Chapter 25
Psychosocial Aspects of Orbitofacial Disfigurement in Cancer Patients

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Abstract The idea of an attractive face is socially constructed through interaction. The face is a fundamental element in the definition of identity and behavior, and individuals endowed with an attractive face are treated better than others. Accordingly, orbitofacial cancer survivors who are disfigured because of their cancer or cancer treatment suffer from stigmatization and social exclusion. Patients with acquired facial disfigurement suffer more serious psychosocial consequences than do individuals with congenital facial disfigurement. However, among patients with acquired facial disfigurement, cancer patients experience less severe social and psychological problems than do trauma patients. With time, as patients' fear of dying of cancer diminishes, the process of dealing with facial disfigurement begins and affects both patients and their family members. Active forms of coping generate better results than do passive coping strategies. Women with facial disfigurement tend to report more stress than men, and partners may experience more stress than patients. Interaction with acquaintances and strangers originates different levels of stigmatization in different social settings. Because facial disfigurement will continue to occur as a result of successful treatment of cancer, surgeons should be educated regarding the psychosocial consequences of facial disfigurement, and the roles that partners and other social actors play in social interaction and stigmatization should be considered in the formulation of protocols.

25.1 Introduction

Advances in medicine are allowing individuals with orbital and periorbital cancer to survive for many years after the cancer is treated [1, 2]. Surgical removal of the malignancy is often required and leaves patients with alterations of their facial

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appearance. Procedures to correct these alterations are common, and increasingly sophisticated facial prostheses are available [3]. Even so, however, the faces of survivors of orbital and periorbital cancer are often notably different from the "normal" face. Survivors' visible facial deformities are associated with stigma—a mark of social disgrace [3–12]. In short, as medicine has developed and allowed more patients to survive, these patients are having to confront the stigma associated with facial disfigurement [9]. This situation requires the attention of surgeons as survivors' quality of life depends not only on physical status but also on emotional and social well-being.

25.2 The Importance of the Face and Its Social "Construction"

People who possess an attractive face enjoy a number of social benefits that other, "less attractive" individuals do not have. People with an attractive face are not only considered physically pleasing but often viewed on the basis of their attractiveness as endowed with positive intellectual, ethical, and emotional characteristics [10, 13, 14]. Individuals with an attractive appearance are often judged to be intelligent, kind, likable, and highly moral, and these individuals are treated better than other, less attractive members of society [4]. This situation persists even in societies that formally stress the importance of moral and intellectual qualities in social living. The power of physical beauty is significant [10]. As we are fully clothed for virtually all of our social activities, the face represents one of the most notable physical attributes: "Beauty is perceived as residing principally in the face" [15–18].

While there is a tendency to consider beauty as universal, it is actually culturally based and socially constructed [4, 8, 19, 20]. Different cultures[1] tend to employ different standards to define beauty and emphasize different facial parts as primary features of a beautiful face. Even in the American-dominated Western world, the parts of the face that define beauty are constructed by the society in which the individual lives.

The face is also one of the standards used to distinguish between individuals who fit social expectations—how we expect someone to behave in a given circumstance—and those who deviate from them [7, 19]. The face is employed in the creation of our understanding of "normality" and ownership of socially desirable characteristics. In this context, the face is used as a significant source of social information both prior to and during social interaction [7, 8, 11, 16–18, 21]. Given this social importance of the face—"one's presentation to the world" [5, 8, 10–12, 18, 21]—facial disfigurement causes "a major upheaval in people's lives" [8] that is reflected not only in people's reactions to the abnormal face but also in the interaction between disfigured individuals and various groups in society [16, 22–24].

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[1] Culture refers to the ways in which members of a society, such as the United States, normally carry out daily tasks such as eating, dressing, and addressing each other. Each society has its own culture as each long-existing group of people developed specific manners for conducting themselves.

