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Quality of Life Before Intensive Care Using EQ-5D: Patient versus Proxy Responses

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Abstract

Objective—To compare patient's retrospectively reported baseline quality of life before intensive care hospitalization with population norms and proxy reports.

Design—Prospective cohort study.

Setting—13 intensive care units at 4 teaching hospitals in Baltimore, MD, USA.

Patients—140 acute lung injury survivors and their designated proxies.

Interventions—Around the time of hospital discharge, both patients and proxies were asked to retrospectively estimate patients' baseline quality of life before hospital admission using the EQ-5D quality of life instrument.

Measurements and Main Results—Mean patient-rated EQ-5D visual analog scale scores and utility scores were significantly lower than population norms, but were significantly higher than proxy ratings. However, the magnitude of difference in average utility scores between patients and either population norms or proxies were not clinically important. For the 5 individual EQ-5D domains, kappa statistics revealed slight to fair agreement between patients and proxies. Bland-Altman plots demonstrated that for both the visual analog scale and utility scores, proxies underestimated scores when patients reported high ratings and overestimated scores for low patient ratings.

Conclusion—Patients retrospectively reported worse baseline health status before acute lung injury than population norms and better status than proxy reports; however, the magnitude of these differences in health status may not be clinically important. Proxies had only slight to fair agreement with patients in all 5 EQ-5D domains, attenuating patients' more extreme ratings towards moderate scores. Caution is required when interpreting proxy retrospective reports of baseline health status for survivors of acute lung injury.

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Keywords

Critical care; Quality of life; Acute lung injury; Proxy; Respiratory distress syndrome, adult; Health status

Introduction

Intensive care unit (ICU) survivors experience worse quality of life (QOL) than age- and sex-matched population norms.(1–8) Compared to other ICU patients, acute lung injury (ALI) patients represent those most likely to have the poorest QOL because of high illness severity, extended ICU stay, and frequent new morbidity after hospitalization.(4;5;9;10)

Reliably benchmarking patient's QOL during their recovery ideally involves comparisons with pre-hospitalization baseline measures. Baseline QOL is also important because it can aid in prognostication and decision making in the ICU.(2) However, most ICU admissions are emergent and unexpected. Hence, baseline QOL cannot be obtained directly from the patient at admission. Alternatively, baseline QOL can be obtained retrospectively from survivors or from proxies. However, QOL obtained from these alternative methods may be subject to bias.

In our own study of ALI survivors, we found only fair to moderate agreement between patient and proxy estimates of the patients' baseline QOL measured by the SF-36.(11) This finding is consistent with another cohort of ALI survivors.(12) However, QOL ratings were comparable between patient and proxy in studies with non-ALI patients such as elective surgery(13), chronic disease(14) and general ICU patients.(15–18)

With these conflicting data on patient and proxy agreement, we sought to further evaluate patient versus proxy assessments of baseline QOL in ALI survivors using the EQ-5D survey. The EQ-5D is much shorter than the SF-36 with only 3 response options for each question; hence, it might produce better patient-proxy agreement. Our study has two specific objectives: (1) to compare baseline EQ-5D QOL measures of ALI survivors versus age- and sex-matched population norms, and (2) to evaluate the agreement of proxy versus patient estimates of baseline QOL.

Materials and Methods

Study Design and Participants

Data for this analysis was obtained from an ongoing prospective cohort study, (19) which consecutively enrolled ALI patients from 13 intensive care units at four teaching hospitals in Baltimore, USA. Eligible patients were ≥ 18 years old and mechanically ventilated with ALI as defined by the American-European Consensus Conference criteria.(20) Relevant exclusion criteria evaluated at the time of ALI diagnosis included preexistence of: 1) comorbid disease with a life expectancy of <6 months; 2) communication or language barrier; 3) cognitive impairment; and 4) no fixed address. The institutional review boards (IRB) of the Johns Hopkins University and all participating institutions approved of this study.

