Quality of life before intensive care admission: agreement between patient and relative assessment

Abstract  Objective: To assess the agreement between patients and relatives concerning the formers’ quality of life (QOL) before intensive care unit (ICU) admission.  Design: Prospective study involving direct interviews of patients and relatives during ICU stay.  Setting: Two four-bed surgical-medical ICUs in a 960-bed teaching hospital.  Patients and methods: A hundred seventy-two adult, co-operative patients consecutively admitted to ICU for more than 24 h, and their relatives were interviewed. The instruments used were two questionnaires suitable for ICU patients: QOL-IT and QOL-SP. Interobserver reproducibility was investigated in 36 patients.  Results: Interobserver reproducibility was nearly perfect (weighted Kappa 0.99 for QOL-IT and QOL-SP). Considering global scores, weighted Kappa was 0.78 for QOL-IT and 0.82 for QOL-SP, with the mean difference between patients and relatives lower than 0.3 for both scores but with limits of agreement wider than 4. Among the items, concordance was excellent in the areas of physical activity and social life for both questionnaires. Gender, living together with the patient and the degree of relationship of relatives did not influence the agreement.  Conclusions: The relatives give global scores for both instruments which can be regarded as acceptable substitutes for those given by patients. However, the wide limits of agreement should make investigators cautious in analysing together scores generated by patients and by relatives. The emotional dimension seems to be assessed less accurately by relatives than the physical one.

Keywords  Quality of life  Intensive care  Proxy responses

Introduction

The principle of liberty, born of the French revolution (liberté, fraternité, égalité), permeated bioethics and bred the principle of autonomy: each individual has the right to determine his own values. When an individual becomes a patient, his values are important for the physician, who needs to know the patient’s quality of life (QOL) before the illness. In fact QOL consists of two dimensions: the subjective, that represents those aspects that are of value to the individual[1], and the objective, which considers health status measurements [2].

Clinicians desire to know the pre-morbidity QOL in order to respect the patient’s preference for intensive care, because a low QOL before intensive care unit (ICU) admission has been shown to be associated with increased in-hospital mortality [3, 4] and worsened QOL 1 year after ICU discharge [5]. Some patients admitted to the ICU cannot answer questions about their QOL, due to their critical condition. Usually, when the
patient cannot co-operate, the intensivist asks the next-of-kin about a patient’s QOL before ICU admission. However, many questions arise: can the information given by the relative replace that of the patient? If there is a difference between them, how much disagreement can be regarded as acceptable?

Investigations on this topic have been performed in chronically or terminally ill patients and their carers [6] and in chronically ill veterans enrolled in adult day health care and their proxies [7] with the Sickness Impact Profile (SIP). They concluded that the agreement is better if the surrogate is a family member and that physical, not psychosocial, scores are highly correlated. An investigation assessing functional status, physical health and cognitive capacity in elderly hip fracture patients and proxies [8] demonstrated that the proxies tend to overestimate the patient’s disability. Considering patients admitted to the ICU, Rivera Fernandez et al. [9], validating a Spanish QOL questionnaire, reported good correlation and lack of statistically significant difference between patient and family member. Badia et al. [10], using EuroQol, suggested this questionnaire could be reliably used with proxies. Diaz-Prieto et al. [11], using EuroQol-5 dimensions, observed a fair to moderate agreement between patient and proxy responses and Rogers et al. [12], using Short Form 36, concluded that relatives are able to give a good assessment only of the functional aspects of QOL.

The aim of the present study was to assess the agreement between the QOL before ICU admission recorded by patients and that reported by relatives using two questionnaires suitable for ICU patients.

Patients and methods

This prospective study was performed in two four-bed surgical-medical ICUs of a 960-bed university teaching hospital. In the hospital there are two additional adult ICUs (a 10-bed mixed ICU and a 6-bed coronary care unit), no cardiac surgery and no burn units. The ICUs where the study was performed serve all thoracic, vascular and high-risk abdominal surgery patients and about half of the hospital medical wards’ patients.

The study was carried out between 07-01-1997 and 06-07-1997. All consecutively admitted adults (age >18 years) who stayed in the ICU more than 24 h were considered. Patients readmitted during the study period were enrolled only at the time of their first admission. The following data were recorded: demographic information, type of ICU admission (medical or surgical, scheduled or urgent), SAPS II [13], APS and APACHE II [14] scores. The study was conducted according to the principles of the Helsinki Declaration.

Before beginning the study, two medical doctors (C.G. and S.C.) had training in questionnaire administration, to use the same behaviour and words to ask questions of patients and their relatives. During the ICU stay, the interviewers assessed whether the patient was aware of self and environment and able to answer questions, that is to be co-operative. Then they explained the purposes of the study to all co-operative patients to obtain their informed consent. Standardised instructions indicated that the questions were related to the patient’s condition about 3 months before ICU admission, to avoid the effect of the illness responsible for ICU admission. Moreover, the interviewers explained the purposes of the study to the relatives visiting the patients and, if they gave their informed consent, the two questionnaires were administered by direct interview, while it was emphasised that they concerned the patient’s QOL about 3 months before ICU admission. If there was more than one relative, the one considered the next of kin by the others was interviewed. To obtain patient-relative pairs, a relative answering the questionnaires was found for each patient answering the questionnaires. Data collected on relatives included gender, degree of relationship and if living with the patient.

Instruments used in the study

The patient’s quality of life was assessed through two questionnaires, which were: (1) generic instruments, which can be used in patients with different illnesses admitted to the ICU; (2) suitable for elderly patients, namely sensitive for individuals at an already restricted level [15]; (3) simple, to be used by patients like those staying in ICU [16]. Briefly, the Italian quality of life questionnaire (QOL-IT) has been validated in this country [17] and the items of the version used are reported in Appendix 1. The answers regarding physical activity and social life are ordered according to the requested ability and the score is given to the first "yes" reported by the patient. The global score is obtained by the sum of scores of different items and ranges from 0 to 20, with the “0” value implying the best QOL. The Spanish quality of life questionnaire (QOL-SP) has been validated in that country [9] and their 15 items are reported in Appendix 2. The score is given to each item according to the answers “yes” or “no”. The items of QOL-SP are grouped in the following three subscales: basic physiological activities (BPA), normal daily activities (NDA) and emotional state (ES). The range of scores for the BPA subscale is 0–9, for NDA 0–15, for ES 0–5 and for the global score, obtained by the sum of subscale scores, 0–29, considering that “0” value implies the best QOL.

Reproducibility

To demonstrate that stable patients show more or less the same results on repeated administration and to verify whether changing interviewer can change the results (high signal-to-noise ratio) [18], interobserver reproducibility of both questionnaires was analysed in a group of 36 patients (males 64%, mean age 72.1 ± 9.7 years). This number corresponds to α error = 0.01 and power test = 0.95, considering an expected correlation coefficient higher than 0.70. The usual time interval between the interviews performed by the two doctors separately was 2 days.

Statistical analysis

Data are expressed as mean ± 1 SD, when indicated. Numerical variables with ordered categories are described as median and interquartile range (25th and 75th percentiles).

Statistical analysis was carried out using a software package (SPSS 8.0 Chicago, Ill., USA) and p values less than 0.05 were selected as significant. Student’s t-test was used for normally distributed continuous variables and chi-square statistics for categorical data.

The Kolmogorov-Smirnov one-sample test for goodness-of-fit showed the distribution of QOL scores was not normal. Therefore,