Burn Outcomes

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What gets measured gets managed

—Peter Drucker

1 Introduction

The following chapter describes important outcomes in the recovery trajectory of burn survivors. Thanks to improvements in critical care, many burns that were fatal 50 years ago are survivable today. Due to this increased survivability burn survivors are faced with a greater sometimes lifelong, symptom burden. As a result, attention has been placed on improving care for persistent conditions with the goal of improving quality of life. To this end, consistent and accurate measures of outcomes that matter to burn survivors and can inform treatment options are essential to drive and assess improvements in care. Outcomes of interest can be broadly categorized into those that deal with scar, function, and mental health including quality of life.

No previously published material requiring permissions was used in the chapter Burn Outcomes.

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2 Outcomes

It is important to understand outcomes in the context of the biopsychosocial model of injury [1, 2]. The model incorporates various injury-related factors in the context of three distinct time periods (Table 1). Research demonstrates that pre-injury factors are determinants of injury occurrence and sequelae following injury [3–7]. Factors related to the clinical care of the patient are part of the growing field of quality improvement [8]. The current review will focus on post-discharge factors including the patient's return to their pre-injury environment and activity. As these factors are consequences of both injury and care, they will be referred to as "Outcomes."

Outcomes are of two types: those which can be measured objectively, and those which are reported subjectively. Objective outcomes include: scar assessments, mental and physical

Table 1 Factors by time period

Pre-injury: determinants	Inpatient stay period: performance indicators	Discharge and life course: outcomes
Demographics	Injury cause	Function
Physical conditions	Treatment	Scar
Psychological conditions	Length of stay	Quality of life
	→ Time	

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disorder diagnoses, and return to function or work. Subjective outcomes are also of great importance and include: pain, pruritis, paresthesia, body image satisfaction, and perceived health and function. Some outcomes are reported as a composite of subjective and objective measures. Although objective measurements yield quantitative results that are easier to compare, it is still difficult to evaluate the interactions between factors, and the outcome's impact on the patient's quality of life. For example, a scar may have only mild erythema, but be very pruritic causing a significant quality of life impact.

Accurate measurement of outcomes require instruments that are reliable, valid, and responsive. These terms mean, respectively, that the instrument returns consistent values upon repeated measurements, that it measures what it purports to measure, and that it can detect change within the range of interest. This chapter focuses on tools that are valid and have their reliability reported. Outcomes of interest have been grouped in the context of the patient journey, starting with the scar, the effect of scar on function, and the overall effect of the injury on the burn survivor's health.

3 Scar

Subjective and objective scar measurement instruments are known as scales and tools, respectively. Scar scales are efficient and easy to implement and do not require an experienced therapist. In contrast, scar tools which provide objective measurement of scar qualities are expensive and require time and training, an exception being digital photography. For assessing treatment methods, both scales and tools are useful. However, because of training, cost, and time commitments many tools are not in widespread clinical use.

Some scales include subjective qualities like pain and itching which patients rate as more important to them than appearance [9]. Those qualities can also compound the psychological impact of the scar. A patient's overall assessment of their scars has been shown to correlate with depression [10]; however, scar scales do not usually include this psychological measures. A quality of life scale can be a useful addition for measuring the global impact of the scar.

The measurable qualities of scar can be categorized as below [11, 12]:

- Color: vascularization and pigmentation
- Dimension: elements of size and thickness
- Texture: irregularity, and matte or shininess
- Biomechanical Properties: pliability, elasticity, and water retention
- Mobility Restriction: freedom of movement of the affected limb or area

Two widely used scar scales are the Vancouver Scar Scale (VSS) [13] and the Patient and Observer Scar Assessment Scale (POSAS) [14]. There are several other scales in use including the Hamilton and Manchester Scar Scales, MAPS, and the Inventory of Potential Reconstructive Needs scale [11]. However, there is no consensus on a best scale.

In the Vancouver Scar Scale, the caregiver rates pigmentation in three levels, vascularization and thickness in four levels each, and pliability in six levels. The scar is given a total score from 0 to 13. Modifications to the VSS exist which include itching and pain categories. These categories are patient rated on a visual analog scale, often a 100 mm line marked at the end points by "none" and "extreme." Another modification to the VSS exists which allows for a more accurate pigmentation rating for non-Caucasian patients [15].

In the POSAS, all categories are rated from 1 to 10. The patient rates pliability, thickness, color, relief, pain, and itching while the observer rates pliability, thickness, vascularization, pigmentation, surface roughness, and surface area. All scores are combined to give a total score.

A scale's reliability is its tendency to produce similar values upon repeated application, either when applied repeatedly by the same observer (intra-observer reliability) or by different observers (inter-observer reliability). A frequently used measure of the latter is Intra-class Correlation Coefficient (ICC), which is a value between 0 and 1 representing reliability. ICC values above

0.75 are considered "good" and those above 0.9 "excellent." [16] In a study on linear surgical scars, POSAS had an ICC of 0.86 [17]. The VSS, in a burn population, had an ICC of 0.81 [18]. Early scar scales had poor reliability [11]. To remedy this, multiple observers would rate the scar and average their scores, thus reducing variance. POSAS itself is a sum of patient and observer scores, and this is a possible reason why its reliability is higher than the VSS.

