

## Burn Survivors' Experience of Core Outcomes during Return to Life: a Qualitative Study

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### ABSTRACT

**Introduction:** Burn is one of the main and common health problems that face the victims with significant challenges in their lives. The main purpose of caring and rehabilitating these people is returning them to their previous life situation. Thus, the present study was conducted with the purpose of determining the experience of burn survivors with regard to returning to life in order to be able to obtain new concepts of acceptable implications in the present cultural and religious context.

**Methods:** The present study is a qualitative study that was conducted using qualitative content analysis and in-depth unstructured interviews with 15 burn survivors in 2012 and 2013 in Tabriz.

**Results:** During the process of qualitative analysis, the content of the category "balance", as the core essence of the experience of participants, was extracted according to three sub-categories: a- the physical integration (physiological stability, saving the affected limb), b-connecting to the life stream (self-care, getting accustomed, normalization), and c- return to the existence (sense of inner satisfaction and excellence).

**Conclusion:** The results of this study confirmed the physical, psychological and social scales introduced by other studies. Also proposed the concept "return to the existence", that can be measured by the emergence of a sense of inner satisfaction and excellence in the individual, as one of the key and determinant scales in returning the victims of burn to life.

## Introduction

Burn is one of the main and common health problems in the world<sup>1</sup> and Iran.<sup>2</sup> The victims of burn events face several physical, psychological and social problems that challenge their return to life.<sup>3</sup> Thus, the main purpose of rehabilitation in these people is returning them to their previous life situation.<sup>4</sup>

In this regard, consequences are considered one of the determinant scales for the pursuit of caring and rehabilitating programs.<sup>5</sup> Measuring consequences provide the ability of providing care standards in a service system, caring and comparing the use of these services at national and international

levels, interpreting investigations and audits for quality improvement and cost effectiveness of goals, and facilitating patient review and clinical management.<sup>3</sup>

There are few studies done on measuring consequences in burn care.<sup>5,6</sup> On the other hand, unique conditions of burn patients such as the wide range of burn injuries, multiple impacts on the lives and the influence of contextual factors on the long-term adjustment have made these patients highly heterogeneous.<sup>7,8</sup> This heterogeneity has impeded the investigation of consequences as a scale for determining the return of victims of burn to life.<sup>9</sup>

Previous studies showed that many factors outside the control of burn health care centers

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such as intrinsic motivation, family support, and social and economic backgrounds have an effect on burn consequences and return of victims back into society.<sup>1</sup> Culture, education, social status, job experience and family dynamics play significant roles in the ability of the patient to recover and return to a productive life, thus, the return of burn patients to life is complex and multi-factorial.<sup>9</sup>

Today, conducting studies in terms of period and quality of improvement of these individuals has become more important due to the high number of survivors from severe burns.<sup>8</sup> In particular, during the last few years, much debate can be observed in related literature on the issue of measuring burn consequences as a index for the investigation of their return to normal life. However, the findings are few in this regard<sup>10</sup> and most quantitative studies do not present a perspective on describing the experiences of burn victims.<sup>11</sup> In addition, despite various studies in burn centers.<sup>12</sup> and international discourse on measuring consequences in these people, clinical guide and measurement tools are still discussed. This shows that there is no clinical and scientific consensus in relation to the type of outcome, evaluation method and choosing the best measurement method in various phases of recovery process among the burn associations.<sup>13</sup> Therefore, in order to modify these scales for broadening the variety of problems that burn survivors experience, more studies are required.<sup>14</sup> The researchers also believe that factors before burn have a significant effect on the life after burn which is necessary for the precise interpretation of obtained clinical consequences, while not attending to this point in the existing scales has reduced the efficiency of these index.<sup>15</sup>

On the other hand, according to the presented definitions of health, in order to return burn survivors to the society, the minds, emotions and spirits of these people should be attended to in addition to their physical health so that the individual can

have the best possible condition in life.<sup>16</sup> This is always a hard situation for the individual which also depends on the person's physical and mental strength and adaptability to cope with the environment<sup>17</sup> thus, more understanding of the behavior and processes should be obtained in programs of rehabilitation and returning of the patients to life.<sup>18</sup>

As we discussed before, burn survivors, experiences has an effective role in determining the indexes of returning to life in care and rehabilitation programs. So according to the limitations in qualitative and quantitative studies in this regard<sup>5</sup>, and also the effect of cultural and religious context on these indexes<sup>19</sup>, this study was conducted with the purpose of determining the experience of burn survivors. It is expected that according to the results of this study we can obtain new concepts of acceptable implications for returning to the life in such people.