Those who suffer from facial disfigurement are often stigmatized [4, 19]. In his now-classic work on social stigma, the renowned sociologist Erving Goffman indicated how blemishes of the face are conditions that almost inevitably lead to the creation of stigma [21]. For Goffman, stigma is not reserved to specific groups of people; rather, it is a "relational" phenomenon—that is, it exists because we interact with other people and in so doing judge them according to established cultural standards. Frances Macgregor describes the negative responses that facially disfigured individuals encounter in their everyday lives as follows:

> [They] are subjected to visual and verbal assaults and a level of familiarity from strangers not otherwise dared: naked stares, startled reaction, "double takes," whispering, remarks, fugitive looks, curiosity, personal questions, advice, manifestation of pity or aversion, laughter, ridicule and outright avoidance. Whatever form the behaviors may take, they generate feelings of shame, impotence, anger and humiliation in their victims [10].

25.3 State of the Psychosocial Research on Facial Disfigurement

Research on the psychosocial aspects of facial disfigurement remains sparse and attracts even less attention than the already limited research associated with other forms of deformity [25–27]. The research on facial disfigurement to date stresses that facial disfigurement can be approached from at least three different directions. First, facial disfigurement has functional implications: patients encounter limitations as they attempt to carry out normal activities, and these limitations signal to others that patients are different. Functional implications also have consequences in terms of how patients feel about themselves and how others feel about and/or respond to them [8, 10, 14]. Second, facial disfigurement can be viewed in terms of the individual's reactions to his or her disfigurement, including reactions such as stress, anxiety, and coping strategies. Most psychological studies of facial disfigurement focus on patients' reactions [28]. Third, facial disfigurement has social implications—implications regarding how disfigured individuals interact with others and how others interact with disfigured individuals in various social contexts [8, 11, 27]. This third approach to studying facial disfigurement stresses the importance of social settings—e.g., the workplace, the street, shopping malls, restaurants—and the manner through which these settings aid in the construction of collective perceptions and actions toward the facially disfigured.

25.3.1 Psychosocial Consequences of Facial Disfigurement Caused by Cancer and Cancer Treatment

Studies of the relationship between cancer and disfigurement in general point out that while the social perception of cancer has changed in recent decades, this disease engenders a wide variety of attitudes and responses that differentiate it from other pathological situations [29]. Often, these attitudes and responses are stigmatizing [30]. However, differences have been recorded between reactions to forms of cancer that are perceived as uncontrollable—such as breast cancer—and those that are perceived as controllable—such as lung cancer due to smoking. Because the latter are seen as deriving from the patient's voluntary actions, more stigmatizing reactions are expected [31]. In the case of cancer-generated facial disfigurement, patients tend to experience responses based on "sympathy" when it is clear that the disfigurement is cancer generated, but when disfigurement is not clearly cancer generated, stigmatization tends to occur [32].

A limited number of studies have examined facial disfigurement caused by cancer. In general, individuals with acquired facial disfigurement suffer psychosocial consequences that are different from and, at least to some degree, more pronounced than those experienced by individuals with congenital disfigurement [19, 27]. However, among individuals with acquired facial disfigurement, cancer patients experience less severe social and psychological problems than do individuals who have been disfigured because of trauma [33]. For cancer patients, "fear of dying is immense" [29, 34], and this situation affects their perception of disfigurement and the behavior of those who interact with them [35]—patients are initially preoccupied more with the evolution of their cancer than with the social consequences of the scars that it left on their faces [27]. However, as this fear of dying diminishes, the process of dealing with disfigurement begins and affects both patients and their family members [5, 32, 34].

25.3.2 Patient Factors Affecting the Psychosocial Impact of Facial Disfigurement

While works on stigma in general are numerous, works on stigma caused by facial disfigurement in particular are relatively rare [8, 14, 25–27]. The literature on facial disfigurement to date tends to approach disfigurement and stigma from the point of view of the patient and emphasizes the individual's subjective state of mind and the strategies that he or she employs to successfully adapt to disfigurement [9, 11, 34]. It is reported that patients who employ active forms of coping, such as seeking out social support, have a better quality of life than those who adopt passive coping strategies, such as denial or avoidance [35]. (Denial is the process by which patients refuse to accept their condition of being disfigured. Avoidance refers to attempts to cope with disfigurement by avoiding contacts with others.) Furthermore, patients with enhanced social skills and greater social support have better chances of coping with stigmatization [33]. Women with facial disfigurement tend to report more stress than do men, and partners may experience more stress than do patients [27].

