ORIGINAL ARTICLE

“More than Scabs and Stitches”: An Interview Study of Burn Survivors’ Perspectives on Treatment and Recovery

Kimberly Dukes, PhD,[*,†] Stephanie Baldwin, MD,[*,‡] Joshua Hagedorn, BS,[*] Emily Ruba, BS, BA,[*] Katherine Christel, BA,[*] Evangelia Assimacopoulos, MD,[*,‖] Brian Grieve, BA,[*] and Lucy A. Wibbenmeyer, MD[*,$]

Sustaining a burn injury often results in a life-long recovery process. Survivors are impacted by changes in their mobility, appearance, and ability to carry out activities of daily living. In this study, we examined survivors’ accounts of their treatment and recovery in order to identify specific factors that have had significant impacts on their well-being. With this knowledge, we may be better equipped to optimize the care of burn patients. We conducted inductive, thematic analysis on transcripts of in-depth, semistructured interviews with 11 burn survivors. Participants were purposefully selected for variability in age, gender, injury size and mechanism, participation in peer support, and rurality. Survivors reported varied perceptions of care quality and provider relationships. Ongoing issues with skin and mobility continued to impact their activities of daily living. Many survivors reported that they did not have a clear understanding or realistic expectations of the recovery process. Wound care was often described as overwhelming and provoked fear for many. Even years later, trauma from burn injury can continue to evolve, creating fears and impediments to daily living for survivors. To help patients understand the realistic course of recovery, providers should focus on communicating the nature of injury and anticipated recovery, developing protocols to better identify survivors facing barriers to care, and referring survivors for further support.

The treatment and recovery from a burn injury can affect a survivor’s appearance, mobility, daily function, and emotional wellbeing. Recovery from a large burn can be a life-long process,[1,2] and even smaller burns can have long-term impacts on individuals’ quality of life (QOL).[3–6]

Qualitative methods have been used to study aspects of burn care and to understand the perspective of burn survivors. This includes survivors’ experiences with pain and early adaptations after injury,[7–12] the burn recovery narratives of older adults[13] and children or their parents,[14–18] and the impact of burn injuries on relationships.[19,20] An increasing number of qualitative studies investigate the lived experience of recovery for burn survivors.[7,18,21–33]Qualitative studies offer the opportunity to explore survivors’ experiences in depth and on their own terms, by allowing them to introduce elements of their perspectives that are unknown to clinicians. A deeper understanding of patients’ perceptions can inform and improve patient-centered care.[8]

In this study, we examined survivors’ accounts of their treatment at various points in the recovery process, with the goal of improving patient-centered care for burn survivors.

METHODS

We conducted semistructured interviews with 11 burn injury survivors and used thematic analysis to identify factors that were influential in the recovery process. The study was conducted at an academic tertiary care hospital in an American Burn Association (ABA) verified burn center.

This study builds on a previously published study,[34] which contacted 968 adult burn survivors who were treated over a 10-year period to fill out QOL surveys. Out of 150 patients who completed the surveys, 67 offered to participate in interviews. For this qualitative follow-up study, one researcher (S.B.) used purposeful sampling to select participants to ensure breadth of experiences. She selected for variation in the following characteristics: gender, age at time of burn, time since burn, total body surface area (TBSA), rurality, distance from tertiary care center, peer support participation, mechanism of injury, level of education, and QOL range on survey responses. Other survey data were not used for sampling or linked to participants in the qualitative study.

Data Collection

One researcher (S.B.) interviewed all participants individually during 2016. Semistructured interviews used open-ended questions to explore the domains of hospitalization and physical and psychosocial recovery. Interviews used a prospectively developed list of questions covering the injury, hospital stay, recovery, support services, and impact on self, family, work,

*From the *University of Iowa Carver College of Medicine, Iowa City, USA; †Iowa City Veterans Affairs Health Care System, VAMC, Iowa, USA; ‡MercyOne Medical Center - North Iowa, Mason City, USA; ‖Department of Emergency Medicine, University of Iowa Hospitals and Clinics, Iowa City, USA; and $Department of Surgery, University of Iowa Hospitals and Clinics, Iowa City, USA.*

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Address correspondence to Lucy A. Wibbenmeyer, MD, University of Iowa Carver College of Medicine, 200 Hawkins Dr, Iowa City, IA 52242, USA. Email: lucy-wibbenmeyer@uiowa.edu

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and social life. Interviews were conducted in the participant's home (n = 6), a private room near the participant's home (n = 1), over the phone (n = 1), or in a private office at our hospital (n = 3). All interviews were digitally recorded and transcribed verbatim.

