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Abstract:

QUALITY OF LIFE OF ADOLESCENTS WITH CHRONIC DISORDERS: AN OPTIMISTIC VIEW

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Quality of Life (QoL) is a complex, multi-dimensional concept, but has become an important item on the agenda for chronic illness research. Children and adolescents may view their QoL differently from adults / parents. We investigated how adolescents with various chronic disorders rate their QoL compared with healthy peers and parents.

Sample, methods

We invited all adolescents (12-19 yrs) with chronic physical illnesses, but without mental retardation, treated at Erasmus MC-Sophia Children's Hospital and their parents to submit a large web-based survey. 1039 adolescents (28.5%) and 779 parents (21.4%) responded. General questions about life and health, QoL, preferences and competencies for care were included in the survey. QoL was studied using two newly developed, standardised European screening instruments. KIDSCREEN-10 is a short generic health-related quality of life measure, applicable for both healthy and chronically ill children and adolescents aged 8 to 18. To measure the impact of chronic illness on QoL we used the related DISABKIDS-12 measure. For parents, standard proxy measures were used. Data analysis was performed with SPSS.

Results

National and international reference data are available for KIDSCREEN and DISABKIDS. Unexpectedly, young people with chronic disorders report better QoL on the KIDSCREEN than their healthy peers. Boys and younger adolescents are more positive about their QoL than girls and older adolescents respectively. QoL is also significantly related to level of functional disability, VAS-ratings of self image and visibility of the disorder, general health and the general self-efficacy scale. Parents rate their childrens' QoL lower than the youngsters themselves.

Conclusions

Adolescents with chronic disorders generally rate their QoL as high, whereas parents are less positive. Our results, however, do not imply that chronic conditions do not have a major impact on young people's lives. Chronically ill adolescents' positive appreciation of life provides an essential starting point for care.

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