The Dissertation Committee for Inci Ozum Ucok
Certifies that this is the approved version of the following dissertation:

TRANSFORMATIONS OF SELF IN SURVIVING CANCER: AN ETHNOGRAPHIC ACCOUNT OF BODILY APPEARANCE AND SELFHOOD

Committee:

Madeline Maxwell, Supervisor

Dana Cloud

Jurgen Streeck

Rajiv Rimal

Leslie Jarmon

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by

Inci Ozum Ucok, M.A., B.A.

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Dedicated

to those who know to love

and

who have learned to love along the way

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> Yet, if there was beauty and grace in the perfect, intact, sensuous breast, can there be beauty of a different sort in the breast that has been biopsied and cut and irradiated and poisoned? I think so. The human body is its own art form and is beautiful not only as it was created but also in the many shapes it takes on as it travels through life. Bodies with scars have not left the art behind. The scars simply mark the trail, the passage taken. Just like the moon and the sea and the fluctuating changes within us, the art of the altered breast is different but stays with us. Shocking? For some. Reassuring? For others.
>
> Nancy Snyderman, M. D.

> "One option is to reconstruct your life, but not your breasts."
>
> Stephanie Byram, Ph.D

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Inci Ozum Ucok, Ph.D.
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This study focuses on the transformations of self in some breast cancer survivors, particularly as related to changes in bodily appearance (due to radiation, chemotherapy or surgery.) Analyzing various discourses of cancer survivors (such as excerpts of talk from interviews, journal entries, photographs and public presentations), I study the ways in which selves are reconstituted in relation to a change in physical form due to medical treatment (such as, hair loss or having one or both breasts removed.) The lived experiences of individuals create the basis for understanding appearance as a bodily experience rather than mere image or representation. Using ethnographic methods, I explore the viewpoints of the women who suffered through cancer treatment and the meanings of appearances they constructed in social interaction with others.

By integrating symbolic interactionist and phenomenological approaches to the study of physical body and self, this study locates the self in the body as a *reflective* process emerging through social interaction. I emphasize *appearance as bodily experience* in terms of its visual and tactile aspects and examine its implications on women's selves, self-presentations and social interactions. Using Goffman's (1959, 1963) concepts of self-presentation, stigma and interaction order I show the ways in which my participants experienced "stigmatization" due to temporary or permanent bodily changes. Furthermore, I demonstrate that stigma management not only pertains to public life but also intimate contexts.

Observing the inseparability of appearance and self as a common theme in the discourse of survivors, I argue that appearance is more than just an expression of self but it constitutes the self, or a part of self. It is in some way through our looks, along with the responses of others to it that we grow up with, that we come to recognize ourselves as who we are. Breast cancer survivors interviewed in this study reported a "loss of self" as a result of a change in physical appearance which they attributed to their inability to integrate their altered physical appearance as a part of themselves. While some survivors accepted the way they look and made it a part of their selves, others *resisted* the change and managed their image to restore their selves. This shows us that the role of the individual in shaping the definition of the self is evident, "through the little ways in which we resist the pull" (Goffman, 1961), as opposed to the notion of self as a fluid product of others imputations. Despite their different choices, survivors showed an effort to maintain the coherence of the self in moments

of change and uncertainty. This active and autonomous view of self challenges the characterization of appearance and beauty practices as oppressive and thereby challenges the understanding of women as passive and manipulated by cultural ideologies.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER ONE: INTRODUCTION

Being diagnosed with a life-threatening illness transforms one's life starting at the moment of diagnosis. People cannot immediately grasp the realness and the meaning of what just happened to them upon hearing the words "You have …" Once the reality of the situation starts settling in, people rediscover the taken-for-granted aspects of their lives, their relationships, priorities and most importantly, their bodies.

In the ordinary course of daily life, we seem to forget about our bodies unless there is "news" about them (such as losing or gaining weight, having a new haircut etc.) We are usually not aware of our breathing, walking and most other bodily experiences. Our bodies become present in our daily lives and in social interaction when there is a "problem" with them. It is when our bodies interfere with the ordinary features of everyday life such as breathing, talking and driving that they become visible to us.

Many researchers have studied the effects of a diagnosis of a life-threatening illness on one's self. They demonstrate that it challenges previous assumptions about the relation between body and self (Charmaz, 1995; Kelly and Field, 1996), disturbs one's sense of wholeness (Bury, 1982; Charmaz, 1991; 1994a; 1994b; 1995; Murphy, 1987), and threatens the integrity of the self (Kestenbaum, 1982). Furthermore, Charmaz (1994a, p. 238) indicates that, "as people learn how intrusive their illnesses are, the discoveries of self that they make are typically framed in loss (Sarton, 1988; Veith, 1988)." Feelings such as sorrow, betrayal and shame accompany the loss of one's familiar definition of self (Charmaz, 1994a.) Yet crises and losses may result in a renewed and transformed self, leading to a deeper meaning and understanding of life (Charmaz, 1994a, p. 238).

> Through resolution, ill people are able to put their illness and themselves into a new perspective. The discoveries of self become positive and they view themselves as having grown; they see new strengths in themselves (Sandstrom, 1990; Weitz, 1991). They re-interpret their feelings and shift their viewpoints.

For instance, Dianne Mortwedt Kramer (2001) explains the changes in her following her diagnosis with cancer as follows:

> I actually feel changed/transformed at the cellular level.... I appreciate all my senses and my creature comforts much more now.... I give myself much more permission to be me now: I'm more spontaneous; I laugh more; I'm less intense.... My soul is deeper, wiser, older. It's grown or expanded or been reconstructed. I feel remodeled or, more accurately, transformed. It's something that happened to me, maybe in spite of me.... I like who I am better now. I'm more real. I'm tougher.... There's so much more dimension, depth, beauty, realness, compassion, and clarity than in the world I used to belong to. I feel proud of our having earned our citizenship here. We didn't choose this citizenship, but we've gone through a lot to get here. It's a place of the heart – and a place of paradox (Kramer, 2001, I'm More Real; I'm tougher).

Distinguishing the two worlds before and after her diagnosis with cancer, Kramer refers to an "earned citizenship" in the new world she now belongs to, where she feels transformed, and her appreciation for life and for her being is richer and deeper. Despite the difficulties and suffering Kramer went through following the diagnosis of a life-threatening illness, she states that she likes who she is better now and that she feels proud of where she belongs.

Similarly emphasizing the positive influence of illness on her, a young woman with multiple sclerosis ironically prescribes a disease for healthy people to enjoy life: "I can laugh, which again so many can't and that's sad, because there's nothing wrong with them and their bodies. Maybe they should get a disease" (Charmaz, 1994, p. 239). Paradoxically, experiencing serious chronic illness might result in realization of new meanings about one's self and life. It is a difficult balance to achieve, however, to allow "definitions of illness to touch and shape the self without becoming inundated by them.... In order to gain a sense of resolution and renewal, ill people need to be aware of their illness and appraise its implications upon their emerging selves" (Charmaz, 1994, p. 241). That is, a life-threatening illness does not automatically offer positive transforming effects and new meanings to people by itself. It is by being mindful of the illness experience and reflecting on it that people might make it meaningful for themselves.

In this research, I study the discourse of breast cancer survivors to find out about their experiences of a transforming self in relation to the visible bodily changes they experienced. In the following, I present the purpose of this study, the theoretical framework, benefits and the importance of this study on the meaning of appearances for research on social interaction.

Purpose of the Study

This study focuses on the transformations of self in the reported experiences of some breast cancer survivors, particularly as related to changes in physical appearance due to radiation, chemotherapy or surgery. Using various data sources from cancer survivors (including interviews conducted for the study, published journals, photographs and public presentations), I study the ways in which selves are reconstituted in relation to a changed bodily appearance (ranging from temporary hair loss to mastectomy.) Social interaction and relationships played a significant role in these processes of transformation where support from intimate others and friends reinforced the creation of an integrated identity and the realization of new meanings about one's self.

The reported experiences of individuals constitute the main source for understanding *appearance as a bodily experience* in this study. I use the term “bodily appearance” to refer to physical appearance as an embodied phenomenon rather than mere image or representation, that is, as a form which is not pulled apart from the body/self.

My research questions are:

What are the emergent themes in the narratives of breast cancer survivors that relate to self after a change in bodily appearance?

What are the cultural implications of breast cancer survivors’ talk about appearances?

Theoretical Framework

An analysis of the reported experiences of survivors provides an opportunity to examine the discursive construction of the self and the body, and specifically, the relation between physical appearance, self and image (presentation of self before the others) mainly because cancer is not only a threat to one’s body but it might also challenge one’s appearance (looks), self and social relations.

For the purpose of this analysis, I use a definition of self as a social process formed in interaction with others. Mead's (1934) explication of social self provides a framework for understanding the meaning(s) attached to physical appearance through the responses of others. Mead defines self as "that which can be an object to itself" (1934, p. 140), and states that unless an individual is an object to himself s/he is not a self in the reflexive sense.

> The individual experiences himself as such, not directly, but only indirectly, from the particular standpoints of other individual members of the same social group, or from the generalized standpoint of the social group as a whole to which he belongs. *For he enters his own experience as a self or individual, not directly or immediately, not by becoming a subject to himself, but only in so far as he first becomes an object to himself* just as other individuals are objects to him or in his experience; and *he becomes an object to himself only by taking the attitudes of other individuals toward himself* within a social environment or context of experience and behavior in which both he and they are involved (Mead, 1934, p. 138) [Emphasis added].

Mead emphasizes that the individual appears in his/her own experience as a self by becoming an object of his/her experience and by responding to one's self as another person would. After a self has arisen, the individual is able to carry on an inner conversation with himself as he would with other people (conversation of gestures.) That is, an individual might start to say something (vocal gesture) and that calls out a reply in herself (such as it would in another person), which, then might change what she was going to say (similar to how others responses to us might change the direction of the conversation.) In this way, one can engage in dialogues with herself. I refer to this *reflexive* self that is created in interaction in discussing the meaning of appearances in this study.

By locating the self in the body, Merleau-Ponty (1976) plays a significant role in our understanding of the relation between bodily experience and self. Arguing that all human experience comes out of our bodily position, Merleau-Ponty (1976) emphasizes bodily experience as the source of selfhood. Rather than being just "an object in the world," it is through our bodies that we come to know the world and our relationship to it (Merleau-Ponty, 1976, p. 5). Taken together with Mead's (1934) conceptualization of conversation of gestures that is essential to the development of self, Merleau-Ponty's focus on the body offers some useful insights for the examination of how the physical body and self constitute each other. One might engage in a self-body dialogue by acting towards the body as an object of experience and making it "a part of the conversation of gestures composing self." (Mead, 1934) A change in one's bodily experience might disrupt one's ongoing self-body dialogue as it might mean not being able to experience one's body/self as one is used to in terms of visual, tactile and behavioral (what one can or can not do) aspects. For instance, the mirrored image of one's body after a mastectomy or the experience of one's body when hugging others or making love might be so unfamiliar that it might lead to alienation from one's own body. Most survivors in this study reported a "loss of self" because they could no longer integrate their altered physical appearance as a part of themselves. By integrating symbolic interactionist and phenomenological approaches to the study of physical body and self as suggested by March (2000), this study locates the self in the body as a *reflective* process emerging through social interaction and examines the ways in which self is (re)constituted in surviving cancer.

Furthermore, this study relies on Goffman's (1959, 1963b) concepts of "presentation of self" and "stigma" in discussing the meaning of appearances that result from social interaction with others and its implications on one's self. Drawing attention to the distinction between "self" and "performed self," Goffman (1959) emphasizes that the social self needs to be continually achieved in and through interaction. It is through self-presentation that selves are constructed and maintained in interaction. The self is not an independent fixed entity that resides in the individual, but the production of self in interaction is a *mutual* accomplishment, as an image presented by the performer, which in return is credited or discredited by an audience. The role of the audience in the mutual construction and the maintenance of self in interaction become significant in discussions of "stigma." Goffman (1963b) describes "stigma" as an undesired differentness an individual possesses that violates the social expectations of people and results in the discrediting of the person from a whole, usual individual to a tainted, devalued, discounted one. Physical deformities, blemishes of individual character (such as dishonesty, alcoholism, mental disorders etc.) and the stigma of race, religion, nation, are the three main categories of stigma that Goffman (1963b) distinguishes. "Stigmatization" is a major concern for breast cancer survivors who experienced temporary or permanent visible bodily changes.

Hair loss, for instance, affects one's presentation of self where a bald female attracts looks and stares, resulting in feelings of vulnerability and discomfort. Receiving unfamiliar responses from others to one's changed looks make some women question who they are. Furthermore, a "deviant" appearance disrupts one's social relationships including the public as well as the intimate ones. Goffman's (1959, 1963b) concepts of self-presentation and stigmatization constitute the basis for my discussions of the effects of a changed physical appearance on one's self and social interaction and the meaning of appearances.

Locating Mead's (1934) "reflexive self" in the body, I examine the implications of the visual and tactile changes in women's bodily experiences on their selves, self-presentations and social interactions. A change in bodily appearance might be experienced in terms of its visual aspects (such as seeing one's self as bald in the mirror as well as being seen and responded to as bald) or as a tactile experience of her body (such as hugging people or making love after mastectomy.) I emphasize *appearance as bodily experience* in terms of its visual and tactile aspects in discussing its implications on one's self and social relations. Finally, I use "image" to refer to one's self-presentation in front of the others (Goffman, 1959) and "appearance" for "looks." A change in one's physical appearance influences her self-presentation, thus, her image. In some cases where "image" includes the implications of physical appearance, I use "image" and discuss the two concepts together.

Benefits of the Study

This study contributes to the emerging literature on the relationships among the physical body, image, self, and social interaction. Integrating Mead's (1934) concept of social selves with Merleau-Ponty's (1976) discussions of embodiment, it shows that through the responses of others to our physical body and by internalizing those responses we make our bodily appearance a part of who we are.

This research provides a unique perspective to discussions on the relation of the body, self, the visual presentation of self and social interaction by viewing *appearance as a bodily experience*, and discussing the implications of a changed bodily appearance on one's self and the order of social interaction. Unlike many studies, which analyze the body as a symbol or text disconnected from the actual body, it does not separate appearance from the body, but locates it in the body.

Furthermore, it extends Goffman's (1959, 1963b) concepts of "self-presentation," "stigma" and "interaction order" to include issues of bodily appearance and self in surviving breast cancer, a context where intimate interaction is emphasized as well as public interaction. Goffman (1963b) emphasizes the management of stigma in public life while he only briefly acknowledged that an individual's stigma might have implications for intimate/domestic relationships. In his discussion on personal identity and stigma, Goffman (1963b) focuses primarily on the techniques of information control such as passing and covering depending on the degree to which an individual is personally known to others. This study examines the ways in which a diagnosis of cancer might stigmatize individuals, the implications of it for one's self, intimate/domestic affairs and public interaction, and the ways in which some survivors responded to their situation.

Breast cancer survivors interviewed in this study reported a “loss of self” as a result of a change in physical appearance which they attributed to their inability to integrate their altered physical appearance as a part of themselves. Giving a voice to breast cancer survivors for their experiences, this research adds to the interactionist research on the sociology of chronic illness and disability with its emphasis on the processes through which meanings of appearances develop from social interaction with others.

This study also offers insight to contemporary feminist scholarship by incorporating the actual experiences and voices of women, which illustrate how survivors actually made decisions regarding the transformations in their appearance. By examining how women actually engage in the production of their bodies, this study emphasizes the agency of individuals in the production and maintenance of their bodies. An implication of this study for feminist theory is the finding that women did not just act as “cultural dupes” trapped in the ideologies of the beauty industry but resisted the views of others in constructing their sense of self. Thus, it shows that the body can act as an active entity rather being seen just as a “product of discourse.”

The American Cancer Society (ACS) states that breast cancer is the most common cancer among women, other than skin cancer. It is the second leading cause of cancer death in women, after lung cancer. The statistics showed that about

192,200 women in the United States were expected to have invasive breast cancer in 2001. About 40,200 were expected to die from the disease in 2001. Breast cancer death rates declined significantly from 1992 to 1996, with the largest decrease in younger women-- both white and black. This decline is stated as the result of earlier detection and improved treatment (http://www.cancer.org/downloads/STT/BrCaFF2001.pdf). Furthermore, the ACS notes the importance of staying active and fighting depression during treatment and recognizes the importance of interaction and a supportive environment.

As I discuss in detail in the next section, despite the large number of research on various aspects of cancer (social, medial, psychological), not much attention have been paid to the processes of social interaction in surviving cancer. This study points to the significance of the social and interactional aspects of the experiences of cancer survivors in the transformations of self in surviving cancer. This research aims to show that there exists a potential for the constitution of a renewed and transformed self in surviving cancer. It might prove useful for people suffering through cancer treatments, as well as their loved ones, to go beyond living a diminished quality of life and create meaningful and valued lives.

Appearance and Social Interaction

Despite the growing interest in the medical, social and psychological dimensions of cancer, little attention has been directed toward the processes of social interaction, over the course of cancer treatment and recuperation. It is well documented in the literature that variables such as age, marital status, education and reconstruction are related to a person's adjustment to mastectomy and recovery (Bloom, 1982; Funch & Marshall, 1983; Meyerowitz, 1980; Eckenrode, 1983; Goldberg, Stolzman & Goldberg, 1984; Schain, Wellish, Pasnau & Landsverk, 1985; Wellisch, 1985). Moreover, research suggests that change in or loss of a breast affects a woman's perception of her social self as well as her physical being (Bloom, 1982; Carroll, 1981), and that surgery and related treatments may entail major changes in self-concept (Goldberg, Stolzman & Goldberg, 1984; Mastrovito, 1974; Sutherland, 1967). Similarly, studies on the side effects of cancer treatment such as hair loss, which varies from slight thinning to complete baldness, indicate that loss of hair results in low self-esteem (Baxley, Erdman, Henry & Roof, 1984).

There has been a lack of research, however, regarding the processes through which meanings of appearances emerge from social interaction with others. As opposed to viewing the self as a constant set of attributes that are internally circumscribed within a biological organism, the position taken here is that questions of identity can be studied fruitfully as they arise in social interaction (Carbaugh, 1996). Even very subtle aspects of communication can affect someone's performance or self-concept (Kovarsky, Duchan & Maxwell, 1999). From the work of George Herbert Mead (1934), Kenneth Gergen (1991), and others (Blumer, 1969; Burkitt, 1991; Harre & Gillet, 1994), the notion of a socially situated, mutable self that is subject to change through interactions with others has emerged. Studying the implications of hair loss or mastectomy on one's self by taking one's social interactions with others into account provides an opportunity to find out about the ways in which people interactively create meaning about their bodies and themselves. Positive responses of others to one's changed appearance that support and validate one's identity play a significant role in how one experiences her body, self as well as the decisions she makes in surviving cancer. Family and friends can help the creation of an integrated self that is challenged by diagnosis and treatment through caring, encouraging and accepting relationships.

Kaiser (1998, p. 95) emphasizes the importance of placing the self in the context of social interactions and social life and states that, "No person exists in a vacuum or forms impressions about his or her own appearance apart from others. It is through the social transactions with others in the social contexts of everyday life that we formulate ideas about who we are or how we see and evaluate our bodies and appearances."

Similarly, Stone (1965) defines appearance as a social process through which selves get established, maintained and changed. The presentation of our appearance influences the response of others:

> In appearances, then, selves are established and mobilized. As the self is dressed, it is simultaneously addressed, for, whenever we clothe ourselves, we dress "toward" or address some audience whose validating responses are essential to the establishment of our self (Stone, 1965, p. 230).

Our appearances and the visual presentation of ourselves influence social interaction and the self. Receiving validating responses from others to the way we dress and look allows the maintenance of self in interaction. Unconventional or "unusual" looks, however, might disrupt social interaction and discredit the self. A bald female, for instance, receives looks and stares from others that might make her uncomfortable. In this research, I emphasize the role of social interaction in understanding the transformations of self in relation to a changed physical appearance in surviving breast cancer. Thus, this study aims to fill the gap in the social interactionist research on the processes through which meanings of appearances emerge from social interaction with others.

In the following chapter, I review the existing research on the discursive construction of the body and selfhood and discuss the contributions of the present study to the literature. Then, in Chapter Three, I discuss the methods for data collection and analysis and provide information on the sources of participants as well as the procedures for the recruitment of participants. In Chapter Four, "From Diagnostic to Aesthetic: Moving Beyond Diagnosis," I analyze two contradicting discourses on the aesthetic consequences of cancer treatment, the representations of women in the catalogues and pamphlets distributed in a meeting of the Look Good Feel Better (LGFB) program, and the "Stephanie Project," a verbal and visual documentary of a woman's experience of surviving breast cancer. My analysis of the excerpts from the Stephanie Project demonstrate the emergence of a reintegrated and positive sense of self through aesthetic discourse and supportive relationships contrary to diagnostic discourse as well as the discourse of the LGFB pamphlets catalogue that focused on what was wrong with the body. In Chapter Five, "The Meaning of Appearance in Surviving Cancer," I provide excerpts from my interviews with breast cancer survivors and examine the implications of altered image on social interaction and self-definition through their eyes. Finally, in Chapter Six, “Discussion,” I focus on the cultural implications of the findings of this study and suggest some directions for future research.

CHAPTER TWO

THE SELF AS AN EMBODIED EXPERIENCE

The Discursive Self

Discussions on *being* a body and *having* a body are significant to the studies on the discursive construction of the body and self. Our bodily existence might have a central role in constituting our social relations, order of interaction and experience of self as well as being constituted by them. In this chapter, I review existing research on the discursive construction of the body and the self, and discuss the contribution of the present study to the literature.

Neetleton and Watson (1998) emphasize the centrality of bodily experience in everyday life by referring to the body as something we *have*.

> If one thing is certain, it is that we all have a body. Everything we do we do with our bodies – when we think, speak, listen, eat, sleep, walk, relax, work and play we 'use' our bodies. Every aspect of our lives is therefore embodied (Neetleton and Watson, 1998, p. 1).

An even more prominent role is given to the body in phrases like, "I am my body." Fraleigh (1987, p. 25) refers to the paradox of our understanding of self due to the fact that

> The self is that which says I and that which at the same time exists I. Bodily existence is given in "I am." I *am* body at the same time I claim to *be* a body; or more curiously and dualistically put, as I claim to *have* a body. When I say "I have a body," I distance myself from my body in order to be in possession of it. I hold it apart, I objectify it (Fraleigh, 1987, p. 25).

The reflexive nature of self as that which can be both the subject and the object of experience, then, results in a dualistic understanding of the body and the self. Accordingly, since the ‘90’s a number of researchers have indicated that the living, experiencing body has been neglected in social theory (Featherstone & Turner, 1991; Frank, 1990, 1991a, 1991b; Freund, 1988; Kotarba, 1994; Shilling, 1993; Neetleson & Watson, 1998; Olesen, 1994; Turner, 1984, 1991, 1996; Williams & Bendelow, 1998; Zola, 1991). Such authors criticize studies that focus on issues such as agency and social structure without taking the voices of the subjects into account, investigated the self without the body or analyzed the body as a site of representation, a symbolic form rather than a lived entity. As Freund (1988, p. 839) writes, “The subject matter of social sciences is supposedly living, breathing human creatures of flesh and blood. Yet, both psychology and anthropology, as well as sociology, in particular, have a curiously ‘disembodied’ view of human beings.”

In contrast to Freund’s (1988) view that the body has long been studied as a symbolic rather than an experiential entity, a site of representation for power/gender relations and social control, some scholars claim that it might be more exact to refer to this negligence as “submergence” (Turner, 1996), an “absent-presence” (Shilling, 1993) or the “secret history of the body” (Featherstone & Turner; Turner, 1996; Williams & Bendelow, 1998). For instance, Shilling (1993, p. 24) explains that:

> The body as a physical component of social control had a habit of appearing in some of their [classical sociologists] most important writings on methodology and modernity. This is particularly evident in Marx’s analysis of how the development of capitalist technology linked and subordinated

> working class bodies to machinery, and Weber's writings on the rationalization of the body within bureaucracy.

Focusing on the body as a physical structure controlled and shaped by power relations, however, does not account for the embodiment of persons. Similarly, the political significance and implications of the physical body in social theory are exemplified in Turner's (1996, p. 37) statement that on a wider social scale, "as Karl Marx constantly reminded us, society could not exist without the constant and regular reproduction of our bodies and without their allocation to social places." It seems, however, that even if some scholars were concerned with the "body as a physical component of social control," the focus remains on the body as a symbolic rather than an experiential entity. The discussions of the body as a political symbol do not include such issues as how people related to and experienced their bodies within that political system or how people reacted to being subordinated as working class bodies. That is, the body as an actual, lived entity is not mentioned.

Shilling (1993, p. 10) explains that both Foucault and Goffman share a social constructionist view that the body is shaped, constrained and even invented by social forces and they "have placed the body at the core of their respective analyses of the 'interaction order' and disciplinary systems." They differ, however, in their identifications of what these forces are and analysis of how social forces affect the body. Foucault (1973, 1980) focuses on how our experience of embodiment is constituted and controlled by discourse. He treats the body as a discursive product of power/knowledge and discusses the ways in which various discourses—on health, sexuality, criminality etc— operate to discipline the body. According to Foucault (1980), power invests in bodies through these discourses as it operates to manage, control and reproduce them. For instance, contemporary discourses on health, beauty, diet and exercise influence the way people make sense of and take care of their bodies: "The care of the body is not simply about health, but about feeling good: increasingly, our happiness and personal fulfillment is pinned on the degree to which our bodies conform to contemporary standards of health and beauty" (Featherstone, 1991). Furthermore, the particular practices of body care to achieve the standards promoted by discourses (that is, the discipline regimes that operate on the body) might undergo transformation. For instance, applying a Foucaudian approach to dress and appearance, Wilson (1992) argues that self-discipline emerged in the twentieth century to take the place of external forces of control. Even if it might at first seem like the dress codes today are less rigid and constraining than the nineteenth century corset that functioned to discipline the body,

> we have the modern corset of muscle required by contemporary standards of beauty. Beauty now requires a new form of discipline than no discipline at all [sic]: in order to achieve the firm tummy required today, one must exercise and watch what one eats. While the stomach of the nineteenth-century corseted woman was disciplined from the outside, the twentieth century exercising and dieting woman has a stomach disciplined by exercise and diet imposed by self-discipline (Entwistle, 2000, p. 20).