Several scar measurement tools report higher reliability than what can be achieved with scar scales. However, not all tools have been studied in detail and their reliability is yet to be determined. Some reliable tools include 3D cameras which can measure scar surface area to within 2% [12]. The DSM II Colormeter measures erythema and pigmentation based on how melanin and hemoglobin absorb red and green light. Its ICC for the measurement of melanin has been reported as 0.91 and its ICC for erythema has been reported as 0.91 in one study and 0.68 in another [12]. The Cutometer, which measures skin elasticity, has a range of reported reliabilities from 0.11 to 0.93 [12]. Finally, ultrasound devices, in particular the Dermascan C was measured to have an excellent reliability of 0.9 for measuring scar thickness [12].

Digital photography, the most accessible scar rating tool, can be used to objectively measure color. Also, if electronic records can accommodate digital photographs a measure of scar progress can be transferred between caregivers.

4 Mobility, Function, and Work

Scar can affect outcomes in the domains of mobility, function, and work. These domains are loosely related yet one can have good function with poor mobility and good mobility and function but a delayed return to work. This delayed return can be due to psychological factors, skin issues, or pain. We will consider the three topics in this section.

Mobility is frequently impaired by contracture, which follow burns. Burned skin, muscle, and ligaments can tighten and scar will continue to contract for a period of time with consequences lasting years. Contractures of major joints (hip, knee, elbow, and shoulder) can impact performance of daily tasks. Treatment using splinting, casting, ROM exercises, and surgery can potentially improve mobility. Contractures frequently improve during inpatient rehabilitation. In one pilot study, 65% of major joints affected by contracture improved by at least one level of severity during inpatient rehabilitation [19] (i.e., one level corresponding to 60° mobility for the shoulder). It is interesting to contrast the success of this noninvasive rehabilitative approach with surgery, in which 88% of joints treated returned to normal function, but the remaining 12% reported adverse outcomes. It is important to measure these changes objectively in order to identify if therapy is effective, or more importantly when therapy does not improve mobility, suggesting that other options such as surgery are required.

The patients ability to perform simple tasks is predictive of their physical health-related quality of life [20]. Range of motion is commonly tracked as part of rehabilitative efforts [21]. The importance of inpatient rehabilitation has led to integrated rehabilitation services which lowers length of stay, improves resource utilization and decreases waiting times for services [22]. Early ambulation has also been found to be beneficial and early sitting while in ICU was investigated and found to be safe [23].

The simplest objective measure of joint mobility is degrees of active and passive ROM as measured with a goniometer. It is important to evaluate the progress of the patient relative to their pre-injury ROM and relative to the uninjured population. However, it must be remembered that the number of degrees may not reflect an improvement in function.

Function refers to the ability to perform simple tasks and to live independently without assistance. Information on function, which is more subjective than mobility, can be quantified using scores such as the FIM (Functional Independence Measure). The patient's ability to perform 18 simple tasks is rated from 1 (Total assistance required) to 7 (No assistance required). Assessment of function should be performed by

the clinician, not the patient. Scores above 110 indicate an ability to manage at home with no assistance. Each deficit of 5 points corresponds to 1 h of assistance needed with tasks per day. In one study, the motor component of FIM increased by 29 points between admission and discharge to a rehabilitation facility, corresponding to 6 fewer h of assistance required at home. This displays the type of progress that can be made in improving function and the utility of meaningful measures. FIM is highly reliable and has an ICC score of 0.95 [24].

The measurement of specific areas of function is still evolving in the context of burn injury. For example, hand function impairment is common in burn survivors. One instrument for its measure is the Michigan Hand Questionnaire. It has been validated for the general population although not yet the burn population. Hand function is also a domain in the nine domain model of the BSHS-B, discussed below. In a study of hand function, all patients showed improved hand function scores by discharge yet still remained below normal uninjured levels [19].

Returning to work is an important outcome in establishing a pre-injury quality of life. For a third of burn inpatients, time to return to work will be greater than 2 years [25]. Of a number of factors analyzed as predictive of returning to work, %TBSA was the most significant, followed by % Full Thickness and Length of Stay [26]. Interestingly, age was not found to be predictive. Those with a length of stay less than 10 days would return to work within on average 2 months, while those with a length of stay greater than 30 days took longer than 2 years on average to return to work [26]. Further predictors of a greater than 1 year return to work were: the occurrence of a burn at work, an etiology of electrical burn, and receiving inpatient rehabilitation [25].

Barriers to returning to work, as reported by burn survivors were, in order: pain, neurologic problems, impaired mobility, and psychiatric problems [25]. As both physical and psychological problems must be overcome, returning to work demonstrates excellent adaptation to the injury including good progress in the domains of function and mobility, and is therefore a useful indicator of recovery progress.

5 Development of Post-discharge Outcomes

As burns impact physical and psychological health, it is important to consider patient-centered outcomes both in judging treatment efficacy and in establishing baselines for expected quality of life through which we can work to improve patient care.

