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Survival and quality of life after intensive care

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Abstract *Objective:* To determine survival and changes in quality of life (QOL) after hospital discharge in patients who had stayed in an intensive care unit (ICU).
Design: Prospective study by direct interviews during ICU stay and 6 months after hospital discharge.
Setting: Surgical-medical ICU.
Patients and methods: We interviewed cooperative, adult patients admitted consecutively to the ICU for more than 24 h, living near the hospital, who gave informed consent. The following QOL domains were investigated: residence, physical activity, social life, perceived QOL, oral communication and functional limitation.
Results: One-year survival was 82.4% (predicted 84%). Mortality was 36.3% after urgent neoplastic surgery, 19.4% for medical admissions and 4.9% after non-neoplastic surgery. Of 160 patients studied, eight cases, older and already deteriorated at the first interview, could not respond to the perceived QOL item after ICU discharge. In the other 152 patients, physical activity was reduced in 31% (usually slightly), social life had worsened in 32% and functional limitation increased in 30%. The perceived QOL did not change.
Conclusions: After hospital discharge, the survival of ICU-admitted patients is comparable to that of the general population and not related to ICU treatments. Most patients maintain their physical activity and social status at the preadmission level. Any worsening, if present, is slight and does not influence perceived QOL.

Key words Outcome · Intensive Care · Quality of life

Introduction

Intensive care causes suffering to patients and their relatives and is also expensive. As it was primarily instituted to save lives, the outcome initially focused only on survival. The Second European Consensus Conference in Intensive Care Medicine stated: "mortality is an insufficient measure of ICU outcome ... Future outcome evaluation of intensive care should incorporate quality of life" [1]. Quality of life (QOL) does not mean the same for all investigators: some focus only on health status, sometimes collecting information from patients' relatives [2, 3], while others, considering "QOL a uniquely personal perception" [4], assess both health-related dysfunction and perceived QOL [5]. The evaluation of a therapy should include a comparative study. If we consider intensive care as a treatment, we should measure QOL before and after ICU admission and, as a consequence, the patients who are not able to cooperate during their ICU stay should not be included. Some authors studied only post-ICU status [2, 5–8], some considered it before and after ICU [3, 9, 10], and only one study has investigated perceived QOL before and after ICU [11].

Our study was conducted in a group of ICU-admitted patients to determine long-term survival and to analyse

change in physical activity, social functions and perception of life measured by a direct interview during their ICU stay and 6 months after hospital discharge.

Patients and methods

This prospective study was performed in a two four-bed surgical-medical ICUs of a 1100-bed teaching hospital with two additional adult ICUs (a 10-bed mixed ICU and a 6-bed coronary care unit). Our ICUs serve all thoracic, vascular and high-risk abdominal surgery patients and about half of the medical ward patients of the hospital. There are no cardiac surgery or burn units.

The study was done between 1 July 1993 and 31 June 1994. 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 (due to trauma, medical or surgical, scheduled or urgent and neoplastic or non-neoplastic), SAPS II [12], APS and APACHE II [13] scores computed as indicated by the authors. Subsequently, in reviewing patients' medical records collected in our database, we noted underlying diseases, grouped according to the organ system concerned (cardiovascular, respiratory, renal, hepatic or other), if the patient was on medication for that illness or if the diagnosis was unequivocal following medical history or instrumental examination. We also recorded if the ICU course was complicated and treatments performed in the ICU (blood transfusion, dopamine infusion, antiarrhythmic drug administration and artificial ventilation lasting more than 3 days).

During the ICU stay, two medical doctors (M. B. and P. C.), each in one of the two ICUs considered, interviewed all cooperative patients resident less than 30 km from the hospital and explained the purposes and the requirements of the study to obtain informed consent. All the patients who accepted answered the questions which were related to their condition about 3 months before ICU admission [3], to avoid the effect of the illness responsible for ICU admission. The questionnaire was usually administered the day after ICU admission at 2 p.m.; if the patient appeared not fully alert at that time, it was administered the day after. The follow-up was done at 6 months, when the interviewer contacted surviving patients to invite them to participate in a survey. This second interview was conducted by the same doctor who had examined the patient during the ICU stay.

