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Predictors of health-related quality of life in chronically ill children and adolescents over time

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ABSTRACT

Objective: This study aims at identifying predictors of generic health-related quality of life (HRQoL) in chronically ill children and adolescents over time. The newly developed computer-adaptive test Kids-CAT was used to assess five dimensions of HRQoL.

Methods: Longitudinal data from the Kids-CAT study on children and adolescents with asthma, diabetes and juvenile arthritis ($n = 248$; aged 7–17 years) were assessed at three measurement points over six months. Individual growth modeling served to investigate effects of sociodemographic, disease- and health-related as well as psychosocial factors on HRQoL dimensions Physical Well-Being (WB), Psychological WB, Parent Relations, Social Support & Peers, and School WB over time.

Results: Besides effects of sociodemographic variables on HRQoL dimensions Social Support & Peers as well as School WB, we found that a longer duration of the disease was associated with better Physical WB. Lower scores were found for patients with juvenile arthritis compared to those with diabetes in HRQoL dimensions Physical WB and Social Support & Peers. Disease control was positively related to Physical and Psychological WB over time. Mental health problems were negatively associated with four, and subjective health complaints with all five HRQoL dimensions over time. Parental mental health was positively related to the patients' HRQoL score in Parent Relations over time.

Conclusions: HRQoL as a multidimensional construct is associated with a wide range of different factors. Pediatricians should consider potential mental health problems and subjective health complaints in their patients. Finally, parental HRQoL can affect HRQoL in chronically ill children and adolescents.

1. Introduction

The prevalence rates of chronic health conditions in children and adolescents have increased in the past decades [1]. Physical symptoms of chronic diseases (e.g., pain, fatigue), the burden of managing the condition (e.g., worries, distress, daily hassles, potential family conflicts) as well as restrictions concerning the participation in normal life activities (e.g., illness related days lost days in school, less contacts with peers, difficulties to access leisure activities) can affect the lives and the well-being of children and adolescents with chronic diseases [2–4].

Asthma, diabetes and juvenile idiopathic arthritis (JIA) are chronic health conditions which can have substantial impact on the lives of children and adolescents with these diseases [5]. In asthma, sudden unexpected exacerbations and frightening episodes of respiratory distress can cause anxieties, and poor adherence can result in poor physical functioning and a lack of participation in physical activities. JIA is characterized by severe, recurrent or chronic pain and physical limitations; further, it is known that medication for JIA can come with strong side effects. Diabetes care requires several management procedures per day, high level of control and dependency from parents and

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severe life threatening events in the case of poor adherence.

The subjective perspective of patients on their health and well-being can be measured using the multidimensional construct of health-related quality of life (HRQoL), which is an important outcome measure in research and clinical routine. The multidimensionality of this construct is represented by physical, psychological and social aspects of well-being. As a dynamic and subjective construct, HRQoL is best assessed by self-reports, even in children and adolescents (as long as age-appropriate measures are used and respondents do not suffer from very severe mental or physical health conditions) [6,7]. Besides traditional paper-pencil questionnaires used to assess generic HRQoL in children and adolescents (for an overview see e.g. [7]), Computer-Adaptive Tests (CATs) are based on larger item banks and provide an innovative way of measuring HRQoL. CATs allow a precise and reliable estimation of outcomes by administering the most informative items for every individual, which are automatically chosen from the larger item bank by an algorithm. The newly developed and validated German Kids-CAT tool is a state-of-the-art instrument to assess self-reported generic HRQoL based on methods of modern test theory covering the five dimensions Physical Well-Being (WB), Psychological WB, Parent Relations, Social Support & Peers and School WB [8]. The Kids-CAT includes item banks with 26 to 46 items per dimension, from which the most suitable items are algorithm-based chosen for each respondent [8].

Previous studies on factors affecting HRQoL in chronically ill children and adolescents have mainly analyzed cross-sectional data collected by traditional questionnaires. These studies reported mixed evidence for sociodemographic factors. Better generic HRQoL was found for younger compared to older children and adolescents with asthma [9]; a similar result was found in young patients with diabetes type 1 [10]. Some studies among children and adolescents with asthma, diabetes and JIA did not find a gender-specific difference in HRQoL [9,11], but most studies reported lower HRQoL for females compared to males with chronic conditions [12–14]. A higher socioeconomic status (SES) seems to be related to better generic HRQoL in children and adolescents with diabetes [15]; to our knowledge, no studies investigated this association in children and adolescents with asthma and JIA so far.

