ORIGINAL ARTICLES

Psychological and Quality of Life Outcomes in Pediatric Populations: A Parent-Child Perspective

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Objectives To compare the levels of quality of life (QoL) and psychological adjustment of children with different chronic health conditions with healthy children; to compare the QoL of parents of children with a chronic condition with parents of healthy children; and to examine the role of parents' QoL and children's psychological adjustment (ie, internalizing/externalizing problems) on children's QoL.

Study design The sample comprised 964 family dyads composed of 1 parent and 1 child/adolescent aged 8-18 years with diabetes (n = 85), asthma (n = 308), epilepsy (n = 68), cerebral palsy (n = 94), obesity (n = 110), or no medical conditions (n = 299). The children completed self-report measures of QoL and psychological adjustment, and the parents completed a questionnaire on QoL.

Results Children with epilepsy and obesity reported the lowest levels of QoL and elevated levels of psychological problems, and parents of children with obesity reported the lowest levels of QoL. Adolescents reported worse adjustment than children. Regression models revealed that children's internalizing and externalizing problems were important, although distinct, explanatory factors of QoL across all groups.

Conclusion Children with chronic conditions, particularly epilepsy and obesity, are at increased risk for maladjustment. A routine assessment of QoL and psychological functioning should be performed in these children to better understand how specific conditions affect the lives of children with chronic conditions and their families. Family-oriented pediatrics should be considered, particularly in the treatment of obesity. *(J Pediatr 2013;163:1471-8)*.

Medical advances in the diagnosis and treatment of childhood chronic health conditions result in increased rates of survival. Consequently, children's and adolescents' quality of life (QoL) has increasingly been recognized as a key health outcome measure that should complement traditional health indicators (eg, survival rates).[1] Based on the World Health Organization's definition of health, QoL has been conceptualized as a multidimensional and subjective construct that reflects an individual's subjective assessment of several domains of his or her life, including physical, social, and psychological functioning.[2,3] Given the subjective nature of this construct, it has been argued that QoL should be self-reported by both adults and children whenever possible.[3] However, children have traditionally been viewed as unreliable informants of their QoL, although there is growing evidence that they are able to provide this patient-reported outcome.[4]

It has been found that the QoL of chronically ill children is frequently compromised,[1,5,6] as is the QoL and psychological adjustment of their parents.[7] Moreover, a recent meta-analysis indicated a greater risk of internalizing and externalizing problems in children with chronic physical illnesses.[8] Studies comparing children's and parents' QoL across several conditions may be particularly useful for pediatric health care providers, allowing the identification of high-risk populations and facilitating understanding of the unique impact of each condition on the psychosocial functioning of children and their families.[5,7] Although valuable efforts have been made to compare the QoL of children with different conditions,[1,6] such studies have relied solely on proxy reports of children's QoL and have not analyzed the influence of children's age on their outcomes, but rather have evaluated children and adolescents as a single group. However, childhood and adolescence are distinct developmental stages characterized by different maturational issues and developmental tasks,[9] and these stages should be studied independently. Moreover, although there is general agreement that a childhood health condition affects and is affected by the entire family,[10,11] and a number of recent studies have stressed the relevance of studying and promoting the psychosocial adjustment of parents,[7] research on the differential impact of different chronic conditions in children on parents' QoL is remarkably limited.

BMI	Body mass index
CP	Cerebral palsy
GASE	Global Assessment of Severity of Epilepsy
HbA1c	Glycated hemoglobin
QoL	Quality of life

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To further understand the impact of a chronic condition on children's lives, it is important to identify the determinants of children's QoL. Children's psychological adjustment has been noted as a key predictor of QoL,[12] but its role in the context of pediatric chronic conditions has been theorized more than investigated, and the differential impact of internalizing and externalizing problems has not yet been ascertained. In addition, given the widely acknowledged interrelationship between children's and parents' adjustment,[10,11] parental QoL is hypothesized to be an important predictor of children's QoL.

To fulfill the aforementioned research gaps, in this study we aimed to: (1) compare the levels of self-reported QoL and psychological adjustment (internalizing/externalizing problems) of children with a chronic condition (asthma, diabetes, obesity, cerebral palsy [CP], or epilepsy) with those of healthy peers; (2) compare the QoL of parents of children with different chronic conditions and parents of healthy children; and (3) examine the influence of children's psychological adjustment and parents' QoL on children's QoL. We hypothesized that children with chronic conditions would exhibit decreased QoL and more psychological problems than their healthy peers, and that the parents of chronically ill children would report lower QoL. We also hypothesized that more psychological problems and lower QoL among parents would be associated with poorer QoL among children.

