Quality of life of children with chronic illnesses: A Review of the Literature

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Abstract

The objective of the present study is to review the literature pertaining to the quality of life (QoL) of children with a chronic illness. The instruments that have been developed to measure QoL are categorized into two groups: those which are referred to parents and those which are referred to children. Also there are “disease specific” instruments and disease “general” instruments. The instruments that measure QoL of children with chronic illnesses are now used for the evaluation of new therapies and to measure the influence that a certain disease has on the every-day activities of a patient.

Keywords: Chronic illness; assessment; quality of life; instruments.

1. Introduction

In the recent years there has been an increasing interest in the assessment of the quality of life in chronic diseases in both adults and children. In particular the concept of health-related quality of life has become increasingly important and many researchers have developed instruments to measure it. The issue of QoL (Quality of Life) is important in order to evaluate interventions, compare outcomes in clinical trials, organizing programs of care, assessing the outcomes of new treatment (Eiser & Morse, 2001). The health – related quality of life is the physical, emotional and social aspects of life influenced by an individual’s disease and/ or its treatment (Britt et al., 2009; Bullinger et al., 2006; Sawyer et al., 2004). Although HRQL is now considered to be a sub domain of the more global construct of QoL the later is itself generally conceptualized as a broad assessment of well-being across various domains (Davis et al., 2006).

Childhood chronic illness – such as asthma, diabetes, cancer, etc.- has long been thought to have a negative impact on the quality of children’s lives. Researchers use a variety of measures in order to assess HRQoL (Health –

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Related Quality of Life). They use self-reports or reports by other persons (such as parents, nurses, doctors, teachers). The child-specific self-reports measures have improved the participation of children in the evaluation of their quality of life (Goldbeck & Melches, 2005). As Brütt et al. (2009) mention self-report questionnaires can be used for children who can read and write or otherwise they can be interviewed. Some measures can be used for both parents and children. Also researchers use generic or specific-disease methods. Generic measures can be used to all population subgroups (healthy, non-healthy) and the results can be compared between them. As for the condition, specific instruments they are focused on a specific illness (e.g. asthma) and they are examining a variety of aspects (social, emotional, schooling) that they are related to this specific condition (Davis et al., 2007).

The present study aimed to identify available cross-cultural chronic generic measures (that they have been used in many countries) and currently available condition specific measures of the HRQoL of children with chronic illness (asthma, diabetes, cancer and cardiac problems). In particular we attempted to classify the measures according their type, the respondent person and the age target group. Also to make recommendations for future development of HRQoL to children who suffer from chronic illness.

2. Method

A systematic review was conducted to identify paediatric conditions-specific and generic QoL and HRQoL measurements for children and adolescents with chronic illness aged 0 to 18 years old. Studies were identified using PubMed, Medline, PsychoLit electronic databases. To identify papers we used the terms children with medical conditions or chronic illness and QoL or HRQoL. The inclusion criteria of the questionnaires were related if they were designed to measure QoL or HRQoL for children with chronic illness, addressed to parents or children or both. For each study the following information was recorded: the title of the instrument, the domains that they have been assessed, the age of the population and the respondent (parent or child). Questionnaires (generic) that they were designed to measure QoL that was not addressed for children with medical conditions were excluded. We included only chronic generic instruments which according to Brütt et al. (2009), they are focusing on a chronic condition and they were used in many countries. Also instruments that they were focusing on treatment specific conditions they were excluded. In our study we only focused on four specific chronic illnesses (asthma, diabetes, cancer and cardiac problems).

3. Results

Table 1 shows the six condition-specific and the three generic instruments identified. Among the generic measures all included provision for parent and child assessment. Among the specific-condition measures four included child and parent evaluation, and two included children only. The chronological age of children and adolescent range from 7 to 18. The number of domains assessed ranged from two (Juniper et al., 1996b) to nine (Robitail et al., 2007). Emotional, psychological and physical factors are the most common domains indentified in most instruments of our research. Social interaction and activities were also frequently mentioned.

