

HHS Public Access

Author manuscript *Burns*. Author manuscript; available in PMC 2022 May 01.

Published in final edited form as:

Burns. 2021 May ; 47(3): 692–697. doi:10.1016/j.burns.2020.07.022.

Social Factors and Injury Characteristics Associated with the Development of Perceived Injury Stigma Among Burn Survivors

Evan Ross, MD¹, Tom Crijns, MD², David Ring, MD PhD², T. Ben Coopwood, MD²

¹Department of Surgery, University of Texas Medical Branch, 301 University Street, Galveston, TX 77555, USA

²Department of Surgery and Perioperative Care, Dell Medical School at the University of Texas at Austin, 1501 Red River Street, Austin TX, 78712, USA

Abstract

Improvement in burn survival has shifted the focus of burn care from beyond merely preserving life to improving the quality of life for burn survivors. Healthy psychosocial function is critical to the development of sustained elevations in quality of life after injury, with social and community integration serving a crucial role. Accordingly, the experience of social stigma could pose a significant hindrance to the process of recovery. In this retrospective analysis of patient-reported outcomes following burn injury as captured in the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Burn Model Systems database, we examined the patient and injury characteristics associated with the subsequent experience of social stigma by burn survivors. Using multivariable regression analysis, we found that facial burns and amputations are independent risk factors for experiencing social stigma, while male sex and increased community integration were protective. Taken together, these findings suggest a role for targeted counseling for patients who sustain facial burns and/or amputations, as well as the continued investment in burn-survivor outreach programs aimed at improving social support for survivors.

Keywords

Facial burn; stigma; amputation; community integration

Introduction

In its original Greco-Roman context, the term *stigma* referred to a physical mark made upon an individual's person to identify that they were held in bondage as slaves; these marks –

[®]Tom J. Crijns, Department of Surgery and Perioperative Care, Dell Medical School, The University of Texas at Austin, Health Discovery Building; MC Z0800, 1701 Trinity St., Austin, TX 78712, USA, tom.j.crijns@gmail.com.

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often either brands or tattoos on the individual's face – were intended to cause those that bore them to feel the shame of their diminished social standing [1]. In more modern context, while stigma has morphed to include both seen and unseen characteristics that mark an individual as somehow afield from accepted norms, the term retains the element of social shame [2]. People with physical appearances that differ from the average or expected appearance are at risk for experiencing a degree of stigmatization in which other members of their community treat them with disrespect based only upon their appearance.

Burns, especially those to the face or hands, are often devastating and complex injuries. Burns can lead to significant scarring that results in a pronounced alteration in both physical function and appearance [3]. Because of these changes, burn survivors may be at risk for experiencing social stigmatization, which can lead to social isolation and a decreased quality of life [4]. As the field of critical care has advanced, mortality after burn injury has continuously decreased [5,6]. Accordingly, providers who care for burn survivors are beginning to shift their attention away from merely preserving life to improving quality of life after recovery. The development of scars and their related physical, social and psychological sequelae have become a central focus of research aimed at improving the lives of burn survivors [7].

Because the perception of social stigmatization may influence a burn survivor's quality of life as they recover from their burn, it is important to explore factors that may contribute to the development of patient-perceived social stigma after injury. While it seems intuitive that there would be a connection between injury severity or location and measures of impaired psychological and/or social function, previous research into the impact of burn scars on psychosocial function has generally demonstrated that injury characteristics alone are inadequate to explain psychological and social outcomes after burn injury [3,8]. In the specific context of body esteem, it appears that social stigmatization may play a moderating role [9].

Therefore, we are interested in determining which patient and injury characteristics are associated with the development of patient perceived injury-related social stigma after burn injury. We performed a retrospective analysis on a large database and asked: What injury characteristics (including burn and graft size as well as anatomical location) contribute to patient perceived social stigma, accounting for sex, age, race, and pre- and post-injury community integration?

