



Understanding patient-important outcomes after critical illness: a synthesis of recent qualitative, empirical, and consensus-related studies

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Purpose of review

Patients surviving critical illness frequently experience long-lasting morbidities. Consequently, researchers and clinicians are increasingly focused on evaluating and improving survivors' outcomes after hospital discharge. This review synthesizes recent research aimed at understanding the postdischarge outcomes that patients consider important (i.e., patient-important outcomes) for the purpose of advancing future clinical research in the field.

Recent findings

Across multiple types of studies, patients, family members, researchers, and clinicians have consistently endorsed physical function, cognition, and mental health as important outcomes to evaluate in future research. Aspects of social health, such as return to work and changes in interpersonal relationships, also were noted in some research publications. Informed by these recent studies, an international Delphi consensus process (including patient and caregiver representatives) recommended the following core set of outcomes for use in all studies evaluating acute respiratory failure survivors after hospital discharge: survival, physical function (including muscle/nerve function and pulmonary function), cognition, mental health, health-related quality of life, and pain. The Delphi panel also reached consensus on recommended measurement instruments for some of these core outcomes.

Summary

Recent studies have made major advances in understanding patient-important outcomes to help guide future clinical research aimed at improving ICU survivors' recovery.

Keywords

critical illness, health-related quality of life, mental health, outcome assessment, physical function

INTRODUCTION

Advances in medicine have reduced short-term mortality from critical illness [1,2]. Coupled with increasing demand for critical care services from an aging population [3,4], there is a growing number of ICU survivors. However, surviving critical illness frequently comes at a 'cost', with new or worsened long-lasting impairments affecting physical [5–7], cognitive [8–11], and/or mental health status [12–14], collectively known as 'post intensive care syndrome' (PICS) [15]. Related to these impairments, ICU survivors also commonly have impaired quality of life [16,17], delayed return to work [18,19], and increased healthcare utilization [20–22].

As focus shifts toward understanding and improving the functional status of ICU survivors, there is a rapidly growing number of studies evaluating these outcomes [23***]. However, the critical care community must advance its understanding of post-ICU outcomes, in part, to ensure patient-

centered research, which dictates inclusion of outcomes that patients consider important (i.e., patient-important outcomes) [24]. Furthermore, understanding patient-important outcomes allows researchers to prioritize and standardize evaluation

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KEY POINTS

- Heterogeneity in the outcomes and measurement instruments used in studies of ICU survivors after hospital discharge creates a major barrier in synthesizing results to inform a comprehensive understanding of ICU survivorship.
- Understanding patient-important outcomes is necessary for researchers and clinicians to advance research and care for ICU survivors.
- Patients, family members, researchers, and clinicians consistently supported physical function, cognition, mental health, and return to work as important outcomes, with social health being an area for future investigation.
- An international consensus panel, that included substantial patient and caregiver representation, recommended the following core set of outcomes for use in all studies evaluating acute respiratory failure survivors after hospital discharge: survival, physical function, cognition, mental health, muscle/nerve function, pulmonary function, health-related quality of life, and pain.

of these outcomes. In this review, we synthesize existing literature regarding patient-important outcomes for ICU survivors, with emphasis on a 5-year program of research in this area that was funded by the National Heart, Lung and Blood Institute (grant R24HL111895; www.improveLTO.com).

HETEROGENEITY IN MEASURED OUTCOMES AFTER HOSPITAL DISCHARGE FOR ICU SURVIVORS

We conducted a scoping review [23^{***}] of 425 publications examining ICU survivors after hospital discharge demonstrating great variability in reported outcomes. For instance, quality of life was the most frequently reported outcome (276/425 (65%) articles), whereas physical activity limitation (requiring in-person assessment of patient performance) was the least reported outcome (6%) [23^{***}]. Such variability reflects the growing nature of this field of research and the lack of standardization in outcomes evaluated. Inconsistently evaluating outcomes prevents a comprehensive and comparable representation of ICU survivorship across studies.

Our scoping review also identified 250 different outcome measurement instruments used in 425 articles [23^{***}]. For example, at least nine different instruments were used to evaluate posttraumatic stress disorder in ICU survivors [23^{***}]. Such heterogeneity in measurement instruments limits comparison across studies, impedes meta-analyses [25], and

increases the chance of selective reporting of study results [26]. This scoping review [23^{***}] underscores the importance of understanding patient-important outcomes and standardizing measurement instruments to improve the relevance and rigor of ICU survivorship research.

WHAT ARE PATIENT-IMPORTANT OUTCOMES?

