Cancer and Facial Disfigurement: Reducing Survivors’ Stigma in Social Interaction

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Patients with orbital and periorbital cancer expect to be cured or survive for several years after their malignancy is detected and surgically removed. However, despite advancements in reconstructive surgery, survivors often remain facially disfigured and spend significant portions of their lives dealing with stigma, a mark of social disgrace. Although research remains limited, this article describes a qualitative study of social interaction leading to stigma in individuals with facial disfigurement caused by cancer surgery, as well as the experiences of their family members. In particular, the current study focused on interaction between patients and strangers and acquaintances (secondary groups). In-depth interviews with patients and their family members were conducted and analyzed using Grounded Theory. Three primary patterns of interaction were identified: intrusion, sympathy, and benign neglect. Those patterns refer to conditions that are increasingly unfavorable to the creation of stigma, where intrusion and sympathy foster stigma but benign neglect does not. Through that knowledge, oncology nurses will be able to better inform patients and family members on the conditions leading to stigma.

Progress in cancer care has increased long-term survival for patients with cancer (American Cancer Society, 2009; Mood, 1997; Parker, Davis, Wingo, Ries, & Heath, 1998). For patients with orbital and periorbital cancer in particular, several studies have shown improved survival (Davis, Roumanas, & Nishimura, 1997; Dropkin, 1999). Appropriate and often curative surgical procedures for those patients entail the removal of portions of the face that are affected by cancer. A common consequence of that type of intervention is the alteration of the patient’s face and the permanent facial disfigurement that ensues (American Cancer Society, 2009). Surgical procedures to restore the function and appearance of the facial structures are often used. In addition, the availability of sophisticated prostheses has increased, but they often are costly and difficult to use (Davis et al., 1997). Despite the availability of those procedures, notable differences from the normal face are not rectified. As a result, cancer survivors typically live the rest of their lives with facial disfigurement.

The face is important in social relations as a central element of communication (Kish & Lansdown, 2000; Macgregor, 1990) and an item used to make judgments about normality and ownership of socially desirable characteristics (Furness, Garrud, Faulder, & Swift, 2006; Goffman, 1963; Hawkesworth, 2001; Hughes, 1998; Ishii, Carey, Byrne, Zee, & Ishii, 2009; Macgregor, 1974); therefore, individuals with an abnormal face often experience stigma and are treated differently than other members of society. Those individuals are labeled as different and treated accordingly (Bull & Stevens, 1981; Callahan, 2004; Furness et al., 2006; Hawkesworth, 2001; Hughes, 1998; Kent, 2000; Macgregor, 1974, 1990; Millstone, 2008). According to available literature, patients with facial disfigurement view interaction with acquaintances and strangers as a constant source of stigma. Acquaintances and strangers are seen as exercising prejudice (negative feelings and beliefs) or discrimination (actual differential treatment) against patients. However, the characteristics of the interaction process have not been mapped out clearly, leaving a gap in the available knowledge on the manner in which stigma is actually created (Hughes, 1998; Macgregor, 1990; van Doorne, van Waas, & Bergsma, 1994).

This article illustrates the results of qualitative research on patterns of social interaction leading to the creation of stigma in individuals with facial disfigurement caused by cancer and its associated treatments, as well as the experiences of patients’
family members. In particular, the current study focused on identifying patterns of interaction between patients with facial disfigurement, strangers, and acquaintances. Acquaintances are referred to as members of secondary groups, defined as having interactions that are impersonal, temporary, and based on business and formal interests or specific types of activities. Healthcare providers can use this information to enhance the quality of life of cancer survivors and their families and to improve the overall knowledge of those involved in cancer survivorship.

