
ORIGINAL ARTICLES

The special case of complicated grief in women at high risk for breast cancer

DAVID K. WELLISCH, PH.D., AND MARIE M. COHEN, PH.D.
Department of Psychiatry, UCLA School of Medicine, Los Angeles, California
(RECEIVED April 15, 2009; ACCEPTED October 17, 2009)

ABSTRACT

Objective: Exploration of complicated grief focusing on the relationship of post-traumatic stress disorder (PTSD) and complicated grief in a population of women at high risk for developing breast cancer. Special reference is made to women who have experienced a material death.

Method: We reflected on the clinical attributes of the Revlon UCLA High Risk Clinic population in terms of their own perceived risk of developing breast cancer. For part of our population, their perceived risk was coupled with their reactions to the loss of their mothers to breast cancer. We compared and contrasted this pattern of reactions to those described by Lichtenthal et al. (2004) in their developmental review of complicated grief as a distinct disorder.

Results: We concluded that our population of women differed from Lichtenthal et al.'s (2004) model for complicated grief. Lichtenthal's group postulated that the key element of complicated grief involves the protracted nature of separation anxiety and distress and excludes PTSD. In our populations, the daughter with complicated grief experiences a combination of separation anxiety and a type of PTSD involving anxiety over the perceived certainty of her own future diagnosis of breast cancer. It was noteworthy that Lichtenthal's model population was composed of individuals caring for terminally ill spouses. Significantly, the spousal caretakers did not have an ongoing genetic link to their partners whereas our population is genetically linked. We postulate that this accounts for the unique presentation of complicated grief and PTSD in our population.

Significance of results: We submit that this combination of complicated grief and PTSD requires a cognitive reframing of their perceived inevitability of developing breast cancer and desensitization techniques to help high risk women pursue preventative health care rather than avoiding it.

KEYWORDS: Complicate grief, PTSD, High-risk, Breast cancer

INTRODUCTION

This article has three goals. First, we explore the variants of normal and complicated grief in our population of women at high risk for breast cancer.

Second, we consider our high risk population in the context of Lichtenthal et al.'s (2004) developmental review of complicated grief as a distinct disorder. Complicated grief is a disruptive psychological condition that differs from normal grief in that it extends beyond 14 months following the death of a loved one and is characterized by strong yearnings for the deceased, avoidance of reminders of the deceased, and feelings of loneliness and emptiness. We argue that our population represents a particular subtype for

Address correspondence and reprint requests to: David K. Wellisch, Department of Psychiatry, UCLA School of Medicine, Neuropsychiatric Institute and Hospital, Center for the Health Sciences, 760 Westwood Plaza, Los Angeles, CA 90024-1759. E-mail: dwellisch@mednet.ucla.edu

complicated grief, partially due to our population's demographics, such as age and marital status, and partially due to its lifelong elevated genetic risk of developing breast cancer. Finally, we explore an aspect of complicated grief previously underappreciated in the psycho-oncologic literature: In daughters of breast cancer patients, it is a form of grief extending far beyond the actual death of the mother (or sister), potentially even extending over the daughter's whole life span.

REVIEW OF THE LITERATURE ON MENTAL HEALTH AND HEALTH CARE UTILIZATION IN HIGH-RISK WOMEN

Women with an increased risk of breast cancer experience cancer-specific and generalized psychological distress (Lerman & Schwartz, 1993). Women who are positive for a family history of breast cancer and whose mothers died of the disease have significantly higher breast-cancer-related distress than women who are family-history positive but whose mothers have not died of breast cancer or than women who are family-history negative (Erblich et al., 2000). However, when screened using modules of the Structured Clinical Interview of the DSM-IV, less than 10% of the women enrolled in a high-risk registry met criteria for a clinical disorder (Coyne et al. 2000). In fact, when compared to two age- and education-matched samples, women in a high risk registry showed clinically significantly *lower* (20% vs. 28%) anxiety/depression than did women who attended a general medical practice clinic (Butow et al., 2005). Different methods of assessment may yield different findings about high-risk women. For instance, in a sample in a Family History Clinic (High Risk), 13% of the women met diagnostic criteria for an affective disorder by structural interviewing using standard assessment and diagnostic criteria, whereas 26% did so by a standardized psychological questionnaire (Goldberg et al., 1988).

