

Turner Syndrome: Awareness of Health Issues

Abstract:

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Turner syndrome (TS) is an important cause of short stature in girls and occurs in approximately 1 in every 2000 live female births. Affected girls may also experience a wide range of problems. We aim to examine the perception of health issues that are related to TS.

An increased prevalence of obesity, hypertension, autoimmune thyroiditis, coeliac diseases, inflammatory bowel disease and social vulnerability has been found in adolescent patients with TS^{1,2}. Adults with TS may need counselling and preparation concerning assisted fertility and may exhibit a wide range of problems such as obesity, hypertension, aortic dilation, osteoporosis, autoimmune thyroiditis or sensorineural deafness, for example^{1,2}. In adults with TS, life expectancy may be affected due to an increased risk of aortic dissection and ischemic heart disease. Those, who did not have access to focused health care, may have low Quality of life. Follow up by a multidisciplinary team to improve life expectancy and reduce morbidity was recommended³. We therefore set out to examine the perception of health issues that are related to TS. Ethical approval was obtained from our local hospital ethics committee. Girls with TS were recruited to the study if they genetically confirmed TS and aged over 12 years. Of 35 girls who were invited, 32 agreed to participate. The participants have been asked to complete self-assessment questionnaire regarding the health problems which adult with TS can experience. Girls with TS and their parents or guardians were contacted either in the outpatient clinic or by telephone. Those who expressed initial agreement received questionnaire form. A minimum duration of 1 week was given to return the form. To our knowledge, this is the first study to examine the perception of health issues in Irish girls with TS.

Data were available from 32 girls with TS (Table 1). Mean (SD) age is 16.7(2.61) years (range 12.4-20.2 years). Approximately, half of the girls reported that health issues related to TS include obesity [18 (56.3%)] or heart problems [17 (53.1%)]. Of 32 girls, 14 (43.8%), 11 (34.4%) and 10 (31.3%) perceived that adults with TS experience hearing issues, eye problems and fractures, respectively (Table 1). Approximately 1 in 6 girls (15.63%) reported that adults with TS exhibit numbers of health issues including heart, hearing, obesity, fracture and ocular. Of 32 girls, 2 (6.3%) feel that TS patients experience no health issues. We underline the importance of discussing the health issues that are related to TS with girls with TS and their parents.

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References

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