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Sonia Frick
Dominik E. Uehlinger
Regula M. Zürcher Zenklusen

Assessment of former ICU patients' quality of life: comparison of different quality-of-life measures

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S. Frick
Medical ICU, University Hospital, Geneva, Switzerland

D.E. Uehlinger
Division of Nephrology,
University Hospital of Bern, Switzerland

R.M. Zürcher Zenklusen (✉)
Medical-Surgical ICU,
Hôpital des Cadolles, 2000 Neuchâtel, Switzerland
e-mail: Regula.Zuercher-Zenklusen@ne.ch
Tel.: +41-32-7229165
Fax: +41-32-7229229

Abstract *Objective:* To compare three different measures to assess quality of life (QOL) after an Intensive Care Unit (ICU) stay: a standardized telephone interview, a satisfaction scale, and the Sickness Impact Profile (SIP). *Design:* Prospective study, evaluating QOL 6 months after ICU discharge. *Setting:* Medical ICU of a Swiss tertiary-care university hospital. *Patients and methods:* Patients admitted to the ICU between July and November 1998 for more than 24 h were included. Six months after ICU discharge overall QOL and health-related QOL were evaluated. Of the 118 patients approached, 85 returned valid questionnaires. *Results:* The majority of patients indicated good QOL 6 months after ICU stay on each measure. A correlation for both overall and health-related QOL was found between the SIP and the satisfaction scales, between SIP and the telephone interviews, between the telephone interviews and satisfaction scales. The correlation between rating by scale or telephone interview and SIP in patients with cardiovascular disease differed from patients with other diagnoses. *Conclusions:* For the global assessment of overall or health-related QOL after ICU stay, long questionnaires such as SIP may be replaced by a short, structured telephone interview or, better, by a satisfaction scale. Quantitative measures such as SIP may be needed for comparison of therapeutic interventions or specific functional or psychosocial aspects.

Keywords Quality of life · Health-related quality of life · Functional status · Satisfaction scale · Sickness Impact Profile · Nottingham Health Profile

Introduction

Measuring outcome is an ongoing field of research. Among various outcome criteria, quality of life (QOL) has emerged as an important attribute for clinical investigation and patient care. Decision making in the management of critically ill patients may be influenced by the appreciation of the patients' future QOL. However, prospective assessment is very difficult, and the measurement of current QOL is problematic. QOL is a subjective parameter including various aspects of daily life, such as physical, functional, emotional, mental and social well-being, and it is further influenced by economic status, spirituality, and many other parameters. Little agreement exists on what QOL exactly means, but most authors consider that overall QOL, covering all aspects having an impact as mentioned above, should be distinguished from health-related QOL, i.e., QOL defined by health and disease status [1, 2].

An important aspect in the measurement of QOL as an outcome parameter is the amount and kind of information needed to derive a meaningful measure of it. The diversity of QOL questionnaires administered in intensive care unit (ICU) patients illustrates this problem [3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14]. Questionnaires are considered the gold standard whereas interviews and satisfaction scales are considered as little reliable [9, 11]. Most of the questionnaires were originally developed for one specific patient group, for example, transplant patients [15], to analyze specific aspects of disease course. Some of the questionnaires, as the Nottingham Health Profile (NHP) [16] and the Sickness Impact Profile (SIP) [17, 18] have been validated for intensive care patients. Both questionnaires are extensive and time consuming. They do not provide pure health status measures but combine the measurement of physical, psychosocial, and several independent categories related to daily living. They are said to be quantitative indicators of patients' autonomy and disability, reflecting thereby objectively patients' QOL. The weighting of the single items, however, was not done by patients but by healthcare professionals and healthy persons. These questionnaires could therefore be considered to reflect society's view. The crucial question of whether this rating truly reflects each patient's individual perception of his or her QOL remains open to debate.

In contrast, satisfaction scales present global ratings and are much less time consuming. They directly reflect the patients' opinion and therefore correspond to the individual's perceived QOL. Interviews with simple questions such as "how do you feel" and "how are you" allow exact subjective rating under certain conditions [19]. However, they risk eliciting vague answers if – following social conventions – respondents answer with "fine" regardless of their actual feelings. Furthermore, they may provide insufficient sensitivity to detect impairment in specific domains of QOL [19].

