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ORIGINAL ARTICLE

Living with visible scars: The social stigmatization of burn survivors.

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ABSTRACT… Objective: To assess the social stigmatism, in adult burn survivors with visible scars, that they face in the society. **Study Design:** Cross-sectional study. **Setting:** Department of Plastic Surgery and Burns, Sheikh Zayed Medical College and Hospital, Rahim Yar Khan. **Period:** May 2022 to April 2023. **Material & Methods:** The study included 64 participants aged 16 to 55 years who were awaiting reconstructive surgery and had experienced visible scarring from burns for over six months. Data on perceived stigmatization were collected using the Perceived Stigmatization Questionnaire (PSQ). The demographic profile, burn characteristics, and socio-economic factors of the participants were also analyzed. Statistical analysis was performed using SPSS 27, including post-stratification chi-square tests. **Results:** Of the 64 participants, 87.5% reported experiencing perceived stigmatization, with gender being a significant factor. Notably, 91.7% of females reported stigmatization, compared to 75% of males. Marital status, educational level, scarred body parts, visibility of scars in public, and age at the time of burn were also strongly associated with perceived stigmatization. The study revealed the mean scores for three domains: Absence of friendly behavior (2.58 ± 0.64), Confused/Staring behavior (3.15 ± 0.57), and Hostile behavior (2.19 ± 0.72). **Conclusion:** This study underscores the prevalence of perceived stigmatization among burn survivors, particularly those with visible scars on their face and hands. The findings emphasize the importance of social support and awareness campaigns in mitigating these challenges. Greater efforts are needed to address the psychosocial issues faced by burn survivors and promote empathy and inclusivity in society. Further research is crucial to understanding the experiences of burn survivors from diverse backgrounds.

Key words: Awareness, Burn Survivors, Cross-sectional Study, Psychosocial Impact, Perceived Stigmatization, Social Support, Visible Scarring.

INTRODUCTION

According to the World Health Organisation information on the prevalence of diseases worldwide, burn injuries are the fourth most common traumatic injury.[1] About 265,000 people die due to burn injuries around the world and about 48.9% of burn injury patients in Pakistan are between 10-29 years of age.[2] The effects of burn injuries are dual-edged; in addition to leaving physical scars, they also have an adverse effect on a person's mental health, sense of self, and social support.[3,4] The face serves as the primary medium for interpersonal communication and offers crucial clues about a person's identity, age, sociocultural background, and emotional state.[5] In the media, people with obvious scars have long been stigmatized.[6] With the stigma of disfigurement, it is very difficult to improve one's self-worth, confidence, and ability to deal with others' invasive reactions. Simple tasks like crossing the street, taking a bus, or entering a place of worship become agonising experiences of dodging terrified looks and finger-pointing. Their appearance is never allowed to be forgotten. When they look in the mirror and when they become aware of how other people perceive them are the two key moments that affect how their bodies are perceived to have changed. Burn victims who have had changes to the appearance and functionality of bodily parts begin to experience shock after being released from the hospital.[7] The main obstacles experienced by burn survivors are cultural stigma and perceived social rejection, and their lack of adequate coping

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mechanisms may hinder effective rehabilitation.[8] The psychosocial aspects concerned with the society are more enhanced when the burn area is the visible area of the body like face and hands. According to a study, 79% burn survivors indicated that they feel socially stigmatized mainly due to the presence of scar and keloids that are visible even in clothes.[9] Burn s' lack of social support should be a major worry because it may be detrimental to their chances of surviving and to their physical and mental wellbeing. I have designed this study to evaluate this aspect of the burn patient's life and to emphasize the importance of assessing individuals when they come in contact with the view of society, outside the context of a Burn Unit. It is expected that this research would help evaluate reactions burn patients have to face and the hurdles that come their way due to their appearance. Health care providers must therefore evaluate social comfort in order to address the psychosocial issue that burn patients face both during and after the recovery process.

MATERIAL & METHODS

This descriptive cross sectional study was conducted at Department of Plastic Surgery and Burns Sheikh Zayed Medical College and Hospital Rahim Yar Khan from 8 April 2023 to 7 May 2023. The study comprised patients aged 16 to 55 years awaiting reconstructive surgery who had post burn visible scaring involving face and hands for more than 6 months who were contacted for data collection.

Approval was obtained from the institutional ethics review committee (683/IRB/52MC/SZH), and informed written consent was obtained from the subjects. The sample size of 64 was selected using purposive sampling technique, taking a 79% proportion of burn survivors who experience social stigmatism at 95% confidence level with a margin of error of 10%. The outcome variable i.e., social stigmatism was assessed using Perceived Stigmatization Questionnaire (annexure).