**Literature Review**

Stigma is a mark of disgrace attached to people who are considered different (Goffman, 1963). Difference is socially constructed and is the outcome of discrepancies between an individual’s virtual social identity (i.e., expectations about what that individual ought to be) and his or her actual social identity (i.e., the attributes he or she actually possesses) (Goffman, 1963). When actual social identity is perceived as departing from normality, the individual is stigmatized. Stigma is attached to features of individuals that are viewed as deeply discrediting and that separate the person from the perceived normal group. However, stigma’s actual genesis is relational, as the individual constantly is compared to other members of society. Therefore, specific individual characteristics generate stigma in some instances but not in others (destigmatization). Stigma is generated by the existence of several blemishes, including those of individual character (e.g., dishonesty, imprisonment, radical political behavior, addiction); tribal stigma, which is related to a person’s reference group (e.g., religion, ethnicity, race); and abominations of the body (e.g., physical abnormalities including facial disfigurement).

Stigma has been studied widely, such as in works on stigma generated from diseases (i.e., cancer and AIDS) (Fife & Wright, 2000), physical disabilities (Cahill & Eggleston, 1995; Susman, 1994), and mental health (Angermeyer & Matschinger, 1994; Corrigan & Penn, 1999). The abundant literature on mental health also has underscored important limits of stigma’s use as a concept. For example, stigma has been studied with a strong individualistic focus, it often is used by people who do not belong to stigmatized groups, no consensus has been reached on a common definition, and the existence of multiple definitions allows criticism that the concept is too inclusive to be informative (Cahill & Eggleston, 1995; Link & Phelan, 2001). In addition, uncertainties exist about its manifestations because felt stigma (the individual’s shame associated with a blemish) is much more common than enacted stigma (the existence of overt episodes of discrimination).

Despite the wealth of contributions, stigma caused by facial disfigurement has been the subject of only a small number of works (Clarke, 1999; Clarke, Rumsey, Collin, & Wyn-Williams, 2003; Hughes, 1998; Kent, 2000; Kish & Lansdown, 2000; Pruizinsky, Levine, Persing, Barth, & Obrecht, 2006). Those analyses stressed the social importance of the face and the problems that affect individuals who display visible facial blemishes. In addition, research has indicated that the face represents one of the most notable physical attributes and is a significant source of social information prior to and during social interaction (Anderson & Franke, 2002; Cole, 1998; Furness et al., 2006; Goffman, 1963; Hawkesworth, 2001; Hughes, 1998; Macgregor, 1974). Therefore, people possessing an attractive face are not only considered physically pleasing, but often are viewed as endowed with intellectual and emotional characteristics (e.g., intelligence, kindness, high morality) and are treated better by others than less attractive individuals (Bull & Rumsey, 1988; Cash & Pruizinsky, 2002; Feingold, 1992; Kish & Lansdown, 2000; Macgregor, 1990). Individuals with facial disfigurement commonly engender negative responses from other members of society (Callahan, 2004; Hagedoorm & Molleman, 2006; Kish & Lansdown, 2000).

Patients with cancer who have facial disfigurements are focused primarily on surviving cancer. However, when survival is apparent, those individuals become concerned with disfigurement, which affects patients as well as their family members (Bonanno & Choi, 2009; van Doorne et al., 1994). The association between cancer and disfigurement is persistent; therapy almost inevitably mandates surgical removal of the parts of the face affected by cancer, making it an undesirable consequence of successful medical intervention (Callahan, 2004; Millsopp et al., 2006; Valente, 2004).

A limitation of the literature is the lack of attention on the social process that generates stigma (Clarke, 1999; Furness et al., 2006; Kent, 2000; Thompson & Kent, 2001), particularly the fact that disfigurement and stigma are socially constructed and generated through processes of interaction that involve multiple actors and take different forms according to the settings in which they unfold (Kent, 2000). Although evidence indicates that society is the primary source of stigma (Callahan, 2004; Hagedoorm & Molleman, 2006; Kish & Lansdown, 2000; Pruizinsky et al., 2006; van Doorne et al., 1994), the manners in which stigma emerges require further investigation (Bonanno, Choi, & Esmaeli, 2008). More specifically, because stigma does not occur homogeneously, identifying the circumstances in which it appears in interaction and the ways in which interaction can be directed to avoid its occurrence is important. For example, van Doorne et al. (1994) indicated that interaction with strangers almost certainly leads to the creation of stigma; however, those authors stressed that interaction with acquaintances requires additional investigation. The current study addresses that knowledge gap.

