

Evaluation of Health-related Quality of Life in Paediatric Patients with Acute Lymphoblastic Leukaemia

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ABSTRACT

Objective: Health-related quality of life (HRQOL) measurement is used for assessing the impact of diseases and medical treatments on physical, psychological and social aspects of an individual's health and life. The Paediatric Quality of Life Inventory™ (PedsQL™) is a widely used instrument to measure paediatric HRQOL in children. The aim of this study is to investigate the HRQOL in paediatric patients with acute lymphoblastic leukaemia and determine the precautions for improving the quality of their life.

Methods: Paediatric Quality of Life Inventory™ 4.0 was administered to 75 paediatric patients with acute lymphoblastic leukaemia, and 50 healthy age- and gender-matched children.

Results: Health-related quality of life scores were significantly lower in patients with acute lymphoblastic leukaemia than in healthy controls in this study.

Conclusions: It is thought that determination of the psychosocial, as well as the physical impacts of the disease on the child, will positively influence the treatment given by improving the quality of life of both the child and the family.

Keywords: Acute lymphoblastic leukaemia, paediatric quality of life Inventory™ (PedsQL™) 4.0, quality of life

Evaluación de la calidad de vida relacionada con la salud en pacientes pediátricos con leucemia linfoblástica aguda

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RESUMEN

Objetivos: La medición de la calidad de vida relacionada con la salud (CVRS) se utiliza para evaluar el impacto de las enfermedades y tratamientos médicos en los aspectos físicos, psicológicos y sociales de la salud y la vida de un individuo. El Inventario de Calidad de Vida Pediátrico (PedsQL™) es un instrumento ampliamente utilizado para medir la CVRS pediátrica en los niños. El objetivo de este estudio es investigar la CVRS en pacientes pediátricos con leucemia linfoblástica aguda y determinar las medidas para mejorar la calidad de su vida.

Métodos: El Inventario de Calidad de Vida Pediátrico (PedsQL™), versión 4.0, fue administrado a 75 pacientes pediátricos con leucemia linfoblástica aguda, y a 50 niños sanos pareados por edad y sexo.

Resultados: Las puntuaciones de calidad de vida fueron significativamente inferiores en pacientes con leucemia linfoblástica aguda, comparadas con las de los controles sanos en este estudio.

Conclusiones: Se cree que la determinación de los impactos tanto psicosociales como físicos de la enfermedad del niño influirá positivamente en el tratamiento dado para mejorar la calidad de vida, no sólo del niño sino también de la familia.

Palabras claves: leucemia linfoblástica aguda, Inventario de calidad de vida pediátrico (PedsQL™) versión 4.0, calidad de vida

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INTRODUCTION

Acute lymphoblastic leukaemia (ALL) is the most common type of childhood leukaemia, accounting for about 75 to 80 per cent of childhood leukaemias (1). As a result of prolonged and complex treatments and increased survival rates, the severity of the physical side effects, and also psychological effects of the disease are increased.

Quality of life is defined as an individual's perception of one's position in life in the context of culture and value systems, as well as in relation to one's goals, expectations, standards and concerns (2). The World Health Organization defines health as being "not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being" (3). The health-related quality of life (HRQOL) measurement refers to the impact of health and illness on an individual's quality of life. Chronic illnesses, frequent hospitalizations, medical procedures which cause pain and emotional distress, and uncertainty of survival can negatively impact childhood development and adaptation. The Paediatric Quality of Life Inventory™ (PedsQL™), first developed by Varni *et al* (4), is a widely used instrument to measure paediatric HRQOL in children aged 2 to 18 years. The PedsQL was found to be valid and applicable to the Turkish children (5).

This study was carried out to assess HRQOL among children with acute lymphoblastic leukaemia compared with healthy children.

SUBJECTS AND METHODS

Seventy-five children (5–17 years of age) who were treated and followed-up at the Division of Paediatric Haematology and Oncology during one year after the diagnosis of ALL and fifty age and gender-matched healthy controls with similar sociodemographic characteristics, normal growth and development, recruited from healthy children attending our well-child clinic were enrolled in the study. The data were collected using PedsQL 4.0 between September 2009 and February 2010.

The 23-item PedsQL generic core scales encompass physical (eight items), emotional (five items), social (five items) and school functioning [five items] (4, 6, 7). A five-point response scale is used (0 = never a problem; 4 = almost always a problem). Items are reverse scored and linearly transformed to a zero to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) with higher scores.

The scoring included a physical health summary score that represented a physical functioning scale score (eight items), and a psychosocial health summary score that was the sum of the items answered in the emotional, social and school functioning scales (15 items). The higher scores indicate better HRQOL.

The study was approved by the hospital institutional review board. Written informed consents were obtained from parents.

Statistical analysis

Statistical analyses were performed using SPSS 11.0 soft-

ware (SPSS Inc, Chicago, IL, USA). Results were expressed as means \pm SD for quantitative variables and proportions and percentage. The analysis was conducted using Chi-squared test, analysis of variance (ANOVA) and Tukey's multiple comparison test to analyse qualitative variables. *p*-values of < 0.05 were considered statistically significant.

RESULTS

Thirty-six patients with ALL were aged between five and nine years, 21 were between nine and thirteen years and 18 were ≥ 13 years. Nine controls were aged between five and nine years, 21 between nine and thirteen years and 20 ≥ 13 years. The male:female ratio was 0.78 for the patients and 1.08 for the controls.

