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## Daughters of Breast Cancer Patients Genetic Legacies and Traumas

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### INTRODUCTION

One could fairly ask, does a chapter on daughters of breast cancer have a rightful place in a book on multigenerational legacies of trauma—especially given that most of the chapters of this volume deal with the psychosocial sequelae of war, repressive governments, and urban violence? After some soul searching, we decided that the chapter deservedly belongs in the book. The protagonists of this chapter, daughters who are often also sisters, nieces, and granddaughters (or all of the above) of breast cancer patients, bear a genetic legacy of trauma, past visions of suffering, and fears from the past carried forth into the future. Their traumas, fears, and psychic scars do not come from a political regime, but rather from the possible mutation of a gene. This gene, now identified as BRCA-1 and BRCA-2 (for Breast Cancer 1, or Breast Cancer 2) has been localized on the short arm (small part) of chromosome 17 (Futureal *et al.*, 1994). Given this now-identified reality, these women must learn to live with several conflicts. On the one hand, the “perpetrator(s)” of their suffering (who has passed the increased risk and vulnerability for breast cancer on to them) is the same person (or often persons) with whom they empathize, or for whom they mourn and grieve. On the other hand, they have a vulnerability for which there is no definitive medical treatment at present. Thus, they must learn to cope with and adapt to a threat that has been termed the “Damocles Syndrome” (Koocher & O’Malley, 1981). The nature of these daughter’s trauma differs from that of victims of political oppression in two distinct ways that greatly complicate their adjustment. First, their aggressor is internal, invisible, and, until fairly recently, mysterious and unknowable. This contrasts with victims of political repression in which the persecutor is external and distinct. Second, although for the victims/survivors of political persecution the trauma reverberates psychologically, the distinct physical threat generally ends. The Holocaust ended, as did World War II and Stalinist Russia. For the survivors of their mother’s breast cancer, the physical threat will never end, the potential aggressor will never go away, die, be overthrown, or even be reduced in power or potential risk. In fact, the risk increases with age.

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*International Handbook of Multigenerational Legacies of Trauma*, edited by Yael Danieli. Plenum Press, New York, 1998.

This chapter describes (1) the “real” physical and biological risk for this population and provides an overview of the literature about the psychological risk factors for this population; (2) the UCLA High Risk Clinic, and includes some outcome data on a subset of the population reflecting the impact of the management/intervention program; (3) a spectrum of coping/adaptation difficulties, with six associated case vignettes illustrating some of these difficulties; and (4) emerging perspectives on psychotherapies for these daughters of breast cancer patients to deal with their traumatic legacies and future coping/adaptational challenges.

## PHYSICAL/BIOLOGICAL AND PSYCHOLOGIC RISKS

### Physical/Biological Risks

The risk of breast cancer can be defined in at least three ways. These include (1) *absolute risk*—which relates to rate of mortality of or from cancer in a general population. Given 1,000 women, absolute risk is how many out of that 1,000 will get breast cancer in their lifetime; (2) *attributable risk*—which relates to how much risk could be prevented by altering factors of public health or mass behavior. Examples would be the public lowering of dietary fat consumption, or women lowering the average age by which they give birth; and (3) *relative risk*—which compares the incidence of breast cancer in a group with a particular risk factor to a population without that risk factor (Love, 1995). For the purposes of this section, particular emphasis will be placed on *relative risk*, the risk factor involved in having at least one first-degree relation (either a mother, daughter, or a sister) who has had breast cancer. Having at least one first-degree relation is a basic requirement for participation in the UCLA High Risk Clinic.

The greatest risk factor in *absolute risk* is age. As age increases, absolute risk also increases substantially. For example, the average risk of a Caucasian American developing breast cancer at age 30 is about 1 in 5,900. By the time the same woman is age 50, the average risk factor is about 1 in 590. By the time the same woman is age 80, the average risk is about 1 in 290 (Stomper, Gelman, Meyer, & Gross, 1990). Similarly, the risks of both developing and dying from breast cancer by decades (of age) increase over the life span. For the average Caucasian American woman, the risk over her entire life span (birth to age 110) is about 3.75%. This, however, is not evenly distributed over the decades. For example, a woman between 35 and 45 years of age has a probability of 0.88% of developing breast cancer and of 0.14% of dying from breast cancer. However, a woman between 65 and 75 years of age has a probability of 3.17% of developing breast cancer and of 0.43% of dying of breast cancer (Seidman, 1985). Ethnic differences in *absolute risk* do exist. A Caucasian woman, by age 75, has about a 8.2% probability of developing breast cancer; a black woman has about 7% probability, and a Japanese American woman has about a 5.4% probability (Berg, 1984). Reasons for these racial differences may refer back to the concept of attributable risk, with such issues as percentage of dietary fat consumed by ethnic groups being possibly causal (Hirohita, Nomura, Hankin, Kolorel, & Lee (1987).