In many fields, researchers are focused on understanding outcomes that matter to patients. Within critical care, some researchers have advocated focusing on patient-oriented outcomes, rather than disease-oriented outcomes, in randomized controlled trials (RCTs) [27]. A recent systematic review reported that after excluding mortality as an outcome, only six of 112 (5%) ICU RCTs used ‘patient-important’ outcomes (e.g., physical function, quality of life) as primary outcomes [28^{*}].

In determining patient-important outcomes, it is imperative to clarify the involvement of patients in these processes [29]. Patient-important outcomes should put weight on the ‘preeminence of the patient’s values and preferences’ [30]. Hence, patient involvement is paramount in this process.

Methods for engaging patients in determining patient-important outcomes include undertaking qualitative research, conducting surveys, and/or having direct patient participation in related meetings or conferences. Family/caregiver perspectives on patient-important outcomes are also vital as they are often informants of ICU survivors’ recovery in both research and clinical settings. Researcher and clinician perspectives also must be understood given their role as key stakeholders in designing studies and translating research findings into clinical practice. Ultimately, patient, family, researcher, and clinician perspectives must be synthesized to gain a cohesive and representative understanding of patient-important outcomes for ICU survivorship research.

PATIENT AND FAMILY PERSPECTIVES ON PATIENT OUTCOMES AFTER HOSPITAL DISCHARGE

Both patient and family perspectives have been evaluated in understanding patient-important outcomes after hospital discharge for ICU survivors.

Understanding patient outcomes after hospital discharge through qualitative research

In our qualitative study investigating the recovery experience of ICU survivors after hospital discharge,



FIGURE 1. Summary of thematic analysis from qualitative interviews of acute respiratory failure survivors [31[■]] organized using the National Institutes of Health's Patient-Reported Outcomes Measurement Information System framework [32].

we conducted telephone-based, semistructured interviews [31[■]] with 48 survivors of acute respiratory failure (ARF) recruited from 35 hospitals across the United States. Survivors were interviewed at a median of 9 (interquartile range: 7–13) months after ICU. The interview began with open-ended questions about recovery followed by structured prompts guided by the US National Institutes of Health's (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS) framework [32]. The interviews were recorded, transcribed, coded, and categorized under physical, mental (including cognition), and social health (Fig. 1). Themes from the interviews largely focused on health issues and specific impairments, consistent with well-documented post-ICU morbidities reported in existing empirical studies [5,6,8–10,12–14,33[■]]. Consistent results were also reported in a recent Danish qualitative study evaluating patient-important outcomes through interviews with 10 ICU survivors [34[■]].

Notably, our qualitative study also elucidated social aspects of recovery [31[■]], not widely explored in prior empirical studies [23[■]]. In our qualitative study, patients expressed distress about employment status, interpersonal relationships, and participation in social activities and hobbies. Patients described positive and negative thoughts and emotions related to the psychosocial aspects of recovery. For example, a survivor wished to have died in the

ICU, whereas others reported gratitude for surviving, a new-found positive outlook, and valuing their health more.

To put these findings into context, we also conducted a systematic review of qualitative studies that reported ICU survivors' outcomes after hospital discharge [35[■]]. This review excluded studies conducted in specialty ICUs (e.g., trauma ICU) or focused on specific diseases/syndromes [e.g., acute respiratory distress syndrome (ARDS)]. A total of 22 studies were identified, with 19 (86%) published after 1999. Synthesis of these 22 studies demonstrated consistency with the themes outlined above regarding physical, mental (including cognition), and social health, with the psychosocial aspects of recovery [31[■]] encompassed as part of the 'Global Satisfaction with Life' domain in this systematic review.

Importance of specific patient outcomes to patients and family after hospital discharge

To address the issues of feasibility in ICU survivorship research, it is important to understand which minimum set of outcomes is most important for inclusion in all relevant research studies. Hence, we surveyed a national cohort of ARDS survivors ($n=78$) and family members ($n=80$), including 55 patient-family pairs, to empirically evaluate this issue [36[■]].

For this survey [36¹¹], we proposed and refined a list of 19 potential outcomes based on existing research and review of the World Health Organization International Classification of Functioning, Disability and Health [37], the U.S. NIH PROMIS framework [32], and the Society of Critical Care Medicine (SCCM) PICS framework [15], along with additional patient and clinician input (Table 1). Survey respondents were asked whether each of the 19 outcomes should be measured in *all* research studies of ICU survivors. Support for an outcome was defined as a response of either agree or strongly agree (versus neutral, disagree, or strongly disagree). Overall, 15 (79%) of the 19 outcomes were supported by at least 80% of the patient and family respondents as important to be measured in *all* research studies of ICU survivors. The most highly rated outcomes were physical function/symptoms, pulmonary function/symptoms, cognitive function/symptoms, mental health conditions/symptoms, pain, fatigue, and return to work or prior activities. Social roles, activities, or relationships; survival; and sexual function/symptoms had the lowest level of support. Family members' level of support for each outcome was similar to patients', including within the subset of patient–family member pairs.

