Journal of Critical Care 48 (2018) 352–356

Contents lists available at ScienceDirect

Journal of Critical Care

journal homepage: www.journals.elsevier.com/journal-of-critical-care

Patients' perceptions and ICU clinicians predictions of quality of life following critical illness☆

Michael E. Detsky [a,b,c,*], Rachel Kohn [a,d,e,f], Aaron M. Delman [a], Anna E. Buehler [a], Saida A. Kent [a], Isabella V. Ciuffetelli [a], Mark E. Mikkelsen [c,f], Alison E. Turnbull [h,i,j], Michael O. Harhay [a,e,g]

[a] *Palliative and Advanced Illness Research (PAIR) Center, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA, United States*
[b] *Sinai Health System, Toronto, ON, Canada*
[c] *Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, ON, Canada*
[d] *Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA, United States*
[e] *Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, PA, United States*
[f] *Division of Pulmonary, Allergy and Critical Care Medicine, Department of Medicine, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA, United States*
[g] *Department of Biostatistics, Epidemiology and Informatics, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA, United States*
[h] *Outcomes After Critical Illness and Surgery (OACIS) Group, Johns Hopkins University, Baltimore, MD, United States*
[i] *Division of Pulmonary and Critical Care Medicine, School of Medicine, Johns Hopkins University, Baltimore, MD, United States*
[j] *Department of Epidemiology, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, United States*

ARTICLE INFO

Available online xxxx

Keywords:
Quality of life
Critical illness
Long-term outcomes
Survival
Functional status

ABSTRACT

Purpose: To determine how patients perceive their quality of life (QOL) six months following critical illness and to measure clinicians' discriminative accuracy of predicting this outcome.
Materials and methods: This prospective cohort study of intensive care unit (ICU) survivors asked patients to report their QOL strictly at six months compared to one month before their critical illness as better, the same, or worse. ICU physicians and nurses made six-month QOL predictions for these patients.
Results: Of 162 critical illness survivors, 33% ($n = 53$) of patients reported six-month QOL as better, 33% ($n = 54$) the same, and 34% ($n = 55$) worse. Abnormal cognition and inability to return to primary pastime or original place of residence ($p < .05$ for all) were associated with worse self-reported QOL at six months in multivariable regression. Predictions of patient perceptions of QOL at six months were pessimistic and had low discriminative accuracy for both physicians (sensitivity 56%, specificity 53%) and nurses (sensitivity 49%, specificity 57%).
Conclusions: Among survivors of critical illness, one-third each reported their six-month post-ICU QOL as better, the same, or worse. Self-reported six-month QOL was associated with six-month function. ICU clinicians should use caution in predicting self-reported QOL, as discriminative accuracy was poor in this cohort.

1. Introduction

The months and years after surviving critical care often entail physical [1], cognitive [2,3], psychological [4], and work [5] challenges for patients. These symptoms are broadly termed post-intensive care syndrome (PICS) [6] and can negatively impact patients' quality of life (QOL) [7]. Intensive care unit (ICU) clinicians' awareness of PICS and impaired QOL informs their clinical discussions, and thus shared decisions with critically ill patients and their surrogates. However, the value of this information exchange is dependent on the quality of the clinicians' ability to predict longer-term outcomes, including how patients will perceive their QOL.

QOL is an important patient-centered outcome in ICU practice and research. Most ICU studies [8] use validated QOL scales such as the EuroQol 5 Dimensions (EQ-5D) [9] or the 36 item short form health survey (SF-36) [10]. While these validated measures provide meaningful and objective estimates of QOL, they contain certain gaps for ICU patients [11]. For example, these measures of QOL may fail to detect important aspects of health beyond physical and mental health, including social health, gratitude, or motivation to change [12], and may omit patients' baseline level of happiness and how they adapt to change [13]. Indeed, patients have varying degrees of adaptability to permanent changes and new limitations (e.g., stomas [14] and spinal cord injuries [15]), which may alter their QOL perceptions. Accordingly, this study had two primary objectives. First, we sought to determine how patients perceived their six-month QOL following critical illness.

☆ This work was done at the University of Pennsylvania and subjects were enrolled from the University of Pennsylvania Health System.

* Corresponding author at: Mount Sinai Hospital, 600 University Ave, 18-232-1, Toronto, ON M5G 1X5, Canada.

E-mail address: michael.detsky@sinaihealthsystem.ca (M.E. Detsky).

https://doi.org/10.1016/j.jcrc.2018.09.034
0883-9441/

Second, we sought to measure ICU clinicians' discriminative accuracy of predicting critical illness survivors' perceptions of six-month QOL.

2. Materials and methods

2.1. Patients

We conducted a prospective cohort study in five ICUs (three medical and two surgical) in three hospitals within the University of Pennsylvania Health System [16,17] located in Philadelphia, Pennsylvania, USA. Patients were enrolled from October 2013 to May 2014, and six-month follow-up was completed in December 2014. We included adult patients who spent at least three calendar days in the ICU and required life-sustaining therapy, defined as mechanical ventilation for >48 consecutive hours, vasoactive infusions for >24 consecutive hours, or both, within the first six days of ICU admission. Patients were enrolled between ICU days three to six. We sought patients' or surrogates' consent for the patient to participate, and surrogates' consent for researchers to contact them directly during follow-up when patients became eligible for enrollment. We also consented the patients' physicians and nurses to participate. The University of Pennsylvania Institutional Review Board approved this study.