Materials and Methods

Because the Burn Model Systems database contains only de-identified data, our Institutional Review Board (IRB) waived human subjects research oversight for this study. After obtaining approval via Burn Model System Standard Operating Procedure #604, we performed a retrospective review of the Burn Model Systems Database of the years 2014 through 2020. As part of participation in the Burn Model Systems surveys [10], burn survivors complete a number of patient-reported health related quality of life measures. Decisions regarding which instruments are included in the Burn Model System are made by a consortium of stakeholders, including burn survivors, their loved ones, and providers

across disciplines throughout the entire continuum of burn care. Of particular relevance to the present study, the Burn Model System database includes the Quality of Life in Neurological Disorders (Neuro-QoL) stigma scale [11], which we used to quantify patient perceived injury-related social stigma. This scale contains statements such as "Because of my illness, some people avoided looking at me" and "Because of my illness, I felt embarrassed in social situations" to which patients rate their level of agreement on a fivepoint Likert scale. Additionally, patients complete the Community Integration Questionnaire (CIQ), which measures the degree to which a patient can function independently as well as the degree to which they are able to participate in community life, including leisure activities and friendships. The CIQ contains questions such as "How often do you travel outside the home?" and "Who usually plans social arrangements such as get-togethers with family and friends?" Both the Neuro QoL and the CIQ were originally designed and validated in patients with neurological injury [12,13] but have been adapted for use with burn survivors in the NeuroQOL, the original instrument's term 'illness' has been replaced with 'injury', and in the CIQ the terms 'head injuries' have been replaced with 'burn injuries'. Of note, the CIQ has recently been validated for use in burn survivors [14].

Our study included all patients in the Burn Model Systems database who were 18 years or older when they sustained a burn injury, and who had completed both the CIQ and Neuro QoL stigma questionnaires. Four hundred thirty-one patients out of 839 (51%) who did not complete either questionnaire at 1-year follow-up were excluded. Our primary outcome was the Neuro-QoL stigma score, and we accounted for sociodemographic factors as well as injury characteristics such as burn size, graft size and anatomical location of injury. We identified a total of 408 patients (275 males, 67%) who met the current study's inclusion criteria, with an average age of 47 years, a median total body surface area (TBSA) burned of 12%, and a median graft percentage of 4.9%. Nearly half of the patient cohort (48%) were burned on their head, face, or neck, while 80% of patients were burned on their hand or forearm; in 75% of patients the dominant hand was involved in the injury (Table 1).

Statistical analysis

To identify factors associated with patient-perceived stigma (Neuro-Qol score) at 1-year post-injury, we performed bivariate analysis of factors potentially associated with the perception of disease-related social stigma. Pearson and Spearman rank correlation was performed for continuous variables, and Student's t-tests and one-way Analysis of Variance (ANOVA) were performed for categorical variables when appropriate. The following explanatory variables were accounted for: age, sex, race, burn type, circumstances of injury, burn location, involvement of the dominant hand, limb amputation, TBSA burned, percentage of body grafted, length of hospital stay, number of operating room visits, and pre- and post-injury (baseline and 1-year) community integration score. We performed multivariable linear regression analysis seeking factors associated with the Neuro-QoL score. Regression coefficients, standard errors, and 95%-confidence intervals were reported. All *P* values <0.05 were considered statistically significant. The variables race, burn type, and circumstances of injury were pooled for analysis. There was notable multicollinearity between the variable burn location 'forearm or hand' and 'involvement of dominant hand'; and between the variables 'percentage of body grafted, 'length of hospital stay', and

'percentage of body burned'. The variables with that were the least predictive of the Neuro QoL stigma score were excluded from the model: percentage of body grafted, forearm and/or hand involvement (dominant hand involvement was more predictive), and length of in-hospital stay.