Patients in medical ICUs comprise a heterogeneous population who undergo multiple interventions and treatments. In most instances it is almost impossible to evaluate the impact of one particular intervention on one specific aspect of QOL. We therefore believe that it is often more important and more revealing to know how former ICU patients deal with and feel about residual physical, mental, and/or psychological handicap overall rather than to detect an impairment in one selective domain of QOL. Being convinced that evaluation of QOL is a very important outcome measure that should be assessed regularly, we challenge the maxim of cumbersome, extensive questionnaires being the only valuable tool for its evaluation. If a simple global rating could reliably replace extensive questionnaires, the assessment would be much easier, much less time consuming, and consequently performed more frequently.

Therefore we designed this study to compare the assessment of QOL by a global rating such as a telephone interview or a satisfaction scale, on one hand, and by a detailed questionnaire, the SIP, on the other.

Methods and materials

Patients

All 157 patients consecutively admitted to one of the two six-bed adult medical ICUs of a Swiss tertiary-care 1000-bed university hospital between July and November 1998 were contacted by telephone 6 months after ICU discharge by one of the investigators. Exclusion criteria were a native language other than German and the inability to perform the standardized telephone interview. They were informed about the intention of the study, and after giving informed consent to participate, a standardized telephone interview was performed as explained below. Following the telephone call a SIP questionnaire and a satisfaction scale were mailed to each patient, explaining again the aim of the study. Age, diagnostic category, length of ICU stay and Simplified Acute Physiology Score [20] were extracted from the hospital chart. The study was conducted according to the principles established in Helsinki, and it was approved by the ethics committee of our institution.

Of the 157 patients admitted to the ICU during this period 37 died during their hospital stay or within 6 months, 2 were excluded for not being German speakers, and 18 refused to participate. Thus 100 patients gave informed consent and were included, and all of these completed their telephone interviews. Of these, 85 returned valid and 2 returned invalid (i.e., incomplete) questionnaires, corresponding to a response rate to written questionnaire and satisfaction scale of 87%. Clinical characteristics of study patients and their primary system failure at admission are summarized in Table 1.

Instruments used

Standardized telephone interview

One of the investigators (S.F.) who did not have previous contact with the patients called all patients for a standardized telephone interview of at least 8 min duration. For the assessment of the functional status as the equivalent of health-related QOL all patients were asked about their independence or their need for help with regard to three distinct fields of their daily life: body care, household management, and outdoor mobility. Patients who were independent in respect to all three activities were considered "completely independent" or having good health-related QOL, those who were limited with one or two of the three activities were considered "partially dependent" or having fair health-relat-

Table 1 Clinical characteristics of study patients (n=85): demographic data and primary system failure

Age, median (range; years)	65 (24–86)
SAPS, median (range)	22 (6–80)
ICU stay, median (range; days)	2 (1–14)
Hospital stay, median (range; days)	14 (1–180)
Primary system failure, (patients; n)	
Cardiovascular	49
Acute coronary syndrome	29
Shock/CPR	4
Pulmonary	3
Neurological	8
Gastrointestinal/liver	4
Infectious	6
Sepsis	1
Septic shock	2
Other	15

ed QOL, and those who needed help with all three activities were considered "fully dependent" or having bad health-related QOL.

Overall QOL was assessed by asking the patients open questions such as: "How are you? How are you pleased with your present life considering all important aspects? How would you judge then the overall quality of your present life?" and letting them explain in their own words how they felt. At the end of the interview the investigator summarized the patient's statements and let the patient conclude with either "good," "fair," or "bad" as an estimate of his/hers overall QOL.

Satisfaction scale

Similar to the UNISCALE [15], the satisfaction scale consists of ten check boxes which range from 1 to 10, with 1 indicating lowest and 10 indicating highest QOL. The scale is considered another easy way of global rating of QOL, allowing patients to express their subjective feeling of satisfaction or dissatisfaction in a more anonymous way than in the telephone interview. The principle was explained to each patient at the end of the telephone interview and the satisfaction scale was then sent, together with the SIP questionnaire, by mail. On the written form patients were asked to check one of the boxes between 1 and 10 with respect to their satisfaction with their current health status for perceived health-related QOL and with respect to the satisfaction with their current overall QOL, including not only health but all aspects of life that they considered to have an impact (Appendix).

Sickness Impact Profile

The SIP was developed in the United States in 1978 and has been validated as a reliable method for evaluating QOL in various patient populations and severities of illness, including ICU patients [11, 18, 19, 21, 22]. It has been translated to different languages such as Dutch [18, 23], Chinese [19], and German [24, 25, 26] and has been validated in these cultures. For these reasons we decided to use SIP as gold standard.

