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**Optimizing Breast Cancer Care for African American
Women: Patient Perspectives**

by

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B.A. (University of California, Berkeley) 1991

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A Prayer for Black Women

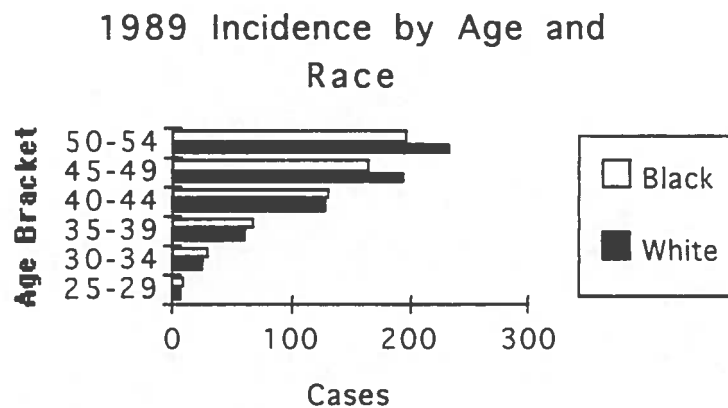
*I pray for sound mind,
unbroken health,
work fit for my soul,
good loving;
and for every sister contemplating death,
a reason for living.*

Renita Weems

Introduction

Over the past 20 years, breast cancer has become a prominent disease in the life of every woman in America. In 1973, US women had a one in twelve chance of getting the disease in their lifetime⁵¹. Currently, rates are closer to one in nine⁵². Breast cancer is now the most common cancer in American women and the second most common cause of cancer related death⁵². Recent trends in breast cancer across the United States are tracked and presented in the Surveillance Epidemiology and End Results (SEER) monograph, a publication of the National Cancer Institute (NCI). The most recent SEER monograph is a compilation of statistics covering trends in the epidemiology of all types of cancer from 1973-1990.

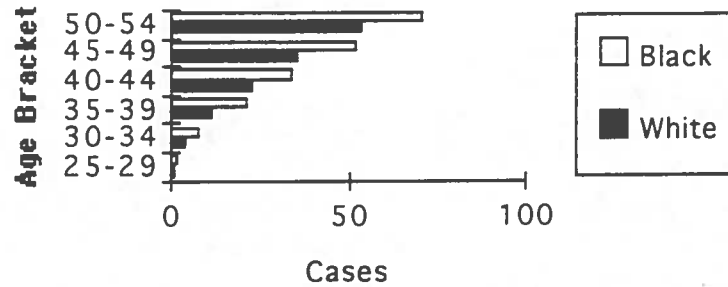
A survey of SEER statistics over that period reveals a disturbing difference in the relationship between breast cancer incidence and mortality by race. Data in graph 1 show a lower incidence of breast cancer across age for black women.



Graph 1. Breast cancer incidence by race and age in numbers/100,000⁵¹.

Paradoxically, as the data in graph 2 illustrate, this same group suffers a higher breast cancer mortality rate relative to US white women.

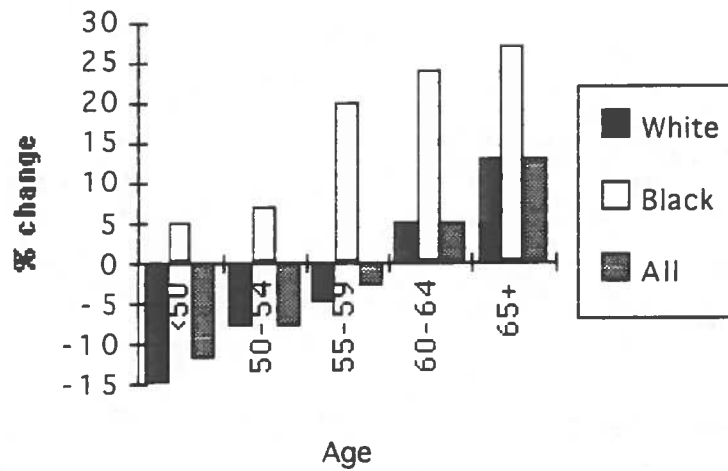
1989 Mortality by Age and Race



Graph 2. 1989 mortality rates/100,000 by age and race⁵¹.

Although these data are specific for 1989, they clearly reflect breast cancer trends over the past 20 years. Sadly, even with increased attention to more aggressive treatment protocols, these trends have not changed. The data in graph 3 suggest that they may in fact, be getting worse.

Mortality Trends 1973-1990



Graph 3. Changes in mortality rates from 1973-1990 by race and age⁶¹.

Data from the US Department of Health and Human Services in 1995 corroborate this trend. In January of that year, after 6 years of treatment protocols calling for aggressive use of chemotherapy and hormone replacement therapy following

surgery for primary breast cancer. the HHS announced a "victory" in disease outcome. Unfortunately, the victory varied by race. While white women showed a 5.5% overall decline in mortality, black women suffered a 2.6% increase in mortality over that same time period^{1,2}. While Donna Shalala and other federal officials celebrated what they called the "5 percent decrease," they quietly asked what is happening with African American women?

