Assessing quality of life in children and adolescents: development and validation of the Italian version of the EQ-5D-Y

Luciana Scalone1,2, Carlo Tomasetto3, Maria C. Matteucci3, Patrizia Selleri3, Serena Broccoli4, Barbara Pacelli5, Giulia Cavrini4

1Research Centre on Public Health, Department of Clinical Medicine and Prevention, University of Milano – Bicocca, Italy; 2CHARTA Foundation, Milan, Italy; 3Department of Education, University of Bologna, Italy; 4Department of Statistics, University of Bologna, Italy; 5Epidemiology Unit, Local Health Authority, Bologna, Italy

Correspondence to: Luciana Scalone, Research Centre on Public Health, University of Milano - Bicocca, Department of Clinical Medicine and Prevention, Villa Serena, Via Pergolesi 33, 20052 Monza, Italy. E-mail: luciana.scalone@unimib.it

Abstract

Background: Although assessment of Health Related Quality of Life (HRQoL) in paediatric populations is gaining interest, it is not sufficiently assessed. While a number of specific paediatric instruments have been developed, some users appear to prefer generic tools such as the EQ-5D, which is a widely used and recommended tool to describe and value health across many different adult populations. We adapted the EQ-5D generic instrument into the EQ-5D-Y (youth) for the assessment of HRQoL in children and adolescents, and investigated the feasibility, acceptability, validity and reliability of this new version of the tool.

Methods: The Italian version of the EQ-5D-Y was administered to 415 children and adolescents from a general population aged between 8 and 15, and to 25 paediatric patients diagnosed with Acute Lymphoblastic Leukaemia (ALL).

Results: The Italian version of the EQ-5D-Y was found to be feasible and acceptable for self-completion in the target age-group, with less than 1% refusing to complete it and no invalid answers given. Convergent and divergent validity tested with a child specific standard instrument was satisfactory overall. The test-retest reliability was moderate to good in all the domains of the descriptive system, and the Visual Analogue Scale (VAS) showed optimal levels of reliability (Intraclass Correlation Coefficient = 0.82). As regards known-group validity, compared with the youths from general population, the ALL patients reported more difficulties in four of the five domains of the descriptive system and, on average, had a lower VAS score.

Conclusions: The Italian version of the EQ-5D-Y shows to be a promising tool for assessing HRQoL in children and adolescents from 8 to 15 years of age. Future studies should further investigate and optimize its applicability to clinical research and carry out economic evaluations within the health system.

Key words: Health-Related Quality-of-Life (HRQoL), EQ-5D-Y, health, children, adolescents

Introduction

Health-Related Quality-of-Life (HRQoL) in paediatric populations is gaining particular interest in the contexts of research, health care and policy making, and a number of instruments for measuring HRQoL in youths have been developed in the last decade [1-3]. Most of the available instruments for measuring HRQoL in paediatric populations have been specifically developed for children or adolescents. However, previous research suggests that it is also possible to measure HRQoL in youths by modifying existing HRQoL instruments used for investigating HRQoL in adults, as long as the wording of instructions, items and response options are adapted to the needs of these younger respondents [2]. This latter approach has some potential advantages for clinical research and health economic evaluations, such as facilitating the comparison of HRQoL between different age groups (e.g., adults and youths), or enabling the tracking of individual changes in HRQoL over time. It should be noted that this would be particularly beneficial in longitudinal studies investigating HRQoL in chronic or progressive conditions, or in long-term treatments that continue from childhood through to adulthood.

The EQ-5D is a brief, generic measure of HRQoL designed for use in adult populations [4]. It consists of two parts: a descriptive system including five domains – mobility, self-care, usual activities, pain or discomfort, anxiety or depression – and a Visual Analogue Scale (VAS), which quantifies general HRQoL with a score