

Crossing A New Bridge: Understanding the Abyss of Transition of Care for Teenagers and Young Adults with Osteogenesis Imperfecta

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Disclosures

- Consultant: Orthopediatrics, Angitia
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Background – Osteogenesis Imperfecta (OI)

- Genetic condition – inadequately or improperly synthesized type I collagen
- Common orthopaedic manifestations - long bone deformities, fractures and scoliosis

Tremendous range in severity



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Background – Osteogenesis Imperfecta (OI)

- Cohesive multidisciplinary care is essential
- As patients age, they are often unable to continue following up at pediatric centers experienced in treating OI
- **Transition of care for young adults with OI to adult hospitals is difficult and a challenge to continuing high quality care**



Purpose

- Investigate the types of orthopaedic surgeries required in young adult OI patients
- Report the outcomes of surgery in this age group compared to a matched pediatric cohort

Methods

- Single-center, retrospective
- Ages 18-35 years
- Procedures 2018-2024
- Minimum 1 year follow-up
- Adult patients were matched to a pediatric patient <18 years
 - Matching based on bone segment and Ol severity
- Outcomes (complications and reoperations) compared between adult group and pediatric group
- Chi square test

Results

- 21 adult OI patients underwent 29 surgeries
- Mean ages:
 - Adult – 22 years
 - Pediatric – 13 years
- Adult surgeries:
 - 74% revision procedures
 - 66% for deformity, nonunion or pain
 - 34% for treatment of acute or subacute fractures

Surgeries	Number
Humerus rodding	11
Femur rodding	7
Tibia rodding	4
Removal of hardware	3
Olecranon ORIF	1
Femoral neck fixation	1
Greater trochanter resection	1
Rod back-up	1

Results

Complication	Adult group	Pediatric group
Nonunion	4	0
Delayed union	2	0
Nonunion and rod prominence	1	0
Rod migration and prominence	1	3
Transfixion pin prominence	1	0
Peri-implant fracture	1	1
Elbow stiffness	1	0
Chronic pain	1	0
Transient radial nerve palsy	0	1
Peri-implant fracture and nonunion	0	1

- No difference in reoperations between the adult and pediatric group ($p = 0.24$)
- Significantly higher incidence of complications in the adult group (57%) versus pediatric group (26%) ($p = 0.04$)
- Significantly higher incidence of nonunion or delayed union in the adult group (30%) versus pediatric group (4%) ($p = 0.04$)

Case Example



19 year-old young woman with OI with a right ulna fracture (location and pattern likely related to bisphosphonate use)



4 months postoperatively with a nonunion and broken 2.6mm non-telescopic rod



4 month post-revision with a 3.2mm non-telescopic rod and supplemental plate fixation and bone grafting



Conclusions

- **Young adults with Ol** exhibit a high incidence of complications compared to pediatric patients
 - **Nonunion**
 - **Delayed union**
- Ol patients continue to require surgical interventions into adulthood
- Highlights need to **optimize and expand care for Ol patients transitioning to adulthood**

Thank you



OI Team - OI Awareness Week 2026