

QUALITY OF LIFE IN OSTEOPENESIS IMPERFECTA: A PRELIMINARY REPORT.

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Purpose:

To evaluate the physical, mental and social impact of the disease. Participants: Thirty people with OI were evaluated. There were 21 females and 9 males between 20 and 50 years (mean 33).

Design:

Prospective mail survey.

Methods:

Three different questionnaires were used. These are: 1.- A generic epidemiological part specifically addressed to people with OI. 2.- The SF-36 Health Survey, which is a validated physical and mental health outcomes instrument with normative data available. It explores 8 domains: Physical Function (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Function (SF), Role Emotion (RE) and Mental Health (MH). 3.- A functional questionnaire regarding social aspects and performance in activities of daily living (ADL).

Results:

Eighteen patients had fractures at or before birth and were considered to be congenita type, the rest were tarda type. When the SF-36 results were compared to those of the US population, the scores were lower in all eight domains but reached significant difference only in PF ($p<0.00001$), BP ($p=0.0046$) and RP ($p=0.0028$). When stratified for type of OI, those with congenita type scored significantly lower than the US population in PF ($p<0.000001$), BP ($p=0.006$), VT ($p=0.012$) and RP ($p=0.047$) whereas the tarda type only scored lower in PF ($p=0.000081$) but higher than the US population in GH, VT, SF, RE and MH (although not significantly). In education, 23% had a post graduate degree and 53% had attended college (almost 60% completed). Socially, 57% have never been married and 43% did not plan on having children. Functionally, only 13% had some deficit with ADL. Hearing loss over time seemed to be an important factor of distress.

Conclusions:

This is the first study to assess quality of life in OI using a validated self-assessment questionnaire, the SF-36. These preliminary data show that despite the important physical limitations imposed by this condition, people with osteogenesis imperfecta have normal psychological and social roles. They devise functional strategies that permit high levels of function in spite of significant physical disabilities.

Reference: Proceedings of the 7th International Conference on Osteogenesis Imperfecta. Montreal, Canada, 1999.