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TWO GROUNDED THEORIES OF WOMEN LIVING WITH CANCER

by

Lesley Martin

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Committee in Charge:

Professor Tom Boyce, Chair
Professor Henrik Blum
Professor Adele Clarke

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The thesis of Lesley Che Martin is approved by:

Chair — Date 5/20/98

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Spring 1998

This thesis is dedicated to my mom,

Patricia Jean Perica
September 17, 1940-September 19, 1994,
who
taught me the value
of listening,
showed me the strength
of women,
and
shared with me an enduring
love.

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INTRODUCTION

This thesis is a grounded theory analysis of nine women who are currently living with cancer. While it is not (and cannot be) any complete story of life with cancer, it does seek to elucidate two particular phenomena of life with cancer. The first one I have entitled "women live cancer" whereby I describe the processes involved in understanding and coping daily with a cancer diagnosis. The second one is best described as the "experiences of displacement" the participants in my study feel as they negotiate a "new" life with cancer.

WHY ME? MY MOTIVATION/WHO I AM

This study is my attempt to start/join a conversation/dialogue about how women understand and integrate a cancer diagnosis. This question, and others like it, have been my passion ever since my mom's cancer diagnosis in 1992. It is extremely hard for me to believe that she has been dead for almost four years. In so many respects, this project is about my mom. Her experiences were not given proper voice, oftentimes because there was either no space or no inclination to do so.

I am currently a medical student at a small, relatively unknown program that is the joint effort of two large, prestigious universities. It is a unique program in that the students undertake a master's thesis and earn an MS while obtaining the MD degree. It is nontraditional in that we are exposed to the rich personal contexts in which health, illness and disease occur. Our program is interested in training physicians to be sensitive to the social, political, and economic environment of not only the patients, but also of the biomedical system. However, because we are medical students, we are taught, sometimes in subtle ways and sometimes in overt ways, to model the following: The information-bearer, the physician, has almost ultimate control and power over the conversation,

therapy, and diagnosis. "Medicine is still called upon to make the final decision in identifying and legitimizing illness" (Herzlich & Pierret, 1987, p. 190). In most encounters, the physician determines what is valuable, worthwhile. The patient becomes less visible. Research has been done about the lack of control patients have in the clinical setting. One study by Beckman and Frankel (1984) showed that during 74 office visits, only 17 (23%) patients were able to complete an opening statement of their concerns.

As I am being trained to become a physician, I am being trained to value my words over others', my thoughts over others', my experiences over others'. However, because of my personal experience as a nonmedical person whose mother was extremely sick, I realize the profound importance of the sick person's story of her illness. In fact, one's interpretations of what is happening inform the choices one makes and the thoughts one has with regards to the illness. For example, believing that one caused the illness, through lifestyle habits or through toxic emotions, necessarily affects how one experiences the illness. Additionally, being burdened by the details of the illness, as in being unable to fulfill "normal" roles and/or not having a safe place to talk about the illness, can add complexity to the diagnosis.

I am attuned to the fact that the stories of the sick person take place outside biomedicine. The stories are personal accounts and provide a continually unfolding understanding to the person with the disease. Patients seek meaning of a diagnosis of cancer and seek to integrate this meaning into the context of their whole life (O'Connor, 1990). Unfortunately, there is very little room in the medical encounter to address, discuss, or consider the implications of these stories. In fact, according to Strauss, et al (1984), "Health personnel, who care for those with chronic illness, are not rewarded for employing their experiential knowledge [of chronic illness]" (p. vii).

I am dually placed in that as I am training to become a medical doctor, I am listening to stories that, while medical in some aspects, are largely social and relational. Diseases have both a "technical, objective or scientific dimension and a socially experienced, lived

dimension" (Gifford, 1986, p. 215). Undertaking this research while in medical school is powerful in that I am learning to understand disparate processes of a disease-the objective, medical disease and the social, relational illness. Charmaz notes the utility of grounded theory for physicians, because it can provide physicians with different ways of understanding how and why patients' actions and beliefs occur (1990). O'Connor's research on how cancer patients construct meaning studied 30 people 6 months after a cancer diagnosis. She found that how people experience meaning (of cancer) is not "readily understood or recognized by health care professionals" (p. 168). Cassell furthers this by writing that one cannot understand illness and suffering without considering personal meaning (1982).

WHY THIS TYPE OF RESEARCH?
QUALITATIVE VERSUS QUANTITATIVE

Prior to the modern practice of medicine by doctors, various lay healers provided health care to their communities. Help against illness was invested in multiple players; mostly women, these were midwives and folk healers who gained their sources of information from the "aggregate experience of preceding generations" (Geary, 1995, p. 24). The information was gathered from Europeans, Native Americans and Africans and resulted in a "rich tapestry of knowledge" (Geary, 1995, p. 24). During the late 19th century a transformation occurred. The rise of the "experts" usurped the lay healers' authority; "the triumph of science was as inevitable as human progress or natural evolution: the experts triumphed because they were *right* " (Ehrenreich & English, 1978, p. 33). Science states there is one world to know and that humans can know this world by the information gathered through their senses (Nelson, 1995). The birth of science and its attendant consequences resulted in a reduction of the types of knowledge. No longer a

tapestry, knowledge became the "truth" that is testable, falsifiable, predictable and uniform for all knowers (Nelson, 1996; Dickson, 1990).

Western biomedicine is dominated, at present, by a positivist agenda that is reductionist, decontextualized, unconcerned about the value and importance of interconnection of things and is blind to the value of relationships (Candib, 1995). The scientific goals of rationality, neutrality, and objectivity dictate that physicians be guided by these principles, and be unaffected by wider social, cultural and political forces (Mishler, 1981). Allopathic medicine is a linear discipline; a "subjective" patient narrative is verified by the "objective" physician and her physical diagnosis, a diagnosis is made, and treatment is prescribed. There is little discussion about and little interest in the ways patients experience their symptoms, the ways patients view their medical problem, and the multitude of ways persons can and do heal. My research is a conscious decision to listen to the woman with the disease/illness and hear her words.

According to Mishler (1981), the biomedical model is treated as the representation of reality, and is not understood to be a representation of reality. Arksey also writes that scientific knowledge is not "discovered" by experts and disseminated to the wider public, rather it is the result of verification of these audiences in this knowledge (1994, p. 449). Mishler (1981) further elucidates four key presuppositions, the so-called "silent assumptions" (p. 1) of biomedicine: 1. the definition of disease as a deviation from normal biological function; 2. the doctrine of specific etiology; 3. the belief in generic diseases; and 4. the scientific neutrality of medicine. Inherent in these assumptions is that biomedicine strips social contexts from meaning, illness is autonomous and the treatment absracts illness from the social, cultural and institutional context in which illness occurs.

Upon further inspection, one can find faults with these assumptions. Whereas biomedicine determines etiology to be biologically specific, alternative thinking can determine etiology to be the result of a disturbance in social relationships (Mishler, 1981). How is biomedicine unresponsive to this thinking? Additionally, the etiology of cancer is

not yet found and namable. Although biomedicine considers the term "breast cancer" to be sufficient to explain the disease, individual women's experience with breast cancer cannot ever be described by one term. And, scientific knowledge is anything but neutral. In fact, "scientific knowledge is implicitly structured to be consistent with wider cultural ideas" (Arksey, 1994, p. 450).

From the beginning, I was interested in qualitative research in order to capture the words of women with cancer. Although trained in the natural sciences, I believe qualitative research methods allow a richer understanding of the phenomenon of interest. The "hard sciences" strip context away from the phenomenon of interest, so as to render it almost meaningless. To study human reactions to a diagnosis of and life with cancer, one must necessarily consider context. As Audre Lorde (1980) writes, "Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived" (p. 9). There is a subjective dimension that is implicit in and fundamental to human experiences. "Reality is constructed through human action, and does not exist independently of it. This does not mean that the world exists only in our heads; rather, the world as a meaningful reality is constructed through human interpretive activity" (Mishler, 1981, p. 141). To qualitative researchers, the context informs the phenomenon and therefore must be analyzed. According to Blumer (1979) "It is absolutely necessary to include the relevant subjective elements in a sociological analysis of human society, yet the instruments (human documents) for getting such subjective elements do not allow us to meet the customary criteria for scientific data" (p. xviii).

As a feminist, I believe women's knowledge is different than medicine's knowledge of their experiences. This work is feminist because I believe the essential meanings of women's lives can only be grasped by listening to women themselves. This work intends to center and make problematic women's diverse situations and the institutions, such as biomedicine, that influence these situations (Olesen, 1994, p. 158). When addressing women sociologists and researchers, Dorothy Smith (1979) wrote "We

have not known how to begin from our own center, how to begin from our own experience, how to make ourselves as women the subjects of the sociological act of knowing (p. 154). For a woman, ways of knowing are intertwined with her concept of herself (Belenky, 1986). I believe that women's knowledge of their situation and, specifically, of their disease/illness has been little valued by medicine and its practitioners. Women respond to medical crises out of their personal, unique rationality (Olesen, 1994, p. 161; Herzlich & Pierret, 1987, p. 202). It has a logic all its own. This is the motivation of my research question; that is, how do women experience and talk about cancer?

Unlike past qualitative and ethnographic research projects, the researcher today should not be a silent player. Whereas prior notions of research involved the researcher as invisible and as employing the "god trick" (Haraway, 1988), postmodern research demands that the researcher be visible and accountable. Researchers are no longer able to think themselves invisible during interviews, participant observations, and field note gathering. Historically, "researchers/writers self-consciously [carried] no voice, body, race, class, or gender and no interests into their texts" (Fine, 1994, p. 74). Today, postmodern researchers are very interested in how their unique individuality shapes the analysis, and ultimately, the final research product. My position as a member of a family who lost our mother as the result of cancer and my position as a person with status, due to race and class, inform my analysis as a researcher. But, my position is also as a feminist, one who is very committed to the care and empowerment of women.

Because I am a medical student and am doing research that I believe "place(s) me in social struggles *with* those who have been exploited and subjugated" (Fine, 1994, p. 72), I am "working the hyphen" (Fine, 1994) between self and other. Fine describes working the hyphen as examining the hyphen "that both separates and merges personal identifies with our inventions of Others" (p. 70). This intends to open space in order to rethink how researchers and social science have identified, spoken for and of this invention "other." By working the hyphen, I am physically and emotionally "unpacking notions of scientific

neutrality, universal truths, and researcher dispassion" (Fine, 1994, p. 71). I can not hear these women's words and not be affected by their stories of horror, chaos, rupture, regrowth. Their words will inform my medical career.

CANCER

While any discussion of cancer will, by virtue of its complexity, be incomplete, I venture to describe certain aspects of cancer that help form the context of cancer in the United States today. I aim to situate cancer. Cancer is the second leading cause of death for women in the United States and causes 22% of all deaths (Primono, 1995, p. 665). In some ways, cancer is inexplicable. Its causation, its age of onset, its prime candidate(s), and its outcome are not exact and predictable. Cancer has been written about for at least 400 years. As a disease, cancer defies science's understanding. The Germ Theory, which postulates that disease is caused by germs, does not explain most cancers, even though as a modality of causal thinking, it dominates oncology as a discipline. Koch's postulates, which provide criteria for establishing that organism X causes disease Y, do not fit for any one particular etiology of cancer. It is difficult, if not impossible, to predict who will get which type of cancer. In fact, the advent of technology to test for BRCA1 and BRCA2, the genes believed to cause certain types of breast cancer, is fraught with confusion about whom should be tested, what a positive test might mean, and how the individual can be protected from insurance companies in the event of a positive test.

Cancer is ubiquitous and, at this point, its cause is (relatively) unknown. In Illness as Metaphor, Sontag speaks to the socially-constructed ramifications of not understanding cancer's etiology: "cancer fills the role of an illness experienced as a ruthless, secret invasion-a role it will keep until, one day, its etiology becomes as clear and its treatment as effective as those of TB have become" (p. 5). Further, "any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance" (Sontag, 1990, p. 58).

Certainly science understands some etiological variables. Tumor suppressor genes and oncogenes are segments of the chromosomes that when deleted or otherwise altered have been implicated in a variety of cancers. Radiation by way of X-ray machines and

nuclear bombs and sunlight have been shown to be factors that can and do alter chromosome integrity. "Tobacco is a known cause of cancer of the lung, bladder, mouth, pharynx, pancreas, kidney, stomach, larynx, esophagus, and possibly colon" (Ames & Gold & Willett, 1995, p. 5260). The carcinogenic mechanisms of tobacco smoking are not well understood (Ames & Gold & Willett, 1995); some scientists postulate the carcinogenic effect of cigarette smoking is the oxidative burden of carbon monoxide in smoke, others postulate that smoking may in fact be a confounder for lifestyle choices like the consumption of alcohol and poor nutrition. Breast cancer incidence has been linked to age at menarche, number of pregnancies, time spent lactating, age at menopause, genetic predilection and other difficult-to-grasp variables like height (Kelsey & Bernstein, 1996). Colon cancer has been linked to high fat diets and to low fiber diets that allow digested materials to move through the colon at slower rates, thereby increasing their ability to alter colonic mucosa (Block & Patterson & Subar, 1992). Added to these various etiologies is the non-changeable category of genetic predisposition. If family members have certain kinds of cancers, susceptibility is increased. Colon and breast cancer are prime examples of the burden of heredity (Claus, 1994).

What does all this mean? The answers are not yet discovered. Scientists do not know exactly what relative amounts of each of these factors--lifestyle choices, genetics, environmental insults--are necessary and/or sufficient to cause cancer. Instead, the causation of cancer is attributed to a melange of these attributes. To add to the confusion, any individual person knows, or knows of, people who smoked until they were 95 years old and died of a fall, rather than cancer. We, in the collective sense, know people who have healthy diets and "get" colon cancer. We know families where breast cancer is widespread and others where it is found in only one woman. We know examples that do not fit the mold. We know the outliers. And we are confused. We are scared, too. According to Sontag (1990), a disease that is mysterious and feared is "felt to be morally, if not literally, contagious" (p. 6).

