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Survivorship Research: Studying the Past to Define the Future

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“Study the past if you would define the future.”

- Confucius

We have been challenged. Our patients and their families, our professional societies, our colleagues and collaborators have all challenged us to understand and improve the experience for survivors of critical illness. [1–3] With a decline in mortality in recent years [4,5], the field has turned much of its attention to studying the longer-term outcomes and experiences of those we have rescued with our acute care interventions. As Turnbull and colleagues show us in this issue of *Critical Care Medicine*, we have seen a steady increase in the number of studies reporting the physical, cognitive, mental health, and quality-of-life outcomes of ICU survivors – from 3 studies in 1970 to more than 300 since 2000. [6] With the increase in number of published studies, so too has there been an increase in the tools and methods used to assess outcomes in ICU survivors. This proliferation of methods has resulted in a heterogeneous body of literature. The field of post-intensive care survivorship research is now at a critical juncture – where do we go from here?

In their article in this issue of *Critical Care Medicine*, Turnbull and colleagues show us where we have been. [6] They present the findings of an impressive undertaking – a scoping review of outcome measures used in ICU survivorship research. [6] Using the methodological framework of the scoping review introduced by Arksey and O’Malley in 2005 [7], the authors explore the breadth and nature of published research reporting the physical, cognitive, mental health, and quality-of-life outcomes of ICU survivors. In reviewing 15,464 citations and 425 full articles published between 1970 and 2013, several key themes emerged. First, research on critical care survivorship has dramatically increased over the last 40 years (as shown in Figure 2 of their paper) and there is no sign of a plateau in sight. Despite this increase, outcomes research is still a small area of investigation within

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the field of critical care overall – the 425 articles reviewed represent less than 2% of all published articles in critical care over these 43 years. [6] Second, the majority of the published literature on ICU survivorship outcomes consists of relatively small cohort studies with a median sample size just over 100 subjects and reports outcomes at only one time point within 6 to 12 months after discharge. [6] The impact on survivors at more distant time points remains largely unknown. Third, a significant proportion (38%) of published papers did not report loss to follow-up in their studies. [6] This leaves us as readers limited in our ability to critique the findings reported in these studies. We cannot critically evaluate survivorship bias without understanding the proportion of patients that cannot or choose not to participate in follow-up.

Finally, and perhaps most impressively, this work by Turnbull et al. displays the proliferation of outcome measures used in survivorship research. The authors report that 250 unique instruments were used in these 425 studies. [6] Progress in this field is hampered by this heterogeneity. We are unable to easily compare findings across studies. Methodologies such as the meta-analysis cannot adequately synthesize such incredible diversity. Researchers designing cohorts and randomized controlled trials are left without a clear consensus on which outcome measure(s) to choose. Studying several outcome measures, the current path chosen by many, may increase the cost and burden to our patients. The need for our community to define a core set of outcomes is clearly apparent.

Why then did the authors choose this methodology? With the intent of examining the extent or nature of a field of research, the methodology of the scoping review is purposefully broad. [7,8] It is most useful for topics that have not been extensively reviewed in the literature or for which the existing literature is complex or diverse. [8] The scoping review has a different purpose than a systematic review and there are key differences in the output and interpretation of the findings from these two different methodologies. [7–11] A scoping review seeks to map the body of literature of a complex topic and reports only a limited number of aspects for each included study. [7] In contrast, the goal of a systematic review is to sum up the best available evidence on a specific question. [7–11] Rigorous systematic reviews carefully evaluate the methodological quality of included studies with the goal of evaluating bias. [10,11] In contrast, scoping reviews generally do not evaluate the quality of the studies they include. [10,11] This gives the scoping review permission to show us all studies that exist for an area of interest – the good and the bad. While it may suggest gaps in the literature, we must remember that there may still be areas where **quality** evidence is lacking. For example, the results of Turnbull and colleagues suggest there is some consolidation around key instruments for assessing participation restriction after critical illness with an increasing number of studies using Katz's Activities of Daily Living [12, 13]. This review does not evaluate if the studies using this measure were high quality studies nor does it evaluate the psychometric properties of this instrument in this patient population. To date, there are actually no studies evaluating the reliability or measurement error of this instrument in the ICU population. [14] We must be careful not to interpret the findings of this scoping review as instructions for which outcomes should constitute the necessary “core outcome set”. As Turnbull et al. explain in their review, the development of a core outcome set will require deliberate work – stakeholders must be surveyed, psychometric properties

evaluated, qualitative studies performed to ensure appropriate patient-centered outcomes are represented, and acceptance sought from the research community. [6] This scoping review is only the first step, yet an important first step in this process (supplemental figure E1).

The magnitude and scope of the limitations faced by our patients surviving their stay for critical illness are increasingly apparent to us. With over 300 publications in this arena over the past 15 years, we are rising to the challenge of studying survivorship. Our intent is strong, yet our toolbox needs refinement. With the past of outcome measurement in ICU survivorship research now displayed before us, we must rise to the next challenge – deliberately, carefully, methodically defining our future.

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