Patients were generally consented after discharge from ICU.(21) Thereafter, consented patients provided the name and contact information for their closest proxies. At the time of this study, only one version of the EQ-5D was available, which is now known as the EQ-5D-3L. This EQ-5D instrument was generally administered in person to patients and before hospital discharge, while proxies, who were generally not available in hospital after

patient consent, were interviewed via phone. Both patients and proxies were instructed to estimate baseline QOL, defined as just before the onset of the illness that resulted in patients' ALI hospitalization. Proxies were explicitly instructed to respond using the patient's perspective.(22;23)

The EQ-5D QOL(24) instrument consists of two sections: the descriptive system and the visual analogue scale (VAS). The descriptive system assesses the following five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each domain is assessed using a single question with three possible response options: no problems, some problems, or extreme problems. The individual domains can be converted to a utility score, a continuous range from −0.59 to 1.00, with 1.00 indicating "full health" and 0 representing death.(25) A negative EQ-5D utility score represents a health state valued as worse than dead. The VAS records the respondent's self-rated health state on a 0 to 100 scale where the endpoints are labeled 'Best imaginable health state' (100) and 'Worst imaginable health state' (0).

Statistical Analysis

For both the VAS and utility scores, the mean of paired differences between patient and proxy and between patient and age- and sex-matched population norms(26) were compared using t-tests. Additionally, the mean of paired differences in the utility scores was compared to the estimated EQ-5D minimal important difference (MID) of 0.074, (27) using a t-test.

For each EQ-5D domain, the mean difference between each patient-proxy pair was calculated. Agreement between patient and proxy responses was measured using the Cohen's kappa statistic (unweighted and weighted).(28) The kappa statistic can range from −1 (complete disagreement), to 0 (no agreement), to +1 (perfect agreement).(29) For the weighted kappa, weights were assigned using a standard method for linear weighting proposed by Cicchetti and Allison.(30) Given that each EQ-5D domain consists of 3 response options, the weights used were 1 for perfect agreement, 0.5 for responses that differed by 1 response level and 0 for comparing the maximum difference of 2 response levels (i.e. "no problems" vs. "extreme problems"). Based on the kappa statistic, patient-proxy agreement was qualitatively described according to recommendations from Landis and Koch: poor ($\kappa < 0$), slight (κ 0 – 0.2), fair (κ 0.21-0.4), moderate (κ 0.41 – 0.60), substantial (κ 0.61-0.8), or almost perfect ($\kappa \geq 0.81$).(29)

In addition, Bland-Altman plots were used to explore the relationship between differences in patient and proxy responses as a function of the patient response.(31) A traditional Bland-Altman plot would display the average of the patient and proxy responses along the horizontal axis. However, for this analysis, it was assumed that the patient response is measured without error, so that the patient response is most reflective of the true underlying quality of life and most appropriate for the x-axis. For the Bland-Altman plots, linear regression models were used to estimate the mean difference in patient and proxy responses as a function of the patient response.

For all analyses, $p < 0.05$ was considered statistically significant. All data were analyzed using STATA version 10.0 (College Station, TX).

Results

A total of 187 participants were potentially eligible for this patient-proxy QOL analysis. Of these, 40 were not eligible for the following reasons: patient cognitive impairment (n=24); no proxy available (n=9); death or hospice care prior to completion of surveys (n=7). Only 7 (5%) of 147 were excluded due to either the patient or proxy declining to complete the

survey. Hence, the EQ-5D data were analyzed for 140 patient-proxy pairs. Patients were mechanically ventilated for an average (standard deviation) of 12.6 (11.3) days. Table 1 describes baseline characteristics of the patients included in this study.

When comparing patient reports versus matched population norms (Table 2), the mean paired difference in VAS score was 10.6 (95% Confidence Interval (CI): −14.9, −6.3) points lower in patients. The mean paired difference in utility scores was 0.108 (95% CI: −0.151, −0.065) points lower in patients than the population norms, but this difference was not significantly greater than the estimated EQ-5D minimal important difference of 0.074 (p=0.121).(27)

The distribution of responses among proxies within each patient response option is presented in Table 3. The mean-paired difference for the patient-proxy comparison (Table 4) demonstrated significantly better ratings by patients for both the VAS and the utility scores, with a mean paired difference of 9.3 (95% CI: 3.5, 15.1) and 0.108 (95% CI: 0.060, 0.155), respectively. However, the magnitude of the mean-paired difference in utility score was not larger than the EQ-5D minimal important difference of 0.074 (p=0.165).(27)

The weighted kappa statistics revealed that patient-proxy agreement was “slight” to “fair” for all 5 EQ-5D domains (kappa range: 0.20 – 0.34) with relatively similar results from the unweighted kappa (range: 0.16 – 0.32; Table 5). Analysis of Bland-Altman plots for both the VAS and utility scores reveals that for both EQ-5D utility and VAS scores, proxy evaluations tended to attenuate the patient ratings. For example, when patients reported VAS scores greater than 60, most proxies provided lower scores, which are represented by the open circle symbols appearing above the horizontal line on the plot that represents no difference between patient and proxies. Points below this horizontal line indicate that proxies provided higher scores than patients which occurred universally when patients reported low VAS scores (e.g. scores less than 40).