Reports of the anti-cancer benefits of oat bran, whole wheat, fiber, antioxidants like vitamins C, A and E, and beta-carotene, tofu, soybeans, forsaking red meat, pork and potato chips are plastered in our newspapers and magazines. We can hardly read the newspaper or watch the evening news and not see or hear a report on "startling new evidence that _____ prevents cancer." One can fill in the blank with almost anything. The effects are astounding: the health food/vitamin industry has grown exponentially in recent years. The bags in the produce section of most grocery stores remind us to eat five servings of fruits and vegetables a day in order to maintain an anti-cancer diet. There is a national public health campaign to reduce the number of smokers.

Lurking along the sidelines is a low grumbling about the environment. Rachel Carson's Silent Spring makes sense to some people. Some are convinced that the increase in cancer rates is due to the technological and industrial revolutions and their concomitant production of toxic byproducts and wastes that are unlikely to be safely removed. Grass-roots groups like Toxic Links are pushing hard to force the industry giants to consider the poisoning of the environment as contributing to the etiology of many cancers. A recent nonfiction book entitled A Civil Action is a stunning tale of a cancer cluster of childhood leukemia in Woburn, Massachusetts. This book describes the painful inability of the families in Woburn to receive justice from the companies that dumped toxic byproducts into the ground, allegedly polluting the ground water that served a circumscribed part of Woburn. As an aside, this book is classified as "Current Affairs."

Yet, even the role of the environment is contested. A famous and well-published biochemist at the University of California, Berkeley, Dr. Bruce Ames, believes that cancer clusters are merely the result of shared, unhealthy lifestyles. He has published much to counter what he calls the sensational and unfounded belief that environmental pollution and pesticides cause cancer. However, many public health researchers claim there is strong evidence of an association between a toxic environment and cancer.

CANCER AND CHRONIC ILLNESS

It is worthwhile to develop a reasoning behind the connection/relationship between cancer and chronic illness because sociological/qualitative literature on cancer seems so sparse, particularly if one wants to learn about "how" people live with cancer. While I read the more extensive research on chronic illness, it became clear how similar the process(es) of chronic illness are to the process(es) of cancer.

For example, Strauss, et. al. (1984) identify seven variables that "define" chronic illnesses, and these will be listed below. A reading of these variables need not be in-depth to see how one might draw parallels between chronic illness and cancer. Chronic illnesses are long-term, uncertain, multiple diseases, disproportionately intrusive on lives, expensive and require both greater efforts at palliation and a wide variety of auxiliary services (pp. 11-15). Part of the beauty of Chronic Illness and the Quality of Life is that the authors capture the essence of daily life stressors under the rubric "multiple problems of daily living" (p. 16). These include not only the apparent medical work of symptom control and of following regimens, but also the less obvious need to prevent social isolation and help with confronting items attendant with chronic illness: psychological, family and marital problems.

Perhaps the most instructional aspect of this book is the conceptualization of the illness trajectory. It is defined as "the physiological unfolding of a sick person's disease and the total organization of work done over the illness course plus the impact on those involved with that work and its organization" (p. 64). The illness trajectory is meant to capture more than just the management of the disease; it is also meant to include the "handling of contingencies" (p. 64). "Trajectory covers not only the physiological changes but also the nonmedical aspects, including social or role performance changes, self-identity alterations, and the evolving sequence of work to manage the disease" (Primono, 1995, p. 652). This trajectory is used by the sick person and others to document where the sick

person is along the trajectory. The person with the illness, her family, friends, physician(s), and other healers each interpret the location of the sick person differentially (Strauss, 1984). Of course a person's reading of where along the trajectory the sick person is is informed by each's personal style, i.e. optimist or pessimist, each person's own experience with disease, and to whom each person is speaking. The sick person, for example, may speak "truthfully" about her location on the trajectory in order to obtain services. However, she may also downplay her location in order to protect others, as when speaking to her children. The assessment of where the sick person is is continually undertaken in order to make necessary social arrangements.

The trajectory can be broken down into three phases: crisis, chronic, terminal. The crisis phase is the beginning and is characterized by signs and symptoms of disease and the stage of diagnosis. This is somewhat problematic with respect to cancer because sometimes cancer is found during screening exams such as breast self exam, mammography, stool hemoccult testing, etc, and sometimes it is found during periods where the person is not feeling particularly sick. For example, among my participants, a few women responded that they didn't believe they had cancer, because they didn't feel sick. The second phase is termed the chronic phase and it is referred to as stable, in that the work of living with a new identity, that as a person with cancer, can be undertaken. It is assumed that the chronic phase is relatively crisis-free, and if crises occur, they are minor when compared to initial diagnosis. However, the chronic phase can become punctuated with exacerbations or flare-ups that require extra effort on the part of the sick person and her family. For example, problems due to cancer treatment might need separate medical attention; recurrences may occur during this phase. When the exacerbations become exceedingly frequent or exceptionally great, the trajectory moves into its third phase, the terminal phase. It is the herald of the downward course leading ultimately to death. The foregoing is the generic illness trajectory. The rate of speed a particular illness assumes as it progresses through each phase is dependent on that illness and the person who has the

illness. The number of flare-ups during the terminal phase is likewise unique for the person and the illness. The chronic phase may be called stable; however, it is misleading to think that this phase, which may last for years, is trouble-free.

NATURE OF THE STUDY

I conducted interviews from October, 1996 to February, 1998. These interviews lasted about 90 minutes to 2 hours. They usually took place in the participant's home, but others were completed in my apartment, in public (one participant was homeless), and in an office. With permission, I tape-recorded the interviews and the tapes were transcribed.

Originally, I had selected the Women's Cancer Resource Center in Berkeley as the site from which I would solicit participants. Because I wanted to use this site, I trained to become a volunteer. I have been a Bett's volunteer for about 2 years (the program is named for Ms. Betts, one of the founders of the Women's Cancer Resource Center); I provide one-on-one support to an Oakland woman with cancer. I posted a flyer in the Center, and I sent solicitation letters to the support group leaders and asked them to distribute these to their groups. When in January, 1997, I had received only 2 calls from women, I requested permission to hang flyers in public spaces.

I posted flyers in restaurants, corner markets, bars, bookstores, UCSF and outside grocery stores in Oakland, Berkeley, and San Francisco. I received 7 of my 9 interviewees after posting flyers in public spaces.

NINE WOMEN

The women who participated in my study are a fabulous group. In the beginning, I was interested in why a woman would want to be in this study. I was skeptical about the ways in which women might find a study like this personally beneficial. But, after the second interview, I realized how desirous women are/were to tell their stories. I learned of the various reasons women chose to participate: to hear herself tell the whole story to someone who wasn't invested in the story, to support studies about women with cancer, to help a graduate student, to be able to *tell my story*. These women were very giving of

their time and of their energy; some were sick during the interviews. They were wonderfully open and emotional with me and I am extremely grateful.

I will introduce them here with the disclaimer that details and their names have been altered to protect their anonymity. Toni is a "thirtysomething" African American woman who has a son in elementary school; she and her son live in a working-class neighborhood, and she was unemployed at the time of this interview. Her last treatment for breast cancer was a few months prior to this interview. Olivia is a 56-year-old white woman who has adult children who do not live with her; she lives in an upper-middle class neighborhood and is an art student. Olivia was diagnosed with skin cancer many years ago. Mercedes is a 38-year-old Mexican woman who has no children and was/?is currently temporarily homeless; she is currently finishing her associate's degree. It has been almost 5 years since Mercedes was diagnosed with thyroid papillary carcinoma. Pam is a 35-year-old white woman who has a very young child, and lives with her physician husband and child in a suburb-type neighborhood. Pam has recently started academic work on a Ph.D. degree. Pam was diagnosed with lymphoma, and is currently taking therapy. A single parent, Latrivet is a 40-year-old Black woman who lives with her 4 children, her mother and stepfather in a poor, working-class neighborhood. Latrivet works in a school as an aid and is completing her undergraduate degree. Her mastectomy was about 3 weeks prior to this interview. Astrid is a 47-year-old woman who recently quit her job after a second recurrence of her cancer. She and her recently-retired husband live in a middle-class neighborhood and are planning to travel. While her second recurrence is in her stomach, Astrid's original diagnosis was breast cancer. Eleanor is a 50-year-old woman and is a practicing medical doctor. She, her husband and their 3 children live in a middle-class neighborhood. Eleanor was diagnosed with breast cancer one year ago. A Ph.D. student, Kelly is a 40-year-old white woman who works for the Center for Disease Control and Prevention. She does not have children. Kelly was diagnosed with colon cancer. Linda is a 54-year-old white woman who currently works as a nurse. She has 3 adult children and

she lives with her "mate" in an upper-middle class neighborhood. Linda was diagnosed with breast cancer 9 years ago and is in remission.

Their cancers were of many types: thyroid papillary carcinoma, colon cancer, lymphoma, skin cancer, and breast cancer. Four of these women have annual household incomes less than $15,000. Three of the women have husbands; 2 identified as lesbians, although neither had partners at the time of the interview. They have a variety of types of medical insurance: Medi-Cal, Veteran's medical benefits, membership in a large HMO, and private insurance.

METHODOLOGY

INTRODUCTION TO.....

I chose to employ grounded theory methodology in the analysis of these data. I chose this method because it seemed the most easily accessible methodology for a first-time researcher. By using Strauss' and Corbin's Basics of Qualitative Research: Grounded Theory Procedures and Techniques, I was able to "do" research in a step-by-step fashion. According to the Handbook of Qualitative Research, "It (grounded theory) gives the researcher a specific set of steps to follow that are closely aligned with the canon of 'good science'" (p. 204). What could be better for a person whose academic training has been scientific?

However, before I continue to discuss grounded theory, mention must be made about my hesitancy with respect to this methodology. Like some other researchers, I believe that breaking the data into bits and pieces may result in some loss of the essence of the women's words. As a feminist and one exquisitely tuned into the de-valuation of women's words and experiences, I question the ability of grounded theory to protect and respect women's words. Particularly when I consider the precarious "place" some of these participants occupy in this world, I am somewhat uncomfortable in breaking down their stories.

GROUNDED THEORY AS A THEORY

Symbolic interactionism is the sociological and social psychological theoretical perspective that underlies grounded theory. It has roots dating back to the early 20th century, to the time of the American pragmatist philosophers: Mead, Dewey, James, and Pierce. This perspective believes that people act towards things based on the meaning these

things have for them, that the meaning of things results from the process of social interaction, and that these meanings are modified through an interpretive process (Denzin, 1992). To be more concrete, women with cancer act towards cancer in ways that reflect the meaning cancer has for them. And this meaning is informed by the context in which the disease occurs and how women understand cancer. Hunt, Jordan and Browner (1989) also found that women cancer patients acted for reasons that made sense in their own lives.

According to Denzin (1992) symbolic interactionism has both interpretive and interaction heritages. "Interpretive interactionists endeavor to capture the voices, emotions, and actions of those studied. They focus on those life experiences which radically alter and shape the meanings persons give to themselves and their experiences" (Denzin, 1992, pp. xv-xvi). The goal of symbolic interactionism is to make understandable the lived experience of people. This lived experience of people is the starting point in grounded theory. The researcher can "attend to how they construct their worlds" (Charmaz, 1990, p. 1162). "Symbolic interactionists assume that as thinking, acting, creative individuals, human beings respond to the actions of others after interpreting these others' intent and action" (Charmaz, 1990, p. 1161).

Grounded theory is about developing theory while simultaneously gathering data and doing the analysis. With its foundation in pragmatism, grounded theory attempts to "develop fresh theoretical interpretations of the data rather than explicitly aim for any final or complete interpretation of it" (Charmaz, 1983, p.111). "Grounded theory is a rendition of a reality that cannot actually be known, but is always interpreted" (Annells, 1996, p. 386). "The grounded theorist does not believe it sufficient to report about a respondent's viewpoints but assumes the further responsibility of interpreting what is observed, heard, or read in order to write about categories of meaning" (Barnes, 1996, p. 431). Grounded theory is about constructing theories that will have fit, understanding, generality, and control (Strauss & Corbin, 1990). In keeping with its theoretical foundation, grounded theories are concerned largely with the "*patterns* of action and interaction between and

among various types of social units" (Strauss & Corbin, 1994, p. 278). Grounded theorists aim to create theoretical categories and then analyze relationships among these categories (Charmaz, 1990). Grounded theory is also referred to as the constant comparative method; therefore, grounded theorists continually make comparisons within the data and with other data sources.

As noted above, the practice of medicine is based on preexisting information, structure and theory, and patients' stories are made to fit. Conversely, grounded theory is built inductively from the phenomenon of interest (Strauss & Corbin, 1990). This is very appealing to me. As someone who does not have and has never had cancer (yet), I am skeptical to think I may know what is relevant and important to these women who have cancer. To think I may know what any conversation about cancer would/should contain places me directly in line with the powers of the patriarchal structure. Grounded theory allows me to not be in total control of the content of the conversation. Grounded theory begins with general research questions, the so-called open-ended questions. Unlike other, more traditional methodologies, grounded theory does not seek to test a hypothesis that was developed from existing literature.