In a Danish study of ICU survivors (see above), 36 outcomes from qualitative interviews with ICU survivors were distilled to 20 outcomes using semi-structured interviews of a different group of ICU

survivors [34¹²]. Thirty-two patients were asked to rank these 20 outcomes by importance [34¹²]. Because of different methodology for composing the list of potential outcomes and for ranking outcomes, these results are not directly comparable with our survey findings. However, this Danish list of outcomes overlap with many of the outcomes evaluated in the survey-based research described above (Table 1).

RESEARCHER AND CLINICIAN PERSPECTIVES ON PATIENT OUTCOMES AFTER HOSPITAL DISCHARGE

Understanding researcher and clinician perspectives is an important consideration as they are primary stakeholders in designing research studies evaluating ICU survivors and in translating research findings into clinical practice.

Researcher perspectives on important patient outcomes after hospital discharge

Using the same list of 19 outcomes rated by patients (see above, and Table 1) [36¹¹], we surveyed an international sample of 121 researchers [36¹¹], who were corresponding authors of the ICU survivorship publications in our scoping review [23¹³]. Researchers rated their level of agreement (using the same five-

Table 1. List of 19 outcomes and descriptions provided to respondents [36¹¹]

Survival (how long do people live after leaving the ICU?)
Pain
Fatigue (are you feeling tired, having too little energy to get through the day, or needing more rest?)
Muscle and/or nerve function (have you felt weak, sore, or numb?)
Physical function/symptoms (how easy it is to walk, dress, or eat?)
Pulmonary function/symptoms (do you have trouble breathing, shortness of breath, or cough?)
Swallowing function/symptoms (do you have any trouble swallowing foods or liquids?)
Gastrointestinal function/symptoms (do you have stomachaches, nausea/vomiting, diarrhea, constipation, gas, or indigestion?)
Sleep function/symptoms (do you have trouble falling asleep, staying asleep, or a need for a sleeping medication?)
Sexual function/symptoms (do you have a decreased desire for sex, inability to have sex, or pain or discomfort during sex?)
Cognitive function/symptoms (do you have problems with memory, communication, concentrating, or understanding instructions?)
Mental health conditions/symptoms (do you have trouble with emotions and mood, anxiety, depression, posttraumatic stress disorder, or worrying?)
Type of residence (when you left the ICU, did you go to a rehabilitation center, nursing home, or to your own home?)
Return to work or prior activities (are you doing the same things you did before the ICU? Did you return to your prior job full-time or part-time?)
Healthcare resource utilization (are you seeing more doctors or physical therapists, taking new medications, or have you returned to the hospital? Do you need help making doctors' appointments?)
Financial impact on patient (are you dealing with hospital bills or lost income from time off work? Do you have to pay someone to help with your care or transportation?)
Impact on family and/or caregivers (do you feel you are a burden on family or friends? How does being sick affect other people in your life?)
Social roles, activities, or relationships (are you still able to connect with others, maintain friendships, and romantic relationships? Able to complete activities with/for others?)
Satisfaction with life or personal enjoyment

point scale used with patients and families, above) with having each outcome measured in *all* studies of ICU survivors after hospital discharge. These researchers were from 26 different countries, with self-reported expertise in physical (79% of respondents), cognitive (52%), and mental health (61%) outcomes. A total of 71 of 121 (59%) respondents had clinical training, with 53 (43%) being critical care physicians.

The five outcomes with the strongest support (i.e., 'agree' or 'strongly agree') were survival, physical function/symptoms, cognitive function/symptoms, mental health conditions/symptoms, and return to work or prior activities. The five domains with the least support were gastrointestinal function/symptoms, swallowing function/symptoms, sexual function/symptoms, financial impact on patient, and impact on family/caregivers.

Clinician perspectives on important patient outcomes after hospital discharge

Clinicians play a vital role in translating research findings into clinical practice. Hence, clinician perceptions of research outcomes are important. As a part of our program of research, we conducted two separate modified Delphi consensus projects with clinician participants, during in-person meetings held in the United States ($n=44$) and in Australia ($n=85$) [38[■]]. Participants were physicians [United States, 16 (36%); Australia, 3 (4%)], physical therapists [12 (27%); 73 (86%)], and others [16 (36%); 9 (11%)]. Using an *a priori* threshold for consensus of at least 70% of respondents agreeing to 'always' measuring an outcome in studies of ICU survivors after hospital discharge, the following outcomes reached consensus in either or both studies: survival (United States 72%; Australia 95%), physical function/symptoms (95%; 99%), cognitive function/symptoms (80%; 86%), mental health conditions/symptoms (62%; 72%), health-related quality of life (90%; 80%), return to work or prior activities (72%; 66%), and type of residence (54%; 78%).