The current body of biomedical literature offers a myriad of explanations for the dismal breast cancer outcomes suffered by African American women. However, it is conspicuously incomplete. The voices and perspectives of Black women dealing with breast cancer illness and survival are virtually absent. Also conspicuously absent is any discourse on the 5 years following breast cancer treatment--the period which precedes "survival" in biomedical terms. This is important, because the conclusions drawn in the biomedical literature serve as the main guide, not only to the way physicians approach patient care, but also to the design of medical intervention to correct poor breast cancer outcomes for African American women.

The goals of this work are first, to critically review the current literature on differential outcomes between African American and white women with breast cancer. Second, this research will elicit the voices of Black women coping after breast cancer treatment in order to discover the ways in which they think about their health and survival. Finally, based on the relevant themes elaborated by the women, I will make recommendations for further epidemiologic studies and for ways to optimize health care delivery to Black women with breast cancer.

Review of the Current Literature

Various reasons have been put forth for low incidence and high mortality rates in breast cancer for black American women. The biomedical discussion focuses primarily in three areas: general health behaviors/lifestyle; preventive health behaviors; and clinical features of disease.

The literature first draws contrasts in the general health of black and white American women with breast cancer in order to explain differences in survival. The bases for popular comparisons include nutritional status, and body mass indices (BMI or degree of obesity)^{11 13}. Some studies attribute poor general health to certain dietary practices and the sequelae of those practices. These studies suggest that "poor" nutrition can result in poorer 5 year survival rates than "good" nutrition in all populations¹³. Any disparity by race would seem to validate the role of nutrition in differential breast cancer outcomes for black and white women.

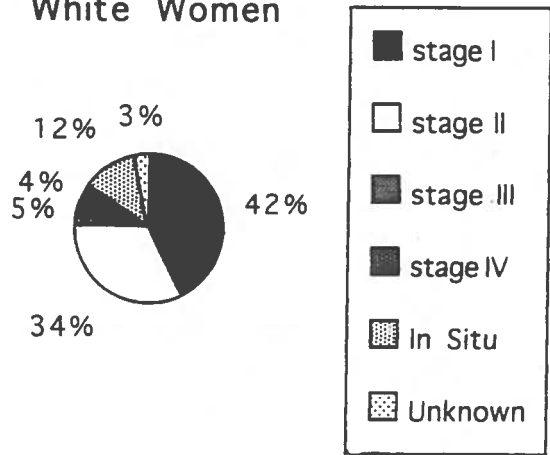
One study reported that women with higher serum albumin and hemoglobin levels had higher survival rates after treatment for breast cancer than those with lower levels. Using these indicators to determine nutritional status, black women were shown to have lower levels of serum albumin levels and hemoglobin in the blood, and thus "poorer nutritional" status than white women¹³. It is of interest to note that although these indices of nutritional status have been correlated to breast cancer outcomes, they have never been shown to be determinants of survival. Building on the foundation of general health status as an explanatory model for disparate mortality rates, other researchers focused on comparisons of body mass index.

Increased Body Mass Index (BMI or obesity), has been cited by some authors as a contributor to lower survival outcomes^{13 35}. Again, because increased BMI results in poor outcomes across race, it is incumbent on the researcher to show that black women are more obese than white women, in order to explain disparate outcomes. Using data collected from medical records, Hunter (1993) showed that black women

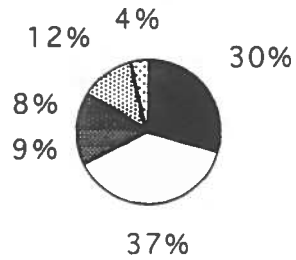
diagnosed with breast cancer are generally heavier than white patients. Coates (1989) corroborates this study, adding that very overweight women in his study had the worst survival rates. In both studies, high BMI correlated positively with black race and negatively with outcome. Obesity has been implicated in masking palpable lumps and contributing to late discovery of a breast mass. It has also been connected to poor outcomes because of the potential disruption of the hormonal mechanisms of gonadotropin, prolactin and estrogen, which may result in hormonally mediated breast changes¹³.

The next two categories--preventive health behaviors and clinical features of disease-- are linked by the natural history of breast cancer. The most popular clinical explanation for breast cancer trends by race is that a higher mortality rate is associated with late stage tumor at the time of diagnosis^{11,13,43}. Tumor stage primarily indicates the size of the tumor and whether or not malignant cells are found in the lymph nodes under the arm (axillary lymph nodes)³³. Data from the SEER monograph confirm that a higher percentage of black women present with later stage tumors at the time of diagnosis. These statistics are widely accepted in biomedicine.

Stage at Diagnosis
White Women



Stage at Diagnosis
Black Women



Graph 4. Stage at diagnosis for white and black women in 1990. In situ lesions are surgically resectable and particularly non-invasive⁵¹.

In order to substantiate the claim that black women present with later stage tumors, a large body of the literature focuses on preventive health behaviors to explain why this phenomenon occurs. Popular discussions in the literature analyze patient delay between symptom discovery and physician care; underutilization of Self Breast Exam (SBE); and underutilization of mammography screening^{14,35,43,67}. Common medical thought holds that early detection of a breast tumor results in the discovery of a smaller tumor; less advanced in stage, and thus, more amenable to treatment. Small tumors (lower in stage) have a better 5 year prognosis than larger (later stage tumors)³³.