Being a multidimensional, cumulative health index, the SIP consists of a list of 136 questions, divided into 12 categories of daily living. Three of these categories (ambulation, mobility, and body care) can be aggregated into the "physical dimension." The categories of social interactions, alertness behavior, emotional behavior, and communication can be aggregated into the "psychosocial dimension," while the other five – sleep and rest, eating, work, home management, recreation and pastimes – are "independent categories." The questionnaire can be completed with the help of an interviewer or can be self-administered. Patients are asked to indicate those items that describe a dysfunction which they experience for the time being. Through predetermined weights based on the relative severity of each dysfunction as judged by healthcare professionals and healthy persons, a dysfunction score is attributed to each question. Category scores and overall scores for total SIP and subgroups are then calculated. The higher the score, the more severe is the dysfunction. A score of 0–5 is found in a healthy population, a score of 5–15 corresponds to moderate disability, and a score higher than 15 shows significant impairment of QOL. Reliability, validity and sensitivity to change have been confirmed in the original version [17, 27].

Statistical analysis

The software package SYSTAT was used for data analysis (Systat 8.0, SSPS, Evenston, Ill., USA). Values are given as mean ±standard deviation or as median and ranges for parameters that do not follow normal distribution. Methods included parametric and nonparametric comparison of means, analysis of variance and univariate and multivariate regression analysis. Prediction errors were calculated as rooted mean square prediction errors [28]. Spearman's correlation coefficients were calculated from the correlation between different scales.

The SIP score was defined as the gold standard and was compared with health-related and overall QOL assessed by telephone interview and by the satisfaction scale. Health-related and overall QOL assessed by telephone interview were compared with their corresponding values on the satisfaction scale. Nonparametric receiver operating characteristic (ROC) curves were calculated assuming any impairment of QOL as "true signal" (SIP >5) or severe impairment of QOL as "true signal" (SIP >15).

Results

As assessed by telephone calls, 62 patients (73%) considered their overall QOL as good, 19 (22%) as fair, and 4 (5%) as bad. Physical independence was considered complete (good health-related QOL) in 70 patients (82%) and partial (fair health-related QOL) in 15 (18%); none of the responding patients considered him-/herself totally dependent (bad health-related QOL).

Assessment by the satisfaction scales with a minimum of 1 and a maximum of 10 showed a mean value of health-related QOL of 6.4±2.3 and of overall QOL of 7.2±2.5. Detailed results of the assessment by SIP are shown in Table 2. Total SIP score was 7.3±10.4 with a physical subscore of 6.2±11.0 and a psychosocial subscore of 6.1±9.3. Patients showed most dysfunction in the SIP categories of "recreation and pastimes" (14.5), "sleep and rest" (11.2), and "home management" (9.3). Of the 86 patients 49 (57%) had a total SIP score of 0–5 (as would be expected in healthy persons), 23 (27%) a score of 5–15 (moderate compromise), and 14 (16%) a total SIP score of over 15 (severe compromise).

Correlations between the different QOL measures are summarized in Table 3. Correlation coefficients are negative as high scores in SIP correspond to a bad QOL whereas high scores in the global rating by scale or tele-

Table 2 Sickness Impact Profile structure and score (*n*=85)

Category	Score (mean ±SD)
Sleep and rest	11.3±16.5
Home management	9.3±18.4
Work	6.6±13.0
Recreation and pastimes	14.5±18.6
Eating	2.1±3.6
Body care and movement	4.8±10.5
Mobility	7.6±15.7
Ambulation	8.6±13.4
Emotional behavior	5.5±11.8
Social interaction	6.6±9.3
Alertness behavior	8.4±17.5
Communication	3.1±9.4
Physical dimension	6.2±11.0
Psychosocial dimension	6.1±9.3
Total	7.3±10.4

