Quality of life and psychological well-being in GH-treated, adult PWS patients: a longitudinal study

L. Bertella, I. Mori, G. Grugni, R. Pignatti, F. Ceriani, E. Molinari, A. Ceccarelli, A. Sartorio, R. Vettor, C. Semenza

Journal of Intellectual Disability Research, 51: 302-311, 2007.

Background: Prader–Willi syndrome (PWS) is a congenital alteration of chromosome pair 15. It is characterized by short stature, muscular hypotonia, hyperphagia, obesity, behavioural and emotional disturbances, hypogonadism and partial Growth Hormone (GH) deficiency. The aim of this study was to assess the long-term effect of GH treatment on the psychological well-being and Quality of Life (QoL) in an adult PWS group.

Methods: a total of 13 PWS patients, their diagnosis confirmed by genetic tests, and their parents were recruited for this study. The participants were administered the 36-Items Short Form Health Survey (SF-36) and the Psychological General Well-Being Index (PGWBI), for the assessment of QoL and psychological well-being, at the beginning of GH treatment, and at following intervals of 6, 12 and 24 months. Modified versions of the same questionnaires were given to the parents.

Results: significant improvement with respect to the baseline was found, on both scales, in the evaluation of both physical and psychological well-being, although the parents' evaluation was less optimistic than that of the patients.

Conclusion: our findings suggest that the amelioration of QoL and psychological status is sustained in patients who continue GH treatment.