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Patients' Perceptions and ICU Clinicians Predictions of Quality of Life Following Critical Illness

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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<0.05 for all) were associated with worse self-reported QOL at six months in multivariable regression. Predictions of patient perceptions of QOL

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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.

Keywords

quality of life; critical illness; long-term outcomes; survival; functional status

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. 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 Figure 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=0.007) and the multinomial logistic regression (p=0.03) (Table 1). Although patients with shorter durations of mechanical ventilation reported better QOL (p<0.001) 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=0.02) and return to

primary pastime ($p=0.006$) were associated with better QOL (compared to worse QOL). Normal cognition ($p=0.008$) and return to their original place of residence ($p=0.04$) were associated with QOL being the same (compared to worse QOL) (Table 3). Results were unchanged in sensitivity analyses examining patient- and surrogate-reported outcomes separately (Supplemental Material, Appendix Tables 1–4).

3.4 ICU Clinician Predictions of Six-Month QOL

ICU physicians and nurses overestimated that patients would report worse QOL at six months, compared to their actual reported six-month QOL (50% and 45%, respectively) (Table 4). The discriminative accuracy in predicting reported six-month QOL was 56% among physicians and 49% among nurses for predictions of worse QOL, and 53% among physicians and 57% among nurses predictions for non-worse QOL predictions. These findings were consistent when limited to confident predictions (Table 5).

4. Discussion

In our study, critical illness survivors were equally likely to perceive their QOL six months after critical illness as better, the same, or worse than one month prior to their critical illness. Perceptions of six-month QOL were not associated with patient variables at ICU admission or hospital discharge. However, QOL perceptions of six-month QOL were associated with six-month functional outcomes including returning home, engaging in primary pastimes, and cognitive function. The discriminative accuracy of ICU clinicians in predicting perceptions of six-month QOL was poor, even when restricted to confident predictions.

The proportion of patients who reported six-month QOL as the same or better, compared to one month prior to critical illness, is similar to earlier studies that asked for patients' perceptions of QOL following critical illness [21–23]. Our more recent data suggests that when patients survive critical illness, up to two-thirds of survivors report QOL as stable to improved. There are multiple reasons why patients may self-report QOL better than expected. First, we asked individual patients to compare their QOL at six months to their QOL prior to critical illness. Patients' perceptions of this difference are important, as it provides insight into how patients may adapt to current health states. They may consider elements of their lives to be important that they did not recognize prior to critical illness. Alternatively, patients may demonstrate resilience that leads to post-traumatic growth following critical illness [24]. Second, we used a single-item question that asked patients to form a summative opinion of their current QOL. The advantage to a single-item approach is that it allows patients to summarize their QOL based on all contributing factors. While scores for certain elements of validated measures such as physical function may be low, some patients may not consider their physical function to be a major contributor to overall QOL. This may be especially true if their physical function was poor prior to critical illness.

There were no clinically important differences in patient variables at ICU admission or hospital discharge (aside from having a neurological condition), when stratified by reported six-month QOL. This highlights how challenging it is for clinicians to predict future QOL. Future studies should focus on collecting detailed information at baseline and in follow-up to prospectively determine elements that contribute to QOL. This could include evaluating

patients' values and preferences prior to critical illness and in follow-up, and determining if any changes occur after a potentially life-altering event. One proposed theory that could be tested in this regard is 'prospect theory,' which has patients consider outcomes based on relative, rather than absolute terms [25]. For example, if patients with poor baseline physical and cognitive function survive critical illness, they may have a smaller relative decline in their function compared to a previously healthy individual [26]. While our finding that abnormal baseline function had no association with how patients reported six-month QOL, it is possible that our measure of baseline function may be too crude to detect important differences [17].

Another key finding is that ICU clinicians had difficulty predicting how patients would report six-month QOL. There are multiple potential reasons to explain this discordance that require further examination. First, the activities, symptoms, and functional abilities that patients consider when evaluating their own QOL vary. Second, patients with poor baseline function prior to critical illness may be willing to accept worse outcomes after ICU care relative to those who were high-functioning prior to critical illness [26]. Clinicians, who base QOL assessment on their own values and experiences as high-functioning members of society, may not appreciate this cognitive characteristic. Third, clinicians would be unlikely to appreciate the adjustment patients experience after changes in health states, as this varies between patients and in patients over time as they adapt (or not) to new disabilities [14, 15]. While we found that ICU clinicians tended to be overly pessimistic about their patients' future QOL, in other related work, physicians tended to be overly optimistic that their patients would have good outcomes at one year [27].