Much has been written about the intention to seek care after the discovery of a breast mass. Doctors and researchers call this patient initiated delay^{14,43}. Delay in seeking clinical care may result in a later stage tumor at diagnosis. Current research points to this behavior as a major factor influencing breast cancer related mortality rates^{13,14,35,43}. Acknowledging that utility--the perceived usefulness of treatment; affect--the attitude of the patient; and social norms and habits may influence care seeking behavior, researchers set out to determine whether black and white women differ with respect to the interaction of each of these factors with delay behavior⁴³. Investigators hoped to explain the disparate mortality rate for black women breast cancer victims by correlating intention to seek care with stage at diagnosis.

The results indicated that the perceived utility of treatment more positively influenced Caucasian women than African American women⁴³. The assertion that black women are less educated about breast cancer treatments and have had fewer experiences with a family member breast cancer patient attempt to explain the difference in perceived utility of treatment. A similar explanation was suggested for the small effect of social norm on the intention of black women to seek care as compared to its effect on the intentions of white women. In this study, the assertion that black women are generally uneducated about breast cancer justifies the finding that they tend to underestimate the prevalence of cancer, the effectiveness of treatment and subsequent

survival rates⁴³. Some researchers have suggested that this ignorance about breast cancer is normative and favorable because African American women often prefer not to know if they have the disease⁴³. These assertions fuel the literature on the underutilization of mammography.

The efficacy of mammography is determined by its ability to reduce mortality rates and increase breast cancer survival²². Mammography screening has been shown to accomplish this goal more effectively than Self Breast Exam or Clinical Breast Exam by detecting breast masses before they are clinically palpable or symptomatic^{33,55}. Studies of screening in asymptomatic populations have shown that efficient mammography screening detects tumors at stages early enough to effect a 31% decrease in mortality^{29,61}. The majority of the studies assessing use of mammography explain differential outcomes by showing that black women are less likely to have a mammogram.

Studies using mammography as a predictor of late stage at clinical presentation tend to address issues affecting the acquisition of mammography screening. It has been suggested that differences in perceptions of breast cancer and mammography determine whether or not a black woman will successfully pursue this intervention⁵⁵. In his study of 186 African American women in an inner city clinic setting, Price (1992) points to lack of education about breast cancer, religiosity, and presence or absence of physician recommendation as factors informing black women's perception of the utility of mammography. The study showed that the subjects were not sure of the causes of breast cancer, with a large portion of the sample not knowing that oral contraceptives do not cause cancer, or that drinking too much alcohol may contribute to increased incidence. More than half of the sample believed that they were less susceptible to breast cancer because they held strong faith in God. In the literature, these beliefs contribute to poor preventive health behavior and contribute to the severity of the clinical features of disease, i.e. stage.

Until late in 1994, these were the popular explanations for differential breast cancer outcomes by race in breast cancer. Taken together, they create a cohesive medical logic which predicts that the black woman with breast cancer is a woman of high body mass due to poor nutritional habits; she is uneducated about cancer and is negatively influenced by her social surroundings. She therefore refuses to have a mammogram even though her physician has recommended it, because she prefers not to know that she has the disease anyway.

Against a backdrop of equal access to care and facile health related behaviors, the black woman is painted as an obese, uneducated, religious fatalist. As a result of her ignorance, denial and neglect, she presents to her doctor with a late stage tumor in her breast. She is then rendered, by her own precarious mixture of indolence and power, subject to poorer outcomes than a white woman who usually has her tumor diagnosed early and at a less advanced stage.

In the fall of 1994, a new entry to the clinical features of disease category was registered. In addition to tumor stage, the category 'clinical features of disease' includes what oncologists and pathologists call tumor grade. Tumor grade takes into account, among other features, the level of maturity of tumor cells (cellular differentiation) and the presence or absence of various hormone receptors on the cell surface (cellular morphology). These clinicopathologic features of disease appear to provide a clinical basis for the differential outcomes in breast cancer. A tumor composed of more immature cells (less differentiated) has a poorer prognosis than one composed of mature (more differentiated) cells³³. Further, the absence of hormone receptors on the tumor cell surface renders it less receptive to newly developed adjunctive chemotherapy treatments like tamoxifen ³³. It has now been documented that black women present not only with later stage tumors, but also with higher grade tumors (less differentiated, absent hormonal receptors)²⁹. These tumors have the poorest prognoses. With its scientific basis and presumed objectivity, the findings regarding tumor grade have the

weight to dictate much of the direction of future differential outcomes research, while effectively maintaining the focus on lifestyle and health related behaviors of victims.

This portrayal of Black women in the biomedical literature on breast cancer outcomes is disturbing for a number of reasons. First, it takes as the main issue the comparison of whites and blacks in terms of health with no real attention to differences mediated by social forces. The results of this type of comparison substantiates the observations of one African American law professor who writes, "in a racist society that incorporates beliefs about the inherent inferiority of African Americans in contrast to the superior status of whites, any attention to the question of difference that may exist is likely to be pursued in a manner that burdens rather than benefits African Americans⁴¹." The literature's greatest potential for harm rests in its influence on both physician's attitudes toward health care delivery to this group and the development of breast cancer interventions for black women. Under the influence of this body of literature, physician attitudes and breast cancer interventions will continue to ignore issues concerning access to care; the role of the physician in the doctor-patient interaction; and psychosocial issues of concern to survivors.