As stated before, the term *relative risk* compares the incidence of breast cancer in a group with a specific factor and a comparable group without the same factor. When *relative risk* is described, the comparison group's risk is set at 1, with the risk group's calculated risk set at a figure above 1. Dupont and Page (1987) studied reproductive factors and risk of breast cancer. Regarding menstrual history, if age at menstruation is prior to 12 years, relative risk is calcu-

lated at 1.3. If menopause is after age 55, with greater than 40 menstruating years, relative risk is calculated at 2.0. Regarding pregnancy history, if a first child is born prior to age 20, relative risk is calculated at 0.8 (below 1, a preventive factor for breast cancer). This escalates to a relative risk of 1.4 if a first child is born after age 30. Nulliparity confers a relative risk of 1.6. Sattin *et al.* (1985) calculated relative risks of having a family history of breast cancer. Having any first-degree relative (mother, sister, daughter) confers a *relative risk* of 2.3. However, when the breast cancer was diagnosed in the relative, it confers a differential degree of *relative risk*: If the cancer was premenopausal in the first-degree relative, *relative risk* is calculated at 2.7, whereas if the cancer was postmenopausal, *relative risk* is calculated at 2.5. If a woman has both a mother and sister with breast cancer, *relative risk* is calculated at 13.6. Breast cancer in a second-degree relative (aunt, grandmother) confers a *relative risk* calculated at 1.5. However, these calculations are not straightforward, but form an interactional matrix. For example, there is an interaction for any given woman between her family history of breast cancer and her own history of onset of menses and time of pregnancy and first childbirth. In addition, age at which relative(s) was diagnosed with breast cancer is increasingly seen as important in risk calculation for a woman (see Claus, Risch, & Thompson, 1994).

### Psychological Risk/Coping

Limited data exist at present to shed light on how high-risk women function and cope psychologically. In a study comparing high-risk women with a closely matched comparison group, no differences were found on psychological symptoms (Wellisch, Gritz, Schain, Wang, & Sian, 1991a). Kash, Holland, Halper, and Miller (1992) found 27% of high-risk women elevated on reported psychological symptoms to a level justifying psychological intervention. Kash, Holland, Osborn, and Miller (1995) later compared these high-risk women to normals, Hodgkin's survivors, and leukemia survivors, and did not find differences on a global measure of psychological symptoms. The high-risk women were, however, highest of the four groups on reports of depression and especially on feelings of alienation from others. A study of women at high risk for ovarian cancer (a close extension to women at high risk for breast cancer) used a path model to predict psychological distress. Overall, the sample showed moderately high levels of distress. High scores on monitoring were associated with high perceived risk, and elevated levels of intrusive thoughts and psychological distress (Schwartz, Lerman, Miller, Daly, & Masny, 1995).

Another way to assess the psychological status of high-risk women is through use of coping styles. In one study of women undergoing diagnosis of breast masses, (self)-identifiers used significantly less denial than did non(self)-identifiers. Self-identifiers were significantly more likely to have a family history of breast cancer (Styra, Sakinofsky, Mahoney, Colapinto, & Currig, 1993). Wellisch *et al.* (1991a) compared high-risk women to a comparison group on coping styles and found no differences between the two groups. The majority of both groups used high rates of problem-focused and seeking-of-support modes of coping. Neither group was prone to use avoidance or ruminative modes of coping. Josten, Evans, and Love (1985) identified a list of five key emotional states of high-risk relatives. These are applicable to women at high risk for breast cancer. They include (1) fear, (2) denial, (3) guilt, (4) anger, and (5) grief. This is by no means a complete list of key emotional conflicts or problems of this group, but it contains some of the key emotional conflicts presented by this population. Each of these will be personified in the case vignettes to be presented in the coping/adjustment difficulties section.

## THE STRUCTURE OF THE UCLA HIGH RISK CLINIC

The UCLA High Risk Clinic was created in July 1993, and has been in existence for 26 months at the time of the writing of this chapter. In that time period, the clinic has enrolled and is following 275 women at high risk for breast cancer. To be enrolled, a woman must have at least one first-degree relative (either a mother or a sister) who has had breast cancer. At present, the clinic meets one-half day per week and sees 4–6 new patients and 2–4 follow-up patients during that clinic day. Demography on 160 of the clinic patients is presented in Table 1. As can be seen by the demographic data, the majority of patients are over age 40, but a significant minority (39%) are below age 40. A significant majority have had a mother with breast cancer, although a sizable minority (21%) have had either a sister, or a sister and a mother with breast cancer. Little, if anything, is known about the traumatic impact on having sister versus a mother with breast cancer. The demographics show an exact 50/50 split between patients who have and have not experienced a familial breast cancer death. Patients are generally seen for follow-up visits 6 months after the baseline visit, with ultrahigh-risk or ultra-anxious patients generally seen at 3-month intervals, four times annually. Most patients are seen twice annually.

Treatment in the High Risk Clinic is performed within a multidisciplinary team structure. The services offered and their providers are listed in Table 2. Patients come to the clinic and are seen by all the care providers in one place. This is an alternative to trying to find and assemble individual care providers such as mammographers, risk counselors, or psychologists in

**Table 1. High Risk Clinic Patient Demographics (*N* = 160)**

Age of high-risk patients		
20 to 40	39%	<i>N</i> = 62
41 to 60	54%	<i>N</i> = 87
Above 60	7%	<i>N</i> = 11
Ethnicity of high-risk patients		
Caucasian	94%	<i>N</i> = 151
Latina	2%	<i>N</i> = 3
Asian	4%	<i>N</i> = 6
Relationship to relative with breast cancer		
Daughter	78%	<i>N</i> = 125
Sister	13%	<i>N</i> = 21
Both	9%	<i>N</i> = 14
Relative's survival status		
Relative is feeling well	40%	<i>N</i> = 64
Relative's cancer is active; she is ill	10%	<i>N</i> = 16
Relative has passed away	50%	<i>N</i> = 80
Patient sought therapy to deal with breast cancer in relative		
Yes	25%	<i>N</i> = 40
No	75%	<i>N</i> = 120
Patient's self-rated grief (related to familial breast cancer)		
Minimal to low	44%	<i>N</i> = 0
Moderate to high	56%	<i>N</i> = 90
Patient's self-rated depression (related to familial breast cancer)		
Minimal to low	82%	<i>N</i> = 131
Moderate to high	18%	<i>N</i> = 29