The previously-discussed Danish study also asked ICU nurses ($n=54$) and anesthesiologists ($n=17$) to rank 20 patient outcomes with respect to the greatest challenges facing ICU survivors [34[■]]. The nurses' five highest ranked outcomes fell under physical (fatigue), cognitive (concentration and memory), and mental health (depression and anxiety) categories. For the anesthesiologists, the five highest ranking outcomes all fell under physical (fatigue, activities of daily living (ADL), strength) and mental health (depression and anxiety) categories. For anesthesiologists, cognition-related outcomes of concentration and memory ranked as 9th and 12th among the 20 outcomes. These results are not directly comparable with

our survey findings, above, because of differences in the composition of the list and methods for ranking outcomes.

Patient versus researcher and clinician perspectives on patient outcomes after hospital discharge

Patients, researchers, and clinicians had the highest level of support for the following four outcomes after hospital discharge: physical function/symptoms, cognitive function/symptoms, mental health conditions/symptoms, and return to work or prior activities. Notably, these outcomes fit within the SCCM PICS framework [15]. Survival was the top-rated outcome by researchers and clinicians; whereas this was the second lowest rated outcome by patients. This difference could be explained by the sample consisting of all ICU survivors and family members of mainly ICU survivors (rather than decedents), potentially leading to lower awareness of high mortality rates for critically ill patients [39]. Also, researchers may rank survival more highly due to their awareness of the importance of accounting for death when evaluating functional outcomes after hospital discharge [40[■]], and the common practice of evaluating mortality as the primary outcome in critical care studies [28[■]].

In the previously-mentioned Danish study [34[■]], anesthesiologists highly ranked outcomes involving physical function and mental health; whereas nurses also highly ranked cognitive function. In contrast, among the 32 Danish patients surveyed, physical outcomes were highly ranked, comprising seven of the eight highest ranked outcomes (lack of physical strength, fatigue, decreased walking distance, dyspnea, difficulties with ADL, less independence, and pain).

SYNTHESIZING PATIENT-IMPORTANT OUTCOMES TO GUIDE RESEARCHERS

To mitigate the heterogeneity of evaluated outcomes, many areas within healthcare are establishing core outcome sets (COS). A COS is a minimum set of outcomes recommended to always be evaluated within a specific field, to facilitate comparison of results and meta-analysis [25,26,41,42]. Building on a COS, a core outcome measurement set (COMS) is a minimum set of outcome measurement instruments used for measuring the COS. Recently, there have been several COS/COMS projects within critical care [43]. Our NHLBI-funded infrastructure project (R24HL111895) aimed to establish a COS and COMS for follow-up of ARF survivors after hospital discharge [44[■],45[■]].

There are important clarifications on what a COS/COMS entails. For example, a COS/COMS for studies evaluating ICU survivors after hospital discharge does *not* mandate that all critical care studies perform evaluations of ICU patients after hospital discharge; this COS/COMS applies *only* to ICU studies that have a goal of evaluating postdischarge outcomes. Furthermore, any COS/COMS does not preclude researchers from evaluating additional outcomes and additional measurement instruments. A recommended COS/COMS aims to be relatively brief to help ensure feasibility for inclusion in all relevant studies.

We used a modified Delphi consensus process (Fig. 2), with an international consensus panel, in developing a COS/COMS for studies evaluating ARF survivors after hospital discharge [44^{¶¶},45^{¶¶}]. The consensus panel consisted of four stakeholder groups: patient and caregivers (25% of panel members), researchers (45%), clinicians and representatives of professional associations (25%), and US federal funding bodies (5%). Researchers and clinicians were represented from around the world (representing >16 countries from six continents), whereas patients/caregivers and representatives of professional associations were included from the four English-speaking countries with the greatest number of publications in the field of ICU survivorship: [23^{¶¶}] USA, Canada, United Kingdom, and Australia.

In this modified Delphi process (Fig. 2), consensus on each outcome/instrument was defined *a priori* as at least 70% of panel members rating an outcome as ‘critical’ for inclusion into the COS/COMS and 15% or less rating it as ‘not important’. If any of the minority stakeholder groups (patients/caregivers or clinicians) commonly voted an outcome or measurement instrument as ‘not important’, then that outcome/instrument was assured to not achieve consensus for inclusion in the COS/COMS. Results from our program of research, as described in the preceding sections, were shared with the international panel as part of the COS/COMS consensus process (Figs. 2 and 3) [44^{¶¶},45^{¶¶}].

