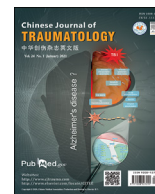




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## Original Article

## Perceptions and experiences of female burn survivors with facial disfigurement

Zainab Habib<sup>a,\*</sup>, Rukhsana Saddul<sup>b</sup>, Fatima Kamran<sup>a</sup><sup>a</sup> Institute of Applied Psychology, University of Punjab, Lahore, 54590, Pakistan<sup>b</sup> Government College for Women University, Sialkot, 51310, Pakistan

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## ABSTRACT

**Purpose:** This study aimed at exploring the perceptions and experiences of female burn survivors with facial disfigurement in Pakistan.**Methods:** Two different quantitative and qualitative studies were conducted, of which the data were collected from 100 burn patients. A pilot interview protocol was developed. An indepth interview of five female burn survivors with facial disfigurement was taken in Lahore, Pakistan. The transcripts were analyzed using thematic analysis and four major themes were identified, respectively physical appearance, posttraumatic growth, relationships and coping strategies.**Results:** Thematic analysis reflected differences in attributional style, perceptions and individual experiences of female burn survivors with facial disfigurement. The study showed the importance of physical appearance for different burn survivors and how their life had changed after suffering from a burn injury. **Conclusion:** It could be easy to have a positive outlook towards life and accept visible differences post injury for the burn survivors, who are grateful for life, get a strong family support and have available resources. On the contrary, with low self-esteem, lack of a family support and available resources, patients would be dissatisfied with their life.© 2020 Chinese Medical Association. Production and hosting by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## Introduction

Burn injury is a significant issue and yet ignored in Pakistan. In the assessment of the global studies of disease 2010 study in Pakistan, the injury rate of flame and high temperature substances is 5.8 per 100,000 populations. A facility-based study of burn injury from Karachi evaluated the death rate among adults between 15 and 55 years, which showed a considerably higher rate at 10.2 per 100,000 populations. Some risk factors with confirmation included: female, age over 50 years, fire burn, inhalation injury, and the damaged body surface area >40%. However, most of the existing knowledge regarding burn injuries in Pakistan is from single-center studies in specialized burn hospitals in major cities.<sup>1</sup> According to the data, it is difficult to estimate the true number of burn wounds of the general population. And because of only a few specialized burn centers, people know little about the epidemiology of burn injury, which results in an important knowledge gap in Pakistan.<sup>2</sup>

In one of the studies, the facial disfigurement of burns was portrayed as “the physical and psychological experience of a person whose face is scarred, blemished, or deformed due to burn injury”. For example, appearance change might be a change of the self-perception, not only of the age.<sup>3</sup> The social psychosocial incapacity is one of the main reasons to cause the stress of burn patients with facial disfigurement. They are exposed to visual and verbal assaults, invasion of privacy, pity and ridicule from others, all of which create patients’ sentiments of disgrace, barrenness, outrage and mortification. They feel insecure and have evasion behavior, in a condition of psychological misery. They are in significant trouble with social communication, particularly the first-time gathering.<sup>4</sup> A study of Vickery et al.<sup>5</sup> showed that the facial disfigurement due to burn injury additionally impacts the well-being of family members, who might develop psychological issues too.

A report of Acid Survivors Foundation (ASF) indicated that females have been most influenced by burn brutality in Pakistan. Between 2007 and 2016, around 56% of the 1375 casualties of burn assaults announced were females. Although the ASF affirms the information in the reports of burn brutality based on various nationwide sources, it is hard to distinguish the gender of the casualties because of absence of recognizable feature. There are 168

\* Corresponding author.

E-mail address: [zainabbokhari@gmail.com](mailto:zainabbokhari@gmail.com) (Z. Habib).

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such unfortunate casualties in a 10 year database of the ASF. Assuming that these unfortunate victims are all women, the actual number of women burn victims will be as high as around 68%.<sup>6</sup> In the 73 burn assaults in 2016, about 7 out of 10 unfortunate casualties were females. The information of ASF additionally demonstrates that transgender people are starting to be the target of arsonist. In 2016, a transgender individual was harmed in a burn assault in Pakistan. The ASF reports that between 2007 and 2016, most burn assaults occurred in Punjab, particularly South Punjab. Actually, in the information of ASF, the burn brutality in the South Punjab district is simply a tip of the iceberg. In spite of the decreased number of burn assaults in South Punjab reported by ASF in 2014, it is astounding that similar information demonstrates the assault number are rising step by step every year prior to 2015.<sup>6</sup>