The Paediatric Asthma Quality of Life Questionnaire (Juniper et al., 1996a), aimed to analyze QoL changes in those patients who changed their health status either as a result of treatment or natural fluctuations in their asthma and to differentiate these patients from those who remained stable.

The Paediatric Asthma Caregiver’s Quality of Life Questionnaire (Juniper et al., 1996b), focus on the experiences, anxieties and fears of parents and caregivers of children with asthma based on the idea that due to the child’s illness they are limited in daily activities.

The Diabetes QoL revised has been developed by Faulkner (2003). This questionnaire is a modification of the DQoL (Diabetes Quality of Life) instrument (Ingersoll & Marrero, 1991). This revised version is composed of a 17-item Diabetes Life Satisfaction subscale, a 23-item Disease Impact subscale and an 11-item Disease-Related worries subscale.

The Diabetes QoL for Youth (DQoLY) (Skinner et al., 2006) is also a modified version of The DQoL instrument (Ingersoll & Marrero, 1991). The DQoLY is a shorter version of the DQoL and has been tested in 18 countries across Europe. It seems that this instrument will enhance the acceptability of assessing QoL in adolescents with diabetes making it more feasible to introduce as a part of daily routine care.
Table 1. HRQoL questionnaires for children

| Author                | Questionnaire                                      | Domains                                                                 | Respondent          | Age of the child |
|-----------------------|----------------------------------------------------|--------------------------------------------------------------------------|---------------------|------------------|
| Juniper et al. (1996a) | Specific Condition/Paediatric Asthma Quality of Life Questionnaire | Activity limitation, Symptoms, Emotional Function                        | Child               | 7-17             |
| Juniper et al. (1996b) | Specific Condition/Pediatric Asthma Caregiver’s Quality of Life Questionnaire | Emotions, Activity                                                      | Parents and primary caregivers | 7-17             |
| Faulkner (2003)       | Specific condition/Diabetes QoL                   | Psychological (e.g. Disease-Related Worries Subscale), Social (e.g. disease impact Subscale), Physical (e.g. Global Measure of Health) | Parent and Child    | 10 to 18         |
| Skinner et al. (2006) | Specific Condition/Diabetes QoL for Youth (DQOLY) (Revised) | Impact of diabetes, worries about diabetes, satisfaction with treatment, satisfaction with life | Child               | 10 to 18         |
| Varni et al. (1998)   | Specific Condition/Pediatric Cancer QoL Inventory (PCQL) | Physical, Social, Psychological and Cognitive functioning and disease/treatment-related symptoms | Parent and child    | 10 to 18         |
| Marino et al. (2008)  | Specific Condition/Pediatric Cardiac Quality of Life Inventory (PCQLI) | Impact of Disease, Psychosocial impact, emotional, environment           | Child and Parent    | 8-18             |
| Simeoni et al. (2007) | Chronic Generic Measure/DISABKIDS                  | Independence, Physical Limitation, Emotion, Social Inclusion, Social Exclusion, Treatment | Child and Parent    | 8-16             |
| Maes & Bruil (1995)   | How Are You? (HAY)                                | Physical, Cognitive, Social Functioning, Physical complaints and Happiness | Child and Parent    | 7-13             |
| Robitail et al. (2007) | KIDSCREEN                                         | Physical Well-being, Psychological Well-being, Moods and Emotions, Self-Perception, Autonomy, Parent Relations and Home Life, Social Support and Peers, School Environment, Social Acceptance (Bullying), Financial Resources | Child and Parent    | 8-18             |
The Pediatric Cancer QoL Inventory (Varni et al., 1998) was developed to be a standardized assessment instrument to assess systematically pediatric cancer patient’s health-related quality of life outcomes. Large variability in symptoms and health-related problems were found as expected given the wide heterogeneity in the patient population sampled. The findings underscore the importance of measuring both patient report and parent report of patient symptoms and problems in pediatric cancer health related quality of life assessments.