## 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 in in-depth unstructured interviews administered to burn survivors. After obtaining the permission and approval from Ethics Committee of Tabriz University of Medical Sciences, 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.<sup>20</sup> In order for the initial access to the participants, the list of all burn patients older than 15 years who have discharged from burn sections of Sina Teaching Health Center in Tabriz, and 6 months have passed from their burning, were used for the purpose of this study that was conducted in 2012 and 2013. Those who were

willing to participate in the study were selected after being ensured that their information will be kept confidential. Then, regarding the effective factors on burn patient's 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 type, percent and severity of burn, the interval after the burn.

The sample size was determined with data saturation when the researcher realized that no new data will be added in relation to the research question in the codes, sub-categories 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.<sup>20,21</sup> 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 office, patient's house, or hospital with the consent of the participants. The length of each interview was between 45 to 120 minutes 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 determined as analysis unit<sup>22</sup> and each word, sentence, or paragraph was considered as meaning unit with regard to explicit and hidden content and its summarized conceptual elements were tagged. Various codes were compared with each other based on the similarities and differences and then the categories and sub-categories were formed based on congruence of the content.<sup>20</sup> 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 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. Finally, the transferability of the study was ensured by describing various demographic information and external checking using patients who have had similar experiences.

## Results

During qualitative content analyses three determinant consequences in returning to life was extracted from the data: a- the physical integration, b- connecting to the life stream, and c- return to the self. More categories and details are shown in figure 1.

### *Physical Integration*

The results of this study showed that the first phase of return was conducted through achieving physiological stability and saving the affected limb and its consequence was physical integration.

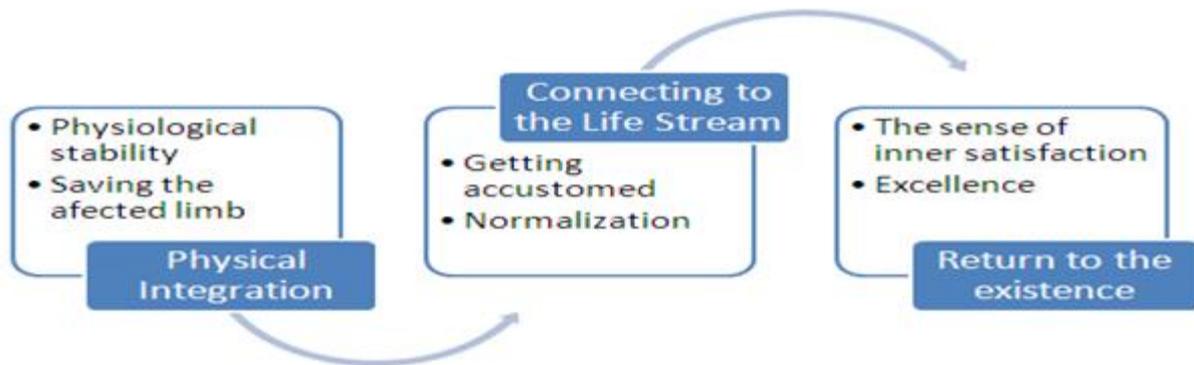
### *Physiological Stability*

Burn experience, depending on the severity of burn, is a terrible, fast and unpredictable threat for the physical life in the first phase that faced the participants with unintentional and physiological responses. In order for the participants to return to physical health in this phase, they survived by physiological and internal conscious and unconscious responses.

Physiological stability generally starts with saving from the event, putting out the fire, removing the individual from the scene and transporting him to the hospital by others and continues with the efforts of the doctors and nurses for keeping vital organs and hemodynamic stability in the hospital.

**Table 1.** An instance of open ended questions during the interviews with the participants

1. Express your experiences and emotions with regard to returning to life again.
2. What changes occurred in you and your life?
3. What positive and negative consequences have burn caused in your life?
4. When and how did you feel that you have returned to life?



**Figure 1.** Core outcomes during return to life

"Flames of fire reached me, my hands and face burned, I ran while I was only crying: "I am burned". Then, I don't know how they put out the fire (P 6)".

After transporting the patient to hospital, treatment of systemic symptoms caused by burn such as preventing shock and bleeding and keeping the balance of the internal environment of the body including water, electrolyte, and preventing infection were among the treatment and care programs in the hospital.

