With special thanks to Margit Wewer from Curias

**BACKGROUND AND AIM**

In the Netherlands there are approximately 1,000 people with OI. The national expertise centers that treat the majority of people with OI in the Netherlands are the Isala Clinics in Zwolle for adults and the Wilhelmina Children’s Hospital in Utrecht for children. In both clinical practice and research, the focus has been mainly on the orthopedic, genetic and pharmacological outcomes of OI, while still little is known concerning the psychosocial consequences of the condition.

The goal of this project was to ensure all people with OI in the Netherlands are aware that OI has psychosocial consequences and that everyone has access to adequate formal and informal treatment.

**THE PROJECT**

1. evaluated the frequency and type of the psychosocial challenges experienced in Zwolle for adults and the Wilhelmina Children’s Hospital in Utrecht for children. In both centers that treat the majority of people with OI in the Netherlands are the Isala Clinics.

**RESULTS**

252 responses were received.

- 164 adults with OI
- 42 parents on their own behalf as carers
- 38 parents on behalf of their children
- 8 children with OI.

**ACTIVITIES CAUSING PSYCHOSOCIAL ISSUES**

In children, most challenges are experienced at school or while playing sports, and the main reasons for experiencing barriers are fear of fractures and problems in mobility. Adults reported problems in relation to sports and mobility (66% of adults with a mild OI type vs. 61% of adults with a severe OI type) and at work (43% of adults with a mild OI type vs. 31% of adults with a severe OI type).

**EMOTIONS**

Anger and grief are reported in almost 50% of the children, according to their parents. 63% has problems with being dependent on others as a result of their OI. In adults, anger and grief are reported more frequently with the mild type (30% versus 15-23%), and these feelings seem to diminish with advancing age. Feelings of fear are reported more frequently by those with the severe OI type.

**CURRENT CARE AND FUTURE NEEDS**

55% of the children sought help for their psychosocial barriers from various types of professionals, of which 65% was satisfied with the help given. In adults, psychosocial help was sought by 36%, of which 75% was satisfied with the care given. Psychosocial barriers are independent of the type of OI. 44% of the adults with OI think more attention should be paid to psychosocial complaints.

**CONCLUSION**

Psychosocial problems appear to be more common in OI (40-60%) than in other chronic diseases (35%). These psychosocial barriers are independent of the type of OI. In every age category, people with OI are faced with specific challenges that need to be overcome. There is a need to improve both the screening and the treatment of the psychosocial consequences in osteogenesis imperfecta.

**IMPLEMENTATION AND TAKE HOME MESSAGE**

Implementation of adapted screening procedures has started. Subsequently, education materials (brochures and videos) have been developed for both patients and professionals. A workshop format was also developed and tested to facilitate the expression of the psychosocial consequences and to create more openness around this theme within the community of people with OI.

**METHODS**

A digital survey was constructed based on existing literature, the Positive Health Model of Machteld Huber, and clinical experiences of professionals working with people with OI and representatives of the OI community in the Netherlands. People with OI were asked to participate via an email from the patient association and expert centers.

Data were analyzed according to gender, type of OI (mild or severe) and age category. Subsequently, focus group sessions were held with people with OI in the age category 18-49 years (in 2 separate groups according to type of OI), with 1 group of people over 50 years of age (any type of OI) and with 1 group of teenagers (12-15 years) with a severe type of OI. 3 interviews were held with teenagers aged between 12 and 17 years with a mild type of OI. Results were discussed with a group of dedicated professionals and 4 representatives of the OI community.

**MORE INFORMATION**

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With the participation of people from the OI community in all phases of this project, we have been able to create sustainable change for this important topic in the Netherlands!