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

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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 HRQOL was not measured longitudinally. In a longitudinal study in ICU patients in Spain, a statistically significant reduction in HRQOL 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 HRQOL 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

HRQOL 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 problems, 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 HRQOL 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).

Table 1 Socio-demographic and clinical characteristics of surviving patients. (*LOS*: length of stay)

Comparisons between four groups of admission diagnostic categories: Kruskal-Wallis, *$P < 0.001$.

	Trauma	Scheduled	Unscheduled	Medical	All
Number of patients	62	181	19	72	334
Male (%)	77	62	42	64	64
Low level of education (%)	56	78	79	86	75.5
Median (interquartile range)					
Age*	32 (24–55)	61 (52–66)	65 (53–68)	55 (40–64)	57 (44–65)
SAPS II*	31 (22–39)	26 (19–32)	41 (34–49)	30 (20–40)	28 (20–35)
ICU LOS*	16 (9–27)	4 (2–6)	19 (11–28)	6 (3–22)	5 (3–16)

Statistical analysis

The socio-demographic and clinical characteristics of patients in the four diagnostic categories were compared using the Kruskal-Wallis test. Scores 3 months prior to admission to the ICU and 12 months after discharge were analyzed for the sample as a whole and by diagnostic category. For the EQ self-classifier, percentages of patients reporting problems on each EQ-5D dimension at both visits were compared using the chi-squared test, and EQ-VAS scores of patients at baseline and follow-up visits were compared using the Wilcoxon matched-pairs signed-rank test, due to non-normal distribution of EQ-VAS scores. For the same reason, scores on the EQ-VAS are expressed in medians and inter-quartile ranges.

The chi-squared test was used to compare proportions on each EQ dimension at the baseline visit between proxy and patients, and the Wilcoxon matched-pairs signed-rank test was used to compare EQ-VAS scores at the two visits and also to compare the size of change in EQ-VAS scores when using proxy-patient ratings or patient-patient ratings. When calculating the percentage of patients at each level of severity in each dimension of the EuroQol-5D, if there were less than five patients in more than one of the three levels, levels 2 and 3 (moderate and severe problems respectively) were combined and the analysis was performed for patients reporting problems compared to patients reporting no problems (level 1). Values of $P < 0.05$ were regarded as statistically significant.

Results

After one year, 12 (3.2%) patients from the original sample could not be located and 41(11.4%) had died (seven in the trauma group, 17 in the scheduled surgery group, four in the unscheduled surgery group, and 13 in the medical group). Completed questionnaires were obtained for all of the remaining 334 patients at the second visit (88.6% of the original sample). Two hundred and seventy-three (81.7%) responses were obtained in telephone interviews, whilst 22 (6.6%) were obtained in face-to-face interviews performed in the patient's home. Thirty-nine (11.7%) forms were self-administered and returned by mail. Proxy responses in the second visit had to be used for 28 (8%) patients.

Table 1 shows the number of patients per diagnostic category and the socio-demographic and clinical characteristics of patients in each category. There was no comparison of the socio-demographic and clinical characteristics of the responding patients and those for whom responses could not be obtained, as the latter only constituted 3.2% of the original sample.

Table 2 shows the number and proportion of patients reporting problems in each EQ-5D dimension as well as EQ-VAS scores before admission to and 1 year after discharge from the ICU for the group as a whole and for each diagnostic category. In all diagnostic categories, except the scheduled surgery group, the number and percentage of patients reporting problems increased at the second visit in almost all EQ dimensions, though the increase in the number and proportion of patients reporting problems was noticeably greater in the trauma group. In the unscheduled surgery and medical groups, deterioration was generally slight and not statistically significant. In the scheduled surgery group, there were noticeable improvements in all dimensions of the EQ-5D, with the largest difference being in the mobility dimension, where 79% of patients reported no problems 1 year after discharge compared to 48% 3 months prior to admission to the ICU. Self-rated overall health on the EQ-VAS remained unchanged for the group as a whole, though when the data were examined by diagnostic category, statistically significant deterioration was seen in the trauma group ($P < 0.001$), and statistically significant improvement in the scheduled surgery group ($P < 0.001$). There was a slight and statistically significant ($P < 0.05$) deterioration in the unscheduled surgery and medical groups. As with the study sample as a whole, however, the overall results mask substantial variation within the latter two groups.