Turning to cancer-specific worries, approximately 66% of a high-risk breast cancer clinic sample reported that worries about breast cancer interfered with their functioning across several life domains, including mental health and role functioning (Trask et al., 2001). A systematic study of cancer-related post-traumatic stress disorder (PTSD) in high-risk women revealed rates of current threshold and subthreshold PTSD to be 16% whereas 24% reported past (threshold and subthreshold) PTSD using DSM-IV criteria (Hamann et al., 2005). This differed only slightly from women in the clinic sample who had a diagnosis of breast cancer (current, 17%, past, 28%; Hamann et al., 2005).

Several studies examining health care utilization by high-risk women including screening for BRCA genes, mammographic screening, and breast self-examination reported relationships between health care and mental health.

A meta-analysis of controlled trials in BRCA genetic screening found that genetic counseling improved the knowledge of cancer genetics (pooled short-term difference = 0.70 U, 95% confidence level [CI] = 0.15 to 1.26 U), but did not alter the level of perceived risk (pooled short-term difference = -0.10 U, 95% CI = -0.23 to 0.04 U). No effect was noted in controlled trials on general anxiety (pooled long-term effect = 0.05 U, 95% CI = -0.21 to 0.31 U) or on cancer-specific worry (pooled long-term effect = -0.14 U, 95% CI = -0.35 to 0.06 U) (Braithwaite et al., 2004).

However, in another meta-analysis of the impact of genetic counseling, generalized anxiety was significantly reduced (average effect size $r = -0.17$, $p < .01$), as was accuracy of perceived risk (average effect size $r + 0.56$, $p < .01$; Meiser & Holliday, 2002).

As regards mammography, there is a generally positive correlation between a patient's perceived risk and her compliance with recommended mammography screening ($N = 52,766$, $g = 0.19$; Katapodi et al., 2004). In a systematic review, women at elevated risk for breast cancer do not appear to experience high levels of anxiety associated with mammography compared to women at normal levels of risk.

Furthermore, women recalled for additional mammographic studies experienced elevated levels of anxiety whether or not they belonged to the elevated risk group, although there were significant differences between the two groups (Watson et al., 2005).

In studies of the effects of anxiety on breast self-examination (BSE), women who are at higher risk for breast cancer and who have higher anxiety are less willing to perform monthly self-breast exams and do not come to the doctor's office for clinical breast examinations ($p < .02$; Kash et al., 1992). In a study evaluating BSE in a cohort of high risk women, 57% of them report performing monthly BSEs, 20% report doing the exams less than once a month, 10% of the women never did them, and 13% of the women examined themselves at least once a week. Women below age 40 who examined their breasts more frequently than recommended (i.e., at least once per week) were significantly ($p = .03$) more distressed than other women in the sample (van Dooren et al., 2003).

HIGH RISK CLINIC DESCRIPTION

The Revlon-UCLA High Risk Clinic was founded in 1993. Its purpose is to care for the physical and emotional needs of women who are at heightened risk of breast cancer (e.g., because of family history),

but who do not themselves specifically have breast cancer or a history of breast cancer. These women may have one or more first-degree female relatives with breast cancer or have physical conditions that elevate risk (ADH, LCIS) or both. They are followed by a team including a nurse practitioner, a medical oncologist, a clinical geneticist, a psychologist, a physician specializing in lifestyle management/nutrition, and mammography staff especially focused on high-risk women. Patients typically come at 6-month intervals, but may come more often if they present substantial clinical anxiety about their condition or situation.

The initial intake visit includes the following: (1) collection of detailed family histories (both maternal and paternal) and development of a family genetic pedigree; this generates a cancer risk analysis calculation (Gail et al., 1989), which is then presented to and discussed with the patient; (2) medical counseling about issues such as use of estrogen replacement and possible medical interventions (i.e., Tamoxifen) for risk reduction; (3) learning breast self-examination, first from an actual breast model, and then on oneself if possible; (4) exercise and nutritional planning to lower risk by lowering the basic blood level of circulating estrogen and planning for weight reduction/weight maintenance; and (5) exploring psycho-social life history of traumas related to familial breast cancer and exploring barriers to implementation of lifestyle changes.

A demographic profile of a subset ($n = 160$) of the High Risk Clinic population is presented in Table 1. As this table shows, most of the women in this sample rated their grief related to familial breast cancer as “moderate to high.” Table 1 also shows that half of the women have experienced a death due to breast cancer, with the most having had their mother as the breast cancer patient.

