

■ CNE Article

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

Alessandro Bonanno, PhD, and Bitá Esmaeli, MD



© iStockphoto.com/Andreea Erim

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 decreasingly favorable 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.

Alessandro Bonanno, PhD, is the Texas State University System Regents' Professor of Sociology in the Department of Sociology at Sam Houston State University in Huntsville, TX, and Bitá Esmaeli, MD, is a professor of ophthalmology in the Section of Ophthalmology, Department of Head and Neck Surgery, at the University of Texas MD Anderson Cancer Center in Houston. The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff. Bonanno can be reached at soc_aab@shsu.edu, with copy to editor at CJONEditor@ons.org. (First submission March 2011. Revision submitted June 2011. Accepted for publication July 12, 2011.)

Digital Object Identifier:10.1188/12.CJON.153-159

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 often are 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'