Data Analysis

The transcripts were uploaded into MAXQda,[35] a qualitative data management software program. Thematic analysis[36,37] was conducted in an iterative process involving two stages of analysis. In both phases, coding of the transcribed interviews occurred in groups of 3 to 6, with members coming to consensus on grouping statements into themes and subthemes. In the first round of coding, team members (K.D., S.B., E.A., B.G., and L.W.) met regularly to develop and refine a shared codebook of thematic codes with definitions, and to discuss emergent findings. Changes to code definitions were systematically logged. Subsequently, team members (K.D., S.B., J.H., E.R., K.C., and LW) conducted a second round of focused coding to further explore survivors' experiences during recovery. All transcripts were read and independently coded by K.D., S.B., L.W., and at least two other members of the research team.

We reported this study using the Consolidated Criteria for Reporting Qualitative Research (COREQ).[38] The study was approved by the local Institutional Review Board.

RESULTS

Interviewee Characteristics

All participants were over 18 years old and had a length of stay (LOS) over 5 days per previous study inclusion criteria. Seven participants were women, four were men. Age at time of burn ranged from 4 to 56 years, while age at time of interview ranged from 31 to 56 years. Time since the burn ranged from 3 months to 26 years. The TBSA of participants' injuries ranged from 0% to 15% to greater than 50%. The mechanisms of burns included: assault, work accident, cooking accidents, self-infliction, yardwork accident, and an accident related to manufacture of illicit drugs. Distance from the tertiary care center ranged from 15 to 135 miles. Five participants lived in rural areas. Five had reported using organized burn peer support.

To protect the privacy of participants and avoid unintentionally revealing their identities, we do not provide identifying information (gender, age, or burn size) associated with quotations in the Results section. Patient's time from injury is reported.

Hospital Memories Persist

Most participants expressed gratitude for their providers and care received at the tertiary care center. In the words of one participant,

> *"There are no words to show my appreciation… I really don't know how to say thank you. It's not enough."* (2 years)

However, when asked about their hospital stays and treatments, participants also reported memories of lack of rest due to noise and disruption, communication mishaps, and feelings of depersonalization, pain, and fear. Others expressed confusion about who their doctor was, lack of awareness about support programming or services, or confusion about appointments or procedures. These examples could have negative consequences, and could occur even for patients with extensive experience in ongoing burn treatments. For example, despite having undergone over 60 procedures since injury, one survivor did not realize a procedure was scheduled until receiving a reminder the day before, and then was surprised to learn on arrival that the procedure was a 5-hour pedicle flap surgery rather than a 2-hour laser treatment:

> *"My driver said, 'I can only be here another three hours! I cannot stay until you finish.' [I thought] 'What am I going to do?'"*

Participants reported that sometimes they experienced depersonalization and lack of privacy during their hospital stays.

> *"I was naked one day…and they had all these medical students around me and the lady… was drawing on me and pointing and stuff and I didn't feel like a person. … And then,*
> *there was another patient and then it was me and it was just a curtain separating it. I didn't feel like I had a lot of privacy. Then, a guy … just walked in and stared at me and then he walked back out."* (1 year)

A recurring theme was how strange, terrible and frightening burn treatment and hydrotherapy seemed to participants. Many perceived treatments and locations as frightening. For example, the hydrotherapy room was described as "pretty freaky" and "totally weird." Many participants used graphic terms for the unfamiliar treatment methods. One participant described the experience as "They basically just skinned you." Another summed up the overall treatment experience as "torture":

> *"It is torture at the burn unit …. It's the afterwards. The skin. Showering. The ointment. Being wrapped up and unwrapped, and then the showers. No, it's hell."* (2 years)

Skin and Mobility Issues Require Continuing Adjustment

Survivors reported ongoing issues with their skin and mobility that continued to impact activities of daily living. Many did not have realistic expectations or clear understanding of the recovery process.

Participants often elaborately described their injured or grafted skin. Common themes included the evolving characteristics of skin, mobility issues, and wound care. Participants often mentioned that they felt surprised by these issues and sometimes unprepared to care for them. Even years after an injury, participants described fragile and dry skin, unsettling scars, tightness, or sensation issues that disrupted their everyday living. One survivor 9 years out from their injury stated,

> *"I always wear a long-sleeve shirt when I go outside to keep my grafted skin from getting sun tanned or burnt…It would be cracking all the time."*

Another compared the skin's tightness to how a turtle would feel with a shell. Others noted continuing issues with fragile or itching skin.

