

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

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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)

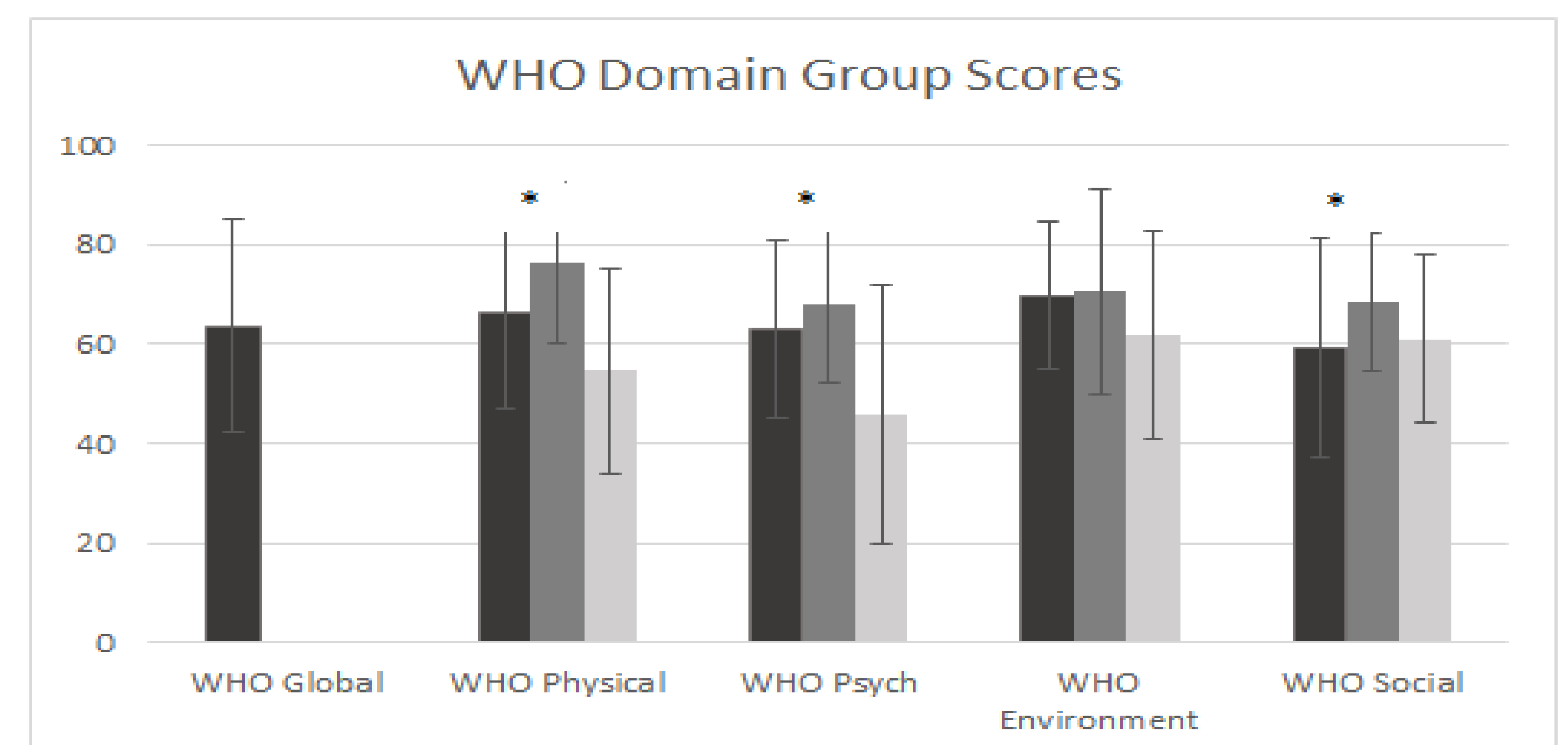
This study was part of the European dsd-LIFE study, a non-interventional, clinical, cross-sectional multicenter study in 14 European centres in 6 European countries, i.e. Germany, France, the Netherlands, Poland, Sweden and the United Kingdom (UK).

- 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).

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Sex differentiation, gonads and gynaecology or sex endocrinology

Sebastian Franik

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