A “looser” (Foucault, 1980) form of power over the body has emerged, which calls upon individuals to monitor their own behavior rather than the external, physical disciplining of the body. Power, then, might invest itself on the bodies in different forms and practices, and through a variety of discourses—sexuality, medicine, beauty etc. In *The Birth of the Clinic*, for instance, Foucault (1973) describes that the ways in which medicine viewed the body throughout history are based on certain forms of knowledge and mechanisms of power. Medicine “is itself a moral and political enterprise (i.e. bio-power) concerned with the regulation, surveillance and control of bodies through the medical regimen” (Williams and Bendelow, 1998, p. 29-30).

Despite the significance of Foucault’s work in social theory, his account of the socially constructed body does not inform us about the ways in which discourses on the body are lived and experienced by individuals. In what ways do individuals adopt and put these discourses into practice in their own lives? What do these practices mean for people? Is resistance to discourse possible? These are some of the questions that are not addressed by Foucault. He produces an account of the body as an object of power/knowledge, which is criticized due to a lack of interest in the “materiality of the phenomenal body as an *active*, experiencing, intentional entity” (Williams & Bendelow, 1998, p. 35). Thus, the agency of the bodies in responding to and resisting discourse is undermined (Entwistle, 2000) and bodies are assumed to be “passive bodies” (McNay, 1992) without agency or power.

Following Foucault, beauty as cultural discourse became a framework of interest through which the female body, femininity and beauty are analyzed as a product of cultural discourses (medical, popular, scientific etc.) For example, Bordo (1989, 1990, 1993) focuses on images of the female body as a site for exploring how gender/power relations are constituted in Western culture. Bordo (1993) examines the relation of discourses to contemporary bodily phenomena associated with femininity— hysteria, eating disorders, agoraphobia, and more routine beauty practices like dieting and bodybuilding, to understand why women are preoccupied with their appearance.

The rise of feminism is considered as an important factor in highlighting the importance of the body (Frank, 1991b; Shilling, 1993; Turner, 1996). Addressing the body as a basis of systems of subordination and domination and social relations of inequality (e.g., sexual division of labor, commodification of women's bodies etc.) feminist theorists examined "what it is about the embodied existence of people that has maintained men's domination over women" (Shilling, 1993). Similarly, as Davis (1995) explains, whether the emphasis is on *beauty as oppression* or *beauty as cultural discourse*, feminist theorists have focused on how the beauty system functions to control women. In the first perspective, beauty is treated as an essential factor regarding the social subordination of women (Baker, 1984; Chapkis, 1986; Wolf, 1991). Women are presented as victims of beauty and ideologies of femininity (Davis, 1995). Davis (1995, p. 57), however, criticizes the feminist approaches to beauty in their lack of emphasis on

> questions which concern women's active and knowledgeable involvement in practices which are also detrimental and/or degrading them. Despite their differences, both oppression and cultural discourse models of beauty account

> for such ambivalencies by assuming that women who choose to have cosmetic surgery do so because they have had the ideological wool pulled over their eyes. They are cultural dupes.

Thus, women's lived experiences with their bodies seem to be left aside in contemporary feminist scholarship. There is a need for studies that include women's lived experience and their own interpretations of their relation with their bodies. Accordingly, Williams and Bendelow (1998, p. 65) suggest, "a shift in the analytical emphasis from a concern *about* bodies (i.e., the problem of order and representation) to one which emerges *from* bodies (i.e., body use, the embodiment of social action.)"

The majority of anthropological studies on the construction of bodily aspects of self and identity also focus on the ways in which bodies are ordered through the use of ritual and symbolism and undermine the living, experiencing body. For example, Kaphcan (1993) analyzes body marking among Moroccan women through the ritual of henna art as a way of inscribing cultural discourses on the body (passage to womanhood.) In the collection of a variety of anthropological studies on the body that Young (1993) gathered together, the "surface of the body as a site of representation for cultural discourses" constitutes the central theme. While providing a significant perspective on the social construction of the body, these symbolic approaches to the human body are concerned with issues of representation and lack of attention to issues of lived experience (Neetleton and Watson, 1998; Williams and Bendelow, 1998.)

The lack of attention to our bodily experience is also relevant in our everyday lives. Unless we make our bodily presence an object of our awareness, our bodies might go unnoticed since they are so common to us in the sense that water is common to fish. Leder (1990) points out the “taken-for-grantedness” or the “absence” of our bodies from our awareness in our day-to-day lives:

> While in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterised by absence. That is, one’s own body is rarely the thematic object of experience. When reading a book or lost in thought, my own bodily state may be the farthest thing from my awareness ... the body, as a ground of experience ... tends to recede from direct experience (also cited in Neetleton and Watson, 1998, p. 10).

We do not always orient to our bodies; thus, our consciousness of the body as a direct object of experience might not be always present. Ordinarily, when there is something new about our bodies, such as, having a new haircut or losing/gaining weight, we become more aware of our bodies, at least for a while. Paying attention to our breath as an object of consciousness during meditation is a practice where our awareness of our bodily existence is heightened. A major context in which we become aware of our bodies is when there is a problem with the body. A change in the functioning of the body or the appearance of it due to illness makes the body a focal point of attention. As reported by the survivors I interviewed and as indicated by many studies on illness, the body cannot be taken for granted anymore when there is a serious problem with it and some people no longer feel at home in their own bodies.

Addressing the implications of even minor changes in bodily appearance, Neetleton and Watson (1998) emphasize that regardless of the extent to which we are aware of our bodies, we carry out ‘bodily’ routines in the morning, prepare our body for public display, look at our body in the mirror and may be affected by small bodily changes that we notice.

> Yet another gray hair, the size of our stomach, a spot that has just appeared on our chin. Even the most minor bodily changes may, for some of us, impact upon how we feel about facing the day and all the social interactions that it may comprise... Our body-image, how we perceive our body, may in turn affect our ability to relate to others and will influence how others respond to us (Neetleton and Watson, 1998, pp. 1-2).

Presentation of our bodies to others influences the responses of others to us as well as our responses to our selves. Moreover, people do not just respond to our bodies as separate objects, but as an extension of our selves. For instance, failing to manage one's body appropriately according to the order of social interaction might result in embarrassment and "stigma" (Goffman, 1959, 1963b, 1971) making the person vulnerable. As Merleau-Ponty (1976) notes, we do not orient to our bodies as an object but as the "envelope of self." The implications of our bodily demeanors on ourselves—including the control of the body in terms of its aesthetics, movement, and appropriateness in general— in making us acceptable, desirable or not, then, makes bodily changes (and bodily matters in general) significant.

The Embodied Self

Merleau-Ponty (1976), locates the self in the body, and emphasizes that all human experience comes out of our bodily position. He focuses on the experiential dimensions of being located in a body. Rather than seeing the body as a passive object, Merleau-Ponty (1976, p. 5) states that our bodies "give us our expression in the world" and that, we become *visible* in the world through our bodies. Thus, Merleau-Ponty brings our bodily experience to the front as the existential ground for being. Furthermore, instead of viewing the body merely as a textual entity (a representation) produced by discursive practices, Merleau-Ponty shows that it is an active vehicle of being that we not only act on, but also, act *with*.

Goffman's (1959, 1963a, 1971) work emphasizes the agency of the individual in the production and maintenance of bodies in everyday life practices such as preparing our bodies for presentation, managing our bodies as we walk in public spaces or wait in line. He shows that failure in the management and control of bodies might result in embarrassment and/or "stigma" due to an interruption of the social order.

Emphasizing that it is through *self-presentation* that selves are constructed and maintained in interaction, Goffman (1959, 1967) states that when the order of interaction is disrupted the maintenance of selves are threatened. The "interaction order" consists of a state where individuals tend to conduct themselves during an encounter so as to maintain both their own face and the face of the other participants.

> This means that the line taken by each participant is usually allowed to prevail, and each participant is allowed to carry off the role he appears to have chosen for himself. A state where everyone temporarily accepts everyone else's line is established (Goffman, 1967, p. 11).

Thus, it is through the interaction order that individuals are able to produce and maintain a sense of who they are. Changes in bodily appearance due to cancer treatments, however, might result in "stigmatization" (Goffman, 1963b) and threaten the integrity of one’s self and the maintenance of interactional encounters. Among the major types of “stigma,” “an attribute that is deeply discrediting” (Goffman, 1963b, p. 3) are bodily disfigurements, “blemishes of individual character” (such as mental disorders), and group affiliation. An individual who has an “undesirable differentness” that violates the expectations of others is discounted and devalued due to his/her stigma.

The emphasis on the presentation of self in Goffman’s (1959) work created a sphere in which Goffman is said to affirm the disappearance of the self as argued by postmodern social theory (Battershill, 1990; Dowd 1991; Gergen 1991; Langman 1992; Tseëlon, 1992). These scholars argued that in Goffman’s work, “selves are no more than images created in conformity with situational expections” (Schwalbe, 1993, p. 333). Taken as a text, self-presentation is claimed to have no fixed meaning from a postmodernist view and any meaning that it might have is not under the control of the individuals who create them. “On this reading of Goffman, there is no warrant for seeking a true self beneath the images, since what you see is all there is to get.” (Schwalbe, 1993, p. 333)

Schwalbe (1993) agrees that there is an overlap between Goffman’s analysis of self-presentation with poststructuralist and postmodernist analysis of the self’s demise but, he also states that there is more to the self than image in Goffman. As opposed to a “decentered” notion of self in Goffman, Schwalbe (1993) demonstrates that in Goffman’s work, the reality of the self as a unified, autonomous entity is evident in moments of decision, resistance and feeling. When individuals make decisions regarding what face to present in an encounter, what kind of repair work to do when there is a need for it, they act as "image *makers*" (Schwalbe, 1993, p. 337) displaying that they are not merely images. Schwalbe (1993) further argues that in moments when individuals take a stance and try to assert themselves over against others who would prefer them to act differently, that is, in the moments of resistance, the reality of self becomes evident.

Goffman's discussions of "interaction order," "self-presentation," and "stigma" illustrate an embodied self where bodily actions and the management of bodies play a significant role in the maintenance of social interaction. Rather than emphasizing the self as a text, Goffman (1959, 1963a, 1971) shows the ways in which individuals give impressions through their bodily actions and presentations including how we carry our bodies in various social situations, our facial expressions and our failings to manage and present our bodies appropriately. For instance, he starts *Stigma* quoting a letter from a sixteen-year-old girl who was born without a nose and became so desperate in her relations with others that she was considering to commit suicide. Throughout the rest of his book Goffman illustrates the various kinds of stigma and their implications in public settings as well as techniques people use to manage their stigma. Reducing an understanding of Goffman's self and self-presentation to just an image of self would be to ignore the embodied self he demonstrates through his work.

Goffman's notions of "interaction order," "stigmatization" and "presentation of self" carry significant implications for this study on bodily appearance, self and social interaction. A change in one's bodily appearance brings about changes in one's experience of self and social relationships. For instance, the unconventional, unusual look of a bald female might receive looks and stares and the disruption of interaction, resulting in her stigmatization. In addition to the visual change, the tactile experience of one's body also changes as a result of mastectomy, which carries implications for one's presentation of self in public and private contexts. Changes in one's visual or tactile experiences of self might lead to various decisions and actions to avoid "stigmatization," and to maintain one's self and the interaction order.

This study points to women's agency in being able to actively make sense of and make decisions regarding their own bodies and bodily appearances. In accordance with Schwalbe (1993), it shows that the reality of a unified self is manifested in the moments of resistance when individuals take a stance and try to assert themselves against others who would prefer them to act differently. This active and autonomous view of self questions the unilateral characterization of appearance and beauty practices as oppressive and an understanding of women as manipulated and passive. In doing so, it does not ignore the influence of culturally defined social relations that the body is located within in shaping the body. Instead, it starts from women's perspectives to show how they actually engage in the production of their bodies.

The Embodied Self in Illness and Disability

The emerging literature of chronic illness and disability emphasizes the centrality of bodily experience in everyday life. There is a growing sense of need for empirical research on the discursive construction of the "lived body" among students of disabilities. Such studies are very insightful in filling the absence of the "voices emanating from the bodies themselves." (Neetleton & Watson, 1998, p. 12)

In addition to focusing on the consequences of chronic illness in the management of daily life (Locker, 1983; Jobling, 1977; Strauss, 1975), research has emphasized the significance of experiencing chronic illness as a part of people's life stories and for creating self and identity (Corbin and Strauss, 1987; Charmaz, 1987, 1995; Kelly, 1992; Sandstrom, 1990; Yoshida, 1993.) People struggle with the identity problems that chronic illness brings, primarily as they work to regain a sense of control and balance over their disrupted lives.

Interactionist research on chronic illness reflects upon the personal bodily experiences of ordinary men and women and examines the implications of illness for self and identity (Bury, 1982; Charmaz, 1991; Corbin & Strauss, 1987; Frank, 1991a; Kelly, 1992; Kotarba, 1994; Yoshida, 1993.) The position taken by interactionists is that questions of identity can be studied fruitfully as they arise in social interaction (Carbaugh, 1996).

Arthur Frank's (1991a) *At The Will of the Body*, and Kathy Charmaz's (1991) *Good Days and Bad Days* are two works celebrated for providing interactionist accounts of the body as lived experience. Situating the experience of chronic illness in the body, both books demonstrate the “return of the body” to theoretical accounts of the body. Charmaz’s (1991) work focuses on the experience of chronic illness from the perspectives of sufferers and examined how people make sense of illness. Based on interviews with chronically ill people, Charmaz (1991) explores the implications of living with chronic illness for the emerging self. Narratives of chronically ill people revealed three stages of experience: chronic illness as interruption, intrusion and immersion. Each stage depicts the impact of illness on the relation between body and self and the meaning of time. Defining illness as an interruption assumes that illness is temporary and that recovery is expected in a short duration of time. Thus, it is something to “struggle against and to defeat” (Charmaz, 1991, p. 12) with no indication of an altered future. When the effects of illness continue, people are forced to accommodate it. Chronic illness becomes a permanent part of life. Intrusive symptoms disrupt daily activities and require efforts to control those symptoms and keep the illness in the background of one’s life. When illness cannot be contained in the background anymore and demands changes in the structure of people’s lives, people experience immersion in illness. Each way of experiencing illness indicates a different relationship to time. Furthermore, a changed relationship to time influences the meanings of illness and the changing self in illness (Charmaz 1991).

Frank (1991a) survived a heart attack at the age of thirty-nine and was diagnosed with cancer a year later. He vividly illustrates his experience of becoming ill, his changing body and self, his relation with the medical system, treatment and the meaning of illness. Referring to illness as a “dangerous opportunity” that both forces and allows one to discover the value of one’s life and choose the kind of life one will lead, Frank (1991a, p.2) states that, “even continuing illness and dying contain opportunities for renewal.” Frank (1991a, p. 4) further emphasizes that, “renewal is easiest if it is a shared process,” and demonstrated the socially achieved character of the meaning of illness throughout his account of his experience.

There are a couple other interactionist studies on the bodily aspects of self and identity in chronic illness focus on the consequences of radical surgery (Kelly, 1992) or injury such as traumatic spinal cord injury (Yoshida, 1993.) The studies on chronic illness and the body are just a start signaling the significance of the centrality of the body in our lives. How we experience our bodies in a variety of contexts still remains to be explored.

Self and Appearance

Davis’ (1995) work, *Reshaping the Female Body*, focuses on issues of self and identity in relation to a changed bodily appearance. Based on interviews with cosmetic surgery recipients, plastic surgeons and field work in medical settings, it offers insight into women’s lived experience with their bodies. Davis (1995) describes her motivation as giving voice to the experiences of women: “While contemporary feminist scholarship on beauty enables me to be critical of cosmetic surgery and the beauty system it sustains, it falls short when it comes to making sense of my friend’s experience” (Davis, 1995, p. 57). By focusing on women’s experiences with cosmetic surgery, "how they actually decide to have cosmetic surgery, and how they access their actions after the fact," Davis (1995, p. 58) shows how cosmetic surgery might be seen as a way to become "ordinary" ("Being ordinary" is used in contrast with an experience of being different or abnormal in physical appearance and suffering due to such experience.) Thus, cosmetic surgery becomes a way to avoid "stigmatization." Showing that cosmetic surgery can enable women to renegotiate a sense of self in relation to their bodies, Davis (1995, p. 58) concludes:

> In this way, it intervenes in the disempowering tension of Western feminine embodiment-the entrapment of objectification. Cosmetic surgery can provide the impetus for an individual woman to move from a passive acceptance of herself as nothing but a body to the position of a subject who acts upon the world in and through her body. It is in this sense that cosmetic surgery can, paradoxically, provide an avenue toward becoming an embodied subject rather than an objectified body.

Davis' work illustrates that taking women's actual experiences into account provides us with insight on how women make decisions about their bodies as agents rather than victims.

Another book that accounted for women's agency and active participation in their experiences of their bodies is Foltyn's (1989) *The Importance of being beautiful: The social construction of the beautiful self*. Emphasizing that being beautiful is primarily a social process; Foltyn (1989) shows that in the experiences of her respondents beautiful women usually grow into their looks in contrast to the idea that beautiful people are born that way. She explains that a woman recognizes herself as beautiful and develops a beautiful self through the responses of others valuing her physical appearance. Foltyn's (1989) research provides an in-depth discussion on the rewards of being beautiful, where beauty can be a form of social dominance, as well as the problems of being beautiful. She shows that when women become "beauty focused" and overemphasize the beautiful self, they might develop a problematic self. Thus, giving a "voice" to her participants allowed Foltyn (1989, p. 181) to find out about the trap of being beautiful, "making a woman hostage to the conception of herself as a beautiful woman" in addition to the benefits that beauty can provide.

Gimlin's (2002) recent study on women's own interpretations of their participation in bodywork, *Bodywork: Beauty and Self-Image in American Culture*, focuses on the ways in which people negotiate the relationship between body and self in the context of social structure. She conducted her study in four different settings; a hair salon, aerobics classes, a plastic surgeon's office and a social and political organization for fat people. Questioning the positioning of women as just "recipients" of culture, Gimlin examines the ways in which women ""renegotiate identity by changing their bodies" and "position and reposition themselves— consciously or not— in relation to contemporary ideologies of beauty" (2002, pp. 7-8).

Sault's (1994), *Many mirrors: Body image and social relations*, brings together a collection of studies that emphasize the significance of the reciprocal relationship between body image and social relations in defining each other. She states the need to consider both the cultural context (traditions, ideologies) and social relationships of the people to reach a full understanding of the meaning of body image. Her book includes a variety of articles analyzing different aspects of body image such as how people alter their bodies to express who they are and their relationship to others, the effects of a violent forced change in body image (rape) on one's social relationships, the process of internalizing racism by changing the body image etc. Incorporating cross-cultural studies on the production and consumption of bodies in various contexts, Sault's (1994) book expands our understanding of "body image within a system of culturally defined social relations" (1994, p. 1).

There are few other empirical studies that focus on the relationship between bodily appearance and issues of self and identity from an interactionist perspective. I located studies which focus on tattoos as body alterations shaping one's self (Sanders, 1988; 1994), tattoo collecting as a process of becoming deviant and as a transformative experience (Vail, 1999) and red hair as a form of deviance in shaping one's self (Heckert & Best, 1997.)

There is a growing number of studies on the body as lived experience with an emphasis on social interaction. There are a variety of contexts in everyday life that still remain unexplored, however, --from fashion to yoga, maternity to aging and more-- where people interactively create meaning about their bodies and themselves. I was able to locate one book, *The Body in Everyday Life* (Neetleson and Watson, 1998) that brings together a variety of empirical studies that focus on how ordinary women, men and children talk about their bodily experiences not only within the context of illness and disability, but also in terms of emotions, aging and gender. Expanding the range of contexts in which empirical studies have explored embodied experience, Neetleson and Watson’s (1998) book provides valuable contribution to the literature on the “lived” body.

Despite the emphasis on the implications of physical changes on self and identity in the studies of chronic illness, the role of social interaction in the creation of the meaning of bodily appearances has not been the main focus of research. Locating the self in the body, I study the implications of a changed bodily appearance on women’s experience of self and social interactions in surviving breast cancer. The role of social interaction in the creation of the meaning of bodily appearances and the (re)construction of self is emphasized. Taking into consideration the ‘lived’ experiences of cancer survivors who went through disfiguring cancer treatment, this study aims to fill the gap in interactionist research on the discursive (re)construction of the self with respect to changes in bodily appearance. Furthermore, it provides insight on the “stigmatization” of individuals in private and intimate contexts as well as public settings.

This study differs from anthropological or cultural studies research on images in that it does not examine images of self per se, or bodily appearances as cultural artifacts or texts, but focuses on *bodily appearance as experience* and the interactive creation of its meaning. Through close listening to the repetitive themes in the narratives of survivors, this study explores the cultural implications of breast cancer survivors’ talk about appearances.

This research further contributes to the literature by demonstrating that women can become active participants in their bodily experiences and have a choice in the decisions they make regarding their bodies. Thus, it shows that women aren't just "recipients" of cultural ideologies or "dupes of culture" but may resist cultural meanings.

In the following chapter I explain the methods for data collection and analysis used in this study.

CHAPTER THREE

ENTERING THE FIELD

> Ethnographic inquiry requires that researchers pursue and present the viewpoints of those with whom they have contact. Thus, ethnographers strive for intimate familiarity with the lived experiences of those they study and they attempt to convey as fully as possible the viewpoints and practices of these people to others. (Prus, 1996, p. 103)

Rooted in the experiences and activities of people surviving cancer, this study inquires about the effects of changes in bodily appearance and image on the self. In doing so, it aims to achieve "intimate familiarity" with the lives of cancer survivors and the ways in which they experience and make sense of the world. "This means talking to people about their experiences and activities, as well as observing their behavior and inquiring into their meanings, concerns, practices, and, wherever feasible, participating in those same situations ourselves" (Dietz, Prus and Shaffir, 1994, p. 2). Thus, viewpoints of the people studied, the meanings and interpretations they attach to themselves or others constitute the primary basis of this study.

This study relies primarily on three sources of data: observation, participant-observation and interviews.

The first context I observed was a meeting of the "Look Good Feel Better" (LGFB) program, a collaboration of the American Cancer Society, The Cosmetic, Toiletry and Fragrance Association, and the National Cosmetology Association. It is a "free national service which teaches female cancer patients beauty techniques to help enhance their appearance and self-image during chemotherapy and radiation treatments." (www.lookgoodfeelbetter.org, June 24, 2002) At this gathering, licensed cosmetologists helped cancer survivors address problems about hair loss, skin, and a variety of other image related issues. The main philosophy underlying the LGFB program is that, "if a woman with cancer can be helped to look good, her improved self-esteem will help her approach her disease and treatment with greater confidence." (www.lookgoodfeelbetter.org, June 24, 2002) A couple of representatives at The American Cancer Society told me about the success of the program when they indicated their unwillingness to let me in the meetings as an observer. I was given permission to attend only one session because they were concerned that the presence of an outsider might affect the effectiveness of their service.

Gatherings

The following are the words of a survivor on the website of the LGFB project:

> The *Look Good...Feel Better* program has given me an immeasurable gift. It has filled my everyday with tenderness, compassion and humor. It made me feel special and beautiful, and gave me back my confidence and made me feminine again. (http://www.lookgoodfeelbetter.org, June 24, 2002)

I recently learned that the LGFB also has a program for teenagers, which is open to girls and boys of ages 13-17 who are undergoing treatment for cancer. Similar to the group meetings for women cancer survivors, teenagers go through an interactive session on skin and hair care, nutrition, fitness and social life. There is an online component of LGFB for teens that is called "2bMe," which provides information on coping with cancer through colorful and attention-gathering animations (www.2bme.org/2bMe.html). The following answer is provided on the 2bme web page for the question "Why offer appearance tips?":

> Because the appearance-related side effects of cancer can sometimes be the most upsetting. We often tie our self-worth to appearance and peer approval. By looking good and feeling better about themselves, teens may be able to approach their disease, treatment and recovery with greater confidence. (Plus teens are always curious about skincare.)

The LGFB program acts from a basic assumption that people feel better when they look good. Coming together, sharing experiences and learning about how to cope with the social implications of their illness help people better deal with it. Restoring one's appearance and having a healthy looking image allows a person to *blend in* with other people. For instance, a girl comments on the website of LGFB :

> (Skincare, wigs, hats, headwear—) It just makes you feel good about yourself. Like you're in the swing of things and know that you're still like everybody else. You can still make yourself look pretty even though you may not feel it all the time (www.2bMe.org/2bMe.html).

Similarly, a guy indicates: "It's one less thing to worry about. You don't have to worry about people saying, 'Oh, look (at) that person!'" Not becoming the focus of attention and "passing" as "normal" by *looking* normal play a significant role in feeling better. Furthermore, it is not only looking normal but also feeling pretty by looking pretty that contributes to feeling good as this girl expressed:

> It makes you feel good, ‘cause you know, you put make-up on, walk around, and you feel pretty. And you look different—and everybody sees you—and you feel like a better person all over. It brings a smile to our face.” (www.2bme.org/2bMe.html).

Thus, it is not looking different that is considered problematic but looking different that does not evoke positive responses from the others. As the above quote indicates, looking different in a positive way makes one feel better and brings a smile to her face. Finally, one guy indicated his interest in learning how to apply make-up on his face contrary to the common sense thinking that males won’t be interested in this “make-up stuff.”

Stephanie Byram, whose experience of surviving breast cancer constitutes the verbal-visual documentary *Stephanie*, however, emphasizes the life transforming effects of cancer and suggests that, “One option is to reconstruct your life, but not your breasts.” In her text “Look Good, Feel Better?”(Byram & Brodsky, 1997) Stephanie questions the importance and meaning attributed to appearances:

Look Good, Feel Better?

Why is it that I never see anyone without hair?

Why is it that my doctor insisted I would want to reconstruct my breasts?

Is it so important to hide our appearances, to hide our cancers?