*Saving the Affected Limb*

Following the relative balance in physiological performance and vital organs, various operations were conducted such as debridement, graft and also restoration of shrinkage joints. Following medication orders, bath and daily dressing, help with feeding, excretion, reducing pain and maintaining comfort and physiotherapy of the limbs are among the care program in

specialized burn centers. Saving the affected limb was done with the efforts of the treatment team for healing the wounds, returning limb functions and helping them do daily activities in the length of stay in hospital and then with the help of family at home.

The experience of most participants in the study showed that for all of them, pain was one of the disruptive factors, and due to the movement limitation caused by it, one of the most important barriers of return of limb normal movement was self-care and thus dependence on others. With the wound closure, the pain severity noticeably decreases, but with the increase in the width and depth of burn, performing roles and self-care are still the main problems of the participants. In this phase, the importance of the strength of the individual and the role of family are undeniable for returning limb functions to the individual.

"At first, I couldn't even take fruit to my mouth with a fork. My older sister fed me. The whole family had a division of labor. Each person was responsible for a set of actions. For example, my second sister who stayed with me in the hospital helped me with exercising my limbs (P1)".

*Connecting to the life stream*

The findings of the present study showed that with discharging from hospital and going home, the participants enter the life stream through the process of getting accustomed, and continue life through the process of normalization. These two concepts formed the category "connecting to the life stream".

*Getting Accustomed*

For most participants of entering the life stream experience, returning to life was not before burn, but was considered a beginning for joining a new stream of life. In fact, characteristics such as tolerance and patience, the relative improvement of wounds, removal of physical pain on the one hand, and trying to be social by hiding the scars, doing daily activities and resuming previous roles on the other hand satisfied them for a new life. In this way, they gradually move from hopelessness towards hopefulness in the future and connecting to a new stream of life in light of self-confidence and striving to achieve goals. The role of family support was very important against psychological and spiritual threats caused by feeling lack of balance in life and achieving hope.

According to the findings, the main characteristic of this concept is getting accustomed, that formed with the passage of time and frequent confrontations with life limitations after burn. Obtaining information, having the intention of improving their situation in life, achieving independence and willingness to strive for further growth were among other important features of this concept.

"After the physical pain decreased a little, other pains came to me, but, the people

around me had significant roles, for example assume if I had no one to support me, look after me, support me emotionally, I might have been unable to cope with this much suffering (P1)".

"Well, hope is also so much important; my family, teachers and especially friends helped me very much (P5)".

With the entrance of the participants to society, the necessity of social life makes the person make a mental effort for another dimension of return, i.e., returning to the society. This effort is made through activities such as covering the scars or cosmetic surgeries for preventing deformities, physical limitations and ease at interacting with others. Covering the deformities, the participants gradually participate in the society and after facing other people's reactions, they get accustomed to their new life situation.

"When I faced people, and they were seeing me for the first time, they asked me about the scars, but the second time they didn't ask anymore; in fact the repetition of observations made it normal for the others; and I also gradually got accustomed to it (P8)".

"I had a bad feeling. Every one watched me in a strange way. Seeing my own face was difficult for me at first. When I was somewhere, I would cover my face with a scarf or something, then I covered only some parts, gradually, I got accustomed to it and went out without the covers (P5)".

*Normalization*

With the passage of more time, the remaining deformities were less important to the participants and being among people was less upsetting and thus other people's reactions gradually became normal for them. With the normalization of new conditions, they did not try to cover the scars anymore.

In this phase, having financial capability for continuing life and succeeding in light of efforts to improve the conditions of life after the burn was enough for accepting the new life. They tried less to change the situation

they have got accustomed to. The motivation to return to previous physical appearance or to have a special emotional communication such as marriage was less, and this gradually imposed the feeling of dailiness to them. This feeling was the distinctive feature of normalization concept. Not feeling upset among others, attending less to burn scars, and trying less for covering scars or consenting to cosmetic surgeries are among the important features of normalization. This way, the stream of life shifts from getting accustomed (awareness and trying to get better) to normalization (accept and satisfying to the new situation).

"I kind of became carefree. I trust in God, I am pleased to whatever God wants (P9)." In this situation, the participants felt less upset from being in the society and the scars were less pesky. Thus, cosmetic surgeries were observed less.

"Many tell me that LASER surgeries have developed very much. But, other things, other than my appearance, are my priorities. It is not at all important to me. I don't know. Thinking of other developments was more important for me than beauty. Now, I want to be with my father and look after him (P1)".

#### *Return to the existence*

Two sub-categories, i.e., a sense of inner satisfaction and excellence formed the category "return to the existence". The main feature of this category was the quality of self-perception in life after burn according to which the participants assumed themselves in a spectrum of losing themselves to finding themselves.