Although the "relevant" details of the phenomenon are intended to be discovered while doing the analysis, the initial research question must be articulated. Not only am I present and accountable in the analysis, I am present in the original research question; it "is somewhat dependent on the 'worldview' of the researcher. Although the research focus may emerge from a variety of sources, the actual formulation of the question arises from the researcher's notions about the nature of reality, the relationship between the knower and what can be known, and how best to discover reality" (Annells, 1996, p. 379). According to Belenky, et al (1986), "...for our basic assumptions about the nature of truth and reality and the origins of knowledge shape the way we see the world and ourselves as participants in it. They affect our definitions of ourselves, the way we interact with others, our public

and private personae, our sense of control over life events, our views of teaching and learning and our conception of morality" (p. 3).

For example, one of my first questions during the interviews was to ask each woman to tell me a story about her cancer. Presumably, she could start anywhere she felt comfortable. If I had asked her to tell me the story of her cancer from diagnosis (which may be the natural tendency of a medical student), I may have inadvertently closed the door on her cancer story that, for her, may have started 14 years prior. Sometimes, however, the story she was willing to share with me began after diagnosis. My training as a grounded theorist taught me the value of the open-ended question, however, my personal belief that an individual's account may be complicated and defined by elements other than biomedical milestones allowed me to structure my questions in such a way as to allow for the complexity of human experiences. Further, my worldview is that people are multiple, that stories change according to unseen variables, that stories are partial, and that truth is changeable informed not only my research questions, but also my analysis.

One of the most clear examples of how people can be of multiple, sometimes conflicted minds, was when Kelly, a Ph.D. student in public health asked me my opinion about her cancer. As an epidemiologist (she works for a government office as a public health official while obtaining her Ph.D.), Kelly had done extensive research on her colorectal cancer and knew everything about staging classification, survival statistics, the genes implicated, randomized controlled trials of drug treatment, among other things. She was far more knowledgeable than any other participant about her cancer, and yet still felt she didn't know enough and used our interview to ask questions.

I believe there is local knowledge that is greatly impacted by the context in which it is known. I believe that knowledge is socially constructed and that it is constructed by "communities of knowers" (Nelson, 1995, p. 22). Biomedicine is not immune from local knowledge. There are differential styles of physician disclosure of a cancer diagnosis among nations. This reminds us that the practice of oncology is shaped by medical

technology and scientific knowledge, but also by "local popular and medical cultures" (Good, et. al, 1990, p. 60) as well. "There are 'local' variants of international biomedical culture which are powerfully influenced by societal and institutional contexts, traditional medical cultures and the history of cosmopolitan medicine with those contexts" (Good, et.al., 1990, p. 60).

GROUNDED THEORY IN PRACTICE

Coding in grounded theory occurs in 2 different ways, at different times and for different purposes. The first phase, so-called open coding, provided me with the opportunity to "see" what the women were saying. Because I do not have the training of a sociologist or researcher, the names I gave the codes were usually common-usage words. These codes were about emotions, actions, frustrations, narratives about particular symptoms and particular doctors, etc. Consider the following list: prediction/ways of knowing, temporality, necessity as mother of invention, speechless and couldn't stop talking, lack of understanding, lack of information, questioning, betrayal, family history, fearless telling, dependency, appearance, information gathering, accommodation to symptoms, comparison to previous fears, comparison to others with cancer, dealing=emotional work of cancer, isolating, ownership of care, realization.

I used open coding to break the data into bits and pieces in order to identify categories and the properties of the categories. Once named, the variation of the codes are considered by specifying "process, causation, degree, dimension, type, or a particular type of ordering" (Charmaz, 1983, p.120). For example, when looking at the code "information gathering," I looked at the surrounding data to ask the following: Why did she gather information? How did she learn of gathering information? Was it useful? If she quit, why did she quit gathering information?

I then used the second phase of coding, axial coding, to put the codes together in a way that made new connections between categories and subcategories. Axial coding involves "specifying a category in terms of the conditions that give rise to it; the context in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those strategies" (Strauss & Corbin, 1990, p. 97). Axial coding was rearranging the codes into my developing theoretical picture. Examples from the data follows: control, biomedical discourse, roles of the woman, dealing with cancer, disclosure, etc. Developing the categories sometimes was problematic because oftentimes different subcategories fit into different categories. For example, disclosure is a code I used, during open coding, to name all the ways in which these women told others of their diagnosis. During axial coding, I looked for the motivations, conditions and outcomes of disclosure. At times, disclosure was about dealing with cancer (fearless telling) and at times about protecting oneself from judgment and becoming victimized (fearful telling).

After axial coding, I constructed pictorial diagrams that helped me organize my categories. Initially I was stumped as I believed all my categories should fit into one pictorial representation of life with cancer. However, I settled down and realized that not all my categories would or should fit in one picture. Different categories represented different aspects of the experiences these women had. So, I began to ask the conceptual questions. And, as trite as this seems, some of the categories fell beautifully into place.

Grounded theory aims for the production of theories that are generalizable to other phenomena, but are built from the phenomena of interest. These theories consist of relationships between concepts and "coherent group of general propositions used as principles of explanation for a class of phenomena" (Strauss & Corbin, 1994, p. 278). The theories are meant to be dense in conceptual relationships that are "embedded in a thick context of descriptive and conceptual writing" (Strauss & Corbin, 1994, p. 278). Further, these theories are about process, not about individuals.

Mention must be made that while the analysis seems to move in an orderly, stepwise fashion from coding to categorizing to theory development, it doesn't quite work this way. Two reasons explain why doing grounded theory is not orderly and setpwise. First, coding, categorizing and theory development occur simultaneously; as I conducted the later interviews, I returned to the earlier ones in order to re-code and further think about my research questions. Second, grounded theory is not static. Theory development can be started, and can later be discontinued if the theory is not sustained. Because grounded theory is built from within the data, if I felt there were hints of a category, I would use later interviews to see if a category was sustained. For example, after my first 3 interviews I got a glimpse of a category about displacement that I wanted to see if it was sustainable. I included in my subsequent interviews questions relating to the participant's experiences of changed relationships both with herself and with others. The interviewing, coding, analysis and theory development happened simultaneously at times.

I am being/becoming sensitive to the contexts of these women. Some of these contextual elements are more overt, as with her race, class, sexual orientation, ethnicity. Others are more subtle and may be acknowledged by her. I am constructing an analysis of their experiences. I am allowing the theory to be built from what they say and what I interpret. I am not hypothesis testing.

We code for what is there, but grounded theory admonishes us also to code for what isn't there (Charmaz, 1983). Toni and Latrivet did not speak explicitly about being Black women and having cancer. But, cancer and most other medical conditions differentially affect and impact Black people. Sometimes the disease burden is greater and usually the medical care is less appropriate. Beyond the physical and medical aspect, Toni and Latrivet have cancer experiences that may not be similar to the experiences of white women. As Audre Lorde (1980) writes about the woman from Reach for Recovery, who provides "falsies" to Audre post-mastectomy, "But I needed to talk with women who shared at least some of my major concerns and beliefs and visions, who shared at least

some of my language. And this lady, admirable though she might be, did not" (p. 42). Additionally, the women whose annual household incomes were less than $15,000 expressed more frustration about their medical care than did Pam, whose husband is a physician.

THE CONDITIONAL MATRIX

The conditional matrix, as explicated by Strauss and Glaser, provides an opportunity to consider the environment and background in which the phenomenon is happening. Grounded theory is transactional; it is interested in the interactive nature of events. An analytical tool, the conditional matrix, helps the researcher be sensitive to the range of conditions that impact the phenomenon. As shown in Figure 1, the inner nested circles pertain to conditional features that most closely impact action/interaction. The outer nested circles are those features most distant from action/interaction. The actions and interactions women with cancer perform/undertake/do exist within the domains of self, structural, comunity and national.

SELF

Obviously the disease occurs in the person and who she is, what her identity is helps form a lot of the ensuing actions/interactions. Although the disease occurs in the person, her roles in relationship to others are affected. Women have multiple roles in families. She is mother/spouse/partner/daughter and these roles can become problematic when the emotional and physical force of the illness become great. She may be unable to meet her child's needs because she is immediately and/or chronically burdened by the illness. She may feel a sense of responsibility and sadness as her family life is disrupted/ruptured by the cancer. She may experience relationship problems with her partner. Oftentimes negotiations must occur in order for her to fulfill her caretaker role. Alternatively, her spouse/partner and/or children can become a source of much-needed

help. She may rely on her mother to provide care that she has not needed since childhood. Her spouse/partner may have to assume some of the roles she has traditionally held within the family. Her roles outside the family can also become problematic. She may be unable to create income for herself and her family; likewise, she may be unable to continue her education at the pace she maintained previously. What she has done prior to diagnosis will have to be re-considered, re-contextualized.

For most of these women, the diagnosis of cancer will be her first experience with significant illness. She is unprepared; there may be no life experiences that she recognizes as being helpful to dealing with cancer. She may need to develop a new, or utilize a preexisting sense of agency that will enable her to do the work of cancer. Learning how to speak to doctors, becoming assertive about her needs, educating herself about cancer, obtaining information and resources that she needs, learning how to negotiate medical and/or alternative care are a list of the few tasks that can become salient to her. There are many tasks to learn, and her ability and desire to learn these or at least acknowledge them are dependent on many factors. For example, her physical and emotional health are indicators as to her level of ability/desire. Who she is, how she handles life's troubles impacts her ability/desire. Does she embrace chaos well, does she feel comfortable with new roles, new "issues?" Further, she may be unable to access certain aspects of agency because of her economic situation. Seeking a therapist to discuss fear of death and disability or anything else is an option if she can afford it.

Having direct exposure to persons with cancer either in their family or through their employment informs her own personal narrative. Perceptions of risk or previous thoughts of her susceptibility to cancer may materialize as issues of fear and guilt. This experience could provide a context through which to judge/understand her own experience. Decisions could be made based on this context.

The specter of death is common with a diagnosis of cancer and is a haunting hallmark of cancer. The future is jeopardized and hence discussions/thoughts about length

of life, quality of life, ways of living abound. My reading of the situation follows: If I die tomorrow, what will I have wanted to accomplish? How will I have wanted cancer to transform my life? What "good" can I make of this (sometimes awful) thing?

In summary, her life prior to cancer informs her life after/with/near cancer. Her choice of agency is impacted by who she is. Her ways of dealing with death, disability, and illness are shaped by her individual self.

STRUCTURAL

Of course, one does not live in a vacuum. Even when she must do so much work in her home, family, and self, structural elements of cancer become very important to her work. When diagnosed, she is thrust into the dominant discourse. Discourse "is used to refer primarily to language, but including other significations such as images and gestures, which are a part of particular field of activity such as health promotion" (Grace, 1995, p. 330). The treatment modalities of slash, burn, and poison seemingly become the only ways in which to heal her body. The first post-diagnosis step is that she is told to get an oncologist and this person will be in charge of her medical care. Usually she is not supported nor encouraged by this person in charge to seek other treatment modalities.

Where she is diagnosed and whether she receives an oncologist depends upon her type of medical insurance. For example, Toni was unable to maintain her student status when diagnosed. As a result, she lost the medical insurance provided by her university and she became a Medi-Cal member. Her status diminished, she had to learn how to access services that are not willingly and graciously given to Medi-Cal members. Further, because she is African American and is now receiving government services, she says, "...I'm not treated the same as (before)..." Medical insurance reflects one's status in this capitalist economy. And, medical insurance determines what type of care she receives. One of the participants is a Black woman who receives her care at an HMO that serves a large Black population. She has been writing to the HMO to complain about the care she

received during and after her mastectomy. Further, she believes "our doctors" do not get the current information on cancer treatments.

The many providers of medical care can become a source of confusion and frustration and can add to the overall burden of cancer. Some participants relay stories about receiving inadequate care from their providers. Sometimes the person is not heard, not prepared for the side effects of the treatment, not considered a thinking person, not cosidered capable of being smart enough to be an active member in her care. The Medi-Cal member above states that she is "constantly fighting...letting them know that" she's not a just a Medi-Cal patient. However, some of the providers have been very good to these women. "She makes me feel comfortable." "Some of them are nothing short of angels." "She [the doctor] listens to you." Again, the type of medical insurance allows or disallows these women to select different providers when they feel their needs aren't being met.

Another structural element is what I term the standard operating procedure. When diagnosed, she is advised to gather lots of information in the form of pathology reports and in the form of information newsletters from, for example, the American Cancer Society and National Cancer Institutes. It is recommended that she attend support groups for persons with cancer. Other resources include contacting women that have the same type of cancer. If she has breast cancer and undergoes a mastectomy, she is advised to hook up with Reach for Recovery to obtain the "falsies." It is assumed that information, others like her, others with cancer will be helpful to her. These participants spoke of having too much information and of scaring themselves by reading too many things. They spoke of wanting only to speak to persons with "positive" stories. Toni speaks of becoming terrified of support groups because "this is a room preparing to die."

Race and ethnicity are structural elements because they are socially constructed. An African American, Toni states, "You have to be really aggressive about straightening it out, these preconceived notions that some people have in the health care profession." Toni also states that she is "questioned about things I don't know if a white counterpart would be

questioned on..." Because Toni developed an addiction to the narcotics that were freely prescribed. This is a not-unexpected side effect when persons are prescribed narcotics for pain. She relates to me an incident in which pain medication prescribed to her came up missing from a pharmacy. Her doctors believed that she had sent someone into the pharmacy to pick up the prescription so that she could have another one ordered. "It was important for me to clear my name up." She was very vulnerable because she had admitted to the addiction and then the medication disappeared from the pharmacy. This incident might not have occurred if she had been white and/or wealthy.

COMMUNITY

The Bay Area is rich with support groups and organizations that provide various resources to women with cancer. These resources include support groups, low-cost therapy, non-Western biomedical treatment information and services, etc. Some of the participants either used or had heard of these resource centers.

