Long-Term Outcomes Following Burn Injuries

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2.1 Introduction

As a result of the declining length of inpatient hospitalization after major burn injuries, patients are being discharged with multiple, long-term physical and psychological challenges, such as ongoing pain, intensive physical therapy, contractures, amputations, and psychological distress. These challenges can persist for many years, requiring specialty multidisciplinary burn care. Issues associated with long-term adjustment have been recognized as a priority for research and clinical practice. In this chapter, we will begin by using a biopsychosocial model to examine various factors of long-term burn recovery. We will also discuss various aspects of emotional distress, pain, pruritus, sleep, and body image issues, and conclude with recommendations for treatment.

2.2 The Biopsychosocial Model of Recovery

A person's response to stress is a function of their personality style and coping mechanisms and how these interact over time with the environmental factors that are present. Univariate models are insufficient to explain a person's response to a burn injury and their long-term outcomes. More sophisticated, theory-driven biopsychosocial models are needed to explain outcomes of burn injury. Researchers have identified pre-burn psychological disorders, injury characteristics (e.g., burn size and location, acute pain levels), lack of social support, and ineffective coping styles as risk factors for poor post-injury adjustment [1].

2.2.1 Pre-burn Emotional and Physical Health

A person's pre-burn level of physical and emotional functioning can greatly impact their course of recovery from their ICU stay to years beyond discharge. For example, those patients with substance abuse disorders, diabetes, COPD, and other medical comorbidities have lower survival rates, longer lengths of stay, and fair poorer overall. The available research largely supports the impression that individuals with burns severe enough to warrant hospital care often have pre-existing chaos and dysfunction in their lives. In several reviews of the literature, it was found that the incidence of mental illness and personality disorders was higher in burn unit patients than the general population [2–4]. For example, Patterson et al. [3], estimated that the presence of premorbid psychiatric disorders ranged between 28% and 75%, higher than expected in the general population. These disorders include depression, personality disorders, and substance abuse. Another study by Patterson et al. [5] found patients with burn injuries scored higher on premorbid levels of psychological distress, anxiety, depression, and loss of behavioral and emotional control when compared to a national normative sample. These studies also found that individuals with pre-existing psychopathology often cope with hospitalization through previously established, dysfunctional and often disruptive patterns. Such dysfunctional coping styles, in turn, had an adverse impact on hospital course that increased length of stay and led to more serious psychopathology upon discharge and throughout their outpatient recovery.

2.2.2 Injury Characteristics

Researchers have begun to focus on potential variables from acute hospitalization that may have a long-term impact on adjustment [6, 7]. Total Burn Surface Area (TBSA), length

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of hospitalization, and days spent in the ICU or on a ventilator have been used as indicators of the severity of a burn injury. Research on the relation between these variables and outcomes has been equivocal. Patterson et al. [3] cautioned against using TBSA as the sole predictor of emotional outcome, citing studies that have shown significant emotional distress in persons with relatively small burns, and little to no distress in persons with large burns. High inpatient pain levels have also been found to lead to long-term distress. The amount of pain that a person reports in the hospital supersedes both the size of their burn and the length of hospitalization as predictors of long-term outcome at six months, one year, and two years post discharge [6, 8]. Location of the burn has been found to predict adjustment, with those persons with burns on their face or hands showing more emotional distress than those with more hidden burns [9].

2.2.3 Coping

In the general literature on coping, Lazarus and Folkman [10] proposed a comprehensive model of stress and coping that is based on the notion that a person's appraisal of the demands and consequences of a situation and the amount of control they perceive to have over the situation will lead to selection of a particular coping strategy. A number of organizing terms have been used to categorize coping styles [11]. The extent to which a coping strategy involves approaching a particular stressor, versus avoiding the stressor, is a widely used classification [12]. For instance, active strategies such as problem-solving, information seeking, and social support seeking can be construed as approach-oriented coping, and strategies that involve disengagement, denial, or distraction can be viewed as avoidance-oriented efforts. Neither approach-oriented nor avoidance-oriented coping behaviors are inherently adaptive or maladaptive; coping effectiveness is better determined by the characteristics of the individual and the situation [10]. However, reviews of the literature on coping with chronic illness have suggested that approach-oriented coping styles are more favorable towards physical and emotional health outcomes in medical populations [13].

