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

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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.