Outcome Metrics After Burn Injury

From Patient-Reported Outcome Measures to Value-Based Health Care

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KEYWORDS

• Outcomes-based research • Quality improvement • Value creation

KEY POINTS

- Although there are many ways to consider improving outcomes for burn patients, they share a common thread which is the patient.
- Because outcomes like survival will be a foundation for evaluation, new metrics and techniques offer potential to go beyond survival to long-term outcomes that are important to patients.
- With new innovations in care, understanding the cost of care and its impact on long-term outcomes will also be critical as we strive to deliver better value in burn care.
- What we learn from patient-reported outcome measures and evaluating the value of burn care will help shape the future of how we treat burn patients.

INTRODUCTION

One of the fundamental goals of burn care is to try and return the patient to a similar or better functional status than they had before their burn injury. As a specialty, burns has worked to do that through multidisciplinary care, improvements in technology and techniques, innovations in research, and publishing results to share that knowledge with others in the burn community. At the core of this, the focus has always been the patient. We also want to know if what we are doing improves patients' well-being, and better understand how a burn injury impacted patient's lives. This not only includes the external wounds, but the internal injuries that are not visible (eg, posttraumatic stress disorder, depression, concerns about body image, sleep, nutrition, and many more).

As we continue to ask more questions, and listen to the responses patients provide, we are starting to expand our understanding of outcomes for burn survivors. Outcomes research is important because it allows us to critically evaluate our results and try to find ways to be better, share our experiences with our colleagues, and improve the care and results delivered to the patient. This article focuses on outcomes research in burns from a historical perspective, and highlights some of the current innovations and future directions for where outcomes research in burn care could head.

HISTORY OF BURN OUTCOMES

Burn outcomes have developed in a historical manner like many other areas of medicine and surgery. We wanted to know how we did so we

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started measuring things that were simple, tangible, and easy to measure. Some of the first outcomes metrics to seem to include mortality and duration of hospital stay. These metrics were easy to obtain and are meaningful. If a patient did not survive their hospitalization, discussions about their quality of life and return to work become less relevant. In the earlier stages of burn care, mortality rates were high, so being able to survive was important. When we consider that in the 1930s the burns injuries were lethal when 50% of the total body surface area was involved[1] and has improved to between 70.0% and 79.9% of the total body surface area, with recent data highlighting that improvements in burn care lead to increased survival.[2] These changes were due to many improvements in understanding the pathophysiology of burn injuries as well as new developments in their treatment. There were several innovations that led to major paradigm shifts in burn care (eg, topical antimicrobials, understanding nutrition, the metabolic response to burn injury, early excision and grafting, advances in ventilator care) and it was through such disruptive innovations that advances in care were made.

The next traditional outcome metric used was duration of stay. In isolation, it is a difficult metric to interpret because it is influenced by several factors that were patient related (total body surface area of the injury, inhalational injury, age), and system related access (enteral nutritional support, optimal pulmonary care with lung protective ventilation, physical and occupational therapy, early excision and grafting). The more effective a burn center is in these areas, typically the better their outcomes. Duration of stay, even when adjusted for patient-related variables is still a very basic metric, one that is ubiquitous to many areas in medicine. These and other measures were the beginning of outcomes research and were based on provider's thoughts of metrics that were important.

PATIENT-REPORTED OUTCOME MEASURES

As burn care has improved and more patients survive burn injuries, mortality and duration of stay were not sufficient metrics alone to evaluate success in treating burn patients. Survival alone was not enough, and asking how people survived began to become more important. Generic metrics like the Short Form 36 were developed and are one of the earlier validated patient-reported outcome measures (PROMs) and has been translated into multiple languages owing to broad applicability to a wide range of patients. It includes the following domains: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, and mental health.[3]

In terms of the latest developments in generic PROMs, it has been the Patient-Reported Outcome Measurement Information System (PROMIS) from the National Institute of Health. The key features of PROMIS are that it is standardized allowing common domains and metrics to be compared across conditions and diseases, it is validated, it can be compiled in a variety of ways to provide flexibility in its administration, and it is very inclusive (irrespective of literacy, language, physical function or "life course"). PROMIS allows for questions to be compared across diseases and medical problems. They have also designed PROMIS to simplify the administration and scoring of PROMs, which can include computer adaptive testing based on an individual's response to previous questions. For further details on PROMIS, readers can explore their comprehensive web site (http://www.nihpromis.com). Another unique project being undertaken focuses on translating scores from 1 PRO into PROMIS, and is known as the PROsetta stone (eg, the Short Form 36); for more information on this please see (www.prosettastone.org).

One of the criticisms of generic PROMs is that they are not as applicable to disease-specific concerns. As a result, there have been efforts to develop burn specific outcome measures. It started with the Burn Specific Health Scale (BSHS), a 114-question instrument.[4] It is cumbersome, much like the original Short Form 36 was shortened to the Short Form-12, the BSHS was abbreviated to the BSHS-B, a shorter version of 40 questions.[5] Other PROs from a reconstructive perspective include the validated metrics like the Vancouver Scar Scale[6] and the Patient Observer Scar Assessment Scale[7] have been developed to look at characteristics of scars. Although imperfect, these represented some of the first outcome metrics for evaluating hypertrophic burn scars. The Patient Observer Scar Assessment Scale is unique because it relied on assessments from both the patient and the provider.

As we continued to better understand outcomes for burn survivors, the specialty gained a deeper appreciation of *how* patients survived their injuries. Some of the latest validated burn-specific PROMs have been developed through a multigroup effort from the Shriner's Hospital for Children and the American Burn Association based on their collaborative efforts to develop the Burn Outcome Questionnaire.[8] This work grew to develop a Burn Outcome Questionnaire for children between

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