Some research has suggested that the selection of a specific coping strategy will depend on the individual's appraisal of the amount of control they have over the situation. For example, if a person appraises the situation as being more controllable, then they will use a strategy in which they will attempt to actively problem-solve or mobilize resources; if they appraise low levels of control, then they will likely employ strategies in which they distract their attention away from the stressor [14]. Little research has attempted to characterize the adaptiveness of specific coping strategies in burn patients over time. It is also unknown if a person can be taught a specific coping style, especially when under such considerable stress as recovering from a burn injury.

2.2.4 Emotional Distress

The first year or two following a burn injury seems to be a time of substantial distress [3, 15–18]. Clearly, mood disorders [9, 15, 19–23] and anxiety disorders [15, 19, 20, 22, 24, 25] are the most common symptoms of distress; however, patients may also experience a myriad of other problems, including sleep disturbance [26–28], body image concerns [29], and sexual problems [30, 31]. It is important to recognize that although patients may not meet full DSM-V criteria for a diagnosis of the disorder, individual symptoms can cause a great deal of distress and should be treated [32, 33].

2.2.5 Post-traumatic Stress Disorder

The reported frequency of acute stress disorder (ASD) following a burn injury ranges from 11% to 32% of patients [20, 34–39]. While the frequency of post-traumatic stress disorder (PTSD) is approximately 23–33% of patients 3–6 months after a burn injury [34, 40], that percentage ranges from 15% to 45% at one year following the injury [15, 20, 37, 41]. In contrast, community-based studies show that the lifetime prevalence of persons with PTSD is 1–14% [42]. The large variability in reported rates of diagnosed ASD/PTSD is likely due to differences in measurement strategies and measurement timepoints. However, most researchers and clinicians agree that even if patients do not meet a formal diagnosis of ASD or PTSD, the majority of burn survivors are having at least some of the symptoms of this disorder (e.g., nightmares, intrusive thoughts, hypervigilance, avoidance) that negatively impacts their quality of life. When identifying possible risk factors for the development of PTSD, pre-existing anxiety or depressive disorders are associated with an increased risk of developing PTSD. Further, the baseline symptoms of ASD at discharge and at 1 month predict presence of PTSD at 1 year [43], suggesting that symptoms do not decrease over time if left untreated. In addition, burn patients who have a comorbid diagnosis of PTSD are higher utilizers of medical services. Injury-related characteristics such as total body surface area burned and the location of the injury have repeatedly failed to predict who will suffer from such trauma. In contrast, issues such as the patient's mental health history, social support, and coping style hold significant promise as predictive factors. We recommend a screening tool such as the Post-Traumatic Stress Disorder Symptom Checklist – Civilian version (PSCL-C) [44] to identify those suffering from symptoms of PTSD.

2.2.6 Depression

Research that has attempted to identify rates of depressive disorders following a burn injury has been fraught with challenges. In their comprehensive review, Thombs and colleagues [45] found that most of the studies have been at single centers with small sample sizes with poor rates of recruitment and retention. In addition, the multiple approaches and measures used have led to a wide variation in reported rates of depressive symptoms and diagnosable disorders. For example, the range of reported symptoms in the first year after a burn injury is 2–22% and the prevalence rate after one year is 3–54% [46]. There seem to be much lower prevalence rates of depression when a structured interview is used as compared to a standardized measure. But even when standardized measures are used, the rates vary widely. The most common standardized measures are the Hospital Anxiety and Depression Scale (depression subscale) (HADS) [47] and the Beck Depression Inventory (BDI) [48]. The HADS does not include questions with somatic symptoms, but the BDI does. Oftentimes it is difficult to differentiate between what symptoms can be attributed to the medical disorder and what are somatic symptoms of depression, which could account for the higher reported rates of depression when using the BDI versus the HADS. The general consensus among the medical community is that if a person meets criteria for a DSM-V diagnosis, they should be diagnosed and treated, even if symptoms can be accounted for by the medical condition. This approach is known as the inclusive approach. The rationale behind this approach is that the origin of symptoms is less important than the distress that they are causing and patients will benefit from treatment. Typically, patients are underdiagnosed for mental health disorders in the medical setting and are overlooked for treatment that could enhance their quality of life [49]. In recent years, the 9-item Patient Health Questionnaire [50] has been recommended for use as a screening tool in primary care and other medical specialty clinics and may prove to be useful in the burn setting.

