Using the EuroQol-5D to measure changes in quality of life 12 months after discharge from an intensive care unit

**Abstract**  
**Objective:** To compare changes in the health-related quality of life (HRQOL) of critical care patients by diagnostic category.  
**Design:** Prospective, cohort study. HRQOL assessed 3 months before admission and 1 year after discharge from the intensive care unit (ICU). Patients were classified as: trauma injury (TI), scheduled surgery (SS), unscheduled surgery (US), and other medical conditions (MC).  
**Setting:** Department of Intensive Medicine, University Hospital of Bellvitge, Barcelona, Spain.  
**Patients:** Three hundred and thirty-four patients admitted to ICU from October 1994 to June 1995 (62 TI patients, 181 SS patients, 19 US patients, and 72 MC patients).  
**Interventions:** Surgical and medical procedures.  
**Measurements and results:** Changes in HRQOL varied considerably between diagnostic categories, with TI patients having significantly worse HRQOL one year after discharge from the ICU compared to 3 months prior to admission [change in median EQ Visual Analogue Scale (EQ-VAS) score from 100 to 65, \( P < 0.001 \), and SS patients reporting improved HRQOL (change in median EQ-VAS scores from 60 to 75, \( P < 0.001 \)). Slight deterioration was observed in the other two diagnostic categories. Twelve months after discharge, the EQ dimension in which the largest proportion of patients in all groups reported problems was usual activities (47% of SS and US patients; 69% of TI patients). Using proxy scores at baseline or follow-up had little effect on results.  
**Conclusions:** The degree and direction of change in ICU patients’ HRQOL 1 year after discharge depends considerably on diagnostic category. Proxy responses can be reliably used with the EQ-5D when measuring change in HRQOL.  

**Keywords** EuroQol 5D · Health status · Health-related quality of life · Intensive care

**Introduction**  
Health-related quality of life (HRQOL) instruments are increasingly used to measure patients’ health status and to evaluate the effectiveness of health care interventions [1]. When measuring the outcomes of critical care patients, HRQOL measures are an important complement to other outcome indicators, such as survival.

A number of studies have examined patients’ HRQOL at varying times after discharge from intensive care units (ICU) [2, 3, 4, 5]. Cross-sectional studies comparing HRQOL in patients discharged from the ICU with the health status of general population samples have found considerably better HRQOL in the general population [6]. Evidence for poorer health status among patients discharged from the ICU may be misleading, however, if the prior health status of the ICU patient is
not taken into account. In one of the few longitudinal studies performed to date, a more complex picture emerged, in which it was found that whilst level of activity and activities of daily living had deteriorated 12 months after discharge from the ICU, overall perceived health had improved [7].

A more accurate picture of ICU outcomes might also be obtained if the diagnostic category is taken into account, as prior health status has been shown to vary across such categories [8]. Presenting results for ICU patients as a whole may obscure the fact that some types of patient improve whilst others remain stable or deteriorate. One study which examined this question found that health status 6 months after discharge from the ICU differed between COPD, suicide, and other patients [9], although HROQOL was not measured longitudinally. In a longitudinal study in ICU patients in Spain, a statistically significant reduction in HROQOL was found for coronary and medical groups, but not for surgery patients [10].

Coupled with the need to examine data longitudinally, and to take into account the possibility of variations in outcomes by diagnostic categories, the need to use proxy respondents is common in this population of patients [8], and the effect of using proxy respondents in longitudinal studies has rarely been examined to date [11]. One of the few studies to do so found that using proxy-patient ratings may tend to underestimate the degree of benefit [7].

The aim of the present study was to compare the HROQOL of patients in four diagnostic patient categories at admission (trauma, unscheduled surgery, scheduled surgery, medical) 3 months prior to ICU admission and 12 months after discharge. A further objective was to determine whether the degree of perceived change would be similar if proxy, as opposed to patient, ratings of health status were used to describe health status at the first visit.

Patients and methods

The patient sample used for the present study has been described in detail elsewhere [8]. Of the patients included in the earlier study, 375 were discharged alive from the hospital (69 trauma patients, 198 scheduled surgery patients, 23 unscheduled surgery patients, and 85 medical patients). These patients formed the initial sample for the follow-up study reported here. Patients for whom a follow-up rating at 12 months after discharge could not be obtained were considered lost to follow-up. Permission to perform the study was obtained from the Hospital Ethics Committee.

Health-related quality of life measurement

HROQOL was measured using the Euroqol 5D (EQ-5D) questionnaire [12]. The EQ-5D is a generic health status measure consisting of three parts: the descriptive system or self-classifier, a visual analogue scale (EQ-VAS) for the measurement of overall self-rated health, and the EQ Index. In the present study only the results using the descriptive system and the EQ-VAS are described. The descriptive system measures health in five dimensions: mobility (MO), self-care (SC), usual activities (UA), pain/discomfort (PD), and anxiety/depression (AD). Patients mark one of three levels of severity (level 1 = no problem, level 2 = some/moderate problems, level 3 = severe/extreme problems) in each dimension, and can therefore be classified into any one of 243 (3^5) possible health states. The EQ-VAS is a 20-cm vertical, hash-marked visual analogue scale on which respondents are asked to rate their overall health between 0 (worst imaginable health state) and 100 (best imaginable health state). The Spanish version of the EQ-5D has been validated in the Spanish population [13].

In order to measure health status 3 months prior to admission to the ICU, the EQ-5D was completed by proxies when patients were admitted to the ICU, as well as by patients themselves whilst in the ICU and when their health state permitted it (baseline visit). Proxies were defined as persons who had lived with the patient for at least the previous 3 years or someone close to the patient who had known the patient for the same amount of time [8]. Both proxies and patients were asked to rate patient’s HROQOL 3 months before admission to the ICU. Agreement between self-administered and proxy-administered scores were found to be high for the MO, SC, and UA dimensions, but slightly poorer for the PD and AD dimensions [8]. Given that using proxy-patient ratings may tend to underestimate the degree of benefit [7], separate analyses were performed to determine whether using patient-patient or proxy-patient ratings led to differences in results, either in individual EQ dimensions or on the EQ-VAS.

Follow-up administration (second visit)

The hospital patient registry was used to obtain information on patients who had died in the hospital following discharge from the ICU. Patients discharged alive and/or family members of patients discharged alive were contacted to determine the patient’s survival status and their willingness to participate in the study.

Patients confirming their willingness to participate were sent the following materials by mail: a) a letter explaining the study objectives and requesting his/her collaboration as well as instructions for completing the questionnaire; b) a letter to a relative or other proxy, explaining the study objectives and requesting his or her collaboration in responding for the patient if necessary. Relatives were asked to help patients if they were able to respond to the questionnaire but had difficulties reading or writing. In the case of serious disability, relatives were asked to answer the questionnaire on behalf of the patient; c) a copy of the EQ-5D questionnaire; d) a stamped addressed envelope with a return address for the completed questionnaires.

If no reply was received after 3 weeks, the patient was contacted by telephone. If the patient or a relative was available he or she was asked if they had received the questionnaire. If they had not received the questionnaire the address was confirmed and the material was sent again. If the material had been received, the patient and/or relative was asked if they had completed the questionnaire, and if not they were asked to respond by phone. Patients without a telephone or those not wishing to complete the questionnaire by phone were interviewed at home by intensivists from the ICU (MG, HT, EF).