Changes in psychological test results between the initial clinic visit and the first follow-up visit at 6 months are depicted in Table 2 for a subset of the High Risk Clinic population ($n = 77$). The data reflect a significant reduction in Personal Risk Rating ($p = .001$) over the 6 months. There was a trend toward reduction in state (reactive) anxiety, but with little change in trait (characterological) anxiety. This is to be expected, because desensitization to the clinic usually occurs between these two visits. The anxiety score of 41st percentile is clinically significant (40th percentile is the cutoff score; Spielberger, 1983). Depressive symptoms (CES-D) shifted slightly between the two visits. However, the depressive symptoms are substantially below the cutoff score for the CES-D of 16, and in the normal range for depressive symptoms (Spielberger, 1983). Thus, these data show that it is easier to shift the patients’ perception of risk than to shift their emotional states (anxiety and depressive

Table 1. High risk clinic patient demographics ($N = 160$)

	%	<i>n</i>
Age of high-risk patients		
20 to 40	39	62
41 to 60	54	87
Above 60	7	11
Ethnicity of high-risk patients		
Caucasian	94	151
Latina	2	3
Asian	4	6
Relationship to relative with breast cancer		
Daughter	78	125
Sister	13	21
Both	9	14
Relative’s survival status		
Relative is feeling well	40	64
Relative’s cancer is active; she is ill	10	16
Relative has passed away	50	80
Patient sought therapy to deal with breast cancer in relative		
Yes	25	40
No	75	120
Patient’s self-rated grief (related to familial breast cancer)		
Minimal to low	44	70
Moderate to high	56	90
Patient’s self-rated depression (related to familial breast cancer)		
Minimal to low	82	131
Moderate to high	18	29

symptoms) characteristically presented in our High Risk Clinic.

COMPARISON WITH LICHTENTHAL’S FINDINGS

Lichtenthal modeled her concept of complicated grief on the work of Horowitz et al. (1997) and Prigerson and Jacobs (2001). These two research teams designated the term “complicated grief” to distinguish it from the “normal” and painful emotional, behavioral, and cognitive responses to loss that usually subside after about 6 months. In complicated grief, unresolved responses continue to disrupt the individual’s ability to function normally beyond the 1-year anniversary of the death, and even 14 months after the loss as measured by Horowitz et al.’s (1997) assessment analyses at 6 and 14 months. Those time points, rather than 12 months, were chosen in order to avoid confounding the data with anniversary reactions (Horowitz et al., 1997). Bereaved individuals variously describe strong yearnings for the deceased, feelings of aloneness/emptiness, difficulty in sleeping, and strong avoidance of reminders of the deceased.

Table 2. Changes on psychological testing from baseline to first follow-up visit (N = 77 patients)

Variable	Mean score at baseline visit	Mean score at 6-month follow-up visit	<i>p</i>
State anxiety symptoms (STAI–State) ^a	41.00% (<i>SD</i> 25.40)	36.32% (<i>SD</i> 13.01)	.13, n.s.
Trait anxiety symptoms (STAI–Trait) ^b	36.80% (<i>SD</i> 11.73)	35.55% (<i>SD</i> 11.57)	.20, n.s.
Depression symptoms (CES-D) ^c	10.51% (<i>SD</i> 11.81)	9.58% (<i>SD</i> 10.48)	.39, n.s.
Personal risk rating (0–100% estimate of lifelong risk)	54.37% (<i>SD</i> 22.60)	45.30% (<i>SD</i> 23.18)	.001

^a40th percentile indicates significant symptoms of clinical anxiety state.

^b40th percentile indicates significant core (chronic) anxiety.

^c16 is cutoff score for significant likelihood of diagnosis of depression.

Our results with our study population at the Re-vlon–UCLA High Risk Clinic are in broad agreement with Lichtenthal et al.'s (2004) description of the constellation of symptoms, as well as with the criteria for duration, which can last a lifetime. A large subset of women in our population does not experience the relief from normal grieving that usually occurs by 12 or 14 months after the death, as reflected by the large percentage (56%) of self-rated grief scores in the moderate to high range (see Table 1), whereas only 18% of patients rated their depression as moderate to high. Therefore, they are clearly differentiating between the experience of grief and that of depression (Clayton et al., 1968, 1974) In fact, they go on to experience the onset of complicated grief, which waxes and wanes for the duration of the high-risk woman's lifetime. This is partially because of her biologic/genetic legacy and partially because of the particular nature of the (deceased) mother–daughter relationship. The experience of being at high risk never ceases and may thus maintain indefinitely the complicated grief phenomena.