Several studies have also found that depression rates tend to be stable from discharge to at least the first year following a burn injury [21]. Although it is commonly assumed that these rates will decrease after the first year, no longitudinal studies have looked at depression rates longer than 1 year post-injury. Thombs et al. [46] found seven studies that reported on risk factors for depression following a burn injury. As mentioned earlier, many of the identified risk factors encompass premorbid functioning, such as employment status, medical illness, and prior depression. Those who suffered from depressive symptoms in the year prior to the burn injury were five times more likely to be diagnosed with a mood disorder at hospital discharge [15]. Other risk factors include female gender, and a visible burn [9]. Although research in this area has been fraught with methodological problems making it difficult to pin down actual rates of depressive disorders, the ABA quality consensus committee recommends a brief screen for depressive symptoms during the inpatient hospitalization, at discharge and at follow-up clinic visits [51]. Referrals to mental health professionals can be made for more in-depth assessments if warranted by the responses on the screening tool.

2.2.7 Pain

Burn pain varies greatly from patient to patient, shows substantial fluctuation over time, and can be unpredictable due to the complex interaction of physiologic, psychosocial, and premorbid behavior issues [52]. Burn pain that is reported after the initial injury is not reliably correlated with the size or depth of a burn. Specifically, a patient with a superficial (second degree) burn may show substantially more pain than one with a full thickness (third degree) burn, due to both physical factors (e.g., location and mechanism of the injury, individual differences in pain threshold and tolerance, response to analgesics) and psychologic factors (e.g., previous pain experiences, anxiety, depression). As a result, it is critical to realize that predicting the amount of pain or suffering a patient will experience based on the nature of, or the physiologic response to, their burn injury is not possible, and furthermore, the patient’s pain experience can change dramatically over the course of both inpatient and outpatient care. It is also important to note that pain can continue well beyond wound healing.

Chronic pain is defined as pain that lasts longer than six months or remains after all burn wounds and skin graft donor sites have healed. The mechanisms and treatment of chronic burn pain are inadequately studied and poorly understood. Although most acute burn pain results from tissue damage, it is important to be aware that pain from nerve damage may also be present, particularly in severe injuries associated with extremity amputations, and represent an anatomic source for chronic burn pain complaints. Because there are identifiable sensory changes in patients who suffer burn injuries, it is unclear as to whether or not these patients’ pain should be defined as chronic pain or is simply an ongoing form of acute or neuropathic pain. Regardless of the label used to classify post-burn injury chronic pain, ongoing pain has the potential to have a significant negative impact on the quality of life of burn survivors.

Malenfant et al. [53] found evidence for changes in the central nervous system that could maintain pain for years after a burn wound has healed. They found that significant sensory losses and sensory changes were found not only in burn sites but also in the non-injured areas. Tactile sensibility deficits were significantly associated with the presence of painful sensations. This was greatest in deep burn injuries that required skin grafting.

Choiniere et al. [54] interviewed 104 burn survivors who were 1–7 years post-burn injury. The mean time since burn injury was 37 months, and the mean Total Burn Surface Area (TBSA) was 19%. Surprisingly, 35% reported ongoing pain. Of those reporting pain, 75% said it interfered with work, 56% said it interfered with sleep, and 67% reported interference with social functioning. In a sample of 236 burn survivors 1–9 years post-burn injury with a mean time since injury of 47 months, and a mean TBSA of 20%, Malenfant et al. [53] found a similar rate of patients with ongoing pain (36%). Work interference was reported by 67% of those with pain, 36% reported sleep difficulties, and 47% reported disturbance in social activities. Recently, Schneider et al. [55] reviewed the natural history of neuropathic-like pain after a burn injury. Over a 2-year period they found 72 patients in their outpatient clinic that described symptoms consistent with neuropathic pain. The average pain rating was 7/10 and persisted for more than 1 year after the injury. In this study, gabapentin and steroid injections were used to treat the pain about one-third of the time. Other interventions included rest, massage, use of pressure garments, and elevation.