It is ironic that the black woman breast cancer victim is given sole credit for diminishing her own health, and yet she is never asked to participate in the creation of structures which will improve it. The voices of African American women are conspicuously missing from the literature; but it is imperative that they be heard. Their experiences are real and as such lend practical insight to the shaping of physician attitudes and to the development of interventions which will optimize breast cancer care for African American women.

Methods

In order to begin to understand African American women and the experience of breast cancer in their own terms, I chose qualitative methods, with particular attention to Black Feminist Thought. Black feminist thought predicates that the primary responsibility for defining one's own reality lies with the people who live that reality; those who actually have those experiences ¹⁶. This contrasts the literature on Black women and breast cancer outcomes where the voices of black women are consistently absent. Qualitative methods facilitate the creation of a definition of health by and for black women with breast cancer. On a much larger scale, it also offers the opportunity to challenge the race, gender, and class oppression so conspicuous in the picture of black women with breast cancer painted by the literature. It is my aim through this method to increase the volume of these voices so that Black women may claim their natural right, as black feminist bell hooks writes, "to define (their) reality, shape (their) new identity, name (their) history and tell (their) own story."

Study Design

This study represents a follow up to research undertaken by Dr. Bill Satariano at the University of California, Berkeley; and Dr. Jay K. Harness, a surgeon at Highland Hospital⁵⁷. The original intent of that 1992 study was to look at how African American women were coping after breast cancer and how their physical functioning changed over time. This study was initiated shortly after diagnosis and continued at two week intervals over the course of 10 weeks. The two week interval was chosen because past studies had used varying time periods between interviews. The researchers at Highland wanted to know what kinds of changes took place over short intervals in time.

The subjects were 16 African American women who were in the process of treatment for breast cancer at the hospital. The data collected in this quantitative study at

the end of 1994, were incomplete but revealing. It is the unfortunate limitation of quantitative research that informant responses which modify the options provided by the researcher are frequently ignored because they cannot be quantified. The current study focuses on ascertaining the significance of these modifications; looking to more clearly understand the complexities of the simplistic answers to multiple choice questions. Further, it attempts to illuminate common and recurrent themes in the interviews; not for the purpose of quantification, but rather for the purpose of building and understanding the context within which the woman lives and survives the breast cancer illness.

Subjects

Participants were identified through physicians records in the department of surgery with permission from Dr. Jay K. Harness. All cases of breast cancer treated at Highland, regardless of the use of surgical intervention, can be tracked through the department of surgery. Of the original 16 women interviewed between 1992 and 1994, nine were willing to be interviewed again, seven could not be located, and one refused to participate. The social worker at Highland who works with many of the cancer patients, referred one woman who was not on the original list. She was invited and agreed to participate. The themes presented here are based on a total of 10 African American women who have completed treatment for breast cancer at Highland hospital in Oakland.

All respondents were still within the 5 year window after primary breast cancer treatment; i.e. not technically "survivors". Their current ages ranged from 36 to 72 with an average (and median) age of 56.2. Six of the ten had had a mammogram within two years of diagnosis. One had had her last screening three years before the diagnosis and three of the women had never had one. One of the respondents who had never had one was 34 years old when she was diagnosed, so at the time, it was appropriate, according

to American Cancer Society guidelines, that she had never been screened. Seven of the women had no insurance at the time of diagnosis and three had Medi-Cal.

As for clinical characteristics, seven of the women were diagnosed in early stages of the disease (Stage I-IIa) and three were diagnosed with stage III or greater. This did not necessarily correspond to mammography utilization. As for treatment, four of the women underwent Modified Radical Mastectomy (MRM), two had lumpectomy only, and four had lumpectomy (excisional biopsy) with axillary nodal dissection (AND). AND is used to determine the extent of spread of the disease and for staging. Following surgery, seven of the women had radiation therapy, four took 3-6 weeks of chemotherapy and three currently take tamoxifen. One of the women taking tamoxifen was participating in a clinical trial and was not sure whether or not she was taking a placebo.

The Survey Instrument

The instrument used in each interview was designed as an open ended qualitative instrument and can be reviewed in appendix A. It was not designed to uncover a cause and effect relationship between psychosocial stressors and breast cancer outcomes. However, the design allowed the women to talk at length about their experience with the illness and how they felt all the different stages of treatment affected their lives, if at all. There are a few questions which provide limited choices to the respondent. The apparent limitation of these questions is addressed by follow up with open ended inquiries. Follow up questions were intended to allow the respondents to modify the scope of the choices so that they could best represent their lives and experiences.

The first section of the instrument was organized to provide pertinent demographic and contextual data. Background survey items included closed ended questions about age, marital status, living arrangements, employment status at the time of the interview, educational background, insurance status at the time of diagnosis, and

current breast cancer status. These pieces of information, or context builders helped set the tone for the responses to the remaining questions. Other questions address the respondent's general feeling on that particular day; and the respondent's feelings about sharing her experience with breast cancer. Among these initial questions, current breast cancer status was expected to have an impact on the woman's sense of well being and health at the time of the interview.

The second part of the instrument elicits open ended vignettes as told by the respondent herself. The vignettes covered topics such as medical encounters at the time of diagnosis, treatment and follow up; social networks and familial interactions; friendships, and social groups. The third category of vignettes were meant to elicit the most important factors in the respondents current living situation, clarifying respondent identified sources of strength. The fourth category of vignettes was recommendations for ways to make the experience better, if at all possible.