PSYCHOLOGICAL RISK FACTORS FOR COMPLICATED GRIEF

Several investigators have demonstrated certain risk factors for complicated grief that extend back into childhood (Prigerson et al., 1997; Kelly et al., 1999; van Dooren et al., 1998). One major factor is an insecure attachment style (Bowlby, 1973), characterized by excessive dependency, compulsive caregiving, and defensive separation (protective distancing). As noted in developmental psychology work by Bowlby (1973, 1980), each child develops an “internal working model” on which he or she relies to create a basic theory of self, the other, and the world. These models derive from interactions between the child and his or her caretakers, the primary attachment figures. Out of these interactions, a child forms mental schemas that help him or her interpret interpersonal experiences. The secure attachment model provides a child

with an internalized self structure, the belief that a protective, supportive figure is available to the child, and the belief that, with time, the child will become competent to deal with the world (Neimeyer et al., 2002, p. 243). An insecure attachment model develops when parents are unavailable and/or rejecting, leading the child to feel incompetent and devalued. In these circumstances, the world seems unpredictable, and access to supportive, competent individuals is uncertain. Consequently, the child feels insecure about his or her ability to meet the world's demands successfully. In adulthood, such individuals may move between attachment styles variously characterized by excessive dependency in marriage, compulsive caregiving, or defensive separation in which the person is emotionally alienated and overly self-reliant.

STYLES OF INSECURE ATTACHMENT

Among the population of women with complicated grief at our high risk clinic, we have noted two different styles of insecure attachment. At one end of the continuum are women who seemingly cannot tolerate any separation from their children. They homeschool their children, do not work outside of the home themselves, and do not engage in expected normal separations from their children in order to exercise, take classes, go on outings with adult friends, or spend time with their own partners/spouses. One woman told us, “My mother left me from the time I was seven (the date of the initial cancer diagnosis), and I never want my children to feel that.” She was the designated caregiver for her mother, as well as for her sister and her father until the mother died when our patient was 13 years old.

At the other end of the continuum are women unable to form secure attachments with anyone, be it a friend, spouse, or child. Their sense of foreboding about their own longevity, coupled with the grief they experienced over the loss of their mothers, leads them to avoid emotional intimacy and enduring relationships. Instead, they develop a defensive emotional

self-reliance and an avoidance of any affectional ties or find themselves caught in an approach/avoidance dilemma about attachments in which these women could be characterized as unstable or temperamental.

It should be noted that, in the van Doorn et al. (1998) study of risk factors for complicated grief, their subjects were individuals caring for their terminally ill spouses. The mean age of the spousal caretakers was 62 years, whereas the mean age of our high risk clinic population is 42 years old. Hence the developmental stages of their and our populations are different, with different ramifications for overattachment (i.e., to the spouse vs. to dependent children).

RECONSTRUCTION OF ONE'S PERSONAL NARRATIVE

A fundamental issue for our high risk population concerns their success or failure in reconstructing their sense of self after their mother's death. We view our population as susceptible to complicated grief because of the dual challenges posed by reconstructing their personal narrative (their own construction of their sense of self, i.e., their story) after their mother's death and by their overidentification with the mother's biological and physical being (Neimeyer, 2001).

The work of reconstruction requires that such a woman acknowledge uncertainty about her own survival and, hence, about achieving life goals such as marriage, creating a family, and having a career. The woman must shift her belief system, such that the seeming "inevitability" of a shorter life span becomes replaced by the "possibility" of a longer life. With that shift, the woman can "take the risk" of re-investing in the world of relationships, marriage, work, and children despite the continued risk of loss. Key to this reconstruction is successfully working through the loss of the mother who provided a sense of continuity and affirmative support. Such success includes developing the ability to remember her without being mired in pain, anxiety, and reveries about the relationship severed by death. Another sign of success is the surviving daughter gently distancing herself from total identification with her (deceased) mother's being, body, biology, and fate.

This psychological work is demanding in that we do not imply that the daughter should "forget" or deny her mother's experience. Specifically, the daughter can realize that she is not bound to repeat her mother's experience. We want these daughters to acknowledge their own experience of surviving their mothers' illness and to recognize that "biology is not destiny" in every situation. If they are released from that conviction, then they can remember the memory of their mother's illness and death without being dominated by it. Furthermore, they do not have to

internalize their mother's entire experience of illness and death in order to maintain a successful attachment to her. The result of successful grieving would allow the daughter to remember her mother and not be retraumatized. Unsuccessful grieving, which can devolve into complicated grief, leaves one mired in reveries about the past and its lost relationships. These kinds of reveries promote overattachment to the lost person, as well as an inability to create a world with new opportunities for attachment. Such unsuccessful grieving limits participation in the present.