Finally, Dauber [56] mailed out a survey to members of a burn survivor support group and of the 358 respondents, 52% reported ongoing pain, 66% said that it interfered with their rehabilitation, and 55% said the pain interfered with their daily lives. Respondents in this study also reported that thoughts of the accident and depression made their pain worse. In these studies, TBSA and skin grafting have been the only predictors of chronic pain. The majority of respondents had not tried relaxation, imagery, or hypnosis. It is important to note that the average length of time since the burn injury in two of these studies was 3–4 years. This is well past the one-year time frame that medical professionals believe it takes for burn injuries to be completely healed.

In order to provide comprehensive and consistent analgesic care for burn patients, many burn centers advocate a structured approach to burn analgesia that incorporates both pharmacologic and nonpharmacologic therapies, targets the specific clinical pain settings unique to the burn patient and yet can be individualized to meet specific patient needs and institutional capabilities. Such structured protocols help to avoid both the undertreatment of burn pain and concerns regarding opioid addiction. A discussion of specific pharmacological protocols used to treat burn pain is beyond the scope of this article and can be found elsewhere [57, 58].

2.2.8 Nonpharmacological Chronic Burn Pain Management

Two approaches that have been empirically tested for chronic pain include hypnosis and cognitive behavior therapy. Although hypnosis involves much more than just avoidance or distraction, the end result is often similar in that this technique takes a person's focus off of the painful procedure they are undergoing. Hypnosis is an altered state of consciousness characterized by an increased receptivity to suggestion, ability to alter perceptions and sensations, and an increased capacity for dissociation. It is believed that the dramatic shift in consciousness that occurs with hypnosis is the cornerstone of an individual's ability to change their awareness of pain [59]. Hypnosis involves several stages, including building clinician–patient rapport, enhancing relaxation through deep breathing, suggestions for deepening the hypnotic state and narrowing their attention, providing posthypnotic suggestions, and alerting [60]. The posthypnotic suggestions allow us to do hypnosis at any time prior to the painful procedure, thus eliminating the need for our presence during the procedure. We typically use a rapid induction analgesia format described by Patterson [60] and originally published by Barber [60], but there are numerous scripts for hypnotic analgesia that can be used directly or with improvisation. However, the technique should only be used by trained clinicians who can assess the risks and benefits of this powerful technique.

Cognitive restructuring is frequently used as a coping technique for patients with chronic pain [61, 62]. However, there are reports in the literature of using this technique for various type of pain, including that from dental work and surgical procedures [63]. A handful of studies have looked at this approach with burn pain [64, 65]. Catastrophizing has been found to have the largest link between thoughts and pain. This distorted thinking style exaggerates any sensation of pain, or setback, and becomes a point of perseveration for the patient. For example, a minor setback in therapy following a planned surgery (such as a contracture release), a wound infection, or simple fatigue, can turn into thoughts such as "I can't take this anymore; I have to start all over again; I will never recover."

The first step in cognitive restructuring is to identify and stop negative, catastrophizing thoughts. Thoughts such as "this is really going to hurt" and "I can't handle this pain" only lead to an increase in anxiety and a subsequent increase in pain. Patients can learn to recognize these negative thoughts and stop them, perhaps by picturing a stop sign or red light in their mind. They can also distract themselves by turning their attention to another topic. Children as young as seven years of age have been taught to use this technique successfully [64, 66].

