The main concern of burn survivors in Iran

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ABSTRACT

Background: The present work was conducted to study the burn patients’ experiences to get an insight into their main concerns when they suffer the tragic event, recover from it, and adjust back in the society, so that better rehabilitation programs can be planned corresponding to their needs as well as to the needs of the society and the existing situations.

Materials and Methods: In this qualitative study, 17 burn survivors were enrolled. Unstructured interviews were used for data collection. All the interviews were recorded, transcribed, and analyzed using qualitative content analysis method.

Results: Based on the existing elements of the explicit textual meanings, two categories of threat and disturbance were formed. The category of “threat” was extracted from the following five subcategories: (a) Threat to physical life; (b) threat to the process of living; (c) psychological threat; (d) spiritual threat; and (e) social threat. The category of “disturbance” was extracted from the following three subcategories: (a) Sensory disturbance: Suffering pain; (b) self-concept disturbance; and (c) behavioral disturbance.

Conclusions: Burn survivors experience severe pain, enduring and suffering in their daily activities after burn. Passing through these difficult trajectories is perceived as a threat and disturbance in self-integrity.

Key words: Burn, Iran, qualitative research, survivors

INTRODUCTION

Burns are one of the commonly encountered and major health problems all over the world, especially in developing countries.[1] Surveillance of injuries in Iran has shown that burns are the most common cause of unintentional home-related injuries, accounting for 40% of those injuries in all ages.[2] According to result of a survey conducted in Iran, 12% of all deaths in all ages are due to unintentional injuries and burns are the second most common cause of injury-related deaths after road traffic accidents.[3] Also, another study conducted in Iran showed that burns are the 13th most frequent cause of the burden of disease in the country.[4]

Psychological and physical disorders including scars, contractures, and amputation are frequent consequences of burns;[1] as a result, burn is one of the most costly damages from the economical point of view as well. Needless to say, the damages from long-term physical ability loss or psychological impairment or beauty deformities are beyond any estimation[5] and give rise to a formidable challenge for Iranian health system in terms of treatment and rehabilitation.[6]

In Iran, researches on the psychiatry symptoms of burn survivors show that most of these people suffer from major depression and anxiety.[7] Also, another study showed that their quality of life is unfavorable.[8] So, burn survivors in Iran have many challenges with regard to physical integration, connecting to the life stream,

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How to cite: Zamanzadeh V, Valizadeh L, Lotfi M, Salehi F, Khalili A. The main concern of burn survivors in Iran. Iranian J Nursing Midwifery Res 2016;21:410-6.
and returning to the self during coming back to life.\textsuperscript{[9]}

In addition, people’s negative thoughts and behaviors provide the grounds for difficulties in burn survivors in Iran.\textsuperscript{[10]}

Numerous studies have investigated the effects of the complications on physical performance and vital power of the body and the ensuing physical, emotional, social, professional, and economical\textsuperscript{[11]} consequences imposed on the patients; however, they say little concerning the description of the burn experience as an important factor in understanding the patient in an attempt to reduce the agony and suffering which they go through.\textsuperscript{[12]}

Qualitative studies conducted in the past 30 years,\textsuperscript{[13,14]} however useful they may have been, have not really provided a clear comprehensive account of the true nature of the patients’ worries.

The paucity of qualitative research in the field in Iran,\textsuperscript{[10,15]} in addition to the religious and cultural contexts peculiar to the country\textsuperscript{[15]} make it imperative that we look for the true concerns and worries of the burn victims.

The present study was conducted to know the burn patients’ experiences in order to learn about their main worries and concerns in going through the tragic event and in the process of returning back to society.

\textbf{Materials and Methods}

The present study is a qualitative research study that was conducted using qualitative content analysis in order to determine the meanings and themes related to key consequences of returning to life through in-depth unstructured interviews administered to burn survivors. After obtaining the permission and approval of Ethics Committee of Tabriz University of Medical Sciences (number 7199), purposeful sampling was used in order to fulfill the purpose of the study. The logic of this method allows to extract all the regular patterns obtained from different individuals for the best understanding of the intended phenomenon.\textsuperscript{[9]} All burn patients older than 15 years who had been discharged from the burn ward also 6 month have been passed from their burn accident were used for the purpose of this study which was conducted in 2012 and 2013. Those who were willing to participate in the study after being ensured that their information will be kept confidential were selected for the study. Then, based on the effective factors on burn patients’ experience, 15 participants were included in the study in order to achieve maximum variety in the participants with regard to gender, age, job, education, the kind, percent, and severity of burn, the interval after the burn, and also their willingness to participate in the study. The sample size was determined with data saturation when the researcher realized that no new data could be added in relation to the research question in the codes, subcategories, and categories. Through the process of constant comparison, it was observed that no new data that cause a change in the formed categories or the characteristics of the existing categories will be added to the study.\textsuperscript{[9]} First, unstructured interviews, and then, semi-structured interviews were used for data collection. For instance, open-ended questions were used during the interview with regard to the purpose of the study [Table 1].