From this modified Delphi consensus process (Fig. 2), the international panel recommended eight outcomes as part of the COS: survival, physical function, cognition, mental health, muscle/nerve function, pulmonary function, health-related quality of life, and pain. (Fig. 2) [44^{¶¶}]. The recommended COMS [45^{¶¶}] (Fig. 3) includes the following measurement instruments: date and location of death (for survival); EQ-5D (for the outcomes of health-related quality of life and of pain); and Hospital Anxiety and Depression Scale and Impact of Event Scale-Revised (both for mental health outcomes). Many more resources related to the COS and COMS are available at the study website created for dissemination of these results and related research infrastructure aimed at ICU survivorship studies: www.improveLTO.com.

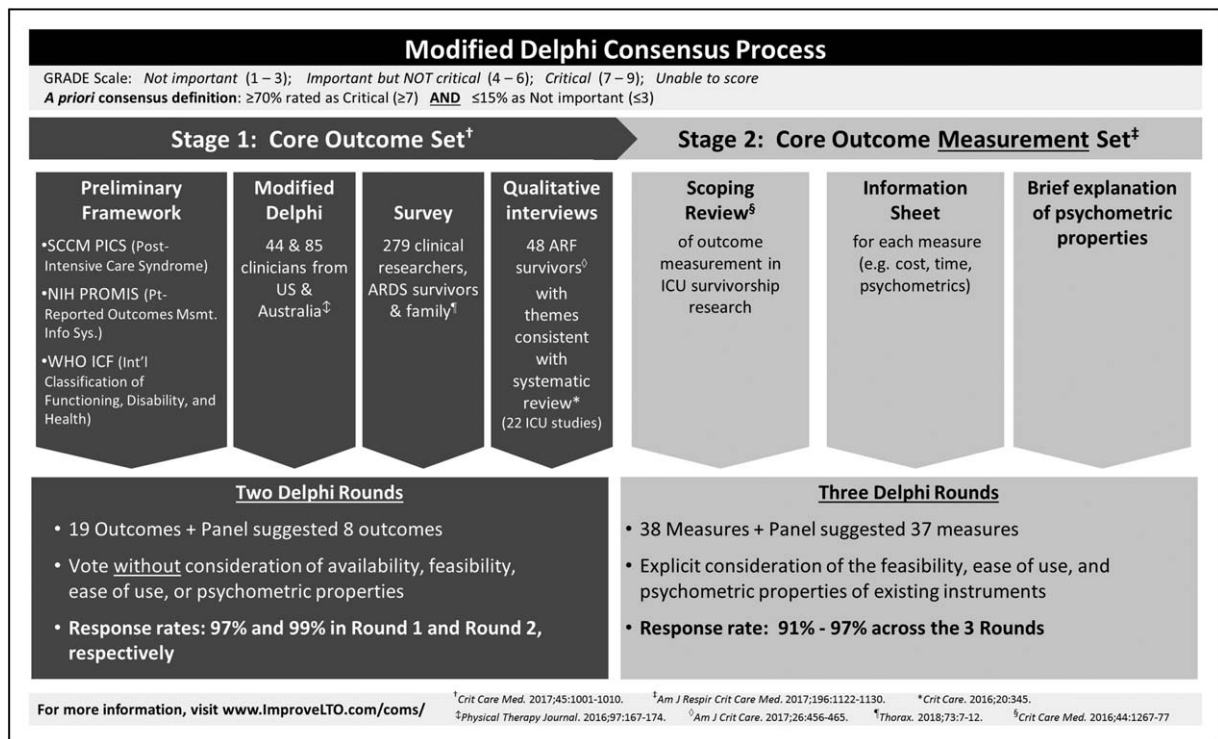


FIGURE 2. Summary of the modified Delphi consensus process.