Results

In bivariate analysis, the categorical variables female sex (P=0.016), race (P=0.042), circumstances of injury (P<0.001), anatomical location of burn (face, P<0.001; trunk, P=0.002; shoulder and upper arm, P=0.002; forearm and or hand, P=0.002; dominant hand, P=0.009), and limb amputation (P<0.001) were all found to be associated with a higher Neuro QoL stigma score at 1-year post-injury (Table 2). The following continuous variables were all associated with greater patient perception of stigma: younger age (P=0.003), greater TBSA burned (P<0.001), greater percentage of body surface area grafted (P<0.001), longer length of hospital stay (P<0.001), higher number of OR visits (P<0.001), and lower 1-year post-injury community integration score (P<0.001).

After controlling for confounding variables in multivariable analysis, burns to the head, neck or face (Regression Coefficient [RC]: 2.4; 95% Confidence Interval [CI]: 0.10 to 4.8; P=0.041) and limb amputation (RC: 6.9; 95%CI: 3.2 to 11; P<0.001) were independently associated with greater patient perception of social stigma, whereas male sex (RC: -3.6; 95%CI: -5.8 to -1.4, P=0.001), and higher patient 1-year post-injury community integration score was associated with less perception of stigma (RC:-1.0; 95%CI: -1.4 to 0.61, P<0.001) (Table 3).

Discussion

This study adds to the nascent literature focused on the experience of social stigmatization in adult burn survivors. The experience of social stigma is a complex phenomenon, likely to be mediated by patient, injury, and social factors, as well as the significant interactions between these domains. Because patient-perceived social stigmatization is likely to negatively influence a burn survivor's quality of life during recovery, it is important to identify factors associated with patient-perceived social stigma after injury to best support patients' psychosocial recovery; for example, using an iterative focus-group and interview technique with survivors from the Netherlands, Kool and colleagues identified the negative impact of stigmatization on quality of life after burn, while also identifying the closely related concept of invalidation that might drive survivors to become socially isolated [15]. In the present study, we sought factors associated with patient-perceived social stigma. Patient-perceived social stigma was inversely correlated with the patient's post-injury community integration score.

The fact that facial disfigurement is associated with higher levels of perceived social stigma is not surprising - the extent of the impact that facial injuries can have on patients' lives in terms of mental health has been documented in previous studies [16–18], though the relationship between facial injury and self-esteem is not straightforward and may involve the

interaction between a number of moderating factors, including age [8,19]. Other research into the connection between scarring and a patient's body image or self-esteem have identified the moderating role of other psychological factors – both Lawrence and Thombs have published evidence suggesting that the degree to which the burn survivor values physical appearance moderates the relationship between scarring and self-reported body image [20,21]. Intriguingly, individuals who are burned as children often show average to above-average self-esteem and tend to possess normal to positive body images, suggesting that by and large they successfully adapt to the change in their appearance [22,23].

We found that post-injury community integration score was negatively associated with the perception of stigma, suggesting that patients with stronger community support are protected from perceiving stigmatization. Conversely, it may also indicate that patients who perceive more stigma feel less capable of connecting with others. This is broadly in line with previous findings from Fauerbach and colleagues, who described the unfortunate stability of the "Alienation" dimension of psychological distress as measured by the Brief Symptom Inventory from hospitalization through 2 years after discharge – a dimension that they hypothesize to represent feelings of "social disconnectedness" [24]. When taken in context of previous research, this finding further emphasizes the importance of sufficient social support during recovery from injury, and efforts aimed at connecting burn patients with community resources as well as other survivors should continue – for example the Phoenix Society and their ongoing programs like Take Charge of Burn Pain, as well as burn camps for young survivors, the attendance of which is associated with improved social skills in adolescents [25].