Taken together, the two parts of the survey provide a means to the goal of qualitative phenomenological research: the elucidation of the experience of breast cancer and its connection to overall well being. In the tradition of qualitative research, the survey was used as a loose guide for conversation. If experiences shared by the respondent created entree into an area not explicitly covered in the original format, that particular line of questioning was followed. Since interviews were tape recorded, this information could easily be included in the resulting transcriptions.

The Interviews

Accounts of the ten women's individual experiences were obtained through interviews conducted by an African American female graduate student. All of the interviews lasted between 1-3 hours with the variance being due to the respondents desire to discuss relevant issues. Interviews took place in the homes of nine of the

respondents. One interview took place at the college campus where the respondent was taking classes.

Each interview was tape recorded as it occurred. The interviewer also made written notes and observations about the surroundings which would be missed by the use of audio equipment alone.

Biologic staging and grading data, as well as side notes and physician assessment were taken from medical charts. Permission to review medical charts was obtained from the subjects at the time of the interview.

Transcriptions

Of the 10 interviews performed, only 9 were transcribed from tape. One interview was destroyed due to technical difficulties during the interview. Regrettably, the respondent's thoughts and feelings were not recorded in full, and time constraints precluded re-interviewing before the completion of this paper.

Transcripts from each interview were prepared by the interviewer with notations for follow up questions to be asked by phone. The benefit of using the same person for data collection and transcription is that analysis is enhanced by complete familiarity with material. Because I witnessed the interview, I could attempt to translate what I heard on tape to the paper--including the distinction between genuine and nervous laughter. My experience in linguistics contributed to an astute attention to the details of the various tones, and inflections in their speech.

Data Analysis

After transcribing, I coded prevalent themes in the interviews by hand. Both concordant and conflicting responses from the subjects were included in thematic categories.

Critiques of Qualitative Methods

There are a number of areas where bias can be introduced by the methodology. Critics claim that qualitative methods are too subjective because the interviewer and subject may bring value-laden baggage to the interaction. Subjectivity in the methodology may be further complicated by the researcher's role in the creation and discussion of themes and theories. These factors may pose threats both to synchronic reliability and theoretical validity. Before addressing these issues, it is important to point out that all research is value-laden. Ironically, the "objective" biomedical literature on differential breast cancer outcomes demonstrates this point.

Potential problems of synchronic reliability were addressed by triangulation of raw data, field notes taken at the time of the interviews and notes taken during the time of the transcription. Each of these pieces was considered important in formulating themes since it is entirely possible that the researcher was in a varying frames of mind at each of the stages of the data collection, transcription and interpretation. Initially, the research design included two focus groups to fortify the development of themes. However, these were aborted due to time constraints of the researcher. Coincident observations from these three data sources supported synchronic reliability in the development of relevant themes.

In order to insure theoretical validity, the interviews were both tape recorded and transcribed. Direct quotations consistent across tape and transcription served as the corner stones in the formation of theory. This is not to suggest the absence of a role for inference or intuition. In fact, inference by the researcher was essential to uphold the praxis of Black Feminist Theory in the interpretation of data. Within this paradigm of thought, the experiences of black women are to be articulated, compared and judged primarily by the experiences of other black women ¹⁵.

The nature of the open ended instrument, with consequent variability in the means of eliciting information may pose a threat to instrumental validity. In this study,

instrumental validity was addressed by comparing the articulation of experiences by the subjects with breast cancer experiences discussed by Black women authors and health organizers. These writers' unsolicited contributions to global experiential knowledge serve as a natural validity check for this study, adding weight to the development of health theory.

Since each of the women were only interviewed once, it is difficult to determine whether or not their responses might differ in the future, thus changing the character of the theories developed herein. This was not directly addressed in the design of the study. It might be addressed in the future by administering the survey several times over a predetermined time period.

Results

The themes presented here represent the commonalities in breast cancer experiences of the 9 African American women treated at Highland Hospital. Unlike much of the literature on Black women with breast cancer, the themes take into account doctor-patient interactions; social support; follow up after treatment and the impact of these elements on their sense of health or overall well being. These themes are all relevant to survival since the term is defined as the interval of life between the time of diagnosis and the time of death.

I. Concept of Health

Because biomedicine would hope to impact the health of these women through the delivery of medical services and the development of health interventions, it is crucial to come to an understanding of the way this group thinks about their own health. The term 'health' is so common that it is easy to assume that each use of the word has the same implications. The hegemonic perception of health is the somaticist view which comes from biomedicine. It assumes that if one could just, remove, repair or adjust bodily parts and functions, that this handiwork would create health and last forever⁶. This comes in direct contrast to the definitions of health as discussed by the group of respondents.

This group of women clearly articulated an inseparable connection between the mind and the body. Physical health for this group was at times on equal footing with mental and emotional health. Further, the connection between the two provided a constant means of interplay and impact.

"That's what counts. If you can't live and be happy, what are you living for, Kim (interviewer)? Cuz life is too short. "

"Because if you don't think positive about your inner self, your innerself has a lot to do with your healing and your mind. And if your mind and body does not cooperate as one, you can't get healed baby."