**Table 2. UCLA High Risk Clinic for First-Degree Relatives of Breast Cancer Patients**

Services offered	Provider
Risk counseling	Medical oncologist
Nutritional counseling	Physician specialist in nutritional medicine
Psychological counseling	Psychologists—2 Ph.D.'s, 1 M.A.
Breast evaluation—Exams, breast self-exam teaching	Nurse practitioner
Mammography	Radiologist—specialist in breast imaging
Exercise instruction	Kinesiologist

several different places. The team is then able to meet as a group and create a coordinated care plan to meet the needs of each patient. This creates elements of the “holding environment” (Winnicott, 1965) to be further discussed in the section on psychotherapy for trauma resolution. The roles of the team are seen as interfacing and facilitating the patient in learning the facts about genetics, risk, nutrition, and exercise, practicing interventions such as breast self-exams, and following treatment guidelines such as annual mammograms. Studies have demonstrated that high levels of breast-focused anxiety in this population can make breast self-examination impossible for high-risk women to perform (Kash *et al.*, 1992). This is a good example of a skill that requires the combined efforts of psychological stress/anxiety reduction (by the psychologist), skills training (by the nurse practitioner), and knowledge implementation (by the medical oncologist).

The initial baseline visit is usually the longest, the most involved, and the most emotionally intense for the new patient. This initial visit includes obtaining a basic medical history (including family medical history) by the nurse practitioner and a basic psychological history/database by the psychologist; initial risk counseling by the medical oncologist, and initial nutritional assessment and counseling by the nutritional physician; and initial exercise assessment and counseling by the exercise specialist. If needed, a mammography can be performed during the initial visit as well. In the first visit, the nurse practitioner begins assessment of and teaching breast self-exam (BSE) skills, first with a breast model and then with the patient on herself. The nurse practitioner also does a careful breast exam on the patient. The psychological testing that is performed in the first visit includes (1) the Center for Epidemiologic Studies—Depression Scale (CES-D), (2) the Spielberger State-Trait Anxiety Inventory (STAI), and (3) a personal risk estimate of the patient’s perceived risk of breast cancer in her lifetime on a scale from 0% to 100%.

The team meets as a group and creates a care plan for each patient based upon all of these contacts and databases.

The psychological structured interview for the first visit generally requires 40–90 minutes to administer. In this interview, the patient’s experiences with her most significant relative with breast cancer are fully explored. In addition, her own psychological history, coping and adaptation modes, health management and compliance issues, and current personal stresses are also fully explored and discussed. This is often cathartic for the patient and of great importance to the staff in formulating a care plan.

Follow-up visits are generally less intensive and less involved than the initial visit. Every follow-up visit includes a breast exam by the nurse practitioner, further BSE teaching, a psychological follow-up interview by the psychologist, and the same protocol of psychological testing as at baseline. More risk counseling, nutrition counseling, exercise counseling, and

**Table 3. 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) <sup>a</sup>	41.00% ( <i>SD</i> 25.40)	36.32% ( <i>SD</i> 13.01)	.13, ns
Trait anxiety symptoms (STAI-Trait) <sup>b</sup>	36.80% ( <i>SD</i> 11.73)	35.55% ( <i>SD</i> 11.57)	.20, ns
Depression symptoms (CES-D) <sup>c</sup>	10.51% ( <i>SD</i> 11.81)	9.58% ( <i>SD</i> 10.48)	.39, ns
Personal risk rating (0–100% estimate of lifelong risk)	54.37% ( <i>SD</i> 22.60)	45.30% ( <i>SD</i> 23.18)	.001

<sup>a</sup>40th percentile indicates significant symptoms of clinical anxiety state.

<sup>b</sup>40th percentile indicates significant core (chronic) anxiety.

<sup>c</sup>16 is cutting score for significant likelihood of diagnosis of depression.

possibly specialized medical evaluations (if lumps are detected) are often performed. A special, structured follow-up psychological interview probes stresses, impediments to change, successful changes, and unmet needs by the clinic. It also provides an opportunity for further elaboration and processing of important psychological issues noted in the initial interview. A group intervention program has been developed and will be implemented. It is described in the emerging perspectives on psychotherapy section of this chapter.

Data about changes on psychological tests from baseline to follow-up for a subset (*N* = 77) of the High Risk Clinic are shown in Table 3. As Table 3 reflects, state (current) anxiety is reduced between the baseline and follow-up visit. The reduction is to a level below clinically significant anxiety. As expected, trait (characterological) anxiety is not reduced between these two visits. The reduction of state anxiety perhaps reflects the relief the patient feels about being contained within the clinic structure that binds her anxiety. In contrast, depression symptoms, which we view as grief states rather than clinical depression, are scarcely reduced between these two visits. Exploring past traumas and losses may not allow the reduction of these symptoms compared with state anxiety. The reduction in personal risk rating of 9% is a major accomplishment for both staff and patients. It reflects the efforts by all of the staff, especially the oncologist risk counselor, to facilitate increased knowledge in addition to lowering anxiety. Perceived risk estimates can be viewed as highly correlated with the reduction of state anxiety. However, as encouraging as the data on personal risk rating reduction are, two cautions are necessary. First, an average risk rating of 45.30% is, in all likelihood, still far above what the “real” risk actually is for these patients (see Gail *et al.*, 1989). Thus, more work is clearly required in this area. Second, many follow-up visits have shown that these perceived risk ratings do not remain constant but fluctuate with the patient’s level of anxiety and life stress.