Table 3 shows in more detail the direction and size of change in health status for each diagnostic category and for each EQ dimension. In each EQ dimension, patients can remain the same, or improve or worsen by 1 or 2 levels (for example, in the pain/discomfort dimension patients can move from 'moderate pain/discomfort' to 'no pain/discomfort', which would represent an improvement of one level, or they can move from 'extreme pain/discomfort' to no pain/discomfort', which would represent an improvement of 2 levels). This table shows that, for example, although there may appear to be little change in patients in the medical category overall, a considerable number of patients in that category actually reported improved health, particularly in the pain/discomfort and anxiety/depression dimensions, although

Table 2 Change in HRQOL by diagnostic category on admission. (*Pre* 3 months before ICU admission, *Post* 1 year after ICU discharge, *NS* non-significant)

	All		Trauma		Scheduled		Unscheduled		Medical	
	n = 334		*n* = 62		*n* = 181		*n* = 19		*n* = 72	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Number (%)										
Mobility										
No problems	209 (63)	229 (69)[b]	59 (95)	28 (45)[c]	86 (48)	143 (79)[c]	15 (79)	13 (68)	49 (68)	45 (63)
Some problems	123 (36)	91 (27)	3 (5)	28 (45)	95 (52)	37 (21)	4 (21)	5 (26)	21 (29)	21 (29)
Extreme problems	2 (1)	13 (4)	0	6 (10)	0	0	0	1 (5)	2 (3)	6 (8)
Self-care										
No problems	301 (90)	258 (77)[c]	59 (95)	34 (55)[c]	160 (88)	164 (91)	19 (100)	13 (68)	63 (88)	47 (65)[a]
Some problems	29 (9)	56 (17)	3 (5)	22 (35)	19 (10)	13 (7)	0	4 (21)	7 (10)	17 (24)
Extreme problems	4 (1)	19 (6)	0	6 (10)	2 (1)	3 (2)	0	2 (11)	2 (3)	8 (11)
Usual activities										
No problems	197 (59)	160 (48)[b]	59 (95)	19 (31)[c]	75 (41)	95 (53)[c]	17 (89)	10 (53)	46 (64)	36 (50)
Some problems	91 (27)	104 (31)	3 (5)	22 (35)	68 (38)	59 (33)	2 (11)	5 (26)	18 (25)	18 (25)
Extreme problems	46 (14)	69 (21)	0	21 (34)	38 (21)	26 (14)	0	4 (21)	8 (11)	18 (25)
Pain/discomfort										
No problems	156 (47)	176 (53)	54 (87)	31 (50)[a]	52 (29)	97 (54)[c]	10 (53)	10 (53)	40 (56)	38 (53)
Some problems	142 (42)	135 (41)	7 (11)	25 (40)	104 (57)	72 (40)	7 (37)	8 (42)	24 (33)	30 (42)
Extreme problems	36 (11)	22 (6)	1 (2)	6 (10)	25 (14)	11 (6)	2 (11)	1 (5)	8 (11)	4 (6)
Anxiety/depression										
No problems	194 (58)	219 (66)	55 (88)	38 (61)[b]	86 (48)	124 (69)[c]	14 (74)	13 (68)	39 (54)	44 (61)
Some problems	99 (30)	78 (23)	6 (10)	14 (23)	68 (38)	42 (23)	4 (21)	3 (16)	21 (29)	19 (26)
Extreme problems	41 (12)	36 (11)	1 (2)	10 (16)	27 (15)	14 (8)	1 (5)	3 (16)	12 (17)	9 (13)
Vegetative state	0	0	0	0	0	1	0	0	0	0
Median (interquartile range)										
EQ-VAS score	70 (50–90)	74 (50–88)	100 (90–100)	65 (50–80)	60 (40–75)	75 (60–90)	85 (65–90)	75 (50–83)	78 (50–90)	70 (45–85)
Statistical significance	NS	$P < 0.001$	$P < 0.001$	$P < 0.05$	$P < 0.05$					

[a]Changes on a given EQ dimension significant at $P < 0.05$. Chi-squared test
[b]Changes on a given EQ dimension significant at $P < 0.01$. Chi-squared test
[c]Changes on a given EQ dimension significant at $P < 0.001$. Chi-squared test

the number of patients reporting improvements in those dimensions was balanced by the number of patients reporting deterioration.

