Quality of life in patients with Klinefelter Syndrome – a multicentre study


Affiliations: 1Department of obstetrics and gynaecology, Radboudumc, Nijmegen, The Netherlands 2Department of pediatric urology, Radboudumc, Nijmegen, The Netherlands 3Department of internal medicine, Radboudumc, Nijmegen, The Netherlands 4Department of urology, Radboudumc, Nijmegen, The Netherlands 5Department of health evidence, Radboud Institute for Health Sciences, Radboudumc, Nijmegen, The Netherlands 6Department of pediatric endocrinology, Bicêtre hospital, Paris Sud University, France 7Department of Andrology and Reproductive Endocrinology, Medical University of Lodz, Poland 8Department of Endocrinology and Metabolic Disease, Centre Hospitalier Universitaire de Toulouse, France 9Departments of plastic surgery and medical psychology, VU medisch centrum, Amsterdam, The Netherlands 10Department of pediatrics, hospital des enfants, Toulouse, France 11Centre of Reproductive Medicine and Andrology, Clinical Andrology, University Hospital Münster, Münster, Germany 12Medizinische Klinik und Poliklinik IV, Department of Endocrinology, University Hospital Munich, Munich, Germany 13Department of pediatrics, Sozialpädiatriisches Zentrum Lübeck, Universitätsklinikum Schleswig-Holstein, Germany 14Department of pediatric endocrinology, Amalia Childrens Hospital, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

Conclusion
QoL in European men with Klinefelter Syndrome is significantly worse compared to a healthy but not to a psychiatric reference population. Especially the presence of discrimination, less social participation and mental or somatic health problems is associated with a negative physical, psychical and social QoL.

Introduction

• With a prevalence of 1 in 660 males, Klinefelter Syndrome (KS, 47XXY) is one of the common sex chromosome disorders.
• Klinefelter syndrome (KS) is associated with an increased risk of lower socioeconomic status and a higher risk for morbidity and mortality, which may have a significant impact on quality of life (QoL).
• Psychosocial well-being, which included subjective well-being, self-esteem, body image and psychological distress, was shown to be impaired in men with KS.

Objective
The objective of this study is to investigate QoL in a large European cohort of men with KS and to associate QoL with social activities, age at diagnosis, hormonal substitution, presence of health problems and experienced discrimination.

Material and Methods

dsd-LIFE study (www.dsd-LIFE.eu)
This study was part of the European dsd-LIFE study, a non-interventional, clinical, cross-sectional multicenter study in 14 European centres in 6 European countries, i.e. Germany, France, the Netherlands, Poland, Sweden and the United Kingdom (UK).

• Participants were asked to fill out a digital Patient Reported Outcome (PRO) form that comprised various existing and self-constructed questionnaires on health status, mental health, quality of life, psychological well-being, psychosexual outcome, treatment, fertility, experiences with care and sexuality.
• We used a healthy (n=1324) and psychiatric (n=77) reference population reported by Skevington et al., 2012, for comparison of the mean scores for the World Health Organisation Quality of Life – BREF (WHOQOL-BREF) domain scores (Skevington et al., 2012*).

Results

Quality of Life

• WHOQOL-BREF domain scores (Y axis, 0-100) for men with Klinefelter syndrome from the dsd-LIFE study (dark, n=206), for the healthy reference population (grey, n=1324) and the psychiatric reference population (light, n=77).

• * = p<0.05, values showing dsd-LIFE group compared to the European reference population; unpaired two-tailed T-test.

• Presence of physical or mental health problems and experienced discrimination was associated with a worse QoL (p<0.001, B=-14.1, 95% CI -20.8 - -7.3 / B=-15.7, 95% CI -22.7 - -8.7).
• Participation in social activities was associated with a better QoL (p=0.01, B=4.1, 95% CI 0.9 – 7.4).

Contact: S.Franik@Radboudumc.nl

Institute for Health Sciences
Radboudumc