> *"The worst part is the itching…Itching really bothers… there's no way to control it. Medication doesn't help. Nothing helped." (4 years)*
> *"My skin rips real easily now. If I get out there in anything over 80 degrees, I still get…big water blisters [on] my arms. If it's under 40 degrees, they start turnin' a blackish color." (5 years)*

Survivors with arm or hand injuries in particular spoke of the everyday difficulties they encountered throughout recovery due to limited mobility and dexterity. Daily struggles included opening doors, brushing their teeth, holding a glass, writing, and cutting food. These struggles could continue for years, and for four participants they were persistent. In the words of a survivor 5 years out from the injury, recalling immediate struggles,

> *"Because of my arms being contracted the way they were, when I had to use the bathroom, wipe, or something, I couldn't really reach back there right because it was contracted so far… My arm now, I still can't straighten it completely."*

After discharge, survivors confronted the challenge of looking at their wounds and performing wound care, and some survivors felt intimidated by their home wound care needs. Bleeding and scabs evoked panic and worry. "I was always afraid at first. …I didn't realize it was scabs," one participant recalled, describing an online search that relieved some of the fear. Another participant described perceiving "raw meat" in the mirror. One survivor months out from their injury recalled:

> *"They give you all this stuff and tell you what to do, but it's like you really don't know how to do it. It's really scary, pulling all that stuff off and seeing all that."*

Even with formal instruction, wound care was overwhelming and provoked fear for many survivors. Similarly, educational processes intended to familiarize patients with upcoming procedures also could be frightening:

> *"When I got the skin graft…they gave you a book [Operative Teaching Book], and they showed you. At that point, I was still so upset about the burn, I couldn't even look at it, … it upset me to look at the book, to see what they were gonna do to me." (Months)*

Many survivors required assistance from home nursing or family members. In the months and years following a burn, participants reported using different "home remedies" to help soothe, soften, or treat their scars, including cocoa butter, shea butter, coconut oil, lemon juice, skin massage, or stretching and yoga. Some also turned to music lessons or sports to force themselves to stretch and gain dexterity.

> *"Actually, my mom … got me involved in gymnastics. That way, I would put pressure on my hands and flatten my hands out more. I took piano lessons to increase the flexibility. I did softball, work[ed] on my hand/eye coordination with my arms and stuff."*

Healthcare providers were able to help moderate these fears for some. The patient who feared wound care and "pulling off all that stuff," found some comfort in her clinic experience after discharge.

> *"She (clinic nurse) showed me how to cut the dressings and put 'em on and clean and how to be sterile. She gave me different ideas about how to keep the bandages in place… They helped me, too, up at the clinic."*

Recovery Involves Far More than Physical Recovery

In describing their recoveries, participants discussed the lasting trauma of the injury and the feeling that others may not adequately understand. A few survivors, regardless of the size of their burn, spoke about the lifelong challenges that the injury provokes.

> *"It was a traumatic time for me. Today, I still don't talk about it much. Because how do you tell somebody that your hands are out here in front of you, and there's blue flames comin' up off your fingers and your skin?...It is just like people in the war. They just don't talk about it." (5 years)*

Participants described the difficulty of fully explaining the impact of the injury to others, including the idea that "healing" might involve more than physical rehabilitation. A relatively recent survivor summed up this difference powerfully:

> *"A lot of people, they'll be like, 'How are you doing? Are you healed?' I'm like, 'Well, the wound is healed.' There's so much more to it than just scabs and stitches when they're healed. People don't understand that sometimes…. I don't think people really understand… what a burn is." (Months)*

Indeed, some participants struggled to share these lasting impacts even with those closest to them, and even after many years since the injury. One participant discussed how grown children and grandchildren had slowly learned to accept his/her new limitations. However, other participants described their loved ones' frustration or incomprehension about the physical, emotional, and cognitive issues that can affect survivors and sometimes restrict their activities or capacities. These issues included new temperature or socialization preferences, limitations in their ability to organize bills, and even new worries about dementia and cognitive decline. One participant described how long it might take family members—or the survivor—to adapt to new, postinjury realities:

> *"Sometimes [my spouse] understands but there's a lot of things that [they] don't. [They} still [think] I'm the same old me sometimes too and [expect] things to be done right now or the same old way, but it just can't happen that way anymore. You would think after almost nine years we'd both be getting used to that but you just don't." (9 years)*

DISCUSSION

Survivors of burn injuries reported ongoing emotional and physical issues during their long recoveries. Their memories of inpatient treatments included miscommunications with healthcare providers and feelings of fear, pain, and depersonalization. They also described their perception of treatments as strange and disturbing. Years following injury, skin and mobility issues continued to impact participants' activities of daily living, sometimes in ways they felt unprepared for.

Survivors' accounts provide us with a deeper understanding of our patients' perceptions of their treatments and recovery and the continuing challenges they face. This nuanced understanding can help us provide better patient-centered care and offer appropriate resources to ensure successful adjustment after the injury.