This study has important limitations. First, the measure of QOL in this study is a self-reported, non-validated measure. Patients or surrogates may inaccurately estimate QOL prior to critical illness due to recall bias. Second, we cannot compare our outcome to validated measures, such as the EQ-5D [9] or SF-36 [10], since these were not collected in our study. Third, we relied on surrogates to report QOL if we were unable to contact the patient, which may be influenced by surrogates' own values and preferences. However, our sensitivity analysis assessing patients and surrogates separately demonstrated similar results. Fourth, we asked clinicians to predict six-month QOL on ICU days three to six. This time horizon may be too early for clinicians to understand patients' priorities prior to their critical illness, and what will impact their QOL following their critical illness. Fifth, our sample size may limit the power of this study to show differences in the association of baseline and hospital discharge patient variables with perceptions of six-month QOL. Sixth, we did not have a concordant measure of our six-month QOL outcome at baseline as our cohort was constructed based on admission to the ICU. As a result we had to rely on patient or surrogate recall to examine our research question.

In summary, in our cohort of ICU survivors who received life-support, we found that survivors were equally likely to perceive their six-month QOL as better, the same, or worse than prior to their critical illness. Patient variables at the time of their ICU admission and hospital discharge were not associated with patients' self-reported six-month QOL, but cognitive and physical function at six months was associated with six-month QOL. ICU clinicians had poor discriminative accuracy in predicting how patients would perceive future

QOL, even when they were confident in their predictions. Based on these findings, clinicians should use caution when prognosticating future QOL.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Patient Variables at Intensive Care Unit Admission and Six-Month Quality of Life

Patient Variable	Worse QOL n=55	Same QOL n=54	Better QOL n=53	Adjusted Same vs. Worse RRR ^a (95% CI)	Adjusted Better vs. Worse RRR ^a (95% CI)
Age, median (IQR)	57 (48–68)	60 (50–69)	64 (52–70)	1.01 (0.98–1.05)	1.02 (0.98–1.05)
Male	32 (58)	33 (61)	32 (60)	0.74 (0.29–1.91)	0.77 (0.30–2.01)
Race (non-white)	25 (45)	17 (31)	14 (26)	0.38 (0.12–1.13)	0.52 (0.16–1.67)
Some college or more	30 (56)	25 (46)	34 (64)	0.69 (0.26–1.81)	1.89 (0.71–5.05)
Married	28 (51)	24 (44)	27 (51)	0.46 (0.18–1.18)	0.72 (0.28–1.89)
Employed or student	16 (29)	22 (41)	19 (36)	2.25 (0.67–7.64)	0.76 (0.23–2.48)
Living in house or apartment	51 (93)	53 (98)	52 (98)	1.23 (0.08–19.19)	1.94 (0.09–40.17)
Private health insurance	20 (36)	20 (37)	21 (40)	0.54 (0.18–1.61)	0.99 (0.33–2.98)
Hospitalized in the past year	37 (67)	37 (71)	27 (55)	1.11 (0.42–2.94)	0.61 (0.24–1.54)
Able to ambulate 10 stairs	41 (75)	46 (85)	46 (87)	0.67 (0.05–9.42)	0.30 (0.01–6.02)
Toilet independently	46 (84)	49 (91)	50 (94)	0.53 (0.07–4.14)	2.19 (0.23–21.23)
Normal cognition	47 (85)	45 (83)	49 (92)	0.08 (0.01–0.77) ^a	1.11 (0.06–20.38)
Normal baseline function ^c	36 (65)	41 (76)	43 (83)	10.23 (0.65–160.07)	2.34 (0.09–62.95)
Functional comorbidity index	3 (2–5)	4 (2–5)	3 (2–5)	0.95 (0.65–1.40)	0.80 (0.54–1.17)
Medical comorbidities	3 (1–4)	2 (2–4)	2 (1–3)	0.67 (0.27–1.66)	1.17 (0.48–2.86)
Neurologic	17 (31) ^b	9 (17) ^b	4 (8) ^b	0.66 (0.15–3.01)	0.18 (0.04–0.85) ^b
Congestive heart failure	17 (31)	16 (30)	25 (47)	1.39 (0.40–4.87)	1.59 (0.46–5.52)
Coronary artery disease	20 (36)	16 (30)	25 (47)	0.56 (0.14–2.14)	1.18 (0.32–4.39)
Peripheral vascular disease	10 (18)	15 (28)	5 (9)	3.80 (0.92–15.70)	0.42 (0.08–2.19)
Chronic obstructive pulmonary disease	12 (22)	11 (20)	9 (17)	2.28 (0.60–8.69)	0.90 (0.21–3.82)
Chronic dialysis	3 (5)	6 (11)	4 (8)	7.53 (0.90–63.27)	3.72 (0.42–32.92)
Liver disease	2 (4)	4 (7)	2 (4)	5.73 (0.63–51.94)	1.22 (0.11–13.30)
Obesity	21 (38)	24 (44)	19 (36)	2.31 (0.66–8.06)	0.97 (0.30–3.13)
Malignancy	13 (24)	12 (22)	12 (23)	0.88 (0.23–3.40)	0.55 (0.14–2.15)

All values listed as n (%) unless otherwise specified.

Abbreviations: QOL, quality of life; RRR, relative risk ratio; CI, confidence interval; IQR, interquartile range;

^a p<0.05^b p<0.01^c Defined as living at home and able to ambulate 10 stairs and toilet independently, and have normal cognition

Table 2.