Lobbying intensely about the increasing incidence of breast cancer in the Bay Area and nationwide is another function of these resources. There is social mobilization in the Bay Area, particularly around breast cancer. However, one of the participants was thrilled that I was doing a study about women with cancer. I inferred from her interview that she was not aware of the vast array of services, or that the services were not meaningful to her.

Grass-roots organizations deal with environmental racism and environmental toxins. They work hard to drum up community support for challenging the location of more toxic dump sites in the Bayview Hunter's Point area, for example.

NATIONAL

Recently the Federal government passed legislation that enables family members to take time off work to care for sick family members. They can do this without penalty from their employer. And, as of January 1, 1997, employees can change jobs without fear they will lose their insurance coverage because of a pre-existing condition. These benefits are helpful for families dealing with illnesses like cancer. People with chronic illnesses have in

the past had to stay at jobs in order to keep their insurance coverage. Medical insurance is increasingly becoming a luxury item and very few can afford to buy personal coverage for themselves and/or their families. These two laws reduce the punitive burden from chronic and acute illnesses.

Additionally, National Public Radio reported two weeks ago that HMOs are reconsidering the 48-hour stay payed by most providers following a mastectomy. This struck me because one of the participants who had had mastectomy 3 weeks prior to our interview was complaining about what she considered a too-short stay after her surgery.

There is a large national conversation occurring about preventing cancer and containing it. It is difficult to pick up any popular media and not see some new evidence that _____ prevents cancer. In fact, one of the participants had recently heard on the news that grapes fight cancer. As such, she will try to eat more grapes. However, the news that ____ prevents cancer will be followed by a story a few weeks from now that _____ doesn't prevent cancer. It is a confusing maelstrom of information that is ever-changing, ever-conflicting.

CORE ISSUES

Any attempt to list, cover or discuss the core issues in the analysis will, due to lack of time and space, be incomplete. However, I would like to list some of the categories, the issues I found, along with some of the data that prompted the codes and categories. I want to demonstrate a range of issues that were used in the development of the theories. One thesis is not enough space to analyze all these issues and construct theories about them. The following were selected based on the criteria that the supporting data would be compelling. I have provided subtitles and have included some of my comments.

Although the following is meant to be a partial listing of core issues, the following theories are derived partly from these issues.

INTERNAL

I am struck by how internal this process of identity formation and "handling" and "dealing with" and "discovering" cancer is. When faced with this disease, these women buckle down, think about who they are, whom they want to be, and all this work, this processing is done internally. Although some seek outside therapy as a way to "handle" and "deal," this kind of work is very internal. Also, it is independent of their medical and/or physical work. There are very few references to talking with partners, friends, family members, whomever about <u>this</u> work. Mathews et al (1994) conducted a study on Black women's narrative about advanced breast cancer and they report the same findings, "These narratives...contain very little commentary on the social roles played by others in the illness, most probably because others are excluded as much as possible from knowing about the condition..." (p. 792). In developing a Cancer Attitude Inventory, Berrenberg (1991) found isolation and rejection to be a "major problem" for patients with cancer (p. 36). As Mercedes says, *...just wanting to figure out what sort of future I had, what my life meant to me, so a lot of it was just internal, I didn't have anybody to speak with...*

Toni says, *...you know it's just this internal thing with me...* Pam tells me that she didn't know how to have conversations with people around her, because of lack of time, or lack of skills, or lack of connection with others. Olivia says, *...they could not be available to me ...I had actions I was taking, but it was pretty lonely...*

For Toni, the poverty and desperation she felt coupled with an ever-growing list of needs made me feel that she felt no one could address her physical needs, let alone her emotional needs.

> *...so, you know, it is frustrating and it's frus' you know it's frustrating because people, you know, they they don't really understand...the kind of support that you need, you know, it's it's just not always there and people just don't understand I mean, I couldn't say that I would understand if I hadn't had it, you know, if I hadn't gone through it myself, what people need, you know, just the amount of assistance and in so many different areas, you know, just through my own, you know, trying to create things to do for my son and uh you know just getting him to school, really just difficult, just having the basic stuff, let alone trying to create these things in my life was just almost impossible...*

UNIQUENESS

A diagnosis of cancer is unlike other diagnoses because the person with cancer is rarely free of cancer. Astrid beautifully describes this reality, when telling me about one of her conceptualizations of life with cancer which she calls *dancing with cancer. I really like (this) because it means the song will end and it will finish* . When Linda called me to set up an interview, she surprised me by saying that she finished her chemotherapy for breast cancer 9 years ago. I asked her about responding to a flyer entitled "Are you a woman living with cancer?" She said, *...if you have ever been diagnosed, you always think it*

could come back, and I think it changes your life... The persistence of a cancer diagnosis is well described.

Mercedes alludes to a differential aspect of cancer not related to its persistence. When I ask her how she's doing battling cancer, she asks me, *What am I going to judge it against?* There are few personal narratives that provide a framework with which to judge a diagnosis of cancer.

Not only is cancer unique among other diseases, individual cancers are unique, too. Muzzin (1994) also reports the differential nature of cancer experiences due to cancer producing "different physical and physiological effects..." (pg. 1204). In describing the metaphors that encumber the diseases of tuberculosis and cancer, Sontag (1990) describes tuberculosis as affecting the lungs, part of the "upper, spiritualized body" (p. 17), and cancer as "attacking parts of the body that are embarassing to acknowledge" (p. 17). Twenty years later, I found this sentiment among my population. Kelly was diagnosed with colorectal cancer. She feels hesitant to attend support groups because she feels that all the other women will have breast cancer; in fact, she thinks

> *it would be easier to be a woman with breast cancer than it would (to) be a woman with colon cancer...even though it [breast cancer] probably is more disfiguring, I don't know, it seems like a woman's thing, and you could talk to other women about it. And it's something women think about, even women who don't have breast cancer think about it and worry about it...feeling like I don't really have this to share with somebody.*

Even Kelly's prior fears did not include colon cancer: *I worried about ovarian cancer....I never thought about colon cancer.* After her lymphoma diagnosis, Pam provided self hope by thinking through a dimensional analysis of cancer severity:

> *And you know the idea of breast cancer, I mean, running the gamut of different kinds of things it could be from you know a lymphoma which is sort of not a big deal in the cancer world or certain kinds of lymphomas*

> *aren't as life-threatening to something that could be a systemic kind of you know leukemia or bone cancer or it coulda been, coulda been breast cancer, um how many nodes were involved, da-de-da-da-da.*

By thinking about all kinds of cancer, she felt reassured because lymphoma has a relatively *charming prognosis.*

Latrivet extends this not-all-cancer-is-the-same idea into treatment. When she was paired up with another woman for support who had breast cancer shortly after diagnosis, she realized that the other woman had a lumpectomy and not mastectomy as Latrivet did. She told me,

> *...but I didn't feel as ah connected with her in that we went through, it's the same thing, but you, you, you're going through it differently...She had a lumpectomy, which is only you losing part of it, but it's still there, but then I lost the whole thing...*

The part is not the whole.

Astrid and Olivia provide another range of variation of uniqueness. Both chose "alternative therapies," either as the only therapy or as an adjunct to Western biomedical therapy. While not entirely similar in thinking about or approach to cancer treatment, both women view cancer as being a response of a body to emotional, spiritual, psychic pain. Astrid describes her cancer as *the situation I've created in myself...*

Many women attended support groups. When asked what advice these women would give to other women newly-diagnosed with cancer, some described with great clarity the importance of selecting the right support group. In one instance, this meant selecting a support group consisting of people in a similar illness phase. For example, Toni says:

> *I don't think they should just let people loose with these support groups (she's laughing)... I mean walking in cold and going into that group I just, I never, I never cried so hard in my life and there was, I was paralyzed when*

I left that group, I just, because all I, that's what I then thought was going to happen to me...and then when I went to a long-term or survivors or a living with cancer, was full of primarily long-term survivors, most of those people had been in remission for years and years and years, you know it was like, well, okay they're okay, I can be okay <mm> you know, you didn't have to like look around the room and find somebody okay, they were okay for the most part and they still knew that they had cancer and could have conversations with you about where you were at and give you assistance and support without having to walk around with that fear that, you know, this woman across from me is going to be dead, I don't want to sha', I didn't want to open up I didn't want to get close to anybody in that room I, I, I was not ready to get close to anybody in that room because they really, to me everybody in there even was, if they looked healthy, it just was like, everybody in this room's gonna d', this is a room preparing to die <mm> and I don't wanna, I don't wanna deal with this, I don't want to come back here.

Eleanor feels similarly about support groups. She has been a member of a newly-diagnosed support group for about a year. Most of the original members are seeking to redefine the group as the needs of newer members do not adequately reflect the needs of the women who have been post diagnosis for 1-1 1/2 years.

Kelly and Mercedes both spoke of the differences between being a lesbian with cancer and a heterosexual woman with cancer. Kelly said,

...I thought it would be really, I think, to be a heterosexual woman having this huge scar down the middle of you. I mean, not all men are like that, but men can be more like that, focused on the woman's body being perfect, than women...

Because Mercedes' female partner left her shortly after diagnosis, Mercedes thinks it is harder to be a lesbian with cancer. She says,

> *I think that it would be more accepting in a heterosexual um realm than it is in the homosexual one, I think, I think a male would be much more accepting, because, you know, men want to be strong and they want to protect the woman, right, so, I think, I think they would be willing to accept that much more than I think it as a woman...*

ROLES

Women have a myriad of roles. One of their most important is caretaking of themselves and their families. Oftentimes this caretaking manifested as protecting family/friends from the contingencies of cancer. For example, Toni said to her boyfriend,

> *I was like there's no way I'm going to marry you, you know, um because even though, I guess somewhere in my mind I was thinking about it, like, why would you marry somebody you don't even know if they're going to be alive?*

Pam's sister had cancer 16 years prior; she says,

> *I was really afraid to tell her specifically because I didn't want to bring up all of her painful stuff, uh and I told her this is real-, when I told her I says this is really hard because I don't want this to trigger all sorts of, a flood of old, bad emotions that you've dealt with or tucked away, um and she was okay about that, I guess, you know, that's what she says um,...*

Latrivet likewise didn't want to upset her favorite uncle,

> *I just couldn't bring myself to tell him at that time because he was so happy..and it just seemed like I was just gonna, well, it wasn', well, I was gonna be giving him bad news if I told him right then, so I waited a couple days and I called and told him...*

One of Linda's daughters was 26 at the time of her diagnosis. Linda believes her daughter's husband is less than supportive of her daughter, especially around her fear about her mom's potential death. As a result, her daughter *...end(ed) up talking to me, probably at times when I couldn't be a heck of a lot of support because I was so much in my own thing.* Eleanor's teenage daughter has *been really knocked.* When Eleanor heard her crying in her room one night, she *put her in the rocking chair she had when she was a baby, and she'd sit in my lap and I just would hold her...there's nothing I could do...* While Eleanor's time of initial diagnosis and surgery were relatively easier on her family, her first round of chemotherapy was terrible. *I felt bad for them (her family), and I also felt then that at that point I just could not...there was not much left of me to take care of them and help them.*

A single mother, Toni has had a difficult time meeting the needs of her 7-year-old son:

> *So, um, that's, that's been the biggest challenge for me is trying to keep his life (her son's) normal or as stable as possible and that's, that has just been so incredibly hard, you know just mustering the energy when you just don't have it...and then try to fix something to eat, or try to read a story and try to plan, create some fun and you're not having fun you know so many times I just wanted to send him somewhere to stay with someone else, you know, someone else or another family member or something, but then I thought that that would probably, maybe be worse, because I just, it's really the hardest thing that I deal with, is just him and making it happen, you know, just getting him dressed and ready for school, some days, it's like how am I going to do this? I don't have a clue how I'm going to roll myself up out of this bed and get him fed and to school, let alone anything else, so..um..that's, that's the biggest thing that I deal with..even today.*

Latrivet lives with her four children, her mother and stepfather. When I went to her house for the interview, I saw her stepfather lying in a hospital bed in the living room; he had a stroke 4 years ago. During our conversation, Latrivet told me how shortly after her mastectomy, her inability to care for herself added more caregiving work on her mother who already provided care to her husband.

DISPARITY

These stories were, without fail, the most difficult things for me to hear, analyze, digest. There were many words about the mismatch between what women expected and/or anticipated and what occurred. They were uncertain and frustrated by a myriad of things. There is a discrepancy between what Toni expects and what providers do/know; and she explicitly identifies this as a *big old problem for me.*

Muzzin (1994) conducted a study on persons with cancer in Canada and found a preponderance of unmet needs. "These unmet needs include desire for information about the disease, treatment side effects, giving injections and prostheses; ventilation of feelings and dealing with fear or recurrence, spiritual help, pain, sleep, respite or time away from caregiving" (p.1202).

Much disparity was experienced when dealing with treatment and/or its side effects. Pam struggles with symptoms created by treatment,

> *but when I needed help from her to help me with hair, the hair loss or the fact they didn't tell me my eyebrows were going to fall out or my eyelashes and the rest of my you know hair anywhere else you can think of [we laugh] um, they never said a word about that um...*

Mercedes is extremely articulate about her providers not sharing information about potential side effects. She says this at the end of a story about unanticipated side effects from radiation therapy for her thyroid carcinoma: *so I have to really be cautious, I was never*

told that this may happen to me um, you know so in that, in that sense, it seems like you're kinda losing grip on reality.