Is it something to be ashamed or embarrassed about?

Is it so important to conform, to avert the stares and the whispers?

Stephanie challenges the taken-for-granted assumptions and the unspoken rules of how people appear, work towards conformity and look “normal.” She problematizes her doctor acting as an agent of cultural discourses on appearances and doubted the social meanings of looks, illness and conventions. The *Stephanie Project* will be discussed in more detail in Chapter Four as I analyze how Stephanie created a new sense of self through her experience of breast cancer.

Due to the privacy and sensitivity of the topic, I was not allowed to do any audio- or video-recordings in the LGFB meeting that I attended; however, I took field notes without identifying individuals and collected pamphlets and brochures that provide information and guidelines on coping with the side effects of cancer treatment (i.e., wig care, turbans and hairpieces, hats etc.) Throughout the session, the theme of a lost self in relation to changes in image emerged repeatedly through audience comments such as “I don’t feel like myself” or “I feel like I am losing myself.”

I continued my research on the Internet where I came across a variety of personal and institutional sites on many issues related to cancer (i.e., diagnosis of cancer, responses to diagnosis, managing the effects of illness, stories of cancer, issues related to the process of dying and care for the dying etc.) The Internet presents a great opportunity for conducting preliminary observations and gaining access to many different peoples' experiences and stories about cancer.

Upon checking the web site of the “Stephanie Project” (1997), a woman’s verbal-visual documentary on breast cancer, I contacted the people who created the project. I first contacted the photographer of the project, who encouraged me to contact Stephanie Byram, whose life story is the basis for the project. Stephanie was interested in my research plans and agreed to meet with me to learn more about my project. I conducted an interview with her and later attended two of her public presentations. In the first presentation I attended, Stephanie addressed a group of approximately twenty women called “Women Spirit” at her church and showed slides from the “Stephanie Project” as she talked about her breast cancer experience (January 16, 2001). Her speech was followed by a discussion, which I was given permission to record both by Stephanie and the audience members. The second and final presentation I observed and recorded was held at Carnegie Mellon University (March 1, 2001). Stephanie and the photographer of the project spoke to a group, which consisted of about thirty students and the presenter’s friends and colleagues. No personal information about the audience was collected and no visual record of the audience was made in either of the presentations.

The feelings of loss expressed by Stephanie Byram both on the web site of the "Stephanie project" and in her speeches were similar to those I observed at the meeting of the "Look Good Feel Better" program. "Loss of self" was a recurring theme in both contexts. Stephanie, however, was able to reconstruct a new self as she transformed through her breast cancer experience. In the next chapter, an analysis of Stephanie Byram's experience will illustrate the transformation and reconstitution of self during long-term illness.

In addition to the web sites, pamphlets, brochures and public presentations, my observations also include published diaries, books that focus on life stories and experiences of people surviving cancer, advertisements and health campaigns on breast cancer in a variety of popular magazines, calendars that focus on impressions and images of women with breast cancer, and other popular materials. These observational materials have been helpful in providing information about the general context of chronic illness, diagnosis and survivorship and in sensitizing me to the priorities and concerns of people diagnosed with chronic illness, specifically breast cancer survivors. As Dietz et al. (1994, p. 21) indicated, however, "observational material on its own is an inadequate basis on which to build an ethnographic study because one would have to make extensive inferences regarding people's meanings and intentions."

Participant-observation

I engaged in participant-observation as a volunteer in the oncology unit of a renowned hospital in a midwestern city. "... The participant-observer role allows the researcher to get infinitely closer to the lived experiences of the participants than does straight observation" (Dietz et al., 1994, p. 21). As a volunteer, I distributed snacks to the patients, changed "waters" every hour, folded towels etc. My participant observation role gave me an opportunity to interact with cancer patients, thus allowing me to observe and share their "lived" experiences. My volunteering experience for over three months yielded observations and field notes (with no identifying information) that I wrote after I left the hospital. I did not initiate any attempts to talk to the patients as a part of my research, or enact my researcher role while in the hospital context. Like the other student-volunteers, I worked to help the nursing assistants in reducing the extensive amount of work they had to perform, and they frequently expressed appreciation for our assistance. This phase of my fieldwork gave me an opportunity to collect general impressions and to make contacts to pursue later.

My observations at the oncology unit provided me with very valuable information and experience regarding the worlds of chronically ill people, but only in one specific context: the hospital. People usually stay at the hospital when they are waiting to be diagnosed or when they are so sick that they need to be taken care of by the medical staff. Thus, my observations at the hospital did not allow me to access the ongoing daily routines and practices of cancer survivors. Participating in events that gathered cancer survivors together such as the “Race for the Cure,” however, gave me opportunities to both participate and observe the “life-worlds” of the survivors as they actively engage in daily life.

The Komen Race for the Cure Series is considered to be the largest series of 5K runs/fitness walks in the world, and it is organized by The Susan G. Komen Breast Cancer Foundation. The purpose of the foundation is “to fight to eradicate breast cancer as a life-threatening disease by advancing screening, education, treatment and research” (http://www.pittsburghraceforthecure.org/ race/aboutkomen, June 15, 2002). Through a network of volunteers, the Komen Foundation raises funds to support research, breast cancer education, and treatment and screening projects. Both races that I attended were very emotional and powerful events where thousands of people gathered together, including the families and friends of survivors to support their loved ones and the efforts to find a cure for breast cancer. I also saw a number of dads with kids waking in memory of their wife/moms that touched me deeply. Survivors identified themselves by wearing pink shirts and hats. People joined together, walking with their kids of all ages, carrying signs on the backs of their shirts that say “In memory of...” or “In celebration of...” and attending various activities, created an atmosphere of connectedness. The following image is from the cover of the “Pennsylvania Health and Fitness Magazine” depicting a scene from a Race for the Cure (RFC) event.

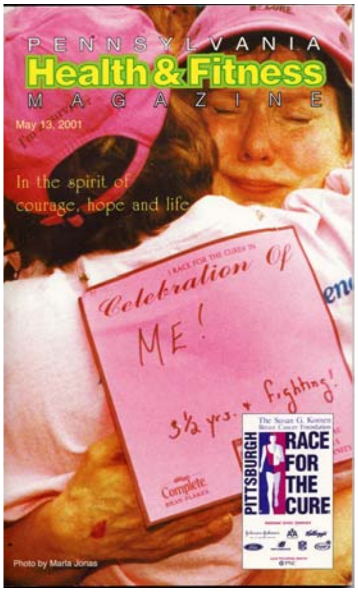

Figure 1. Race for the Cure

Source: Pennsylvania Health & Fitness Magazine, May 10, 2001

This image was not an unusual one to see during the RFC I attended where survivors, families, friends did not hesitate to show and share their emotions. This lady in the picture stated the number of years she has been a survivor on the form at the back of her shirt, celebrating her self. People cried, laughed, sang and danced together, creating bonds that gave them strength in their "fight against cancer."

There were many different booths that provided resources on different aspects of breast cancer and advertised institutions affiliated with the treatment of it. The whole event was an opportunity to learn about the different dimensions of breast cancer (from medical, social, nutritional perspectives to name a few) and survivorship where one could observe survivors with their families and friends engaged in various activities.

I volunteered at the Race For the Cure office for a short period of time (over a month) before the 2002 race. I worked with volunteers who are breast cancer survivors and helped fold pamphlets, open envelopes and fill forms. During my experience I realized that the "race office" is a very supportive environment for survivors where they could freely discuss breast cancer without hesitating about the "appropriateness" of the topic or the response of other people. It was a very energetic and dynamic environment with hardworking volunteers taking their jobs seriously as well as having a good time with each other by sharing jokes, experiences or information. The strong connectedness of the survivors made me feel like an outsider from time to time, especially in moments where I was not able to connect with them at the level of sharing experiences. For instance, when someone shared a story with me or with a group I was present in, I had no personal story to share with her or with the group to show my acknowledgement or understanding of the topic. "Understanding" seems to be very insufficient when compared to "experiencing" when the topic is something like breast cancer. I felt like an outsider, and I was when I wasn't able to attend the 10th Anniversary of Race for the Cure because it was "survivors only." Having shared an experience or not made a big difference in entering the lives of the others who are struck with a life-threatening illness.

I experienced similar feelings of being an outsider when I volunteered at the hospital and tried to find another way to greet patients than "How are you?" when I entered their rooms. It didn't seem to make much sense to ask a cancer patient how s/he, is especially in the hospital, so I came up with ways to avoid it and create alternative greetings such as "Good Morning," "Good Day" or "Hello, what is going on today?"

Interviews

In addition to attending events and activities related to breast cancer and my volunteer work, I conducted interviews with cancer survivors. Due to the private and sensitive nature of the research topic, an intermediary who knew that a potential participant was a cancer survivor (i.e., the director of a cancer related organization, a cancer advocate) helped me find interviewees. The intermediary provided information about the study, the researcher's name and contact information to the people who had already identified themselves as cancer survivors to him/her. After getting the consent of the survivors through the intermediary, I made appointments for interviews with them.

I conducted eighteen interviews (including two phone interviews) where repetitive emergent themes were clearly identified after the twelfth interview. Individual interviews varied between approximately thirty minutes up to two hours. Even though the participants were selected randomly, all eighteen interviewees were women. The average age was fifty-three, thirty-seven being the youngest and seventy-four the oldest. Fifteen of the women had completed their treatments. Two women were still being treated with a drug called Tamoxifen, which is usually used for five years following radiation or chemotherapy, and one woman was still going through radiation. Half of the respondents had had a lumpectomy and half mastectomy (single or double). Only one person reported that she had immediate reconstruction. Two women reported that they had reconstruction in later years after their treatments. Unless the participants chose to disclose whether they had reconstruction I did not ask. Two of the interviewees reported that they hated their reconstruction and one had it removed whereas the other woman had another operation to have it readjusted. Most women who had a mastectomy had chemotherapy treatment and lost their hair, while the women who had lumpectomies reported that they had radiation unless their cancer metastasized to the lymph nodes (in which case they had chemotherapy.) Thirteen women reported that they lost their hair due to treatment.

The interviews took place in the participants' homes or in the researcher's private office depending on the preference of the participant. I interviewed five women at the Race for the Cure office since they either worked or volunteered there, or it was a convenient place for them to meet with me. The interviews focused on the following questions: 1) Can you tell me about your experience of surviving cancer? 2) What changes, if any, did you experience/observe in your self in relation to changes in your appearance/image?

The participants were informed that they did not have to disclose information that might cause discomfort to them or that they might consider private. It was also emphasized that the participants might terminate the interview or withdraw from the study at any point. To maintain the confidentiality of information, both audio and video- tapes will be kept in a secure place and the information is coded (i.e. the names of the participants or any other information that might reveal personal information about the participant.) The tapes will be retained for future studies (as indicated in the consent form in Appendix A.)

Analysis

Similar to Charmaz (1987, p. 284), I consider the notion of self in chronic illness as “an emergent structure or organization” that “may shift or change as the person reflexively interprets the identifications and images that self and others confer upon him or her.” That is, I start with the assumption from literature that cancer treatment that affects the appearance is a challenge to the self and that it is a moment of change in self. I conducted the analysis of the data simultaneously with data collection.

I listened to my recorded interviews for repetitive themes in my participants’ talk about their experiences. I took notes on the emerging themes until the point that there were no more new topics, that is, until my data reached “saturation.” “Responses of others” was a major theme that each of my participants spent a lot of time to share. There were two sub-categories discussed regarding the implications of the responses of others to one’s bodily appearance: 1) on one’s social interactions, and 2) on one’s self. Furthermore, “resisting or accepting the responses of others” came up as a significant decision for women that demonstrated their “agency” in matters regarding their bodies.

I used textual analysis in examining the images from the product catalogue of American Cancer Society (ACS) and the pamphlet of the Look Good Feel Better (LGFB) program.

In the next chapter, I discuss the implications of being diagnosed with a life-threatening illness for identity and self, and the ongoing struggle to redefine oneself in light of a diagnosis. My analysis of the excerpts from the “Stephanie Project,” a verbal-visual documentary of a woman’s experience with breast cancer, demonstrate the emergence of a reintegrated and positive sense of self through aesthetic discourse and supportive relationships contrary to diagnostic discourse and the discourse of the LGFB pamphlet and the ACS catalogue that focused on what was wrong with the body. In Chapter Five, I analyze excerpts from my interviews with eighteen breast cancer survivors and explore the repeating themes in their narratives on the implications of a changed bodily appearance on self-definition and social interaction. Finally, in the Discussion, I discuss my findings on the relation between bodily appearance and self, and the cultural implications of breast cancer survivors’ talk about appearances.

CHAPTER FOUR

FROM DIAGNOSTIC TO AESTHETIC: MOVING BEYOND DIAGNOSIS

> Diagnosis represents a linguistic moment of great import in disability: It articulates the key distinction between being abled and disabled; it labels the condition for the purposes of medical, educational, and legal institutions; and fuses identity and disability in the social experience of the individual and those in contact with him or her (Barton, 1999, pp. 260-261).

The above quotation points to the impact of diagnosis on the positioning of individuals in terms of social capacity. Diagnosis not only serves to identify the nature of a disease or disorder and suggest potential courses of action, but transforms an ordinary adult into an ill patient (Charmaz, 1989, p. 28). A physician's validation of illness through diagnosis puts a person into the "sick role" (Parsons, 1953). Thus, being diagnosed with a serious illness like cancer carries significant implications for issues of identity and self. Corbin & Strauss (1987) emphasized the potential for identity disintegration and transformation from the moment of diagnosis of chronic illness:

> Chronic illness can not help but separate the person of the present from the person of the past, and affect or even shatter any images of self held for the future (especially if the illness is severe or debilitating.) ... the who I was in the past and the who hoped to be in the future, in whole or in part, are rendered discontinuous with the me of the present. New conceptions of who and what I am, past, present, and future must arise out of what remains (Corbin & Strauss, 1987, p. 272).

It is this potential for "identity reconstitution" when the person begins to reintegrate the self and regain a sense of wholeness (Corbin & Strauss, 1987) that will be explored. With a diagnosis of cancer people work toward regaining a sense of balance and control over their disrupted lives. Cancer is not just an acute illness;

many of the treatments take a long time and are at least temporarily debilitating, leading to pain, nausea, fatigue among other implications. Even if treatment is successful, patients are not told they are "cured" but "in remission." A cancer patient is "followed" for evidence of recurrence for a number of years. The effects of cancer may be long-term, then, even after recovery. There may be some similarities to chronic illness.

Selma R. Schimmel, a cancer survivor and the creator of a nation-wide radio talk show on cancer writes about the impact of diagnosis on the life of the individual:

> Before cancer or a life-threatening illness, we kind of tap dance through life ... When we get cancer, the dance changes ... And then you realize that areas of your life need reprioritizing. The diagnosis adds new stress to your personal, professional, and financial responsibilities. Issues of mortality come to mind, and, in addition to your emotions, you must also deal with everyone else's. And somehow in the midst of this emotional upheaval, you still have to keep a clear head in order to make decisions about your medical care. As your health takes center stage, your days may be a series of doctor's appointments, consultations, and continued medical evaluation. You've become a cancer patient (Schimmel, 1999, pp. 3-4).

In a similar vein, one artist explains changes in her life from the moment of diagnosis onward: “When I was diagnosed with my breast cancer in 1992, I was forced to stop and reconsider my life. The first change I made was to drop out of the fashion business and paint full time. I began to paint with obsessive urgency as if making up for lost time” (Ades, 2000, Artist's Statement, para. 1).

The personal reflections of Schimmel (1999) and Ades (2000) emphasize the impact of diagnosis and chronic illness on everyday life. The shock of being diagnosed with a life-threatening illness, fear of dying, loss of independence and becoming a patient are central to discussions on the challenges presented by diagnosis. In addition to these profound issues, there is another shock– the shock of the effects of the disease or treatment on the body. In fact, there is an *aesthetic challenge* experienced following the diagnosis of breast cancer that has major consequences for many.

In this chapter I first present people's responses to diagnosis. Next, I discuss the aesthetic consequences of cancer treatment; share my experience and observations in a meeting of the Look Good Feel Better (LGFB) program that I attended where cosmetologists educate survivors on how to cope with appearance-related side effects of treatment, and provide an analysis of the catalogues and pamphlets. I argue that the images of women in the American Cancer Society (ACS) product catalogue (2000) and the LGFB pamphlet serve as cultural discourses that function to maintain the existing definitions of *beauty*, *femininity*, and *gendered appearances* even in times of crisis by providing a collection of looks that are "appropriate" and "desirable." In privileging some appearances and discounting others, they construct meanings for what is "beautiful" or "deviant," "familiar" or "strange," "acceptable" or "unacceptable."

Finally, I provide my analysis of the "Stephanie Project" as an alternative discourse that questions the existing definitions of "beauty" and "femininity" and emphasizes the reconstruction of one's life and identity through supportive relationships rather than physical appearance. The excerpts from the Stephanie Project—a visual and verbal documentary of a woman's experience with breast cancer— show the transformation and reconstitution of self in relation to a changed bodily appearance. I argue that the construction of an aesthetic self served as a turning point for moving beyond the initial diagnosis and identity disintegration. Contrary to diagnostic discourse and the discourse of the LGFB pamphlet and the ACS catalogue that focused on what was wrong with the body, aesthetic discourse helped transform one individual's way of seeing her own body as beautiful.

Responses to Diagnosis

Diagnosis doesn't come alone. It is accompanied by a broad spectrum of emotions including fear, anger, disbelief and loneliness (Varricchio, 1997). In the following, I briefly discuss each of these reactions.

Fear and Anger

Among the most immediate reactions to the diagnosis of cancer is fear: fear of dying, fear of the unknown, fear of pain and fear of losing control (Charmaz, 1991; Kahane, 1990; Schimmel, 1999). Bella (January 26, 2002), a breast cancer survivor whom I interviewed, explained that people's reactions might be extreme—ranging from getting lost in tears to ignorance— upon learning that they or someone they love have cancer.

> Now I have another friend when she discovered her breast cancer … she was literally *wailing* OAAH I HAVE BREAST CANCER I DON'T WANNA DIE I HAVE TWO DAUGHTERS and she was *wailing* on the phone and I was just letting her wail and listen to her.

Uncertainty of the situation might expand the range of fears including when one might die, implications of illness, recurrence etc.

> I'm afraid of everything. I am fifty-seven and newly diagnosed with prostate cancer-I'm having surgery in a few days. I'm afraid I'm going to die before the surgery, I'm afraid I'm going to die during surgery, I'm afraid they won't get all the cancer, I'm afraid I'll be impotent and incontinent forever, I'm afraid I'll be 'cured,' then get it again. I'm even afraid that it won't come back, but I'll live the next twenty years afraid that it *will* come back (Schimmel, 1999, p. 93).

Sometimes, anger precedes fear as indicated by this cancer patient:

> I'm too angry to be afraid. I've been mad at everyone and everything since my diagnosis. I'm only in my early thirties. I eat perfectly, I work out everyday, and gear my life toward staying healthy, but I still got 'ball' cancer! That pisses me off (Schimmel, 1999, p. 94).

Disbelief

Despite the intensity of the emotions experienced upon diagnosis, the "meaning" of diagnosis might not be clear initially. Rather, the unexpected news and an improbable present might throw people into a separate reality where events seem unreal (Charmaz, 1991). The following lines of a cancer survivor illustrates this very well: "...The diagnosis changes your life in a split second. When you hear those words 'You have cancer,' everything stops. Nothing feels real" (Schimmel, 1999, p. 4).

Similarly, Murphy (1987, p. 24) recounts his own experience of being diagnosed with a benign spinal cord tumor,

> ...Many are unable to assimilate the full meaning all at once and may sit dazed for hours until the heavy weight of truth finally sinks in. It took time for me to realize the significance of what I have heard, enough time for my psychic

> defense system to become mobilized and throw up a wall between me and an unpalatable reality (Murphy, 1987, p. 24).

In response to these initial disorienting experiences, physicians may let their patients discover the meaning of the diagnosis over time:

> I said, 'Well, what is this problem?' And they put me in a hospital and took a lot of tests, and they said, 'Everything is fine Ron, but- so we've come up with multiple sclerosis, a possible multiple sclerosis.' I said, 'What is that?' And they said, 'You'll learn about it.' And I did (Charmaz, 1989, p. 18).

Loneliness

Feelings of loneliness and isolation also accompany the diagnosis of a life-threatening illness. One cancer survivor recollects that her first feeling upon diagnosis "was total isolation. I didn't feel like anybody knew what I was going through, how I was feeling" (Schimmel, 1999, p. 14). Another individual reveals that feelings of separation continue as one goes through treatment:

> You can't just call up somebody and say 'Gee, I am feeling rotten because I had chemo today.' They have no idea what you're talking about. I went to a concert when I still had the drainage under my arm from lumpectomy. I thought I was the only person in the world that had cancer. I felt absolutely alone (Schimmel, 1999, p. 130).

In response to reported experiences of loneliness that accompany the diagnosis of a life threatening illness, some patients take a more active role against isolation. As Stephanie Byram, a breast cancer survivor of eight years who passed away in 2001, explains: "When told to have a life threatening illness, some people withdraw into themselves. I on the other hand seek connections outside of myself both physically and spiritually" (Byram & Brodsky, 1996a, photo.10.html).

Sandstrom (1990) discusses how the diagnosis of AIDS results in especially painful and extreme feelings of isolation. Parents, siblings, or colleagues ostracize them. Furthermore, several of them were asked not to return home for visits. For people with AIDS, support group relationships became the central source for emotional support and the formation of social ties. Sandstrom argues that people diagnosed with AIDS are able to construct identities linked to their lived experience and to sustain a sense of self-worth by taking an active role in developing social relationships with others. On the other hand, the patients who adopt defensive identity management strategies by disguising or restricting their interactional involvements with others are less successful in building a positive self-image. Thus, seeking and creating social connections allow people to affirm and embrace their new identities and preserve a sense of dignity.

Diagnosis as an Aesthetic Challenge

In addition to the fear of dying from breast cancer, some people fear the effects on their bodies. When I first read the following response by a woman diagnosed with breast cancer, I was deeply influenced by it: “No longer voluptuous. I would just die” (Phillips, 1999, p. 1003). I was at the beginning stages of my study and I suspected that it could have been an exaggerated instance. It was not. Unprepared for the way one might look after a mastectomy, many women feel mutilated when they see their bodies after surgery for the first time (Blumberg, 1991; Davis, 2000). While my participants focused primarily on surviving cancer and becoming healthy again, they also emphasized the importance of appearance/image related matters. Image related issues might be secondary to survival issues; however, the suffering due to a loss of control of one's bodily appearance and self-presentation was a major theme in my research and seemed to be as debilitating for some women as the illness itself.

Shirley (March 1, 2002), explained that not having hair was a constant reminder of her illness and that most of what was going on was out of her control. Losing control of one's appearance might result in feelings of vulnerability as one survivor who managed her appearance to regain control over her life, indicated:

> Wearing bright colors and makeup and pulling myself together before I go out is a way of protecting my vulnerability so people don't make assumptions. It's like camouflage. It's sort of like camouflage is the door and I can open it or not. It is another way of having control over my disease. I choose whom I share my vulnerability with (Donnally, 1991, p. D5).

Losing one's hair due to chemotherapy is not a matter of choice. It is imposed on the self and one has to deal with it. Thus, image-related changes due to illness differ from those where one has a choice. Recently, a doctor friend of mine had all her hair shaved, and despite the looks and stares and a variety of feedback she gets from others she does not suffer from her changed image and being bald. She told me that she has always thought about shaving her head but was never prompted to actually do it until a recent experience she had with a young chemotherapy patient of hers. Her patient lost her hair due to treatment and was sad about it. My friend commented on how beautiful she looked and the next day she had her hair shaved. The difference between my friend's and her patient's experiences, however, is that my friend’s experience was an act of choice. Anticipating the responses she would get from others, she made a decision to change her appearance. She told me that she wasn’t disturbed when people commented on her look, but when people that she knew ignored it and interacted with her as if there was nothing different. On the other hand, survivors who lost their hair in indicated to me that they just wanted to fit in and that they did not want to be a focus of attention. That is, survivors who had no control over their loss of hair wished that others would treat them as normal. My friend who is not sick and shaved her hair by choice, however, looked for reactions from others. Thus, control seems to play a significant role on the meaning of a changed appearance for the individual who experiences it (and, probably for those who respond to it.)

Similarly, people who shave their heads for ideological purposes or to affiliate themselves with a group (such as punks, skinheads etc.) do not lose control over their lives upon changing their appearance. Their new appearance might even allow them to get the desired responses from others that they anticipated. If they wanted to attract the attention of others by shaving their hair, for instance, it would be an achievement when they did receive that response. In the case of a cancer survivor, as in the above quote, however, a person loses control over the responses of others to her appearance at the same time with her unintended physical change. Enhancing her appearance to look “normal” gives one an opportunity to choose when and with whom to share the implications of the illness. Thus, managing one’s appearance might allow one to regain control of her presentation of self in their social interaction with others and protect herself from the responses that she might not want to receive. The meaning of appearance in surviving breast cancer will be further discussed in detail in Chapter Five.

In the following, I provide my experience and observations of the Look Good Feel Better session that I attended. My analysis of the images in the pamphlets and catalogues distributed during the session demonstrate the ways in which cultural discourses on gendered appearances provide models for what is "acceptable," "appropriate," and "beautiful." Thus, it gives us insight on how institutionalized discourse might privilege certain types of appearances over others and promote notions of renewed "femininity" even when a person's life is in crisis.

Look Good Feel Better

As mentioned in the previous chapter, the "Look Good, Feel Better" project is a free public service program, a collaboration of the American Cancer Society, The Cosmetic, Toiletry and Fragrance Association, and the National Cosmetology Association, that aims to help women undergoing cancer treatment to regain a sense of self-confidence and control over their lives by providing information and education on how to cope with appearance-related side effects of treatment. The only people who are allowed in the sessions are survivors and the cosmetologist who conducts the session due to the privacy and the sensitivity of the topic. The families of the survivors are not allowed either. It took me a period of three months to complete the paperwork and contact the administrators explaining them the purpose, the benefits and the confidentiality of my study. My initial intention was to write an ethnography on the meaning of appearances based on the interactions in these meetings. I was given permission to attend to one meeting, however, and that was the end of the story.