Discussion

This prospective cohort study examined patient-proxy agreement in retrospectively reported baseline EQ-5D QOL of 140 ALI patients. Patients reported worse baseline QOL than population norms. The 140 patient-proxy pairs in this cohort had only slight to fair agreement in all 5 domains of EQ-5D with proxies responses biased toward the EQ-5D response option of “some problem” when the patient chose either “no” or “extreme” problems. On average, proxies (versus patients) reported lower baseline VAS and utility scores. However, the magnitude of this difference in utility scores was not clinically important.(27)

The importance of establishing accurate baseline QOL status of ICU patients motivates this analysis. In this study, patients retrospectively reported worse baseline QOL than the normal population, consistent with prior studies.(2;5;6;8;11;32) Consequently, using population norms as a substitute for a patient’s baseline QOL status may exaggerate the QOL impairments frequently observed during recovery after ICU.(2;4–8) Proxies may be potential source of patient baseline status. However, prior studies have reported varying degrees of agreement on QOL between proxies and patients.(11–18)

Despite the EQ-5D being markedly shorter and having fewer response options than the SF-36, there was only slight to fair agreement in all five domains between patients and proxies in this study. However in a population of trauma patients, agreement among the EQ-5D domains between patient and proxy were moderate to substantial.(33) Moreover, in a prior study evaluating agreement between patient- and proxy-reported baseline EQ-5D for general ICU patients, there was moderate to good agreement in mobility, self-care, usual

activities, and pain/discomfort domains, and fair agreement for anxiety/depression domain, and very similar VAS scores.(15) These results were replicated by the same group with a larger cohort.(34) In our study, patient-proxy pairs had fair agreement in all the domains, with mobility having the best agreement and pain having the worst agreement. These results may differ from ours due to differences in patient populations, including higher severity of illness in our cohort. Additionally, proxies in our study were interviewed via phone after the patients' ICU discharge, while in the other ICU studies, proxy interviews were conducted via a self-administered survey immediately after ICU admission. Consequently, it may be that our study found proxies to be unreliable sources of patient's baseline EQ-5D because our study design and cohort of patient were substantially different from the prior research that did not demonstrate problems with patient and proxy agreement in using the EQ-5D instrument.

There are several potential limitations of this study. First, there is no estimated EQ-5D MID for ICU survivors. We do not know if the MID cited in this study (27) is applicable for ICU patients, but provided it as a reference point for consideration. Second, data was not available for 25% of survivors. However, the majority of these missed assessments were unavoidable due to death, discharge to hospice, or cognitive impairment, which is consistent with other studies.(34;35) Only 5% of eligible patients or proxies declined to provide EQ-5D responses, comparable to similar studies.(15) Third, this study did not collect data on the nature of the relationship between patient and proxy, but interviewers made earnest attempts to reach the closest proxy available, as designated by the patient for this purpose. Furthermore, other literature has shown that patient-proxy relationship has no effects on agreement.(17;18;34) Lastly, the difference in mode of administration may have influenced our results since patient interviews were conducted in-person while proxies' were conducted by phone.(36) However, by allowing for more than one mode of administration, the study offered flexibility to patients and proxies, which potentially minimized non-response bias, given that proxies were infrequently available for in-person assessments.

Conclusions

Our comparison of patient-proxy agreement in retrospective reporting of ALI patient's baseline QOL prior to hospital admission revealed slight to fair agreement for all EQ-5D domains with evidence of proxy reports biased towards less extreme responses. These findings indicate that caution should be exercised if retrospectively obtaining baseline QOL data from proxies for survivors of acute lung injury.