2.2. Baseline data collection

We collected patients' clinical and demographic data through interviews with patients or surrogates at the time of enrollment and using the electronic medical record (EMR). We also used the EMR to collect admission data, consult notes, discharge summaries, and ICU flow sheets. We collected information on patients' major medical comorbidities, functional comorbidity index [18], employment status, and Acute Physiology and Chronic Health Evaluation (APACHE) III scores [19].

2.3. ICU clinician predictions of QOL at enrollment

When patients were enrolled, we asked ICU physicians and nurses: *"If the patient is still alive in six months, how do you expect the patient would rate his or her quality of life at that time, compared to his or her quality of life within the month before this hospitalization?"* ICU physicians and nurses provided a trichotomous prediction of "better", "the same", or "worse" and their prediction confidence using a 5-point Likert scale, ranging from 1 ("not confident at all") to 5 ("very confident").

2.4. Follow-up

We attempted to contact the patient at six months by phone or email. If the patient was known to have a baseline cognitive disorder, we contacted the surrogate first. If initial attempts to contact the patient were unsuccessful, attempts were made to contact the patient or surrogate, and the interview was completed with the first individual we reached. If contact was not achieved within 5 attempts over 2 weeks, the patient was considered lost to follow-up.

2.5. Outcome assessment

The primary outcome was patients' self-reported six-month QOL compared to one month before their critical illness as better, the same, or worse. The other six-month outcomes that were collected included the patients' ability to toilet and ambulate 10 stairs independently, ability to remember most things, think clearly, solve day-to-day problems (i.e., a measure of cognition from the Health Utilities Index) [20], return to original residence, return to primary pastime, and return to baseline, which is a composite of being alive, at home, and having the same level of function with respect to toileting, ambulation, and cognition [17].

2.6. Statistical analysis

We summarized variables using medians and interquartile ranges (IQRs) or proportions. We used chi-squared or Kruskal-Wallis to test associations of six-month QOL with patient variables at three time points: 1) baseline during ICU admission, 2) hospital discharge, and 3) six-month follow-up. We performed multinomial logistic regression at these same time points to determine patient variables associated with six-month QOL. Multinomial models provide effect estimates in terms of relative risk ratios (RRRs), in contrast to a logistic regression which produce odds ratios. RRRs provide relative measures of the difference between better and the same six-month QOL with worse QOL as the reference group. We performed a sensitivity analysis using patient-reported QOL and surrogate-reported QOL separately.

We created 3 × 3 tables to compare clinician-predicted QOL to patient- or surrogate-reported QOL at six-month follow-up. To calculate discriminative accuracy, we defined disease positive status as reporting a worse QOL at six months and disease negative status as reporting QOL as better or the same. ICU clinicians' predictions of worse QOL at six months were treated as positive test results and predictions of better or the same were treated as negative test results. Thus, in this study, sensitivity is the probability that a patient with a self-reported worse QOL at six months was correctly predicted to have a worse QOL at enrollment, and specificity is the probability that a patient who reported the same or better QOL at six months was correctly predicted to have the same or better QOL at enrollment. We also calculated sensitivity and specificity for the subset of predictions when clinicians reported confidence in their predictions (i.e., 4 or 5 on the Likert scale [16]). We conducted analyses using Stata version 13.0 (StataCorp, College Station, Texas).

3. Results

3.1. Survival and QOL

Of the 303 enrolled patients, 24% ($n = 72$) died in the hospital, and 19% ($n = 58$) died between discharge and six months. Of the remaining 173 patients, 4 were lost to follow-up and 7 omitted responses to six-month QOL (see Supplemental Material, Appendix Fig. 1).

For self-reported QOL among the remaining 162 patients, compared to the month before ICU admission, 33% ($n = 53$) of patients (or their surrogates) reported six-month QOL as better, 33% ($n = 54$) the same, and 34% ($n = 55$) worse. When patients reported QOL (51% of subjects), they most frequently reported better QOL for themselves (39%, $n = 32$) compared to surrogates who most frequently reported worse QOL for the patient (38%, $n = 30$) (see Supplemental Material, Appendix Table 1).

3.2. Patient variables and QOL

At ICU admission, a neurological comorbidity was associated with worse six-month QOL in both the unadjusted comparison ($p = .007$) and the multinomial logistic regression ($p = .03$) (Table 1). Although patients with shorter durations of mechanical ventilation reported better QOL ($p < .001$) in an unadjusted comparison, no patient variables at hospital discharge had statistically significant associations with six-month QOL in multinomial logistic regression (Table 2).

3.3. Patient functional outcomes at six months and QOL

At six-month follow-up, all patient outcomes were associated with differences in six-month QOL (Table 3). In multinomial logistic regression, normal cognition ($p = .02$) and return to primary pastime ($p = .006$) were associated with better QOL (compared to worse QOL). Normal cognition ($p = .008$) and return to their original place of residence ($p = .04$) were associated with QOL being the same (compared to worse