In February 1995, the Vital Statistics Offices were asked for a recent vital status report of all patients discharged from the hospital. Therefore, the follow-up of survival ranged from 8 to 20 months. The 1-year expected survival of all discharged patients was computed on the basis of the life-table of the district population edited by the Italian Epidemiological Statistics Institute (ISTAT), discriminating for sex and age.

Instrument used in the study

QOL should describe the sum of patients' physiological and psychological functions, their capacity for meeting their social needs and their owen perception of their situation [14]. The instrument to measure our patients' QOL should be: (1) not disease specific, because patients are admitted to the ICU for different illnesses [15]; (2) suitable for our patients, who are usually elderly, namely without a ceiling or floor effect to be sensitive to changes realised at an already restricted level [16]; (3) brief and simple, to be used by patients like those staying in the ICU [15], and (4) validated in our country, if we use a questionnaire originally designed in a different language, due to the influence of translation and cultural setting [17].

The lack of such an instrument induced us to create our own (see Appendix) which considered the following domains.

Residence. We distinguished not only institution and home, but also, in the latter case, if the patient was living alone or with others (wife/husband or children), because in our country the family traditionally takes care of disabled parents and there are very few places in rest and nursing homes.

Physical activity. The Karnofsky scale [11] and activities of daily living [7] were considered not sufficiently sensitive for our patients, all of whom were cooperative and usually self-caring. The sickness impact profile [5, 18] appeared too tiring for ICU patients and too time-consuming for doctors. Therefore, we chose a ladder similar to those used by others [3, 6], but with more steps, to investigate the ability not only to work or make different efforts but also, if the patients do not strain themselves, to be self-reliant (e.g. go out for a walk).

Social life. The patient was free to describe his/her leisure activities. If he/she did not report them, the interviewer tried to have at least one answer from those proposed, which considered the ability to take pleasure in performing activities more or less complex from a neurological point of view.

Perceived QOL. This subjective assessment was made using a verbal scale: best-good-fair-poor-worst.

Oral communication. The doctor weighed the ability of the patient to be understood, in a manner similar to that proposed by Vazquez Mata et al. [3]. If oral communication was absent, the patient was considered non-cooperative.

Functional limitation, considering age. This was evaluated by the interviewer as: absent, mild, severe or patient totally dependent.

The analysis of the investigated domains was performed scoring each item as reported in the Appendix. The global QOL was obtained by the sum of scores of different items and ranged from 0 to 24.

The questionnaire was applied to a group of 37 elderly patients (males 62%, mean age 69.9 ± 8.2 years), admitted to general surgery wards; this number corresponds to α error = 0.01 and power test = 0.95, considering SD = 3 and minimum difference = 3 [19]. Patients were first interviewed after hospital admission, before surgical intervention, and then when they returned for surgical examination, usually 7 days after hospital discharge. At the time the investigation was planned, the theoretical prediction was that surgical intervention should deteriorate QOL. All the investigated domains changed significantly (Wilcoxon test): residence ($p < 0.05$), physical activity ($p < 0.001$), social life ($p < 0.001$), perceived QOL ($p < 0.05$), oral communication ($p < 0.05$) and functional limitation ($p < 0.001$); the global score rose from 4.3 ± 2.3 to 9.6 ± 2.6 ($p < 0.001$). Interobserver reproducibility was analysed on 87 interviews (signs test): agreement was perfect 81 times in oral communication ($p = 0.68$) and 79 times in functional limitation ($p = 0.72$).

Analysis of data

Data are expressed as the mean ± 1 SD, when indicated. Statistical analysis was carried out using a software package (Statgraphics 7.0) and p values less than 0.05 were selected as significant. Student's t-test was performed to compare two means, Wilcoxon signed-rank and Spearman rank correlation (r_s) tests were used for non-para-

metric data and χ^2 statistics for categorical data analysis. Cronbach's α [20] was used to evaluate the internal consistency of the questionnaire.