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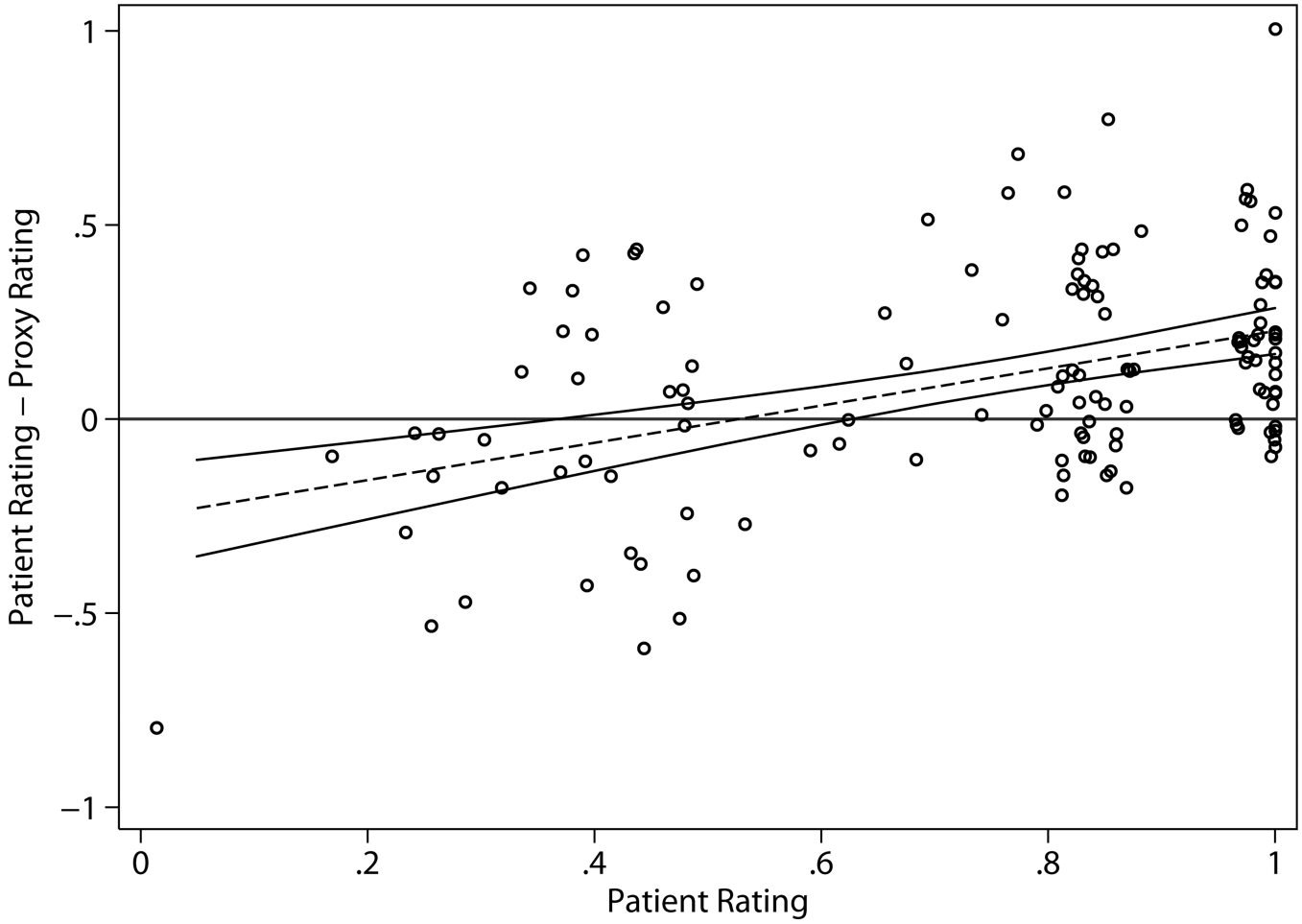