### **COPING/ADJUSTMENT DIFFICULTIES RELATED TO FAMILY LEGACIES OF BREAST CANCER**

At present, most factors specifically related to coping/adjustment difficulties of daughters of breast cancer patients are not sufficiently known. A study of 60 daughters of breast cancer patients suggests two variables: (1) the developmental stage of the daughter at

the time of her mother's illness (adolescence being more stressful than preadolescence or adulthood), and (2) the survival status of the mother (death from breast cancer). Both variables predict less positive adaptation (Wellisch, Gritz, Schain, Wang, & Sian, 1991b). Compas *et al.* (1994) also showed adolescent girls whose mothers had breast cancer to display more symptoms of anxiety and depression than either preadolescents or young adults, a finding that appears to further validate the developmental variable. Studying children of breast cancer patients, Lichtman, Taylor, and Wood (1985) concluded that problems were more likely to occur in daughters than in sons. They suggest three factors that predict greater risk to and strain upon the mother-child relationship: (1) poorer prognosis (in the patient), (2) poor adjustment to the cancer (by the patient), and (3) more severe surgery (mastectomy vs. lumpectomy).

A constellation of three factors appears clinically particularly to bear upon the traumatic memories and coping/adaptation of our patient population. Depicted in Table 4, these include (1) the timing of mother's breast cancer (pre- or postmenopausal), which reliably divides daughters into those who were preadolescents or adolescents versus adults when their mothers were diagnosed: It also provides a quick but accurate estimate of the degree of biological risk of the daughter, since premenopausal breast cancer in the mother confers higher lifetime risk in the daughter (see Claus, Risch, & Thompson, 1990); (2) the mother's survival status: The daughters whose mothers and/or other female relatives died of their disease almost always presents more traumatic memories clinically; and (3) the quality of the mother-daughter relationship after the diagnosis: Does the daughter present the relationship as intact and well functioning, or as strained or broken in the wake of the illness, treatment, and (possibly) dying experience?

Table 4 presents a spectrum of coping/adjustment based on these factors, ranging from *Best* (Category 1) to *Worst* (Category 8). These factors are neither exhaustive nor inclusive. These merely serve as a clinical starting point. Other variables that deserve consideration may include how the family as a whole copes with the illness, the responsibilities presented to the child during the mother's illness, the parents' coping styles and capacities, the chronicity of the illness and the entire realm of the family's emotional atmosphere prior to the illness (functionality vs. pathology).

### Clinical Vignettes

The following are six patient clinical vignettes derived from the High Risk Clinic patients at UCLA that represent varying levels of trauma and adjustment (see Table 1).

**Vignette Number 1.** Ms. M. represents coping/adjustment Level 1, the lowest level of trauma and the best level of adjustment. She is a 47-year-old, married executive whose mother was diagnosed with breast cancer 3 years ago at age 66. Her mother's illness was cured by a lumpectomy plus radiation to the local breast area. She reports that their relationship, which was quite good and harmonious prior to her mother's breast cancer, became closer and more (positively) bonded after the diagnosis. Her psychological needs are met by visiting the clinic twice a year, and she does not wish, nor clinically appear to require, additional psychological help outside the clinic. She reports her mother's breast cancer to have been a "wake-up call" to reassess and change her health habits. Her participation in the program led her to decrease her dietary fat consumption, exercise more regularly, take vitamins, and lose 5 pounds. Her psychological test scores in depressive and anxiety symptoms are all very low and in the normal range.

**Table 4. Spectrum of Daughter's Coping/Adjustment Difficulties Based on Legacy of Trauma Associated with Mother's Breast Cancer**

Daughter's coping/adjustment level	1 ("Best")	2	3	4	5	6	7	8 ("Worst")
Timing of mother's breast cancer	Postmenopausal	Postmenopausal	Postmenopausal	Pre-menopausal	Postmenopausal	Pre-menopausal	Pre-menopausal	Pre-menopausal
Mother's survival status	Survived	Died	Survived	Survived	Died	Died	Survived	Died
Status of relationship (postcancer)	Intact	Intact	Strained	Intact	Strained	Intact	Strained	Strained



**Vignette Number 2.** Ms. J. represents coping/adjustment Level 3. She is a 41-year-old, married clerical worker whose mother was diagnosed 4 years earlier at the age of 61. Although her mother's illness was put in remission by mastectomy plus chemotherapy, she could not be told that she was cured. Reportedly always a nervous woman, the mother became obsessively agitated and ruminative about this sense of threat. She became clinically depressed in the wake of her illness and treatment, and was placed on antidepressant medication in an attempt to reduce her ruminations about the possibility of recurrence. Having struggled to maintain boundaries with her mother, Ms. J. lost her ability to remain separate and found herself in a role reversal with a "needy, insatiable baby." Ms. J. indicated that all this had a strong impact on her own marriage, her ability to concentrate at work, and on her decision to not have children. Ms. J. reported that her relationship with her mother severely deteriorated. Her ability to be patient with and supportive of her mother seemed to erode. When Ms. J. first came to the clinic, she was well into the clinical range on tests of symptoms of both depression and anxiety. She was referred to, and accepted, individual therapy and was placed on antidepressant medication. She requested frequent visits to the High Risk Clinic and has been seen every 3 months for the last 2 years. Over that time, her symptoms have reduced but remain in the clinically significant range. On each visit to the clinic, every patient is asked to rate her estimation of her risk of breast cancer in her lifetime. This estimate can range from 0% to 100% (lifetime) risk. Ms. J.'s ratings have fluctuated from estimates of 100% perceived risk to 50% perceived risk. All her risk ratings are higher than her actual (real) lifetime risk. Along with all others in the High Risk Clinic, she has been repeatedly and intensively educated about the concept of lifetime (inherited) risk, real versus perceived risk, and given our estimates of her own risk based upon her family history, both orally and in the form of a chart to take home.