Concerning disease-related factors, Kalyva and colleagues [13] found among children and adolescents with diabetes later age of onset to be associated with better overall generic HRQoL. Regarding disease control or disease severity, Stahl-Pehe and colleagues [15] found poor glycemic control (HbA1c) related to lower overall generic HRQoL, as well as to lower HRQoL according to the dimensions Physical and Emotional Well-Being, Self-Esteem, Family and School in children and adolescents with diabetes. A systematic review reported negative associations between asthma severity and HRQoL in children based on nine out of 14 included studies [16]. In line with this review, Varni and colleagues [9] found positive associations between better asthma status and better HRQoL according to the dimensions Physical Health, and Emotional as well as School Functioning. Further, Naughton and colleagues [17] investigated young patients with diabetes and reported lower overall generic HRQoL as well as lower HRQoL according to the dimensions Physical Health, Emotional, Social, and School Functioning for those with one or two compared to those without any comorbid disease. Disease-related factors have been investigated mainly in cross-sectional studies so far, the need for longitudinal study designs has been emphasized lately [16].

To our knowledge, the association of HRQoL with psychosocial factors in chronically ill children has been rarely investigated so far. From studies on general populations it is known that children with mental health problems have worse overall generic HRQoL than children without mental health problems [18,19]. Further, the presence of subjective health complaints seems to be related to lower overall generic HRQoL in schoolchildren [20]. There is not much evidence regarding the association between child HRQoL and parental HRQoL. Walker and colleagues [21] found no relationship between child and

parental overall generic HRQoL based on a sample of children with asthma. However, Giannakopoulos and colleagues [22] found in a general population sample that a better parental mental health status was associated with better overall generic HRQoL in the child according to several HRQoL dimensions.

The present study aimed at investigating effects of socio-demographic, disease- and health-related and psychosocial predictors of HRQoL in chronically ill children and adolescents with asthma, diabetes and JIA based on longitudinal data gathered at three measurement points over six months. Longitudinal studies on predictors of HRQoL in chronically ill children and adolescents are very scarce. We analyzed longitudinal HRQoL data assessed by means of the Kids-CAT. We investigated associations of sociodemographic (i.e., gender, age, SES, migration status), disease- and health-related (i.e., type of the disease (asthma, diabetes or JIA), duration of the disease, comorbidity, disease control, and subjective health complaints) as well as psychosocial factors (i.e., mental health problems and parental HRQoL in terms of parental physical as well as mental health) with HRQoL based on longitudinal data. Previous HRQoL research showed mixed results for sociodemographic factors, and left a dearth regarding effects of disease-related as well as psychosocial factors on generic HRQoL in chronically ill children and adolescents. Based on the literature we expected to find associations of sociodemographic variables (i.e., age, gender, and SES) with HRQoL in the investigated chronically ill children and adolescents. We further expected HRQoL in chronically ill children to be related to disease- and health-related factors (i.e., comorbidity, disease control, and subjective health complaints). Moreover, we assumed associations of psychosocial factors (i.e., mental health problems and parental HRQoL) with HRQoL in children and adolescents with asthma, diabetes and JIA.

2. Methods

2.1. Study design and participants

The prospective longitudinal Kids-CAT study investigated $n = 312$ children and adolescents aged 7 to 17 years with an ICD-10 diagnosis of bronchial asthma (J45), diabetes mellitus (E10–11) or JIA (M08). Participants of the observational Kids-CAT study were recruited consecutively at two specialist outpatient departments at the University Medical Center Schleswig-Holstein in Kiel and Lübeck. For study inclusion, children and adolescents as well as their parents needed to be able to read and understand German language. Written informed consent was gathered from the children and adolescents as well as from their parents. Data were collected from June 2013 to October 2014, the response rate was 78.6% [23]. Three major measurement points were conducted covering 6 months (baseline (t1), 3-month follow-up (t2), and 6-month follow-up (t3)). Self-, parent- and physician-reported information were gathered by means of an online-survey (self-reports), a paper-pencil questionnaire (for parent-reports), and an additional short questionnaire (for physician-documented data). The Kids-CAT study was approved by the universities' ethics committees (Kiel and Lübeck), and the Chamber of Psychotherapists Hamburg, Germany. More details on the Kids-CAT study are reported elsewhere [23,24].

In the following longitudinal analyses, cases could only be analyzed, if i) data were available for at least one of the three measurement points, and if ii) clusters of missing data in longitudinally measured variables allowed a reliable estimation. Overall, this led to a sample under analysis including $n = 248$ children and adolescents (aged 7 to 17 years) with asthma, diabetes and JIA.

2.2. Measures

2.2.1. Health-related quality of life

The newly developed Kids-CAT tool [8] was used to assess generic HRQoL at each measurement point of the study covering dimensions

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