Ideally, we want patients to transform their catastrophic thoughts into a positive statement. This is known as reappraisal or reframing. For example, they may change the thoughts in the above example to "I have been through this wound care procedure before and it did not hurt as much as I thought it would," or " I have a very high pain tolerance and can cope with whatever will happen." Patients may also benefit from being taught the difference between "hurt" and "harm" when interpreting their pain sensations [67]. Specifically, an increase in pain is often a good sign with respect to burn wound healing. As discussed early in the chapter, deep (third degree) burns often destroy nerve endings and limit the capacity for nociception. In deep burns that begin to heal or in more shallow burns, skin buds develop that are highly innervated and sensitive to pain and temperature. Explaining this healing process to patients can help them to understand the nature of their pain and to reframe negative thoughts into reassuring, positive ones.

2.2.9 Sleep

Sleep problems are one of the most common complaints of burn patients once they are discharged from the hospital, yet likely one of the most undertreated. Sleep problems are best viewed as a symptom rather than a disease and are frequent even in the absence of burn injury, affecting up to 50% of normal adults in the USA [68]. Addressing sleep in a general population as insomnia can lead to distress, impaired functioning, increased accidents, and decreased work productivity [69, 70]. With burn survivors, poor sleep can affect issues such as therapy performance, pain control, adjustment, and even wound healing. Thus, addressing sleep after burn injuries is an important issue to address in addition to the variety of other complications survivors have to face.

A burn injury and its treatment present a multitude of factors that can interfere with sleep. Early in care, the hospital setting and nature of care can be highly disruptive factors. Frequent painful and intrusive treatments, noisy settings, metabolic imbalance, and awakening to take vital signs are the rule rather than the exception. As wounds heal, pruritus (itch) can become extremely unpleasant, in addition to the pain. Anxiety and depression can also interrupt sleep in themselves, but the medication to control burn-related complications such as pruritus, pain, and depression also has an impact on sleep. It is not surprising then that patients with burn injuries will experience impaired sleep for long periods of time, first from the issues associated with hospitalization and later as a function to the transition home.

Given all of these factors, it is not surprising that the few studies that have been done on sleep quality with burn survivors reflect high levels of disruption. Rose and colleagues [71] followed 82 children with severe burn injuries and reported serious sleep disturbance one year after injury. Sleep disturbances included nightmares, bedwetting, and sleepwalking. Approximately 63% of the sample complained of needing daytime naps, which is far greater than the norm. The few studies that have monitored polysomnogram (PSG) in burn survivors have reported increased total sleep time, decreases in stage 3 and 4 sleep, decreased rapid eye movement (REM) sleep, and increased arousals when compared to age-matched controls [72–74].

With respect to treatment for sleep disorders after burn injuries, there is little question that healthcare professionals entertain pharmacologic options far too early and to the exclusion of more benign options. Clinicians should work with the patients on nonpharmacologic interventions before turning to this option. Nonpharmacologic options include sleep hygiene, stimulus control, sleep restriction, relaxation therapy, cognitive-behavioral therapy, and light therapy. Sleep hygiene interventions include changing the environment (e.g., quiet rooms), reducing daytime naps, establishing regular sleep/wake schedules, reducing stimulants from late afternoon to prior to bedtime when appropriate (e.g., caffeine, candy, nicotine, alcohol), decreasing stimuli at night (e.g., internet, TV), and proper timing of food and exercise. Stimulus control involves creating the bed as a stimulus for sleep by having the patient go to bed only when sleepy and removing competing stimuli from the bedroom (e.g., television), sleep restriction focuses on having the patient remain in bed only when asleep. Cognitive-behavioral therapy can help patients work with the dysfunctional thoughts that disrupt sleep, relaxation therapy is self-explanatory, and light therapy can address disruption of circadian rhythms. A full review of the medications used to treat sleep disorders after a burn injury is reported by Jaffe and Patterson [28].