Results

During the study period, 328 consecutively admitted adult patients stayed in the ICU more than 24 h. Thirty-seven died in the ICU and 31 in hospital after ICU discharge. Therefore, observed hospital mortality was 68 patients (20.7%); predicted hospital mortality was 64 patients (19.5%) according to SAPS II. The remaining 260 patients were discharged from the hospital and were eligible for the study of 1-year survival.

Survival after hospital discharge

The vital status of 11 patients could not be determined by any of the methods described and they were considered missing at the first month. One-year mortality predicted for the group according to ISTAT life tables was 42 subjects (16%) and cumulative observed survival was 97.6% at 1 month, 94.4% at 3 months, 87.7% at 6 months and 82.4% at 1 year (fig. 1). Considering the 249 patients followed during 1 year, none of 13 trauma patients died. The mortality in patients admitted to the ICU after elective surgery was 13 of 69 neoplastic cases and 4 of 78 non-neoplastic ones ($p<0.05$). In patients admitted to the ICU after urgent surgery, 4 of 11 neoplastic cases and 2 of 42 non-neoplastic cases died ($p<0.01$). The mortality after medical admission was 7 of 36 patients, higher than that observed after non-neoplastic surgery (19.4 vs 4.9%, $p<0.05$). The 1-year mortality was lower in patients without underlying diseases (7.2%) than in patients with one or more underlying diseases (18.8%; $p<0.05$), but the number and type of underlying diseases did not appear to be associated with mortality. The incidence of complicated course and treatments like blood transfusion, dopamine infusion, anti-arrhytmic drug administration and artificial ventilation lasting more than 3 days were not different in 1-year-surviving and non-surviving patients.

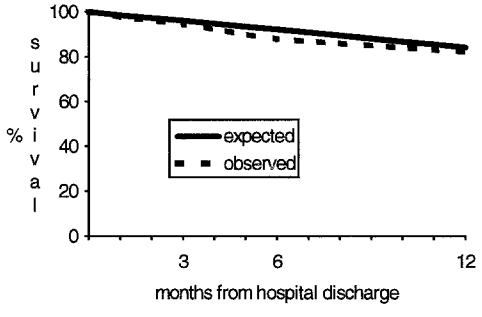

Fig. 1 Cumulative observed survival of 260 patients discharged from hospital versus expected survival according to sex and age

QOL

Six months after hospital discharge, the survey was not done in 15 patients unable to cooperate during their ICU stay, 3 patients who refused the first interview, 12 patients resident more than 30 km from the hospital, 30 patients who died in the intervening period and 4 terminally ill patients too sick to be interviewed at the time of the survey.

Of the remaining 196 patients eligible for the QOL study 6 months after hospital discharge, 160 came to the second interview and 36 were missing. Of these latter patients, 11 were not found, 6 did not attend the survey interview, and 19 missed the first interview because of a short ICU stay and ICU discharge on Sunday. The study group and missing cases did not differ for sex (males 68 and 65%, respectively), age (69.1 ± 10.4 vs 65.7 ± 17.4), SAPS II (29.8 ± 11.6 vs 28.9 ± 11), APACHE II (13.3 ± 4.7 vs 12.8 ± 4.9) and type of ICU admission; only ICU and ward (post-ICU) lengths of stay (4.8 ± 10.8 vs 2.2 ± 1.3 days and 15.7 ± 16.7 vs 9.9 ± 5.9 days, respectively) appeared significantly ($p<0.01$) shorter in missing cases.

At the second interview eight patients were not able to answer the item about perceived QOL due to their poor neurological condition. Compared to the other 152 patients, they were older (79.1 ± 4.7 vs 68.7 ± 10.4 years, $p<0.0001$), more frequently ICU-admitted after urgent surgery ($p<0.05$) and had a shorter ICU length of stay (2 ± 1.2 vs 5 ± 11.2 days, $p<0.01$). Gender, SAPS II, APS and APACHE II, incidence of neoplastic surgery or medical admission, presence of underlying diseases or complicated ICU course, and hospital length of stay were not significantly different. None of these eight patients improved in any of the investigated domains and the sum of scores of residence, physical activity, social life, oral communication and functional limitation worsened in six out of the eight.