Table 4 shows a comparison of using proxy-patient or patient-patient median ratings for the two visits using the EQ-VAS. Although proxy EQ-VAS ratings were higher at the first visit, which means that using these ratings at the first visit would tend to slightly overestimate the reduction in HRQOL, there were no statistically significant differences in the size of change on the EQ-VAS using proxy-patient or patient-patient scores. EQ-VAS values may differ from those shown in Table 2 as patients for whom only proxy ratings could be obtained at either of the visits were excluded from the analysis for Table 4.

Discussion

Previous studies have found that the quality of life of patients surviving ICU tends to be significantly poorer than that prior to admission [7, 10], and poorer than that of samples of the general population [2, 5, 6, 14]. Nevertheless, in determining the effectiveness of intensive care it is important to take into account both the health status of patients before admission to the ICU as well as their diagnostic category. Previous studies have also indicated [14], that whilst previously healthy patients suffer considerable deterioration in HRQOL due to serious illness or insult, those with a pre-existing chronic condition and consequently with diminished HRQOL, improve slightly or do not change. When patients included in the present study were analyzed as a group, there was apparently little change in health status. However, a more in-depth analysis showed that outcomes varied considerably according to diagnostic category, with trauma patients experiencing a considerable worsening in quality of life, scheduled surgery patients experiencing a considerable improvement in quality of life, and unscheduled surgery and medical patients experiencing a slight deterioration.

Table 3 Changes between baseline and follow-up visit in terms of number of levels of change in each EQ-5D dimension, by diagnostic category

	Increased 2 levels	Increased 1 level	No change	Decreased 1 level	Decreased 2 levels
Mobility					
Trauma	0	1	29	26	6
Scheduled	0	67	103	11	0
Unscheduled	0	2	13	3	1
Medical	0	8	43	6	5
All	0	78	188	46	12
Self-care					
Trauma	0	2	33	21	6
Scheduled	1	14	154	10	2
Unscheduled	0	0	13	4	2
Medical	0	5	46	15	6
All	1	21	246	50	16
Usual activities					
Trauma	0	2	18	21	21
Scheduled	17	41	85	32	6
Unscheduled	0	1	9	6	3
Medical	1	6	44	14	7
All	18	50	156	73	37
Pain/discomfort					
Trauma	0	3	33	21	5
Scheduled	9	65	86	17	4
Unscheduled	0	6	9	3	1
Medical	3	17	31	21	0
All	12	91	159	62	10
Anxiety/depression					
Trauma	1	3	37	11	10
Scheduled	13	50	94	22	2
Unscheduled	0	3	12	2	2
Medical	7	13	34	17	1
All	21	69	177	52	15

Table 4 Comparison of patient and proxy scores on the EQ EQ-VAS at baseline and patient scores after 12 months, by diagnostic category. There were no statistically significant differences on the EQ-VAS using proxy-patient at baseline. (*Pre* 3 months before ICU admission
Post 1 year after ICU discharge.)