Two women spoke explicitly about being shocked at the diagnosis. Some couldn't believe it because they didn't feel sick. As Latrivet said, *I couldn't believe, I thought he was talking about somebody else, I even told him, I said, 'You're not talking about me, I'm not sick, I work every day, I go to school every day, I'm making good grades in school. You talk', you talking about somebody else.'* Toni said, *This is a mistake.*

The physical act of medical care became problematic. Toni recalls her struggle with home medical care, *...[her physician] sent me home to...take care of my wounds only..she didn't tell me what it was going to look like...* Later,

> *I went in the bathroom to fix the wound and I started taking the tape off and I..never seen anything like this before and I fainted because it was just flesh hanging out, I mean I could see down into the bone and sh' they had expected me to be able to clean this, and I remember sitting in the bathroom the first, I only glimpsed at it for a moment and I just got hot and I never fainted before in my life...*

Latrivet talks about the inherent contradiction of chemotherapy,

> *And I've seen a lot of people die from cancer that the chemotherapy helps, helps them die. Because you're so tired..you don't want to do anything and if you're tired and don't want to do anything, you don't have that..extra push there, extra willpower there...*

As is often heard, the treatment is worse than the disease. Sontag (1990) describes this as being the result of the "language of warfare" (p. 64) surrounding cancer. Because the body with cancer is "considered to be under attack, the only treatment is counterattack" (p. 64).

BEING CONSTRUCTED

These women were constructed in many ways. For example, Toni was constructed by providers in the medical setting because she lost her position as a person with "good" medical insurance. She became very poor at the time of diagnosis and is now a Medi-Cal member. She shares with me the frustration she has about the vigilance she must maintain in order to be respected:

> *and and so there was a change in the treatment and so I'm constantly fighting or, you know, or letting them know that uh that's not who I am, you know, it gets tiring, it gets tiring, you know, sometimes I find myself you know letting them know that I have knowledge of medical terminology, that I do not need to be you know condescended to, they don't have to tell me they're going to do 'a little procedure' or we're just gonna make it, explain everything in, like, you know, use baby words so that my little baby brain can understand it (laughs) so you know I'm constantly you know on guard you know letting them know that you know, wait a minute, I'm not to be dismissed, I hate being on state care and I'm not just this typical (she laughs) what ever that means, welfare, AFDC-loving person, this is, and how you know quick they are to make certain assumptions you have to really be aggressive about straightening it out, these preconceived notions that some people have in uh the health care profession about who I am as soon as I walk through the door <mm> um..um..*

Pam was fearful about people in her work environment knowing about her cancer because she wanted to protect herself from becoming part of the *gossip mill.* According to Muzzin (1994), social stigma is attached to a label of cancer; "it is understandable that individuals might try to 'deny' their diagnosis in public, or when, for example, they are with coworkers" (p. 1202). Sontag agrees (1977): "Since getting cancer can be a scandal

that jeopardizes one's love life, one's chance of promotion, even one's job, patients who know what they have tend to be extremely prudish, if not outright secretive, about their disease" (p. 8). Pam says:

> *I was pretty private about who I told and I really didn't want people I worked with to uh really poking around in my private life and a lot of people I worked with had zero respect for that and made it, made a, you know, I was getting e-mail from people I didn't even know saying, oh, I hear you're seriously ill, I mean not a lot of respect going on there...*

Prior to her diagnosis with colon cancer, Kelly had been starting paperwork around getting pregnant. A lesbian, she was beginning conversations about how to get pregnant. After diagnosis, Kelly approached this subject again with one of her doctors. Kelly believes she was discouraged from trying to get pregnant because she has a uterine fibroid and was diagnosed with cancer. The endocrinologist asked her if she had thought about what would happen if Kelly would leave an orphan. As Kelly says, *If I was a heterosexual woman who was postoperative and having sex with my partner (she) wouldn't be able to ask me these questions.*

UBIQUITY OF BIOMEDICINE

One of the interesting themes is how well the national discourse of cancer surveillance, detection and treatment is inculcated in these women. Latrivet expressly states that she got a second opinion about her biopsy results, even though *she knew he [the first doctor] probably was right...* Further, three of the women noticed a difference in their breasts that prompted the medical intervention. These women knew that feeling a difference in breast tissue warrants a call to the physician. Catching cancer early is part of the conversation about "beating cancer" that some people, including some of the participants, believe in. Particularly for the women with breast cancer, "catching it early" is

the key to successful treatment. Latrivet provides a stunning example of how this information works in her mind. She realizes there will be a week between the biopsy that identified her cancer as *very aggressive* and *growing rapidly* and the surgery date. She is concerned about the delay and asks her doctor, *...if we wait...how can you be sure that it's not gonna spread any place else?*

Due to the nature of breast cancer and its spread to nearby lymph nodes, the participants with breast cancer were articulate about the fear that their cancer will spread. There is a difference in cancer that is localized and one that is widespread. It was as if once faced with the threat of cancer, the absolute next insult would be for it to spread. Toni explains,

> *I think that I wasn't afraid (when they told her she had cancer), but when they did tell me that it had spread to my lymph nodes, that kind of got me...that I have to say still was the little thing that gnaws me...when something's wrong, I think, please...don't let it spread, don't let it spread, don't let it spread...I'll deal with the cancer but just don't let it spread.*

Toni was asked what advice she would give to a woman in her condition of being diagnosed with an aggressive form of breast cancer. She believes that the woman should do what the doctors tell her and have the breast removed, because *you don't want to take a chance on it going to other parts of the body...*

TWO THEORIES

THEORY #1: WOMEN LIVE CANCER

This is the first theory I worked out about this research. It is not especially deep; however, it is a good first theory for a first-time researcher.

The following is a basic social process that describes the process of living cancer. In fact, O'Connor (1990) writes that "learning to live with the cancer was an important aspect of these patients' search for meaning. All of the respondents described at least one action, belief, or attitude that helped them participate in life despite the cancer diagnosis" (p. 172). I purposely leave out a preposition to encourage me and the reader to broaden our thinking about the ways in which one can live cancer: she can live with cancer, live in spite of cancer, live subsumed by cancer, live next to cancer, live sadly with cancer, live in control of cancer, live against cancer, and so on.

Categories are constructed by grouping concepts that seem to be related to the same phenomenon. "Categories have conceptual power because they are able to pull together around them other groups of concepts or subcategories" (Strauss & Corbin, 1990, p. 65). As I worked with the concepts, I became aware that some of these were tools. These tools, either already present or newly created, become what she uses (or chooses not to use) to live cancer. These tools that are selected, evaluated and modified help form the range of variation of the preposition. As a quick example, metaphorizing cancer as a bad dream is using metaphor construction as a tool that more easily allows her to maintain a state of temporary denial. In this case, she would be living unaware of or in denial of cancer.

Figure 2 is a schema of this theory. Grossly, I divided these tools into action/physical tools and emotional tools. Obviously a lot of tools were both physical and emotional. Under action tools, I considered things she does while living cancer. For example, she may seek the benefit of a therapist to deal with emotional stuff; she does her medical appointments and therapy; she seeks the benefit of alternative healers; she changes

lifestyle habits like diet. Three of the participants volunteer at local cancer support centers in order to share their experiences with newly-diagnosed women. One woman wrote a letter to Congress stating the medicinal benefits of marijuana use.

Under emotional tools, I considered things she thinks about and the ways in which she conceptualizes cancer: metaphor construction, drawing on prior illness experiences, constructing games that become predictive of longevity. For example, Olivia realizes that her fear of cancer helped precipitate her skin cancer. Mercedes creates different animated conceptual pictures in order to deal with cancer. Astrid's knowledge of cancer is that she *created* cancer in order to be able to better hear herself about taking better care of herself. Latrivet visualizes Pac Men eating cancer cells. She also pictures herself shooting at clowns, as if in a carnival; the clowns are the cancer cells and the carnival is her body.

Metaphor construction deserves its own discussion. Metaphor is meaningful because "one aspect of experience is invigorated by another" (Radley, 1993, p. 112). The significance of metaphors, according to Radley (1993), is not in the comparison, as it is in the "reflecting one reality through another" (p. 113). When Mercedes thinks of cancer as a 2-year-old child--*...'cause a 2-year-old child, they're always crying and nagging and they're just all over the place and they get into things* --she provides a different reality for cancer. According to Mathews (1994), "Lakoff reports that metaphors serve an important mapping function in cognition by introductin information from physical world source domains into target domains in the nonphysical world..." (794). A prescinding metaphor is one in which the abstract becomes tangible. For Pam, the new life she will undertake after diagnosis is abstract and ungraspable; she constructs a film metaphor in order to make tangible the future.

All these women discussed with me how they provide a utility to the diagnosis of cancer. As Latrivet says, *It's a wake-up call, it's time for you to come out of the darkness you been in.* Pam is interested in developing ways of integrating balance into her life post-diagnosis. Linda says that after 9 years, she is *right here today, I'm right here today. I*

used to fret things more in the past. That's definitely gone. Astrid says, *Everything became real clear to me.* They develop explanations for themselves that encompass utility, thereby allowing a cancer diagnosis to be constructive.

One of the tools that can be both action and emotion is signifying/designifying. Pam says, *I'm not going to be one of these anniversary people because I really don't want to think about that stuff.* She is referring to how she doesn't keep track of dates, therapies, or emotions during treatments. On the other hand, Mercedes keeps track of everything. Another of these dually-placed tools is disclosure. Disclosure can be for emotional reasons, as when Toni tells me she tells *anyone who would listen.* Disclosure can also be for very practical reasons like getting time off work. Kelly and Latrivet had to inform their jobs so that they could be excused from work. Eleanor's friends constructed a massive phone tree to enable her friends to have information and to provide meals. When anything significant happened, they mobilized the phone tree, so that Eleanor and her immediate family didn't have to answer *400 phone calls.*

While these tools are being used, they are continually being evaluated and modified. One of the action tools I have named is standard operating procedure. I mean this term to encompass all the things women are told to do once diagnosed, a sort of post-diagnosis discourse: read literature, educate herself, get a copy of the pathologist's report, go to support groups, call certain resource centers. Some of these she will choose to do and others she will not choose to do. Even though she may choose to go to support group meetings, she may not find these to be particularly helpful. Toni says about support groups,

> *...I don't think I got afraid until I would go to some of those support groups and things like that and I, I would look around the room or I'd hear people sharing and I, this person is sick or someone had died or um..someone had been in remission and they came out and that's why I stopped going to support groups cause it just, it was like I didn't feel that*

way and and when I would see it then all of a sudden I would...THEN I would become afraid...

Latrivet talks about reading the pathologist's report and becoming scared and,

I've got this um um copy of my pathology report and I kind of think, it's a good idea to know what's going on with you, with your body after, you know, you have your surgery and how many lymph nodes were found and the bigness of the tumor and how many tumors and if it has spread or things like that, but you can know too much. And I think when they give you those copies of those papers and everything and you want to kn-, is so many things on there you wanna know...you just um get 'em and go over 'em and over 'em and over 'em and over 'em and you, you, you conjure up ideas in your head, what they might mean, but then it could mean this, too, and it's, sometimes it's more depressing than helpful, 'cause I, I have a copy of both mine... And further, *I asked for 'em...see I was like focusing on the numbers a lot, like how many centimeters it was, like they, they took out 2 tumors, and one was like 1 to 2, I mean 0 to 1 centimeter, and by the time they took it out, it was 1.5. And, the other one was between 2 and 3, and it was 3.5 when they took it out, so to me, I was sad...but right now, I'm just, I have them over in the corner and I'm not even looking at 'em. It said, even said something about metas-, metastic, and you know what metastic means is, it's not just in one place, it's spread, so I saw that and I, I started thinking about that and I started thinking about um even, even from this literature that I would get from the NCI, about th-, it can spread to the liver, the lungs, the brain, and places like that, I stopped looking at those, because my, it would seem like my, my imagination was just like, getting the best of me...*

When asked what advice she would give a woman with cancer, Latrivet, without hesitation, tells me, *I would not look at the pathologist's report.*

Pam, a self-described metaphor enthusiast, provided the best example of evaluating and changing an emotional tool. She used a film metaphor to capture her desired cancer experience. Because of her sister, Pam had pre-existing knowledge from which she could design and select from options about how she would live with cancer. She decided the time period, which she named 6 months, between diagnosis and some "end" would be spliced out of the film of her life. During this 6 months a lot would be different; she and her husband would have to renegotiate their lives, but when this cancer period was over, she would cut out this piece and the film of her life would be unchanged by cancer. *So I'd have conversations, like, with [her husband] about how, well, this is just, this is gonna be a bad six months to a year....* She attempted to design a 6-month mini-exile, so that she could take care of cancer and <u>then</u> return to her normal life.

However, after more involvement with her own illness, she realized that she was incapable or unwilling to do that. She was unwilling to splice out the cancer film. Sometime into her designated 6 months, she decided that the film couldn't be spliced back together because the style of the "cancer" film would necessarily affect the style of the later (post-cancer) film, and the splicing couldn't be smooth. *You can't do it because the director is different, the colors of the film are different, the actors have changed their life motivations, you can't put it back together...* In so much as slicing out a cancerous tumor <u>may</u> remove the entire cancer and leave the body "healthy," slicing out the cancer experience does not remove it entirely and cannot leave the future film unaffected

Because these women are individuals with individual contexts, each narrates her experiences differently. Her beliefs and access are shaped by her race, ethnicity, class, sexual orientation, and other things that make her identity. Astrid believes she created cancer and wants to make this cancer experience a positive one. In fact, she views her

second recurrence as *the last time I need to go through this...* Linda, on the other hand, grew angry while talking about the other discourses on healing, like self-healing:

> *I've seen so many people who wanted to live and did everything they could from meditation to alternative, and not be able to heal themselves, and there was some sort of thing put on them that they didn't try to heal themselves.*

Further, these women do not have the same access to tools, nor do they have the same beliefs about the utility of certain tools. For example, it is more easy and do-able to change physicians if one has good medical insurance. One is able to see a therapist if one can afford it. One is able to metaphor-ize cancer if she has the time, space, inclination and luxury to do so.