The changes in all the investigated domains of QOL in 152 patients are reported in Table 1. *Residence* did not change significantly and most patients (72%) at follow-up lived with their wife/husband as before. The change in *physical activity* is detailed in Table 2. The analysis of *social life* showed that at the first interview, 95 patients reported some leisure activity and at the survey, 58 were in the same condition. The number of patients in contact with only relatives (score 4) rose from 1 before ICU admission to 3 after hospital discharge. The analysis of *perceived QOL* showed that, of 79 patients reporting best–good perceived QOL before ICU, 67% remained at the same level; of 49 cases who reported a fair perceived QOL, 40.8% improved and 18.3% worsened; of 24 patients with poor–worst perceived QOL at the first interview, 66% improved. Considering the evaluations of the

Table 1 Change in domains of quality of life 6 months after hospital discharge versus before admission to the intensive care unit ($n = 152$)

	Number of patients (%)		
	Improved	No change	Worsened
Residence	3 (2)	145 (95)	4 (3)
Physical activity	22 (14)	83 (55)	47 (31)*
Social life	16 (10)	88 (58)	48 (32)**
Perceived quality of life	42 (28)	70 (46)	40 (26)
Oral communication[a]	13 (8)	129 (85)	10 (7)
Functional limitation[a]	22 (15)	84 (55)	46 (30)*
Global quality of life	44 (29)	37 (24)	71 (47)**

* $p<0.01$, ** $p<0.001$
[a] Parameter evaluated by the interviewer

Table 2 Physical activity before intensive care unit (ICU) admission (pre-ICU) and 6 months after hospital discharge (post-ICU). The scores from 0 to 6 measure the levels of activity reported in the Appendix. The *dashed line* indicates patients who did not change their physical activity

PRE-ICU \ POST-ICU	0	1	2	3	4	5	6
0	24	12		3		2	2
1	3	37	7	6		3	1
2		7	6	6	1	1	
3	1	1	3	7		1	2
4		2		1	5		
5			1	1	1	4	
6					1		

same physical activity

interviewers, *oral communication* was not significantly modified and *functional limitation* was significantly changed ($p<0.01$). The relationship between physical activity reported by the patients and functional limitation evaluated by the doctor was strong ($r_s = 0.66$).

The mean global QOL score was 5.6±3.6 (median 5, 95% confidence interval (CI) 0.57] at the first interview and 6.6±3.8 (median 6, 95% CI 0.61) at the second and the difference is statistically significant ($p<0.001$). Considering the global QOL, of 71 patients whose status worsened, in 52 their score rose by 1–4, in 12 by 5–8 and in 7 by more than 8 (maximum value = 11). These 71 patients were compared with the remaining patients: as shown in Table 3, only their hospital length of stay was significantly longer than that of patients whose global QOL improved or did not changed. The incidence of underlying diseases, complicated course in the ICU and treatments considered were not different.

Table 3 Demographic and clinical data of patients whose global quality of life worsened versus those who improved or did not change 6 months after hospital discharge

	Global quality of life	
	Worsened	Improved or not changed
Number	71	81
Sex (% males)	65	72
Age (years)	69.9±9.0	67.5±11.5
SAPS II score	31.1±11.5	28.2±11.7
APS score	8.3±4.8	8.2±3.7
APACHE II score	13.5±5.2	13.1±4.4
Neoplastic surgery	25 (35%)	21 (26%)
Non-neoplastic surgery	37 (52%)	44 (54%)
Medical admission	7 (10%)	14 (17%)
Trauma	2 (3%)	2 (3%)
ICU length of stay (days)	6.5±15.6	3.7±3.9
Hospital (post-ICU) days	18.3±21.5	13.3±10.6*

*$p<0.05$

Discussion

Our results are difficult to compare with those in the literature due to differences in the patient population, the starting point and the duration of follow-up. The ICU admits mostly surgical patients and the mean age of our cases is higher than that reported in other studies performed in multidisciplinary ICUs [2–6].