**Methods**

Five burn patients with severe facial disfigurement from Lahore, Pakistan were included in the study (Table 1). The inclusion criteria were: (1) patients that underwent reconstruction surgeries or were in waiting list for reconstruction surgeries, (2) patients that were followed up on regular, (3) patients living in their own residence or shelter home, and (4) patients with partial or full-thickness burn. The exclusion criteria were: (1) patients above 50 years old, and (2) patients with physical disability, (3) severe psychiatric disturbed. A semi-structured interview was conducted with five female burn survivors with facial disfigurement to acquire their perceptions and experiences after burn injury on the quality of their life. Formal permission was obtained from the authorities of the selected organization in Lahore, in which the nature of the research study was thoroughly explained. The interviews were conducted on different days. Meanwhile the participant’s consent was taken, and the nature of the study was explained to them. Participants who fulfilled the inclusion criteria were then interviewed about the perceptions and experiences after burn injury with facial disfigurement. The participants were additionally probed for a better understanding of their current quality of their life. After completion of the interview, the patients were thanked for their cooperation.

**Results**

Thematic analysis was used to reflect the textual data, the aim of which is to analyze the experiences of the interviewees.<sup>7,8</sup> Transcripts were analyzed to identify similar themes in a text that appeared to be a particular meaning. Across the dataset, themes were compared for similarities and differences through interviews. The similar themes were placed into one category. The transcripts were re-read and checked to clarify sub themes so that the titles of different categories could reflect the experience. Four key themes after identified include: physical appearance, posttraumatic growth, relationships and coping strategies. The themes emerged in the transcripts are as follows.

**Table 1**  
Characteristics of the participants.

Case No.	Age (year)	Marital status	Education	Occupation	Monthly income (Rs.)	Cause of burn injury	Type of burn injury	Time of burn injury (year)
1.	23	Married	Nil	Hairstylist	10, 000	Acid attack	Chemical	6
2.	45	Widow	School level	Nil	–	Acid attack	Chemical	19
3.	25	Widow	FA	Trainee	15, 000	Incident	Gas	21
4.	19	Single	School level	Trainee	10, 000	Acid attack	Chemical	4
5.	29	Single	BA	Front desk officer	8, 000	Incident	Flame	22

FA: faculty of arts, BA: bachelors of arts.  
-: no data.

*Physical appearance*

The notion of physical appearance in the transcripts was to describe the importance of the appearance of burn survivors in their lives and how the appearance affected the quality of their life after the injury. Some patients’ life had taken great changes after burn injury as the injury has completely changed their face, and even they could not recognize their own face now. Facial disfigurement impacted their lives, and thus most of the patients feel worthless and useless. When going out for work or some other reasons, all of them almost covered their face with a veil to protect them from any kind of stigmatization. Some patients described that they had gone through reconstructive surgeries, which were helpful to have a better look and boost their confidence. A few of them mentioned that the society overvalue the appearance of people in Pakistan and the media, beauty products and cosmetic surgery set certain standards about the appearance.

Perceived stigmatization, self-perception and perception of others are some of the issues faced by the burn survivors. An acid burn survivor (case No. 1) was attacked by her husband 6 years ago. People still make fun of her face and sometimes they are scared after seeing her facial disfigurement. It shows the importance of the appearance and indicates perceived stigmatization of facial disfigurement after burn injury. Another acid burn survivor (case No. 4) who is single and suffered from burn injury 4 years ago. Before her injury, she had a happy life but now things have changed. She is a burn survivor and expressed an apprehension of her appearance because she lost one of the eyes and she is disfigured now. She had a stigma due to the facial disfigurement when she compares herself before and after burn injury. She feels uncomfortable and anxious while others stare at her because of facial disfigurement, which reminds her about the incident that happened to her.

The theme of physical appearance shows that facial disfigurement is an obstacle of interaction with other people for burn survivors. It also highlights how the survivors have been through it in the long run. Having strong curiosity of the reason of injury, blaming on the survivors unreasonably, and treating the survivors impolitely, all of them influenced the life of the survivors. Day by day, they become used to the perceptions and attitude of other people, try to ignore them and ultimately divert the attention to other aspects of life.

*Posttraumatic growth*

The burn survivors described different factors, which have aided in posttraumatic growth of survivors. Perception of others towards the facial disfigurement is a hindrance for many burn survivors in personal growth. The survivors also reported that they have changed in a positive way owing to the visible differences. Post-traumatic growth is a great challenge for these survivors as they are not only coping with the injury but also live with the visible differences at the same time. Becoming productive and resourceful

was of utmost importance to almost all the burn survivors. All those who are back to work have reported the remarkable difference in their lives after burn injury, which give the survivors a sense of achievement and satisfaction and closely improve the quality of life. Those people accepting the injury have shown gratitude and optimism to cope up with the injury, which is the way to express their feelings and emotions. The factors that influenced burn survivors' posttraumatic growth included: acceptance and gratitude.