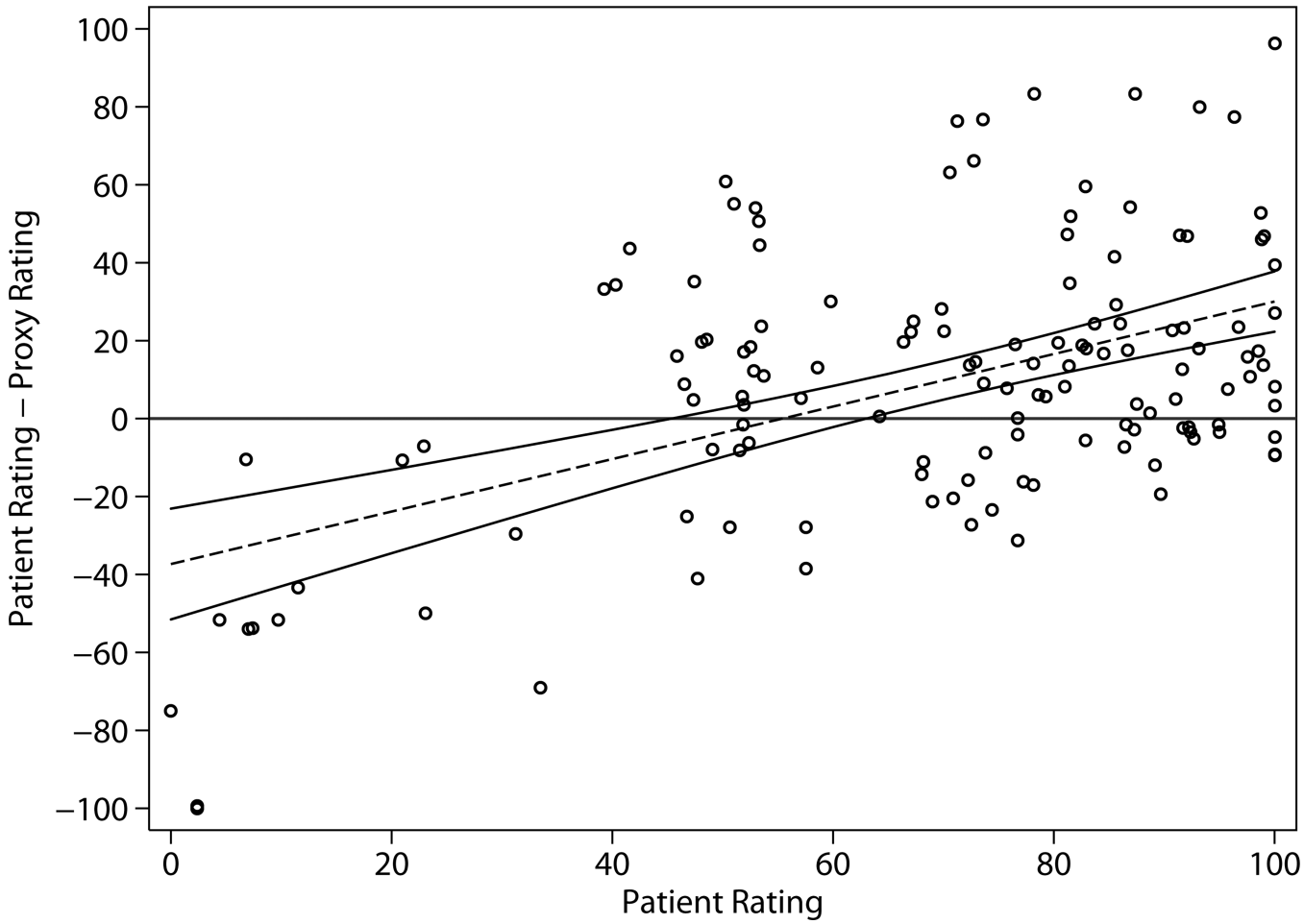

Figure 1. Bland-Altman Plots for EQ-5D Utility and VAS scores

1a: EQ-5D utility score

1b: EQ-5D visual analogue scale score

These figures display the relationship between patient-rated EQ-5D score and the difference between patient- and proxy-rated scores. The dashed line is the fitted linear regression of the relationship, while the upper and lower lines represent the 95% confidence interval.