For 125 children, PedsQL reference data were collected. The physical health summary, psychosocial health summary and total scale scores of the children with ALL were significantly lower than healthy controls [$p < 0.05$] (Table). No significant age and gender effect on the quality of life scores was observed between groups.

Table: Health related quality of life scores of patients with ALL and controls

	Patients with ALL (n = 75)	Controls (n = 50)	<i>p</i>
Physical health summary score			
5–9 years	56.18 \pm 16.6	72.9 \pm 3.63	0.002
9–13 years	60.8 \pm 21.8	67.4 \pm 24.8	0.041
≥ 13 years	44.2 \pm 20.8	86.4 \pm 13.7	0.000
Psychosocial health summary score			
5–9 years	56.28 \pm 17.7	72.2 \pm 16.4	0.001
9–13 years	70.31 \pm 10.8	65.13 \pm 18.2	0.049
≥ 13 years	59.49 \pm 13.06	69.68 \pm 16.7	0.017
Total scale score			
5–9 years	57.3 \pm 17.1	69.13 \pm 15.7	0.002
9–13 years	66.2 \pm 13.2	66.42 \pm 20.1	0.036
≥ 13 years	55.6 \pm 13.3	80.4 \pm 11.2	0.002

p < 0.05 is statistically significant

HRQOL: health-related quality of life; ALL: acute lymphoblastic leukaemia

DISCUSSION

Acute leukaemias are characterized by clonal expansion and arrest at a specific stage of normal myeloid or lymphoid haematopoiesis (1). Acute lymphoblastic leukaemia is the most common type of childhood cancer. Recently, it has been stated that attempts at early diagnosis, new diagnostic methods and chemotherapy regimens and developments in bone marrow transplantation have affected the cancer survival rates (8). Currently, 60–70% of the children with cancer survive. The high survival rates and increased life expectancy in children as a result of early and effective treatment, access to the best medical service, quality of life and psychosocial approach are more important (9). The number of studies investigating quality of life in patients with cancer is increasing. In these reports, it has been noted that stress is not only affecting quality of life, but also physical symptoms related to cancer and

results of cancer treatment (10).

The benefits of HRQOL measurement have been reported as facilitating patient-physician communication, improvement in patient satisfaction, identification of hidden morbidities in paediatric clinical care, impact on clinical decision-making and improvement in patient outcomes over time (11).

Measurement of HRQOL in children is difficult because of the need for different instruments in different age groups. Generally, there are two types of HRQOL questionnaires: generic and condition-specific instruments (12). Generic questionnaires have been designed to be applied to patients independent of their health condition, age and type of disease. These questionnaires focus on general issues of health or illness rather than specific features of a particular disease and have a lower responsiveness and sensitivity than the condition-specific questionnaires (12). Condition-specific measures of HRQOL address the challenges associated with a particular disease, such as cancer and are more suitable for evaluation of clinical trials designed to assess a particular treatment, comparison of different treatment modalities, efficacy and side effects of treatments (13). Compared to the generic questionnaires, disease-specific ones are more likely to be clinically sensitive, more responsive to detecting changes, can be administered quickly in the clinic and interpretation of their scores is less complex (12). The disadvantages of the disease-specific measures are that they may simply not be available for every illness and rare diseases, and cannot be used in patients with multiple chronic conditions (12). The generic questionnaires are preferred in those patients (14).

The PedsQL is a brief 23-item measure applicable for healthy school and community populations, as well as paediatric populations with acute and chronic health conditions; it evaluates quality of life in four areas of functioning (4, 6, 7). The consistency, feasibility, validity, reliability and sensitivity of PedsQL have been demonstrated in many studies (6, 15–17). It has been reported that mean scores were significantly lower in children and adolescents with chronic illnesses than their healthy peers (6, 17–20).

Children with cancer try to cope with not only the disease itself but also with side effects of chemotherapy and radiotherapy such as pain, anorexia, cachexia, taste changes, alopecia, bone marrow suppression, fatigue, insomnia, anxiety and depression (21, 22). The signs and symptoms of post-traumatic stress disorder, depression, anxiety, social isolation, behavioural disorders, self-concept disturbance and body-image disorder are observed shortly after the diagnosis (23–27). The diagnosis of cancer also affects families of the patients and disrupts their everyday life (28, 29). The impact of disease and treatment on family functioning is a distinct concern in paediatric chronic health conditions, given the essential role of the family in the child's adaptation to the disease.

It has been reported that children with ALL had lower scores in physical and emotional functioning (20). Compatible with these reports, the results of this study showed that

HRQOL of the children with ALL were significantly lower than that for healthy children.

The severity and intensity of the disease and the stage of the treatment affect mean scores of PedsQL (30, 31). The scores of HRQOL was significantly worse for the patients with cancer in high-risk groups (25). If the patients were educated in addition to receiving appropriate treatment, the scores of HRQOL were found to be better (32, 33).

Limitations of the current research include measurement of HRQOL by generic questionnaire, a single measurement instead of multiple measurements for evaluating changes over time, not taking into consideration parameters such as level of education, duration of illness, stage of the disease, treatment, complications and concomitant health conditions and being a single centre experience with a small number of patients.

In conclusion, the evaluation of patients with chronic illnesses by measurement of HRQOL is important in designing and performing treatment modalities according to the condition, requirements and expectations of the patients. The healthcare professionals should be informed about the effects of chronic diseases on the quality of life of children and be able to help and alleviate not only the physical problems, but also the psychological consequences to the child, as well as to the parents.

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