Table 3 Comparison of SIP with health-related and overall quality of life (*QOL*) assessed by scale and telephone interviews (*ROC AUC* receiver operating characteristic area under the curve)

	r[a]	Prediction error[b]	ROC AUC >5[c]	ROC AUC >15[d]
SIP total vs.				
Health-related QOL, scaled	–0.71	7.0	0.81	0.77
Overall QOL, scaled	–0.71	6.3	0.81	0.81
Health-related QOL, by telephone	–0.49	8.2	0.71	0.73
Overall QOL, by telephone	–0.47	7.6	0.67	0.72
SIP physical vs.				
Health-related QOL, scaled	–0.60	9.3	0.79	0.75
Overall QOL, scaled	–0.59	9.0	0.80	0.77
Health-related QOL, by telephone	–0.61	10.3	0.78	0.70
Overall QOL, by telephone	–0.60	8.4	0.75	0.81
SIP psychosocial vs.				
QOL, scaled	–0.60	7.9	0.74	0.72
Overall QOL, scaled	–0.66	7.3	0.77	0.74
Health-related QOL, by telephone	–0.32	8.9	0.62	0.70
Overall QOL, by telephone	–0.27	8.6	0.56	0.69

[a] Spearman's rank correlation coefficient. Correlation coefficients are negative since high scores in SIP correspond to a bad QOL, and high scores in the global rating by scale or telephone interview correspond to a good QOL

[b] Rooted mean square prediction error

[c] Assuming any impairment of the QOL as "true" (SIP >5)

[d] Assuming severe impairment of the QOL as "true" (SIP >15)

phone interviews correspond to good QOL. Comparing SIP and satisfaction scales for both health-related and overall QOL, the correlations were significant (r=–0.71, p<0.001). As for SIP and telephone interviews, there was a significant correlation between total or physical SIP and overall or health-related QOL (p<0.01). Comparing the telephone interview with the satisfaction scale, stronger correlations were found with overall QOL (r=–0.50, p<0.001) than with health-related QOL (r=–0.35, p<0.01). The calculation of prediction errors (Table 3) revealed that scaled overall QOL provided the best overall substitute for the more cumbersome SIP in our patients.

ROC curves were calculated to compare the ability to detect patients with a normal QOL (SIP ≤5), on one hand, and patients with severely impaired QOL (SIP ≥15), on the other, with the various scales or telephone interviews (Table 3). Once again, overall QOL by scale proved superior to telephone interview for the detection of patients with normal or severely impaired QOL.

Figure 1 illustrates the correlation between the total SIP and the overall QOL on the satisfaction scale. The correlation is worst in low QOL with disproportionally high SIP scores in the case of very low scaled scores. Multivariate linear regression analysis revealed that the slopes of the regression lines between rating by scale and SIP and between telephone interview and SIP differed in patients with acute coronary syndrome or other cardiovascular diseases from those in patients with noncardiovascular admission diagnosis (p<0.001). QOL assessed by global ratings was worse than QOL judged by SIP in these patients.

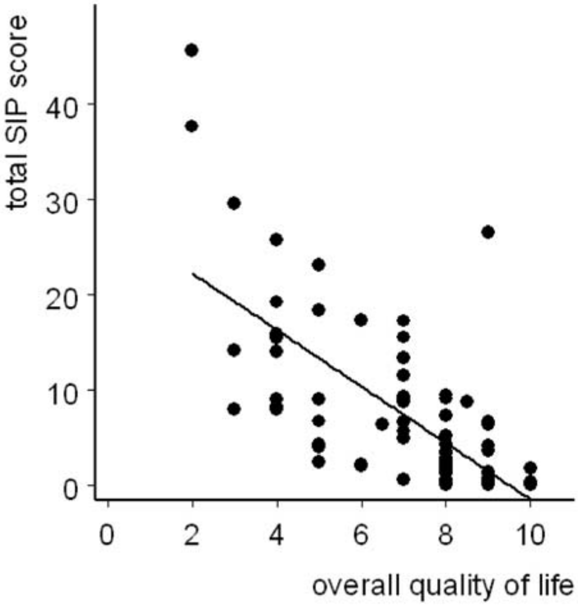

Fig. 1 Linear regression analysis between the total Sickness Impact Profile (*SIP*) score and scaled overall quality of life. *Diagonal line* represents linear regression line

Discussion

Our study allows two main conclusions. First, the results of evaluation of QOL were similar whether assessed by telephone interviews, satisfaction scales, or SIP questionnaire. Significant correlations, although with wide variance, were found between SIP and satisfaction scale, between SIP and telephone interview, and between satisfaction scale and interview, thereby confirming findings of previous studies [9, 11, 19]. The stronger correlation between SIP and satisfaction scale than with SIP and telephone interview is explained by the more continuous nature of the scale. The telephone interview in our study allowed only three possible answers (good, fair, bad) while the satisfaction scale allowed ten. When crosstable analysis with grouped (categorized) data from the satisfaction scale (boxes 8–10 grouped as good QOL, 4–7 grouped as fair QOL, and 1–4 grouped as bad QOL) was performed, we found similar correlations between SIP and scales as with SIP and telephone interviews. Moreover, most former patients of a medical ICU of a medium-sized, Swiss tertiary-care university hospital consider their overall and health-related QOL as good 6 months after ICU discharge. It thereby further confirms earlier studies which found good QOL 6 months after discharge from medical-surgical ICUs for the majority of former ICU patients [9, 11, 19].

