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A difference in perception of quality of life in chronically ill children was found between parents and pediatricians

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Abstract

Background and Objectives: Quality of life measurements can help to estimate the well-being of chronically ill patients, and disclose discrepancies in perception between physicians and patients that might otherwise interfere with the effectiveness of treatment. The objective was to investigate the differences in perception of quality of life between parents of chronically ill children and pediatricians.

Methods: A cross-sectional study was conducted in four tertiary pediatric care centers in The Netherlands. The Health Utilities Index mark 3 (HUI3) was used by 37 pediatricians and 279 parents of patients (children aged 1 to 17 years) with cystic fibrosis admitted either in daycare or for a pneumonia, or patients with newly diagnosed acute lymphoblastic leukemia, juvenile idiopathic arthritis, or asthma.

Results: Differences in perception of quality of life between parents and pediatricians appeared to be dependent of the disease. In patients with acute lymphoblastic leukemia (OR 7.4; [95% CI 2.88–18.97], juvenile idiopathic arthritis (4.7; [95% CI 2.00–11.22]), and asthma (2.3; [95% CI 1.13–4.69]) a difference in perception was more likely to occur than in patients with cystic fibrosis admitted in daycare.

Conclusion: At the onset of a chronic disease, the parents of pediatric patients may be misunderstood by health care professionals, especially in subjective attributes. Assessment of quality of life may contribute to better understanding between pediatricians and parents, and thus may even enhance compliance and treatment effects. © 2005 Elsevier Inc. All rights reserved.

Keywords: Chronically ill children; Health Utilities Index; Longitudinal; Physicians; Parents; Quality of life

1. Introduction

Differences in perception of well-being between patients and physicians may interfere with the effectiveness of treatment. This especially holds for chronic diseases. For example, a survey on the prevalence of pain in patients with metastatic cancer showed that a discrepancy between patients' and physicians' judgments of the severity of the pain was predictive for inadequate pain management [1].

Due to substantial gains in survival rates (e.g., for most cancers and for cystic fibrosis) the prevalence of children with a chronic disease increases [2]. The population (open) prevalence of children suffering from a chronic illness varies widely but the overall rate is about 10 to 20% [3]. Direct assessment of quality of life (QoL) in children is not easy. Very young, cognitively impaired, or very sick children may be incapable of providing reliable and valid answers.

Little is known in the literature about the differences in perception of well-being between pediatric patients and physicians. A recent meta-analysis showed six studies in children comparing QoL between parents and physicians [4]. QoL was measured using the Health Utilities Index mark 2 (HUI2). The objective attributes (sensation, self-care, and mobility) had a higher percentage of agreement between parents and physicians than the subjective attributes (emotion, pain, and cognition). However, none of the reviewed studies revealed the direction of the differences in perception of QoL between parents and physicians.

In the present cross-sectional study, we analyzed the agreement in perception of QoL between parents of chronically ill children and pediatricians. QoL was assessed using the Health Utilities Index mark 3 (HUI3). The aim of this study was to assess the differences in perception of QoL between parents of chronically ill children and pediatricians, to describe the direction of these differences, and to identify determinants of these differences. In the present study the parents were asked to act as a proxy and to assess the QoL of their children. Patients with acute lymphoblastic leukemia

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(ALL) were chosen because the HUI has been successfully used in this group [5–7]. Patients with juvenile chronic arthritis (JIA), cystic fibrosis (CF), and asthma were included because the hospital from which the study was initiated aims to be a center of excellence for these children and their families. Furthermore, we expected the attributes of the HUI3 (pain, emotion, ambulation, and dexterity) to match well with major complaints of these patients. CF patients in daycare had long-lasting experiences with their pediatricians and were relatively mildly affected (in comparison with the other diagnoses) at the moment of the study. We therefore expected *a priori* that these patients would show the least differences in QoL perception between parents and pediatricians. This group served as a reference group in our study.