The following limitations should be kept in mind. First, the current study analyzed patients one year after injury, and our findings may not predict perception of social stigma for a longer time period. It might be speculated that perceived social stigma will further decrease over time, but additional studies are merited. Second, the vast majority of our database was Caucasian, and the number of patients of other races might be too low to detect minor differences in outcomes and had to be pooled for analysis. There is evidence that some cultures may experience a lower degree of community integration after injuries [26], but the current study did not allow for further elucidation of this phenomenon and how it may interact with the experience of social stigma. Finally, as with previous research on this topic, the present study is limited by the lack of validated, patient-centered measurements of scarring [3]; while we could not account for scar severity, a questionnaire that assesses this metric has recently been added to the list of questionnaires that patients complete as part of their participation in the Burn Model System. Instead we used the TBSA burned and the percentage grafted as proxy measures for the extent of scarring.

Conclusions

Our results suggest that patients who are burned on the head, neck or face as well as those who undergo amputations are at increased risk for experiencing social stigmatization. Patients with burns to the head and amputations can be anticipated to benefit from targeted counseling prior to discharge, which will help them anticipate and manage the potential for

stigmatization. The observed association of community integration with less stigmatization supports the value of programs dedicated to improving social support for burn survivors.

Acknowledgments

Funding

This work was supported by the National Institute of Health (NIH) grant 5T32GM008256. The Burn Model System National Database was supported by the U.S. Department of Health and Human Services, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in collaboration with the NIDILRR-funded Burn Model System (BMS) Centers. However, these contents do not necessarily reflect the opinions or views of the BMS Centers, NIDILRR or the U.S. Department of Health and Human Services.

COI/Disclosure:

One of the authors (DR) received royalties from Tornier (formerly Wright Medical) for elbow plates in the amount of less than USD 10,000 per year and Skeletal Dynamics for an internal joint stabilizer elbow in the amount of USD 10,000 to 100,000 per year; is a Deputy Editor for Hand and Wrist, Journal of Orthopaedic Trauma, and Clinical Orthopaedics and Related Research® in the amount of USD 5000 per year; and received honoraria from meetings of AO North America, AO International, and various hospitals and universities.

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Highlights

- Perceived social stigma is most strongly associated with limb amputation and face and neck burns.
- Community integration at twelve months post-injury is protective for the perception of stigma, or patients who perceive more stigma feel less capable of connecting with others.
- The importance of efforts aimed at connecting burn patients with community resources as well as other survivors should be emphasized.
- Patients with burns to the head and amputations can be anticipated to benefit from targeted counseling prior to discharge from the hospital.

Table 1.

Patient demographics.

Variables	Value
Ν	408
Male sex	275 (67%)
Age	47 ± 16
Race	
White	317 (78%)
Black or African American	46 (11%)
Native American or Alaskan	8 (2.0%)
Asian	6 (1.5%)
Native Hawaiian or other Pacific Islander	3 (0.74%)
Other or unknown	28 (6.9%)
Burn type	
Fire or flame	228 (56%)
Scald	50 (12%)
Grease	49 (12%)
Electrical	30 (7.4%)
Other	51 (13%)
Circumstances	
Not work-related	217 (53%)
Work-related	89 (22%)
Recreational	66 (16%)
Assault or self-inflicted	23 (5.6%)
Other	13 (3.2%)
Burn location	
Head, neck or face	195 (48%)
Trunk	215 (53%)
Shoulder and upper arm	164 (40%)
Forearm or hand	326 (80%)
Leg or foot	273 (67%)
Perineal or genital	86 (21%)
Involvement of dominant hand	199 (75%)
Percentage of body burned (median, IQR)	12 (3-30)
Percentage of body grafted (median, IQR)	4.9 (1.4-18)
Amputated limb	29 (7.1%)
Length of hospital stay (median, IQR)	20 (12-33)
Operating room visits (median, IQR)	2 (1-3)
Community integration score (pre-injury)	8.6 ± 2.3
Community integration score (1-year)	8.2 ± 2.4
Neuro-QoL stigma score (1-year)	48 ± 8.4

Continuous variables as mean (±standard deviation); discrete variables as number (percentage).

Table 2.

Bivariate analysis of factors associated with the Neuro-QoL stigma score.