The reconstruction of one's self-narrative can either be progressive or regressive. If it is regressive, the daughter becomes immersed in reveries or reconstructions of past events. We have seen vivid examples of this during high risk cancer clinic visits. In one extreme case, a daughter refused to alter any aspect of her family's home, even with the permission of her father, the bereaved spouse. She wore her deceased mother's clothing, despite the fact that her 53-year-old mother's style was not flattering to this 22-year-old woman. A more positive "relearning of the world" after her mother's death involving rational selective retention could have allowed this young woman to choose pieces of her mother's jewelry that held special meaning for her and to change the home in ways that reflected the tastes of the present occupants, incorporating treasured items of furniture that her mother liked. In this way, the daughter could have affirmed continuity with her mother while acknowledging her own separate identity after her mother's death.

Neimeyer (2001) has examined the construction of an individual's self-concept based on her relationship with parental figures and has studied the impact of bereavement on the self-concept. In the case of the young woman just described, she put aside her own developing self and took on her mother's garments and house as a way of keeping her mother alive and not disrupting her own sense of herself by having to define herself in the absence of her mother. According to Neimeyer (2001), in order to find meaning for herself in this new psychological and actual world, the young woman has to reconstruct her identity and to "interbraid" the loss of another with the loss of oneself (the self mirrored by that other person). Involved in this reconstruction is a choice of significant aspects of one's mother and of memories of her that can then be amalgamated into a new sense of self. Critical to this focus for our population of high-risk women is the daughter's need to thoughtfully and not compulsively incorporate aspects of her mother into her "internal self" so as to live her own life and not erase her own identity in a frightened defense against the anxiety of totally "losing her mother" to death. The main goal is thus to support choice over compulsion.

Another example of regressive reconstruction emerged in the story of a daughter who so identified with her deceased mother that the daughter missed several annual clinic visits, missed her annual mammography appointments, and could not bring herself to do breast self exams. She reported that her mother had so delayed her own care of her breast tumor that her disease was widely metastatic by the time that she sought health care and informed her family.

THE RELATIONSHIP OF COMPLICATED GRIEF AND POST-TRAUMATIC STRESS DISORDER IN OUR POPULATION

Lichtenthal et al. (2004) postulated that the key element of complicated grief involves the protracted nature of separation anxiety and distress. Coping efforts typically involve trying to reorient oneself in a world without the deceased. Lichtenthal et al. (2004) distinguish complicated grief from PTSD by stating that “traumatized individuals are typically anxious about the threat related to the traumatic event, whereas bereaved individuals experience separation anxiety” (p. 648).

Our thesis, based on our population, differs from Lichtenthal et al. (2004) on this issue of separation of PTSD from complicated grief. For our population, we observe that both of these emotional states are present and must therefore be jointly considered. The typical bereaved daughter in our clinical population experiences not only the loss of her mother but also anxiety over the risk of possibly being diagnosed with breast cancer herself.

When we review the DSM-IV diagnostic criteria for post-traumatic stress disorder, we note first that our population has been exposed to a traumatic event involving not only a threat to their mother’s physical integrity (the diagnosis of breast cancer), but also their mother’s actual death from breast cancer. These daughters report responses involving fear and helplessness. A second component of the PTSD diagnosis involves persistent reexperiencing of the traumatic event. Our population of women does describe repeated and intrusive distressing recollections of their mothers’ illnesses and deaths, although they usually report repeated distressing dreams of their parents’ deaths.

Another dimension of reexperiencing the event occurs when these women who are patients at our high risk breast cancer clinic visit the clinic itself or attend appointments in the adjacent hospital. Although they do not experience flashbacks, they do feel as though they are reliving segments of their mothers’ medical visits. When our women subjects attend the clinic, they often report psychological distress at the sight of the hospital, the clinic and adjoining

examination rooms, the physicians’ white coats, the mammography machines, and procedures associated with breast examinations. We conclude that our population physiologically reacts to internal or external cues symbolizing the event of their mother’s illness reflected by their frequent tearing up or crying during clinic visits.

Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness do exist in our population. Our patients frequently tell us that they have never discussed their thoughts or feelings about their mother’s illness and death with anyone prior to their visit to our clinic. Many women in our population admit being reluctant to come to the high risk clinic for their own care because it carries too many painful associations for them. We note that they postpone receiving appropriate health care for themselves. Our women subjects are rarely unable to recall an important aspect of their mother’s illness and/or death, unless they were very young at the time of her mother’s acute illness. Most women in our population do not report feeling detached or estranged from others, nor do they usually experience markedly diminished interest in significant activities. These daughters are not emotionally constricted. However, a significant hallmark of their experience is a sense of a foreshortened future. In one section of our intake questionnaire, nearly every woman tell us that she not only fears getting breast cancer, she is *certain* that she will get it and will not have children or will not see them grow up or will not have a long marriage. This sense of certainty about developing breast cancer seems to heighten our women’s vigilance about changes in the appearance of their breasts. Our subjects experience these symptoms for the duration of their lives, and they acknowledge that these symptoms may interfere with their procuring timely health care. Their dread of developing breast cancer can also interfere with their social and work lives because of their ambivalence about investing in work and in significant relationships, given the risk that work and relationships could be interrupted or severed by the development of breast cancer.

Thus, the actual death of a mother from breast cancer creates the separation anxiety typically related to complicated grief, whereas the risk of breast cancer to the daughter creates avoidance and experiences of distress typically related to PTSD. For our clinical population, images of the deceased mother paradoxically combine a sense of comfort with anxiety. Anxiety casts a shadow on images of the deceased, linked to our daughters’ intrusive memories of their mothers’ disfigurement, pain, debility and suffering. Our women feel that their own future is written in their mothers’ experiences with breast cancer. For some of our women it feels like more

than just a statistical probability: It feels as if their fate is actually sealed.

TREATMENT INTERVENTIONS FOR HIGH-RISK WOMEN WITH COMPLICATED GRIEF

We conclude that this group of women face dual challenges. On the one hand, they must resolve their attachment issues with their mother and create a new and meaningful world without her. On the other hand, as they create this new world, they must learn how to adapt to the threat of a diagnosis of cancer in themselves. The clinical challenge for us as therapists is to alter their belief system about biology being destiny—that is, the daughters' sense that they too will develop and die of breast cancer as did their mothers. Altering this belief system would permit the daughters to feel less trapped in the past and to devote more energy to their present and future.

The First Challenge: Treating Complicated Grief

What interventions can help deal with the complicated grief? We agree with elements of Shear et al.'s (2001) recommendations. Specifically, they recommend imagined reliving of the death, actual exposure to avoided activities or situations, and interpersonal therapy. Shear et al. (2001) accomplished this by having their patients describe the death as if were happening in the present (on audiotape) while being mindful of the feelings evoked. With the aid of the therapist, the patients learned to identify periods of most intense emotion. They then listened to the audiotapes repeatedly at home, in order to achieve a successful desensitization to the "hot spots." We support this style of intervention, because it diminishes the most painful aspects of grief that have blocked access to positive memories from which individuals may try to detach themselves if the memories reignite mourning. When memories are embedded in intense grief, it is impossible to find nourishment within them. We believe that this therapeutic process would best take place in sessions separated from the High Risk Clinic appointments, because the Clinic is too emotionally charged as a site for this desensitization therapy.

We compare treating complicated grief in our population to the remodeling of a house. This metaphor involves examining how a mother's death has confined her daughter living in only a few rooms of her entire emotional home. Our intervention aims at helping the daughter assess what psychological changes would permit her to introduce new color into her emotional and home. We support her efforts to change the psychological floor plan to permit moving into a

richer present with its complement of friends, activities, work, colleagues, and love. We expect this remodeling to proceed slowly, as does home remodeling, with expected flare-ups of anxiety and depression as the woman starts to occupy her newly expanded emotional home. This slow process is reflected in the data on resolution of symptoms of depression and anxiety, which remain little changed between the baseline and the 6-month follow-up visit (see Table 2).

The Second Challenge: Treating Post-Traumatic Stress Disorder

These women also need an intervention to deal with the trauma of having experienced their mother's death and of now experiencing a heightened vulnerability to developing breast cancer because of family history. Devising an intervention requires understanding the daughter's belief system about her perceived vulnerability to breast cancer. Her perception of her risk is usually higher than her actual risk (Braithwaite et al., 2004, illustrate perceived vs. actual risk data). Once her belief system is illuminated for her, a therapist can then help her identify what behaviors are associated with the beliefs. These behaviors range from avoidance of sensible precautions (e.g., scheduled mammography, breast self-exams) to hypervigilance about any changes in her breast tissue or body sensations (Brain et al., 1999; van Dooren et al. 2003). This somatic hypervigilance is a variant of the hypervigilance that is a diagnostic feature of PTSD.