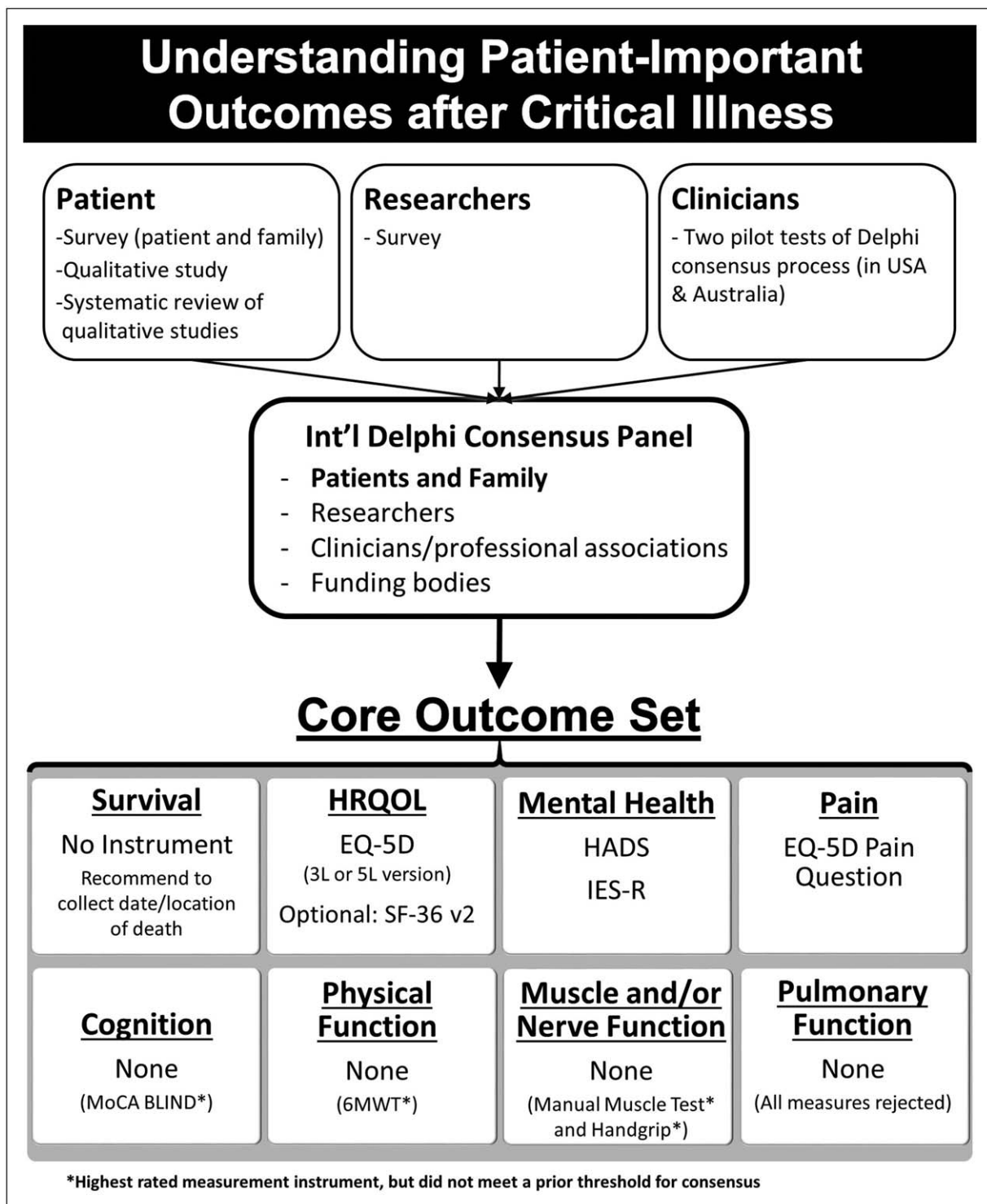


FIGURE 3. Summary of understanding patient-important outcomes in creating a core outcome set [44**]/core outcome measurement set [45**].

CONCLUSION

ICU survivors face many challenges in their recovery after hospital discharge. Clinicians and researchers are increasingly interested in understanding this recovery process and in designing

and implementing interventions to improve the outcomes of greatest importance to ICU survivors. Understanding such patient-important outcomes, as synthesized in this article, can help provide focus for future ICU survivorship research.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

