

Variation of health-related quality of life assessed by caregivers and patients affected by severe childhood infections

ABSTRACT

Background

To quantify the variation in health-related quality of life derived from young patients and their carers using different instruments.

Methods

A hospital-based cross-sectional survey was conducted between August 2010 and March 2011. Children with meningitis, bacteremia, pneumonia, acute otitis media, hearing loss, chronic lung disease, epilepsy, mild mental retardation, severe mental retardation, and mental retardation combined with epilepsy, aged between 5 to 14 years in 7 tertiary hospitals were selected for participation in this study. Three health-related quality of life instruments were applied to both paediatric patients (self-assessment) and caregivers (proxy-assessment).

Results

The EQ-5D scores were lowest for meningitis, bacteremia, pneumonia, acute otitis media, chronic lung disease, epilepsy and mild mental retardation, whereas the Health Utilities Index Mark 3 (HUI3) scores were lowest for hearing loss, severe mental retardation and mental retardation combined with epilepsy. Comparing patient and proxy scores, the EQ-5D exhibited high correlation ($r = 0.77$) while in the Health Utilities Index Mark 2 (HUI2) and HUI3 patient and caregiver scores were moderately correlated ($r = 0.59$ and 0.67 respectively). The mean difference between self and proxy-assessment using the HUI2, HUI3, EQ-5D and EQ-VAS scores were 0.03, 0.05, -0.03 and -0.02, respectively. In hearing-impaired and chronic lung patients the self-rated health-related quality of life (HRQOL) differed significantly from their caregivers.

Conclusions

Caregivers can be appropriate proxies for HRQOL measurement in young patients. The EQ-5D provides the highest correlation in HRQOL measures obtained from the two populations.

Key Words

infection, chronic conditions, child, health-related quality of life, utility, proxy