**Methods**

The current study consisted of in-depth interviews with a purposive sample of 15 patients with cancer who underwent surgery to treat orbital and peri-orbital malignancies that affected their facial appearance. Patients were selected through a records review at a major cancer center in the southwestern United States. Exclusion criteria were being younger than age 18, having surgery in the first six months prior to the interview, receiving active cancer therapy at the time of the interview, and being unable to speak English.

Interviews were conducted from January 2008 to February 2010. Twenty potential participants were contacted; two could not participate because of scheduling problems and three refused because of lack of time or interest. A total of eight men and seven women were interviewed. One family member for each of the participating patients also was interviewed (11 women and 4 men; 9 spouses, 5 children, and 1 sibling). Patients were
aged 31–81 years and family members were aged 30–75 years (median = 66 years). At the time of the interview, postsurgical follow-up time ranged from 10 months to 35 years (median = 5 years). Some patients underwent additional reconstructive surgical procedures. Although the extent of disfigurement varied among patients, all experienced significant alterations in their facial appearance. A semistructured questionnaire was used and patients were asked to narrate their experiences in processes of interaction with acquaintances and strangers in various settings. At the convenience of the patients, interviews were conducted via telephone by the same member of the research team. That technique was used to ensure consistency in the data collection process. As patterns of interaction began to be detected, the sample was expanded through the technique of theoretical sampling. Patients were selected according to specific characteristics (e.g., age, gender, marital status, social class) that emerged as analytically relevant. To further document the narratives, in-depth interviews with one family member for each of the patients were conducted. Family members also were asked to reconstruct processes of interaction experienced by patients in various settings.

The interviews were tape-recorded with the participants’ and family members’ consent, and the transcribed texts were analyzed by the authors using the qualitative methodology of Grounded Theory (Charmaz, 2006). The guiding assumption of the study was to develop analytical categories (variables) that would identify patterns of interaction between patients with cancer who had facial disfigurement and members of secondary groups. Those categories were created to illustrate the collective action process leading to stigma rather than the way patients felt during the interaction process itself. In addition, the current study aimed to reconstruct the experience of family members and the social problems that they encountered while assisting patients in their adjustment to facial disfigurement.

Following the requirements of Grounded Theory, analytical categories were constructed through line-by-line coding and constant comparative analysis (Charmaz, 2006). Once developed, codes were grouped into relevant categories that were saturated as no new relevant properties of those categories emerged. Along with saturation, the negative cases technique was employed to validate categories and their properties (Charmaz, 2006; Holton, 2007). In this case, a deliberate search was conducted for situations that would contradict the analysis; their absence was used to validate the conclusions (Charmaz, 2006). The validation techniques of saturation and negative cases are used commonly in research projects employing Grounded Theory (Charmaz, 2006; Holton, 2007).

**Results**

**Patients**

The analysis generated a model of interaction patterns between patients with cancer who had facial disfigurement and members of secondary groups (see Figure 1). Three fundamental analytical categories were developed: intrusion, sympathy, and benign neglect. Intrusion indicates interaction based on unsolicited attention paid to patients by strangers and acquaintances. People asked unwanted questions, made unwelcome remarks, stared, and made their unspoken curiosity felt. Sympathy refers to unsolicited comments or actions showing support to patients and the desire to be of assistance. Finally, benign neglect denotes a situation in which interaction characterized by people not paying particular attention to patients and giving them the civil inattention or distant attention that characterizes everyday interaction among strangers. The observations suggested that benign neglect is the desired form of interaction because it does not generate stigma.

Interaction patterns change based on the size of interacting groups. Interaction characterized by intrusion in large and small groups generates stigma, known as felt and enacted forms of stigma. Sympathy produces enacted stigma in small groups and enacted and felt stigma within large groups. By definition, benign neglect does not produce stigma in any group, small or large. Following are more detailed illustrations of those patterns.

