

# “O.I. Wish Orthopaedic Surgeons Had Better Strategies to Help with . . .” Results of a Patient- and Parent-Based Survey

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## Abstract:

**Purpose:** Osteogenesis Imperfecta (OI) is a rare genetic disorder caused by a mutation in type I collagen, characterized by bone fragility and deformity. Current treatment methods aim to decrease fracture rates and improve bone density and mobility. Recent orthopaedic surgery research has focused primarily on fracture fixation and outcomes of intramedullary rodding procedures. While surgical techniques continue to evolve, recent trends are focusing on patient-reported outcomes measures (PROMs).

**Methods:** The authors created a 12-question survey in conjunction with the OI Foundation (OIF). The survey was titled, “O.I. Wish Orthopaedic Surgeons Had Better Strategies to Help with . . .” and sought to gather information regarding the aspects of orthopaedic care OI patients and families would most like to see improved. The survey was electronically administered to members of the OIF and the OI Federation Europe (OIFE). 341 individuals completed the survey. The final question of the survey indicated, “Please include any comments you

would like to pass along.” To report on the responses to this question, the answers were grouped into themes.

**Results:** Many of the survey questions we asked were related to childhood orthopaedic surgical interventions. However, 75% of the respondents who answered the age question (254/335) were adults. Regarding surgical intervention for long bones, 16% of respondents recall that they have been told that they could not have surgery because they were too young. Of the 16%, 37.8% were told that <5 years was too young, 13.4% <4 years was too young, and 48.8% <3 years of age was too young for surgical intervention for fractures or deformity. Nearly 22% of respondents were told that their bones were too small to have intramedullary fixation. For the free-text response, the most frequent comments were to focus future research on OI adults (14.9%), focus on pain management (11.8%), and focus on improving rodding surgery techniques (11.3%).

**Conclusion:** The information collected helps reveal trends of the typical orthopaedic advice patients and

families with OI are receiving. The patient and family responses help elucidate the topics requiring focus for the improvement of OI orthopaedic care. Patient concerns and insights most powerfully drive the research questions we should ask to advance the orthopaedic care of OI patients.

**Significance:** This survey highlights the variability in OI treatment for patients of all ages. The responses guide

future OI research with a focus on patient-reported areas for improvement of care.

**Level of Evidence:** Expert Opinion-Level V

**FDA:** FDA clearance is not applicable.

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