Methods

A total of 964 family dyads composed of a child/adolescent aged 8-18 years and a parent participated in the study. Chronic conditions in these dyads included diabetes (n = 85), asthma (n = 308), epilepsy (n = 68), CP (n = 94), and obesity (n = 110); 299 dyads had no chronic condition. Children with diabetes, asthma, epilepsy, and obesity were recruited at the pediatric departments of 3 public and urban hospitals in the central Portugal, and the children with CP were recruited at 10 Portuguese CP association between March 2009 and December 2012. The Ethics Committee and Direction Board of the hospitals and CP associations approved the study.

For inclusion in this study, a dyad with a chronic condition had to meet the following inclusion criteria: (1) youth aged 8-18 years at the time of recruitment; (2) clinical diagnosis of asthma, type 1 diabetes, CP, epilepsy, or obesity; (3) absence of comorbidity with other health conditions; (4) ability to understand and answer the questionnaires; and (5) parent who was the primary caregiver (ie, parents self-identify as primarily responsible for the child's illness management). In addition, children with CP were required to have a minimum IQ of 70, and children in the obesity group were required to have a body mass index (BMI) ≥95th percentile for children of the same age and sex, according to Centers for Disease Control and Prevention growth curves.[13] Participants completed the self-report questionnaires in a consultation office of their health institution. A research assistant was available to assist when necessary. Written informed consent from parents and adolescents aged 13 years or older and assent from children were obtained.

A community sample of healthy and normal-weight children and parents was recruited in 2 Portuguese regular public schools between January 2010 and June 2012. The eligibility requirements for these families included a child aged 8-18 years at the time of recruitment, parent and child informed consent, and child assent. In addition, the child could not have any chronic health condition or developmental delay, and the parent had to be the parent who spent the most daily time with the child. After the Direction Boards of the schools authorized the study, the parents were given a letter explaining the study and the informed consent. Parents who returned the informed consent received a packet with questionnaires to be completed at home and returned 1 week later.

Children's QoL was assessed by the Portuguese self-report version of the KIDSCREEN-10 index.[14,15] This instrument assesses the general subjective health and well-being of children and adolescents aged 8-18 years, and can be applied to both healthy and chronically ill children. The KIDSCREEN-10 index contains 10 items (eg, "Have you felt fit and well?"; "Have you had fun with your friends?"), with answers scored on a 5-point Likert scale ranging from 1 (never; not at all) to 5 (always; extremely), with a higher score indicating better QoL. Adequate internal consistency values were obtained in this study ($\alpha = 0.77$).

Children's psychological adjustment was assessed using the difficulties subscale of the Portuguese self-report version of the Strengths and Difficulties Questionnaire.[16,17] This subscale comprises 20 items (eg, "I worry a lot"; "I am easily distracted, I find it difficult to concentrate") that we clustered into internalizing and externalizing problems according to recent recommendations.[18] These questions are answered on a Likert-type response scale with three options (0 = not true; 1 = somewhat true; 2 = certainly true), with a higher score indicating more psychological problems. Adequate internal consistency values were obtained for the internalizing ($\alpha = 0.67$) and externalizing subscales ($\alpha = 0.72$).

Parents' perceptions of their QoL were assessed using the Portuguese version of the EUROHIS-QOL-8.[19,20] Developed as an adaptation of the World Health Organization's WHOQOL-100 and WHOQOL-Bref surveys, it is a quick indicator of overall QoL. It contains 8 items (eg, "How satisfied are you with your health?"; "Have you enough energy for everyday life?"), with 2 items per QoL domain (social, psychological, physical, and environmental), with answers scored on a 5-point Likert scale ranging from 1 (not at all/very dissatisfied) to 5 (completely/very satisfied), with a higher score indicating better QoL. Adequate internal consistency values were obtained in our sample ($\alpha = 0.83$).

Sociodemographic information was reported by parents and included parents' and children's ages and sexes and parents' marital status. Parents of obese children also reported their weight and height, and were classified into 4 categories

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