Table 1

Description of study participants

Baseline characteristic	N=140[a]
Age, median (IQR) years	49 (40, 60)
Male, no. (%)	75 (54)
Race, no. (%)	
White	88 (63)
African-American	50 (36)
Other	2 (1)
Charlson comorbidity score, median (IQR)	1 (0, 3)
APACHE II score, median (IQR)	23 (17, 27)
ICU admission diagnosis, no. (%)	
Respiratory, including pneumonia	80 (57)
Gastrointestinal	18 (13)
Sepsis (non-pulmonary source)	10 (7)
Infectious disease	9 (6)
Trauma	6 (4)
Cardiovascular	4 (3)
Other	13 (9)
ICU type, no. (%)	
Medical	111 (79)
Surgical	19 (14)
Trauma	10 (7)

Abbreviations: APACHE II – Acute Physiology and Chronic Health Evaluation II; IQR – Interquartile Range

[a]Percentages may not add to 100% due to rounding.

Table 2

Patient versus population norms for baseline quality of life using EQ-5D

EQ-5D section	N[a]	Mean Patient Score	Mean Age- and Sex-Matched Population norm	Mean paired difference [95% CI] (population - patient)	P value for difference > 0[b]	P value for difference ≥ MID[c]
Visual Analogue Score	136	69.2	79.8	10.6 [14.9, 6.3]	<0.001	N/A
Utility Score	134	0.752	0.860	0.108 [0.151, 0.065]	<0.001	0.121

Abbreviations: CI – confidence intervals. MID - minimal important difference

[a]Four patients were missing VAS scores and 6 had missing data for at least one domain, which prevents calculation of the utility score

[b]P-value for testing if the mean paired difference is greater than zero

[c]P-value for testing if the mean paired difference is greater than the minimum important difference 0.074 (27)

Table 3

Distribution of responses among the EQ-5D domains in patients and proxies

Patient Responses		Proxy Responses		
		No Problem	Some Problem	Extreme Problem
Mobility, n	140			
No Problem	74%	65%	30%	5%
Some Problem	24%	18%	64%	18%
Extreme Problem	2%	33%	0%	67%
Self-care, n	140			
No Problem	88%	83%	14%	3%
Some Problem	11%	40%	47%	13%
Extreme Problem	1%	0%	100%	0%
Usual Activities, n [a]	139			
No Problem	78%	69%	19%	12%
Some Problem	18%	40%	48%	12%
Extreme Problem	4%	33%	33%	33%
Pain/Discomfort, n [a]	136			
No Problem	54%	42%	46%	12%
Some Problem	25%	24%	50%	26%
Extreme Problem	21%	18%	39%	43%
Anxiety/Depression, n [a]	139			
No Problem	60%	55%	36%	8%
Some Problem	30%	31%	40%	29%
Extreme Problem	10%	7%	36%	57%

[a] Usual activities and anxiety/depression were missing 1 patient/proxy pair and pain/discomfort had 4 missing pairs.

[b] Percentages may not add to 100% due to rounding.

Table 4

Patient versus proxy comparison for baseline quality of life using EQ-5D

	N[a]	Mean Patient Score	Mean Proxy Score	Mean paired difference [95% CI] (patient – proxy)	P value for difference > 0 [b]	P value for difference ≥ MID[c]
Visual Analogue Score	136	69.2	59.9	9.3 [3.5, 15.1]	0.002	N/A
Utility Score	134	0.752	0.644	0.108 [0.060, 0.155]	<0.001	0.165

Abbreviations: CI – confidence intervals. MID - minimal important difference

[a]Four patients were missing VAS scores and 6 had missing data for at least one domain, which prevents calculation of the utility score

[b]P-value for testing if the mean paired difference is greater than zero

[c]P-value for testing if the mean paired difference is greater than the minimum important difference 0.074 (27)

Table 5

Agreement between patient and proxy baseline quality of life assessment using EQ-5D

EQ-5D domain	N	Kappa [95% CI]	Weighted[a] Kappa [95% CI]
Mobility	140	0.32 [0.19, 0 .45]	0.34 [0.21, 0.46]
Self-Care	140	0.27 [0.13, 0.40]	0.29 [0.15, 0.42]
Usual Activities	139	0.22 [0.09, 0 .34]	0.20 [0.08, 0.33]
Pain/Discomfort	136	0.16 [0.05, 0.27]	0.22 [0.10, 0.35]
Anxiety/Discomfort	139	0.20 [0.08, 0.32]	0.29 [0.16, 0.41]

Abbreviations: CI – confidence intervals.

[a]A weight of 1 is assigned for perfect agreement, 0.5 for responses differing by one level, and 0 for a difference of two levels that is the largest possible disagreement. (30)