	Proxy responses Pre	Patient responses Pre	Patient responses Post
Median (interquartile range)			
Trauma ($n = 40$)	100 (90–100)	90 (80–100)	75 (55–80)
Scheduled ($n = 174$)	60 (40–70)	60 (40–70)	75 (60–90)
Unscheduled ($n = 16$)	88 (63–95)	83 (80–95)	78 (50–88)
Medical ($n = 58$)	80 (55–95)	78 (50–90)	70 (50–85)

Critical care patients differ as to the cause of their admission to the ICU, and these differences are likely to produce different expectations in relation to their health. Some patients are admitted as a result of acute life-threatening illnesses or insults, whilst others are admitted due to exacerbations of pre-existing chronic pathologies, or are admitted for surgical interventions aimed at improving their HRQOL. Trauma patients are the paradigm of patients with good prior HRQOL who suffer a severe life-threatening process. The price of their survival is a deterioration in their HRQOL due to the injuries sustained [15, 16]. On the other hand, patients receiving scheduled surgery have a previously reduced HRQOL and undergo surgery in an attempt to improve their HRQOL and/or survival. It should also be noted that patients receiving scheduled surgery are submitted to careful pre-surgery screening to determine the likelihood of success, a procedure which may contribute to the differences found between groups. Likewise, the scheduled surgery group assessed here included high numbers of cardiac surgery patients and liver transplant patients, who have been shown to have a good response to treatment [17, 18]. A different case-mix would probably lead to different results.

Even within diagnostic categories, the situation may be more complex than it first appears. For example, within the category of medical patients, although overall there appeared to be little change, a substantial number

of patients reported improvements in the pain/discomfort and anxiety/depression dimensions. Results here are also likely to depend on case mix. In the present study, the group of medical patients included patients with pneumonia, acute coronary disease and acute congestive heart failure, poisonings and acute intoxication, stroke, pulmonary embolism, acute haematological crisis, exacerbated COPD, and other medical diagnoses with life-threatening septic and respiratory complications. It is also notable that those patients in the unscheduled surgery group who survived showed considerably less deterioration than patients in the trauma group. This group consisted of patients with acute cerebral hemorrhages, aortic aneurysms or acute peritonitis. Unfortunately, the low number of patients in this group limited the analysis.

A more complete picture of outcomes after critical care in all four diagnostic categories might also require a longer follow-up period, although it is notable that a study of trauma patients at 12 months and 18 months after discharge from the ICU using the Quality of Well-Being Scale did not indicate improvement in those patients between the 12- and 18-month measurement interval [19].

Given the characteristics of ICU patients, it is important to examine the possible effect of using proxy ratings as opposed to patient ratings, especially at the first visit, when a substantial proportion of patients might not be able to complete an HRQOL questionnaire. In the present study, we found that although using proxy scores on the EQ-VAS for the first visit would tend to overestimate the size of the deterioration in the majority of diagnostic categories, the differences in the size of the change were not statistically significant, which means that, although these differences should be borne in mind, the EQ-VAS at least, when used with proxies at the first visit, provides a reasonably accurate estimate of change in the health status of ICU patients. The same was true for EQ dimensions, although the results are not shown here.

From the point of view of the management of these patients, it is noticeable in all of the diagnostic categories that pain in particular appears to be poorly controlled, with almost half of all patients reporting moderate pain/discomfort 12 months after discharge, and 11 % of trauma patients reporting very severe pain on the day of completing the questionnaire. These levels are approximately double those of age and sex-matched reference samples from the non-institutionalised general population [13], and suggest that more could be done to improve patient's quality of life and therefore outcomes on this dimension of HRQOL. Levels of anxiety/depression are also considerably above those for the general population and suggest that means could be sought for improving psychological well-being.

Potential limitations of this study include the fact that the number of patients in some diagnostic categories was somewhat low, particularly in the unscheduled surgery group, and studies with larger numbers are needed to confirm the results found here. It is also possible that recall bias might have influenced patients' ratings of their health status 3 months prior to admission to the ICU, whereby their poor health status in the ICU may have led them to overrate their health status 3 months earlier. It is difficult to control for this type of effect, although the fact that there was considerable agreement between patients and proxies regarding the prior rating may indicate that the effect is not substantial.

In conclusion, a more accurate picture of outcomes in intensive care can be obtained when analysis is carried out by diagnostic categories. There was substantial variability in outcomes by diagnostic category, and even within each diagnostic category. Future studies of outcomes in intensive care units should take this variability into account. Future studies in this area might also consider using the EQ-5D, which proved to be a useful tool in this population.

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