**Intrusion**: A situation that engenders stigma in interaction within small and large groups alike indicates intrusion. Members of interacting groups grant individuals with disfigurement
the particular status of different through the construction of actions based on unwanted attention. Strangers and acquaintances’ questions, stares, and remarks constitute elements that transform disfigurement into stigma. Of particular importance are situations in which patients remain in a still position for long periods of time in full view of others. Because of that immobility, patients tend to feel uncomfortable. However, the felt stigma can translate into enacted stigma because stares, comments, or questions characterized the behavior of others. The unusual shape of a patient’s face makes strangers and acquaintances curious. As that curiosity is made explicit, stigma occurs, even when interacting individuals attempt to conceal their intrusive behavior. The concealed enacted stigma refers to actions of intrusions accompanied by attempts to hide them from patients. Patients tend to resent the unwanted attention of others and often express that resentment by perceiving those actions as “rude” and “inconsiderate.” Simultaneously, patients display unconcerned awareness, a pattern in which patients remain aware of stigmatizing actions but indicate that they are not affected by them.

A patient recalled two episodes that exemplified the pattern of intrusion.

Sometimes I notice that people . . . can tell that this side of my face does not make the same movements [as the other side]. They are probably aware that there is something strange about that woman. . . . The first time that I took my six-year-old to dancing—my six-year-old granddaughter, she dances every Wednesday and then she is at church afterwards. The children have special things going on after dancing at the church. . . . My daughter works a lot and so that Wednesday is mine. I take them and do all of that kind of thing. Well, when I take her to dance, I sit and wait . . . can’t go off and leave her, wait in the room with the other parents and I noticed that some of the mothers were looking at me strangely, not in a mean way or anything like that, but more curious, like there’s something strange about that woman. What could it be? And generally, I have found that if I feel like somebody is making me feel uncomfortable . . . I’ll go ahead and say something.

I went to a wedding shower for one of my daughter’s friends who I didn’t know very well and there were a lot of young women there that I did not know well . . . and I was uncomfortable there. I felt like the majority of them probably did not know that I had this problem and I’m sure they were wondering what was wrong with my face . . . that was an uncomfortable day. . . . I didn’t really enjoy that.

**Sympathy:** Intrusive patterns of interaction in which individuals provide or manifest support to patients with facial disfigurement represent sympathy. It creates enacted stigma in small group interactions and felt and enacted stigma in large group interactions. In the case of small group interactions, supportive curiosity occurs, which refers to questions people ask about patients’ appearance that are accompanied by supportive actions and expressions. The expression “everybody is nice” was reported by patients frequently and captures the sympathy pattern of interaction. Patients do not experience felt stigma because they feel comfortable with the support that strangers and acquaintances offer. In large group interactions, patients may use the offered support to their advantage, even when it is not needed or necessary. That instrumentality is not exercised in small groups. However, interaction in large groups leads to stigma when offered assistance is viewed as unnecessary or exaggerated in relation to patients’ actual physical conditions. When sympathy-guided action transcends established expectations and creates unfounded attention, enacted stigma occurs in small and large groups. For example, because of their status as cancer survivors and individuals with facial disfigurement, patients may be granted what they perceive as undeserved respect, which can lead to felt stigma. Another patient provided an example of sympathy.

People are afraid to say anything or ask anything. They want to be nice. So I’ll have to make the first comment as a joke, and then they’ll feel free to ask about, “Well, okay, what happened?” . . . When I explain that this is because of cancer and that I’m a cancer survivor . . . they become supportive. They say nice things. I could be a horrible person. I’m not a horrible person, but they say good things about you. They say something like, “It’s okay, if you are a cancer survivor.” I do not take advantage of that, but . . . I do feel that if someone wanted to, they probably could because people treat it . . . like something that you should be understanding and forgiving.