The Pediatric Cardiac Quality of Life Inventory (PCQLI) (Marino et al., 2008) is a disease specific instrument for children and adolescents with congenital and acquired heart disease. This is the first disease-specific pediatric cardiac instrument—according to Marino et al., 2008—that is able to discriminate QoL scores between single-ventricle and biventricular congenital heart lesions in both patient and parent groups.

DISABKIDS (Simeoni et al., 2007) is a chronic generic measure. It is a project that took place in seven European countries and is the first instrument for children and adolescents with chronic conditions co-developed into six European languages (Dutch, English, French, German, Greek, Swedish). It allows comparisons across patients with a variety of chronic illnesses.

“How Are You?” is a generic QoL questionnaire (Maes & Bruil, 1995) is a self-report and parent report instrument developed in the Netherlands for 7 to 13 years old children. The items were generated by reviewing the literature and interviewing children with a chronic illness and their families as well as health professionals. The generic portion of the HAY covers functioning in daily life including: physical functioning, cognitive functioning, social functioning, physical complaints and happiness.

The KIDSCREEN instruments (Robitail et al., 2007) are generic QoL measures for healthy and with chronic illness children and adolescents as well as parent/proxy and have been translated and adapted for use in several languages. A score can be calculated and t-values and percentages will be available for each country stratified by age and gender.

4. Discussion

This mini review identified a small number of measures which could be used to assess HRQoL of children and adolescents with health problems. QoL concerns a person’s satisfaction with all aspects of life including physical, social, economic and psychological well-being. HRQoL is a special characteristic of this construct that focuses on the impact of health in a person’s well-being (Upton, Lawford & Eiser, 2008). By identifying problem specific situation for individual children a patient/treatment match can be more readily implement.

Cross-cultural instruments such as DISABKIDS and KIDSCREEN can be used in several countries and they are valuable in assessing HRQoL for children and adolescents with chronic illnesses. Including HRQoL instruments in public health surveys allows researchers to monitor population health status over time, detect subgroups within the general population who might be at risk of poor HRQOL and to assess the impact of public health interventions within a given population (Ravens-Sieberer et al., 2005).

Including children and adolescents in the assessing of their HRQoL it is very important in order to collect information directly from children and not to rely only to parents and caregiver’s opinions.

As Davis et al. (2006) mention it is essential for researchers to develop theories of QoL and empirically testing underlying assumptions of the instruments and in particular in paediatric QoL field it is important to plan programs and interventions in order to increase QoL.

It is common assumption that a lot of work needs to be done so as to improve the quality of life measures therefore the whole applicability in therapeutic work as well as in research. However we need to recognize that the focus on QoL has contributed to the emerging of children’s views for better treatment and care planning. At the same time we need to be aware of the limitations of current instruments without ignoring the whole QoL significant issues. We need to emphasize the need to look at QoL issues not only in terms of constructing narrow clinical instruments but enriching our views on child life experience living with a chronic illness.

References

Brütt, L.A., Sandberg, D.E., Chaplin, J., Wollmann, H., Noeker, M., Kottowska-Häggström, M. & Bullinger, M. (2009). Assessment of Health-Related Quality of Life and Patient Satisfaction in Children and Adolescents with Growth Hormone Deficiency or Idiopathic Short Stature-Part 1: A Critical Evaluation of Available Tools. *Hormone Research*, 72, 65-73.
Bullinger, M., Schmidt, S., Petersen, C., Ravens-Sieber, U. (2006). Quality of life-evaluation criteria for children with chronic conditions in medical care. *Journal of Public Health*, 14(6), 343-355.

Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Graham, H.K., Mehmert-Radjii, O. & Boyd, R. (2006). Paediatric quality of life instruments: a review of the impact of the conceptual framework on outcomes. *Developmental Medicine & Child Neurology*, 48, 311-318.