Survival after hospital discharge

Ideally discharge from the hospital should be regarded as the time when the acute illness has finished and subsequent mortality should be the same as in the general population. Therefore, hospital mortality should be evaluated on the basis of the severity of illness, comparing it with that predicted by the severity scores, and the long-term survival of patients discharged form hospital should be compared with that predicted by life tables. Our patients' hospital mortality was close to that predicted by a third-generation index like SAPS II, and the subsequent survival of patients discharged from the hospital, compared to that of the general population, was 87.7% at 6 months versus the expected value of 92% and, at 1 year, 82%, close to the expected value of 84%. These results agree

with those reported by Zarén et al. [21], but Dragsted et al. [22], who studied 926 ICU-admitted patients after hospital discharge, reported a significantly lower 5-year survival rate than that of the general population adjusted for age and sex. The long duration of their study [22] and the higher mean age and prevalence of surgical admissions in our patients could explain the different results.

Generally, studies performed during the 1980s considered ICU admission to be the starting time of long-term outcome [2, 5, 21, 23, 24]. From this point of view, the survival of our ICU-admitted patients was not different from that reported in the literature [2, 5, 8, 21, 24, 25].

The 1-year mortality of our patients does not appear to be associated with clinical course or treatments applied in the ICU; nevertheless, it is greater in patients with underlying diseases at the time of ICU admission and influenced by a history of cancer as reported in the literature [22]: the death rate increased from 4.9% in non-neoplastic surgical patients (4.7% in urgent surgery, 5.1% in elective surgery), to 18.8% in neoplastic elective surgery and 19.4% in medical admission, to 36.3% in neoplastic urgent surgery. These data, the better survival observed in patients without underlying diseases, and the lack of influence of ICU course or treatments suggest that ICU admission does not affect long-term survival, which seems to be generally good.

QOL

One hundred and ninety-six patients were eligible for the study of 6-months QOL. The missing cases (18%) appeared comparable to the study group for sex, age, severity of illness and type of admission. Their shorter lengths of stay, in the ICU and on the ward after ICU, suggests that their clinical course was eventless. Therefore, we can argue that our results could eventually underestimate the QOL of the ICU population.

The problem of missing cases is frequent in long-lasting studies and it is also important because it can introduce some bias. It has been observed that respondents are older [5, 6] and have longer ICU and hospital lengths of stay than nonrespondents [6]. Our percentage of missing cases is low and there is a difference from the study group, not in age, but in ICU and post-ICU lengths of stay. This could be due to the following causes: (1) our patients are elderly and therefore show a favourable tendency to this type of investigation, similar to respondents of other studies; (2) they gave their informed consent to the study at the time of the first interview, and (3) most of the missing cases were due to organisational problems.

The instrument we used showed good interobserver reproducibility when validated on a sample of patients different from the study group; we did not test intra-observer reproducibility, but it is not unwise to suppose it should be good considering the high degree of interobserver reproducibility. The internal consistency of the instrument in the study group seems to be good (Cronbach's $\alpha = 0.73$, $p < 0.05$).

At the second interview, eight patients were so neurologically deteriorated that they were not able to answer the item about perceived QOL: in comparison with the other 152 patients, they did not appear to be different in severity of illness, but they were older and already significantly deteriorated at the first interview in physical activity ($p < 0.001$), social life ($p < 0.001$), oral communication ($p < 0.01$), functional limitation ($p < 0.001$) and global QOL ($p < 0.001$). Their perceived QOL is less different ($p = 0.048$), confirming a poor relationship between health-related QOL and its personal perception.

