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EDITORIAL

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Quality of life following critical care: moving beyond survival

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As we evaluate the outcomes of critical care and the efficacy of ICU interventions, we need to move beyond focusing on short-term survival. Increasingly, patients, families, practitioners, and regulatory agencies are raising questions about long-term quality of life (QOL): How do survivors feel and function? This information is essential for making decisions at the bedside as well as about the efficacy and efficiency of ICU interventions. The literature on QOL has the potential to make a tremendous contribution to answering these questions of long-term prognosis. Unfortunately, the methodological rigor of the QOL literature relevant to critical care has been less than optimal [1]. If QOL instruments are to be used to evaluate new therapies and provide information that influences decision making in the ICU setting, these instruments need to be both reliable and valid. Reliability is the repeatability of observations when instruments are administered by different individuals and at different points in time. Validity refers to an instrument measuring that which it is intended to measure. At face value, an instrument may appear to be measuring what is intended to measure (known as face validity). Another form of validity study examines the extent to which individual items in a domain measure the same underlying attribute (internal consistency) or different aspects of QOL (factor analysis). Perhaps the most rigorous approach to establishing validity that in "construct validity." A construct is a theoretically derived notion of the domain(s) under scrutiny. An understanding of the construct leads to expectations about how an instrument should behave if it is valid. One approach to construct validity assesses differences between groups (e.g., those with mild chronic airflow limitation may be compared to those with more severe limitation). An even stronger approach compares measures and examines the logical relationships that should exist between a measure and characteristics of patients and patient groups. For example, we would expect a relationship between exercise capacity and dyspnea in daily life whereby, in general, those with greater exercise capacity experience less dyspnea in routine activities.

In establishing the validity of an instrument, validity can best be thought of as on a continuum, one end of which is anchored with "strong validity" and the other end by "no validity," rather than as a dichotomous variable (present or absent). Each individual paper that purports to establish the validity of a measurement tool then moves the truth along the validity continuum, increasing or decreasing it. We cannot make strong inferences from any individual study itself. Rather, the strongest sense of validity comes from synthesizing different studies by different authors using different approaches that seem to be sending a consistent signal, that an instrument does indeed measure what it purports to measure.

One of the difficulties in QOL research is defining exactly what one means by health-related QOL; there is no universally accepted definition. QOL, health status, functional status, and HRQL are often used interchangeably in the literature. Yet each of these terms may reflect quite different aspects of an individual's well-being. Differences in conceptualization of QOL may lead to different measurement approaches which may lead to different results. For example, why do some investigators mea-

sure QOL *in* the ICU and others in the months *following* ICU discharge? Is that which the patient experiences in the ICU a measure of QOL, or does it contribute to the overall well-being of an individual some months later? The answers to these questions are probably related to the investigator's conceptualization of QOL.

Individuals' "well-being" or QOL is determined by their health status as well as by other variables (such as social relationships, employment status, the well-being of others, etc.). Health status measurements include those that assess physical, physiological, or psychological states or function. Health status measures can be further categorized as those that persons, in general, intrinsically value (such as the ability to walk without dyspnea) and those that they do not intrinsically value (such as the performance on exercise tests in a laboratory). Aspects of health status that persons value overlap with components of QOL, and we refer to as HRQL [1]. Given this conceptualization, long-term assessments of HRQL are best suited to answer the question of how survivors of critical illness feel and function. Measurements of actual ICU experience can best be thought of as "quality of care" or process measurements, not measurements of outcomes. They may contribute to long-term outcomes but are not the end in and of themselves. For example, adverse events in the ICU may contribute to the development of posttraumatic stress disorder [2]. It is the development of this disorder and its subsequent impact on long-term HRQL that is of interest in the QOL literature. The occurrence of adverse events in the ICU may be more important to the quality management literature.