The first area of focus suggested by the survivors' accounts is the inpatient hospital stay. This phase of care, largely focused on physical healing, is the time with the most open wounds and the greatest risk for infections. Treating burn injury requires painful procedures, which may unintentionally retraumatize survivors like those in the current study. Although many expressed gratitude for "life saving treatment," all the survivors recounted vividly the unrelenting pain they endured to help heal their wounds. The painful treatments can serve as a trigger, reminding burn survivors of their burn incident.[39] These procedures can also create a sense of vulnerability and a lack of control which can increase distress. Poorly treated pain can also lead to pychosocial issues including posttraumatic stress disorder in susceptible individuals.[40] This was articulated by one survivor who could not touch their donor scars because of the memory of the pain. While pain cannot be completely removed, clinicians could ameliorate pain for patients by giving patients more control, providing deeper sedation, using other modalities (eg, music, aromatherapy, imagery, acupuncture, and distraction), and building the patient's coping skills and resilience.[9–11,41]

The second priority in burn care involves decreasing the distress and the burden of burn wound care for both the patients and their families. Despite instruction, the majority of the survivors in the current study felt ill-equipped to deal with their changing wounds after discharge. Many were frightened by the scabs and bleeding. Visiting nurses and communication with the clinic provided much needed support and served to alleviate many of these fears. Other research has shown that patients may experience distress about the appearance of their burns or fear looking at or caring for their wounds.[42,43] Patients who were more prepared fared better.[43] As many survivors need additional help from family members, the need to instruct the caregivers and to provide this education in multiple forms for adult learners is particularly important. This study emphasizes the need to provide anticipatory guidance as to what to expect from the wound prior to their next clinic visit. For the majority, this instruction should include what to expect years from the injury as well.

Finally, understaffed, busy centers may unintentionally overlook the human factor—that is, patient concerns and feelings—especially when there are administrative factors directing expeditious care. In-patient psychosocial support, unfortunately, is not abundant in many burn centers. For many patients, the adjustment to the injury involves more than the physical condition. Mental health issues including depression, acute stress disorder, anxiety, grief, insomnia, fatigue, and isolation can occur during acute hospitalization as well as years after discharge.[44,45] Licensed mental health providers who are integrated within the burn team can help address these needs while the patient is hospitalized.[46] However, as these mental health concerns lingered and intensified post-discharge for some of our study's survivors, the burn center needs to continue to play a central role in marshalling psychosocial support for burn survivors.[47] This is highlighted by participants who expressed concern at not being able to obtain adequate, or any, psychosocial help upon discharge. As a result, these survivors perceived they had heightened distress, suffering and isolation. As support has been shown to be critical in the burn recovery process, burn centers need to continue to administer support services for their survivors.[47,48] Burn center-led support groups, individual trained peers and online resources can help survivors find individuals with similar "lived experiences."[49]

Our study has limitations. We interviewed a small, purposeful sample of patients who had received burn care at one tertiary care institution, so the findings are not generalizable to all institutions or across all patients. Additionally, participants volunteered for the study. Volunteers may have more interest in reflecting on their experiences, which may be skewed toward adjustment. Their perspectives may not be shared by all burn survivors. The range of time since the injury also raises the possibility of recall bias. Nevertheless, our methodology allowed participants to share their experiences and perceptions in depth and introduce topics they wanted to discuss. This depth and flexibility illuminated our survey findings and also identified additional aspects of the recovery experience. The findings identify key facets of postinjury experience that may be shared by many patients facing long recoveries. Thus, while we cannot generalize from these findings, the findings should be transferable to the improvement of postburn injury recovery in a variety of hospital settings. The study findings also provide us with avenues to explore that may help improve our care and our patients' journey.

Summary of Areas for Future Care and Research

Burn care professionals could consider new strategies to improve patient experience as described throughout the discussion. To address pain control and psychosocial challenges during the inpatient stay, clinicians should consider patient-controlled analgesia, deeper sedation, and non-opioid modalities, and ensure the entire team is trained in trauma-informed care.[50,51] To better support patients' mental health throughout recovery, clinics could embed mental health professionals in both in-patient and outpatient areas. To improve patients' understanding and perceived capacity to care for their evolving wounds, clinicians should instruct the patient and family on discharge and in follow-up visits about their skin, skin care, and how to maintain joint movement. Clinics could promote the use of patient portals, and provide both written and visual instructions available on paper and online to ensure continuing access to wound care advice. Finally, clinics could lead and administer support programs that meet the needs of their patients, encourage patients' participation in peer support throughout recovery, and emphasize that the burn center remains a resource for future questions. Future research could develop and test creative education strategies to communicate with burn survivors at different points in their recovery.

CONCLUSION

Even years later, trauma from burn injury can continue to evolve, creating fears and impediments to daily living for survivors. To help patients understand the realistic course of recovery, providers should focus on communicating the nature of injury and anticipated recovery, developing protocols to better identify survivors facing barriers to care, and referring survivors for further support.

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