Considering the other 152 patients studied 6 months after hospital discharge, the physical activity appeared to be reduced in 31%. As shown in Table 2, a few patients (10%) had a small improvement, most (55%) remained in the same status, some (16%) showed a slight deterioration and a few (8%) had a substantial worsening of their physical activity. This suggests that the physical activity of most ICU-admitted patients does not change, or changes slightly and does not disagree with the data of others: functional handicap in the physical dimension of the sickness impact profile has been reported in ICU patients more than 70 years old, 6 months after hospital discharge [18]; limited activity has been recorded in 26% of 1-year survivors with a mean age of 60 years and in 43% of the ≥ 70-years-olds surviving [26], and a deteriorated physical condition has been found 2 years after ICU discharge in 21% of 90 patients with a mean age of 53 years [2]. Goldstein et al. [9], at baseline and at 1-year follow-up, observed that 72.7% of active patients became sedentary. Of our patients who could be considered physically active, (43 cases scoring 0 in the domain of physical activity), 56% remained active and 35% became sedentary. This difference probably depends on the patient population, because we studied mostly elderly surgical patients; in contrast, Goldstein et al. [9] performed their investigation in a medical and coronary care ICU. In fact, a significant deterioration in QOL of patients in these diagnostic groups has been reported [3].

The functional limitations evaluated by the inverviewer were significantly related to physical activity, suggesting agreement between subjective and objective physical abilities. The percentage of our deteriorated patients (30%) in this domain is not greatly different from the 22.3% reported by Zarén et al. [21].

Perceived QOL did not change significantly in our patients. Rockwood et al. [8], who studied elderly and young patients by questionnaire 1 year after ICU admission, noted that 70% of ≥ 65 years old were satisfied with their present health. Yinnon et al. [11], who used a linear analogue self-assessment score as the mean of nine variables following medical intensive care, reported no significant change between the value before ICU admission

(68±15) and that recorded 6 months later (71±20). The differences in studies could be due to the words used to ask perceived QOL: we measured patients' perception in the absence of specific criteria, Rockwood et al. [8] studied satisfaction of personal health and Yinnon et al. [11] considered not only general feeling of well-being but also e.g. nausea, appetite and anxiety. It is interesting to note that, in our patients, perceived QOL was not correlated with physical activity ($r_s = 0.24$) or with social life ($r_s = 0.05$), indicating that this domain cannot be inferred from health status or social life. Moreover, from a philosophical point of view, QOL is a uniquely personal perception which should be investigated and is really what counts [4]: if the patient says that it is excellent, that is what it is [27].

The global QOL appeared to worsen in 71 of the 152 studied patients, a percentage similar to that reported by Vazquez Mata et al. [3], but in 73% of them the change was small, in 17% it was moderate and in 10% it was important. Patients whose global QOL score increased were not older but stayed longer in the ward, not in the ICU, compared with patients who did not change or improved their global QOL score, suggesting a slow recovery.

Our study shows that the survival of ICU-admitted patients who have been discharged from hospital is similar to that of the general population and influenced more by pre-ICU admission condition (cancer and underlying diseases) than by ICU course or treatments. Six months after hospital discharge, most of these patients maintain their physical activity and social life at the previous level. For those in whom these are reduced the worsening is usually slight and it does not influence subjective perception of QOL. The perceived QOL appears to be a parameter which is independent but essential for investigators.

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Appendix

Domains of quality of life investigated during ICU stay and 6 months after hospital discharge

	Score
Residence	
Living alone at home	0
Living at home with wife/husband	1
Living at home with children	2
Living at home with other relative/friends	3
Living in institution	4
Physical activity	
Working out of home	0
Going up one floor without trouble	1
Carrying a full shopping bag	2
Going for a walk	3
Doing the housework	4
Washing and dressing her-/himself	5
Confined to a chair and bed	6
Social life	
Having leisure activities (e.g. sport)	0
Contact with friends	1
Reading newspapers	2
Watching the television	3
Contact only with relatives	4
Perceived quality of life: how do you feel about your quality of life?	
Best	0
Good	1
Fair	2
Poor	3
Worst	4
Oral communication (interviewer)	
Normal	0
Understandable close to the patient	1
Unterstandable dialogue not maintained	2
Incoherence of speech	3
Functional limitation, considering age (interviewer)	
Absent	0
Mild limitation	1
Severe limitation	2
Totally dependent	3

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