

Abstract

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The aim of this thesis was to describe psychological and social functioning in females with a diagnosis of the sex-chromosome disorder Turner syndrome. Included are a review article and three empirical studies, based on cross-sectional interviews and questionnaire data originating from the multi-disciplinary Western Swedish Turner project. In **Study I**, recent literature in the field is reviewed. This shows that there is an increased risk for psychological and social difficulties at the group level, but also considerable individual variability. It is argued that more attention should be paid to the perspective of the females themselves. In **Study II** it was found that 37 girls with Turner syndrome (age, 7-16 years) had more social and behavioural problems compared with normative data (according to parental rating), although the level of problems did not approach that seen in children referred for psychiatric treatment. The self-concept of the girls did not differ from normative data, although many girls reported peer-related difficulties when interviewed. In **Study III**, 63 women with Turner syndrome (age, 18-59 years) reported psychological well-being and health at the same level as normative data, but they experienced more social isolation. Poor general health was related to more emotional distress. The subjects were employed or working to the same degree as the general Swedish population, but fewer were cohabiting. Both negative and positive consequences of the disorder were reported. In **Study IV**, bivariate analyses showed that, among the 63 women with Turner syndrome, the presence of school difficulties (retrospective data) was related to psychological well-being at the time of the study, as was age at menarche, the presence of sex hormones during adult life (from hormone replacement therapy or endogenous hormones), self-rated hearing impairment, age at diagnosis and age. Regression analysis showed that age at diagnosis and difficulties with school subjects were two separate predictors, explaining 26% of the variation in psychological well-being. The results presented underscore the importance of the psychological and social concomitants of Turner syndrome, and the necessity for an individual assessment of psychological and social problems in the management of Turner syndrome.

Key words: Turner syndrome, psychological factors, social factors, self-perception, self-rated health

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