Interventions are devised so that patients become desensitized to the clinic. The clinic can then become a supportive place rather than a stimulus for bad news. However, as reflected in the State Anxiety scores in Table 2, anxiety reduction is a slow process that requires ongoing support. Patients' feelings of anxiety and avoidance can be voiced explicitly and accepted. In step-wise fashion, the nurse practitioner helps them to learn breast self-examination—a task that tends to be challenging for this group of patients (Kash et al., 1991). Another important team member is the clinical geneticist, who further desensitizes these women to their heightened sense of risk by constructing a family genogram and building a profile of their actual risk. When this provision of genetic information is combined with emotional support, the patient's capacity to absorb accurate information is integrated (Wellisch et al., 1999). These are examples of cognitive behavioral interventions that decrease the PTSD symptoms experienced by this subgroup of our population.

The psychologist allows for ventilation of previously suppressed and repressed anxiety, all the while normalizing these feelings. It cannot be overstated how

often we the staff hear, “This is the first time I have ever spoken about these feelings and memories.”

To summarize our thoughts about the basic interventions necessary for this high risk population, we agree with Shear et al. (2001) in their use of desensitization to deal with complicated grief and aspects of PTSD. Our thesis is that both complicated grief and aspects of PTSD must be effectively addressed if women in this population are to want and to be able to reinvest in life. It is crucial to normalize their emotional reactions and behaviors while reducing the impact and barriers imposed by the symptoms. Specifically, we are concerned about disabling hypervigilance, somatization, and the very powerful tendency to avoid necessary health care. To do this, we suggest working with their PTSD as it manifests itself in their thoughts and behaviors. We observe PTSD symptoms of anxiety especially during the process of breast exams, mammography, and breast self-exams.

The therapy is designed to help a woman accomplish two goals. The first is to shift from having only the nurse practitioner do the breast exam to learning how to do it on her own. The second is to enable the woman to make sense of the information gleaned from examining her own breasts. This involves reframing the patient’s cognitive belief system so as to diminish the anxiety that leads her to catastrophic expectations regarding breast exams and mammography. A successful reframing of the belief system would help to liberate these women from a identification with their mother’s fate and from their own anxiety. We hope that complicated grief and PTSD will be recognized and acknowledged by patients and staff alike, so that interventions can be implemented to liberate both from the crippling belief that biology is destiny.

