



The Pain Experienced by Adults with Osteogenesis Imperfecta



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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 young adults by providing outstanding care and support to patients and their families. Our current research efforts target, among other aspects, the pain experienced by young adults 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.



What Have We Found?

We have investigated the findings of 14 studies and 7 case reports, which have assessed the pain experienced in adults with OI as a secondary outcome.

Adults with OI experience less bone fractures.

Adults have stronger and mature bones, making them less susceptible to bone fractures. Thus, the pain comes from previous fractures and skeletal deformities, rather than new injuries.

There are methodological limitations in assessing pain in adults with OI.

As many as 10 different tools to assess pain were used across studies. These tools lack validity, reliability, and assessed a maximum of two pain dimensions.

There is a preference for brief pain assessments in studies.

The tools examining pain were quicker and easier to use. Often, studies examined pain as a secondary outcome, so the tools were not pain-specific, nor comprehensive.

The low-to-moderate quality of pain research.

Many important aspects were missing from studies. For example, data collection methods were not well supported. Furthermore, since OI is a rare disorder, most participants had OI type I, making results not generalizable for the entire OI population.

A Summary of the Experiences of Adults with OI Related to Pain

Mild chronic pain persists despite surgical, pharmacological, or non-pharmacological interventions.

Mild chronic residual pain persists at least three years after intervention. Majority of the case reports reviewed claim that adults experience chronic pain for several months, despite interventions.

Current interventions provide limited relief.

Adult patients that have used conventional pharmacological treatments (analgesics – tramadol) and non-pharmacological approaches (bracing, modifying activity level) reported feeling very little pain relief after treatment.

Past fractures and skeletal deformities may trigger the start of chronic pain in adulthood.

Chronic back pain. Across all studies, chronic back pain was the most commonly reported among adults with OI.

Back pain is not linked to injury. The pain is due to back deformities or vertebral compressions.

Pregnant women experience severe pain. As revealed in clinical and radiological evidence, the severe pain experienced by pregnant women with OI was due to vertebral compressions.

Comparing the Pain Experienced in Children and Adults with OI.

Fracture incidence rate. Since adult's bones have stopped growing and are mature, they are much less vulnerable to bone fractures.

Pain intensity and location varies. Just like children with OI, adults may experience pain to varying degrees of intensity and in different locations throughout the body.

Pain interferes with daily activities. Adults are also limited in their everyday life due to the pain experienced in relation to OI, which decreases their quality of life, especially in the physical domain.

Emotional impact of pain. Compared to children, there is a lack of literature that investigates the emotional impact of pain on adults with OI.

Recognizing their emotional influence. Both children and adults with OI recognize that their emotions can impact others and want to reduce their caregivers' frustrations as they cannot reduce their pain.

What's next in adult-related pain research?

Long-Term Studies

Studies for OI pain should be done over a prolonged period of time as pain is a long-term symptom and its impact has different repercussions across one's life.

Capturing Real-Time Data

Methods that capture real-time data, such as pain diaries, are needed to track acute pain and chronic pain.

Pain Assessments

Studies should follow the appropriate guideline for pain assessments, which examines all three dimensions of pain. For acute pain, a different guideline is available.

If you have questions or concerns in regards to your own pain experiences, talk to your doctor, nurse, physiotherapist or occupational therapist. You can also connect with OI communities, such as:

- OI Foundation (www.oif.org)
- Brittle Bone Society (www.brittlebone.org)
- OI Australia (www.oiaustralia.org)
- OI Federation of Europe (www.oife.org)
- Care 4 Brittle Bones Foundation (www.care4brittlebones.org)

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