"...I don't have the energy I used to have, I feel tired a lot. A lot of fatigue. And I don't know how much of that is actually physical and how much of it is psychological. Because I think that the cancer may have come back and I think I'm supposed to be sick, I don't know what's going on."

"Oh, to me, it (health) means everything. Because when you have your health and your strength and you feel good, and you're well in your mind, soul, most of your body and your spirit, you couldn't ask for anything else."

"...mental ability...they wasn't able to handle it. It just kind of took them away from what they really were, and I said, thank god, that I was able to keep my sanity and stay with the program as they say. And keep functioning, go about doing what I normally do."

"I think health is both physically and mentally."

This connection is corroborated in the writings of contemporary black authors, local African American activists and in other breast cancer narratives ^{7,28,46}; and may be an indication of the social construction of health. Blum (1983) elaborates this concept: "...definitions (of health) arise out of what the individuals in each society must successfully produce and what they must cope with⁶." The definitions explored in this paper are a result of what black women living in a racist, classist and sexist society must cope with in order to be "fit". Racism, classism and sexism cannot be endured simply through physical fitness. These "isms" inflict their harm on the psychological health of the oppressed. So, it is not surprising to note the strong importance of psychological well being in this definition. Some of the women's comments implied that this strength of mind and spirit must take precedence over the ailing body or further physical dysfunction would occur.

"...I'm not gonna start acting old. Because when you start acting old, then you start having old things happen to you. Your bones getta hurtin and your get these, my mother used to say, imaginary pains that ain't there. This hurts, that hurts, this hurts...."

"And you have to think about more than, you know, you don't sit down and just throw your life away. You know, you gotta keep going. "

The women conveyed a remarkable ability to overcome physical limitation by tapping into these stores.

"I get up in spite of the pain and do what I have to do, go where I have to go. And I thank God that I'm able to do that, cuz, some people my age, they so cripple up, they can't handle themselves, they not able to do anything."

"Just because they say you gonna have something don't mean you're gonna have it. And if you do have it, just deal with it and keep on down the road. Don't let it stop you"

This is not to suggest that the physical component has no bearing at all on the mental/emotional component of health. It is more important to accept the very inclusion of the non-somatic elements into the definition because these women see the relationship between the two components as a dialectic.

"...when everything is functioning properly, the way it should, like it was ordained to be, you (are) a well balanced person...And when we're healthy, we're able to get along with people, our minds, we're pleasant, well groomed. So, it's necessary to have a healthy body."

One respondent made a very clear connection between her physical state and her mental well being. Here, she talks about her emotional health following the physical disfigurement of modified radical mastectomy:

"It just means the world. You know, it's nothing like your health. (It's worth) all the money in the mint. I rather prefer my breast than all the money in the mint. "

Q: Do you feel like not having your breast makes you less healthy?

A: "I think so. I believe so. It seem like, you know, I can't do what I used to do. And I just don't wanna be always going...I just don't enjoy going out like I used to."

This conceptualization of health does not coincide with the dominant view. Consequently academic discussions of psychosocial mediators of health have been relegated to the psychosocial field^{4,24,27,46,62,63}; existing solely at the periphery of the somatic centered discussions of biomedicine. The most significant work in this area has successfully shown a link between psychological well being and breast cancer

outcome. In 1989 Spiegel designed a randomized study of women with metastatic breast disease. He set out to assess whether group therapy had an effect on survival. This type of intervention had been shown in the past to improve psychological well being. The results showed an average 18 month increase survival in the intervention group relative to the control group. When the two groups were compared retrospectively for clinical features of their disease, the intervention group actually had had poorer prognoses by stage at the time of diagnosis than the control group⁶².

Even in the face of Spiegel's findings, the value of psychological health during illness still has yet to enter the realm of the mainstream biomedical approach. As a result, biomedicine's armamentarium for treating the psychosocial aspects of health, short of psychiatry, is limited. However the importance of psychological health stands strong in the psyche of these women and each talked about how to achieve it in her own terms.

II. Health and The Sense of Coherence

The range of health achieving strategies included positive thought/self image; spirituality; and trusting in god.

" God is in your heart. God is wherever you are."

"I kept positive thoughts. I didn't have no negative thoughts. I didn't let nobody with no negativeness around me. If you have to think negative, get away from me and that's just the way I live. I don't let no negative person... I stay on the upbeat."

"...I've been involved in church activity ever since I can remember and I enjoy it. Very, very interesting. Very strengthening and rewarding. It helps me to get through life, through the problems that I'm faced with by knowing the Lord..."

"And if you have the faith that within yourself, that know that within you, you know you gonna come through with this thing, you can do it. But, if you doubt it...have doubts and fear, hey, I don't care what the rest of the folks say, if you don't have the confidence within yourself, it won't matter."

"It's what I think of myself! And what I think of myself that's the only way I can make it. If I don't think good of myself, if I don't think that I can make it, I have what it takes for me to make it in this life, then nothing I say or do will matter. But it's what I think of me. "

"Well, you know, if you know God, that he made the big difference. Because if you got him, you got everything. "

"Well, I always pray to God, you know, that he take care of me. And that...my health, my family. "

"I always from a little bitty kid, I always believed in god. So. You know, he's my...all my being. Cuz if I wasn't strong I couldn't have made it through what I went through...If I hadn't been strong and believed in God, I'da just fell apart. I believe him and that's what makes me strong. "

"And it seemed as though God was sending positive people to me. ...I could see how it could, without positive influence, that you could be almost, really devastated. I just really thank God, because I really had a lot of support..."