Two points seem especially important to consider in therapy for Ms. J. First, she cannot *get* support for her fears from her mother but must rather *give* support to her mother. Therapy reduces this traumatic absence of support. Second is the need to help Ms. J. set limits with her mother *without abandoning her*. This necessitates Ms. J. widening the base of support for her mother while setting limits with her in regard to her own time and availability. This may involve the clinic helping to find appropriate resources for Ms. J., such as a support group for her mother.

**Vignette Number 3.** Ms. B. represents coping/adjustment Level 4. She is a 39-year-old housewife with one child. Her mother died 1 year ago, having been ill for about 3 years and experiencing monumental difficulties in coping with her breast cancer from diagnosis to death. Ms. B.'s father had died from complications of diabetes when she was an adolescent. Since then, her mother had raised her and her brother with a loving but highly anxious style. Although she was able to cope with normal everyday events, the mother's fragile emotional resources were easily overwhelmed by problems. Ms. B. and her brother became, in her own words, "crisis managers" and experienced role reversal with their mother. Breast cancer for Ms. B.'s mother was "the straw that broke the camel's back." She became chronically anxious, and as her disease progressed, she became utterly impaired with anxiety. Ms. B. related a closed loop phenomenon about her mother's inability to cope. As her mother experienced physical symptoms (pain, gastric distress, headaches, nausea), her anxiety level escalated. As her anxiety level increased, her mother focused more upon her somatic symptoms that, in turn, seemed to worsen with such an obsessive focus. Ms. B. and her brother arranged psychiatric help for their mother, who was minimally compliant with her therapy sessions, but essentially noncompliant with antianxiety medications. She repeatedly stated, "I just want this to be over. I just want to die already." As her illness progressed, Ms. B. felt uncomfortable leaving her mother alone at home. This led to

another set of closed-loop dilemmas: Her mother also did not want to be alone, but felt guilty when she stayed with Ms. B. at her house, thinking that she was robbing her grandchild of her mother's attention. Yet feeling intruded upon, she would not accept a companion-aide in her own home. One day, Ms. B., sensing that her mother was saying good-bye, having not heard from her for several hours, went to her mother's home and found her unconscious. Her mother, indeed, had taken a massive overdose of pain medication. Not knowing what to do, whether she should attempt to save her mother or let her die as the mother so obviously wanted to, Ms. B. called for help. Her mother survived the overdose but refused to eat in the hospital after being revived. After extensive consultations between the staff and family, no intravenous feedings were attempted, and her mother died in the hospital about 10 days after her admission. This was the backdrop for Ms. B.'s early participation in the High Risk Clinic.

Ms. B.'s initial visit occurred before her mother's suicide attempt. She was referred to, and accepted, individual, psychodynamically oriented psychotherapy. Prior to her mother's death, she reported extreme pressure and anxiety. Her test scores reflected high situational (state) anxiety with a core (trait) score of anxiety *not* in the clinical range. Thus, her core self was resolute and functional. However, as would be expected, her response to her present situation was highly pressured. After her mother's death, she reported a sense of peace regarding her mother. "She could not cope, she needed to die." For herself, she now experienced near panic. She asked, "Have I inherited her inability to cope if and when I get breast cancer?" She related substantially more fear about a potential inability to cope than about the possibility of getting breast cancer itself. She felt overburdened and overwhelmed with this traumatic legacy, which is based on identification with a mother who could not cope. Ms. B. was left with the internalized image of a mother drowning in anxiety about her own mortality.

This case calls for two therapeutic considerations. The first is dealing with Ms. B.'s ambivalent mourning and grief. Reconsideration of Freud's classic paper, "Mourning and Melancholia" (1915) is helpful here in Ms. B.'s vulnerability to identifying with her mother's style in the context of her own ambivalence (which includes anger and hatred) toward her mother. Helping her accept both her sadness over her mother's death and her own anger and frustration, culminating in the relief that her mother is gone, may possibly reduce the trauma. The second might be to refer her to group therapy with other daughters to be able to learn other styles of coping, thus opening up her (perceived) limited options of "only being like my mother."

*Vignette Number 4.* Ms. W. represents coping/adjustment Level 5. She is a 35-year-old businesswoman who came to the clinic appearing profoundly sad, tense, and guarded. Her mother had died of breast cancer 2 years earlier. Although normally patients require from 40 minutes to up to 90 minutes to complete the baseline structured interview, Ms. W. took 2 hours. Both the story of her family of origin and that of her mother's breast cancer revealed the same basic theme, that is, her mother's inability to face up to and deal with harsh and ugly realities that demanded confrontation and action. In the family, the mother functioned as a "Stepford Wife." She lived in a state of fear and obsequiousness to her alcoholic, abusive husband, who terrorized the family. His emotional and physical abuse of Ms. W. evolved to sexual molestation when she became an adolescent. She bore all of it in silence until, when planning to leave home, she realized that her younger sister would be the next victim. She broke her silence and told her mother, feeling this would be an intolerable betrayal of her sister if she allowed it to happen. But her mother was unable to take action, and her sister, indeed, became the next victim.