Over the past decade several instruments measuring QOL have been used in ICU populations both during and after an ICU stay. These measure both global and disease-specific domains of QOL [3]. Because the more global or generic instruments apply to a broad spectrum of populations, they allow comparisons of the relative impact of various interventions and healthcare programs. Generic instruments may, however, be less responsive to changes in specific conditions or symptoms than specific HRQL instruments. Recently instruments specifically designed for the ICU have been proposed by Italian and Spanish investigators [4, 5]. In this issue of *Intensive Care Medicine*, Cappuzzo and colleagues [6, 7] strive to increase the robustness of QOL assessments by validating the Italian QOL instrument (QOL-IT), further improving the construct validity of the Spanish QOL instrument (QOL-SP), and evaluating the agreement between patient and surrogate assessment of self-reported QOL in a population of 172 ICU patients. In the first of two articles, Capuzzo et al. [6] demonstrate excellent interobserver agreement (weighted $\varkappa = 0.99$) for both the QOL-IT and the QOL-SP instruments, hence substantiating the reliability of the instruments. Moreover, good agreement is demonstrated between the patient's retrospective response and that of the surrogates for both instruments (weighted $\varkappa = 0.78$ for QOL-IT, and 0.82 for QOL-SP). This agreement is particularly important given that for many critically ill patients the physician must rely on information provided by a surrogate. However, contrary to the findings of other studies [8, 9], the degree of relationship of relatives, gender, or living arrangements did not influence the degree of agreement. The power to formulate this latter conclusion may have been limited by the small sample size (172 patients) and the nature of the analysis used in this study whereby information was effectively "lost" when the degree of agreement was arbitrarily partitioned into "good" or "poor" agreement rather than maintaining its continuous measure. Nevertheless, this study adds to the internal consistency and the reproducibility of the QOL-SP instrument which had been previously demonstrated in a Spanish population [4].

In the subsequent article Capuzzo et al. [7] demonstrate the construct validity of the QOL-IT and the QOL-SP instruments against a measure of functional limitation which was evaluated by an independent interviewer as well as the presence or absence of chronic diseases at the time of ICU admission. The authors demonstrate a statistically significant correlation between both the QOL-IT and the QOL-SP and the independent measures of functional limitation and chronic disease. As functional status becomes more impaired, median QOL-IT and QOL-SP scores increase. These results are consistent with the construct validity demonstrated during the original validation of the QOL-SP [4]. In addition, Capuzzo and colleagues demonstrate that patients with chronic diseases have scores significantly higher than do those with acute illnesses. Previous studies utilizing a larger scale, namely the SF-36, as well as a composite instrument made up of validated scales, have demonstrated a greater decrease in QOL after ICU discharge for those patients admitted with acute problems as than in those with chronic comorbidities [10, 11]. Hence care must be taken to stratify patients by measures of health prior to the ICU admission when assessing QOL after ICU discharge. However, the interpretability and responsiveness or sensitivity to change in other objective measures of health status of both the QOL-IT and the QOL-SP has yet to be thoroughly demonstrated. What does an average score of 3 mean? What change in score is a clinically important difference? Moreover, the utility of an instrument that can be used only in awake and cooperative patients while in the ICU is questionable. The patients at highest risk of "poor" QOL may be those who were unable to participate in the study while in the ICU and yet recovered to the extent that they could provide important information on long-term outcomes of critically ill patients.

To date over 30 papers (references available on request) have documented the long-term HRQL of all pa-

tients admitted to the ICU. Synthesizing these data, it would appear that survivors overall have a "reasonable" long-term QOL (compared to premorbid QOL or QOL of a control group). Further evaluations of such heterogeneous cohorts of ICU survivors may not produce new information. Further illuminating the long-term outcomes of critically ill patients would require more focused assessments of particular high-risk subgroups of critically ill patients, such as patients with stroke requiring mechanical ventilation [12] or patients with hematological malignancies requiring ICU admission [13].

In this issue of *Intensive Care Medicine*, Schelling and colleagues [14] contribute to the burgeoning literature on another high-risk group – survivors of acute respiratory distress syndrome (ARDS). They present the results of a follow-up analysis of a cohort that was assembled over 5 years ago. In 1998 they reported that these survivors of ARDS had significant impairments in all domains measured by the SF-36 when compared to normal controls [2]. In addition, they reported a high incidence of posttraumatic stress disorder among survivors of ARDS (27.% compared to 11.9 % in control population).