Davis, E., Nicolas, C., Waters, E., Cook, K., Gibbs, L. Gosch, A. & Ravens-Sieberer, U. (2007). Parent-proxy and child self-reported health-related quality of life: using qualitative methods to explain the discordance. *Quality of Life Research*, 16, 863-871.

Eiser, C. & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood*, 84, 205-211.

Faulkner, M.S. (2003). Quality of Life for Adolescents with Type 1 Diabetes: Parental and Youth Perspectives. *Pediatric Nursing*, 29(5), 362-368.

Goldbeck, L. & Melches, J. (2005). Quality of life in families of children with congenital heart disease. *Quality of Life Research*, 14, 1915-1924.

Ingersoll, G.M. & Marrero, D.G. (1991). A modified quality-of-life measure for youths: Psychometric Properties. *Diabetes Educator*, 17, 114-118.

Juniper, E.F., Guyatt, G.H., Feeny, D.H., Ferrie, P.J., Griffith, L.E. & Townsend, M. (1996a). Measuring quality of life in children with asthma. *Quality of Life Research*, 5, 35-46.

Juniper, E.F., Guyatt, G.H., Feeny, D.H., Ferrie, P.J., Griffith, L.E. & Townsend, M. (1996b). Measuring quality of life in the parents of children with asthma. *Quality of Life Research*, 5, 27-34.

Maes, S. & Bruil, J. (1995). Assessing the quality of life in children with a chronic illness. In J. Rodriguez-Marin (ed.), *Health Psychology and Quality of Life Research*. Alicante, Spain: Health Psychology Department, University of Alicante, pp 637-652.

Marino, B. et al. (2008). The development of the pediatric cardiac quality of life inventory: a quality of life measure for children and adolescents with heart disease. *Quality of Life Research*, 17, 613-626.

Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhar, M., Bruil, J., Duer, W., Auquier, P., Power, M., Abel, T., Czemy, L., Mazur, J., Czimbalmos, A., Tountas, Y., Hagquist, C., Kilroe, J & European KIDSCREEN Group (2005). KIDSCREEN-52 quality of life measure for children and adolescents. *Expert Rev. Pharmacoeconomics Outcomes Rev*, 5(2), 1-12.

Robitail, S., Ravens-Sieberer, U., Simeoni, M.C., Rajmil, L., Bruil, J., Power, M., Dür, W., Cloetta, B., Czemy, L., Mazur, J., Czimbalmos, A., Tountas, Y., Hagquist, C., Kilroe, A. & the KIDSCREEN Group (2007). Testing the structural and cross-cultural validity of the KIDSCREEN-27 quality of life questionnaire. *Quality of Life Research*, 16 (8), 1335-1345.

Sawyer, M.G., Reynolds, K.E., Couper, J.J, French, D.J., Kennedy, D., Martin, J., Staugas, R., Ziaian, T. & Baghurst, P.A. (2004). Health-related quality of life of children and adolescents with chronic illness- a two year prospective study. *Quality of Life Research*, 13, 1309-1319.

Simeoni, M.C., Schmidt, S., Muehlan, H., Debensason, D.& Bullinger, M. (2007). Field testing of a european quality instrument for children and adolescents with chronic conditions, the 37-item DISABKIDS Chronic Generic Module. *Quality of Life Research*, 16, 881-893.

Skinner, T.C., Hoey, H., McGee,H.M.,& Skovlund, S.E. (2006). A short form of the Diabetes Quality of life for Youth questionnaire: exploratory and confirmatory analysis in a sample of 2,077 young people with type 1 diabetes mellitus. *Diabetologia*, 49, 621-628.

Upton, P., Lawford, J. & Eiser, Ch. (2008). Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of Life Research*, 17, 895-913.

Varni, J.W., Katz, E.R., Seid, M., Quiggins, D.J.L., Friedman-Bender, A. & Castro, C.M. (1998). The Pediatric Cancer Quality of Life Inventory (PQLI). I. Instrument Development, Descriptive Statistics, and Cross-Informant Variance. *Journal of Behavioral Medicine*, 21 (2), 179-204.