1. Spragg RG, Bernard GR, Checkley W, *et al.* Beyond mortality: future clinical research in acute lung injury. *Am J Respir Crit Care Med* 2010; 181: 1121–1127.
 2. Wunsch H, Linde-Zwirble WT, Angus DC, *et al.* The epidemiology of mechanical ventilation use in the United States. *Crit Care Med* 2010; 38: 1947–1953.
 3. Carson SS, Cox CE, Holmes GM, *et al.* The changing epidemiology of mechanical ventilation: a population-based study. *J Intensive Care Med* 2006; 21:173–182.
 4. Needham DM, Bronskill SE, Calinawan JR, *et al.* Projected incidence of mechanical ventilation in Ontario to 2026: preparing for the aging baby boomers. *Crit Care Med* 2005; 33:574–579.
 5. Pfoh ER, Wozniak AW, Colantuoni E, *et al.* Physical declines occurring after hospital discharge in ARDS survivors: a 5-year longitudinal study. *Intensive Care Med* 2016; 42:1557–1566.
 6. Herridge MS, Tansey CM, Matte A, *et al.* Functional disability 5 years after acute respiratory distress syndrome. *N Engl J Med* 2011; 364:1293–1304.
 7. Fan E, Dowdy DW, Colantuoni E, *et al.* Physical complications in acute lung injury survivors: a two-year longitudinal prospective study. *Crit Care Med* 2014; 42:849–859.
 8. de Azevedo JRA, Montenegro WS, Rodrigues DP, *et al.* Long-term cognitive outcomes among unselected ventilated and nonventilated ICU patients. *J Intensive Care* 2017; 5:18.
 9. Wilcox ME, Brummel NE, Archer K, *et al.* Cognitive dysfunction in ICU patients: risk factors, predictors, and rehabilitation interventions. *Crit Care Med* 2013; 41:S81–98.
 10. Needham DM, Colantuoni E, Dinglas VD, *et al.* Rosuvastatin versus placebo for delirium in intensive care and subsequent cognitive impairment in patients with sepsis-associated acute respiratory distress syndrome: an ancillary study to a randomised controlled trial. *Lancet Respir Med* 2016; 4:203–212.
 11. Pandharipande PP, Girard TD, Jackson JC, *et al.* Long-term cognitive impairment after critical illness. *N Engl J Med* 2013; 369:1306–1316.
 12. Nikayin S, Rabiee A, Hashem MD, *et al.* Anxiety symptoms in survivors of critical illness: a systematic review and meta-analysis. *Gen Hosp Psychiatry* 2016; 43:23–29.
 13. Parker AM, Sricharoenchai T, Raparla S, *et al.* Posttraumatic stress disorder in critical illness survivors: a meta-analysis. *Crit Care Med* 2015; 43: 1121–1129.
 14. Rabiee A, Nikayin S, Hashem MD, *et al.* Depressive symptoms after critical illness: a systematic review and meta-analysis. *Crit Care Med* 2016; 44: 1744–1753.
 15. Needham DM, Davidson J, Cohen H, *et al.* Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med* 2012; 40:502–509.
 16. Cuthbertson BH, Roughton S, Jenkinson D, *et al.* Quality of life in the five years after intensive care: a cohort study. *Crit Care* 2010; 14:R6.
 17. Dowdy DW, Eid MP, Sedrakyan A, *et al.* Quality of life in adult survivors of critical illness: a systematic review of the literature. *Intensive Care Med* 2005; 31:611–620.
 18. Kamdar BB, Huang M, Dinglas VD, *et al.* Joblessness and lost earnings after acute respiratory distress syndrome in a 1-year national multicenter study. *Am J Respir Crit Care Med* 2017; 196:1012–1020.
 19. Kamdar BB, Sepulveda KA, Chong A, *et al.* Return to work and lost earnings after acute respiratory distress syndrome: a 5-year prospective, longitudinal study of long-term survivors. *Thorax* 2018; 73:125–133.
 20. Ruhl AP, Huang M, Colantuoni E, *et al.* Healthcare resource use and costs in long-term survivors of acute respiratory distress syndrome: a 5-year longitudinal cohort study. *Crit Care Med* 2017; 45:196–204.
 21. Ruhl AP, Lord RK, Panek JA, *et al.* Healthcare resource use and costs of two-year survivors of acute lung injury. An observational cohort study. *Ann Am Thorac Soc* 2015; 12:392–401.
 22. Ruhl AP, Huang M, Colantuoni E, *et al.* Healthcare utilization and costs in ARDS survivors: a 1-year longitudinal national US multicenter study. *Intensive Care Med* 2017; 43:980–991.
 23. Turnbull AE, Rabiee A, Davis WE, *et al.* Outcome measurement in ICU survivorship research from 1970 to 2013: a scoping review of 425 publications. *Crit Care Med* 2016; 44:1267–1277.
- A scoping review that empirically demonstrates the heterogeneity in outcomes and outcome measurement instruments used in the growing field of ICU survivorship research; thus, motivating the need for a core set of outcomes and measurement instruments in future research studies.
24. Domecq JP, Prutsky G, Wang Z, *et al.* Eliciting patient perspective in patient-centered outcomes research: a meta narrative systematic review. Rochester: Mayo Clinic; 2012; Available at: <https://www.pcori.org/assets/Eliciting-Patient-Perspective-in-Patient-Centered-Outcomes-Research-A-Meta-Narrative-Systematic-Review.pdf>. [Accessed 4 June 2018]
 25. Williamson PR, Altman DG, Blazeby JM, *et al.* Developing core outcome sets for clinical trials: issues to consider. *Trials* 2012; 13:132.
 26. Kirkham JJ, Dwan KM, Altman DG, *et al.* The impact of outcome reporting bias in randomised controlled trials on a cohort of systematic reviews. *BMJ* 2010; 340:c365.
 27. de Grooth H-J, Parienti J-J, Oudemans-van Straaten HM. Should we rely on trials with disease- rather than patient-oriented endpoints? *Intensive Care Med* 2018; 44:464–466.
 28. Gaudry S, Messika J, Ricard J-D, *et al.* Patient-important outcomes in randomized controlled trials in critically ill patients: a systematic review. *Ann Intensive Care* 2017; 7:28.
- A systematic review demonstrating that patient-important outcomes were infrequently designated as a primary outcome in randomized clinical trials in critically ill patients.
29. Trujols J, Portella MJ, Iraurgi I, *et al.* Patient-reported outcome measures: are they patient-generated, patient-centred or patient-valued? *J Ment Health* 2013; 22:555–562.
 30. Guyatt G, Montori V, Devereaux PJ, *et al.* Patients at the center: in our practice, and in our use of language. *ACP J Club* 2004; 140:A11–A12.
 31. Eakin MN, Patel Y, Mendez-Tellez P, *et al.* Patients' outcomes after acute respiratory failure: a qualitative study with the PROMIS framework. *Am J Crit Care* 2017; 26:456–465.
- A qualitative study of recovery after hospital discharge in 48 acute respiratory failure (ARF) survivors from across the United States.
32. Carle AC, Riley W, Hays RD, Cella D. Confirmatory factor analysis of the patient-reported outcomes measurement information system (PROMIS) adult domain framework using item response theory scores. *Med Care* 2015; 53:894–900.
 33. Chan KS, Aronson FL, Dinglas VD, *et al.* Are physical measures related to patient-centred outcomes in ARDS survivors? *Thorax* 2017; 72:884–892.
- The analysis uses data from two large-scale follow-up studies of acute respiratory distress syndrome survivors to evaluate associations between physical outcome measures (e.g., 6-min walk test, ADLs) and patient-centered outcomes (e.g., quality of life, rehospitalization, and being alive and at home).
34. Nedergaard HK, Haberlandt T, Reichmann PD, *et al.* Patients' opinions on outcomes following critical illness. *Acta Anaesthesiol Scand* 2018; 62: 531–539.
- A study in Denmark evaluating outcomes important to ICU survivors and assessing perspectives of nurses and anesthesiologists caring for ICU patients.
35. Hashem MD, Nallagangula A, Nalamalapu S, *et al.* Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge. *Crit Care* 2016; 20:345.
- A systematic review of qualitative studies of ICU survivors' recovery after hospital discharge.
36. Dinglas VD, Chessare CM, Davis WE, *et al.* Perspectives of survivors, families and researchers on key outcomes for research in acute respiratory failure. *Thorax* 2018; 73:7–12.
- A national/international evaluation of patient, family, and researcher perspectives regarding which patient outcomes should be measured in studies evaluating ARF survivors after hospital discharge.
37. World Health Organization. International classification of functioning, disability, and health: ICF. Geneva: World Health Organization; 2001.
 38. Hodgson CL, Turnbull AE, Iwashyna TJ, *et al.* Core domains in evaluating patient outcomes after acute respiratory failure: international multidisciplinary clinician consultation. *Phys Ther* 2017; 97:168–174.
- An evaluation of clinician perspectives on patient outcomes that should be measured in studies evaluating ARF survivors after hospital discharge.
39. Brinkman S, Bakhshi-Raiez F, Abu-Hanna A, *et al.* Determinants of mortality after hospital discharge in ICU patients: literature review and Dutch cohort study. *Crit Care Med* 2013; 41:1237–1251.