Patient Variables at Hospital Discharge and Six-Month Quality of Life

Patient Variable	Worse QOL n=55	Same QOL n=54	Better QOL n=53	Adjusted Same vs. Worse RRR (95% CI)	Adjusted Better vs. Worse RRR (95% CI)
Medical ICU	27 (49)	28 (52)	25 (47)	0.73 (0.31–1.73)	0.63 (0.26–1.57)
APACHE III score, median (IQR)	82 (62–115)	85.5 (73–110)	87 (66–102)	1.01 (1.00–1.03)	1.01 (0.99–1.02)
ICU length of stay ^a , median (IQR)	8 (6–16)	7 (5–17)	7 (5–10)	-	-
Hospital length of stay, median (IQR)	18 (15–29)	16.5 (11–29)	16 (11–22)	0.99 (0.97–1.02)	0.99 (0.96–1.02)
Ventilator days, median (IQR)	6 (5–14) ^b	6 (4–14) ^b	4 (2–6) ^b	1.01 (0.95–1.07)	1.00 (0.92–1.07)
Receiving dialysis	10 (18)	5 (9)	6 (11)	0.30 (0.08–1.09)	0.68 (0.27–1.73)
NMBA infusion use	12 (22)	7 (13)	7 (13)	0.31 (0.09–1.15)	0.81 (0.23–2.93)
Analgesia infusion use	38 (69)	39 (72)	28 (53)	1.15 (0.43–3.11)	0.55 (0.21–1.45)
Sedation infusion use	37 (67)	40 (74)	39 (74)	1.56 (0.59–4.11)	1.99 (0.76–5.22)
Systemic steroid use	24 (44)	22 (41)	16 (30)	0.99 (0.41–2.41)	0.68 (0.27–1.73)
Antipsychotic use	23 (42)	25 (46)	18 (34)	1.62 (0.62–4.22)	1.02 (0.37–2.80)
Discharge home	20 (36)	25 (46)	30 (57)	1.32 (0.57–3.07)	1.85 (0.78–4.37)

All values listed as n (%) unless otherwise specified.

Abbreviations: QOL, quality of life; RRR, relative risk ratio; CI, confidence interval; ICU, intensive care unit; APACHE III, acute physiology, age, chronic health evaluation III; IQR, interquartile range; NMBA, neuromuscular blockade agents

^aNot included in multinomial logistic regression model because of collinearity with hospital length of stay.^bp<0.05

Table 3.

Patient Outcomes at Six-Month Follow-Up and Six-Month Quality of Life

Patient Outcome	Worse QOL n=55	Same QOL n=54	Better QOL n=53	Adjusted Same vs. Worse RRR (95% CI)	Adjusted Better vs. Worse RRR (95% CI)
Ambulating 10 stairs	27 (49) ^b	45 (85) ^b	44 (83) ^b	2.15 (0.57–8.17)	1.67 (0.44–6.34)
Toileting	33 (60) ^b	49 (92) ^b	50 (94) ^b	2.11 (0.39–11.42)	2.54 (0.46–14.02)
Normal cognition	24 (44) ^b	40 (76) ^b	38 (72) ^b	3.74 (1.42–9.87) ^b	3.11 (1.19–8.16) ^c
Return to primary pastime ^a	27 (55) ^b	37 (80) ^b	40 (91) ^b	2.13 (0.73–6.21)	5.81 (1.66–20.40) ^b
Return to original place of residence	33 (60) ^b	48 (89) ^b	44 (83) ^b	4.09 (1.10–15.14) ^c	1.66 (0.53–5.26)

All values listed as n (%) unless otherwise specified.

Abbreviations: QOL, Quality of Life; RRR, relative risk ratio; CI, confidence interval

^aReturn to primary pastime includes data for 139 patients.^bp<0.01^cp<0.05

Table 4.

Number of ICU Clinician Predictions of Six-Month Quality of Life

Predictions		Patient-reported quality of life			
		Better	Same	Worse	Total
Physician prediction	Worse	28	22	31	81
	Same	18	28	21	67
	Better	6	4	3	13
	Total	52	54	55	161
Nurse prediction	Worse	22	24	27	73
	Same	20	19	21	60
	Better	11	10	7	28
	Total	53	53	55	161

Table 5.

Sensitivity and Specificity of ICU Clinician Predictions of Six-Month Quality of Life

Predictions	Prevalence of worse quality of life	Sensitivity (%), 95% CI	Specificity (%), 95% CI
All physician predictions	55/161 (34%)	56 (42–67)	53 (43–63)
Confident physician predictions	24/63 (38%)	71 (49–87)	44 (28–60)
All nurse predictions	55/161 (34%)	49 (35–63)	57 (47–66)
Confident nurse predictions	31/73 (43%)	52 (33–70)	60 (43–74)

Abbreviations: CI, confidence interval