#### *The Sense of Inner Satisfaction*

Characteristics like life satisfaction, sense of adequacy in life, focusing on life achievements, thanksgiving, and self-confidence with a spectrum of non-satisfied to full satisfaction are features of this sub-category.

The findings of the study showed that freedom from the painful and agonizing period of burn and entering the normal life

enter the victims to a phase of thinking about their future and their lives, and this is the basic idea for forming self-perception.

"You can never forget those memories, but with the passage of time and when you see you are ahead of the others, these are helpful (P1)." I think God has given me another opportunity, thank God, I have no problem, and I am satisfied with my life (P8)".

"Burning took everything from me. Nothing became as I wanted, I am depressed now, and I am obsessed with complexes (P6)".

"There are situations when you are alone and can think about your life. Unfortunately, I have had many difficulties and agonies in my life; now, instead of advancing, I see that today is worse than yesterday, and yesterday was worse than the day before yesterday, and tomorrow will be worse than today... (P9)".

#### *Excellence*

The concept of excellence was extracted based on characteristics such as putting others on the priority, effort for reducing others' agonies, positive use of the experience of agony, a closer connection with God, being after more excellent goals, focusing on the things we have other than we lack, and a sense of understanding the patients more, especially the burn patients. This concept emerged in a spectrum of cognitive, perceptive and philosophical excellence with a low to high range.

In this regard, the participants expressed some experiences that indicated evaluation and judgment on their quality of life and the amount of goals, wishes, and tendencies or expectations they have achieved. These experiences were achieved when the new life was normal for them or when they had the time for multi-faceted thinking on the life events especially when they were alone. Depending on the effect of contextual factors, this evaluation had sometimes positive and sometimes negative effects on their thought from the self.

"Burning and tolerating it enlarged my

difficult situation, i.e., change my understanding of many things, now, I know how one who is sick or burned feels, what he needs, or how I should treat someone who has lost his beauty(P7)."

"Now, my priorities are my father and mother, they suffered so much for me, now, it is my turn to look after them. God gave me a family I appreciate very much, instead of those things burning took from me".

## Discussion

Findings of this study showed that burn injuries affect all the aspects of one's life due to their destructive nature.<sup>23-25</sup> While going through tough conditions after the burn, burn victims need to try hard in all dimensions to respond to the injuries and return to life.<sup>26</sup> These people face different consequences in their return to life.<sup>12</sup> If they survive the first phase, they will necessarily enter the life stream and gradually become able to return to their duties and roles based on the effective factors.<sup>17</sup> Returning to society and roles is not the end of this journey. Previous studies showed that psychological and mental problems of this group of patients are much more important than physical problems<sup>17</sup>; a consequence that is effective on their self-perception, their assessment of the feeling of achieving excellence and returning to the self.

In returning to life after burn, the first determinant consequence is achieving physical integration that initially occurred through physiological stability and then through saving the affected limb. While for years, death was the key reported consequence in research on burn, this word is the only rough indicator of clinical effectiveness and is not a real index of burn consequences.<sup>4</sup> In this study, the extraction of the concept "physical integration" shows one of the important consequences after burn; due to its wide meaning, it provides the researchers and other personnel with important and effective physical,

psychological, and social dimensions<sup>3</sup> for measuring outcomes in the acute phase of burn.

With the entrance of the individual to the hospital, the efforts of the nurses and the doctors start for returning physiological stability through predicting important acute inflammatory responses<sup>27</sup> and treating local and systemic disorders.<sup>28</sup> This finding is in line with the findings of other studies because these kinds of responses are known well today and in most cases are predictable and treatable with regard to the age of the patient and the burn percentage.<sup>29</sup>

Following physiological stability, the next step for saving and returning of burned limbs function is the local treatment of wounds that starts with daily dressings and will continue with restorative treatments, i.e., debridement and graft in case of deep wounds. Other studies shows that usual interventions in deep wounds include cleaning wounds, removing dead tissues, doing auto graft and allograft for covering the skin that lead to decreasing the stay and the costs<sup>3</sup>, however according to the observations and investigations in this study, allograft was not used for covering the wounds of the victims. Covering the wounds by graft, that is done to hold the balance in skin and other limbs' performance is an aggressive and very exhausting treatment.<sup>5</sup> Physical threat and intense and unbearable pain of the wounds are conscious experiences of agony in the return of the victims to life.<sup>30</sup> Previous studies have referred to it as an inseparable experience of the burn survivors, like the experiences of the participants in this study.<sup>31-33</sup>

According to the results of this study, these people, in the first days of their stay in the hospital, face with disappointing and destructive reality of dependence on others, a reality they have no control on and have to accept it.<sup>34</sup> Thus, in the judgment about the consequences, return to the mental balance is also important in addition to the return to the physical stability.