Breast cancer became an extension of this process in which a malignant perpetrator was loose but could not be confronted. Her mother did not tell anyone she had a lump until the pain

was beyond endurance, and the disease metastatic and incurable. Ms. W. returned home to nurse her mother through the terminal phase of her illness. She related, "Mother almost seemed relieved to die. It was a legitimate way to escape my father." In spite of this appalling history, Ms. W. had been able to marry and have a functional relationship but chose not to have children. She also became assertively self-reliant and successful in her business. We suggested psychotherapy; she cautiously assented. "It did not work," she complained, about the arrangements around the referral. Another referral was suggested, and again she felt it would not be possible due to "circumstances." She experienced the possibility of, in psychotherapy, facing her own mother's helpless dependency, her own sense of betrayal, and her rage, guilt, and fears as overwhelming. However, not unlike many women in our population, Ms. W. could not examine her own breasts without paralyzing anxiety and therefore had to return to the clinic frequently, allowing us to talk with her on this limited basis three to four times per year about her world of traumatic memories. She remains able to face these issues more than her mother but less than she would have if she used conventional psychotherapy. Our goal is to create a working alliance and facilitate trust with Ms. W. that will someday allow for conventional psychotherapy to heal the trauma of her past.

This case presents two major challenges for therapy: (1) of tolerating her resistances prior to even entering formal therapy; (2) of developing trust where little or none had been built in her family. Her transference reaction with the High Risk Clinic "family" is one of "Why should I trust your recommendations? I'll get it alone." Resolution will take a long period of interaction with the clinic prior to years of (formal) therapy.

**Vignette Number 5.** Ms. C. represents coping/adjustment Level 7. She is a 19-year-old, unemployed high school dropout. The staff of the High Risk Clinic was unclear as to how she actually supports herself. Her mother was diagnosed with a breast problem when Ms. C. was 14 years old. Upon reviewing the material Ms. C. brought with her about her mother, it was apparent that her mother had lobular carcinoma *in situ* (LCIS). By strict definition, this was really not cancer, but rather a precancerous condition from which about 17% of patients go on to develop actual cancer. LCIS puts a woman at 7.2 times the normal risk to develop cancer (Rosen, Lieberman, & Braun, 1987). The options available for LCIS are (1) bilateral mastectomy or (2) no treatment but close follow-up (Love, 1995). Unable to tolerate observation alone, her mother, then 38 years old, chose bilateral mastectomy. Because the procedure was performed at the height of the controversies surrounding silicone breast implants, the mother felt that she could neither have implants nor could she tolerate the more extensive tissue transfer techniques for breast reconstruction (Gabriel *et al.*, 1994; Shaw, 1995). Thus, she was left with no breasts, a radically altered body image, and a severely shaken sense of her femininity at age 38. Moreover, this coincided with Ms. C. becoming a very lithe, curvaceous, sexual young woman. She described her mother as first depressed by the loss of her breasts, but then turning angry. She tearfully related to us that her mother told her, "Everyone knows stress causes cancer. You have given me cancer. This is all your fault." Ms. C.'s response was to "get stoned," to spend her adolescence abusing alcohol, marijuana, and cocaine. She dropped out of high school and ended up in Los Angeles, about 300 miles from her parents' home. In her baseline visit to the High Risk Clinic, she was educated that (1) her mother almost certainly did not have actual cancer; (2) her mother's LCIS was not caused by stress from Ms. C.'s behavior during her early adolescence; and (3) based on her mother's experience, her risk of breast cancer was very modestly above a woman whose mother did not have LCIS. We do not know what this meant to her, as she never returned to the clinic.

Planning for therapy in this case reflects the age-related types of problems presented by Ms. C. to the Clinic. Her case makes it difficult to distinguish adolescent adjustment problems from her reactions to the trauma of her mother's breast situation. The first step with this 19-year-old is obviously to form a relationship that will allow for asking whether there is a reality beyond the mother's reality. The process that needs exploring with Ms. C. involved Mother's rage over her breast problem (leading to) displacement of blame onto Ms. C., (leading to) Ms. C. "numbing out" to cope, (leading to) Ms. C. fleeing from the entire family situation. As with Vignette Number 4, accepting slow progress and small gains is crucial.

**Vignette Number 6.** Ms. A. represents coping/adjustment Level 8. She is a 49-year-old divorced woman with no children and has a very successful business to which she devotes the majority of her time and energy. Her mother was diagnosed with breast cancer when she was 12 and died 5 years later, when she was 17 years old, having received the standard treatment of that era, which included Halsted radical mastectomy, radiation therapy, and some chemotherapy. Her mother felt "deformed and mutilated" by her very extensive surgery and was further traumatized by the radiation that burned and scarred her skin. Control over side effects of chemotherapy was perfunctory and not well developed. Ms. A., then in the early phase of her own pubertal development, vividly remembers her mother as "on her hands and knees by her bedside vomiting on newspapers like a dog." She described her mother as "a brittle, proud, and narcissistic woman, totally involved with her looks and image." Her mother was clearly shattered, horrified, and ultimately enraged by this series of events. She forced her husband out of their bedroom and never again shared it with him until she died. She insisted that her daughter (Ms. A.) care for her and no one else. Eventually, she insisted that her daughter move in to her bedroom. Ms. A. described herself as "becoming her mother's slave" during that period. She tried hard to please and calm her but perpetually felt inadequate and unable to fulfill her mother's wishes. As was also typical of that era, a tense and fearful silence descended on the family about the illness. The word *cancer* was virtually never mentioned, not between Ms. A. and her mother, or between Ms. A. and her father, or between the family and the treating doctors. In the last few months of her mother's life, Ms. A. was a high school senior. She remained at home caring for her mother and did not attend school. She was taught how to inject her mother with morphine shots. When the dosages of morphine the doctors had authorized were not containing the mother's pain, they suggested to Ms. A. that "perhaps we should try a placebo. Her pain should be controlled by what we are giving her." Balking at this notion, this was the first time she remembers getting angry at adults who responded to her anger by changing their behavior. During the terminal phase of his wife's illness, her father would greet her mother only once a day, in the mornings, and then not return to her room at all. Ms. A. persisted in this almost indescribably difficult situation, not having a perspective that it could or should be different. She returned to finish school the following year, but felt out of sync with her classmates. She spent the next few years at home "being her father's housekeeper." Although she wished to go away to college, feeling too obligated to her father, she attended college while living at home. The experience left her feeling a "black anger." She is not sure whether she is angrier at her mother for "enslaving" her or at her father for not taking a stand and allowing her to be used in this fashion. Since that time her life has been dominated by (1) a strong sense of frustration and anger at people, no matter whether casual acquaintances or intimate relationships. In her own words, she has "a short fuse, or no fuse at all," and (2) a need to be in charge of others, to control others, to never again "be under anyone's thumb." These themes have been enacted on her life in three divorces and a very successful career in which