	Neuro-QoL s	Neuro-QoL stigma	
Variables	Mean ± SD	-	
Sex		0.016	
Female	49 ± 8.7		
Male	47 ± 8.1		
Race		0.042	
White	47 ± 8.2		
Black or African American	51 ± 9.7		
Other	46 ± 7.7		
Burn type		0.210	
Fire or flame	48 ± 8.6		
Scald	46 ± 7.7		
Grease	46 ± 7.3		
Electrical	49 ± 10		
Other	46 ± 7.5		
Circumstances		<0.001	
Not work-related	47 ± 8.2		
Work-related	48 ± 8.5		
Recreational	46 ± 7.3		
Assault or self-inflicted	56 ± 7.9		
Other	46 ± 7.9		
Burn location			
Head, neck or face		<0.001	
Yes	49 ± 8.4		
No	46 ± 8.0		
Trunk		0.002	
Yes	49 ± 8.8		
No	46 ± 7.6		
Shoulder and upper arm		0.002	
Yes	49 ± 8.7		
No	46 ± 7.8		
Forearm or hand		0.002	
Yes	48 ± 8.6		
No	44 ± 6.7		
Leg or foot		0.523	
Yes	48 ± 8.7		
No	47 ± 7.6		
Perineal or genital		0.072	
Yes	49 ± 8.5		
No	47 ± 8.3		

	Neuro-QoL stigma		
Variables	Mean ± SD	P value	
Involvement of dominant hand		0.009	
Yes	49 ± 8.5		
No	46 ± 8.1		
Amputated limb		<0.001	
Yes	54 ± 9.4		
No	47 ± 8.1		
Variables	Correlation	P value	
Age	-0.16	0.003	
Percentage of body burned	0.24	<0.001	
Percentage of body grafted	0.25	<0.001	
Length of hospital stay	0.26	<0.001	
Operating room visits	0.28	<0.001	
Community integration score			
Pre-injury	-0.0089	0.874	
1-year	-0.31	<0.001	

Bold indicates a statistically significant difference; continuous variables as mean (\pm standard deviation); discrete variables as number (percentage). All variables with P < 0.05 were moved to multivariable regression analysis.

Table 3.

Multivariable linear regression analysis of factors associated with Neuro-QoL stigma score.

Variables	Regression coefficient (95% confidence interval)	Standard error	P value	Adjusted R ²
Community integration score (1-year)	-1.0 (-1.4 to -0.61)	0.21	<0.001	0.13
Age	-0.056 (-0.12 to 0.0083)	0.033	0.087	
Sex				
Female	reference value			
Male	-3.6 (-5.8 to -1.4)	1.1	0.001	
Race				
White	reference value			
Black or African American	2.3 (-1.1 to 5.8)	1.7	0.186	
Other	-0.11 (-4.0 to 3.7)	2.0	0.955	
Circumstances				
Not work-related	reference value			
Work-related	0.28 (-2.2 to 2.8)	1.3	0.826	
Recreational	-0.97 (-3.8 to 1.8)	1.4	0.493	
Assault or self-inflicted	3.0 (-1.7 to 7.7)	2.4	0.210	
Other	-3.9 (-11 to 3)	3.6	0.274	
Burn location *				
Head, neck or face	2.4 (0.10 to 4.8)	1.2	0.041	
Trunk	-1.5 (-4.2 to 1.1)	1.4	0.258	
Shoulder and upper arm	0.17 (-2.5 to 2.9)	1.4	0.903	
Involvement of dominant hand	1.1 (-1.3 to 3.6)	1.2	0.359	
Amputated limb	6.9 (3.2 to 11)	1.9	<0.001	
Percentage of body burned **	0.045 (-0.028 to 0.12)	0.037	0.229	

Bold indicates statistical significance, P < 0.05.

* The variable bum location 'forearm or hand' was dropped due to collinearity with 'involvement of dominant hand'.

** The variables 'percentage of body grafted' and 'length of hospital stay' were dropped due to collinearity with 'percentage of body burned'.