All the interviews were conducted in the researcher’s office, patient’s house, or hospital with the consent of the participants. The length of each interview was between 45 and 120 min on average. Each interview was recorded and then transcribed. Only in two cases, the interviews were conducted again. Constant comparison method and written reminders during simultaneous analysis and data collection determined the variety of participants. Each interview was checked several times for complete understanding. Each interview was considered as an analysis unit,\textsuperscript{[16]} and explicit and latent means of each words and sentences were extracted. Various codes were compared with each other based on the similarities and differences and then the categories and subcategories were formed based on congruence of the content [Table 2].\textsuperscript{[17]} The credibility of the study was confirmed with long involvement of the participants in the study and checking the results by the members. The dependability of the study was achieved by involving more than one researcher in the data analyses separately and comparing the agreement between the analyses of results by the author and the external researchers. In addition, the conformability of the study was ensured by oral description of steps of the study by investigating the raw data, data reduction, combination and reconstruction of data using audit trial, and finally, the transferability of the study was ensured by describing various demographic information and external checking using patients who have had similar experiences.

\textbf{Ethical considerations}

The study was approved by the ethic committee at the Tabriz University of Medical Sciences and written informed consent was obtained from each participant. A letter providing information about the study and the rights of participants was distributed to the participants. Participants were told that they were free to accept or reject participation in the research.

\textbf{Table 1: An instance of open-ended questions during the interviews with the participants}

| Question                                                                 |
|--------------------------------------------------------------------------|
| Could you tell us about your emotions and experiences after burn?        |
| How did you get along with the conditions after the burn?                |
| What changes did the accident bring about in you and your life?          |
| How did the accident affect your concept of yourself?                    |
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Table 2: Examples of meaning units, condensed meaning units, codes, subcategories, categories

| Meaning units                                                                 | Condensed meaning units         | Codes               | Subcategories             | Categories    |
|------------------------------------------------------------------------------|---------------------------------|---------------------|---------------------------|---------------|
| “I missed everybody, but I didn’t feel so, when I got back home”            | Tendency to go back home        | Ambivalences        | Psychological threat       | Threat        |
| “I was worried about my parents, it was difficult for me, that bothered me more than my physical pain” | Non-physical pain related to anxiety |                      |                           |               |
| “I asked God why I’m here, why it all happened to me, is it justice?”        | Traveling inside and asking God the reasons of their problems | Feeling conflict with God | Spiritual threat |               |

Table 3: General characteristics of participants of the study (P17)

| Age (years), frequency | Sex, frequency | Education, frequency | Marital status, frequency | Economic situation, frequency | Occupation, frequency | TBSA, % | Cause, frequency | Agent, frequency | Time after accident (years) |
|------------------------|----------------|----------------------|---------------------------|------------------------------|-----------------------|---------|-----------------|-------------------|--------------------------|
| Range=39               | Female=9       | Master’s degree=1    | Divorced=3                | Well=7                       | Teacher=1             | Range=44 | Deliberate=3    | Oil fire=3        | R=29.5                   |
| Mean=37.47             | Male=8         | Elementary=4         | Married=6                 | Medium=9                     | Housekeeper=7         | Mean=27.47| Accidental=14   | Thermal=1         | Mean=7.47                 |
| SD=13.37               |                | Diploma=7            | Single=7                  |                              | Retired=1             | SD=12.9  | Private=4       | Electricity=7     | SD=8.36                  |
|                        |                | High school=3        |                            |                              | Worker=2              |                       |                 | Flame=5          |                           |
|                        |                | Guidance school=1    |                            |                              | Employee=2            |                       |                 |                  |                           |
|                        |                | Associate degree=1    |                            |                              |                       |                       |                 |                  |                           |

TBSA: Total body surface area

RESULTS

Table 3 shows the characteristics of participants. During qualitative content analyses, two categories, (a) threat and (b) disturbance, were formed from the data [Figure 1]. Details of the subcategories and categories are as follows.

Threat

The category of “threat” was extracted from the following five subcategories: (a) Threat to physical life; (b) threat to the process of living; (c) psychological threat; (d) spiritual threat; and (e) social threat.

Threat to physical life

The burn experience was, in the first phase, an unpredictable, fast, and horrifying threat to the physical life, which resulted in people showing involuntary physiological response.