In the session that I attended as an observer, topics of discussion included what to expect during chemotherapy and radiation, coping with hair loss, skin and nail care, makeup, hair and wig care. A cosmetologist, who was a breast cancer survivor, and a nurse, conducted the workshop in a meeting room of a local hospital. The audience consisted of five women. After watching a video that provided information on the project for approximately fifteen minutes, the cosmetologist, who was a cheerful, talkative woman with long, curly, bright red hair, briefly shared her story and explained her motivation for being there. She said that she wanted to show other women that they did not have to *look sick and feel alone* as they went through treatment but they could restore and maintain a healthy appearance as they go about their lives. She encouraged the participants to ask any questions they might have and added that the nurse would assist in nutrition and health related topics. The liveliness and good humor of the cosmetologist promoted a warm, friendly atmosphere in the room and brought out hope and optimism. Being a survivor, the cosmetologist presented herself as a credible source of information and was able to deeply connect with the rest of the group. The audience members who were silent and serious at the beginning of the session were encouraged to share their experiences and ask questions. I realized that two of the participants looked pale, tired and in ill health.

One woman's hair looked thin and wispy. The other participants had 'normal' looking hair and I could not distinguish if anyone had a wig on or not.

One of the audience members who was recently diagnosed asked many questions on how to deal with hair loss such as when to buy a wig, what kind of a wig to buy (synthetic or made of real hair) and how to decide if she needs to shave her hair. The other women also showed interest in these issues and listened to the cosmetologist attentively. Among the suggestions were to have a short haircut, to be gentle on your hair (i.e., use a soft brush, mild shampoos, towel dry,) to get a wig *before* hair loss occurs, and wear sunscreen if you are outside without your head being covered. The cosmetologist explained that not everyone loses her hair and it depends on the type of treatment. But usually people notice their hair coming off in pieces or lumps while in the shower or on their pillows. She suggested that shaving one's hair at that point helps and makes one feel more in control of the illness.

During the discussions, the women received lists of local wig and hair salons that provide services for cancer patients, resource guides for hairpieces, turbans and wig care, and a catalogue that provided information on products such as, hats, wigs, scarves, silicone breast forms, special bras and swimsuits. I provide a variety of images from the catalogue along with an analysis in the upcoming paragraphs. The name of the catalogue is "tlc" that stands for "tender loving care." The purpose of the catalogue is stated as "to make this difficult and challenging time easier for you by helping you look better, feel better and be more comfortable" (American Cancer Society, 2000, p. 2). The underlying assumption is that helping women cope with the *appearance related* effects of cancer treatment makes it easier to deal with the challenging times of surviving cancer. The catalogue reduces the effects of cancer treatment to appearance related issues through the language it uses: “We know that the effects of cancer treatment, combined with the responsibilities of home, family and job can *seem* overwhelming. Now, in private, at your leisure, you can select products for your special needs …” (American Cancer Society, 2000, p. 2) [emphasis added]. The appearance related factors during treatment of cancer are framed as the central point of that difficult and challenging time. Furthermore, it is suggested that by managing one’s appearance through the products in the catalogue, the overwhelming effects of cancer treatment will be made easier. The catalogue does not suggest that the disease itself is a devastating experience and the appearance related effects could add to it. On the contrary, it presents the appearance related issues as the main concern.

There are a variety of images in the catalogue where women are presented wearing different kinds of hats (classical, casual etc.), wigs and turbans. The majority of the models in the catalogue are middle aged, white and their styles represent middle-upper middle classes. There is one African-American woman with a light skin tone and another one who might be of mixed race, with very light skin tone and blue eyes. Furthermore, the catalogue does not provide many resources for younger women (except for hats); all the hairstyles of the wigs look very conventional and middle-aged.

During the LGFB session I attended, the cosmetologist distributed free makeup kits and mirrors for a demonstration depending on each woman's skin type and color. A volunteer model was selected and the cosmetologist applied makeup on her as she explained each product and its application. The rest of the participants put makeup on as they watched and listened to the instructions of the cosmetologist. Women seemed to enjoy the process and the end results and they complimented each other at the end of their make up session. One woman smiled and said "It's been a while since I last saw color on my cheeks." At that point, I forced myself to hold my tears and control my facial expression; I was deeply touched by the whole process.

During the session I maintained a smile when optimistic, encouraging and positive conversations were exchanged, but I actually was sad and overwhelmed. I was new to the whole experience and it was the first time that I met so many survivors altogether sharing their concerns and fears. It was a very emotional two-hour session for me. I was the only one in the group who was not in the role of an educator or a participant. As I observed the group, I felt like an outsider, and I was. I did not know how to show my deep respect, support and affection for the survivors in the group. I was not sure how to act and interact with the women whose lives were at risk. Thanking the energy and the cheerfulness of the cosmetologist, I sat silently and smiled when they did. It seemed like words of an outsider don't make much sense in this context unless you are a survivor sharing your experience with others or a caregiver working to save lives.

At the end of the two-hour session, the participants seemed happier and relaxed. They shared jokes, laughed more and walked out together chatting. Knowing what one might expect and how to deal with it provides relief in uncertain times like this. Learning the techniques for restoring appearance allows one to regain some control on some aspects of her life such as her looks and self-presentation. Sharing make-up and style tips in a group of women actually seemed to restore a sense of casual normalcy. Being able to concentrate on enhancing their appearance instead of hiding it seemed restorative. Sharing their private and sensitive experiences with other survivors in a supportive context seemed to alleviate the emotional distress and the tension that was present at the beginning of the meeting.

When I started my initial interviews, I asked about the experiences of cancer survivors regarding changes in their appearance and the implications of those changes on one's definition of self. It didn't take me too long to realize that surviving cancer is a unique experience. "There are guidelines but few roadmaps, and with breast cancer each path is singular" (Davis, 2000, p. x). After my second interview where I got the same answer as in the first one, "I can't tell you about other women but I can tell you about my experience," I changed my question to ask about the *personal* experiences of women. Cancer is a unique experience, even though people may look for meetings, presentations and support groups "to find someone that [they] can relate to and feel comfort in knowing that [they are] not alone" (Davis, 2000, p. xv).

Charmaz (1995, p. 667) points to one of the reasons for the importance of appearance when she wrote, "When changes in appearance are sudden and visible, particularly women may define those changes as tests of their love relationships." I heard stories of women whose husbands left them within a year after learning about their illness. These were not the personal stories of my interviewees who reported that their spouses were very supportive throughout their experience but their friends', relatives' or acquaintances'.

The "aesthetic challenge" is a common one for women. A fashion photographer once told me that most of his customers come to his studio telling him "Make me beautiful." When I asked him about the reasons that people go to him to have their pictures taken, he said: "For self esteem and or for the thrill of it. Another reason is to capture their youth and make a document of their beauty ... I am sometimes under pressure to make them "flawless". Other times, I help them feel much more confident than they were before they came in ... In a way a session of photos can help rebuild a broken self-esteem. Or, a session can confirm a good self-esteem." (Andrew, August 11, 2001) One woman wanted to have sexy photos to get her boyfriend back, another woman who had been stabbed asked for nude photos of her body and a breast cancer survivor who had a mastectomy had her nude photos taken and "commented on 'loving' the images. She thought her scarring was much worse, and the untouched photo results (untouched-up) on film set her at ease. Her husband liked them, too. She said she felt sexier after seeing them.

Snyderman (Davis, 2000, p. x) put it poetically when she wrote:

> Yet, if there was beauty and grace in the perfect, intact, sensuous breast, can there be beauty of a different sort in the breast that has been biopsied and cut and irradiated and poisoned? I think so. The human body is its own art form

> and is beautiful not only as it was created but also in the many shapes it takes on as it travels through life. Bodies with scars have not left the art behind. The scars simply mark the trail, the passage taken. Just like the moon and the sea and the fluctuating changes within us, the art of the altered breast is different but stays with us. Shocking? For some. Reassuring? For others.

The above quotation brings to mind the question of whether we see our changed bodies as beautiful or mutilated, shocking or reassuring. What are the discourses available to us that affect our actions and decisions about our bodies in our efforts to be at ease with them? In the following, I provide images from the product catalogue prepared by American Cancer Society (ACS) and a pamphlet advertising the LGFB program, which were distributed in the LGFB session that I attended, and illustrate how certain cultural discourses might privilege some appearances over others and emphasize what is wrong with our bodies upon a physical change. I argue that such discourses function to deepen the divergence of the body and self experienced by survivors rather than reinforcing the creation of an integrated identity.

In the website of the “Look Good, Feel Better” (LGFB) Program (www. lookgoodfeelbetter.org), there is a section where women who attended a LGFB workshop express their thoughts and feelings: “I just found out I had cancer and a big concern for me was that I was going to look sick; this class showed me I could still look beautiful,” “I feel like a new woman—a real person! Words cannot express the boost in morale your program has given me!” The first woman contrasts “looking sick” and “looking beautiful,” positioning them as two separate states. She expresses her appreciation of the LGFB program in showing her how the two can exist together. That is, she learned that *one could be sick without looking sick*, which she valued.

The second woman indicates a significant relation between her looks, feelings and identity, such that her enhanced appearance refreshes her femininity as well as making her feel like a “real person.” Looking sick, then, as this statement suggests, might be experienced as a diminishment of one’s femininity and of the validity of one’s existence, reflecting how one defines these terms. In the following, I show that the representations of breast cancer survivors in the LGFB pamphlet and the images in the ACS catalogue serve as cultural discourses on gendered appearances that provide a model for what is “acceptable,” “appropriate,” and “beautiful.” The suggestions and models offered for people when there is a “problem” with their bodies provide models for renewed femininity during/after cancer treatment. They promote notions of appearance that are possible even when a person is sick and invite the readers to compare themselves to those images. The overall message is that women should hide the signs of their illness for the comfort of others as well as their own. Rather than functioning as a discourse that might help reintegrate one’s changed appearance and self, these images might motivate one to question one’s own *femininity* and *validity.*

In the product catalogue of ACS, there is a real-life story of a survivor, Debbie Burchett, who was diagnosed with breast cancer at the age of forty-four. She had a recurrence four years later. After learning about “tlc,” Debbie ordered a sweater and a matching hat. She was so pleased with them that she wrote a letter to the ACS, including her before and after pictures: “My before-and-after make-up and a wig or a hat every morning is a magical process. Thank you for all your support and all you provide to patients like me." (American Cancer Society, 2000, p. 14)

Figure 2. Before-and-after no.1

Source: American Cancer Society, "tlc" catalogue, Spring/summer 2000, p. 14

Before-and-after photos are commonly used in popular style magazines, TV programs and diet ads, especially in the U.S., to show a transformation in someone after a major physical change that is widely assumed as desirable (such as weight loss.) The product(s) being advertised are then linked to the transformation and depicted as the main cause of it, thus, attempting to persuade the audience to buy the product. The positioning of the two images as before-and-after in the above figure suggests that the image on the left is the discounted one that fails to meet the expectations and standards and that needs improvement to look like the one on the right side. The images put side-by-side advocate the one on the right as "beautiful," "acceptable" and as a "model." It is the framing of the images that lays out the "gap" or the "deviance" between the two and constructs the one on the right as "superior." When we look at the images carefully, we see that the difference between the two images lies in the adornment of one's body, or the lack of it, through make-up, earrings, a hat with a wig and emphasized eye brows. The image on the left reflects a clean, simple, peaceful face of a *bald* woman with a hesitant smile. The one on the right side has hair and a hat, eye make-up and emphasized eyebrows, glossy lipstick and earrings. She does not have a hesitant, but a full smile. The conventionally adorned body is framed as the one that is "beautiful" and "desirable" whereas the bald headed image is positioned as missing something. Debbie, who is depicted in the pictures, is quoted as viewing this process of transformation of her image as "magical," indicating her delight and excitement about her new look. She showed her appreciation to ACS in her letter. Debbie's preference for achieving a conventional appearance conforms to the "demands of visibility" (Gilman, 1999), the desire not to stand out.

These images represent cultural discourses on *gendered appearance* and provide a model for the reader for what is "acceptable" and "beautiful." Being bald as a female is not offered as an option, but as something to be "corrected." The "diminished" femininity of a woman is enhanced by the color choice (soft pink) of the sweater and the hat, hair, pastel colored make-up and earrings. Thus, being sick does not necessarily prevent a woman from looking feminine if she follows the rules to manage her image. The suggestions and models offered for women when there is a "problem" with their bodies show a lot about the cultural ideals of gender. It seems, then, that it is significant for a woman to present herself with hair on her head and color on her face to be acceptable in the U.S culture. An even more emphasized look that fits and adds to this description is the following image, which was the cover of the same issue of the “tlc” catalogues.

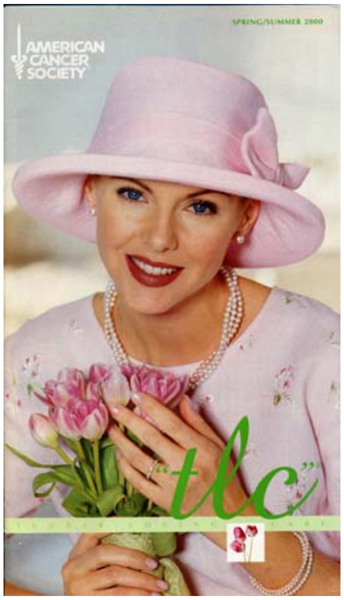

Figure 3. “tlc” front cover

Source: American Cancer Society, “tlc” catalogue, Spring/summer 2000, cover page

This image depicts a gentle, soft, feminine, refined lady who presents a well taken care of physical appearance as a whole. She looks more adorned than the model in the previous figure and has a more fashionable and sophisticated style. Her head is carefully covered with a stylish, very feminine looking pink hat with a ribbon on the side. With her pearl earrings that match her necklace and bracelet, soft pink elegant dress and polished nails, she represents an upper middle class look, not necessarily an everyday person that one would usually meet on the street (except for high fashion streets like Madison Avenue.) She has flawless-looking skin and soft-looking hands holding the flowers in a caring manner—as if she is holding a baby.— This image, like the previous one, provides a model for renewed femininity during/after cancer treatment and offers itself as an alternative to survivors. With the softness, and the colors, and the accessories she looks even more feminine than many ordinary people going about their lives, so it is not likely that most survivors looked like that even before they got sick. Thus, the image suggests that women can look even more ideally feminine during/after treatment. It promotes notions of appearance that are possible even when a person is sick and engages the reader in a dialogue where readers might question their own looks. Comparing one's self to this and similar references, a reader might wonder if there is something wrong with her appearance or whether she looks good enough to meet the standards depicted by such images (especially during times of great vulnerability and need for support, as in surviving a life-threatening illness.) The promotion of such grooming and style when somebody's life is at risk through the frame of "helping" women to cope with the effects of cancer by managing their appearance might serve as a continuation of the discourses that work to discipline women (through their appearance) even in times of crisis. The catalogue functions as a guide that provides the "appropriate" models and images that one might choose to look like and the supplies and resources that one might need to achieve that look. It suggests women that they *should* make the effort in spite of how bad they feel. By offering these alternatives over the others, the catalogue indicates which is "preferable" and "desirable."

The images in the catalogue present alternatives for a variety of occasions including casual hats as well as formal ones, wigs, head wraps, hairpieces attached to hats and bandanas and even sleep wigs. That is, there are a number of alternatives provided for different cultural/social expectations of various public and private spaces (including the intimate, where one uses a sleep wig).

Figure 4. Sleep wig

Source: American Cancer Society, "tlc" catalogue, Spring/summer 2000, cover page

The "sleep-wig" got my attention the most among the others due to its suggestion for one's physical appearance in the most intimate space, the bed. The catalogue offers an "appropriate" look for even when one is sleeping. The woman in the following picture looks like a scene from the movies with full make-up on and well-dressed hair. This picture presents the idea that one could - and should - manage her image in every minute of the day, thus, the name "around-the-clock sleep-wig." The woman in figure 4 is depicted as sleeping alone with her wig and make-up on. It suggests that "stigma management" is not only relevant in the public scene, but also in one's private space and even when one is alone. The before-and-after images in the

LGFB pamphlet are more diverse in that they represent women from a variety of backgrounds. They look above thirty years of age, however, and younger women are not represented. The most significant point that got my attention in these pictures is that the "before" pictures depict these women by themselves with their non-managed images (bald or little haired heads, no make-up, no accessories.) In the "after" pictures, however, they all are engaged in some sort of a social or business activity, alone or in interaction. In the next two pictures, in figures 5 and 6, the two women in their "before" pictures look like they don't know what to do, as if they are sitting and waiting. They are not only shown alone but their backgrounds are also empty, they stand alone in the pictures juxtaposed to empty rooms with no connection to the world.

Figure 5. LGFB 1

Source: Look Good … Feel Better pamphlet

Figure 6. LGFB 2

Source: Look Good… Feel Better pamphlet

In the "after" pictures, however, they not only have hair and make-up, but they are engaged in social activities in rooms full of furniture and colors, in the world of the “real.” These images help illustrate the words of that woman on the LGFB website when she wrote that she felt like a “real person.” With their images managed to fit the social expectations, the identities of these women in the “after” pictures are restored. They are not shown in their surreal corners of the world anymore but in the “real” world acting like “real” people do, engaging in interactions, social activities and business. Thus, an association between illness, physical appearance and identity is suggested in these pictures, where a sick woman with no hair and make-up is left alone in a disconnected world, losing her identity. The “previous” pictures reminds of criminal photos taken upon arrest with shaved heads, as they leave their social identities behind along with their clothes, accessories, personal belongings and hair and are prepared for their new identities away from the “real” world.

For instance, in the “before” picture below, this woman looks scared. She is alone in an empty room in front of a blank wall, has a baldhead and looks directly at the camera. The grayish backlighting does not add much energy or vividness to the picture, either.

Figure 6. LGFB 2

Source: Look Good… Feel Better pamphlet

There aren't many clues in the picture to indicate her identity, the room is empty, and she doesn't look happy or familiar in any sense. She is stripped of her identity like a criminal. The person looking at the picture can easily get confused if s/he doesn't know the context of it. In the "after" picture, however, she is shown in a professional setting in a professional outfit, has a wig on and she is fully smiling as she interacts with others. She doesn't look directly into the camera anymore but has eye contact with the person she is in interaction with. Her identity is restored (as well as the room's identity), along with her physical appearance and image.

The woman in the "before" picture in figure 5, assumed the posture of the famous sculpture "The Thinker" by Rodin, resting her chin on her hand. She looks directly into the camera with a gloomy expression even if she has some indications of a smile in her face.

Figure 5. LGFB 1

Source: Look Good… Feel Better pamphlet

In the "preferred" after-picture, however, she is busy with painting her pottery, she is smiling and she has make-up, a wig and a place in the world. Figures 4 and 5 suggest a transformation in the lives of these women related to their appearances.

Except for the similarities of the following two pictures with the previous two figures in terms of framing, the women in the following are smiling in the "before" pictures. They don't look as scared or deep in thoughts in their empty little corners of the world as the women in the previous pictures did. Thus, even if there still aren't many clues to indicate their identities, their situation does not seem as problematic as the previous figures. At least they have a familiar expression in their faces and they *look* happy despite the fact that they are posing for the camera. By fulfilling our expectations of posing, they suggest a familiarity and, thus, a seemingly less problematic situation. Also, they tell people that they don't have to give up their lives and their hopes just because they are sick.

Figure 7. LGFB 3

Source: Look Good… Feel Better pamphlet

Figure 8. LGFB 4

Source: Look Good… Feel Better pamphlet

They both still are alone, however, in an empty room, whereas in the "after" pictures with their image restored, they are shown in the real world, one woman in a business setting and the other in her wedding gown getting prepared for yet another transformation in her life. Thus, once again the significance of managing one's appearance in restoring one's identity and transforming her life is emphasized.

Representations of breast cancer survivors in the LGFB pamphlet and the images as well as the various products in the ACS catalogue serve as cultural discourses on gendered appearances that provide a model for what is "acceptable," "appropriate," and "beautiful." None of the images present being a bald female as an option, but as something to be "corrected." Through the framing of images as before-and-after, certain images of women such as soft, pink, feminine, refined, upper class and with styled hair are depicted as “desirable” and “superior” whereas others are discounted as “deviant,” failing to meet the standards and in need of improvement to look like the suggested one. “Diminished” femininity of a woman is overcome by the color choices (soft pink) of her outfits, accessories (hats, jewelry), make-up and various items that fit the “loving tender care” philosophy such as pink tulips, soft textured scarves etc. Thus, it is shown that being sick does not necessarily prevent a woman from looking feminine if she follows the rules to manage her image.

The suggestions and models offered for people when there is a “problem” with their bodies provide models for renewed femininity during/after cancer treatment and show a lot about the cultural ideals of gender. They promote notions of appearance that are possible even when a person is sick and invite the readers to compare themselves to those images. Thus, a reader might wonder if there is something wrong with her appearance or whether she looks good enough to meet the standards depicted by such images (especially during times of great vulnerability and need for support as in surviving a life-threatening illness). Looking at those pictures might be frightening—Does being accepted and supported depend on attending to one’s appearance? Will the woman who does not take care of her appearance be left lonely? Rather than functioning as a discourse that might help reintegrate one’s changed appearance and self, these images might motivate one to question her self.

The pictures of the LGFB pamphlet suggest an association between illness, physical appearance and identity where a sick woman with no hair and make-up is left alone in a disconnected world, losing her identity. Thus, maintenance of identity is connected to how it is displayed to and created with others. This is relevant to Mead's (1934) concept of "social selves," as well as Goffman's (1959) "presentation of selves" that emphasizes the construction and maintenance of selves through self-presentation in social interaction.

The "before" pictures depict women alone in an empty room with their non-managed images (bald or little haired heads, no make-up, no accessories.) In the "after" pictures, however, they all are engaged in some sort of a social or business activity, alone or in interaction and look happy and "fit." Thus, the pamphlet points to the idea that the identities of these women in the "after" pictures are restored when their images are managed to fit the social expectations.

The images of women in the ACS catalogue and the LGFB pamphlet serve as cultural discourses that function to maintain the existing definitions of "beauty," "femininity," and "gendered appearances" even in times of crisis by providing a collection of looks that are "appropriate" and "desirable." In privileging some appearances and discounting others, they construct meanings for what is "beautiful" or "deviant," "familiar" or "strange," "acceptable" or "unacceptable."

In the next section, I analyze the "Stephanie Project" as an alternative discourse that questions the existing definitions of "beauty" and "femininity," and emphasizes the reconstruction of one's life and identity through supportive relationships rather than physical appearance.

Diagnosis and Transformations of Self:

The Stephanie Project

The transforming effect of a serious medical condition on the self seems to start at the moment of diagnosis. Thus the diagnosis does not just announce illness; it may signal the transition to a "disabled" (Barton, 1999), "marginal" (Sandstrom, 1990) self through which the individual gets socially re-positioned as a medical body. In keeping with this, the term "diagnostic self" will be used to refer to the transforming state of an individual post diagnosis where the self is conceptualized as "medical," "disabled," "diseased," "differentiated" and even "lost."

Stephanie Byram, a breast cancer survivor and an advocate, chronicled her personal experiences with breast cancer over time through photographs, journaling and a series of interviews (Byram and Brodsky, 1996a, 1996b, 1997). Creating a website from these materials titled "The Stephanie Project," Stephanie and her photographer publicly presented their visual-verbal documentary in various contexts such as on a college campus, at Stephanie's church etc. A movie called "Stephanie" was later made by a filmmaker, which won an Emmy award in 2002. The image of a "diagnostic self" is revealed in her early photographs of her chest after surgery. Stephanie characterizes the photograph in Figure 1 as one of her "least favorite" and most "clinical" (see Figure 1).

> This is one of my least favorite photographs. It's a very sterile photograph. You can't see my eyes. The audience is not allowed to see any emotion from me. Instead the reason for doing that is that it forces or allows perhaps the audience to be voyeuristic in looking at my chest, in looking at something that might be very uncomfortable to look at had my eyes been there. This

> photograph is very sterile and clinical this is perhaps something you might expect to see in a medical textbook. It's not a passionate photograph at all. (Byram & Brodsky, 1997)

Figure 9. Shock

Source: http://www.cmu.edu/cfa/design/people/sford/stephanie/ high/shock.html

In exposing her chest after surgery, Stephanie emphasizes the absence of her eyes and relates that to the sterility of the photograph. By cutting off the eyes and depersonalizing the image, Charlee Brodsky, the visual artist of the Stephanie Project, literally and figuratively framed Stephanie as a "medical body," a specimen to be analyzed. In short, the whole person is reduced to a medical sample, a diagnostic body. Stephanie reported that she posed like this for women who had never seen a mastectomy (Byram & Brodsky, 1996, interview.1.html). This "clinical" representation of self invites others to examine the body-as-object and represents Stephanie as a "diagnostic self" that had experienced both physical and emotional loss.

The construction of a diagnostic self, created by viewing the body in terms of what is wrong with it (or what is missing), reveals itself in two themes in the talk of cancer survivors; “divergence of self and body” and “loss.”

The Divergence of Body and Self

In the verbal and visual documentary of her breast cancer experience, Stephanie Byram (1997) writes:

1 Cancer Destroys.
2 It ravaged my sense of Self.
3 My body betrayed me: it could no longer be trusted,
4 especially since I had treated it so well.
5 Suddenly, every body part was suspect.
6 I was no longer a whole.

These comments reveal the devastating effects of cancer on Stephanie’s self-concept and her body. Losing control of her body led Stephanie create a distinction between her body (“my body”) and her self, (“betrayed *me*”): the self and the body were no longer a single unit. The body is construed as an object (“it”), rather than the subject of her being. The issue of control that was mentioned earlier in this chapter comes up in Stephanie’s portrayal of her relation with her body. She frames this relation as “betrayal” since her body acted independently of her and out of her control. Furthermore, it was not responsive to how it was cared for, thus, not trustworthy (Lines 3-4).