THEORY #2: THE EXPERIENCES OF DISPLACEMENT

My initial thinking about exile/displacement was prompted by two particularly articulate stories: one, a metaphor about splicing the experiences with cancer from the film of life; and, two, a belief that when survival time was long enough, "return" to family could occur. I became interested in which experiences of cancer may be described as exile or, my more recent thinking, displacement. I use the term displacement to be descriptive of the experiences of a woman's life being altered in such a way as to rupture her expected, normative life. Being unworthy, undeserving or incapable of normalcy creates displacement. It can be as overt as being unable to mother in the same way, and as subtle as being unable to talk about her illness processes in a way she finds meaningful. Exile may be a useful term to describe extreme displacement, that is, a physical rupturing process where she is so displaced as to be <u>removed</u> from her normal life. When sufficiently convinced these concepts were in my earlier data, I added to my research questions during later interviews how her primary relationships have changed, how people react differently to her, and how she feels differently about herself.

Others have described similar phenomena; Strauss, et al (1984), termed this "pulling away" (p. 75). This pulling away is the result of the illness trajectory (see above for definition) and the social contingencies of the disease. These authors list symptom burden, changed appearance and unresponsive friends/family as causing social isolation. They describe the potential reasons friends/family may withdraw: interactional awkwardness, torture of a visit, cannot face the physical change, and/or cannot speak of dying (p. 77).

Figure 3 provides a pictorial representation of this analysis. In order to speak of displacement, I must describe that from which she is displaced. I select the less-than-extravagant term "normal life" to encompass her life prior to cancer. It comprises many of her subjective and objective elements: feelings, expectations, thoughts, hopes, fears, ways of being in the world, roles, duties, conceptions of self, etc. For each of the women, her normal life is, of course, determined by her individual context which is informed by her race, ethnicity, sexual orientation, class, ability, etc.

The mediators of this displacement are the factors which displace her. These can be named as physical body, personal and social expectations and interpretation. The following definitions will elucidate how these mediate displacement. Physical body is meant to be descriptive of the changes in her physical self that become indicative of a non-normal existence. This changed body, by now having a disease and by now looking different, requires different negotiations through her new life with cancer. Interpretation is meant to be descriptive of how her personal illness meanings are not given proper voice and/or space. However, before one is led to believe that interpretation is merely a relational problem, it must be mentioned that her own personal meaning of cancer may be self-alienating. Personal and social expectations is meant to allow me to discuss how there is an oftentimes painful disparity between what each woman can be and what others (and herself) expect her to be. Kaspar (1994) performed lengthy interviews with 29 women who lived through a breast cancer crisis. She writes of competing public and private

meanings of living with breast cancer; "women encounter varying life experiences in which the rupture occurs and where the distinctions between culturally-imposed themes and personal meanings become particularly clear" (p. 245). Further, the social assumptions made about women (living with cancer) "no longer match their own interior definition of what it means to be a woman" (p. 245).

After discussing each mediator in detail, I will discuss the importance of a threatened future that is so palpable when given a diagnosis of cancer. It is worth mentioning that certain aspects of each of the other three mediators will be seen when discussing a threatened future. The decision to pull out and discuss a threatened future is not intended to imply that it can be separated from the other mediators. Each is informed by and informs the others.

THE MEDIATORS OF DISPLACEMENT

THE PHYSICAL BODY

The best place from which to start this analysis is, of course, at the beginning. Upon diagnosis, many of the participants experienced a displacement from knowledge of her own body. These women did not feel sick, yet were given a medical diagnosis of cancer, one of the most dreaded diseases. Because the typical, characteristic invisible cancer symptoms are found through medical means--"an opaque body that must be taken to a specialist to find out if it has cancer" (Sontag, 1990, p. 12)--a process starts very early whereby these women were displaced from knowledge of their bodies. As Latrivet said,

> *I couldn't believe, I thought he was talking about somebody else, I even told him, I said, 'You're not talking about me, I'm not sick, I work every day, I go to school every day, I'm making good grades in school. You talk', you talking about somebody else.'*

Toni said, *This is a mistake.* Eleanor said, *Well, I think when she did the magnification views I was in a state of shock, and I wasn't--I was just saying well, this really can't be me. This doesn't happen.* After recklessly given a diagnosis of thyroid cancer, Mercedes said, *...this isn't real and I just like, I just bolted out of there...*

In Illness and Self in Society, Herzlich and Pierret (1984) describe this separation from knowledge of one's body. The person is no longer in control of the knowledge of her body. Disease is, by definition, a disorder of the body; however, a designation of diseased need not necessarily be descriptive of one's embodied experience. Note Latrivet's words, *you talking about somebody else.* So begins the rupturing process of cancer. However, from diagnosis forward, the disembodied disease will (hopefully) become the embodied illness. As the disease becomes embodied, other factors will increase further displacement.

One of the attendant consequences of cancer and especially its treatment is a change in appearances. Most of the participants expressed the inherent struggles in dealing with a changed appearance. For some, the changed appearance caused others to think of them differently. And, she sometimes thought differently of herself. For others, the changed appearance affected the ways in which they might meet new people. And for still others, changed appearance transformed the previously private cancer into a public cancer.

Both single at the time of the interview, Kelly and Mercedes talk about their changed appearance, especially in terms of meeting new people. Mercedes talks of the barrier the scar across her neck has created:

> *Yeah, I mean, that's the way I feel, you know I try not to wear anything real revealing sometimes I do, sometimes people just come over here and look at me and I'm like, oh, boy, whatever...*

She attempts to hide the scar in an attempt to cover her difference. Kelly also speaks of her scar:

> *So, then I started thinking about, like, dating people again, When would you tell someboedy that you had cancer? And then I have this big, huge scar down, it's like a 7-inch scar, you know, down the middle of me.*

These women are describing how formerly casual contacts have now become heavy with negotiations.

An appearance change can become a signifier of wellness or illness to others as well as to herself. She becomes displaced from the right to decide how she feels. When Toni started looking better, her son

> *was like, 'Okay, she's back to normal, she's okay, she's, let's go, let's go' and or 'Mommy, when are you going to cook' you know, or whereas you know before when I guess I looked sick or whatever he was, you know, probably still thinking it but, probably didn't expect me to get up and do it and uh, but you know he had needs, and needs to be met, I looked okay to him so you know...*

Her son used how she looked to determine if things could be normal. Note his words *she's back to normal;* even he recognizes that things are not normal because his mom is not doing normal mom things like cook. Her changed appearance can also signify her state of health to herself. We assume that how we feel will be closely matched with how we look when we look at ourselves in a mirror. There is a direct, consistent relationship between what we look like and how we feel. For Astrid, however, her appearance is betraying how she feels. She says when looking in the mirror, *You may feel okay, but you look like you're dying.*

Pam speaks to the displacement changed appearances and the associated reactions of others can create. She struggled with being constructed as gay by others. She says:

> *having hair this short and having a kind of personality I have makes certain kinds of political statements that aren't by choice exactly so I have a lot of people who think I'm gay...it's like anybody thinking you're anything that*

you're not, you know, it'd be like if somebody were gay suddenly had to like look like Martha Stewart for 6 months, it's not your choice..um.. I try to live inside my body, not out here looking at myself..um...'cause I think if you get out there looking at yourself, you create, you just, you fracture yourself into a thousand pieces about well...

What is also interesting about Pam's struggle with construction by others is her experience with her sister's Hodgkins disease about 16 years ago. Dealing with the changes in her sister's hair wrought by chemotherapy at age 19 became a powerful lens through which to judge her own hair loss. It also provides us with a stunning example of how prior illness experiences can manifest. She says,

... I guess my associations with cancer were that it's horrible frightening shit uh, it's, well my sister's hair loss, I distinctly remember that. She came to visit me at school and her hair, she had long, long red hair, very pretty red hair, um but she was in such denial that she couldn't accept the fact that her hair was falling out and she wanted to come visit me at school, I was in college, in the middle of her hair falling out process to go to parties, yeah, she was 16, I was 18, or she was 17 and I was 19, so she comes to visit me at school and you know it's a college dorm and her hair, her part went from this like, you know, normal part line to like an inch to 2 inches right in front of my eyes, it kept falling out and my roommates and this whole college scene was going on and I was just like, the degree to which she was unaware and how public..despite her, her denial made all of it so public and so raw, an' finally and I, I didn't know what to do, you know, what? as a kid, I was 19, what did I know? The pity that she evoked from other people and the pity I felt um I just wanted to get her home to get her, to make it less public for both of us...

Beyond these interpretations of physical changes, the simple fact is that a body altered by surgery is a different body. And these women experience their new bodies as different. Toni describes her body as *one mutiliated breast and the other one has tubes in it.* Eleanor had a mastectomy. She says,

> *And if you have to have surgery, whether you have a lumpectomy or a mastectomy, body-altering surgery, it's very oppressive. But it's right there, right in front of you, and society's so obessed with the breasts. No one's obsessed with prostate, liver, their lungs.*

Reading Eleanor's statement about the privileged (oppressive?) position of the breasts allows us to contrast the multiplicity of these women's feelings about different body parts. Kelly is very upset about her scar from surgery for colorectal cancer. And, she further states *that I think, to be a heterosexual woman having this huge scar down the middle of you. I mean...men can be more like that, focused on the woman's body...*

Some appearance changes are more easily hidden than others; some can allow the cancer to remain private for longer. Eleanor describes this, *So, I think in that way, cancer didn't become that public until I lost my hair.* Because Eleanor works with children, she wore a wig to work. *But it was just too hard to have..[the children ask] 'Why doesn't she have hair, mommy?' We didn't want to scare anyone.* For Astrid, recognizing the power of vanity about her hair was liberating; when I interviewed Astrid, she was bald and beautiful.

> *I had 36 triple E breasts, so I had huge breasts, and I was overweight, and I had blonde hair, which I had been coloring for twenty years and thought it was really still blond. And, then, vanity, it's much more destructive than any chemotherapy, and when I lost my hair, I thought I was going to die. That was the first time I would, like, look in the mirror and go, You might feel okay, but you look like you're dying! It was all fine and dandy until*

my hair fell out, I had a really hard time. So vanity was the biggest issue with me with my hair.

INTERPRETATION

Again, interpreation, is meant to provide a way to think about how her personal constructions of illness meaning are not given proper voice and/or space. The first line along which I will discuss this mediator is how these women were not engaged in meaningful ways. Mercedes provided the aforementioned second example that started my thinking along these lines of displacement. Her experience with exile (and I believe exile is the appropriate term in this case, rather than displacement) is the result of the inability of others to interact with her in a meaningful way. Because of multiple complex reasons, she and her family have been estranged during her nearly 5 year experience with thyroid cancer. In response to a question about whether her family knows about her diagnosis, she replies,

> *...they know, they know, they don't call, they don't write, they don't visit me, I, I do all of that, you know, but that's gonna change and I think that's changing slowly just because they know at...5 years, my.. you know, the ability, the longevity will increase, if you don't have a reoccurrence within 5 years, you know, you're guaranteed at least another 15 or 20 years um so, the warranty is almost there, yeah, so, maybe it just takes time for them, you know, it's just, we all have weaknesses and I feel that's their weakness in life so um I don't put them down, you know, at all, I'm very sorry that they don't speak to me about it, because I really do need their support, but they just, they just can't handle it.....*

She understands her exile will soon be *over*. Her journey is successful because she will survive 5 years and be able to re-enter a life with her family.

Embracing the idea that disease is the result of psychological phenomena, Astrid believes that she is:

> *the kind of person who is very tied into my emotions, so that's a good part of what I believe is the situation I've created in myself, which means a lesson that brings me to a higher level spiritually or evolving as a human being.*

Because of Astrid's unique outlook on her cancer diagnosis (she created cancer in herself), she has had to work very hard to surround herself with people who will allow her to have *a positive* cancer experience. She says, *I really felt like I was on a divine path through the whole experience, and it was, I would say one hundred percent positive. I made it that way.* When others do not allow her to speak positively during support group meetings, she says, *I find it slightly annoying that people don't allow me to have this be a positive experience for myself.* Whereas Sontag describes psychologizing disease as a means of burdening the person with the disease (1990), Astrid believes psychologizing a disease to be more reflective of her personal construction of the meanings of illness.

Pam, like many of the participants in this study, desires cancer to be a transformative experience. Pam feels displacement from her own rights to describe her cancer experience to family members. She is displaced from her own narrative because her family is unable to hear the words she longs to speak about her illness. She feels unable to have conversations with family members and friends about the processes she is undertaking. *...if they'd slow down, they'd find I'm working hard to have things be different...* She realized that she wanted to be different during her illness and ultimately wanted a transformative experience:

> *Cancer, because it does smack you in the face and draw you up and, and, and make you aware of how um unpredictable and fragile life is..um..it brings everything into focus in a big way um so the whole, the camera angles are tighter and sharper..um..Th- I don't want this film to have the*

drama and pace and frenetic quality that my life had before...I want this film to be more about the big moments...

"Things" will be different because she is developing new ways of accomplishing tasks, creating new ways of being in the world, and reprioritizing goals. For example, as a result of her diagnosis and her decisions, she feels it is relatively unimportant to carry on the social niceties she used to easily handle. While tentatively embracing her ideal of a transformative experience, she realizes that her family is unable to be with her as she struggles to identify, embrace, embody, her transformed self.