2.2.10 Pruritus

Pruritus continues to be one of the most common and distressing complications following a burn injury. Pruritus can be severe and interfere with sleep, daily activities and can reopen wounds due to scratching. Post-burn pruritus also tends to be cyclical in that it begins in the early stages of wound healing, peaks at 6 months post-burn and declines after the first year following the injury [75]. Pruritus occurs in both healed and grafted skin, but is more intense where hypertrophic scarring has formed. There is a paucity of evidence-based research in this area, although a plethora of pharmacological and nonpharmacological interventions have been proposed in smaller scale studies. Recently, there has been a greater understanding of the physiological mechanisms underlying pruritus in burn injuries. For example, it is largely believed that pruritus from burns stems from inflammation, dryness and damage to the skin, as well as nerve damage/regeneration [76]. Two review articles on evidence-based treatments for post-burn pruritus have been published recently [77, 78]. Both reviews have found some potentially promising treatments for post-burn pruritus and will be summarized in the table below. Bell and Gabriel [77] used the Practice Guidelines for Burn Care 2006 [78] to classify the studies. They found the most promising treatments with the strongest study designs to be selective antihistamine receptor agonists (Cetirizine/Cimetidine) and the pulse dye laser. Across studies, any antihistamine administration appeared to be better than no administration, but no single antihistamine worked effectively all of the time. Pulse dye laser treatments were used for intense itching in smaller areas with three treatments at one-month intervals; the effects lasted up to 12 months [79]. Combinations of the various treatments may also be more effective than single treatments from one modality [80]. Authors caution that the evidence is based on smaller scale studies and larger, prospective, randomized controlled trials need to be conducted.

2.2.11 Body Image

Burn injuries can cause significant changes in appearance, whether from scarring, contractures, changes in skin pigmentation, or amputations. The impact that these physical changes have on self-esteem and body image has only recently been studied [81–83]. The majority of research on body image has focused on eating disorders or congenital differences (e.g., cleft palate) and there has been little study on acquired changes in appearance (e.g., trauma, burns, etc.). Across disability groups (craniofacial abnormalities, amputations, burns, SCI), there is a wide range of individual differences in terms of coping with visible disfigurement. Specifically, Egan et al. [84] estimated that 30–50% of individuals with visible differences may experience psychological difficulty at some time. This highlights the fact that the majority of individuals adjust to their scars well and can go on to develop an appreciation for their body. Several studies of risk factors for the development of poor body image found that burn characteristics, such as the visibility of the scar, and objective severity of a disfigurement do not predict the extent of distress or negative body image [84]. Instead, personal characteristics such as depression, female gender, and coping style best predicted body image dissatisfaction [81–83].

An additional predictor of body image dissatisfaction is the importance that a patient placed on their appearance before the burn injury. If a person did not place much importance on their appearance before the burn, they tend to be much less distressed by scarring [81] . As such, viewing the visible difference as only a small part of their lives seems to be critical in developing body appreciation. Family and unconditional acceptance play a large role in this process. Parents can help children learn to talk about their scars in a casual way and model positive social responses towards teasing or other stigmatization. Developing hobbies, talents and exploring other aspects of identity (not just physical appearance) will help individuals to put their appearance in perspective. This might be challenging in western society where physical appearance is paramount. It would be beneficial to the field to put more focused research efforts on those people with visible differences who go on to develop a strong body appreciation. Most treatments to address body image concerns have focused on cognitive-behavioral strategies to address a person's appraisal of their appearance, to teach adaptive coping strategies, and to introduce social skills that enhance self-esteem and improve social competence [85, 86]. Two of these programs are the Changing Faces program in Great Britain [87] and the BEST program in the US [88]. Both of these programs include a hospital-based image enhancement and social skills program, along with a series of publications for patients dealing with aspects of scarring and changes in appearance. These programs teach survivors a number of adaptive behaviors in response to the inevitable negative societal responses to a change of appearance.

There has been recent attention on the concept of body appreciation, defined broadly as love and acceptance of one's body and appreciation of its uniqueness and the function it performs [89]. The concept of body appreciation is distinctly different than that of body dissatisfaction, and interventions to promote body image appreciation may be slightly different than CBT approaches for body dissatisfaction. More research needs to be conducted in this area with our burn population. We do a disservice to our patients if we exclusively focus on alleviating symptoms of body image disturbance without recognizing opportunities to promote body image appreciation.