"There were a lot of positive things going along with my being treated for the cancer. I think, had I been more of a negative person that it could have went the other way...."

"That has a lot to do with it. I feel like I'm pretty healthy. And some of it's due to the fact that I went on and did what I had to do to take care of myself."

Although there are a number of coping styles addressed in the psychosocial literature, no one concept is as comprehensive and flexible as Antonovsky's concept of Sense of Coherence (SOC). This concept is readily mapped onto many of these women's chosen coping style: faith.

Aaron Antonovsky developed the concept of sense of coherence in order to explain a person's internal organization of the world which allowed them to cope with various life stressors. He defined the sense of coherence as, "...a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected."²

The sense of coherence is developed in childhood, adolescence and early adulthood. Antonovsky hypothesized that a person with strong SOC will be more likely to engage in activities that are "health promoting; and to avoid those that are health-endangering because past events and the invocation of the person's world view have been consistent, balanced (did not overwhelm coping ability regularly) and provided room for participation in decision making."² A strong SOC provided an internal means, by which these women could maintain psychological well being.

The components of the sense of coherence are comprehensibility; manageability and meaningfulness. Comprehensibility refers to the ability to perceive a situation as making cognitive sense rather than as noisy, chaotic, disordered, random or accidental². Many of the women employed faith in the will of God as a means to comprehensibility.

"They said, you of all people, why did this have to happen to you. I said, why not? I said, the Lord knows for what reason I'm going through this. "

"I believe that God...that the purpose that I have (for having breast cancer) that I could testify that, the word of the lord is true. If you can believe you can receive. I believe that."

In some instances, comprehensibility was spoken of as predetermination:

"But everything that's gonna happen to you is already written down from the day you were conceived in your mother's womb."

In the SOC, manageability refers to the extent that people perceive that their available resources are adequate to meet the demands of the illness. For many of the women in this study, God was available and perceived as adequate to allay emotional distress.

"So I felt with them supporting me (family) and most of all God, I'm in control, he's in control, I didn't have anything to worry about."

"I don't, you know, I don't think I'm never in control. Which is why I'm a Christian. Cuz I leave that up to God."

"...it was, right then when they told me that it was cancer. Right then you know, I kinda was upset. But then I came home and I just put it in the hand of God and I didn't worry about it."

"Cuz I just put it in His hands, you know...I said, I ain't worried about it. I wasn't. I wasn't worried about that. Not at all. Not one bit."

"...after I really accepted the fact that I had cancer and that I had to have the surgery...I just said, Lord I'm in your hands and let your will be done."

The meaningfulness component of the sense of coherence speaks to the belief that life makes sense emotionally. This refers to the internal decision that at least some of the problems and demands of everyday life are worth investing energy in; and can be considered challenges rather than simply as burdens². Many of the women spoke of internal psychic changes which took place in their lives as a result of breast cancer.

"Now, I believe I could really say, I thank God for the experience that I had to go through with and not that I really wanted cancer, but I thank the Lord that I was able to go through it."

"...it was like a really bomb, when this came to my mind. Um. And, uh, although at first, uh, I thought, I felt devastated, then afterwards, uh, I felt like it was a awakening."

"And I thank God for the experience. It made me stronger and it made me lean and depend on the Lord more. It did. The breast cancer illness, it made me stronger. It made me a lot stronger."

This collection has strong religious overtones. This has been discussed at length in both qualitative narratives and in quantitative research ^{10,13,14,28,43,47}. Qualitative researchers have considered it a positive influence in the realm of support, much like the idea of manageability.

On the other hand, in quantitative research, the role of religion/god is interpreted as a reason why African American women delay or refuse treatment. As such, it can be viewed as negative influence on the woman's health seeking behavior. If it influences the woman to make a treatment decision which is seen by the doctor as a contraindication to "health," it is less likely to be supported in the doctor-patient interaction.

But the issue is more complicated. Analysis within the context of the SOC, provides a more comprehensive understanding of the role of religion in each of these women's quest for health during the illness specifically and in the experiences of her life in general. Participation in decision making in this framework consists of taking action under the direction of God or within the parameters of the universal order. This includes making decisions about whether or not to accept treatment and which treatments to accept. So, the women, by making any decisions about treatment within this context are attending to their (psychological) health, but not their (physical) health by direct means. Since pure somaticists are not primarily concerned with psychological well being, they are likely take issue with these decisions, sometimes in ways which may actually harm the woman's (psychological) health.

Inattention to inflicting psychological damage is justified by the physician's medical expertise, their good intentions and membership in the culture that owns and defines the dominant conceptualization of health. Ironically, within the context of the woman's SOC, medical care is only a part of manageability. So, to the women, the doctors are even less than demi-gods because they too are subject to the will of God and derive their perceived power from it.

"And for me, I just have to trust the doctors and to trust God to guide their hands and guide their minds so that they will give me the proper care."

"like I told the doctors when I went in there, I said, 'now, I trust you all for the wisdom and the ability that you all have because I know it had to come from God.' I said, 'but, I am really, totally relying upon the power and divine word of God that He's gonna do the total healing. I'll go through the treatment.' I said, 'but (as) far as my complete healing, I believe in the Lord."