Now, in a follow-up analysis of 50 of these long-term survivors of ARDS, Schelling and colleagues have measured pulmonary function and pulmonary symptoms and repeated their assessments of HRQL. The authors hypothesize that limitations in pulmonary function may not *cause* deficits in HRQL but rather represent an indicator of more severe disease leading to pulmonary failure and ICU treatment. They found that impairments in pulmonary function are still detectable in the majority of survivors years after their illness but are generally mild in nature. Of the 50 patients 23 (46 %) patients had no impairment of pulmonary function, and 27 (54 %) showed impairments in at least one of the five pulmonary function tests (FEV_1, FVC, TLC, diffusing capacity, and arterialized pO_2). Seven of these patients had multiple impairments. Consistent with other studies [15, 16, 17], Schelling and colleagues again reported that survivors of ARDS have impaired HRQL in all of the domains captured by the SF-36 compared to age- and sex-matched population controls. Interestingly, from their previous measurements of HRQL published in 1998 [2], survivors continued to improve their HRQL (as evidenced by increasing SF-36 scores over time). What is perhaps more noteworthy was the fact that patients with multiple (> 1) impairments in pulmonary function present the lowest HRQL, with severe limitations in all domains of the SF-36, and are less likely to be employed than survivors with no or only one impairment to pulmonary function. While this study represents the longest duration of follow-up of survivors of ARDS (median duration of follow-up 5.5 years), the small, select sample and high number of patients lost to follow-up question the representativeness of the data. As acknowledged by the authors, if one assumes that those who died or were lost to follow-up had severe impairments in pulmonary function, the current report underestimates the true incidence and impact of pulmonary abnormalities in long-term survivors.

Is the impairment in HRQL observed in survivors of ARDS causally related to their residual pulmonary injury, or is it due to some other factor, such as their underlying disease, acquired neuromuscular weakness following critical illness, etc.? The answer to this question is important as lung-directed strategies (such as exogenous surfactant or low-volume ventilation) may not have a significant effect on long-term HRQL if the impairment is due to largely nonpulmonary factors. The work of Davidson and colleagues [18] provides the strongest evidence to date that the impairment experienced by survivors is due to residual lung dysfunction. In a prospective cohort study of 73 survivors of ARDS, compared to severity-matched critically ill controls without lung injury, they showed that survivors of ARDS have both worse pulmonary-specific symptoms (as measured by St. George's Respiratory Questionnaire) and clinically important and statistically significant reductions in HRQL (as measured by SF-36). The reductions in HRQL were wide ranging but were most pronounced in the domains that assess physical limitations and the effect of these limitations on one's ability to perform specific roles in society. These findings seem to support the assertion that pulmonary dysfunction following ARDS *contributes* significantly to overall reductions in HRQL observed in survivors. This does not mean that *all* the reduction in HRQL is due to pulmonary dysfunction. As is apparent in the study by Schelling et al. [14], those with normal or minimal abnormalities in pulmonary function tests still have impaired HRQL in some domains measured by the SF-36 compared to controls. Therefore lung-directed interventions that prevent or treat ARDS (such as exogenous surfactant administration and low volume ventilation) have the greatest likelihood of improving the long-term HRQL of survivors of ARDS.

Over the next decade we anticipate a proliferation of QOL measurements in survivors of critical illness. The increasing use of the same validated instruments by different investigators will allow more comparisons to be made across studies of ICU patients and those of non-ICU patients. As the methodological rigor of QOL assessment improves, we can expect to see measures of QOL incorporated into more phase III trials of novel therapeutic agents, in the management of ARDS, sepsis, and other critical illnesses. By using measurement tools demonstrated to be valid, reliable, and interpretable in a population of critically ill survivors, we will be in a better position to explain to patients, families, and others how survivors of critical illness feel and function over the long term.

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