Ophthalmic Oncology explores the unique aspects of ophthalmologic oncology as a medical and surgical discipline practiced at a comprehensive cancer center. Multidisciplinary management of ocular, orbital, and adnexal cancers are highlighted using simple and tried-and-true algorithms. In addition, ocular problems caused as a direct result of cancer treatment are reviewed using illustrative photographs and case presentations.

The content is provided by full-time ophthalmology faculty and fellows at M.D. Anderson Cancer Center. Experts in complementary disciplines such as ophthalmic pathology, dermatopathology, radiation oncology, radiology, and other surgical subspecialties bring a novel perspective to each chapter. Clinical photographs and case presentations help clinicians, practicing general ophthalmologists, orbital and oculoplastics specialists, medical and surgical oncologists, and ophthalmology residents and fellows to correctly diagnose cancers of the orbit, eye, and adnexal structures, initiate appropriate management, as well as recognize and treat common ocular complications of cancer therapy.
Preface

A little over a decade ago, I had the privilege of helping to establish the first full-time ophthalmic oncology service based at a Comprehensive Cancer Center in the United States. Our Ophthalmic Oncology Service at The University of Texas M.D. Anderson Cancer Center has grown to include 4 subspecialty areas of ophthalmology: orbital oncology/ocular plastic surgery, ocular oncology, ocular surface diseases, and neuro-ophthalmology. Ophthalmic Oncology grew from faculty's unique experiences and observations in their ophthalmology subspecialty areas at M.D. Anderson. The book highlights the unique aspects of ophthalmic oncology as a surgical and medical discipline practiced at a Comprehensive Cancer Center. The multidisciplinary management of ocular, orbital, and ocular adnexal (eyelid, conjunctival, and pericocular soft tissues) cancers is emphasized, as well as the current recommendations and practices at our institution. In addition, ocular conditions caused as a direct result of cancer treatment are reviewed using illustrative photographs and case presentations. The authors include ophthalmology faculty members, current and former M.D. Anderson fellows, and experts in complementary disciplines such as radiation oncology, dermatopathology, ophthalmic pathology, radiology, plastic surgery, and other surgical subspecialties.

With an abundance of clinical photographs, clinicians will be able to correctly diagnose cancers of the orbit, eye, and ocular adnexal structures.

I appreciate the contributions of each of the authors who took time out of their busy schedules to meet the deadlines for this project. I particularly thank my three ophthalmology colleagues at M.D. Anderson, Dr. Dan Gombrich, Dr. Stella Kim, and Dr. Jado Schiffman, who not only have helped put together some of the sections in this book as section editors and authors but also because of their unique contributions to the growth of our program in Ophthalmic Oncology at M.D. Anderson. My special gratitude goes to Stephanie Deming and Sue Moreau from the Department of Scientific Publications at M.D. Anderson for their tireless long hours of editing for this book. I also would like to thank Dr. Raphael Pollock for the opportunity to organize and lead this effort and the privilege to edit this book in the M.D. Anderson Solid Tumor Oncology Series. Finally, I am grateful for the support provided by the dedicated staff at Springer—Stacy Lazar, Maureen Tobin, and Laura Walsh.

Bita Esmaeili
Houston, Texas
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Contributors

Syed Mehdi Ahmad Department of Ophthalmology, Baylor University Medical Center at Dallas, Dallas, TX, USA, sma967@gmail.com

M. Amir Ahmadi Department of Ophthalmology, University of Illinois at Chicago, Chicago, IL, USA, mamirahmadi@yahoo.com

Alessandro Bonanno Department of Sociology, Sam Houston State University, Huntsville, TX, USA, soc_aab@shsu.edu

Christopher J. Calvano Division of Ophthalmic Plastic Surgery, Kresge Eye Institute, Wayne State University, Detroit, MI, USA, chris_calvano@yahoo.com

Gerardo D. Camoriano Department of Ophthalmology and Visual Sciences, The University of Texas Medical Branch, Galveston, TX, USA, gdcamori@utmb.edu

Heather Chang Jules Stein Eye Institute, UCLA Medical Center, Los Angeles, CA, USA, hkwon88@yahoo.com

Patty Chevez-Barrios Retinoblastoma Center of Houston, The Methodist Hospital, Houston, TX, USA, pchevez-barrios@tmhs.org

Murali Chintagumpala Department of Pediatrics, Section of Hematology and Oncology, Baylor College of Medicine, Texas Children's Hospital, Houston, TX, USA, muralic@txccc.org

Jin Young Choi Department of Sociology, Sam Houston State University, Huntsville, TX, USA, jyc002@shsu.edu

Garvin H. Davis Department of Ophthalmology, The University of Texas at Houston, Houston, TX, USA, gdavis@uth.tmc.edu

J. Matthew Debnam Section of Neuroradiology, Department of Radiology, The University of Texas M.D. Anderson Cancer Center, Houston, TX, USA, matthew.debnam@mdanderson.org
Chapter 25
Psychosocial Aspects of Orbitofacial Disfigurement in Cancer Patients

Alessandro Bonanno and Jin Young Choi

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

A. Bonanno (89)
Department of Sociology, Sam Houston State University, Huntsville, TX, USA
e-mail: soc_aab@shsu.edu

B. Esmaili (ed.), Ophthalmic Oncology, M.D. Anderson Solid Tumor Oncology Series 6, DOI 10.1007/978-1-4419-0374-7_25,
© Springer Science+Business Media, LLC 2011
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 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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1Culture 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.

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 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
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 orbito-facial 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 orbito-facial 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 orbito-facial 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].

References


Part IV

Ocular Side Effects of Cancer Therapy

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