Perceived Stigmatization Questionnaire (PSQ)

The PSQ consists of 21 items divided into three domains: Absence of friendly behaviour (items 1, 5, 7, 9, 12, 15, 17 and 20), confused/staring behaviour (items 3, 4, 6, 10, 13, 14, 19 and 21) and hostile behaviour (item 2, 8, 11, 16 and 18). The individual indicated how often experiences such behaviour on a scale with response alternatives 1-5 (never, almost never, sometimes, often, always). The scores of the items of the domain Absence of friendly behaviour were reversed prior to statistical analysis. The PSQ total score was calculated by summing the items and dividing by the number of items in the instrument. The same procedure was performed to calculate the score of each domain, by dividing the number of items in the respective domain. Higher scores indicated greater perception of stigmatizing behaviour. People who scored 2.5 or above on the PSQ were considered to have high perceived stigmatisation, whereas those who had low perceived stigmatisation scores, less than 2.5 were considered to be not stigmatized.[10] The internal consistency of the original instrument was assessed by Cronbach's alpha and the value of 0.93 was obtained.[11]

Perceived Stigmatization Questionnaire (PSQ)

1. People are friendly with me.
2. People call me names
3. People avoid looking at me
4. People i don't know act surprized or startled when they see me
5. People people are nice to me
6. People don't know what to say to me
7. People i don't know say Hi to me
8. People laugh at me
9. People are relaxed around me
10. People feel sorry for me
11. People implicate with me (pick on me)
12. People I don't know smile at me in a friendly way
13. People don't know how to act around me
14. People turn around to look at me
15. People are kind to me
16. People bully me
17. Strangers are polite to me
18. People make fun of me
19. People I don't know stare at me
20. People treat me with respect
21. People seem embarrassed by my looks

Data Analysis

This data, along with socio-demographic profile

(like age, sex, marital status, educational status, monthly income, occupational status) and burn characteristics (like age when burnt, scared body parts, size of scar and visible area in public) was analysed using SPSS 27. All the qualitative variables were presented in the form of frequency and percentage tables and the quantitative variables as mean and standard deviations. Effect modifiers like age, gender, marital status, educational status, family income, occupational status, scarred body parts and visible scar area were controlled by stratification. Post stratification chi-square test was applied to see their effect in outcome. P-value equal to or less than 0.05 was taken as significant.

RESULTS

Of 64 scarred burn survivors, 16 (23.9 %) were male while 48 (71.6 %) were female (Table-I).

Variable	Frequency (Percentage)
Gender	
male	16 (23.9%)
female	48 (71.6%)
Marital Status	
Single	16 (23.9%)
Married	48 (71.6%)
Educational Status	
Not formally educated	49 (73.1%)
Primary education	12 (17.9%)
Secondary education	2 (3%)
Complete intermediate education	1 (1.5%)
Monthly Household Income (Rs)	
<10,000	41 (61.2%)
10,000-25,000	20 (29.9%)
26,000-50,000	2 (3%)
>50,000	1 (1.5%)

Table-I. Demographic profile

56(87.5%) of our 64 respondents reported to be stigmatized out of which 12(75%) males reported perceived stigmatization and so did 44(91.7%) females. 8(12.5%) out of total 64 respondents did not report being stigmatized. Regarding individual domains on PSQ, mean score of Absence of friendly behaviour was 2.58 ±0.64, Confused/ Staring behaviour was 3.15 ±0.57 and Hostile behaviour was 2.19 ± 0.72.

Age when burnt	Frequency (Percentage)
1-5yrs	12(17.9%)
6-12yrs	16(23.9%)
13-20yrs	20(29.9%)
21-30	12(17.9%)
31-40	4(6%)
Area visible in public	
face only	36(53.7%)
hands only	12(17.9%)
both	12(17.9%)
Size of scar (cm)	
5-10	52(77.6%)
>10	12(17.9%)
Total burn surface area	
<3	20(29.9%)
3-5	24(35.8%)
5-10	16(23.9%)
>10	4(6%)
Scarred body parts	
Face	32(47.8%)
Hands	12(17.95%)
Hands and face	20(29.9%)

Table-II. Burn characteristics

A statistically significant(p-value=0.00) relation was found between perceived social stigmatism and gender, marital status, educational status, scarred body parts, area visible in public and age when burnt.