There are several potential limitations of our study which might preclude generalized applications of our conclusions. First, the sample size was rather small, particularly if we take into account the heterogeneous casemix of our ICU. However, we found very similar mean scores of most SIP categories and similar mean scores of global ratings as other authors who have investigated larger patient populations from medical-surgical ICUs [9, 11, 19]. Another potential limitation is selection bias. We cannot exclude that the patients who refused to participate in the study did so because of total dependence, and/or because of an inability to answer the questionnaires and that therefore we might have underestimated the number of patients with bad QOL. As we accepted the refusal of a patient to participate in the study without insisting to know why he did so, this point remains hypothetical. Since the main goal of the study was the *comparison* of simplified QOL measures with the more cumbersome SIP, this potential bias may compromise the conclusion of mainly good QOL but should not have negatively affected the finding of good correlations between the various measures. As to a possible bias introduced by the interview technique (all interviews were performed by the same investigator), this of course cannot be excluded. As noted above, the interviewer let the patients describe how they felt and then let them conclude to one of the terms “good,” “fair,” or “bad.” The rather good correlation between the global rating of QOL and health-related QOL as assessed by the telephone interviews, on one hand, and by the satisfaction scales, on the other, allows the conclusion that potential interviewer bias was not an major problem.

Hurel et al. [9] who used the Perceived Quality of Life Scale and NHP as a combination of subjective and objective assessments of QOL, found a fairly good correlation, with wide variance, between NHP and the latter scores. They concluded that NHP is a more sensitive measure than the satisfaction scale, stating that ideally each patient should weight each dimension. Sage et al. [11] who used SIP as a parameter of the “society’s view” combined with perceived QOL by UNISCALE as the “individual’s view,” concluded that especially in the elderly the two health care measures do not always coincide. Short et al. [19] found a clumping of scores and a lack of patients with low scores. They concluded that subjective rating is not sufficiently accurate to act as a rapid diagnostic tool to replace the SIP. We are fully aware of the discrepancy between these authors’ and our own conclusions. We agree that correlation between global ratings and quantitative questionnaires is far from perfect. Simplifications usually result in a decrease in precision; however, the acceptable amount of loss of precision is poorly defined and depends on the goals. Since we are convinced that evaluation of QOL is a very important outcome issue that should be performed regularly, we prefer the somewhat decreased precision and wider variance of global ratings as compared with questionnaires such as the SIP to no evaluation at all. Global ratings by satisfaction scale or by simple questions do not allow detailed analysis with respect to why QOL is perceived as good or as bad or to one or several specific handicaps. Nevertheless, they tell us the essential about the subjective perception of overall well-being. We all know that the ability to cope with physical and/or psychological handicaps is very individual. Many patients adapt amazingly well to their illness and functional limitations. Life unattractive to an observer may be perfectly satisfactory to its owner. On the other hand, minor handicaps can be difficult to accept for certain patients. The latter probably explains, at least partially, why perceived QOL as assessed by global ratings may show wide variance in regard to quantitative questionnaires.

In conclusion, global ratings such as satisfaction scales and interviews may replace cumbersome questionnaires such as the SIP, if overall and health-related QOL of former ICU patients are to be assessed in a *global* manner, and if the assessment of QOL *as perceived by the patient* is the goal. Further studies with larger sample size and with selected patient populations, such as coronary care patients and elderly patients, should be performed to further generalize our findings. Global ratings do not allow quantitative measures of patients’ autonomy and disability. Detailed measures such as SIP will continue to be needed for quantitative measures, comparison of various therapeutic interventions, and when specific functional or psychosocial aspects are to be investigated.

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Appendix: satisfaction scale

1. Please indicate your satisfaction with your current health status, with 1 corresponding to low satisfaction and 10 corresponding to excellent satisfaction. Please check the corresponding box:

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2. Please indicate your satisfaction with your current overall quality of life, with 1 corresponding to low satisfaction and 10 corresponding to excellent satisfaction. Please check the corresponding box:

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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