Stephanie personifies her body as a conscious object, a willful being acting against her. Her sense of self had been fragmented: “I was no longer whole.” Stephanie’s sense of being an integrated self had changed to the point where she no longer trusted her body. Similar changes over the course of a chronic illness have been noted by others: “Bodies change in chronic illness and so do self-conceptions which are reciprocal to bodily experiences, feelings and actions . . . self conceptions undergo considerable transformation” (Kelly and Field, 1996, p. 247). Charmaz (1992), for example, cites the experiences a woman with asthma and the bodily changes she experienced: “I felt like my body betrayed me . . . like my body was sort of foreign territory—it was not the body I knew” (p. 662). The taken for granted idea of a body that serves the needs of the self is altered dramatically. This conflicted separation of body and self continues as people seek to distance their feelings about themselves from their bodies. Rather than living with their bodies, they experience fragmented selves where the body and self are separated. The diagnostic self of Stephanie described here was not only fragmented, there was also a sense of loss on a variety of personal fronts.

Loss

After being diagnosed with a highly malignant and aggressive form of breast cancer, and having surgery to remove both breasts, Stephanie experienced loss. Even though the following photograph was taken seven years prior to a talk she delivered to a local church group in Pittsburgh, she confided that it was still a very difficult picture for her to see.

Figure 10. Why Am I so Sad?

Source: http://www.cmu.edu/cfa/design/people/sford/stephanie/high/shock.html

> I look at my eyes and what I see is all of the- all of the feelings of loss that I was going through at the time and in particular I was ruminating I guess on lost womanhood, lost sexuality and lost motherhood. The most obvious markers of my womanhood were gone. I'd never be able to breast-feed a kid and my sex life would be unalterably changed for the rest of my life. And this photograph captures for me all of that. (Public speech, January 16, 2001)

In recounting feelings that surfaced soon after her diagnosis of breast cancer and the immediate surgery that followed, Stephanie revealed how physical changes diminished her self: she lost her womanhood, her motherhood, and her sexual life. She referred to her breasts in terms of their association to her "femininity" as a physical/visual form, and in terms of their function (in breast-feeding and in her sex life.) Stephanie's changed bodily experience in terms of its visual, tactile and functional aspects resulted in her feelings of loss. The loss expressed by Stephanie was somewhat similar to the experiences of women at the meeting of the “Look Good Feel Better” project of the American Cancer Society that I attended. At this gathering licensed cosmetologists helped cancer survivors address problems with respect to hair loss, skin, and a variety of other appearance/image related issues. The theme of a lost self emerged repeatedly through comments such as “I don’t feel like myself” or “I feel like I am losing myself.” These women, however, referred to a loss of self with an emphasis on a visual change in their physical bodies, that is, loss of hair.

Experiencing feelings of loss, some women refrain from looking at their altered bodies after mastectomy, and avoid being seen by their intimate others: “I tend not to look at myself—it upsets me that I don’t look like a woman anymore,” “Oh, I don’t let him see me, oh no. I couldn’t. He’d be horrified. I always undress in the bathroom now” (Fallowfield and Clark, 1991, p. 66). In hiding their appearance from themselves and intimate partners, ill people may seek to reduce the effects of surgery on themselves and their social identities (Charmaz, 1995, p. 667).

By way of contrast, a physician’s post surgery perspective may be viewed as radically different from that of the patient— different in ways that only serve to heighten the dissonance experienced after a mastectomy:

> When I did wake up from surgery I thought the scars I would have from removing three tiny little growths would be minimal, that my breast would look pretty as much the same as it did before surgery.... Not so! I wasn’t prepared for the ugliness of my breast or the dramatic change in its configuration. The nipple was in the wrong place. I felt misshapen, mutilated. When Dr. Sachs told me after surgery that the breast looked beautiful—from a surgeon’s point of view, I guess- I decided from a woman’s point of view that the man was crazy. He found it hard to understand my reaction (Blumberg, 1991, p. 27).

In sum, the divergence between the objective body and the subjective self, coupled with the experienced sense of loss and dissonance, are all part of the transformation to a diagnostic self. However, the emergence of this diagnostic self does not necessarily mark the end of an individual's identity transformation. In what follows, I will describe the process in which Stephanie's diagnostic self changed over time to reveal a more positive experience of identity.

Moving Beyond the "Diagnostic Self"

The following image represents a significant turning point in Stephanie's self-perception. Through conversations with the photographer, she began to develop a new way of "seeing" her body: the image of a disfigured body was transformed into an aesthetic body. In short, a positive aesthetic meaning and sensibility was constructed through interaction. Stephanie's detailed account of her transformation chronicles one woman's shift in understanding. Perhaps it can help us understand the supportive process and the power of the interactions one has with others. Other women report on the importance of the reactions of others. Stephanie's work shows us one way that interaction can influence change.

Figure 11. Venus

Source: http://www.cmu.edu/cfa/design/people/sford/stephanie/high/venus.html

> After learning my story, many people glance at my chest almost despite themselves, making me feel embarrassed and ashamed. Then we did the "Venus" photo. Like a Michelangelo sculpture with the arms knocked off and the head missing, I now see my torso as a work of art. Although I'm missing some pieces, I no longer feel disfigured. This image was a turning point for me.

By pointing to a similarity between the representation of her body and a famous sculpture "Venus," Stephanie forges a link between the two: both were missing pieces and both were works of art. She is now able to view it as a beautiful sculpture. In comparing her body to a beautiful work of art, she was able to transform herself into something other than a disfigured being. This transformation to a more aesthetic experience of self did not happen in isolation. Rather, it was an interactional achievement built, in part, through her conversations with the photographer:

> I remember when Charlee [the photographer] and I did this photograph. We had done a whole series of me turning around in a circle with this backlighting. And I remember her saying “Stephanie these are so beautiful these are just so beautiful” and I was thinking yeah yeah yeah. You know because it's my disfigured chest. And when we got the photographs back and started looking at them she started pointing out the shadows and the softness and the grace and the curves and all of the things that she as a photographer was seeing. And I began to internalize that message so that rather than seeing my body as mutilated I began to see it as a beautiful body. (Public speech, January 16, 2001)

Stephanie’s body is situated as a beautiful object through the interactive sharing of its aesthetic; its shadows, softness, grace, and curves. In contrast to the traditional discourse of diagnosis with its focus on what is wrong with the body, aesthetic discourse, through it’s emphasis on the pleasing, gracious and artistic qualities of the body, frames a new way for Stephanie to see her body as beautiful. “Through the discursive activity of aesthetic sensemaking . . . the viewer[s] [are] fashioning a *self* vis-à-vis the artwork-as-other” in which “they position themselves in the face of the artwork they interpret” (Bruder & Ucok, 2000, p. 355). The interactive nature of jointly viewing and reacting to artwork permits “viewers [to] cooperate in the mutual formation of their self-sense through art talk” (Bruder & Ucok, 2000, p. 356). By viewing the photograph of Stephanie’s body together and constructing an image of her body as beautiful, Stephanie and Charlee facilitated the transformation of Stephanie’s self. This transformation of self manifests itself in interaction with others in different contexts.

> Self-acceptance happened suddenly. Sitting in a hot tub, I revealed my new body hesitantly to a group of women; none had seen anyone with a mastectomy. To my amazement, no one fainted or looked shocked, no one pitied me. It was a simple meeting of women comfortable with nudity, accepting their bodies and mine. I began to realize how little I had lost. (Byram & Brodsky, 1997, Breasts Equal Sexuality, para. 2)

The accepting responses of others in this intimate public setting were a watershed experience for Stephanie. Doubts about her own body and the potential negative reactions of others disappeared. In her last sentence above, Stephanie reframes the magnitude of loss she stated earlier suggesting that it is not the physical qualities of her body per se that she defines as lost. How others respond to and receive her body is significant in her experience of loss. The approval of her changed body as it was before led to Stephanie's realization that her loss was not major. This acceptance by other woman foreshadowed other positive experiences:

> Later I discovered that I still lusted after the same men who were attractive to me before my diagnosis. Unexpectedly acting on those feelings, I experienced an awakening that liberated me from the stereotypes and fears of owning a "mutilated" body. My flat torso simply didn't matter; the chemistry and intense passion were the same (Byram & Brodsky, 1997 Breasts Equal Sexuality, para. 3).

During my interview with her, Stephanie revealed that incidents like those mentioned above gave her the external validation she needed and allowed her to believe that not having breasts was irrelevant to who she was and what she wanted to do. Moreover, she wrote in her journal that her sexuality and self-esteem had become more secure (Byram & Brodsky, 1997).

In both excerpts above, Stephanie refers to the insignificance of her body per se and emphasizes how she experienced her body with others. Being accepted by other people and experiencing her body as she did before in her relations with others showed her a way to go beyond her fears about her changed body. At the beginning of this section, I discussed Stephanie's experience of a separated body and self, where her body was out of her control. The above excerpts show us that external control is as significant as one's own control of her body, such that when her uncontrollable body was received positively by others, it became acceptable to Stephanie. The nature of this reconstructed self is more apparent in the final text of the Stephanie Project (1997):

1 **Cancer Builds**
2 My body, soul, and mind do not function as separate parts.
3 Struggling for a sense of balance,
4 I pieced together a new Self, unified and wonderfully alive.
5 Reflection has been my salvation.

In this excerpt, Stephanie explicitly mentions of her construction of a new self that was no longer disintegrated. Through reflection, her body, mind and soul had been unified and balanced. In the final line, Stephanie states "reflection" as the source of her recovery. By keeping a journal, creating visual representations of the processes she went through with her photographer friend, and reflecting upon the nature of her disease, Stephanie was able to move beyond a diagnostic self victimized by cancer to an aesthetic self that was reintegrated and capable of positively experiencing social life.

Conclusion

The shock of being diagnosed with a life-threatening illness, fear of dying, loss of independence and becoming a patient are central to discussions on the challenges presented by diagnosis. There is another shock experienced following the diagnosis of breast cancer that this chapter focused on: the *aesthetic* consequences of treatment. Even if one might think that image related issues are secondary to survival issues, the suffering due to a *loss of control* of one's bodily appearance and self-presentation was a major theme and seemed to be as debilitating for some women as the illness itself. Looking sick, might be experienced as a diminishment of one's femininity and of the validity of one's existence as a "real" person operating in the world. Representations of women in the LGFB pamphlet advocate this association between illness, physical appearance and identity through depicting sick women with no hair and make-up as left alone in a disconnected world (empty room with empty walls), loosing her identity. With their images managed to fit the social expectations, the identities of these women in the "after" pictures are restored. They are not shown in their surreal corners of the world anymore but in the "real" world acting like "real" people do, engaging in interactions, social activities and business.

The images of women in the ACS product catalogue promote notions of appearance that are possible even when a person is sick and in crisis. The catalogue functions as a guide that provides the "appropriate" models and images that one might choose to look like and the supplies and resources that one might need to achieve that look. Through the frame of "helping" women look good and feel better in this challenging time of their lives, it works to discipline women in suggesting that they *should* make the effort in spite of how bad they feel.

My analysis of the representations of breast cancer survivors in the Look Good Feel Better pamphlet and the images in the ACS catalogue demonstrated how these images serve as cultural discourses on *gendered appearances* that provide a model for what is “acceptable,” “appropriate,” and “beautiful.” The suggestions and models offered for people when there is a “problem” with their bodies provide models for renewed femininity during/after cancer treatment.

I argued that the images of women in the ACS catalogue and the LGFB pamphlet serve as cultural discourses that function to maintain the existing definitions of “beauty,” “femininity,” and “gendered appearances” even in times of crisis by providing a collection of looks that are “appropriate” and “desirable.” In privileging some appearances and discounting others, they construct meanings for what is “beautiful” or “deviant,” “familiar” or “strange,” “acceptable” or “unacceptable.”

I provided my analysis of the “Stephanie Project” as an alternative discourse that questions the existing definitions of “beauty” and “femininity” and emphasizes the reconstruction of one’s life and identity through supportive relationships rather than physical appearance. The physical changes experienced due to treatment or surgery carry significant implications for the construction of identity and self. Changes in the relation between the body and the self can result in the emergence of a diagnostic self dominated by a sense of loss, fragmentation and a perceived lack of grounding in social reality. Yet, there exists a potential for the constitution of a renewed and transformed self through discursive practices.

One way of moving beyond the debilitating impact of a catastrophic diagnosis was found in the construction of aesthetic discourse; through the interactive creation of beauty in reaction to Stephanie's physical appearance in a photograph, a reintegrated and positive sense of self began to emerge. As Stephanie became more able to view her altered body in a new and positive way, she gained enough confidence to participate in other positive social activities. In contrast to a diagnostic discourse that focused on what was wrong with her body, aesthetic discourse, through it's emphasis on the pleasing, gracious and artistic qualities of the body allowed Stephanie to construct a new and positive way of viewing her changed appearance. Thus, her "disfigured" body was transformed into an aesthetic body, and the "diagnostic self" into an "aesthetic self."

The discourse of the "Stephanie Project" shows that social interaction and relationships --from medical, to aesthetic, to everyday conversations in a hot tub—are central to the constitution and transformation of identity. Contrary to diagnostic discourse as well as the discourse of the LGFB pamphlet and the ACS catalogue that focused on what was wrong with the body, aesthetic discourse helped transform one individual's way of seeing her own body as beautiful. Through discourse that reinforces the creation of an integrated identity, even devastating experiences such as being diagnosed with a life-threatening illness might result in realization of new meanings about one's self and life. After all, who would deny the power of this experience depicted in the following cartoon? And why don't we get to see images like this in the ACS catalogue or the LGFB pamphlet?

Figure 12. Kiss

Source: Clifford, C. (1996). Not now… I'm having a NO HAIR DAY.

CHAPTER FIVE

THE MEANING OF APPEARANCE IN SURVIVING CANCER

Human beings routinely attend to their appearance and prepare their bodies for the social world. Daily appearance practices require the development of knowledge, skills and technique to make our bodies socially acceptable, appropriate and desirable (Beausoleil, 1994; Entwistle, 2000). In accordance with the framework suggested by Entwistle (2000, p. 11), which “recognizes that bodies are socially constituted, always situated in culture and the outcome of individual practices directed towards the body,” this chapter discusses *appearance as embodied experience* rather than mere image. That is, it does not separate appearance/image from the body or analyze the body as a symbol or text disconnected from the actual body, as has been the tendency of most studies. Instead, it locates appearance in the body and focuses on *appearance as bodily experience*. Within the chapter, I sometimes use “lived bodily appearance” to refer to the bodily experience of appearance. A change in bodily appearance, however, might not only be visual experience. In the case of a mastectomy, for instance, a woman’s tactile experience of her body also changes as well as the visual. I emphasize *appearance as bodily experience* in terms of its visual and tactile aspects in discussing its implications on one’s self and social relations. Finally, I use “image” to refer to one’s self-presentation in front of the others (Goffman, 1959) and “appearance” for “looks.” In some cases where “image” includes the implications of physical appearance, I use “image” and discuss the two concepts together.

Much has been written on the politics of appearance, such as the cultural ideals of beauty promoted in the media and the pressures that women face to meet them (Chapkis, 1986; Wolf, 1991); the influences of the beauty industry reinforcing good looks and bodily control as means towards liberation, increased social worth and empowerment (Bordo, 1990; 1993; Peiss, 1990); the commercialization of the body for profit (Hansen and Reed, 1986; Haug, 1987); and the body experienced as a product of contemporary "consumer culture" (Featherstone, 1991). Few have empirically studied, however, how women experience beauty and appearance in their daily lives. Beausoleil (1994, p. 35) suggests that, "the study of women's beauty needs to be refined to account for women's agency and their complex relations to ideal images." Keeping in mind the limitations that culture and social structure put on the negotiations of individuals, this chapter focuses on the meanings the body brings to appearance and emphasizes the inseparability of bodily appearance and the self for the individuals participating in this study.

In the following, I first provide excerpts from the interviews that illustrate the ways in which the responses of others to one's changed bodily appearance influence the experiences of breast cancer survivors in social interaction. All of the breast cancer survivors whom I interviewed talked about their changed appearance *in relation to* other people's responses. Furthermore, my analysis of the excerpts shows the significance of gendered appearances in the order of social interaction. I demonstrate the implications of temporary hair loss, as well as mastectomy on the stigmatization that women experienced both in public and private contexts. I argue that stigma management not only pertains to public life but also intimate contexts.

Secondly, I discuss the implications of altered bodily appearance on one's self and demonstrate how the physical body and self constitute each other. Physical appearance, more than just being an expression of self, plays a significant role in the making of who we are. It is through our physical bodies that we experience the world, become visible, express and constitute ourselves in relation to others. Thus, a radical change in the women's bodily appearance did *not* result in an automatic acceptance and integration of one's new physical appearance as self but resulted in a disruption of the unity of body and self. Survivors worked to reintegrate their changed bodily appearances and selves whether they accepted their new looks as a part of who they are or resisted their new looks and managed their appearance to reclaim the selves they were used to. This shows us that the role of the individual in shaping the definition of the self is evident, "through the little ways in which we resist the pull" (Goffman, 1961, p. 320) as opposed to the notion of self as a very fluid product of others imputations. Furthermore, by resisting the imputations of others, survivors showed that they are not passive absorbers of cultural meanings, images or ideologies but have an active role in making sense of them as well as creating who they are.

Responses of Others

Bodily appearance and social interaction

> One of the things that happens when you get diagnosed is to some extent you feel like a marked person, that you're different than other people especially when you don't have any here [pointing to her hair]. Because if you wear a turban you're the only person wearing something on your head, if you wear nothing it's obvious that you're not in the same state as anybody else (Pat, January 8, 2002).

In the above excerpt, Pat emphasized the deviation in appearance (loss of hair due to chemotherapy) as a significant source for feelings of "markedness." Visible differences such as covering one's head when no one else is doing so, or just exposing one's head with no hair mark an individual. It is due to the visibility of the implications of illness that one's bodily appearance gets oriented to and becomes a part of one's immediate experience. When an ordinary woman becomes visibly different from everyone else, she finds herself positioned as the "other," the "strange" and the "deviant." There is a change in her ordinary way of being as someone who goes unnoticed. With this change in her physical body, she is brought forward into the public eye. The woman in this state cannot take her body for granted; nor can she take body-in-the-world for granted. Thus, the concern for her health and any pain or discomfort are accompanied by a public display of markedness. When she goes abroad among others, she is faced with this sense of alienness. Deviance attracts notice - or one feels it does.

Foltyn (1989) explained that visibly deviant people might perceive that their interaction with "normals" is disrupted due to the responses of normals making the different appearance a “focal point.” When I asked Stephanie, the breast cancer survivor and advocate discussed in the prior chapter, about the implications of losing her hair during treatment, she gave me the following response:

> Yeah not having hair sort of a big one. I don't have hair right now and many times in public places I'm reluctant to take off my hat even though I'm dying of heat exhaustion practically. Although lots of times they do- in restaurants or in movie theatres or offices I will take off my hat but again sometimes I don't. Like I could have today when we were eating sandwiches but again it's a younger environment, I don't feel like really making a statement and so I just rather put up with a little discomfort than have looks (Stephanie, January 15, 2001).

Stephanie covered her head in public and did not expose herself without hair despite the discomfort it caused her. She concealed her actual appearance as a strategy of coping with the reactions of others. Hiding her physical appearance and presenting a “normal” image, allowed her to pass as normal - or feel that she did - and avoid the stigmatized status that she might experience. As Stephanie’s experience demonstrates, when there is a change in one’s physical body, it might influence daily life experiences and interactions with people. One might not continue to receive the responses that one is familiar with from others. As a result, she might not experience her self as she is used to--now that she is someone who needs to work on being considered normal.

Stephanie also mentioned, however, that she took her hat off in public places many times and explained what affects her decisions: her audience. Depending on her expectations for the responses she would receive from an audience, she decided whether to expose her hairless head or not. The young audience, in Stephanie’s view, (for example, on a college campus) might lack a mature reaction to someone who did not look like everyone else. She wouldn't take a risk with them. Going hatless in that environment seemed to her to be making a statement, a sort of defiance that would attract attention. She would rather disguise her baldness with a hat than "make a statement" through her physical appearance. Furthermore, a reference is made to the appropriateness of *gendered appearances* where Stephanie felt like "making a statement" with her baldhead. A bald male, for instance, would not be noticed in the same way as a female who is bald. When I asked Stephanie what kind of a statement she'd be making, she told me that one doesn't see many bald women and the ones you see are usually sick and older than she. She explained that people get confused upon seeing a young bald woman like her and attribute other interpretations to her baldness such as her being a radical feminist. Thus, the unconventional looks of bald women are associated with unconventional identities whereas a bald male can easily pass as "normal" without making any of the above or other statements.

Interestingly, Stephanie explained to me that a bald female not only gets the attention of "normals" but it also invites the responses of other survivors who are willing to share their experiences. Stephanie told that even though she tried to accommodate such moments, she found that intrusive and that it was not a welcome interaction for her. Thus, visibility might serve as a basis for creating commonalities as well as differentiation depending on one's audience.

Depending on the context, wearing a hat might seem "strange" or socially inappropriate (depending on the culture obviously) such as wearing a hat in an office. Wearing a hat on a college campus, however, does not attract the attention of others, depending on the style of the hat. On campus, many people put on baseball caps as well as some other kinds of hats. In this case, it was winter and Stephanie had a winter hat on, which would “pass” as a “normal” look. Being bald as a female on campus, however, would not be considered conventional and be noticed by the young audience on a college campus.

Stephanie’s experience shows that it is not the change in physical appearance per se that has a meaning or shapes one’s actions but the responses of others to it (including the anticipated responses). Receiving feedback that is discomforting and being positioned in a stigmatized status makes one vulnerable and necessitates coping with the situation. One common strategy is disguise.

A visible change in physical appearance can bring attention to one’s bodily presence, make it a part of her immediate experience, and might trigger conversation on it. This is not only the case within the context of illness but also in a variety of everyday life situations. For instance, a friend of ours gets a haircut and we comment on it or she becomes visibly pregnant and her body becomes a frequent topic of discussion. By orienting to our bodies in interaction and responding to them as our object of experience, we make them meaningful: beautiful, ugly, acceptable, non-acceptable, good-looking, ill-looking etc. The bodily changes that one might experience in surviving cancer “bring the bodies” back into experience by focusing attention on them and present a context for people to engage in the construction of meaning on bodies. One should keep in mind, however, that the experience regarding the visual changes in one’s body due to illness differs from those that involve *choice* (such as having a haircut or getting pregnant.) The loss of control over one’s body is manifested by the visible physical changes in one’s body in surviving cancer, which usually results in feelings of vulnerability.

Even a change that is not immediately identifiable can stimulate unwelcome reactions. Someone suffering from pain or the rigors of treatment might not exhibit a specific change but appear generally unwell. For instance, a breast cancer survivor reported in an interview: “I was concerned about my look. If I appeared ill you get feedback from other people about my- you look tired, you look whatever they would use and that would work on me” (Nancy, January 23, 2002). The attention she got from others and the comments she received regarding her appearance when she looked sick worried Nancy and influenced her negatively. Getting feedback on her looks that constantly reminds her of her illness, even at times when she is able to disattend to it, might not always be a positive or desirable experience. It makes it almost impossible for one to take one’s body and bodily appearance for granted which can be overwhelming. Not being able to take one’s body for granted even from time to time might emphasize the disintegration of the body and self, making a person not feel at home in her body. Furthermore, it might create a pressure to look one’s best at all times to avoid or minimize such encounters. These situations might add to one’s emotional and mental distress in surviving a life-threatening illness.

The issue with many of the survivors in my study, as they reflected on their experience, was control – They felt that control over their bodies had been ceded to the disease or the doctors, but they wanted control over how other people responded to them and how they felt obliged to deal with other people. They felt overtaxed by the intrusion on even routine communication of the topic of cancer. One way to maintain some control over their social interactions was to control the appearance they presented to others. Managing one's (visual) self presentation by covering one's head with hats or scarves, enhancing appearance through make-up so as not to look tired or ill or wearing a wig allow one some control over the responses of others and the routine of interaction. Depending on the audience and their responses to their physical appearance, survivors engaged in various image management strategies. Bodily appearance might influence relations with intimate others, and necessitate arrangements to maintain the interaction. For instance:

> My husband had no problem with me being bald. My son did, so I always wore a hat or wore a scarf or something around his friends. I usually walked around the house bald you know it was fall so it wasn't too bad. If I went out in public I always had some kind of a hat. I did buy two wigs and I did wear those when I went back to work. The wigs were almost exactly like my hair so you know that didn't bother me the least (Martha, January 10, 2002).

From Martha's point of view, her decisions about head covering did not come from inside herself; from her own needs, but in response to others. It was her son who was not comfortable with her being bald around his friends, which led Martha to cover her head with a scarf or a hat around them. When she went out in public she put on a hat, but she wore a wig for work. That is, depending on the necessities of the context that she was in she adjusted her appearance so that it would fit others' expectations. Since it would not look "normal" to wear a hat or scarf to work, she picked something that would fit the social requirements of the work place. In her private space and in front of her husband, however, she exposed her head. The significance of *gendered bodily appearance* on one's self-presentation in front of various audiences is implied in this example. Baldness becomes a factor for discrediting Martha's identity as a female and as a mother in the eyes of her teenager son [Martha disclosed her son's age during our interview] and his friends. The anticipation that the unconventional look of a bald female that might not be received favorably by his friends is disturbing for her son whereas he might not have been influenced in the same way if his dad was bald in front of his friends. Similar to Stephanie's experience on a college campus that consisted mostly of a younger audience, the age of Martha's audience might be a factor in addition to the social conventions of gendered appearances that influences her stigmatization in her relation with her son and his friends. Her baldness was not an issue in her intimate relation with her husband. The stigmatized position of his mother in front of his friends might influence her sons' social identity. This might be explained through Goffman's (1963, p. 47) "'with' relationship," where the social identity of those an individual is with might influence one's own social identity. As a teenager, Martha's son's friends might have a significant influence on his social identity, which makes him bothered by his mother's baldness. On the other hand, someone who does not fully depend on others for his social identification might not be threatened as much by the possibility of being discredited through one's relationships (such as Martha's husband).