The investigation of the texts shows that, over 50 percent of those who have suffered from burn have experienced kinds of sleep problems such as problems in falling asleep, frequent awakenings, low sleep quality, waking early in the morning and nightmares.<sup>35</sup> In this phase, pain is one of the most important permanent and effective barriers on the mental balance of the victims that the victims experience for the return of the performance of burned limbs.<sup>36</sup> Other studies also show that more than half of burn victims are suffering daily due to the impact of chronic pain on their work, sleep or social lives.<sup>37</sup> The results of a study done by Esfahlan *et al.*, are in consistent with the results of this study, and showed that patients experience severe pains during medical procedures and experience moderate pains at rest due to inefficient management of pain.<sup>36</sup> While, the researchers believe that inadequate pain relief in the early stages can cause the patients to refuse to participate in the short-term and long-term rehabilitation programs.<sup>12</sup>

The results of this study showed that the support of family and close friends and the sympathy of nurses are invigorating energy resources to help patients endure pain and suffering. Other studies also show that despite all the difficult experiences of burn in this stage, the role of family is very significant in returning physical and mental control and increasing the strength of the person<sup>38</sup>; and the effect of personnel treatment relationship with them is undeniable on two dimensions, *i.e.*, physiological stability and saving the affected limb. For example, therapeutic touch has a significant effect on reducing pain and anxiety among burn patients.<sup>39</sup>

According to the results of this study hospital discharge means recovery and preparation for joining the live stream for most burn victims. Following tolerance and patience in the face of physical pain, the

feeling of partial recovery is a determinant consequence at the moment of discharge.<sup>40,41</sup>

Because it satisfies burn victims to perform daily activities and previous duties, and to enter a new life. This connection to the life stream faces the individual with different reactions by others in their interactions which underlie awareness of the new situation. In a phenomenological study, Moy *et al.*, extracted a new bodily awareness as the life extract in patients with burn injuries. New and hard knowledge of the restrictions is obtained by observing a strange vulnerable body, discomfort, disability and insecurity.<sup>42</sup> In this regard, a number of researchers pointed to the experience of inner dialog or, in other words, inner dialogs that help and guide the patients to wait.<sup>43</sup> According to the present study, strength sources such as self-confidence, family support, and financial security, having a goal, hope and thanksgiving help the patients to overcome feelings such as shame associated with the deformities in this phase and accept the new life, going to the society and joining the live stream. This finding is also confirmed by other studies.<sup>44-46</sup>

The findings of this study also showed that knowledge and the gained experiences in the return to society can provide learning and growth consequences for burn victims.

This finding is in line with the results of Wiechman's study. He pointed out that the growth of positive emotions and excellence can emerge in the life after the event when life priorities have changed, people respect life more, the relations are warmer and more intimate, humans have strong personalities and search for new possible solutions and finally pay attention to spirituality.<sup>47</sup>

The purpose of most rehabilitation programs is to return the individual to the normal stream of life<sup>12</sup>, while the findings of this study showed that a number of victims always suffer from a sense of inner dissatisfaction and insufficiency despite returning to the normal life. A feeling that

does not allow the individual to keep the balance between threatened values and life satisfaction. In other words, such a person has not been able to return to "the self" or the self he has imagined despite returning to the society and normal life. This finding shows that burn survivors might suffer from emotional and, mental problems for years despite having a normal life and returning to previous roles. This is a consequence to which all the people who are responsible for returning the individual to life should attend.

Thus, burn survivors need to achieve an important dimension of return, i.e., returning to the self in addition to returning to the society and previous roles in order to achieve the highest level of life quality after burn. Regarding the nature of the methodology used in this study, the extracted concepts can be used alone as a conceptual model and other studies, with mixed methods, are required to determine measurable indicators of the concept of returning to life.

## Conclusion

Returning to life is considered important and is attended to by all burn rehabilitation programs. In order to achieve this goal, consequences such as the physical integration and connecting to the life stream, that can be investigated by physiological stability, saving the affected limb, self-care, getting accustomed, and normalization, are not enough; and another consequence called return to the self, that can be measured through a sense of inner satisfaction and excellence, is essential. Discovering the category "return to the existence", this study introduced a new consequence for judging the quality of life of burn victims in addition to confirming the mentioned consequences in other studies.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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