Demographically, cancer-generated facial disfigurement is more common among middle-aged men, married individuals, and members of the working class than among other groups [8]. Given the stage of life of such patients (e.g., already in a relationship rather than looking for a partner), the social support available to them (e.g., from a spouse), and the greater focus on basic needs associated with membership in the working class, the negative effects of disfigurement on quality of life tend to be diminished in these patients [27].

25.3.3 Safe Settings for Patients with Facial Disfigurement: the Family and the Hospital

Society is generally viewed as the place that originates stigmatization. Among the few safe settings in society for the facially disfigured are the family and the hospital [8, 11]. In the case of the family, family members generally support and care for patients and offer a social environment free of stigmatization. However, the same literature reports that spouses often feel the negative consequences of stigmatization as they try to shield cancer patients from unwanted interaction [32]. Further, research indicates that spouses are not immune from the influence of society and therefore may display stigmatizing behaviors toward disfigured individuals [21].

The hospital also tends to be a safe setting for patients because of caregivers' knowledge, tolerance, and understanding [8, 10, 27]. Even so, however, the relationship between patients and caregivers may result in episodes of stigmatization. It has been reported that lack of cultural and sociological training on the part of surgeons and staff may lead surgeons to mistake culturally based behavior for psychological and adaptive disorders [11] and may generate stress in patients [27].

25.3.4 Impact of Group Social Interactions on Patients with Facial Disfigurement

Some patients with facial disfigurement are largely unaffected by stigmatizing situations arising from social interaction. However, a larger group of patients experiences problems when interacting in small and large groups, with the level of stigmatization differing according to the type of interaction. Such patients tend to feel comfortable when interacting with close friends and family members. However, they display differing outcomes when interacting with strangers and/or acquaintances. The three general types of stranger or acquaintance behavior that have been studied are (1) unsolicited attention, (2) unsolicited support, and (3) lack of special attention.

When strangers or acquaintances pay unsolicited attention to patients, ask unwanted questions, make unwelcome remarks, stare, or otherwise make their unspoken curiosity felt, patients feel uncomfortable regardless of whether they are interacting in a small or large group.

When strangers and acquaintances provide unsolicited "support" for patients, a number of outcomes are common. In small groups, display of support engenders comfortable interaction between disfigured patients and acquaintances. It also shapes positive interaction in large groups as it is employed to construct advantageous conditions for patients [36]. Instrumentally, support is used even in situations in which support is not needed. Patients feel uncomfortable when support suggests that disfigurement is a greater problem than it actually is and when support creates a situation in which the patient is accorded undeserved respect.

Finally, when interacting individuals do not pay particular attention to patients, both positive and stigmatizing outcomes are possible in small groups [36]. In large groups, patients are comfortable when others do not pay particular attention to them. A large group allows patients to pass unnoticed among strangers.

25.4 Conclusions and Recommendations

It is increasingly common for patients with orbitofacial cancer to be cured of their cancer, and patients who are cured have to spend the rest of their lives with the stigmatizing limitations associated with facial disfigurement. Maintaining a successful social existence is of paramount importance for the overall well-being of these survivors.

At present, surgeons treating patients with orbitofacial cancers have limited exposure during training and later in the development of their medical practices to the results of psychosocial studies on facial disfigurement. It is important, therefore, to increase the exposure of surgeons and other medical personnel to knowledge regarding the psychosocial aspects of cancer-generated facial disfigurement; to increase collaboration between surgeons and social scientists; and to develop protocols that could be incorporated into standard orbitofacial cancer treatment. These protocols should be designed to minimize the negative social consequences of acquired facial disfigurement by preparing patients and their family members to face reactions that they will receive from society.

It is also important to stress that the psychosocial consequences of cancer-generated facial disfigurement cannot be successfully addressed by targeting patients alone. Stigmatization is a complex process that is defined by the collective process of interaction and involves both patients and other social actors, such as family members, caregivers, and strangers. Further, the unfolding of social interaction and its outcomes are affected by a variety of factors, including the size of the group within which interaction takes place, the setting, and the attitudes and actions of interacting individuals. The role played by family members and, above all, spouses should be carefully considered in the development of pertinent protocols [36].

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