40. Colantuoni E, Scharfstein DO, Wang C, *et al.* Statistical methods to compare functional outcomes in randomized controlled trials with high mortality. *BMJ* 2018; 360:j5748.

A methodological article that reviews and empirically illustrates three statistical approaches to analyze functional outcomes (e.g., quality of life) in the setting of 'truncation due to morality'.

41. Clarke M. Standardising outcomes for clinical trials and systematic reviews. *Trials* 2007; 8:39.
42. Dwan K, Altman DG, Arnaiz JA, *et al.* Systematic review of the empirical evidence of study publication bias and outcome reporting bias. *PLoS One* 2008; 3:e3081.
43. Blackwood B, Marshall J, Rose L. Progress on core outcome sets for critical care research. *Curr Opin Crit Care* 2015; 21:439–444.

44. Turnbull AE, Sepulveda KA, Dinglas VD, *et al.* Core domains for clinical research in acute respiratory failure survivors: an international modified Delphi consensus study. *Crit Care Med* 2017; 45:1001–1010.

The report of an international consensus process to establish a recommended set of outcomes that should be measured in all studies evaluating ARF survivors after hospital discharge (refer to www.improveLTO.com/coms for more information).

45. Needham DM, Sepulveda KA, Dinglas VD, *et al.* Core outcome measures for clinical research in acute respiratory failure survivors. An international modified Delphi consensus study. *Am J Respir Crit Care Med* 2017; 196:1122–1130.
- The report of an international consensus process to establish a recommended set of outcome measurement instruments that should be used in all studies evaluating ARF survivors after hospital discharge (refer to www.improveLTO.com/coms for more information).