DISCUSSION

People are more sensitive to exclusion, especially when it is based on unchangeable characteristics of one's look and function. Poor health outcomes have also been linked to perceived discrimination, which is comparable to social exclusion in terms of its nature and effects. Scar severity is a strong predictor of body image dissatisfaction in burn survivors who placed a high emphasis on looks. A study was conducted in burn center in Canada to explore the experiences and attitudes of burn survivors towards perceived stigma and social support.[12] The study found that burn survivors experienced various forms of stigma, such as being stared at or avoided by others, and that social support was essential in coping with the stigma. A systematic review was aimed to synthesize the findings of qualitative studies on perceived stigmatization in adult burn survivors.[13]

Variable	Stigmatized n (%)	Not Stigmatized n (%)	P-Value*
Gender			
Male Female	12(75) 44(91.7)	4(25) 4(8.3)	0.000
Marital status			
Single Married	16(100) 40(83.3)	0(0) 8(16.7)	0.000
Educational status			
not formally educated primary education secondary education completed intermediate education	41(83%) 12(100%) 2(100%) 1(100%)	8(16.3) 0(0) 0(0) 0(0)	0.000
scarred body parts			
Face Hands Face and hands	32(100%) 4(33.3%) 20(100%)	0(0) 8(66.7) 0(0)	0.000
size of scar(cm)			
5-10 >10	44(84.6) 12(100)	8(15.4) 0(0)	0.000
area visible in public			
Face Hands Both	36(100%) 8(66.7%) 12(100%)	0(0) 4(33.3) 0(0)	0.000
age when burnt			
1-5yrs 6-12yrs 13-20yrs 21-30 31-40	8(66.7%) 16(100%) 16(80%) 12 (100%) 4 (100%)	4(33.3) 0(0) 4(20.0) 0(0)	0.035

Table-III. Frequency of perceived stigmatization among burn survivors
***p-value calculated using chi square test.**

A total of 16 studies were included and found that burn survivors experienced various forms of stigma, such as being stared at, ridiculed, or avoided by others, and that this led to negative psychological outcomes such as depression, anxiety, and social isolation.

Another study, conducted in United States examined the relationship between perceived stigma, social support, and psychosocial outcomes in adults with burn injuries over time.[14] The results showed that perceived stigma was negatively associated with social support at all three time points. Additionally, participants who reported higher levels of perceived stigma also reported greater emotional distress and lower levels of quality of life. According to one study, the importance of appearance moderates the association between perceived scar severity and body image. Women who have had burns report feeling stigmatized more than males do, although the gender gap in burn survivors hasn't been as pronounced or as consistent across research as it is in the general population. Our study shows higher percentage of females 75% presenting with post burn visible scars as compared to 25% males.

A study conducted in Indian burn center also showed female predominance with 68.75% females and 31.25% males.[15,16] In this study most of the people belong to low socioeconomic group i.e., 68.8% this is in accordance with most of the studies conducted in Pakistan and India.[15-17] These results may be attributed to poverty, illiteracy and ignorance. 81.3% of the participants were not formally educated and 18.8% had received their primary education. This

low literacy level observed in this study might be due to the lack of awareness that increases the risk of accidents. Another factor may be the low treatment cost in public sector that's why low socioeconomic group prefers government hospitals. Greater TBSA, male sex, advancing age of burn, burn after entering school, and surviving ageing into adulthood were all linked to worse quality of life in a cohort of 50 significant pediatric burns. Female gender and social support are the strongest predictors and higher levels of education and higher socioeconomic status also are predictive.[18-20]

Most of the participants in my study belonged to the age group of 13-20 years (31.3%) when they got burnt followed by age group 6-12 years (25%). Burn survivors may benefit from interventions that address the stigma they face and promote social support. Our study suggests the need for more research to explore the experiences of burn survivors from diverse cultural and social backgrounds. Education and awareness can help reduce social stigmatization by increasing understanding and promotion empathy towards those with visible scars.

CONCLUSION

Majority of the patients with post burn visible scars face perceived stigmatism in their daily routine. Negative gestures, offensive remarks and hostile behaviour on the part of community are the common complains by these people. Social stigmatism was predominantly observed in age group of 26-35 years, married females, primary education, low household income and visible scars on face. Social stigmatism causes body image dissatisfaction that leads to depression and other psychological disorder. Health facilities should also focus on psychological rehabilitation so that when these patients come out of the hospital environment, they should be able to cope with the reactions of the society with their present appearance.

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3	Mehwish Riaz	Conception of idea, data entry, data analysis, manuscript writing.	
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