reports for their children. The tools to assess pain were not always age-appropriate for children with OI.

The main conclusions from the studies we have reviewed are:

- pain is present and problematic
- there are many issues in pain assessment methods

Sensory pain

Pain is mild, yet complex in quality and localization. Despite having used different tools to assess pain in the OI population, all studies have concluded that pain was present to varying degrees of intensity and at different locations. Pain can be short-lived (acute) or mild pain may persist for several months after healing of bone fractures.

Pain can be experienced as the result of bone fractures and musculoskeletal deformities. Children and adolescents are more vulnerable to fractures and injuries as their bones are still growing and maturing. Patients with OI most often report experiencing moderate-to-severe pain at the proximity of joints, such as the anterior and posterior hip regions, shoulders, and ankles.

Affective pain

Describing fracture and non-fracture pain. Children and adolescents rarely use affective words to describe their pain experiences. Instead, they use evaluative words, such as “throbbing” and “uncomfortable” for fracture pain and “annoying” and “aching” for non-fracture pain.

Parents find it difficult to see their children in pain. This was especially true when they had OI themselves and felt guilty for passing on the gene.

Cognitive pain

Pain interferes with daily life and functioning. Children and adolescents with OI experience mobility restrictions, sleep disturbances, a decreased involvement in self-care, school, work, and leisurely activities, and a reduced quality of life.