she employs over 100 people in a garment manufacturing business. She describes her business as “a dog-eat-dog world where she is a top dog.”

In the clinic, Ms. A. singularly stands out among the other 275 patients in having an uncanny ability to split and pit staff members against each other. In two separate situations during a recent visit, she caused staff members to feel humiliated, ashamed, and like failures; she provoked a senior staff member to angrily upbraid a junior staff member for perceived management errors with her. The staff have come to realize that she creates in them the same feelings she felt as a teenage girl trying to care for her enraged, dying mother. She creates a sense of failure, guilt, fear, and paralyzing inadequacy in the staff, much as she described having felt at that time. She had several bouts with psychotherapy, with highly regarded therapists in the community and scorned recommendations for therapy. We continue to see her twice per year in our clinic.

This case presents major challenges to the staff to contain and manage the stresses and provocations presented by this most difficult patient. Ms. A. is less able to “tell” than to “show” the staff what she experienced with her family/mother by means of projective identification (Adler, 1985). The rage she feels upon psychologically revisiting the illness experience with her mother has repeatedly driven her out of therapy. Thus, its management and containment by the staff is pivotal to treating her (Adler, 1985). Ms. A. shares many elements of psychological trauma of her daughters of breast cancer patients. These include role reversal, changes in short- and long-term life plans because of mother’s illness, isolation combined with overwhelming responsibility for the mother’s care, the father’s regression and dependency, and familial silence that markedly intensifies all these problems (Wellisch *et al.*, 1991b). These need to be identified and worked through in therapy.

### EMERGING PERSPECTIVES ON PSYCHOTHERAPY FOR TRAUMATIC LEGACIES

The words *emerging perspectives* in the title of this section are used pointedly and deliberately to signify that, to date, very limited data exist on psychotherapy with high-risk women (Kash *et al.*, 1995). Our clinic has been awarded a grant and has begun a nonrandomized clinical pilot trial of a model of group intervention for this population that will be described below. Thus, the following perspectives are based largely on clinical work rather than on databased outcome studies.

#### Psychological Aspects of the Clinic Structure and Milieu

The structure of a special, high-risk clinic such as the one at the UCLA Breast Center or at the Strang Cancer Prevention Center/Memorial Sloan-Kettering Cancer Center itself can be fundamental as a psychological intervention. Such clinics become special, safe “holding environments” (see Winnicott, 1965) for this unique population. The safety comes from the sense that the staff is highly knowledgeable about their risks both genetically, biologically, and psychologically. The continuity of the staff as they make follow-up visits to the clinic program adds to the sense of a safe and predictable environment. Physically, they feel confident in the nurse practitioner’s skill to find anything suspicious in their breasts. Psychologically, these women know that there will be safety and empathic understanding in revealing their past experiences and traumas around familial breast cancer.

It is important to note that not all the patients in the program experience trauma-based symptomatology. In fact, the opposite is true. At least, by dint of baseline psychological testing,

the majority are not symptomatic. For example, of the first 161 patients in the UCLA High Risk Clinic, 36 (22%) were at or above the cutting score of 16 on the CES-D. Of this same 161 patients, 72 (45%) were at or above the 40th percentile on the STAI, indicating significant symptoms of clinical (present state) anxiety. While the minority of these patients appear to need referral or triage to formal psychotherapy for trauma-based problems, all of these patients benefit from the therapeutic milieu created by the High Risk Clinic team structure.

### Individual Therapy

To effectively deal with the core issues of this population, individual therapy needs to be dynamically oriented. This is especially true when the focus is the resolution of traumatically based symptomatology. To do relaxation therapy or cognitive therapy alone is to ignore or not reach the psychological strata where such trauma exists in these women. Several possible key foci of individual therapy were described elsewhere (see Wellisch, Hoffman, & Gritz, 1996). They include the following:

1. The fundamental act of asking the woman to talk about her familial cancer experience(s). As Vignette Number 6 illustrates, no one may have ever previously asked or given permission to the daughter to talk about these experiences. This may be especially true for daughters whose mothers had breast cancer in the 1950s and early 1960s, when silence about cancer was the operative behavioral/familial rule.