**Benign neglect:** This pattern refers to interactions in which strangers and acquaintances do not pay particular attention to individuals with disfigurement. Benign neglect is a common pattern that characterizes interaction among people who are not familiar with each other. Although people are aware of the presence of others, they do not focus on or pay particular attention to their actions. Macgregor (1974) described benign neglect as the “civil inattention normally granted to others in society” (p. 60). Because of its normality, interaction characterized by benign neglect becomes particularly important in situations in which difference is present. Individuals with facial disfigurement not only feel comfortable during those interactions, but also acknowledge that they are being treated normally without any particular emphasis placed on their physical appearance. A patient said,

I don’t feel any difference [in] the way people treat me. It could be because I wear dark glasses all the time that cover my eyes. But it is possible that people notice that something is different with me. But they are indifferent to me. They don’t say anything . . . they just treat me as a regular guy.

**Family Members**

Family members are affected by patients’ cancer and consequent facial disfigurement. At first, family members experience a period of disruption of their everyday lives, characterized by a transitional phase that coincides with the detection and, later, treatment of the cancer (transition) (see Figure 2). The transitional phase entails the establishment of new patterns of everyday life that emerge abruptly (as the cancer is diagnosed and later treated) and continue to remain significantly different from those of the past (transformation). The new patterns
Cancer
The patient is diagnosed and consequently experiences facial disfigurement, affecting the family member in the following ways.

Disruption
- Transition: establishing new daily patterns
- Transformation: Life remains different following diagnosis and treatment.

Feeling Stigma
Family members become aware of the existence of stigma and its negative consequences.

Isolation
As the patient limits his or her social activities, family members reduce the frequency of their own social engagements.

Increased Responsibility
- Social, emotional, physical, and financial
- Spouses are more affected than siblings and children.

Creating a Supportive Environment
- Facilitation of membership or interaction in social groups
- Shielding the patient and family from stigma
- Creating stronger family ties

FIGURE 2. Model of Action for Family Members of Patients With Facial Disfigurement

Further involve the awareness of the existence of stigma and its negative consequences (feeling stigma). As patients frequently respond to facial disfigurement by limiting their social activities (Hagedoorn & Molleman, 2006; Kish & Lansdown, 2000; Macgregor, 1990), family members also tend to reduce the frequency of their social engagements (isolation).

Under those conditions, family members face a new set of responsibilities and new tasks are added to their daily routines (increased responsibility). The new tasks pertain to several spheres of everyday life, including social (i.e., family members assist patients as they participate in social activities such as visiting friends, going out, shopping, and traveling), emotional (i.e., family members provide emotional support), financial (i.e., family members take a more prominent role as providers of financial resources for the family), and physical (i.e., family members perform additional physical activities to offset patients’ functional limitations). Those tasks are not distributed evenly among all family members. Spouses are more involved in providing support than other family members because they experience more significant changes in their everyday lives.

All family members are actively involved in efforts to create a supportive environment for patients. That task is considered to be most important and occupies the greatest portion of family members’ time and energy. Creating a supportive en-

vironment centers on two often conflicting actions: shielding family members from stigma and facilitation of membership in social groups. In shielding from stigma, family members are called to prevent or control social interactions that have been viewed and felt as stigmatizing by patients or the family members themselves. In facilitating membership in social groups, family members are instrumental in promoting patients’ participation in activities that are hampered by stigma.

Frequently mentioned instances of facilitation include escorting patients to shopping centers, restaurants, gyms, or movie theaters, and to formal and informal social gatherings such as meetings of social clubs or groups of friends. The conflicting nature of those actions rests on the fact that, as family members attempt to protect patients from stigmatizing situations, they tend to limit the frequency of patients’ contacts with others. As they promote patients’ membership in social groups, family members act in ways that increase social contacts with others. In that case, family members must perform conflicting social roles.

The overall result of family members’ involvement is the creation of stronger family ties. Members of the family act in a much more cooperative manner than in the past and express feelings that support enhanced family cooperation.

Implications for Nurses

The current study illustrated the manner in which interaction between patients with cancer who have facial disfigurement and secondary groups engenders stigma. Because limited research is available about that issue, healthcare providers should use the current findings to assist patients and provide information and assistance to patients’ family members. By using a Grounded Theory analysis, the authors also were able to identify analytical categories that define key types of interaction patterns related to the creation of social stigma. Those findings add to the existing research in several ways. The current study indicated that interaction between patients with cancer who have facial disfigurement and secondary groups is not uniform. In addition, van Doorne et al.’s (1994) statement that “the reaction of people on the streets or in the neighborhood is . . . consistent: they stare at most patients with facial defect” (p. 325) should be reconsidered. The current study demonstrates that the behavior of strangers and acquaintances is much more complex than previously recorded and entails many distinct interaction patterns.