At this terrifying stage, because of the unpredictable nature of the accident, the victims fail to take any conscious, calculated action, and the people around have to take quick psychomotor actions to save the person’s life.

“I was struck mute for fear, my feet went numb and I could not escape. Everything happened in the space of a few minutes.” (P1)

On the other hand, unpleasant experience of being transported to hospital, hospitalization, intolerable pain and gloomy environment all lead to a fear, anxiety, and suffering which cannot be stopped for years.

Threat to the process of living

Most of the participants believed that going back home and facing new changes and understanding the reality of changing the process of life had their relief at being discharged from the hospital turn into despair and disappointment, leading to their reappraisal of the concept of recovery.
“Having come back home, I thought I’d get better and become like others, but very much to my despair, I found out the real difficulties were yet to come after that.” (P7)

“I could not do anything, I could not go anywhere, and life was very hard for me.” (P5)

Psychological threat
After getting back to normal life and accompanied by the family, while the physical pain had considerably subsided as a result of partial healing of the wounds, the participants seemed to have found an opportunity to focus on what they had been through and why and how it happened, thereby bombarding themselves with torrents of disturbing thoughts and feelings, and failing to enjoy living and letting negative thoughts and emotions dominate and jeopardize their psycho-spiritual equilibrium. With regard to this point, the participants recalled:

“After physical pains subside, well other sort of pains force their ways into your mind.” (P1)

“I jumped out of bed at night; I thought I would burn again. I was always anxious.” (P9)

Spiritual threat
The incessant psychological pressure on the burn victims in the course of new life, markedly different from the one prior to burns, and the harsh conditions of the new life caused them to feel so desperate and helpless that they began to doubt the existence of God or His mercy.

“When I looked at myself, I thought, at first, that there was no God.” (P9)

Social threat
The accounts of the participants’ experiences regarding interaction with others and their social appearances indicated that social threat began in them in minor degrees of isolation at home and continued through receiving upsetting reactions from others and failing in social interactions, finally manifesting as comparing oneself with others and feeling retarded in the society.

“… I felt so embarrassed everyone was asking me what had happened to my face. It always upset me when I was being asked about it. They would always say, ‘Oh! How badly it’s burnt’.” (P7)

“I left school and got myself to the public.”(P4)

Disturbance
The category of “disturbance” was extracted from the following three subcategories: (a) Sensory disturbance: Suffering pain; (b) self-concept disturbance; and (c) behavioral disturbance.

Sensory disturbance: Suffering pain
Effects on the body’s important organs and the experience of unpleasant sensory perceptions resulting from them, including severe pain, seeing one’s own as well as other patients’ wounds, bad taste of the food, and the peculiar smell of the hospital, breeding experiences of fear and anxiety, and feeling upset, lonely, gloomy, and worried or, in other words, cause sensory disturbance or suffering in the participant.

“The dressing caused horrible pain. Even painkillers were not effective.” (P8)

“… it was all pain…, spending two long months in the hospital not being able to see anything or anywhere … it was all agony.” (P5)

Self-concept disturbance
The psycho-spiritual threats to the participants, on the one hand, and having longer time, on the other hand, to ponder over emotions like insecurity, nonphysical pains, feeling disgusted with others, feeling depressed and fed up with life, feeling not safe, guilty, and unnatural, becoming a different person, feeling ambivalent, feeling miserable and wretched, having an uncertain future, and not going back to the previous life lead to disturbances in the identity and self-concept of the participants.

“You manage to get along with it, but you are no longer the same person you used to be.” (P4)

Behavioral disturbance
The initial stage of sensory and perceptual disturbance, the changes in self-concept, and failing in social interaction had led to behavioral disturbance manifested in the form of unusual behavior.

“I tore up my photos, broke up with my friends, cried and sobbed and screamed. I did not associate with anyone. I said I would kill myself.” (P6)

Discussion
The burn incident is considered to be a terrifying and potentially threatening experience by most people.[18] Based on the findings of the initial stage of physical threat, it was evident that the unpredictable and fast burn[9,19] incidence had commonly led to the injured person’s involuntary psychomotor responses such as screaming, asking for help, and escaping, and also the psychomotor responses of the people around for saving the injured
person’s life and taking him/her to hospital. The clinical studies indicate that significant acute inflammatory burn responses occur due to the release of certain chemicals in the blood in the acute stage as soon as the burn damage is inflicted.\textsuperscript{[20]} The general disorders in the immune system and the resulting shake as a subconscious experience are considered important factors threatening physical life in the early hours and days.\textsuperscript{[21]} The continuation of the physical threat and the excruciating and intolerable pain from the wounds are conscious experiences of the participants’ pain and sufferings in the hospital, which are sort of experiences inseparable from burn.\textsuperscript{[22]} Viazzoli remarks that the patients afflicted with severe burns, at least in the early days of being admitted to hospital, will have to come face to face with destructive and disappointing reality of having to depend on others for their needs.\textsuperscript{[19]}

