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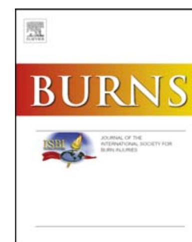

Disfiguring burns and the experienced reactions in Iran: Consequences and strategies—A qualitative study

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ABSTRACT

As the exact stereotyped content of physical attractiveness depends on cultural values, a study was conducted to obtain information concerning psycho-social problems experienced by people with burn disfigurement after being discharged from the hospital, in order to devise psycho-social support programs based on this evidence.

In this qualitative study, individual in-depth interviews were performed with 21 participants. These interviews were analyzed by the content analysis method, upon which five main themes appeared such as: behaviors and beliefs of society, sufferings, assessment of reactions, solutions, and exhaustion.

Our findings maintain that people's negative thoughts and behaviors provide the grounds for difficulties in disfigured individuals, hence taking troublesome measures to confront them.

There exists a need to devise a proper protective plan to train the community, family and the affected individuals themselves, aimed at promotion of levels of awareness, attitude and performance.

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1. Introduction

Burns are a prevalent health issue throughout the world, particularly in developing countries [1].

It is estimated that around 1.1 million burns in America and 1 million in Europe receive medical attention annually [2,3]. In Iran burns are still widespread with a high incidence of mortality. In this country around 724,000 burns occur annually out of whom 335,000 recover by self-treatment, 348,000 receive outpatient services from medical centers, 382,000 would be hospitalized and the remaining 2920 expire [4].

During the 20th century, the survival of burnt patients has significantly improved due to developments in burn care [2,5]. The comparison of epidemiological studies from 1994 to 2004 in Iran confirms the truth of this claim, too [1,6–9].

Burns have numerous consequences such as scars, disfigurement and other dysfunctions from contractures [10] therefore, burn survivors have a challenging and prolonged recovery process [11]. Even after most advanced surgical reconstructions, patients are often resigned to live with an unnatural appearance. Living with scars, especially in a socio cultural context which values physical appeal very much, can be very problematic [12]. The cost to society of the long-term morbidity from loss of physical function or associated psychological and cosmetic impairment is incalculable [13].

Among all disfigurements, facial scars have attracted significant attention for their importance; the face is the center of attractiveness and beauty [14], strongly associated with a person's identity, main channel for environmental perception and presenting one's self and communication [15].

Physical attractiveness has a stereotyped nature. That is attractive people appear to be more intelligent, better adjusted, more dominant and more socially competent [16]. People usually make more positive impressions about them, and thus treat them more respectfully [12]. On the other hand, less attractive people have problems interacting with others. They

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usually receive negative responses, and are subject to discrimination. They experience a higher level of mental distress such as; tension, anxiety and depression [16]. Therefore, disfigurement can leave profound psychological impressions such as adverse effects on body image, quality of life and self-confidence, making social interactions difficult [17]. Disfigurement has a multidimensional nature and contains some individual as well as social aspects [16]. These aspects can influence patients' tolerance to cope with his situation [18]. Although, all cultures tend to have stereotypes based on appearance, the exact content of this stereotype depends to a large extent on the cultural values and can be different in various cultures [16].

The existing literature indicates that most studies which have been conducted tend to investigate psycho-social problems regarding burn disfigurement using quantitative methods by means of specific standardized tools [5,19–23]. In general, the number of qualitative studies carried out on burn disfigurement from the viewpoint of those living with it is rare [16,17].

Phillips illustrates some psycho-social problems such as general anxiety, depression, social anxiety and family dysfunction; then he mentions factors affecting their recovery like sex of patient, age, total body surface area (TBSA), perceived severity visibility, physical functioning, social functioning, psycho-social support and still being in the burn care system in his quantitative–qualitative studies concerning burnt patients and their families [21]. Cartwright et al. also studied the experience of patients living with disfigurement (not necessarily of burns), in order to determine their information needs. In this study in addition to the review of literature, they had interviews and meetings with disfigured patients and their caregivers. Results indicated that these patients are often in need of useful information regarding their condition, especially plastic surgery outcomes, and the ways to cope with their psycho-social problems [18]. Therefore, a qualitative study is needed to gain appreciation about the experience of living with disfigurement, to inform the development of effective clinical interventions, and to understand the psychological and emotional processes involved in adjusting to disfiguring conditions [16,17].

Unfortunately, although it is culturally accepted that appearance and attractiveness play a significant role, no study has been done on the subject so far in Iran. That is why this qualitative study was devised to obtain information regarding psycho-social problems experienced by disfigured burnt patients having scars on their faces after being discharged from the hospital in Iran, so as to plan comprehensive psycho-social programs based on evidence. This article reports part of a greater qualitative study with the grounded theory approach.

2. Methods

2.1. *Design*

A qualitative research method was selected for the study, since this is a subjective and systematic method to describe life experiences and their meanings [24]. Qualitative researchers believe that people are actively involved in social functions and it is through these interactions based on previous experience that they gain knowledge and understanding of the phenomena [25]. A significant characteristic of qualitative research is paying close attention to the participants' viewpoints [26]. Grounded theory methodology is one of the approaches of qualitative research. This methodology explicitly involves generating theory and doing social research as two parts of the same process [27]. Because grounded theory captures social process in social context, the grounded theory research approach is most useful when the goal is a framework or theory that explains human behavior in context [28]. Thus, we have used this method to obtain information regarding the experience of living with disfigurement in order to develop effective interventions.

2.2. *Selecting the participants*

The research population was composed of patients having burn disfigurement on their faces, who were discharged from hospital. The criteria for inclusion were: having facial burn disfigurement, being older than 19 years, being discharged from the hospital, being burnt unintentionally; not having any pre-existing psychologic disease, use of psychedelic drugs, addiction to drugs or use of alcohol prior or after the burning incident.

Purposive sampling method was used to select the participants. Initially the filing systems of hospitals with burn centers were investigated to discover burnt patients being discharged from hospitals. Patients with required characteristics were contacted through phone numbers and addresses taken out of the files. Then necessary arrangements were made to carry out the study. Access to some participants was done through our presence in the plastic surgery clinics. In this way, 21 participants entered this study. Three participants were relatives (mother, wife, sister) of the burn-disfigured individuals, and 18 had burn disfigurement, having experienced burns from 3 months to 50 years ago. There was maximum variety regarding their age, gender, job, marital status, duration of time they lived with this problem, living location and the severity of disfigurement. The sample size was determined by data saturation.

This study was approved by the Medical-Ethics Committee of the University. We also made it known to the participants that their cooperation with the study is completely voluntarily and that they can leave the research whenever they wished to. Both oral and written explanations were provided regarding the purpose of the study, method of data collecting, taping the interviews and also about their names and other information being kept confidential. Each participant gave written consent.

2.3. *Data collection*

After necessary arrangements data collection started at places they felt convenient—their houses or any other location. The main data-collecting tool was in-depth interviews, with the duration of 30–60 min. In addition, differences existed in the individuals regarding the way they talked and gave us the information; as the research continued and we obtained data and categories, it made us feel necessary to refer to some of the participants again to help make the acquired data and

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