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Osteogenesis Imperfecta (OI) Transfer Summary Tool May be Used to Facilitate the Transfer of OI Patients from the Pediatric to Adult Healthcare Systems

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COMMENTARY ON

Carrier J, Siedlikowski M, Chougui K, Plourde S-A, Mercier C, Thevasagayam G, et al. A best practice initiative to optimize transfer of young adults with osteogenesis imperfecta from child to adult healthcare services. Clin Nurse Spec. 2018 Nov/Dec;32(6):323-35. Available from: https://pubmed.ncbi.nlm.nih.gov/30299335/ doi: 10.1097/NUR.0000000000000407

SUMMARY

What happens once youth and young adults with osteogenesis imperfecta (OI) are transferred from the pediatric to the adult healthcare system? To facilitate this process, an interprofessional task force was convened to conduct a knowledge synthesis study, which entailed reviewing the literature, developing guidelines and creating a transfer tool. This study and later research indicate the need for the creation of a transitional care program tailored to the special needs of OI patients and their families.

KEYWORDS

Osteogenesis Imperfecta, Transfer tool, Transition, Health care system

1 | IMPLICATIONS FOR PRACTICE AND RESEARCH

- Integrate the use of the OI Transfer Tool to facilitate the transfer of youth and young adults from the pediatric to the adult care health care systems.
- Create a transitional care program to assist patients and families in the transition process and provide adult healthcare practitioners with the key information and tools to care for youth and young adults.

2 | CONTEXT

Similar to other young adults with a chronic illness, (2) the transition to the adult healthcare system is complex for youth and young adults with OI who have expressed concerns with their transition. (3) The multi-faceted nature of their rare disease, paucity of evidence of research, and absence of tools to facilitate the transfer further compound the issue. (4) This places these patients at heighten risk for complications. (4) Hence, an interprofessional Task Force with international expertise in OI including patient representation was convened to address the notable gap in the transfer of youth and young adults with OI to the adult health care system.

3 | METHODS

Carrier et al. led an interprofessional expert task force at a university-affiliated hospital with international expertise in OI to: 1) review the literature, 2) develop guidelines, and 3) create a tool to facilitate the transfer of youth and young adults with OI from the pediatric to the adult health care systems. Six electronic databases and varying grey sources—literature not published through traditional means—from the US and Canada were searched. Further contact was made with transition program coordinators in Canada or the United States to retrieve published and unpublished transfer tools. All data were extracted, descriptively summarized, and appraised by the Task Force who had no conflicts of interest.

4 | FINDINGS

Carrier et al (2018) reported a paucity of research in this area. After a comprehensive literature review, only 7 studies were identified. Eight transfer tools were retrieved and descriptively summarized. Together, with the paucity of evidence, the Task Force relied on their interprofessional expertise in OI to create the "OI Transfer Summary" tool. This tool comprised 11 sections summarizing the care given in the pediatric health care system, and the follow-up requirements. Therefore, a whole overview of the patient is presented to the new caregivers and offers a starting point for the provision of individualized primary care in the adult health care system.

5 | COMMENTARY

Transferring from pediatric to adult systems may be a challenging event in lives of youth and young adults with OI. (3) To date, clinicians and researchers support the creation of a transitional care program to guide youth and young adults with OI and their families to the adult health system. (3) This program would furthermore support the clinicians in the adult sector to receive the transfer and attend to their health care needs. (3) The OI Transfer Summary tool, along other existing OI passports, (5, 6) may be incorporated into such a program to offer personalized care and optimize communication between transfers. (7, 8) Derived from existing transitional care programs, (9, 10) this program may include emphasis on familiarizing patients with the adult system, such as preparing for adult care provider appointments, visiting clinics and precocious preparation, and including peer mentorship. (3, 8, 9, 11) The OI Transfer Tool would serve as a gateway to facilitate the discussion of these items as the patient completes it in collaboration with the interprofessional team. Moreover, the tool may help prompt educating patients on their responsibilities and assessing for their transfers readiness, (12) which collectively may ease the transition process. However, further research is needed as this tool has not yet been evaluated in practice, and the outcomes of using such a tool are unknown. Nevertheless, ideal practices suggest that bridging the transition process and optimizing the knowledge gap among adult healthcare professionals, a transfer coordinator, and integration of technology could be used to educate and facilitate their access to resources in person and online. (13)

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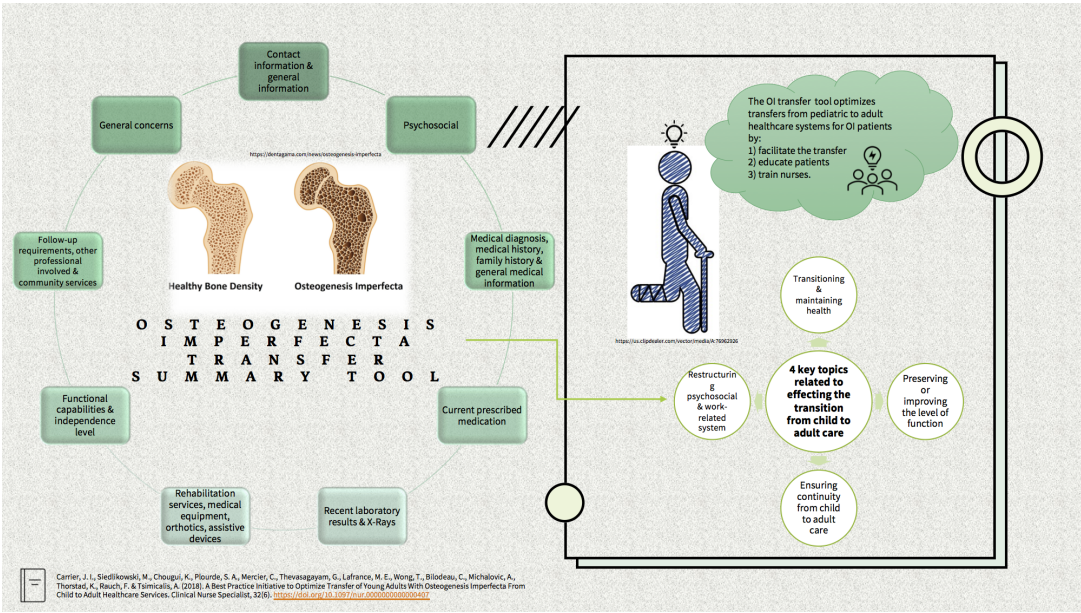

FIGURE 1 An Infographic Summary of the Key Components of the OI Transfer Summary Tool and Objectives Guiding its Creation (1).

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