The following story will be illustrative of the second line of thinking of interpretation as mediator; it will demonstrate that the actions and reactions of others prompted me to think about the ownership of the details of cancer, I wondered whose cancer is it, anyway? During a regular holiday routine, Pam, her husband and their new baby were visiting her family for Christmas. Pam's mother decided to take a family photo of Pam and the grandchildren. Pam didn't want to be in the picture, partly due to her appearance and partly due to her new commitment to the *big moments*. When she tried to explain this to her mom, she was stunned to hear her mother's reply: *And she (her mom) said, well, you could wear your wig. I was like, and what wig would that be?* And not only is she not having conversations with her family, her mother (at least) has applied a narrative to her that is someone else's. Whose cancer story is it anyway?

Because Olivia believes humans are spiritual, emotional, psychic and physical beings, her personal construction of disease is recognizing that a disease is far more than a physical dysfunction. Therefore, healing a disease requires more than biomedicine. As such, Olivia spent much energy and resources finding "alternative" ways of healing: movement therapy, herbal remedies, spiritual books and tapes, etc. She rejected Western biomedical treatment. She felt alienated by others: *...but most people, you know, (said) I had better do what they (the doctors) tell me..* and these people *pulled away, I can see that*

people's fear of death or people's own fear of cancer, they could not be available for me and that was actually harder to deal with...it was pretty lonely...

Linda's construction of the meanings of illness involve believing she had done it to herself. In contrast to Astrid's belief that her cancer is the result of her own actions and that it provides an opportunity to grow and learn, Linda believes she did something wrong, got cancer and *did it* to her family. Linda is particularly sad when describing what she has done to her family. She felt incredibly guilty about *doing it* to her daughters, her mate, her parents. Her assumed roles of being a dutiful mother, dutiful daughter and dutiful partner are challenged as she accepts the realization that she might die. She felt she put her partner in *fear of losing me,* and she felt her parents had already been through so much in their lives. A diagnosis of cancer had threatened her ability to be the kind of woman she had historically been and had intended to be.

Another line of analysis involves a simple interpretation of illness as increasing the number of needs of some of the women in my study. This is not so much a matter of a personal construction of the meaning of illness; however, I believe it belongs in this section because the increasing needs are not met. Toni says,

> *...cancer is just, seems to be one part of it, at some point it's all the other stuff that goes along with it: lack in income, lack of ability to create income, lack of um, you know, self esteem...*

For Toni, who has been schooled in the potential use of support groups and accessing resources in her community (she regularly although infrequently visits local cancer support centers), she finds her position with respect to her needs as being not understood. She continues,

> *...it is frustrating and it's frus', you know, it's frustrating because people, you know, they they don't really understand, you know...the kind of support you need, you know, it's it's just not always there and a lot of it's people just don't understand I mean, I couldn't say that I would understand*

if I hadn't had it, you know, if I hadn't gone through it myself, what people need, you know, just the amount of assistance and in so many different areas...

The inability of a community, be it a local cancer, familial or friend-based, to meet these needs is incredibly isolating. One can almost hear the pain and agony in her written words.

PERSONAL AND SOCIAL EXPECTATIONS

This third and final mediator can most simply be described as elucidating how "that was then, this is now." We can quite easily see the disparity between what she expects to be and what she can be, what others need her to be and do and what she can be and do. The first aspect of this disparity involves considering the roles of women. O'Connor (1990) found that "limitations in functional roles are particularly relevant to life's meaning, because loss of such roles can diminish a person's perceived purpose in this world" (p. 170). Charmaz (1983) wrote an article entitled, "Loss of self: a fundamental form of suffering in the chronically ill." In this paper, she examines the ways in which people with chronic illness experience loss of self. She speaks of the presence of a chronic illness disallowing the person to continue to take actions, and have experiences that formerly allowed the person to develop and maintain former positive self-images. In the United States, we are (partly) who we are because of the job we perform; chronic illness oftentimes precludes persons from performing their previous work. They are denied a way of constructing the self that is very common in the United States. The roles of women in the family become difficult when she has a chronic illness.

One of the most important roles woman has is that of being a mother. Shortly after diagnosis and at the time of this interview (4 months after her last treatment) Toni experienced overwhelming needs. She struggled with meeting multiple daily needs of her own and of her son. She is the single mother of a 7-year old boy and playing the role of parent to him is extremely overwhelming to her. Her increased needs coupled with her

expected roles of mother and provider is displacing in that she is unable to do what she has done before. This is not surprising because the roles of women in a family are so fundamental to the workings of most families. Sick mothers have a doubly difficult time because their own needs are often not met and the needs of others become unmet as she is unable to perform usual roles. As a reminder, she said:

> *So, um, that's, that's been the biggest challenge for me is trying to keep his life (her son's) normal or as stable as possible and that's, that has just been so incredibly hard, you know just mustering the energy when you just don't have it...and then try to fix something to eat, or try to read a story and try to plan, create some fun and you're not having fun you know so many times I just wanted to send him somewhere to stay with someone else, you know, someone else or another family member or something, but then I thought that that would probably, maybe be worse, because I just, it's really the hardest thing that I deal with, is just him and making it happen, you know, just getting him dressed and ready for school, some days, it's like how am I going to do this? I don't have a clue how I'm going to roll myself up out of this bed and get him fed and to school, let alone anything else, so..um..that's, that's the biggest thing that I deal with..even today.*

Toni thought about sending him somewhere, because she was unable to mother in the way she had been able to.

As part of being mothers, women are often responsible for nurturing and caretaking in families. During chemotherapy for breast cancer, Eleanor's family had a difficult time, and she was extremely sick. She lives with her husband and two of her three children. She says, *I felt bad for them, and I felt then that at that point I just could not...there was not much elft of me to take care of them and help them.* Sometimes at night Eleanor would hear her teenage daughter crying in her room. She said, *I put her in the rocking chair she had when she was a baby, and she'd sit in my lap and I just would hold her...there was*

nothing I could do. Again, we hear sentiments of how there was nothing she could do. How incredibly displacing for a mother to recognize there is nothing she can do to assauge the pain of her family.

Another role of women is that of being a partner. Certain cultural and personal expectations with respect to partnering involve believing that one will partner (hopefully for life) and that one's partner will be supportive during a disruptive occurrence like a diagnosis of cancer. Toni, when diagnosed, was in a 3-year relationship with a man. When talk of marriage came up, she was astounded that he would want to marry someone *you don't even know if they're going to be alive.* This conversation occurred early after diagnosis, during treatment. She felt herself to be incapable of normalcy. Her status of being a woman of cancer meant she was undeserving of a normal life expectation of marriage.

Mercedes was rejected by her female partner after diagnosis. They were in a 18-month committed relationship and were living together:

> *I was in a uh relationship for, I don't know maybe a year, year and a half, with another woman and she was a uh nurse, an ICU nurse, and once I got cancer, um, course the relationship started falling apart 'cause she was telling me that I was diseased (she makes a small laughing noise) um you know, she wouldn't have anything to do with me sexually, uhm u' she was very uh uh, let me see, agitated that I was even ill, she blamed me for my own sickness, she said to me that I had made myself sick, which I think is very um untrue, so it took me awhile to really, to rationalize that information, um, let's see and then uh of course the relationship just didn't go anywhere, completely fell apart...*

We do not expect to be abandoned by a partner because of a diagnosis of cancer. We expect to be supported and taken care of during an illness.

During the treatment of Astrid's breast cancer, her husband of 18 years had a romantic affair with another woman. While an affair is in itself disruptive, for this analysis I choose to focus on her reactions to the affair. She provided a thoughtful narrative about why her husband chose to have an affair; she believes her husband was struggling with self love and decided to *take something simply for himself.* From the perspective of this analysis, what is interesting is that she did not feel *deserving* of winning the relationship back. Her diagnosis of breast cancer became an obstacle to believing she deserved to have her relationship which she describes as follows:

> *eighteen years of a perfect marriage, and I mean perfect. We had everything, and I always thought if you connected with each other and did all the work, that it was always fifty-fifty no matter what. But it isn't, because it wasn't. And I never thought that I would ever have to deal with my marriage as an issue, because it had always been so well-tended.*

The burden of cancer on her relationship tipped the fifty-fifty balance. Not only does she describe herself of not deserving of winning the relationship back, but she also felt *not deserving to be successful at this marriage or want to live anymore.* After Astrid and her husband decided to save their marriage, the reactions of others vis a vis their work to keep the relationship going was alienating: *...and our friends that we thought were our friends drifted out of our life and, you know, a lot of disappointing things happen when you decide to save yourself...* The inability of others to engage with them resulted in a reduction of their support network.

THREATENED FUTURE: IN THE MIX

The sentiment "cancer equals death" has long endured in our national conscience. Writing in 1978, Sontag (1990) offers that cancer patients were lied to because cancer was, or was thought to be, a death sentence. As Wilhelm Reich wrote in 1923, "Of all the theories put forward in connection with cancer, only one has in my opinion survived the

passage of time, namely, that cancer leads through definite stages to death. I mean by that that what is not fatal is not cancer" (Sontag, 1990, p. 19). Herzlich and Pierret (1984) write that "cancer is nowadays the very face of death" (p. 88). However, present scientific work in cancer has helped change the former paradigm into one of survivorship. "The funding of cancer research both depends on and promotes a vision of cancer as curable" (Good, et al, 1990, p. 60). Advances in knowledge and clinical treatment are lengthening survival time for most types of cancer. Therefore, the cancer metaphor is changing. However, regardless of what phase along the illness journey a particular woman was, there was some point when she experienced very intimately the former paradigm. All of the participants in the study by O'Connor et. al. thought about death (1990). Cancer equals death. There was some point when she figuratively stepped very close to death and "performed" death. Performing death is a code I developed to name their various actions/thoughts/responses to facing death.

Shortly after diagnosis, Toni describes her days,

...you know or so every now and then it would just kinda creep up on me like that and when I spent so many days just laying on the couch being sick from, just being sick and I mean I would feel like I wanted to just give up...at some point having to reach out, you know, because it was just like a tomb, you know...I would be sitting there sometimes like I was just like waiting to die like, this is bad, this is, this is not going to go away, this is really happening...I don't know what to do and so um there were just some days where I did, I just would lay in there like I was already dead, just counting off days...

Mercedes speaks eloquently about death, also:

I basically gave up uhm completely, I was like, man, I'm ready to die, I used to lie in my room, on the floor, with the light on, just in a straight, stiff

position, as if I were in a coffin or something um so, that was uh, that was my mindset, that I had just given up, there was no, there was no reason for me to, to live um...

Linda designed card games whose outcome would determine her longevity. Of course, after the game she would sometimes discount the possibility that cards could determine her life. She played solitaire, and she says,

And however many cards I could get up at the top would be how many years I'd have to live. So I'd sit there at the table and I'd play. If I couldn't get any cards up to the top, I'd say, 'Oh, this is a ridiculous game.' And then if I'd play and I'd get 52 up to the top, I'd think, 'Oh, this is a stupid game, I couldn't live 52 years if I didn't have anything.' And if I got 5 or 6, I'd say, 'Five or six, that's good enough.' Five or six. Which now it's nine.

The incredible burden of not being able to enjoy and take for granted a normal life expectancy was overwhelming to her. Therefore, she created an easily dismissable way to think about her longevity. If the number of cards was zero or fifty-two, the game was ridiculous, but if the number was five or six, and therefore more realistic given her diagnosis, then the game was good.

Not only does the woman deal with her threatened future, so do her children. Toni relates to me what her 7-year old son said,

...then sometimes, you know, out of the blue he would come to me and he would say, you know stuff like, 'Well, when I get that age, you'll be dead' and I'd say, 'Well, where did that come from?' and you know we would start talking about it and I was like, 'That's not, you know, that's not necessarily so, is that what you're thinking?'

Echoing Toni's son's comments about her longevity, Eleanor's son remarked about hers, he said, *You won't be around when [his sister] gets married. I don't think you have that much life left in you.*

CONCLUSION

In doing this work, I desired to open a space and build a bridge in my mind whereby I could better connect the two lands of sickness, the objective disease and the subjective illness. I desired to partially suspend my scientific training about disease in order to more fully develop my ability to *hear* illness stories. Because my life was so changed by a diagnosis of cancer, I personally needed to spend time thinking about illness and I hoped then, at the beginning, that my professional life would also be enriched. Fortunately, I fulfilled both goals, and more. I learned of the giving nature of sick individuals, of their pain and horror, of their triumphs and their defiance. I learned that it is one thing to pay lip service to context and it is quite another to learn the intricacies of context. And, I was reminded of just how savvy women can be!

As I was thinking of a conclusion to this paper, I found myself again thinking about how my mother would feel. Throughout this work I wondered whether she would participate in a study like this, what she might say, how she would feel, and what she might gain from being a participant. And, now I wonder whether this work has done her justice. I realize that my mother probably wouldn't have been a participant, largely because she would not have felt important enough to be a participant in a graduate research project. And I guess this speaks to the core of this work for me. An individual, and her family, with a disease or illness is <u>most important</u>. Her feelings, experiences, values, expectations, fears, voice and emotions are so very vital to the functioning of herself, her family and, I believe, of her healing. The individual and her social support network deserve a privileged position in all situations involving her (and their) illness. Ultimately, I

hope the women in this study felt greatly valued and important.

