Exploring the Self-Management Needs of Transitioning Young Adults with Osteogenesis Imperfecta into Adult Primary Care Services:

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Background

The Shriners Hospitals for Children-Canada (SHC), located in Montreal, Quebec, serves the largest population of children and youth with osteogenesis imperfecta (OI) in North America. OI is a rare genetic disease associated with bone fragility and decreased bone mass.

SHC is seeking to improve the transition program and associated services provided to the OI population by:

A. Creating a partnership with an adult primary care setting;
B. Providing OI training to the Nurse Practitioners at the adult primary care setting and;
C. Improving the self-management skills of their transitioning OI population.

Aim

The aim of this descriptive qualitative study is to explore the current and future self-management needs of transitioning young adults with OI as they transition from pediatric to adult primary care.

Methodology

After receiving ethical approval, a qualitative descriptive study is being conducted to explore the current and future self-management needs of transitioning young adults with OI.

5 to 20 eligible participants are being conveniently sampled.

Participants are participating in two semi-structured interviews about their self-management needs, before and after they transition into adult primary care.

Participants create a genogram and eco-map, with the interviewer, to highlight their resources, social networks, and sources of support.

A qualitative descriptive analysis is being used for analysis.

Results

To date, 7 interviews with 4 participants have been conducted.

Sample Characteristics

- OI type III (n=2), OI type IV (n=2)
- 2 male and 2 female
- Median age: 27.75 (±5.19) years old
- Age range: 23 to 34 years

Themes

1. No one will ever be ready to leave the Shriners

Participants have strong emotional connections with SHC. They attributed their present quality of life on the treatment they received as children at SHC. Leaving SHC was difficult. They entered an adult system with no one designated to care for their OI. Attempts to navigate the adult system resulted in them “feeling lost in the jungle”.

2. Have demonstrated a capacity to self-manage

Participants described the importance of living a “normal” life, which meant being as independent as possible. They reported ways in which they had overcome environmental barriers and self-managed their symptoms.

3. Need for healthcare professionals knowledgeable about OI in the adult system

The lack of knowledge about OI in the adult health care system was a barrier to proper self-management. Participants wanted to be followed for their OI on a regular, long-term, basis by a multidisciplinary, team knowledgeable in OI.

4. I want to know...

Participants wanted information on available resources and health care providers who were knowledgeable about OI. Participants also wanted to receive information on what to expect with ageing and the effects of OI on other physiological systems.

5. I’m excited about this new program

Participants were excited to see what the NP had to offer. They looked forward to having their OI health concerns addressed by a primary care provider knowledgeable about OI. After meeting with the NP, one participant was still concerned about where to go to treat their fractures.

Implications for Practice and Research

- Improve process of transitioning patients into adult health care system
- Contribute to the creation of evidence-based transition guidelines to facilitate a seamless transition for young adults diagnosed with OI
- Address the ongoing self-management needs of young adults with OI
- Educate pediatric and adult clinicians about the self-management and transitional care needs of young adult with OI
- Contribute to the creation and evaluation of an interactive, e-health platform, for young adults with OI and their primary health care providers.

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