Of the three types of interaction patterns identified, only benign neglect did not engender stigma. Benign neglect refers to the normal pattern of interaction in which people are aware of the presence of others but do not pay particular attention to them. Benign neglect is found in situations involving small and large groups and appears recurrently; therefore, interaction with strangers and acquaintances is not always stigmatizing, as illustrated by existing literature (van Doorne et al., 1994). Patients and their family members should be counseled on the importance of creating conditions that lead to benign neglect as the preferred pattern of social interaction. The steps required to foster the development of benign-neglect–based interaction transcend the objectives of the current study. However, patients, their family members, and the general public should be
educated on the importance of allowing individuals to maintain a private space in public settings. The violation of the sphere of the individual’s private space is the source of the stigma generated by interaction patterns dominated by intrusion and sympathy.

Interaction characterized by intrusion consistently leads to the creation of both felt and enacted stigma. Episodes of felt and enacted stigma occur in small and large group settings, making intrusion the most difficult type of interaction for patients and family members. In that interaction, strangers and acquaintances alike ask questions, make comments, stare, and perform other intrusive actions. Curiosity, immobility, unconcerned awareness, and resentment frequently accompany intrusion. Patients and their families should be advised on the difficulties that episodes of intrusion generate.

During interaction characterized by sympathy, stigma develops in different ways in small groups compared to large groups. Enacted stigma occurs in small groups, whereas both enacted and felt stigma occur in large groups. Although sympathy indicates that interacting individuals either provide or manifest support to patients with facial disfigurement, this interaction ultimately creates stigma. The categories of supportive curiosity, instrumentality, and unfounded respect characterize sympathy. Healthcare providers should inform patients and family members that the desire of strangers and acquaintances to assist patients does not necessarily translate into a positive outcome and may cause patients to experience stigma. Therefore, efforts to educate interested parties on that contradictory situation would be beneficial.

The current study also indicated that acquaintances’ interaction with patients does not differ significantly from interaction with strangers. Strangers as well as acquaintances contribute to the creation of stigma when intrusion and sympathy occur. However, both groups are capable of establishing a positive interaction with patients by enacting benign neglect.

The current research underscores the importance of approaching the issue of stigma for patients with cancer who have facial disfigurement in relational terms. Stigma emerges as the product of interaction; therefore, it involves patients with facial disfigurement and other segments of society as they interact in different ways and with varying results. Although study of the way individual patients respond to disfigurement remains important, an enhanced understanding of the construction of stigma is achieved by considering the collective dimensions of that process, as well as contributions from society and the social groups in which patients interact. Stigma is a collective process that involves a multiplicity of actors, and healthcare providers should avoid presenting stigma as an issue that pertains exclusively to patients’ individual spheres.

Conclusions

The research described in the current study allows healthcare providers to address a new and growing dimension of cancer survivorship. Caregivers can and should counsel patients and their family members on the importance and characteristics of interaction processes that lead to the creation of stigma. Additional research is warranted in this area. In particular, future investigations should focus on specific subgroups of patients and variables such as age, gender, socioeconomic status, and ethnicity. Nurses can assist patients and their family members by informing them of the conditions (intrusion and sympathy) that lead to stigma and the fact that it can be generated by strangers as well as acquaintances. In addition, nurses should reassure patients and family members that stigma is generated by interaction, not patients’ behavior.

Implications for Practice

- Nurses should inform patients with facial disfigurement and their family members that social interaction often—but not always—leads to stigma.
- Intrusion, characterized by unsolicited attention from strangers and acquaintances, is the most common form of stigmatization and should be addressed in patient and family education.
- Nurses should reassure patients and family members that social interaction is the source of stigma, rather than the behavior of patients.

References


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