Studies have found that distress experienced in hospital predicts chronic distress persisting through a 2-year period post-discharge [27]. High in-hospital distress occurred in a third of patients and was associated with poorer psychological health [27]. In many cases, the distress experienced by patients is subclinical yet it can have an impact rivaling physical conditions [9, 28].

In one study, the top 12 sources of distress after discharge were identified [9]. They were, in order: pain, decreased ROM, itch, temperature changes, decreased strength, disliking appearance, uncomfortable scars, skin color changes, financial concerns, long recovery time, poor sleep, and distress related to pressure garments. Patients also rated how much each source bothered them at various time points after discharge. The level of distress from those sources decreases after discharge. But temperature changes, disliking appearance, and changes in skin color took longer than a 2-year period after discharge to decrease. Distress from pain and poor sleep were found to predict a delayed return to work.

6 Quality of Life, BSHS-B, and SF-36 PROMs

PROMs or Patient Reported Outcome Measures capture outcomes that are important to the patient and determinable through survey responses. For conducting PROMs on a large scale, Computer Assisted Telephone Interviews (CATI) may be

ideal because of their high response rate compared to other methods [29].

A systematic review of studies using PROMs in burn survivors found the BSHS-B and the SF-36 were most widely used, each occurring in about 40% of all studies measuring life satisfaction in burn survivors [30]. The BSHS-B was designed for the burn population and is thus a disease-specific PROM. The SF-36 was designed for the general population and can therefore be used to compare impact on quality of life across condition.

The eight categories measured by the SF-36 are: physical functioning (PF), role disability due to physical problems (RP), bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), role disability due to emotional problems (RE), and general mental health (MH). Results in these categories are used to score the composite areas of physical and mental health. Many investigators combine these two scores to reach a single score; however, this was not the original intent of the SF-36 designers, and this interpretation may not have validity as a quality of life measure [31].

The Burn-Specific Health Scale has undergone several improvements since its formulation [32]. Originally, a 114 item survey developed by burn care experts and patients, it was later abbreviated to 80 items as BSHS-A, revised to the 31 item BSHS-R, and expanded slightly to the 40 item BSHS-B [33]. This expansion added the domains of hand function and sexuality which were missing from the BSHS-R [33]. All BSHS questions are scored on a five-point scale from 0 to 4.

The 40 items of the BSHS-B were chosen by applying a factor analysis to the items in previous scales. A factor analysis categorizes items into groups in a way that minimizes the covariance between the groups. Thus, the dependence of one category on another is minimized and each category can have a meaningful interpretation. The factor analysis resulted in nine domains. Subsequently, a second-order factor analysis was done on those nine domains revealing three meta-domains [34]. This is an alternative, psychometrically valid and simpler interpretation of BSHS-B results. The work domain was excluded from factor analysis because it was correlated with two meta-domains, Function and Skin Involvement [34].

Nine and three domain interpretations of the BSHS—B

Simple abilities	Function
Hand function	
Heat sensitivity	Skin involvement
Treatment regimens	
Body image	
Affect	Affect and relations
Interpersonal relationships	
Sexuality	
Work	

A 10-year follow-up of burn patients showed that median scores in all domains of the BSHS-B were at least 3 out of 4, indicating good recovery at the median level. [35] However, the lowest quartile of burn patients scored less than 2 out of 4 in Body Image and Heat Sensitivity, indicating those as problem areas for severe burns. Other domains showed more promising results at the 10-year mark. In another study, over the 2–7 year time frame Hand Function and Interpersonal Relations improved after discharge, but not significantly until the 2 year mark was reached [36].

7 Using Outcome Measures

It is possible to use PROMs and outcome measures in the following ways:

- Compare the effectiveness of different treatments
- Measure a patient's recovery in comparison to an expected baseline
- Compare burn center outcomes to a global average

However, challenges exist here. Firstly, it is impossible to completely standardize the burn injury. TBSA, body part involvement, and % full thickness will be different across injuries and are imperfectly estimated. Also, as noted in the Outcomes section, the patient's pre-morbidities affect their recovery [37]. Even within a burn

center, differences in treatment and rehabilitation procedures and timing can lead to different patterns of recovery. Finally, measuring long-term outcomes are challenging as patients who experience a worsening of their conditions may exit a study making the remaining population artificially healthier.

Another difficulty in measuring quality of life is untangling experienced well-being (how much happiness did you experience yesterday?) from evaluated well-being (How would you rate your life over the last year?). Experienced and evaluated well-being were only weakly correlated in 20,000 studied Americans [38]. This means that high experienced well-being is possible even when life evaluation is poor. The display of post-traumatic growth in burn survivors who retain functional impairments yet live meaningful lives is testament that a high quality of life may be possible for all survivors.

Despite the stated challenges, the evaluation and measurement of burn related outcomes is an important component of burn care. Measurement of outcomes allow us to judge treatment effectiveness accurately; know when a patient is not meeting recovery goals; and evaluate a burn center's practices to improve care. Long-term studies show that health improvement can continue to occur beyond 2 years post-injury and so there is a wide scope of interventions to make meaningful differences in the persistent conditions that affect burn survivors [36].

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