It seems like our bodies become present in our daily lives and in social interaction when there is a "problem" with them. During "ordinary circumstances," however, the body is taken-for-granted to the degree that it might become invisible. One's body might not be made relevant to interaction unless there is "news" about it (such as a new haircut, weight gain/loss etc.) A deviant differentness in one's bodily appearance, however, calls attention to it in a problematic way and disrupts the routine of interaction. The usual rules for "going about one's business" might not work in this change of circumstances and there might occur a need to do something about the unfamiliarity of the situation. Should one respond to it? Ignore it? Even when people choose to respond to a visibly apparent difference, they might not know what to say since there is no "script" to follow. Goffman (1963b) refers to the "uneasiness" that both the visibly stigmatized and the "normals" feel when they encounter each other, especially when they attempt to maintain a conversation. He explains that the stigmatized individual might feel unsure of how the normals will receive and respond to him/her, whereas the "normals" might be anxious trying to figure out when they might be overstepping themselves or making impossible demands of him/her. Both parties might become highly aware of themselves, each other and each other's awareness, which might result in "pathology of interaction" (1963, p, 18). "And since the stigmatized person is likely to be more often faced with these situations than we are, he is likely to become the more adept at managing them." (1963, p. 19)

A woman might engage in appearance management to make her body socially appropriate in order to maintain relations, depending on her audience. When Martha was not concerned about the responses of others such as her husband, she did not enhance her appearance. She covered her head in public, though, and she wore a wig to work, which looked exactly like her hair. The similarity of her wigs to her original hair was comforting to Martha. Thus, Martha managed her appearance depending on her audience and the responses and expectations of them. This approach to appearance is in line with Goffman's (1959) dramaturgical approach of presenting one's self before different audiences ("front region" or "back region.") "Front region" refers to "the place where the performance is given" (1959, p. 107), and "back region, or back stage" is where the suppressed aspects of a performance, "which might discredit the fostered impression" take place. Thus, in Martha's case for instance, the people for whom she prepares an appearance belong to the "front stage," including her son. Her wig is an intimate prop for her performance at work. Her husband, near whom she can drop her front and relax, is a part of her "back stage."

Even if Goffman (1963b) acknowledged that stigma management might be relevant for intimate contexts and that an individual's intimates as well as strangers might disapprove one's stigma, he did not provide a comprehensive discussion on the intimate scene regarding stigma management (except for mentioning a few comments on homosexuality and mental patients.) The excerpt above illustrates that ones intimates, depending on their age and social position, might play a significant role in the stigmatization of a person and her management of social situations. It challenges the popular notion that as people get closer the effect of stigma is less likely to influence their relation or the disapproval of the stigmatized person. Furthermore, although my interviews don't provide me with explanations, the implications of a woman's bodily changes (including both hair loss and mastectomy) on her sexuality constitute a significant part of one's most intimate interactions. Thus, the potential stigmatizing effects of cancer treatment on women's sexual interactions and female identity needs to be considered in discussions on the management of stigma in intimate contexts.

Similar to the response of Martha's son, other survivors reported that their young kids (teenagers and younger) did not prefer their moms without hair. Except in one case, kids did not provide any validating responses but emotional, self-protective or reactive ones. For instance, Pat's son left without saying anything when he entered his mom's room as she was putting on her wig (thus refusing to see her "backstage" activity.) Stephanie's young nephew started crying when he saw her bald. Sandy's son told his mom that he didn't prefer to see her bald when asked, "My son never saw me because he preferred not to. I wear a scarf and hats around the house and wigs when I went to work" (Sandy, March 25, 2002). Although my interviews do not provide me with specific explanations, it is clear that age is a factor in response to bodily appearance. As a generalization, it seems like young audiences do not prefer seeing *uncontrollable* changes in the appearances of those with whom they are close to such as their mothers or relatives. The issue of control is significant here in the sense that a deviant appearance that is created by choice might be tolerated. For instance, Martha's son might have found it interesting if his mother had a spiky hair cut for a change but in the context of illness it gains a different meaning. As a result, it seems like young audiences usually provide reactive emotional responses rather than validating ones to deviant appearances especially when it relates to health-related issues of their close ones. It may be that they react to the illness through their responses to the appearance of illness.

Martha continued her story by providing an example from her work setting (where she registers patients in a hospital) where her *imagined reactions* of patients played a role in her decisions about the visual presentation of the self:

> And then I stopped wearing my wig at work when it was about an inch long. Because growing in with a wig on top of it I would go we had a backroom a little kitchenette in our office [in the hospital], and I would go back and I would take my wig off and I would just SCRATCH my head. They'd just be oh please, why don't you just- the girls would be why don't you just take it off. I said nobody wants to see a bald woman sitting in a desk when they come in and feel sick. But, I had— they had said that to me prior to that, also they said just don't wear one and I said no I can't do that. Somebody sick doesn't wanna come in and see a bald lady sitting there you know (Martha, January 10, 2002).

Despite the discomfort of wearing a wig as her hair was growing in and the positive responses of her officemates, who, preferring her to be comfortable, suggested she take her wig off, Martha continued to wear her wig until her hair reached a length that could be considered socially acceptable. She pointed to her social role in the hospital as an account for her behavior. She emphasized the potential expectations of sick people for a female clerk in the hospital. Martha's explanation contrasted baldness with health as her reasoning for her role as a female clerk demanded she wear a wig ("nobody wants to see a bald woman sitting in a desk when they come in and feel sick.") Apparently, it would be disturbing to sick patients to encounter a sick clerk who is a woman. Thus, gendered bodily appearance is made relevant to social identity once again, this time in a public setting. When one's bodily presence violates the expectations of an audience, as a bald female does, it might result in the disruption of the flow of interaction and discredit one's social identity. To maintain her social role and the routine of interaction, Martha continued to wear her wig until her hair was long enough that she lost her marked condition and she thought she could once again move with taken-for-granted invisibility.

An even more radical effect of cancer treatment is the loss of one or both breasts due to mastectomy. Mastectomy is a permanent change in the body (despite reconstruction options), it is a private and intimate issue, and it involves a tactile experience of the body/self as well as the visual. My participants reported feelings of vulnerability due to not having one or both breasts, especially when they needed to put a swimsuit on or wear a nightgown, dressing or undressing in front of their partners, looking at the mirror (especially for the first time), making love, and hugging people.

The "visibility" (Goffman, 1963b), that is, "perceptibility" or "evidentness," of a particular stigma influences the implications of it on one's self-presentation and social interaction. Goffman (1963b) explains that one's diabetic condition, for instance, might have no effect on an individual's qualifications for face-to-face interaction but might become a factor in issues of job allocation. Even when a stigma is immediately perceivable (such as someone in a wheelchair), it might not interfere with the flow of interaction and could be disattended (around a conference table in a meeting for instance). Thus, the degree to which one’s stigmatized condition interferes with social interaction plays a significant role in the ways in which one experiences the discrediting implications of his/her stigma. In the case of a survivor who had mastectomy, the “evidentness” of one’s stigma varies. In some conditions of dress, there is no visible evidence. Yet, the asymmetrical look or feeling from a single mastectomy, or the flatness of a woman’s chest after a double mastectomy might bring the stigma forward when hugging another person.

Accordingly, my participants reported that looking or feeling uneven or having to insert a prosthesis on one side to look even were very discomforting. Furthermore, I learned that some women choose to have a double mastectomy to look and feel even, although one of their breasts is healthy, which was surprising news for me. Also, some women chose to have a double mastectomy to avoid worrying about getting cancer in the other breast. The next three excerpts illustrate the implications of mastectomy for social interaction.

In addition to the loss of her hair, which was a temporary change in her physical appearance during chemotherapy, Stephanie reported continued feelings of vulnerability due to having both breasts removed:

> I did- and still do feel vulnerable. For instance going to a locker room is difficult for me because it's- especially here on campus where there's a lot of young women who probably have never been exposed to someone who has been through cancer. And, so, that I think can be very disturbing for them to see my body in the shower or changing clothes and they'll throw me glances or they'll throw me looks. You know I can just feel somebody staring at me and that is uncomfortable for me ... I just want to fit in with everybody else I don't, you know, want to be any kind of a model or attraction in a way or curiosity (Stephanie, January 15, 2001).

Once again, Stephanie emphasized the role her audience played in making her feel vulnerable in a more intimate public context, the locker room. As she talked about the responses of young women in the locker room on campus (throwing glances or looks at her body) that make it difficult and uncomfortable for her to go there, Stephanie provided an account for their behavior: Due to their inexperience with people surviving cancer, seeing Stephanie's body could be very disturbing for young college women in a campus locker room. She was certain from their youth to anticipate their reaction. The responses she received from others, such as stares or looks, bothered Stephanie. Due to the unfamiliarity of the visual features of her body, Stephanie experienced her bodily presence as a disturbance to her social interaction. This example is reminiscent of Goffman's (1963b, p. 12) discussion of "mixed contacts," which are "the moments when stigmatized and normal are in the same 'social situation', that is, in one another's immediate physical presence." Goffman (1963b, p. 14) stated that, "during mixed contacts, the stigmatized individual is likely to feel that he is 'on,' having to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not." Accordingly, Stephanie stated that she just wanted to fit in with others rather than becoming the focus of attention or curiosity. This instance illustrates the visual aspect of one's experience of her changed body in social interaction after a mastectomy. Even if the locker room is not necessarily a place where a woman seeks to be desirable, being the center of attention when one does not prefer to, attracting other's looks without inviting them and being positioned as "unusual" is intrusive. I will also discuss the changed tactile experience of one's body following a mastectomy in the following paragraphs.

Another survivor, Lisa, told me about her initial feelings after having a single mastectomy (surgical removal of breast) and emphasized the reactions of others in influencing her decisions about coping with her changed body:

> Just sad, just sad then there is some embarrassment about it you know. I'm flat on one side and I had reconstruction. I hated the reconstruction. I had the implant removed. I've gone through several times of buying prosthesis to wear because I think it makes people more comfortable if I look the way they want me to look (Lisa, December 3, 2001).

Lisa reported feelings of sadness and embarrassment that she experienced after having one of her breasts removed. She then referred to being flat on one side. Lisa's experience shows a link between her physical, bodily presence and her social/moral status. The flatness of her chest on one side, by positioning her as different from other people (the "normals"), as well as trying reconstruction and rejecting it, discredited her social identity and created feelings of shame. Such attributes that result in the reduction of the social value of people are referred as "stigma" (Goffman, 1963b). In dealing with her stigmatized status, Lisa had reconstruction to reclaim a normal status; however, it didn't work. Lisa accounted the role others played in her decisions to cope with her situation and manage her bodily appearance. In an attempt to live up to the demands of others she chose to buy a prosthesis after having her reconstruction removed. By presenting an appearance that conforms to the expectations of others and avoiding "undesired differentness"

(Goffman, 1963b, p. 5), Lisa sought to make others feel more comfortable and sustain smooth and comfortable social encounters. Thus, the implications of a change in one's physical appearance on social interaction play a significant role on creating the meaning of our bodies as desirable or undesirable, acceptable, unacceptable etc. Furthermore, the meaning of our bodily presence constructed in interaction with others influences our social value. Our physical existence and our social identity are interconnected. It is through our bodily presence that people attend to us as social beings. A deviation in our bodies from social expectations might influence our social position, depending on the degree which it brings itself forward and intrudes with the flow of social interaction.

The following excerpt illustrates how the physical changes in Lisa's body became evident in social interaction in terms of her tactile experience of her body and the coping strategy she used to maintain the order of interaction:

> You have a conception ... of what your body looks like you've grown up with it and you know your good points and you know the bad points and you know what you're comfortable what you're not comfortable with. You get used to your body and you get used to how people respond to your body whether it's hugging your kids or making love or just hugging people on the street. And you just sort of know you're used to it and then it's made different. It's not the same. When I hug you I'm not gonna feel the same, so when I hug I always go to the right so that you get this rather than than the flat side of me (Lisa, December 3, 2001).

In the above paragraph, Lisa referred to the body as an object of experience that people become familiar with as they grow up (my body and me). She emphasized one's private and intimate tactile bodily experiences such as making love as well as the public ones (hugging people on the street) in her explanation of her relation with her body, which brings to mind Merleau-Ponty's (1976) focus on our bodily position as the source of all human experience. We not only learn about the world and our relationship to it through our bodies, but we also learn about our bodies and their social position through being bodies. Through the responses of others to our bodily presence in social interaction we find out about the social meanings of our bodies, get used to them and make them a part of ourselves. We become familiar with the physical sensations, feelings and other bodily experiences we have when engaged in physical interaction such as hugging or making love. A physical change in one's body, however, might transform the way one experiences his/her body as well as how he/she interacts with others. Lisa referred to the change in her body in passive voice "and it's made different" since it did not involve much choice on her side. After having a single mastectomy. Lisa did not experience her body as she used to, she did not feel the same when hugging people for instance. This demonstrates the tactile implications of a change in one's bodily appearance. As a means of preserving her accustomed ways of physical interaction, Lisa came up with a strategy that she would hug people on her right rather than the flat side. By doing so, Lisa made it possible for others to disattend her stigma and avoided its becoming obtrusive in the flow of interaction. Managing her stigma by minimizing visible differences and presenting an appearance that conforms to the expectations of others enabled Lisa to feel she passed as "normal" and restored her social identity in her daily interactions.

In this section, I discussed the ways in which a change in one's bodily appearance in surviving cancer might influence social interaction and result in discrediting one's social identity. A "deviant appearance" such as a bald woman, or a woman missing one or both breasts, violates social assumptions, expectations and demands for how one should look and arouses marking responses (looks, stares, flinches etc.). The individual is positioned as strange, less desirable, devalued, "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963b, p. 3), and the routine of interaction is disrupted. To overcome their stigmatized status and maintain routine social interaction, survivors came up with various strategies such as covering their head with hats or scarves, wearing wigs, having reconstruction or using prostheses. I showed how *gendered bodily appearance* implicates stigmatization and the order of social interaction. Finally, I illustrated that stigma management not only pertains to public life but also has a significant place in intimate contexts. In the next section, I will discuss the implications of a radical change in bodily appearance on one's sense of self.

Bodily appearance and self

As significant as the influence of altered appearance on social interaction are the ways in which it might shape one's sense of self. According to Goffman (1959, 1967), people produce and maintain a sense of who they are in interaction through self-presentation. Thus, a change in appearance which implicates social interaction as seen in the prior section might transform one's self.

Entwistle (2000, p. 6) indicates that, "the body constitutes the environment of self, to be inseparable from the self." Lisa's account of the changes in her body -

(earlier in this chapter), for instance, illustrates this point. She sees the body as an environment of self— as something that one grows up as and gets used to. Her emphasis regarding the changes in her body is on how the changes influenced the way she *uses* her body in interaction with others (now she hugs people on her right side). Other accounts of bodily change, on the other hand, emphasized the body's inseparability from one's self, where loss of hair or having hair growing back different than previously created responses such as, "who is this person" or "it wasn't me." For instance, Sandy expressed that it was a significant change to lose her hair all over her body including her eyebrows, eyelashes and pubic hair, and a significant struggle to overcome the changes taking place in her body due to chemotherapy: "You know, you don't have eye brows, you don't have eye lashes and so you know you're— you look at yourself in the mirror and you say who is this... you don't recognize yourself...." A change in her physical body brought about a disruption in Sandy's experience of her body/self.

Earlier, I stated that I use a definition of self as a reflexive experience formed in social interaction. Self arises when one becomes an object to one's experience through the responses of others. Furthermore, one might become an object to one's own experience by "taking the role of the other." (Mead, 1934) By responding to her body as an object of experience, one might engage in an internal dialogue, a reflexive experience necessary for the constitution of self. Upon losing all her bodily hair, the reflection of her body in the mirror was not a part of her experience of self anymore. The body as which Sandy came to know herself - and *be* herself - by reflexively responding to it as a visual object of her experience was not the same. The ongoing self-body dialogue that she was used to was interrupted. Instead, a new dialogue with her body was initiated when she reflected on her changed look, which went like "who is this?" This excerpt illustrates Merleau-Ponty's (1976) point that bodily experience is the source of selfhood and locates the self in the body. It also shows how bodily appearance might be experienced in terms of its visual aspects.

Sandy further explained that her response was not a reaction or non-acceptance, but just a matter of not getting used to her changed appearance when she looked in the mirror:

> You know when you look in the mirror or you— a lot of women I talked to because you put on weight you walk by a mirror and they step back and say who is this, 'cause your whole body has changed and you're so used to your body as it was. You know, thirty pounds lighter I mean you're used to your hair and you're used to your, you know, eyes and eye brows and all of a sudden they're not there ... it's just mentally you can't get used to this new body that's looking at you in the mirror, okay? So it's almost like a stranger looking at you know.... You come from work and you take that wig off and you say 'who is this *it's not me,*' because we've grown up with our body image as we are (Sandy, March 25, 2002) [emphasis added].

Similar to Lisa in the prior section, Sandy emphasized the visual aspects of bodies and stated that people get used to their bodies including their weight, hair and eyes. That is, we internalize the mirrored images of our bodies or the images that others reflect back to us and make them a part of ourselves. A sudden change in one's body such as gaining weight or losing all your bodily hair disrupts the union of the mind and the body. Not being able to identify herself with the mirrored image of her new body, Sandy expressed the alienation she felt by looking at the mirror.

Furthermore, she talked about the image of her changed body as if it had an existence of its own, a separate being that looked back at her in the mirror. Thus, when the bodily appearance of a person is far removed from the image that she identifies herself with, the result might be alienation. Sandy referred to the inseparability of one's bodily appearance and self by stating that people grow up with their body image as who they are. Reclaiming the image that one is used to by wearing a wig allows one to maintain a sense of self, where taking the wig off creates a divergence of body and self, "who is this, this is not me." *Thus, bodily appearance, more than being an expression of self, is a part of the self. A radical change in one's physical features results in change of self.* In symbolic interactionist terms, as we "take the role of the other" (Mead, 1934) and become an object to our selves, we respond to our own bodily appearance. That is, one simultaneously acts as the subject (being the body) and object (responding to the body) of her experience, engaging in a body-self dialogue (Bruder and Ucok, 2000; March, 2000; Young, 1990). This *reflexive* relation with the self-as-object is essential to the development of self (Mead, 1934), where bodily appearance "provide[s] imagery in terms of which we take the role of another" (Harris and Sandresky, 1985, p. 295) [brackets added]. A change in bodily appearance, however, disrupts the ongoing relation between the self and the body by transforming the physical/material basis of this continuous body-self dialogue, and results in an experience of separation/alienation from the body/self "it [the mirrored image] isn't me." This excerpt also points to the experiential dimensions of being located in a body as emphasized by Merleau-Ponty (1976) and illustrates the inseparability of bodily appearance and self. As Merleau-Ponty (1976) emphasizes, it is through our bodies that we become visible, and accordingly, *hair loss is not just a change in appearance, but is a loss of self.*

Furthermore, a person's face is significant in that there is more recognition of self associated with the face (and hair) than other parts of one's body such as one's hands, feet, belly or breasts (at least in western cultures). This might be why hair loss is a devastating experience even though it is temporary.

Even when her hair grows back, a woman might still feel alienated from her body/self if it looks different from one's previous physical appearance. For instance, Shirley explained her experience of her hair growing back after the treatments:

> It came in as it often does, very curly, and of course I was thrilled to have hair. But there was still a problem, which was that *it wasn't me*. It didn't look like me. I was used to me with a sort of a bobbed do turned under somewhat longer. Now the fact that everybody flipped over to the same hairdo and asked why I haven't done it years ago, and it was true. It was adorable you know. Everyone said 'it made you look younger.' Everyone loved it. But there was still this thing in my mind that *it wasn't me*, it didn't look like me (Shirley, March 1, 2002). [Emphasis added].

Shirley's response to her newly growing hair was similar to Sandy's experience when she lost her hair (as discussed in the prior excerpt,) in that Shirley also could not associate her new image with her self ("it wasn't me, it didn't look like me.") Despite the fact that she was very happy to have hair, not being able to identify her self with her look created a problem for her. Put differently, her new hair was not able to restore her disrupted self-body dialogue back to what was organized around her "bobbed do turned under somewhat longer." Rather, it created a new dialogue.

Despite the positive responses of others to her new hair, emphasizing that it made her look younger, and her own favorable response to it, Shirley could not associate her look with her self. She then provided further explanation on how she came to accept her new bodily appearance and make it a part of herself:

> Now my image of me, I think this is often a problem you know, why sometimes women get stuck with long hair, that fat hair from the seven— that they have an image of themselves that gets fixed in their minds that may not be the most attractive or the best image of them. They're used to wearing bright red lipstick from the fifties or whatever and that's what they keep doing because that's the way they see themselves. And I saw myself a certain way and this wasn't me, no matter how adorable it might be, it wasn't me and that took quite a long time. For I think again when it became a conscious decision to keep it short because I liked the way it looked it began to be more acceptable to me. I think what made it less acceptable, even though it was my hair, was that it wasn't the me I was used to and once I decided 'okay this is the me I'm going to be,' it became more acceptable to me (Shirley, March 1, 2002).

Shirley shows that people get attached to the self-body dialogue through which they experience and constitute themselves. Thus, they refer to the same dialogue in creating their visual self-presentation whether it is still fashionable or not. Shirley's story of her experience suggests that when her mirrored bodily appearance did not match her already existing self-body dialogue, she did not experience it as herself. Whether her new look was adorable or not did not make a difference. It was not until a long time later that she made a decision to make her new appearance a part of her self. That was when her changed image became acceptable. This excerpt shows that *our physical bodies and selves are interdependent and they constitute each other*. We respond to our appearance as "I am," as a part of our selves. When her reflection in the mirror changed, until Shirley chose to make it a part of her self, she continued to experience a disunited body and self. She also stated that the fact that she liked her new look influenced her choice. When I asked Shirley about the factors that influenced her acceptance of her new image, she emphasized two things: time and public reaction. She stated that the positive feedback from others, the compliments she received and the comments that her new hair made her look younger made her like and accept her new image.

Responses of others to one's changed image may not always be positive, however, which influences acceptance of a new look. For instance, Lily described her experience of having her hair growing back different from before and how that affected her:

> My hair grew back— when my hair did grow back— I was always bleaching my hair and I decided that, 'oh my goodness I'm just gonna get new hair, I shouldn't do anything,' so my hair grew back with a lot of gray in it. And I felt kind of lost in the crowd because people would walk by me, they would not even recognize me, people that I didn't see on a daily basis. I kind of felt invisible because I wasn't blonde. I wasn't who I've been through all these years ... People who knew me as acquaintances ... you know who would recognize me on the street and come up and say 'how are you," they just walked by me because they weren't used to seeing me looking like that and I totally looked different... (Lily, March 8, 2002).

When Lily's hair grew back in gray rather than blonde, Lily felt invisible and lost. She emphasized the changed responses of others to her appearance as the reason for her experience, where they wouldn't recognize her as they walked by. The difference in the attitudes of the others due to a change in Lily's physical appearance created a divergence from her earlier experiences of herself, "I wasn't who I've been through all these years." *How she experienced herself as a body in relation to others* *was disrupted*. The responses of others to her bodily appearance that she internalized and made a part of her self (such as being a blonde) were not present in her experience anymore. The body that she was, and that she reflected on and constituted her self through, was different. Not being able to experience her self as she was used to, Lily felt lost. This except illustrates the significance of others responses and social interaction in the maintenance of one's self. When the interaction changes, it might become difficult to preserve the self. Lily's experience also shows that bodily appearance has a significant influence on social interaction. A change in one's physical appearance affects the way people respond to each other. Finally, it is clearly seen from this example that people experience their bodily appearance as deeply connected to their selves. The next excerpt further illustrates this point.

Lily colored her hair back to blonde in an attempt to reclaim the self she was used to:

> After probably a year I decided to go back and bleach my hair because I just felt lost. That wasn't me. I'd look in the mirror and I'd say 'who is that person' so I did go back and start coloring my hair again as I do today. But that's who I am. I've been blonde since I can ever remember (Lily, March 8, 2002).

Lily's experience of self is organized around being blonde; she identified herself in part through her blonde hair (and others responses to it as seen in the prior excerpt.) Like Shirley, when Lily looked at her reflection in the mirror, she could not associate her look with her self. She experienced a disunited body and self, which led her to color her hair back to its original color to restore her self. Merleau-Ponty's (1976) argument that the physical body is the source of selfhood is validated once again by this example. Coloring her hair reestablished the self-body dialogue Lily had before and reunified her body and self. In contrast to Shirley, who accepted her new look as a part of who she is now, however, Lily chose to restore her original look and rejected her new image. It is important to note that in both Lily's and Shirley's experiences, only one of their images was desirable: The one that is validated by others in their social interactions.

As a result of a change in one's image, people either accept the way they look and make it a part of themselves (such as in Shirley's case) or resist the change and manage their image to restore their selves (as in Lily's case.) By not accepting the implications of her changed image on her self such as becoming invisible, Lily chose to fit the responses of others to her self to become visible again. This shows us that the role of the individual in shaping the definition of the self is evident, "through the little ways in which we resist the pull" Goffman (1961, p. 320) as opposed to the notion of self as a very fluid product of others' imputations. Despite their different choices, both Shirley and Lily showed an effort to maintain the coherence of the self in moments of change and uncertainty. They did not just become their new image but rather worked on integrating their appearance and self by consciously making choices. This illustrates the reality of a unified self rather than the notion of a self that consists merely of an image and challenges the disappearance of the self as argued by postmodern social theory (Battershill, 1990; Dowd 1991; Gergen 1991; Langman 1992; Tseëlon, 1992). If there is nothing more to the self than image as the postmodernists claim, then one questions why it took such effort and struggle for the survivors to recreate an integrated self? What makes it so difficult to accept a changed appearance/image as one's self?