REFERENCES

- Bowlby, J. (1963). Pathological mourning and childhood mourning. *Journal of the American Psychoanalytic Association, 11*, 500–541.
- Bowlby, J. (1973). *Attachment & Loss: Separation*. New York: Basic Books.
- Bowlby, J. (1980). *Attachment and Loss, Vol. 3. Loss: Sadness and Depression*. New York: Basic Books.
- Brain, K., Norman, P., Gray, J., et al. (1999). Anxiety and adherence to breast self-examination in women with a family history of breast cancer. *Psychosomatic Medicine, 61*, 181–187.
- Braithwaite, D., Emery, J., Walter, F., et al. (2004). Psychological impact of genetic counseling for familial cancer: A systematic review of meta-analysis. *Journal of the National Cancer Institute, 96*, 122–133.
- Butow, P., Meiser, B., Price, M., et al. (2005). Psychological morbidity in women at increased risk of developing breast cancer: A controlled study. *Psycho-Oncology, 14*, 196–203.
- Clayton, P.G., Desmarais, L., & Winokur, G.A. (1968). A study of normal bereavement. *American Journal of Psychiatry, 125*, 168–178.
- Clayton, P.G., Hirjanic, M., & Murphy, G.E. (1974). Mourning and depression. *Canadian Journal of Psychiatry, 19*, 309–312.
- Coyne, J.C., Benazon, N.R., Gaba, C.G., et al. (2000). Distress and psychiatric morbidity among women from high-risk breast and ovarian cancer families. *Journal of Consulting and Clinical Psychology, 68*, 864–874.
- Erblich, J., Bovbjerg, D.H., & Valdimorsdottir, H.B. (2000). Looking forward and back: Distress among women at familial risk for breast cancer. *Annals of Behavioral Medicine, 22*, 53–59.
- Gail, M.H., Brinton, L.A., Byar, D.P. et al. (1989). Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *Journal of National Cancer Institute, 81*, 1879–1886.
- Goldberg, D. & Williams, P. (1988). *User’s guide to the General Health Questionnaire*. NFER-Nelson: E. Windsor Berks.
- Hamann, H.A., Somers, T.J., Smith, A.W., et al. (2005). Posttraumatic stress associated with cancer and BRCA 1&2 genetic testing. *Psychosomatic Medicine, 67*, 766–772.
- Horowitz, M.J., Siegal, B., Holen, A., et al. (1997). Diagnostic criteria for complicated grief disorder. *American Journal of Psychiatry, 154*, 904–910.
- Kash, K.M., Holland, J.C., Halper, M.S., et al. (1991). Psychological distress and surveillance behaviors of women with a family history of breast cancer. *Journal of National Cancer Institute, 84*, 24–30.
- Kash, K.M., Holland, J.C., Holger, M.S., et al. (1992). Psychological distress of surveillance behaviors of women with a family history of breast cancer. *Journal of the National Cancer Institute, 84*, 24–30.
- Katapodi, M.C., Lee, K.A., Facione, N.C., et al. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk of breast cancer screening: A meta-analytic review. *Preventive Medicine, 38*, 388–402.
- Kelly, B., Edwards, P., Synott, R., et al. (1999). Predictors of bereavement outcome for family caregivers of cancer patients. *Psycho-Oncology, 8*, 237–249.
- Lerman, C.L. & Schwartz, M. (1993). Adherence and psychological adjustment among women at high risk for breast cancer. *Breast Cancer Research and Treatment, 28*, 145–155.
- Lichtenthal, W., Cruess, D., & Prigerson, H.G. (2004). A case for establishing complicated grief as a distinct mental disorder in DSM-V. *Clinical Psychology Review, 24*, 637–662.
- Meiser, B. & Holliday, J.D. (2002). What is the impact of genetic counseling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Social Science and Medicine, 54*, 1463–1470.
- Neimeyer, R.A. (2001). Reauthoring life narratives: Grief therapy as meaning reconstruction. *Israeli Journal of Psychiatry and Related Sciences, 38*, 171–183.
- Neimeyer, R.A., Prigerson, H.G., & Davies, B. (2002). Mourning and meaning. *American Behavioral Scientist, 46*, 235–251.
- Prigerson, H.G., Bierhals, A.J., Kasl, S.V., et al. (1997). Traumatic grief as a risk factor for mental and physical

- morbidity. *American Journal of Psychiatry*, *154*, 616–623.
- Prigerson, H.G. & Jacobs, S.C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In *Handbook of Bereavement Research: Consequences, coping, and care*, Strobe, M.S. & Harrison, R.O. (eds.), pp. 613–645. Washington, D.C.: American Psychological Association.
- Shear, M.K., Frank, E., Foa, E., et al. (2001). Traumatic grief treatment: A pilot study. *American Journal of Psychiatry*, *158*, 1506–1508.
- Spielberger, C.D. (1983). *Manual for the State-Trait Anxiety Inventory (STAI)*. Palo Alto, CA: Consulting Psychologists Press.
- Trask, P.C., Patterson, A.G., Wang, C., et al. (2001). Cancer-specific worry interference in women attending a breast and ovarian cancer risk evaluation program: Impact on emotional distress and health functioning. *Psycho-Oncology*, *10*, 349–360.
- Van Doorn, C., Kasl, S.V., Beery, L.C., et al. (1998). The influence of marital quality and attachment styles on traumatic grief and depressive symptoms. *Journal of Nervous and Mental Disease*, *186*, 566–573.
- Van Dooren, S., Rijnsburger, A.J., Seynaeve, C., et al. (2003). Psychological distress and breast self-examination frequency in women at increased risk for hereditary or familial breast cancer. *Community Genetics*, *6*, 235–241.
- Watson, E.K., Henderson, B.J., Brett, J., et al. (2005). The psychological impact of mammographic screening on women with a family history of breast cancer. A systematic review. *Psycho-Oncology*, *14*, 939–941.
- Wellisch, D.K., Hoffman, A., Goldman, S., et al. (1999). Depression and anxiety symptoms in women at high risk for breast cancer: Pilot study of a group intervention. *American Journal of Psychiatry*, *156*, 1644–1645.