We hypothesized that differences in QoL assessment between parents and pediatricians would be greatest for the subjective attributes. With respect to the attribute pain, we expected pediatricians to assess less pain than parents. For the other attributes we had no *a priori* expectations about pediatricians over- or underestimating QoL in comparison with parents of chronically ill children.

2. Methods

2.1. Patients

Patients were enrolled in four tertiary pediatric centers (Wilhelmina Children's Hospital University Medical Center Utrecht, Utrecht; Sophia Children's Hospital Erasmus University Medical Center, Rotterdam; Emma Children's Hospital Academic Medical Center, Amsterdam; and Asthma Center Heideheuvel, Hilversum) in The Netherlands during the interval July 1999 to January 2002. Eligibility criteria included children admitted with newly diagnosed ALL, children with the diagnosis JIA at their first visit to the outpatient clinic, children with the diagnosis asthma at the first visit to the outpatient clinic, children with CF who were admitted for a pneumonia (CF-adm), children with CF who were admitted in daycare for a yearly checkup (CF-day), age 1 to 17 years old (for the patients with asthma 4–17 years old), and the ability of the parents to understand and read the Dutch language.

2.2. Data collection

QoL was assessed using a 42-item interview questionnaire. For each patient one of the parents completed the interview during the first week following admission (ALL, CF-adm), during daycare (CF-day), or after the first visit of the doctor in the outpatient clinic (JIA, asthma). The principal investigator (A.J.J.) administered the interviews. Following the consultation or admission of the patient, the attending pediatrician completed the HUI3 health status classification system (described by Feeny et al.) [8]. For the attribute vision in preliterate children, the words “able to see well enough to read ordinary newsprint” were changed in “able

to see well enough to read picture books.” The pediatricians were ignorant for the parental HUI interviews and completed the HUI3 independently from the parents. Parents and pediatricians were asked to consider the health status of each patient for the preceding period of 4 weeks.

Information from the questionnaires was converted to health state vectors in the HUI3 formats by an established algorithm [8]. The HUI2 and HUI3 are generic multiattribute health status classification systems [9]. They have been used in a number of clinical studies of children with cancer [10,11–20] in studies of extremely low birth-weight infants [21,22] and in studies of survivors of pediatric intensive care treatment [23]. The HUI3 is described in detail by Feeny et al. [9]. Briefly, the HUI3 classification system consists of eight attributes. Each attribute consists of five to six levels representing the range of functioning from normal (one) to severely impaired (five or six). The attributes forming the HUI3 system are vision (1–6), hearing (1–6), speech (1–5), ambulation (1–6), dexterity (1–6), emotion (1–5), cognition (1–6), and pain (1–5). For example, the attribute emotion represents the following levels. Level 1, happy and interested in life; level 2, somewhat happy; level 3, somewhat unhappy; level 4, very unhappy; and level 5, so unhappy that life is not worthwhile.

2.3. Consent and ethics approval

Written informed consent was obtained from all parents and of patients over 12 years of age who agreed to participate in the study. The medical ethics committees of all participating hospitals approved the study protocol.

2.4. Statistical analyses

Single-attribute utility scores and overall utility scores on a dead-perfect health scale were calculated using the single attribute utility function and the HUI3 multiattribute utility function respectively, as described by Feeny [8].

Absolute differences between pediatricians and parents for each attribute were calculated using the formula: attribute level pediatrician – attribute level parent. For each patient the sum of the absolute differences of all attributes (8) was taken. The outcome was dichotomized into either presence or absence of substantial difference between pediatrician and parent. We defined absence of substantial difference if the sum of the absolute differences in all attributes was ≤ 2 and the sum of the absolute differences of the attributes vision, hearing, speech, ambulation, and dexterity (objective domains) was ≤ 1 , and the sum of the absolute differences of the attributes cognition, emotion, and pain (subjective domains) was ≤ 1 .

In all comparative analyses concerning substantial perception differences between groups of patients with various diagnoses, the patients with CF-day were chosen as a reference group. We assumed *a priori* that they had clinically the least acute complaints, and on average, the longest relation with their attending pediatricians. Consequently, we

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