The rest of this chapter discusses resistance to the responses of others to a changed physical appearance as a means of preserving the integrity of one's self, as well as one's relation with her body. *By resisting the imputations of others, survivors showed that they are not passive absorbers of cultural meanings, images or ideologies but have an active role in making sense of them as well as creating who they are.*

Resisting the changes in one's physical appearance and image as well as the responses of others might take a variety of forms. For instance, a woman might initially allow others to influence her decisions to some degree regarding her image, self or social interaction and stand up for her own ideas later, as shown in the following excerpt:

> I stopped wearing my wig when my hair was about probably a half inch long. And one day I went to pick up— it was my night for the car pool for the track team, so I went to pick up Mike [her son], his friends and I didn't wear my wig and the first kid in the mini van slides the doors, looks at me and says 'Hey Misses Johnson' and he goes 'OH COOL hair,' 'cause you know it was like sticking up everywhere, I mean just sticking up. And Mike walks in gets in the car and says 'Mom.' I said, 'Michael I can not do that anymore' and the kid who said 'Cool hair Misses Johnson' said, 'Why did you cut your hair like that?' I said, 'Sweetie I've just been sick, this is just the way my hair is going now.' He goes 'Oh I think it's cool.' You know Michael just looked at me mortified (Martha, January 10, 2002).

When her hair reached a socially acceptable length (for a female), Martha chose to stop wearing her wig, despite her son's discomfort. That is, she resisted her son when it was acceptable for her to appear in public without covering her head.

The unconventional look of her hair triggered positive response from her son's friend, however, it still did not please her son. This excerpt illustrates how our physical appearance plays a role in constituting our relations with others. Martha's spiky short hair projected an image that made her look original to her son's friend and did not disrupt the flow of interaction. Thus, her "deviant" appearance was received favorably by some people and did not suggest a relation to her illness. Martha was not in a position to be stigmatized anymore. The uniqueness of hair, however, triggered the curiosity of her son's friend (along with the unhappy face of Mike probably). Even when Martha pointed to her sickness as the cause of her hairstyle without making a reference to cancer, she continued to receive a favorable response from her son's friend. Mike, however, showed his disappointment through his nonverbal expression. The disapproval of her son did not hold Martha back from her own acceptance of her image and her resistance to her son ("Michael I can not do that anymore.") The agency of individuals in making decisions about their own lives and resisting others responses is evident in this example. Martha's resistance, however, was not totally independent from others, such that she was considerate of her son's and the public's reactions until her hair grew half an inch long.

One might personally have no issues at all with being bald; however, one might become concerned in relation to intimate others, accept their views and manage appearance on a temporary basis. For instance, Jessie explained that she was never bothered because she lost her hair during chemotherapy. To her, the most important thing was to get better because, "It's just hair, it'll grow back in" (Jessie, April12, 2002). Jessie, then described an incident which was the one time she was bothered in relation to her daughter:

> Well I guess the only time it did bother me ... my oldest daughter who was in kindergarten at the time. She was five and the children were going to a Spanish speaking school in Puerto Rico and I would go to pick her up at school. And as we were leaving one day and I would wear my baseball cap, I didn't wear a wig it was of course quite obvious that I didn't have any hair, and apparently two boys were walking behind us and speaking in Spanish and making fun of me and she knew Spanish I didn't. I don't know any Spanish but because she was learning it, she understood what they were saying and when we got in the car she said to me 'Mommy can you wear your wig to school from now on because those boys back there were making fun of you.' And that bothered her and because it bothered her it bothered me so from that point on I wore my wig taking her into school and then picking her up at school but as soon as we got in the car I took it off because it was so itchy and being in a hot and humid climate ... So I would wear the wig on special occasions or to please others in my family so that they wouldn't feel so awkward about it but as far as myself it was fine (Jessie, April 12, 2002).

This excerpt also illustrates the significance of bodily appearance in social interaction where an uncommon, nonconforming appearance might be discredited. Our bodily appearance might become a basis for differentiation, which might receive deprecating responses from some people. Even if Jessie's daughter did not have a problem with her mom's appearance, the responses of some schoolboys concerned her. And she requested her mom wear her wig when she picked her up at school. Thus, one's distinct physical appearance not only affects her own experience and relationships but it might also influence those who are intimately involved with them. This in turn, might have an effect on the person who has a "deviant" appearance. Even if being bald was not an issue for Jessie and she was not concerned about other's responses to her, Jesse was troubled indirectly through her daughter. As a result, she temporarily wore her wig around her daughter's school to please her. Similarly, Jessie wore her wig on some other special occasions to please her intimate family. Rather than resisting other's views she chose to accommodate them depending on the context. Jessie's changed appearance did not directly implicate her relations inside her family but through her relations in public in the presence of her intimate ones.

Problematic situations such as the above show the relevance of our bodily presence to social interaction. A nonconforming physical appearance calls attention to it and makes one's body relevant to social interaction. "Normal" bodies, however, not necessarily become the focal point of interest in the ordinary flow of life. From the above excerpts, we see that the visual presentation of self has significant implications on the "interaction order" (Goffman, 1967). A "deviant" appearance might disrupt the routine of interaction and result in the stigmatization of individuals as well as those who are with them. Rather than resisting other's responses with no exceptions, one might choose to manage her image so as to maintain the routine of interaction in public in the presence of loved ones.

In the rest of this chapter, I discuss the decisions of women who had a mastectomy in accepting or resisting the changes in their bodily appearance and the responses of others. As stated earlier, the changes one experiences due to mastectomy have different implications than hair loss in that it is permanent and more intimate. One might initially accept the changes in one's image and later on experience changes in her decisions due to some external events. For instance, Pam used a prosthesis in coming to terms with her changed body; however, she experienced a change in her relation with her body later and felt depressed when her daughter started developing breasts.

> I have done okay with having mastectomy, having some kind of artificial thing that I put in my bra and stuff like that but I noticed that about last January or February I was starting to get depressed about my physical situation. And my daughters one of them is eleven and the other one is nine and she was starting to develop and I felt like I was starting to hide a little bit so I just had a little may be it's time to do reconstruction (Pam, January 7, 2002).

Pam initially emphasized the management of her appearance in coping with the changes in her body where she used a prosthesis, and she did "okay." The satisfactory presentation of her body, however, was not enough to make her content about her physical situation. When her daughter started developing breasts, Pam became more sensitive about her own image and experienced a change in the way she related to her body ("I was starting to hide a little bit.") Rather than maintaining her acceptance of her body, she was embarrassed about it and she decided to have reconstruction. Thus, other people might have indirect influence on the way one experiences her body. Explicit responses to one's physical appearance might not be necessary for one to change the way she relates to her body. Acceptance or resistance of one's altered body is not fixed, especially in permanent changes such as mastectomy. I observed other survivors who did not have immediate reconstruction but kept it as a future possibility even if they did not want it in the present. People's relations to their bodies change in time, as do as their decisions about their bodies.

Like Pam, Jessie accepted her image after having a mastectomy and did not choose reconstructive surgery. She later changed her decision after her experience at the pool and had reconstruction.

> So again I thought you know it's not the physical thing that makes us up it's what's in our hearts and what's in our heads in human beings that really counts that really makes us. But, again, I had another external experience that happened like with my daughter with the wig issue. I was wearing the prosthesis and we went to the pool during the summer and when you wear a prosthesis and you bend over the weight of it pulls away from your chest ... so I bent over at the pool I think I was actually picking her out of water and I heard these little children who went like gasp because you could see that you know my chest is flat here but- that I have no breast here. And I guess I didn't wanna live with that and my breast surgeon kind of politely encouraged me, 'you know you may want to think about having reconstructive surgery' you know every time I would go to see him for a check up. He kind of munched me into it, I didn't really understand why but you know he said "You're a young woman and this may be something you want to think about.' And I elected to do it and I'm really glad I did. I guess I might have a been a little bit more self-conscious about that than I was letting myself believe (Jessie, April 12, 2002).

Jessie explained that she valued the human capacity to think and love as significant constituents of who we are rather than our physical appearances, suggesting that she did not concern herself much about her changed body. When her flat chest was exposed through her swimming suit as she leaned forward to pick her daughter up, however, she realized the astonished reactions of some children who saw her chest. This external influence, as well as her breast surgeon's encouragement convinced her to have reconstructive surgery. She said her surgeon referred to cultural images of being a *young woman* in supporting breast reconstruction. Thus, he made gendered bodily appearance relevant to Jessie's decisions on her body. Whereas Jessie initially did not pay much attention to such cultural images but valued substance over the physical, material issues, she accepted reconstruction. The responses of others to our physical appearance and the cultural discourses on gendered images might have a significant role in one's decisions on bodily matters especially in times when she is vulnerable such as when surviving a life-threatening disease and its permanent implications.

Stephanie Byram, whose story was discussed in the prior chapter, encouraged women to see that there is an alternative to having breast implants or breast reconstruction. Emphasizing the effects of these surgeries on a woman's body, she suggested coping with the self-image issues as a rational alternative, which "doctors or many of the medical community don't readily present to women." (Byram, Jan 16, 2001) Interestingly, Stephanie's surgeon did not *politely* encourage her but he was very precise and confident in telling her every time she saw him that she *had to* contact a plastic surgeon because she would want to begin a reconstruction "so you must call him." (Byram, Jan 16, 2001) Stephanie, however, *politely* resisted him in telling him that it was not for her.

External validation was an important factor in influencing the decisions regarding the resistance or acceptance of one's changed body after mastectomy. In the following example, Lisa explained that she became comfortable with her changed body through "the constant love of my husband, the attentions of my friends saying 'it's okay we love you anyway'" and was able to resist the negative reactions of other people. Lisa explained that she went through different phases regarding her image following her mastectomy : at first she was embarrassed, then sad, then she tried using a prosthesis, and then she used it but didn't care for it. Now she doesn't wear the prosthesis anymore. The following excerpt includes a couple incidents which were turning points for Lisa in moving beyond these concerns regarding her body:

> ... Being with my big brothers whom I adore, we were on a camping trip and I had the prosthesis in 'cause I was still thinking you gotta wear prosthesis ... They didn't bring a football, so they went back into my swim suit and said we have a football here. So they took the prosthesis and that became a football and it became clear to me that it was much more important to have a football than to have a breast in their lives you know, like they don't care if their sister is missing a breast they needed the football much more you know. And they are in their fif— you know fifty three and fifty eight, you know, like grow up boys ... I think those kinds of things when you say what was the deciding there was kind of that change over time you know, having Beth and Lisa sleep there, having Bob being with me in bed, having brothers say we need a football more than we need a breast get over it and those kinds of— ...And today actually I'm going swimming in an indoor pool for the first time here and I'll just have the swim suit on I'm not putting anything in it just to make other people feel more comfortable, get over it (Lisa, December 3, 2001).

When her brothers made a football out of her prosthesis, Lisa realized the insignificance of her changed body in the eyes of her brothers. The comfort that her brothers, whom she valued very much, displayed changed Lisa's thinking that she *had to* wear prosthesis. The support and strength that her loved ones in her family provided enabled Lisa to go beyond the social/cultural norms that she felt she needed to comply with. It was through her interaction with her brothers, her close friends and her husband that she found the courage and determination to resist the negative responses of others to her bodily appearance. This shows that relations in the private sphere might significantly influence relations in public and empower one to act as an active agent in the maintenance and production of the bodyInstead of working to make others comfortable by managing her image to make her body look appropriate, Lisa now expects others to go beyond their discomfort or shock. She chose to be an agent in affecting others' reactions to her rather than being a passive recipient of their cultural/social discourses.

The following paragraph further illustrates Lisa's resistance to changing her body to match others' views. As she stated clearly, she not only is comfortable with her body but also defined and (re)accepted her changed body as her self.

> And I'm going through a phase right now where I don't give a damn and I don't wear it [the prosthesis] and I'm perfectly comfortable without it. I swim without it. I know that people sort of— it takes them by surprise, but this is now who I am. It's like, it defines me that I have one breast and as I get older I become more and more comfortable. This is the way I am (Lisa, December 3, 2001).

After living through different phases of surviving cancer, Lisa stated that she is in a state now where she does not give much importance to others' judgments of her body. She quit engaging in image management strategies such wearing a prosthesis. Furthermore, she indicated her comfort without a prosthesis. Lisa's story shows that she takes a significant role in choosing to define the way she presents her body in public. Lisa not only resisted the responses of others to her body but also the stigmatization of her body. Acknowledging the fact that people are surprised upon seeing her unconventional bodily appearance, she still does not hold herself back. Rather than living in disguise, Lisa chooses to display her body as she is. She indicated that her new body defines who she is now, that she has one breast. Lisa came to terms with her changed body and was able to reintegrate her self and her body. Furthermore, she linked age and her level of comfort positively; that is, as she got older, she became more comfortable with her body.

In addition to the support and the external validation she received from her family and friends, Lisa mentioned the significance of her association with Race For the Cure (RFC) in her resistance towards other-views as opposed to her own: “I don’t know whether, if I wasn’t involved with the race so much, as I’ve been so instrumental in it, whether I’d have the guts to be such a rebel you know. I mean I’ve been a rebel with or without the race but you never know how you react otherwise” (Lisa, December 3, 2001). A couple other breast cancer survivors who volunteer at the “Race Office” also reported that it is a very open environment where one can hear and share any stories about their experience with breast cancer with others. During my volunteer work at Race for the Cure, I observed women talking about many different aspects of breast cancer, including their own experiences as part of everyday talk. Talk about breast cancer seems to be something that everyone is familiar with around the RFC office, which creates a very liberating context. Privacy did not seem to be a concern among the volunteers. Everyone knew each other. I was surprised at an incident where, during my meeting with one of the directors in an open meeting room, upon an immediate question that popped into the director’s mind, she called out to some volunteer friends of hers in the office and did a quick survey, asking them what could be considered a very private question in another context (“Which side was your cancer?” and, “Are you left or right handed?”). Thus, this RFC office offered itself as a liberating space for breast cancer survivors in which people can support each other in many ways.

Similar to Lisa, Stephanie told about her experiences where she got external validation that she needed to accept her body, and create a unity of her mind and body.

> A couple of things happened. One is that I asked a friend what he thought about dating a woman without breasts and he said 'Well to be honest ... breasts are over rated.' He has dated a lot of women and there is a lot of really ugly breasts out there and he would actually think that to date somebody without breasts would be exotic and very intriguing to him so he saw it as a positive. The other thing that happened is I started getting out a little bit, this is after I healed. I went to California with a girl friend and we went to a spa with two of her friends and in the spa everybody was naked and so I was naked too and I got into the jacuzzi and the women might have looked at my body but they didn't make a big deal out of it. I mean they weren't staring at me, they didn't pass out from fear or whatever. I don't know what I expected, just more gazing or staring or something ... So those things ... I think went along ways towards giving me the external validation that I needed to believe that not having breasts is kind of irrelevant to who I was and what I wanted to do, and how I acted (Stephanie, January 15, 2001).

The stories Stephanie told above show how she found acceptance from other people, including men and women. The responses of others that allowed Stephanie to conduct life-as-usual gave her validation that her new body was not a constraint on who she was and the things she did. When she lost her breasts, Stephanie felt she lost some of her identity (as a woman for instance.) With the support she received, however, she realized that not having breasts was not an important a part of her identity after all, because they didn't affect what she wanted to do and how she acted. From both Stephanie's and Lisa's stories, it becomes evident that the *people with whom one interacts have a significant influence on the reintegration of one's body* *and self. Finding support and acceptance allowed survivors to accept their changed bodies and (re)make them a part of themselves.* Furthermore, they were able to resist the negative responses of others and have an active role in the construction of the meanings of their bodies. Thus, *social interaction that supports the integration of one's identity plays a considerable role in individual's choices to resist the social/cultural norms on bodily appearance*.

Resistance to change and its implications on one's image, self and interactions, however, are not absolute. Even after reaching an integrated state of mind and body, one might still feel vulnerable or have second thoughts about challenging the existing norms and expectations depending on the circumstances or audience. Stephanie (January 15, 2001) explained that she was self-conscious about going to the locker room on campus because of the young audience who might have never been exposed to a woman who had a mastectomy. Similarly, Lisa who expressed her comfort and "wholeness" with her body described her hesitancy about wearing a tight fitting sweater.

> And every once in a while I want to wear a sweater set, you know that are somewhat tight fitting and I think 'Oh I better put the prosthesis in' and I do. And then I think I just won't wear those sweaters anymore, so I wear looser things and I am fine with it (Lisa, December 3, 2001).

Even if Lisa came to terms with her changed body with the support of her brothers, husband and close friends, she experienced uncertainty from time to time in her decisions on the presentation of her self. Wearing tight fitting sweaters without prosthesis might become a challenge to her and she wouldn't choose to use prosthesis. As a result, she avoided such outfits that might challenge her and preferred loose clothing.

In addition to image related resistance strategies, in a session of the Look Good Feel Better project of American Cancer Society I had a chance to observe survivors discussing verbal maneuvers in resisting external influences that might be taken as a challenge. Among a variety of topics that came up during the meeting (such as how to apply make-up, use wigs and other ways in which they can enhance their appearance), breast cancer survivors discussed the discomfort they experienced as a result of being greeted with an emphasized “How *are* you?” which focuses attention on their illness. This evoked a defensive response of, “I’m not gonna let them get me today,” and the survivors came up with strategies of shifting the subject away from their illness to the other person’s life. An example suggested by the facilitator was to greet them back and ask them a question about *their* lives such as “Good, how was your trip last week?”

Two survivors who work at the same place and wanted to be interviewed at the same time, Bella and Nancy, explained that people always said “Oh you look great, you look fantastic” when they met them. Bella said that she got that response even if her image was the same, which made her think that it is a *defensive mechanism* that the other people used because,

> They didn’t know how to interact with me ... So the first thing out of their mouth would be, ‘Oh you look wonderful’ ... So they were concerned about me, but they were probably afraid of saying, ‘How did you feel, what’s going on with you?’ That was sort of like a topic that they could start with to get into the conversation ... I think the reactions of other people is they don’t

> know what to say to you so they'll say something positive and that creates the conversation (Bella, January 26, 2002).

The above excerpt illustrates that a life-threatening long-term illness such as cancer might influence the routine of social interaction even in the absence of visible cues. The structure and meaning of greeting sequences might change such that, as indicated in the prior example, a basic "How are you" might threaten one's identity or people might have difficulty finding their way in interaction. Similar to the disruption in the taken-for-grantedness of one's appearance that is experienced as a result of cancer treatments, survivors experienced an interruption in this basic verbal routine, a verbal taken-for-granted such as greetings. As Bella indicated, people might use appearance-related cues such as complimenting or commenting on her looks to initiate conversation with survivors rather than being open and receptive and asking them what is happening or how they are feeling. Thus, not only survivors but also people who interact with them might come up with strategies to resist the "definition of the situation" that they are in.

Conclusion

In this chapter, I analyzed excerpts from my interviews with breast cancer survivors to illustrate the implications of various changes in bodily appearance (hair loss and mastectomy) from cancer on their social interactions and selves. Distinguishing between the effects of hair loss (a temporary change in physical appearance) and mastectomy (a permanent, intimate bodily change), I emphasized the changes in the visual and tactile bodily experiences of survivors.

A physical change not only transforms one's experience of the body but also how we interact with others. The interviews revealed the significance of the responses of other people in influencing survivors' actions and decisions in coping with a changed body image. Minimizing visible differences and presenting an appearance that conforms to the expectations of others allowed survivors to maintain social interaction without disruption. In addition to covering one's head with hats or scarves, having reconstruction or using prostheses, enhancing one's appearance through make-up so as not to look tired or ill or wearing a wig were among the coping strategies that helped women to maintain their selves as well as preserve social relations in surviving breast cancer.

As a part of my discussion on the ways in which a change in one's bodily appearance in surviving cancer might influence social interaction, I emphasized its implications on one's social identity. A "deviant appearance" such as a bald woman, or a woman missing one or both breasts violates social assumptions, expectations and demands for how one should look and arouses marking responses (looks, stares etc.).

The women feel positioned as strange, less desirable, devalued, “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963b, p. 3) and the routine of interaction is disrupted. To overcome their stigmatized status and maintain routine social interaction, survivors came up with various strategies such as covering their head with hats or scarves, wearing wigs, having reconstruction or using prostheses. I showed how *gendered bodily appearance* might implicate stigmatization and the order of social interaction. Furthermore, I illustrated that *stigma management not only pertains to public life but also has a significant place in intimate contexts*. Although my interviews do not provide me with specific explanations, it is clear that age is a factor in response to bodily appearance. In general, young audiences did not provide validating responses to the appearance-related changes that their close ones experience.

Next, I discussed the implications of a radical change in bodily appearance on one’s self. I showed that *our physical bodies and selves are interdependent and they constitute each other,* and argued that *bodily appearance, more than being an expression of self, is a part of the self.* Through the responses of others to our bodily presence in social interaction, we find out about the social meanings of our bodies, get used to them and make them a part of ourselves. A change in our bodily experience due to changed physical appearance, however, might disrupt the union of the body and the self. For instance, in most cases, loss of hair or having hair growing back differently than previously created responses such as, “Who is this person” or “It wasn’t me.” It is through our bodily appearance that we grow up with that we come to recognize ourselves as who are. As we "take the role of the other" (Mead, 1934) and become an object to our selves, we engage in an ongoing dialogue with our bodies. When this dialogue is disrupted due to a change in the bodily appearance, survivors experienced a loss of self. This shows us that our bodily appearances are not independent from our selves but a part of who we are.

A need to restore the balance between one's self and changed appearance brought about decisions about whether to accept or resist the new image. While some survivors accepted the way they look and made it a part of their selves, others *resisted* the change and managed their image to restore their selves. This shows us that the role of the individual in shaping the definition of the self is evident, "through the little ways in which we resist the pull" (Goffman, 1961, p. 320), as opposed to the notion of self as a fluid product of others imputations. Despite their different choices, survivors showed an effort to maintain the coherence of the self in moments of change and uncertainty. They did not just become their new image but rather worked on (re)integrating their appearance and self by consciously making choices. This illustrates the reality of a unified self rather than the notion of a self that consists merely of an image, and it challenges the disappearance of the self as argued by postmodern social theory (Battershill, 1990; Dowd 1991; Gergen 1991; Langman 1992; Tseëlon, 1992). Furthermore, b*y resisting the imputations of others, survivors showed that they are not passive absorbers of cultural meanings, images or ideologies but have an active role in making sense of them as well as creating who they are.*

External validation played an important role in decisions of acceptance or resistance of one's new image and other's responses to it. Support from family members and friends helped survivors to become comfortable with the changes in their bodies and resist the reactions of other people to their image. From the survivors' stories, it became evident that the *people with whom one interacts have a significant influence on the reintegration of one's body and self. Finding support and acceptance allowed survivors to accept their changed bodies and (re)make them a part of themselves.* Furthermore, they were able to resist the negative responses of others and have an active role in the construction of the meanings of their bodies. Thus, *social interaction that supports the integration of one's identity plays a considerable role in individual's choices to resist the social/cultural norms on bodily appearance*.

Resistance to change and its implications on one's image, self and interactions, however, are not absolute. Even after reaching an integrated state of mind and body, one might still feel vulnerable or have second thoughts about challenging the existing norms and expectations depending on the circumstances or one's audience. Breast cancer survivors resisted the changes in image and the responses of others in a variety of ways. For instance, some initially allowed others to influence their decisions regarding their image, self or social interaction to some degree and stood up for their own ideas later on. Furthermore, some had no issues with changed image personally; however, they managed their appearance and accepted other-views temporarily to please family members or loved ones. Also, in some cases survivors initially accepted the changes in their bodies and changed their decisions later due to some external events.

From the stories of my participants, it became evident that problematic situations bring out the relevance of our bodily presence to social interaction. A nonconforming physical appearance, for instance, calls attention to it and makes one's body relevant to social interaction. Furthermore, it might disrupt the routine of the interaction and result in "uneasiness" in both the stigmatized and the "normals." Conventional bodies, however, do not necessarily become visible in the ordinary flow of social interactions.

CHAPTER SIX

DISCUSSION

In addition to analyzing representations of women in various discourses on breast cancer, this research mainly focused on the meaning of appearance as an embodied phenomenon. That is, it emphasized appearance as bodily experience in terms of its visual and tactile aspects. Responses of people upon seeing a female with a baldhead, for instance, or seeing one's changed appearance reflection in the mirror is discussed under the visual experience of one's body whereas one's experience of hugging people after having a mastectomy is considered as a tactile experience. The lived experiences of individuals constitute the main source for understanding bodily appearance. In this study, I looked for answers to the following questions:

What are the emergent themes in the narratives of breast cancer survivors that relate to one's sense of self after a change in bodily appearance?

What are the cultural implications of breast cancer survivors' talk about appearances?

In general, "responses of others" to one's physical appearance was a significant subject that showed up in *all* of my interviews with breast cancer survivors. In Chapter Four, "From Diagnostic to Aesthetic: Moving Beyond Diagnosis," I analyzed two contradicting discourses on the aesthetic consequences of cancer treatment: 1) The representations of women in the Look Good Feel Better pamphlet and the images in the American Cancer Society catalogue, 2) The

"Stephanie Project," a verbal and visual documentary of a woman's experience with breast cancer.

My analysis of the representations of breast cancer survivors in the Look Good Feel Better pamphlet and the images in the ACS catalogue demonstrated how these images serve as cultural discourses on gendered appearances that provide a model for what is "acceptable," "appropriate," and "beautiful." The suggestions and models offered for people when there is a "problem" with their bodies provide models for renewed femininity during/after cancer treatment. They promote notions of appearance that are possible even when a person is in crisis and continue to work to discipline women's bodies when they are sick.

Furthermore, I showed that an association between illness, physical appearance and identity is suggested through the pictures of the LGFB pamphlet, where a sick woman with no hair and make-up is left alone in a disconnected world (empty room with empty walls), losing her identity. Identities of the survivors in the "after" pictures are restored as the women are depicted in various social settings in interaction with others when their images are managed to fit social expectations. Thus, it is suggested that to maintain one's identity, a woman must present an "acceptable" image as provided by these models. I argued that the images of women in the ACS catalogue and the LGFB pamphlet serve as cultural discourses that function to maintain existing definitions of "beauty," "femininity," and "gendered appearances," even in times of crisis, by providing a collection of looks that are "appropriate" and "desirable." In privileging some appearances and discounting others, they construct meanings for what is “beautiful” or “deviant,” “familiar” or “strange,” “acceptable” or “unacceptable.” Thus, rather than allowing survivors to construct a new and positive way of viewing their changed appearance, the discourses of the ACS catalogue and the LGFB pamphlet focus on what is wrong with one’s body and suggest models to transform one’s body to “correct” it. By doing so, such discourses do not reinforce the integration of one’s changed body and self, but, rather emphasize the separation of the two.