Figure 1

THE CONDITIONAL MATRIX

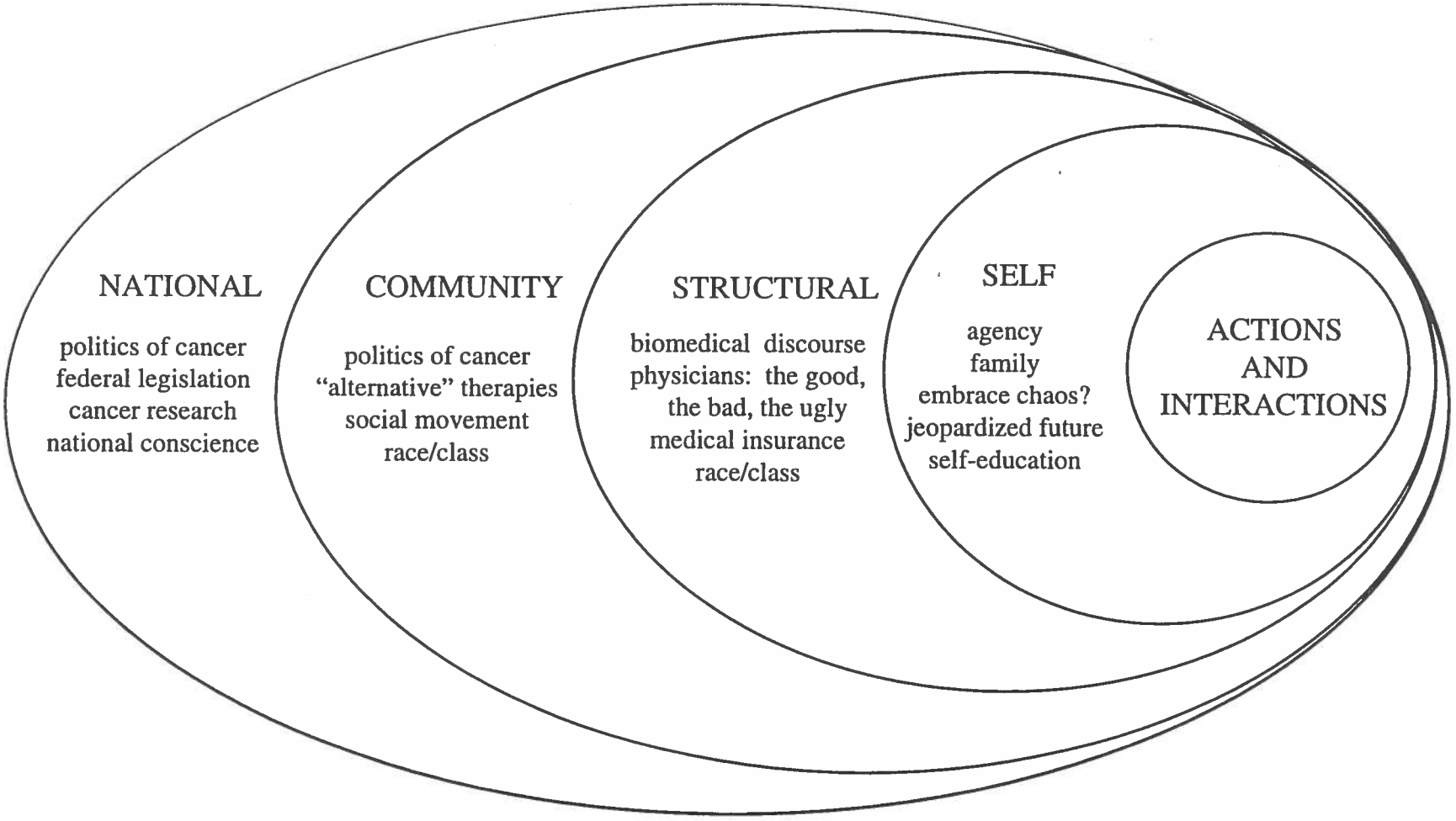


Figure 2

WOMEN LIVE CANCER

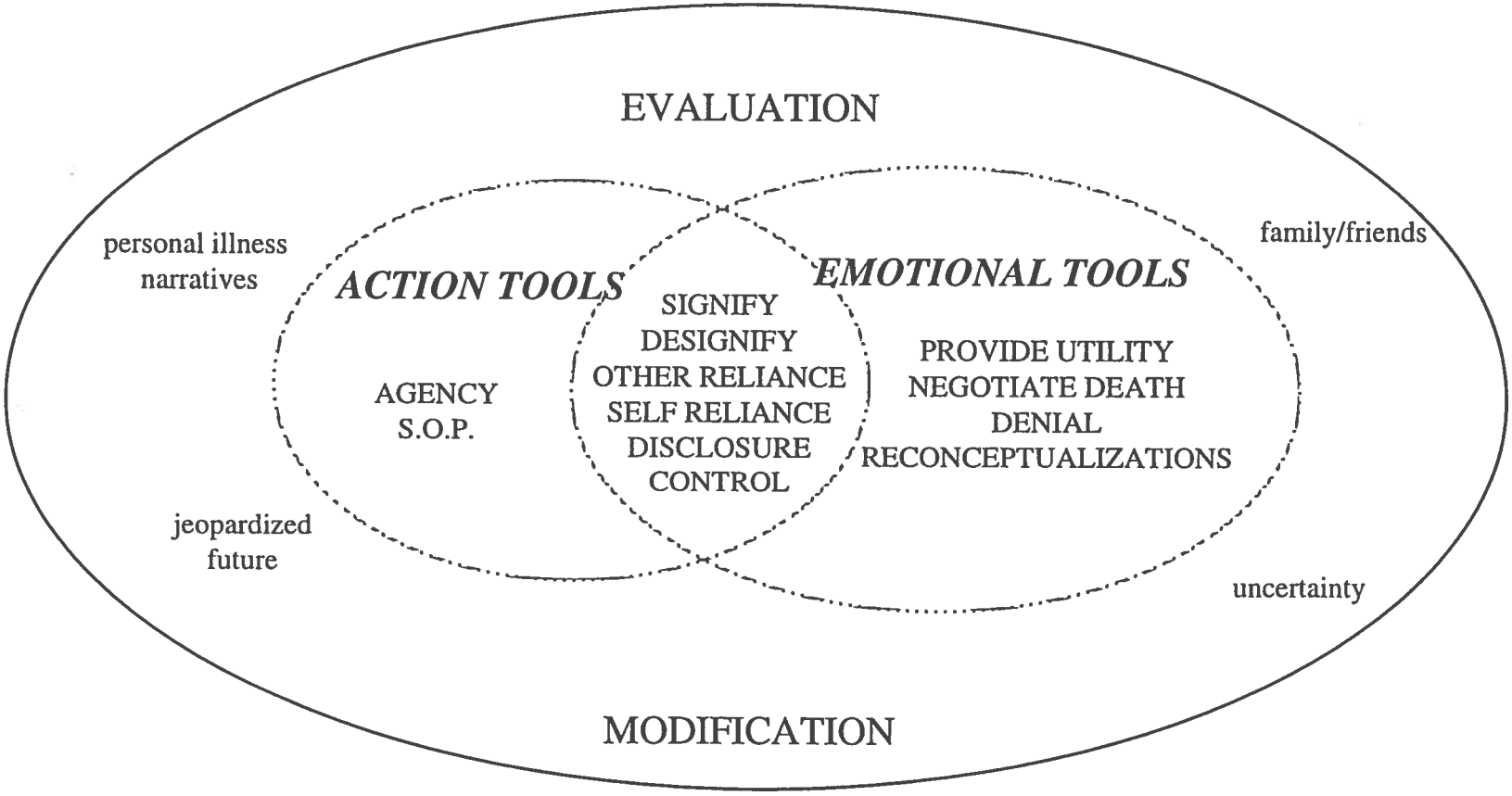
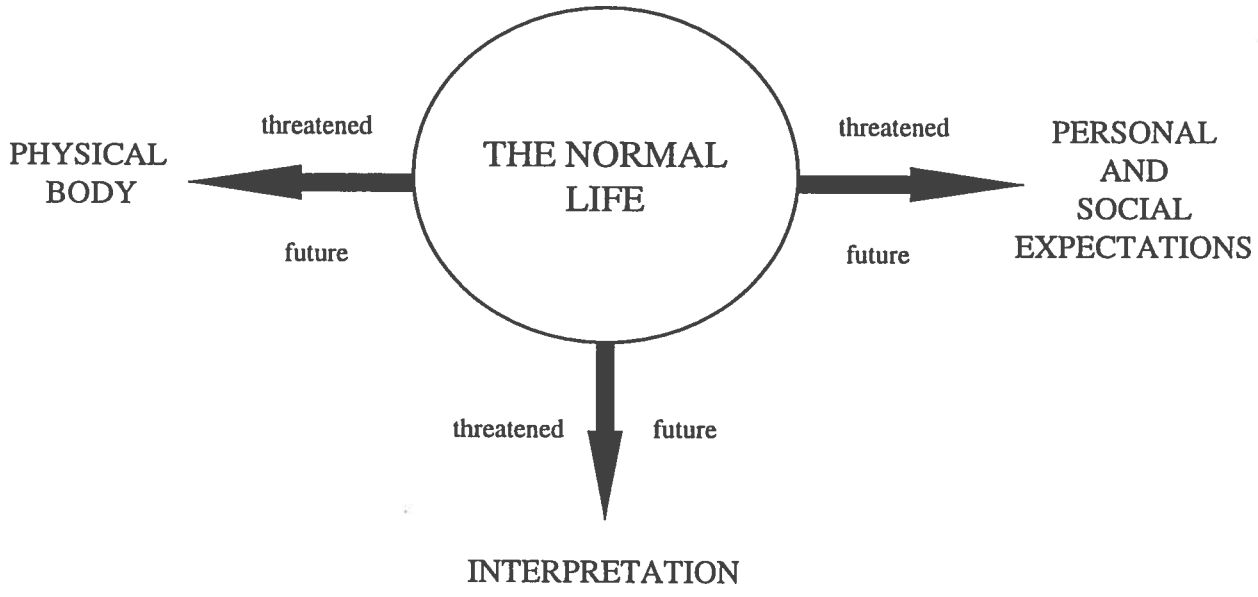


Figure 3

THE EXPERIENCES OF DISPLACEMENT



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e-mail:subjects@uclink3.berkeley.edu

October 9, 1997

Lesley Martin
1887 Alcatraz Avenue
Berkeley, CA 94703

RE: "Women and Cancer" - Continuation of Joint Medical Program Research - Health & Medical Sciences

Dear Ms. Martin:

Thank you for sending a copy of the University of California, San Francisco's current IRB approval for the project referred to above. It satisfies the condition in our letter to you of September 5, 1997, and we are pleased to grant approval as defined in 45 CFR 46.114-Cooperative Research. CPHS policy is not to renew administrative approval to any research project originating in another institution unless the project has a current approval from the IRB of the originating institution.

The number of this administrative approval is 97-8-104. Please refer to this number in all future correspondence.

The expiration date of this approval is September 11, 1998. Approximately six weeks before the expiration date, we will send you a continuation/renewal request form. Please fill out the form and return it to the Committee, according to the instructions. Be sure to include a copy of the current approval from the originating IRB.

Please note that even though the Committee has approved your project, you must bring promptly to our attention any changes in the design or conduct of your research that affect human subjects.

If you have any questions about this matter, please contact the CPHS staff at 642-7461; FAX 643-6272; E-Mail subjects@uclink3.berkeley.edu.

Sincerely,

R. Steinhardt

Richard Steinhardt
Professor of Molecular and Cell Biology
Chair, CPHS

RS:nan
cc: Professor Thomas Boyce
Graduate Assistant
(Graduate Division (SID #12984816)

UNIVERSITY OF CALIFORNIA SAN FRANCISCO
CHR APPROVED
SEP 1 1 1997
APPROVAL EXPIRES
9/11/98

APPENDIX B

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title: Women and Cancer

Purpose and Background:
Lesley Martin and Adele Clarke are conducting a study about how women understand and work with their cancer diagnosis in their daily lives. We would like to ask you to participate in this research.

Procedures:
If you agree to be in this study, you will talk with Lesley for about 1 to 1 1/2 hours in a comfortable, private place such as your own home or some other comfortable place. The conversation will be tape-recorded, if you agree. The interview will consist of questions that focus on what your life was like during your initial cancer diagnosis, how you told your family and friends and how you explain the disease to yourself. In addition, you will be asked to complete a demographic questionnaire.

Risks and/or Discomforts:
Talking about your experiences may be difficult or unpleasant. However, you are free to talk only about those aspects of your life with cancer that interest you. Participation in the study may involve a loss of privacy, but several precautions are taken to avoid this. For example, when tapes are transcribed to written form, both tapes and transcriptions are locked in a cabinet at all times. Your name is not marked on the data; only code numbers are used. Only Lesley Martin and her supervisor, Dr. Clarke, will have access to the data, which will be destroyed after two years. You will never be identified with any stories or quotations in any publications.

Benefits:
There are no direct benefits to you. However, the information you provide will help health care providers to better understand what it is like to receive a cancer diagnosis.

Costs/Financial Considerations:
There will be no costs to you for being in the study.

Reimbursement/Payment:
There is no reimbursement for the interview.

Questions:
You have talked with Lesley Martin about this study and have had your questions answered. If you have any further questions about the study, you may contact either of us at:

Researcher: Lesley Martin, B.A., M.S., Medical Student
1887 Alcatraz Avenue
Berkeley, CA 94703
Home Telephone 510-654-4666

Supervisor/Researcher: Adele E. Clarke, Ph.D.
Department of Social and Behavioral Sciences
Box 0612
UCSF
San Francisco, CA 94143
415-476-0694

If you have any comments or concerns about participation in this study, you should first talk with one of the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00am and 5:00pm, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0616, University of California, San Francisco, San Francisco, CA 94143.

Consent:
You have been given a copy of the consent form and a copy of the Subject's Bill of Rights.

Participation in research is voluntary. You are free to decline to be in this study, you may refuse to answer any questions at any time. You may stop the interview at any time too, without affecting the services you receive at WCRC in any way.

If you wish to participate, sign below.

Date:_____ Signature of Participant:_____

Date:_____ Signature of Researcher:_____
Obtaining Consent

Address (only if you wish to receive a copy of the final report of the research):

_____

Thank you for your time and effort.

July 29, 1997