A woman (case No. 3) who is a widow expressed her gratitude to the owner of the organization and her colleagues because they accepted her after the injury and helped her to move on with her life. This clearly indicates the importance of the positive influence of acceptance from others towards the burn survivors with facial disfigurement. Another woman (case No. 1) who is an acid burn survivor expressed the similar views. When people show their confidence and appreciation towards her, it makes her feel happy and satisfied. In addition to acceptance, another important factor to improve the quality of life is gratitude. Two of the burn survivors (case No. 3 and No. 5) expressed their gratitude towards God. Gratitude was much common found in those burn survivors, who are resourceful and are considered as a valued member of the society.

This theme sheds light on the various factors that are significant in posttraumatic growth. It is not easy for anyone to come out of a trauma as sensitive as a burn injury, but acceptance and gratitude played a key role in most of the cases and changed their attitude towards life in general. The optimistic approach helped them to overcome self-denial and the gratitude made them resilient.

### *Relationships*

The notion of relationships in the transcripts is the significance of the relationship in survivor's life and the influence in the quality of life. For most of the survivors, it is the support of their family to aid them in moving on and help them in adjusting well with injury. The relationships described here by burn survivors included; family support, bonding, care, financial support and future prospects.

An acid burn survivor (case No. 1) said that her family is very good towards her even after the burn injury. They did not make her feel any different, showed more affection towards her and took care of her, which had become her strength. In an interview of case No. 5, she said that her parents always stand by her side and give her strength and courage. Unfortunately, a woman (case No. 2) living with her brother had a good relationship with him before the injury, but now all things have changed for her. She used to earn money before the incident and she was also cared by all her siblings and her parents. Unfortunately no one supports her, even her siblings and relatives and she does not have any other resources.

This theme states the importance of relationships in the lives of burn survivors. Family support is one of the main contributing factors in their lives, which has a positive impact on the survivors. The acceptance and support of relatives influenced the survivors to rebuild the self-image and self-esteem.

### *Coping strategies*

Going through traumatic experience leaves an everlasting impact on people's life and the big challenge to adjust with it is the coping strategies. The foremost one was emotional coping strategy that was found common in all the transcripts. Emotional coping strategy helps them in venting out and makes them feel better. Another important coping strategy that emerged throughout the transcripts was religious coping strategies. Religion teaches people to be patient no matter what goes through in his/her life. Thereby, most of them kept going with their faith and having optimistic

approach towards life. Religion also teaches people to be content in any situation and most of the burn survivors followed the same notion. Despite of facial disfigurement, they exhibited a positive outlook towards life and were found to be content even after going through such pain and injury.

The coping strategies described by burn survivors regarding appearance included: emotional coping strategy, religious coping strategy.

In our study, three cases (case No. 1, 3 and 4) have the same situation of enduring the strong changes of emotion. An acid burn survivor (case No. 4) said that she should remain happy and should be strong, which the burn survivor could keep herself motivated. An important factor here is her family members who stood by her and she did not want to make them upset by crying or staying sad/depressed. Another woman (case No. 1) could not get it out of her mind and always thinks that why that happened to her. There is one case (case No. 3) who got injured because of the gas explosion, and she felt how different people had reacted to her after the burn injury. It was not easy for her to tolerate such attitude, but she dealt with situations in a much calmer manner and coped up well.

Religious coping strategy is to advice burn survivors accepting their injury and showing reliance on their religion. After undergoing four surgeries, the burn survivor (case No. 3) said that she tries to live in a good manner and prays to God. She showed her gratitude and satisfaction with life. A burn survivor (case No. 2) expressed that she asks God for the strength and courage.

It is found that emotional coping strategy is dominant in the coping strategies for burn survivors. Despite the burn injury, the burn survivors showed contentment and gratitude towards life and embraced the difficulties including stigmatizing behavior from others. The qualitative analysis reflects differences in perceptions and individual experiences of burn survivors with facial disfigurement. It shows the importance of physical appearance for individuals and how their life has changed after burn injury. The survivors who had a strong family support, enough resources and were full of gratitude could embrace their visible differences post burn injury and are satisfied with their lives. On the contrary, religious coping strategy can keep them moving on their lives.

### **Discussion**

The findings of the study show that the perception of burn survivors with facial disfigurement about quality of life is influenced by psychosocial factors and personal attributes. Self-perception, support system, financial stability, environmental factors, success of surgeries, life orientation, social comparison, gratitude and coping strategies are the factors which strongly influence the quality of life of survivors.