2.2.12 Return to Work

Returning to work is a major step towards reintegration following a burn injury. Research has shown that the sooner a person can return to work, the more likely they are to return to work and the better state of mental health. Returning to work can be an important part of therapy as it forces a person to get up, out of the house and be active daily. Work can improve mood and improve quality of sleep. The burn team can set a person up for success in this area by encouraging them to contact their employer as soon as possible following the injury and assist with filling out any necessary paperwork. It is rare that a person with a burn injury qualifies for either short- or long-term disability. A gradual return to work plan is recommended that includes consideration of light duty options as soon as possible after discharge, as well as returning to work for a couple of hours for a short time, then progressing to half days and finally full days. Returning to work in the middle of a typical work week can ease the transition as there are only a couple of days of work until the weekend and then they can rest and start again the following week. Patients should be encouraged to consult their state's employment rules, especially if it is an injury that occurred on the job.

2.2.13 Return to School

Similar to returning to work, the sooner a child can return to school, the better they do emotionally and physically. Public schools are mandated to provide accommodations when needed. This may entail allowing a child to wear splints and pressure garments during the day and getting assistance with range of motion exercises. Accommodations for physical education classes might also be necessary for a short time. It is rare that a child would need home schooling or to change schools as a result of their injury. The Phoenix Society has developed a program entitled, "The Journey Back," for parents, teachers, and hospital staff who are assisting a child with a positive return to school after a burn injury. It is important that the child be prepared for questions and comments from classmates about their injury. Healthcare providers and parents need to discuss different questions and scenarios with the child and rehearse appropriate responses prior to returning to school.

2.3 Summary

A biopsychosocial model of burn outcomes can be useful to guide our understanding of the long-term outcomes of burn survivors. The ongoing rehabilitation issues that burn survivors face are complex and can include physical, emotional, social, and vocational challenges. The distress of the injury does not end when patients leave the hospital. Problems with anxiety, depression, sleep, pruritus, and body image can continue for years. All can impact a patient's ability to return to an acceptable quality of life. Further, we have facilitated two burn survivor focus groups this past year to ascertain barriers to returning to an acceptable quality of life. Unanimously, survivors felt isolated once they were discharged from the outpatient clinic services and felt that the secondary conditions mentioned above were not being addressed by their primary care providers, particularly those in more rural communities [52, 53]. They expressed a desire to have more burn-specific interventions once they returned home. The multidisciplinary team approach to care that has long been practiced by inpatient rehabilitation and inpatient burn units should continue after discharge. Patients will continue to benefit from the expertise provided by both burn surgeons and physiatrists, as well as services from a vocational counselor, social workers, physical and occupational therapists and psychologists. Connecting patients and families with the Phoenix Society is critical. The Phoenix Society is a national advocacy group that provides programs and support services for both burn survivors and their families. Finally, more research needs to focus on effective treatments for the various issues that burn survivors face. Treatment interventions for these issues must be sophisticated and flexible enough to account for the large variability in causes of distress.

Signature Programs of the Phoenix Society

- A peer support program (Phoenix SOAR).
- A secure and moderated online support group (Phoenix Connect).
- A program to assist with school re-entry (The Journey Back).
- An annual international conference for both adults and teen burn survivors and their families (World Burn Congress).
- A comprehensive set of tools that offers practical ways to handle teasing, questions, and various social interactions after a burn injury (Beyond Surviving: Tools for Thriving).
- Finally, a variety of online courses for burn recovery.

Summary Box

A biopsychosocial model of burn outcomes can be useful to guide our understanding of the long-term outcomes of burn survivors. The ongoing rehabilitation issues that burn survivors face are complex and can include physical, emotional, social, and vocational challenges. The distress of the injury does not end when patients leave the hospital. Problems with anxiety, depression, sleep, pruritus, and body image can continue for years. All can impact a patient's ability to return to an acceptable quality of life. Patients will continue to benefit from the expertise provided by both burn surgeons and physiatrists, as well as services from a vocational counselor, social workers, physical and occupational therapists and psychologists. Connecting patients and families with the Phoenix Society and other groups of peers is critical. Finally, more research needs to focus on effective treatments for the various issues that burn survivors face. Treatment interventions for these issues must be sophisticated and flexible enough to account for the large variability in causes of distress.

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