2. Exploring the relatively common theme of "I have decided not to have children." Of the six women in the vignettes, three had decided not to have children. Such decisions can be based on traumatic memories and/or fears of perpetuating such legacies in future generations. It can, at times, be based on false or misguided notions of risk. For example, Ms. C. in Vignette Number 5, had an inaccurate risk assessment to herself and future offspring based on her painful and traumatizing guilt toward her mother. Psychological exploration, support, and education may alter her sense of doom. However, education alone is rarely helpful to resolve such misperceptions (see Black, Nease, & Tosteson, 1995).

3. Exploring the presence of sexual conflicts in the daughter. Daughters may be coming into sexuality just as their mothers are (traumatically) losing theirs. This may result for the daughter in a trauma-based legacy of guilt around sexual expression. In addition, daughters may experience fear around sexual pleasure associated with breasts. In clinic interviews, some have stated, "That area (breasts) is off limits. I do not want to get used to pleasure from something I stand to lose." Vignette Numbers 4, 5, and 6 reflect elements of both of these issues. Ms. C. could not have sex without being "stoned," given that her mother was intensely threatened by and jealous of her daughter's intact body image and sexuality. For Ms. W. (Vignette Number 5), sexuality was always a dangerous, volatile area. Her inability to examine her own breasts is symptomatic of both fear and trauma. Ms. A. (Vignette Number 6) not only remained intact while her mother did not, but she also survived to become her father's substitute wife, further complicating her own psychosexual development. A key question in therapy for daughters seem to be, "Is it a betrayal of mother to have sexual pleasure, *including* breast-focused pleasure?"

4. Exploring fathers' roles in the resolution of trauma in their daughters. Was the father able to functionally cope with his wife's illness and then recover? Or did the father's own pathology further complicate the daughter's own recovery (see Wellisch, 1979)? Fathers have been reported to distance themselves from their daughters after their wife's death, or become dependent on and/or seductive with their daughters (as in Vignette Number 6, Ms. A.).

5. Exploring mother's own adaptation/coping style to her illness as a source of identification for daughter (see Stern, 1989). For example, was the mother an anxious denier (as in Vignette Numbers 2 and 3), or isolated and angry (as in Vignette Numbers 5 and 6)? In therapy, daughters can be encouraged to make different choices than their mothers if they themselves develop breast cancer. At the very least, therapy can help such daughters feel that they do not have to "go it alone" as their mothers often did emotionally.

6. Exploring for unresolved (now internalized) anger in the daughters about their forced participation in the experience of their mothers' illness. The key question is whether it has become a facet of a chronic dysphoria or low-level, persistent depression? Vignette Numbers 2 and especially 6 reflect this dynamic, both with a living and a deceased mother. How much this is an extension of the precancer relationship remains to be determined in psychotherapy. The adjunctive use of medication, especially antidepressants, can be important with this population. Hirschfeld and Goodwin (1988) state that the "use of psychopharmacological and psychotherapeutic approaches should not be considered an either/or proposition. The best clinical management often includes a combination of the two in a way that best meets the patient's individual treatment needs" (p. 434). This seems an apt treatment philosophy with such high-risk women.

### Group Therapy

Group treatment is a very important intervention modality for this population. To our knowledge, only one small outcome study has been performed with high-risk women in a group psychoeducational mode (Kash *et al.*, 1995). In this study, a 6-week program of education about risk, breast self-examination, and importance of adherence to screening guidelines was combined with psychological efforts to reduce the sense of isolation, encourage sharing of feelings and thoughts, and create a group milieu. As compared with a control group, the experimental group fared better with regard to decrease in perceived risk, lowering of perceived barriers to screening, and increase in knowledge about breast cancer. These changes persisted over time, up to 1-year follow-up. Our center is beginning a similar psychoeducational 6-week group intervention, with a strong psychological focus on the identification and resolution of grief states. Whether or not a death occurred in the family, significant losses are often present in our clinic population that has not been identified and mourned. What is not yet known about group interventions for this population to deal with trauma is whether they are better than individual intervention, whether they supplement individual intervention, or what the best group mix might contain. In our study, groups will be subdivided in regard to age (< 42 years vs. > 42 years), and in regard to loss status (mother died vs. mother survived), to see if one mix produces better outcomes. The study will incorporate elements of both cognitive therapy and relaxation therapy. These will be taught as well as practiced in a group context. This was an important element in a group outcome study with melanoma patients (Fawzy *et al.*, 1990).

### Family Therapy

Family therapy has not been reported in the literature for this population. It contains important possibilities for trauma resolution. We have experiences with several daughters spontaneously bringing their (breast cancer survivor) mothers with them to their appointments. The daughters' agendas in doing so have appeared to be, as in the words of one such daughter, "Let's finally face your breast cancer experience together fully by actually talking about it together." What we have witnessed in these powerful experiences is the breaking down of silence and of

barriers between mothers and daughters that often lasted decades. Such mothers have related, "I tried to protect her from pain," with the realization that at least some of that pain was/is their own. The guilt of these mothers over the possibility of transmitting breast cancer to their daughter is enormous. This is a very potent modality to consider in trauma resolution for high-risk women. It is, after all, the context of the family of origin where such traumas originated.

## CONCLUSION

This chapter must be viewed as a work in progress. Understanding both the traumas and especially interventions for these traumas in women at high risk for breast cancer are far from fully known. What is clear, however, is that this is a *heterogeneous* group of women, with a variety of predispositions, family circumstances, family experiences with illness, and risk factors. They cannot and must not be viewed as a homogenous group with one trauma and one characteristic response. Similarly, there is no "formula" or "model" for trauma resolution for this diverse group of women. We expect and hope that several pathways and models will be developed and evaluated in the future to remedy the traumas and enhance the coping and adaptation of these high-risk women.

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