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Quality of life in asymptomatic children and adolescents before and after diagnosis of hypertrophic cardiomyopathy through family screening

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INTRODUCTION

Family screening for asymptomatic hypertrophic cardiomyopathy (HCM) is motivated since the risk for sudden death can be decreased by lifestyle modifications and pharmacological treatment. Before embarking on a programme for such screening it is important to evaluate if the knowledge of having a chronic life threatening disease while being asymptomatic affects quality of life (QoL). The aim of this study was to measure QoL in asymptomatic children with HCM before and after diagnosis compared to healthy controls.

METHODS

Quality of life was measured according to Lindström (Soz Präventivmed 1992;37:301) taking into consideration the three spheres of external, interpersonal and personal aspects. Both objective and subjective aspects were covered in all dimensions. QoL was measured using a questionnaire, before and 2 years after diagnosis. The healthy siblings of the patients served as one comparison group. In order to avoid bias from living in the same family a second comparison group of healthy children unrelated to the patients were chosen. The study group consisted of 13 children with HCM, median age 11 years (range 5-18). There were 10 healthy siblings, median age 10.5 years (range 4-16) and the other control group consisted of 31 children with a median age of 11 years (range 2-19).

RESULTS

The total QoL score was similar between groups at baseline and follow-up. The total score for the personal sphere was lower at follow up in the study group compared to both control groups ($p < 0.05$). The total scores for the other spheres were similar between groups at baseline and follow-up. In the interpersonal sphere the satisfaction with social support was lower in children with HCM ($p = 0.01$) than in controls at baseline but not at follow up. Children with HCM had significantly more psychosomatic symptoms compared to both control groups at follow-up ($p = 0.01$) but not at baseline. The subjective QoL was significantly lower in children with HCM compared to controls ($p = 0.002$) at follow-up.

CONCLUSION

Family screening for HCM does not seem to negatively influence total QoL. However subjective QoL variables was lower in the study group and psychosomatic symptoms increased compared to the two control groups.