I provided my analysis of the “Stephanie Project” as an alternative discourse that questions the existing definitions of “beauty” and “femininity” and emphasizes the reconstruction of one’s life and identity through supportive relationships rather than physical appearance. One way of moving beyond the debilitating impact of a catastrophic diagnosis was found in the construction of aesthetic discourse; through the interactive creation of beauty in reaction to Stephanie’s physical appearance in a photograph, a reintegrated and positive sense of self began to emerge. As Stephanie became more able to view her altered body in a new and positive way, she gained enough confidence to participate in other positive social activities. In contrast to a diagnostic discourse that focused on what was wrong with her body, aesthetic discourse, through its emphasis on the pleasing, gracious and artistic qualities of the body allowed Stephanie to construct a new and positive way of viewing her changed appearance. Thus, her “disfigured” body was transformed into an aesthetic body, and the “diagnostic self” into an “aesthetic self.”

The discourse of the “Stephanie Project” shows that social interaction and relationships—from medical, to aesthetic, to everyday conversations in a hot tub—are central to the constitution and transformation of identity. Contrary to diagnostic discourse as well as the discourse of the LGFB pamphlet and the ACS catalogue that focused on what was wrong with the body, aesthetic discourse helped transform one individual’s way of seeing her own body as beautiful. Thus, it is seen that through discourse that reinforces the creation of an integrated identity, even devastating experiences such as being diagnosed with a life-threatening illness might result in realization of new meanings about one’s self and life.

The “loss of self” due to a change in bodily appearance that was analyzed within the Stephanie Project was a theme that came up in the narratives of the survivors whom I interviewed that is explored in Chapter Five, “The Meaning of Appearance in Surviving Cancer.” My analysis of the interviews illustrates the ways in which the responses of others to one’s changed bodily appearance influences the experiences of breast cancer survivors in social interaction. Being visibly different from everyone else due to hair loss, for instance, calls attention to one’s bodily presence and makes her a point of attention. The unconventional look of a bald female disrupts the routine of social interaction and triggers various responses from others. Thus, one’s ordinary presence in public as an unnoticed person changes along with an altered physical appearance. Furthermore, being pushed into the public eye against one’s can result in feelings of vulnerability due to stares and looks. The experience of one’s changed bodily appearance due to cancer is a significantly different experience than other various forms of “deviant” physical appearance that involves choice. It represents a loss of control over one’s body and her presentation of self, which is stated as the main source of the anxiety and suffering by my participants. Shaving your head to purposefully attract attention, to make a statement and to indicate group membership such as the “skinheads,” for instance, differs from having the physical change imposed. I would assume that in the cases where one shaves his/her head for any ideological reasons, the experience would bring gratification rather than suffering to the individual and his/her fellow group members. Accordingly, the discomfort that the survivors experienced in their social interactions prompted them to engage in image management strategies. Presenting an appearance that is socially expectable and “appropriate” allowed my participants to maintain the order of social interaction as they go about their everyday business.

I further discussed the significance and implications of gendered appearances on social interaction and demonstrated how hair loss and mastectomy might influence one’s social identity as a female and result in stigmatization in both public and private contexts. Expanding Goffman’s (1963b) discussions of stigma management in public contexts, I argued that stigma management not only pertains to public life but also intimate contexts. Even if Goffman (1963b) acknowledged that stigma management might be relevant for intimate contexts and that an individual’s intimates as well as strangers might disapprove one’s stigma, he did not provide a comprehensive discussion on the intimate scene regarding stigma management (except for mentioning a few examples on homosexuality and mental patients.) The experiences of some of my participants showed that one’s intimates, depending on their age and social position, might play a significant role in the stigmatization of a person and her management of social situations. Young audiences, for instance, did not favorably receive the unconventional appearance of their mothers. Thus, I questioned the popular notion that as people get closer the effect of stigma is less likely to influence their relation or the disapproval of the stigmatized person.

Mastectomy is a permanent change in the body (despite reconstruction options), it is a private and intimate issue, and it involves a tactile experience of the body/self as well as the visual. My participants reported feelings of vulnerability due to not having one or both breasts, especially when they needed to put a swimsuit on or wear a nightgown, dressing or undressing in front of their partners, looking at the mirror (especially for the first time), making love and hugging people. Interestingly, none of the women I interviewed talked about the tactile experience of hair loss or it’s implications on them. Hair loss was discussed as a visual experience and in relation to the recognition of self by others and by one’s self. Loss of hair was more than just a change in one’s appearance but in self. Loss of hair was loss of self. The loss of breasts, on the other hand, was not directly related to loss of self in terms of an inability to recognize one’s of self. It is a loss of self in terms of one’s intimate and tactile experiences (breast-feeding, hugging, love making etc.) in addition to the visual ones. Even if sexuality is a major issue for a woman who loses her breasts, my participants did not provide information about it (except for one who in very general terms indicated that her breasts had sexual meaning for her) and I did not ask them respecting their privacy.

The "visibility" (Goffman, 1963b), that is, "perceptibility" or "evidentness," of a particular stigma influences the implications of it on one's self-presentation and social interaction. In the case of a survivor who had mastectomy, the "evidentness" of one's stigma might arise due to visual or tactile cues in interaction. For instance, the asymmetrical look or feeling when hugging another person due to a single mastectomy might bring the stigma forward.

Throughout the analysis chapters, my study on bodily appearance and selfhood in surviving breast cancer has developed into a discussion of the ways in which survivors of breast cancer, "respond to the demands of seeing and being seen," as Gilman (1999, p. 3) finely put it:

> In a world in which we are judged by how we appear, the belief that we can change our appearance is liberating. We are what we seem to be and we seem to be what we are! ... And as we see the world, the world is also seeing us, judging us by our appearance. To become someone else or to become a better version of ourselves in the eyes of the world is something we all want. Whether we do it with ornaments such as jewelry or through the wide range of physical alterations from hair dressing to tattoos to body piercing, *we respond to the demands of seeing and being seen* [Italics added].

Upon a change in one's bodily appearance due to treatment or surgery, visibility became an issue for most women, which influenced the maintenance of their sense of self as well as social relationships. Questions of identification and recognition came up as a woman's reflection in the mirror diverged from the image that she was accustomed to as well as in the eyes of the others. "Loss of self" due to a change in one's appearance was a common experience among the survivors who participated in this study. Visible differences, such as covering one's head when no one else is doing so, or exposing one's baldness or flat chest, distinguished survivors from others and changed their social state. As a result, "responding to the demands of visibility" or failing to do so was a significant issue in surviving breast cancer. This is not surprising news, however, where the "rewards of being beautiful" are immense "in a culture that worships feminine beauty" (Foltyn, 1989, p. 3), such that it is a form of social-dominance and self-worth to be a beautiful woman.

Goffman's concept of "self-presentation" (1959, 1967) constitutes the basis of this discussion of bodily appearance, self and social interaction. This study treats appearance as a part of self-presentation in interaction. Emphasizing that it is through *self-presentation* that selves are constructed and maintained in interaction, Goffman (1959) considered the production of self in interaction as an image presented by the performer, which in return is credited or discredited by an audience. Postmodern social theorists (Battershill, 1990; Dowd 1991; Gergen 1991; Langman 1992; Tseëlon, 1992), however, interpreted Goffman to affirm the disappearance of the self, arguing that in Goffman's work, "selves are no more than images created in conformity with situational expections." "On this reading of Goffman, there is no warrant for seeking a true self beneath the images, since what you see is all there is to get." (Schwalbe, 1993, p. 333)

As opposed to a "decentered" notion of self in Goffman, Schwalbe (1993, p. 333) demonstrated that in Goffman's work, "the reality of the self is evident not in conformity but in moments of feeling, resistance and choice." This study on bodily appearance and self in surviving cancer demonstrates that the reality of a unified self is manifested in the moments of resistance when individuals take a stance and try to assert themselves against others who would prefer them to act differently. Thus it provides support for Schwalbe's (1993) interpretation of Goffman. A radical change in the women's bodily appearance did not result in an automatic acceptance and integration of their new physical appearance as self but resulted in a disruption of the unity of body and self. Survivors worked to reintegrate their changed bodily appearances and selves whether they accepted their new looks as a part of who they were or resisted their new looks and managed their appearance to reclaim the selves they were used to. For instance, Lisa stopped wearing her prosthesis and she swims without it despite the surprised looks of the other people. She stated that she was comfortable without the prosthesis and accepted her new self as she was "This is now who I am ... it defines me that I have one breast" (Lisa, December 3, 2001). Similarly, Martha stopped wearing her wig around her son's friends when her hair when her hair grew half inch long and resisted her son's disappointment.

This active and autonomous view of self questions the unilateral characterization of appearance and beauty practices as oppressive and an understanding of women as manipulated and passive. Rather, it points to women's agency in being able to actively make sense of and make decisions regarding their own bodily appearance as well as cultural representations of it. In doing so, it does not ignore the influence of culturally defined social relations that the body is located within in shaping the body. Instead, it starts from women's perspectives to show how they actually engage in the production of their bodies. For instance, in Chapter Four I discussed the influence of social interaction and discursive practices which reinforced the construction of an integrated identity following a diagnosis of breast cancer. Through the interactive creation of "beauty" with her photographer friend, Stephanie Byram was able to move beyond the debilitating impact of her diagnosis and create a renewed self. In accepting her new body and feeling at one with it, Stephanie needed to see it as "beautiful." The efforts of the survivors to enhance (and disguise) their changed image by wearing wigs or scarves to fit the cultural definitions of beauty, on the other hand, shows us that "the meanings of the body are neither free-floating in culture nor created solely by individuals" (Gimlin, 2002, p. 9). Thus, while the negotiation of individual identity to construct the relation between self and the body and the realization of new meanings about one's life are possible, one should also consider the limits that institutionalized discourses places on those negotiations.

Resisting the institutionalized views of what is beautiful, desirable and acceptable does not happen in isolation. The people with whom one interacts have a significant influence on the way she sees her body. Social interaction that supports the integration of one's identity plays a considerable role in individual's acceptance of her body and making it a part of her self. Being received by others and finding acceptance allow people to see their altered bodies in a positive way rather than focusing on what is wrong with them and distancing themselves from their bodies. Stephanie, for instance, discovered a new way of being through her supportive and creative relation with her photographer friend as they created a new way of seeing her body. They constructed a way of looking at Stephanie’s changed bodily form as “beautiful” and taught others this alternative definition of beauty through their presentations. They do not have a big institution to support their efforts, however, such as the Look Good Feel Better Project that is supported by the American Cancer Society, The Cosmetic, Toiletry and Fragrance Association, and the National Cosmetology Association. Thus, the discourses that influence the majority of women are dominated by the institutionalized views on beauty, body and identity. These discourses, as discussed earlier in this chapter, serve to maintain the already existing cultural definitions of “acceptable,” “appropriate” and “desirable” bodies and bodily appearances. Even if some of my participants were able to resist these views, the discomfort that the survivors experienced in their social interactions prompted them to engage in image management strategies. Presenting an appearance that is socially expectable and “appropriate” allowed my participants to maintain the order of social interaction as they go about their everyday business. In order to resist the institutionalized views on the body, individuals need strong support networks, such as their significant others, spouses or friends. It is through these validating social relationships that encourage women to resist the social/cultural norms on bodily appearance and have an active role in the construction of the meanings of their bodies.

In addition to the discourses of institutions through catalogues, pamphlets and various other sources as popular magazines and television that provide ideas and norms on the beauty, desirability and acceptability of our bodies, interactions with people who speak these discourses such as doctors and surgeons affect women's ideas and decisions about their bodies. Some of my participants mentioned about the kind and insistent encouragement of their doctors regarding reconstruction. Rather than presenting a neutral position with an attempt to understand the needs of their patients, these doctors functioned as cultural agents speaking the language of the beauty industry. The people with whom one *chooses to* interact with and listen to is significant in the process of making decisions about and constructing meanings and ways of seeing of one's body.

In this study, Goffman's concepts of self-presentation and stigma are discussed as grounded in the body along with Merleau-Ponty's (1976) discussions of embodiment. I focus on bodily appearance as a constituent of self, in addition to our understanding of physical appearance as an expression of self, and show that we come to recognize ourselves as who we are in part through our bodily appearance that we grow up with and the responses of others to our looks. The construction of self is a lifelong involvement. We change throughout life, sometimes gradually but sometimes suddenly. A radical change of body and self comes with a diagnosis and treatment of a life-threatening illness and challenges the "realness" of people by taking away their control over their lives, their looks, jobs and relationships. The taken-for-grantedness of life that keeps us comfortable becomes a luxurious experience when one is constantly reminded of her illness by the treatments, side effects of treatments, pain, and exhaustion as well as the verbal-visual responses of others. Our bodies also cannot be taken-for-granted anymore as they become visible in everyday interaction when there is a problem with them. A nonconforming physical appearance calls attention to it and makes one's body relevant to social interaction. A "deviant" bodily appearance disrupts the routine of interaction and result in the stigmatization of individuals as well as those who are with them. Thus, this study emphasizes and reminds us the presence of our bodies that we forget about in everyday life and social interactions.

How My Study Differs

This research differs considerably from studies that focused on the medical and psychological aspects of cancer, discussing changes in bodily appearance in terms of the relation between such variables as the loss of hair and self-esteem, or the relation of age, marital status, education and reconstruction to a person's adjustment to mastectomy and recovery. Rooted in the experiences and activities of people surviving cancer, this study inquires about the transformations of self in relation to changes in bodily appearance and image. Thus, the viewpoints of the people studied, the meanings and interpretations they attach to themselves or others constitute the primary basis of this study.

Giving a voice to breast cancer survivors for their experiences, this research adds to the emerging interactionist research on illness with an emphasis on the processes through which meanings of appearances develop from social interaction with others. It is also different from the sociological and feminist accounts that emphasized how bodies are constituted and controlled by discourse in that, rather than treating the body as a symbolic entity, the current study focuses on women's lived experience with their bodies and women as an active producer of meanings, which has long been an overlooked issue in the history of the studies on the body. There are several significant contributions of this study to the studies of social interaction that focus on the body, self and identity: First, it locates the self in the body and shows how the self and the body constitute each other. Thus, it brings our bodily presence back to the discussions of self and identity. Second, it provides a unique perspective to discussions on the visual presentation of self by viewing appearance as a bodily experience, and discussing the implications of a changed bodily appearance on the order of social interaction. Finally, it contributes to the studies on stigma by extending the discussions of stigma management to include intimate and private contexts.

This study offers insight to contemporary feminist scholarship by incorporating the actual experiences and voices of women, which illustrate how survivors actually made decisions regarding the transformations in their appearance. The emphasis of this study is not on the "politics of beauty," however, it might be helpful in making sense of women's responses to beauty ideologies. In analyzing the transformations of self in relation to changes in physical appearance, cancer survivors are considered as active participants in the negotiation of image related cues in interaction, thus active participants in shaping themselves. An implication of this study for feminist theory is the finding that women did not just act as "cultural dupes" trapped in the ideologies of the beauty industry but resisted the views of others in maintaining their sense of self.

For instance, to find out about the everyday enactment of the beauty ideology, Gimlin (2002) analyzed women's own interpretations of their participation in body work in places like a hair salon and an aerobics class. In her study of the interaction of the hair stylists and their customers in a hair salon, she found out that clients resisted the beauty ideologies mediated through hair stylists by arguing that "their middle-class social status [age, occupation] prohibits them from following the beauty suggestions of the hair stylists" (Gimlin, 2002, p. 18) (brackets added). Gimlin's (2002) study carries similarities with my study on bodily appearance in that she showed that women are not just passive recipients of beauty ideology but they respond to the pressures of it. My research on bodily appearance and self in surviving cancer adds to the contexts where she studied bodywork as "work on the self" (Gimlin 2002, p. 3). Breast cancer survivors negotiated the relationship between body and self through the decisions they made regarding the bodywork they chose to engage in regarding their changed image (whether to use a prosthesis, to color hair, to have reconstruction etc.)

By examining how women actually engage in the production of their bodies, this study emphasizes the agency of individuals in the production and maintenance of their bodies. It shows that women can act as an active producer of meanings rather being seen just as a "product of discourse."

Practical Benefits of the Study

This research aims to show that there exists a potential for the constitution of a renewed and transformed self in surviving cancer. Through discursive practices that support a positive and integrated identity, external validation and becoming actively involved in their survival experience by seeking connections, volunteering in various programs and events of cancer related organizations such as Race For the Cure and reflecting on their illness through creative processes such as journaling, drawing and painting helped women who participated in this study to free themselves from getting caught up in their illness and observe what is going on as well as share it with others.

Pointing to the common issues and the active involvement of women in their experiences of surviving cancer, this study might provide insights for people suffering through cancer treatments to go beyond living a diminished quality of life and create meaningful and valued lives.

This research might be beneficial for medical providers to gain specific information about the conceptions and transformations of self one goes through in surviving cancer, as well as the implications of the illness on interactional processes. As Sault (1999, p. 10) indicated, "how the body is recognized in defining personhood is especially important for understanding illness and healing." For instance, acknowledging that the body/self is inseparable from body image and that image constitutes the self might have significant consequences on the quality of health care. Paying attention to such implications of illness as "loss of self" might be beneficial for the recovery of patients.

Furthermore, the various excerpts and stories by breast cancer survivors within the text might serve as reference points for families and friends who share the physically and emotionally difficult times with their loved ones as they go through their own coping experience. Being aware of the processes of transformation women went through and the significant role that supporting and validating social interaction plays in creating an integrated identity might make a difference in approaching the illness experience.

Limitations of the Study

One needs to consider the potential of a researcher bias where the presence of a researcher might influence the "presentation of the selves" (Goffman, 1959), and, thus the conversations between the subjects and the researcher. There might also be a sampling bias due to the small size of the sample (18 interviews) where the majority of the interviewees consisted of middle aged (average age being 53), middle-class white women. Only one participant was African-American. No attempts were made to recruit specifically female participants but all of the interviewees are women. One should keep in mind, however, that the facilitator who helped me find the majority of my participants is a survivor herself and already had contacts with these women. Thus, there might be a bias regarding the recruitment of my participants in that they all are a part of the same social network in one mid-western US city.

My participants did not report experiences regarding the implications of their illness on their sexuality. This brings a limitation to my discussions on “stigmatization” in intimate contexts. Furthermore, the majority of the women I interviewed were married to supportive husbands and none of them experienced a challenge or threat of being left by them. There are many women, however, whose husbands either add more pressures to their suffering or leave. My sample does not represent these instances.

This study does not account for the differences that gender, age, ethnic origin, socio-economic status might create in the experiences of breast cancer survivors, therefore one needs to be cautious in generalizing the findings of this research beyond the participants of this study.

Future Research

In the literature review, the need for studies that explore how we experience our bodies in everyday life was emphasized. Despite the multitude of research which focuses on the body (and the images of the body) as a symbolic form or text there exist few studies that analyze people’s lived relation to their bodies.

As Entwistle (2000, p. 10) stated,

> When dress is pulled apart from the body/self, as it is in the costume museum, we grasp only a fragment, a partial snapshot of dress, and our understanding of it is thus limited.... Without a body, dress lacks fullness and movement; it is incomplete.

He emphasized the significance of studying dress as a “situated bodily practice,” where the “textual body of the fashion magazine is interpreted and embodied in the practice of ‘getting dressed’ (Entwistle, 2000, p. 239).

Studies that approach appearance as embodied experience might make a significant contribution to the emerging literature on the body. For instance, Beausoleil (1994) analyzed the everyday make-up practices of women, and suggested the need for research that focuses on how women actually engage with the ideal images in their daily lives to account for women's lived relation to these images. "How do women experience beauty and appearance in their daily lives? How do these beauty standards enter into women's lives?" were among the questions she suggested for future research (Beausoleil, 1994, p. 34). Furthermore, one might add to the list a variety of body/image related phenomena to be examined as embodied experience, such as the meaning of piercing as bodily experience, or how people talk about hair in hair salons in an attempt to translate the styles in the magazines into actual experience.

Diagnosis of cancer is a crisis for the whole family. The impact of a diagnosis on kids would make a very useful study. Research could distinguish youth reactions to diagnosis and it's implications, in general, from the reactions of sick women's children.

In a recent personal communication, a friend of mine who started recognizing changes in her appearance due to aging told me that she couldn't keep up with her image anymore. She felt the same inside, but her image was changing, so she started experiencing a gap between her self and her image. Transformations of self due to image-related changes in the aging process might be an enriching addition to existing research on aging.

Analyzing the discourse of yoga as embodiment might provide a context for understanding where the body is addressed as an object of experience towards the liberation of self. The philosophy of yoga to "transform the body and the mind will follow" for healing and creating inner peace could contribute to our understanding of our bodily experience of who we are and the relation of the body and the mind.

Analyzing the social interactions and conversations of women in Look Good Feel Better meetings, if one could manage to be allowed in as a researcher whose study might prove beneficial to the participants, still remains as one of my main interests, which, I could suggest to others.

Finally, this current research could serve as a sample for future research on the same topic, increasing the sample size to enable cross-cultural analysis as well as to account for such variables as gender, race, sexual orientation and age.

APPENDIX

CONSENT FORM

TRANSFORMATIONS OF SELF IN SURVIVING CANCER: AN ETHNOGRAPHIC ACCOUNT OF BODILY APPEARANCE AND SELFHOOD

You are invited to participate in a study of appearance and selfhood. My name is Ozum Ucok and I am a Ph.D student at The University of Texas at Austin. This study is my dissertation research project. You are being asked to participate in the study because you are a cancer survivor (or interact with survivors) with the reference of _________. If you participate, you will be one of 10-50 people in this study. The following paragraphs explain the purpose and the procedures of this study and provide contact information if you need it. With the purpose of maintaining privacy, an intermediary who has reason to know that a potential participant is a cancer survivor (i.e., the director of a cancer related organization, a cancer advocate etc.) has contacted you. The intermediary will provide information about the study, the researcher's name and contact information to the people who have identified themselves as cancer survivors to him/her. The researcher will make appointments for interviews with the survivors who contact her.

This study focuses on the transformations of self in surviving cancer particularly as related to changes in bodily appearance and image (due to radiation, chemotherapy or surgery.) Towards this purpose, I will analyze the ways in which cancer survivors talk about themselves in relation to changes in their physical appearance. If you decide to participate, I will be asking you to tell me about your experience of surviving cancer. Depending on your response, the total time for the interview might take as much as 2 hours. I might also contact you again, with your permission, for a second interview, after my preliminary interviews. I will audio- or video record our conversation upon your approval.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. Your responses will not be linked to your name in any written or verbal report of this research project. Towards this purpose, the cassettes will be coded so that no personally identifying information is visible on them, and they will be kept in a secure place (locked in a file cabinet in the investigator's office.)

TRANSFORMATIONS OF SELF IN SURVIVING CANCER: AN ETHNOGRAPHIC ACCOUNT OF BODILY APPEARANCE AND SELFHOOD

(Consent form continued…)

The tapes will be heard or viewed only for research purposes by the investigator and her associates. The recordings will be retained for possible future analysis.

Due to the sensitive nature of this study, talking about your experience and observations might be emotionally difficult. You are not obligated in any sense to share issues that might present any discomfort to you. You are free to terminate the interview or to withdraw from the study at any time.

Sharing your experiences and contributing to the exchange of knowledge on this topic might help other survivors and their families in making better sense of their own experiences. By creating commonalities and raising awareness and knowledge at the personal, social and cultural levels, cancer treatment may improve and, thus, the quality of our lives.

Your decision to participate or to decide not to participate will not affect your present or future relationship with The University of Texas at Austin or any other institution or agency that might be associated with the study.

If you have any questions about the study, please ask me. If you have any questions later, you can call me at 412-661-7016 or my supervisor, Assoc. Prof. Madeline Maxwell, at 512-471-1954. If you have any questions or concerns, at any time, about your treatment as a research participant in this study, call Professor Clarke Burnham, Chair of the University of Texas at Austin Institutional Review Board for the Protection of Human Research Participants at 512-232-4383.

You will be given a copy of this consent form for your records.

TRANSFORMATIONS OF SELF IN SURVIVING CANCER:
AN ETHNOGRAPHIC ACCOUNT OF BODILY APPEARANCE AND SELFHOOD
(Consent form continued…)

You are making a decision whether or not to participate. Your signature below indicates that you have read the information provided above and have decided to participate in the study. If you later decide that you do not want to participate in the study, simply tell me. You may discontinue your participation in this study at any time. I hereby give permission for the researcher to video ____ or audio ____ tape my interview.

____

Printed Name of Participant		Signature of Participant
Date

____

Printed name of the Investigator	Signature of Investigator
Date

I may wish to present some of the tapes I will make in this study to scientific conventions or as demonstrations in university classrooms. All promises of confidentiality will remain in effect. Please sign below if you are willing to allow me to use portions of your interview in such presentations.

____

Signature of Participant				Date

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VITA

Inci Ozum Ucok was born in Istanbul, Turkey on November 2, 1973, the daughter of Mehmet H. Ucok and Tumay Ucok. After completing her work at T.E.D Kayseri College, Kayseri, Turkey, in 1990, she entered Middle East Technical University in Ankara, Turkey. She received the degree of Bachelor of Arts in Management from Middle East Technical University in 1995. In the summer of 1995, she entered Texas Tech University to pursue a Master's degree in Communication Studies and graduated in the summer of 1998. During her graduate studies at Texas Tech University, she taught Business and Professional Communication as a graduate teaching assistant and Public Speaking as a graduate assistant instructor. She worked at Harvard University during the summers of 1997 and 1998 as a graduate teaching assistant and head-teaching assistant. She started her doctorate at The University of Texas at Austin in 1997. She taught Public Speaking courses as an assistant instructor during her doctorate. Her publications include:

Bruder, K. A., Ucok, O. (2000). Interactive art interpretation. *Symbolic Interaction*, 23(4), 337-358.

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Permanent Address: 100 Denniston Ave #16, Pittsburgh, PA 15206

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