Esfahlan \textit{et al}. indicated that the severe pain experiences had a significant relationship with emotional reactions such as anxiety, fatigue, loss of appetite, feeling helpless, and acute stress disorder during stay at the hospital.\textsuperscript{[22]}

Being discharged from the hospital and freed from physical threats and sensory disturbance inspired the participants with hopes of recovery and going back to previous life. This, however, did not last long and turned into disturbance in perception and self-concept upon returning home and facing new changes and understanding the fact that the whole life trend is being threatened.\textsuperscript{[23]} The participants might also experience feelings of loss and sadness resulting from the new changes in life, identity, and capabilities.\textsuperscript{[23]}

Studies indicate that the effects of pain are not limited to the time of being hospitalized, rather the memory of physical pain of the period leads to perceptual disturbances as one of the threatening psycho-spiritual factors, and can be observed for a long time as depression\textsuperscript{[24]} posttraumatic syndrome,\textsuperscript{[25]} and poor adaptation.\textsuperscript{[26]}

As the pain lessens with the skin graft, the participants’ focus is shifted from physical pain to spiritual suffering. They get more chance and opportunity to ponder over the effects of burn on their lives.\textsuperscript{[27]} Some researchers have referred to the experience of inner dialog or, in other words, ‘the patients’ dialogs in the head which helped them to be patient.\textsuperscript{[28]}

Hopelessness and doubts regarding God’s favor and kindness apparent in such inner dialogs jeopardized the spirituality of these people. Nonetheless, studies show that most people had been able to overcome despair and hopelessness by receiving others’ support and through their beliefs regarding God’s power.\textsuperscript{[29]} Earlier studies have indicated that whenever they talked about what helped them adapt, the burn patients repeatedly talked of God or their religious beliefs.\textsuperscript{[30]}

Going back into the company of others and gradually into society while the burn victims are still harboring the experience of disturbance in self-concept and perception and being in an atmosphere fraught with social threats lead to psychomotor disturbance.

Studies in this area indicate that the problem of adapting to others’ conduct in social situations is among the social challenges these patients have to meet, and it can result in the prevention and deterioration of their social skills.\textsuperscript{[31]} Among people with deformed appearance, over half of them, were highly suffered from anxiety in the social interactions,\textsuperscript{[32]} over half of whom have had a long and chronic experience of social pressure.\textsuperscript{[33]} Such effects eventually lead to shyness, social anxiety, and embarrassment\textsuperscript{[34]} which followed by poor social skills, and negative thought about self-concept.\textsuperscript{[35]} All of this problem collectively form the defective cycle of social performance and dissatisfaction with life.\textsuperscript{[31]}

In this study, the main concern in the people with burns manifested itself in the form of experiencing threats and disturbances mentioned above. A good number of studies point to the fact that destructive nature of burn affects a lot of significant aspects of the afflicted people’s lives, including their outward beauty relationship with others and physical and social functions.\textsuperscript{[36]}

Despite the scant theories capable of explaining this kind of human response to such damages, Morse \textit{et al}. in a grounded theory, determined a four-stage process including vigilance, disruption, enduring the self, and striving to regain self. Disruption, in this theory, occurs when the pain becomes overwhelming, and physiologic shock and drug move the patients to a “shattered reality.”

In the above theory, disruption experience is limited only to the acute physical condition. While, in fact, the gradual trend of self-disruption based on the participants’ experiences in this study, and its multidimensionality, indicates that disruption could arise in any stage of the threat, with respect to any of the disturbances, even in the people who have had a quick and perfect pace of recovery.

In this study, we tied to explain of properties of both burn threats and disturbances concepts.
CONCLUSION

Burn survivors experience severe pain, enduring and suffering in their daily activities after burn. Passing through these difficulties which received as threat and perceived as disturbance in self-integrity, these concepts presented in this study can be used to design rehabilitation and palliative care models in compliance with the existing cultural context in Iran. Further research is needed to know how an individual response to threats and disturbances in life after burn.

Acknowledgement

The authors thank the burn survivors who participated in the study and so generously shared their experiences with us. This study was supported by The Research Council of Tabriz University of Medical Sciences. This article is based on a part of the first author’s doctoral dissertation from Tabriz University of Medical Sciences.

Financial support and sponsorship

The Research Council of Tabriz University of Medical Sciences.

Conflicts of interest

There are no conflicts of interest.

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