The research shows the manner treated by others, insecurities of the appearance, and different experiences of growing up and living have a great influence on the self-esteem, self-worth and overall perceptions of survivors.<sup>9</sup> The role of these factors is indeed significant for burn survivors in perceiving their life in general and further defining the quality of life. The current study highlights the same issues and aspects that play an important role in forming the perceptions of burn survivors with facial disfigurement regarding their quality of life. Those who go through a trauma like burn injury daily functioning is characterized by so many aspects. Treating them like others with a welcoming and understanding attitude has a significant impact on them. This instills new hope and optimism in them, and inspires them like everyone else to perform well in life.

Previous research also shows the experiences of people who think they have adjusted positively to a visible difference.<sup>10</sup> Inner strength and positivity, active coping techniques, downward social

comparisons, good daily functioning, spirituality and humor are the key factors to bring a positive difference in their lives. All these factors significantly bring a positive change in their lives, but social support turned out to be the most dominant one. Acceptance of burn injury by support system leads their lives to perceiving in a positive manner and a better satisfaction. The present study supports the findings of the importance of social support, in which the positive attitude of friends and relatives boosts the confidence of participants and helps them to have a better psychosocial adjustment.<sup>11</sup> Family support has always been a positive motivation for them to make a greater progress in life. Although sometimes they get depressed or anxious and feel worthless and low self-esteem, the strong support of family can uplift them significantly.

A research was carried out to investigate the interpersonal relationships, psychological effects, and coping strategies of female acid burn victims through in-depth interviews.<sup>12</sup> The sample comprised of 6 female acid burn victims in two Pakistan cities, Lahore and Jhelum. The research was carried out in two phases. The first phase was based on brainstorming sessions and development of interview guideline. The second phase was based on the interview results with all acid burn victims. Mean age of the samples was 32.6 years. Ten themes were emerged through thematic analysis, including effects of acid attacks on family relations, attitudes of extended family, role of friends, causes of attacks, psychological effects, physical effects, facial disfigurement and body image, people's attitudes towards victims, reactions of victims towards unpleasant concern, and coping strategies.

Javed et al.<sup>13</sup> investigated the effect of education on quality of life and well-being. The samples consisted of hundred educated Muslim housewives and a hundred uneducated ones. In order to collect the data, a snowball sampling technique was used. Quality of life was assessed by using the WHOQOL-BREF and well-being scale was used to assess various well-being dimensions in both the groups. The results showed significant difference between educated and uneducated Muslim women on various dimensions of quality life and well-being.

Bellie et al.<sup>14</sup> examined the posttraumatic growth and social support, coping strategies, dispositional optimism, functioning, post-traumatic stress symptoms, severity and time of burn. The sample included 74 participants, which were from regional burn units. A battery of self-report questionnaires was administered on them. It was found that they experience posttraumatic growth (mean = 1.26, range = 0–4.67). Severity burn, post-burn function and trauma symptoms significantly correlated with posttraumatic growth. Regression analysis proposed a model to explain 51.7% of the variance, with active coping strategies, social support and avoidance coping strategies as significant predictors of post-traumatic growth.

Most of the studies based on burn injury tend to focus on the psycho-social factors associated with post burn injury. However, there is a need to gain an in-depth understanding of the perceptions and experiences of female burn survivors with facial disfigurement by using a qualitative approach, which include their emotions, feelings, behaviors, discrimination from others, coping strategies, resilience, support system, daily life, relationship with others, attitude towards self, and so on. This can aid in exploring the most important aspects of facial disfigurement after burn injury that leads to physical and psychological changes of burn survivors, which results in defining orientation of their life. Thus, this can be instrumental in providing new researches which are mostly not only focused in quantitative research but an understanding of posttraumatic growth after burn injury.<sup>15</sup>

It can be concluded that the process of acceptance, post-traumatic growth and adjustment of burn survivors with facial

disfigurement have an impact on their family life, social environment, personality type and belief. Thus, there is a need to focus more on the curative plan for burn survivors to aid them in overcoming the issues after injury and developing the coping strategies.

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## Ethical statement

The study was approved by the Departmental Doctoral Program Committee of the Institute of Applied Psychology, University of the Punjab, Lahore (No.D/91/IAP) that also serves as a Research Ethical Committee/Review Board of the Institute of Psychology, University of the Punjab, Lahore. A written informed consent was obtained from all the participants before the interview.

## Declaration of competing interest

The authors declare no conflicts of interest.

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