"...because the doctors they don't do, you know. God is guiding them, so. And uh, so I put all my trust...most all of it in God first. But then (in) them. Because he's the one that guided them."

"Cuz, nobody, my husband, my children, nobody, couldn't have did for me what God did for me. (Q: What about the doctors?) "They couldn't either. They couldn't either."

"I was steady praying...let Your will be done. Not mine. But guide the surgeon's hand. Lord you gave the surgeon this knowledge, you know. "

"I told him (the doctor), 'I went to the doctor that gave you some knowledge.' I said, 'I went to the doctor that got more medicine in him and His garment, than you got in your medicine bag.' (Doctor) said 'you a prayin' lady.' I said, 'yes I am.'"

The subordination of median to God (or faith in the grand design of the universe) was stated clearly:

"I seen people they're healthy, you know: took exercise, ate right, still got it. What that tell you? And others say, well, don't smoke. If you smoke you gonna get cancer. I know people that never smoke, never drank and they still got cancer."

Q: Are saying is that it's in God's hands all the time?

"Yea."

"...when I thought about that, I said, Lord if it's your will, please don't let my lymph nodes be cancerous. Let my bloodstream be clear. I said, it's Your will, not mine. And it was God's will that it was clear. "

However, it is important to remember that obtaining a sense of manageability through God did not necessarily mean that the outcome is assured. There is (always) a chance for recurrence.

"So, I don't, you know, worry about it. Cuz I feel very, um, if I do get it again, that's God. That's God. I don't have no control over what happen to us. We don't have no control over that. God, you know, He have control over us. So, if I get it again, that's His choice. If I don't, that's still His choice."

"No, I don't. No I don't. You know I have gotten to the point, (where) I don't worry. Why should I sit here and worry about something that I have no control over, okay? If it's for me to have cancer again, the Lord will prepare me for it. "

These attitudes must be distinguished from what physicians and the biomedical literature call fatalism. This mislabeling results from incongruent conceptions of death and control. Black feminist bell hooks (1993) introduces the idea of accepting death as a part of life for African Americans. She suggests that the history of Black peoples in America has shown them how to live "knowing death was in (their) midst.³⁴" This knowledge translates to an acute awareness of the value of life. These black women do not believe that life was promised forever and consequently, they do not take it for granted. Instead, they live fully so that they can, as hooks puts it, "...meet death ready to go.³⁴" They are not necessarily looking forward to death. (This would be fatalistic.) But they have come to an understanding of it; and, being realistic, they do not believe that they would live forever. They were therefore, comfortably able to turn control over to god and put the course of their illness "in his hands." This is where differing definitions of control between doctor and patient may contribute to hampered communication.

In biomedicine, control is considered as the ability to take action which will directly affect outcome. Outcome in biomedicine is largely measured in terms of life and death (survival or not). In contrast, control for these women, reflected something closer to Antonovsky's 'participation in decision making.' While relevant decisions for these women may have included getting their questions answered, agreeing to treatment methods, or having visitors after hours, these women did not believe that it was their decision whether they lived or died; they did not believe that they could change their fate as it is ordained by God, or any other higher power.

"And, faith, a lot of people don't have it. A lot of people they think that they're doing things themselves. But we're not doing things ourselves. If it wasn't for God, we wouldn't even get up in the mornings. We wouldn't breathe. I could lay down here tonight and if it's my time (to die), I'm not getting up in the morning."

III. Health and Hospital Staff Relationships: A. Doctor-Patient Interactions

In the doctor-patient relationship, the women looked for some sign of concern for her psychological well being, in addition to the (physical) technical expertise in their physicians. That is to say, they expected to be supported in their belief in themselves; in positive thought; and in many cases, in the divinity of God. This does not mean that the women expected their physicians to share their religion. But, they wanted to be heard, understood and respected; not questioned, abused or undermined. They wanted support for their psychological health.

"...what I felt from them was a genuine concern for my well being. I didn't feel that I was a number, I didn't feel that I was not respected. "

"...(the doctors) let me know that, '...you can go through this without any problems, it's according to how you accept it.'"

"They said, '...we go along with you 100 percent. Because if you don't do it, it won't be done. We trust God. We know god. It's through God that we are able to do what we do for the people that are ill.' So I was glad to hear that, that I wasn't going to no atheist doctor, I tell you."

"A lot of them doctors need to get some Jesus in their lives...It would make them take their job more conscientious. More loving, more compassionate, more caring and they would understand you better."

The women hoped the physician would take into account the importance of psychological elements in their approach to the therapeutic relationship.

Q: Did people in the hospital ever talk to you about that?

"About God? I think it'd be helpful. I think it'd be helpful to a lot of people. Cuz a lot of people go there (to Highland) believe in god. You know. I mean, all the patients and things. They believe in God, a lot of em."

"He said, the best thing you can do for yourself right now is to thoroughly enjoy life. You know, he said, most people that make it over the hill is the people that really decide, I'm going to enjoy the rest of this time I have here. Irregardless of whether it's short or long. Those are the people that recover the fastest and stay...stay recovered."

In addition to a certain sensitivity to their paradigms of health, the women were also looking for information from doctors. Positive experiences were more common when the doctors answered questions thoughtfully and informed the woman about everything she would have to go through; from procedures to side effects. Providing information seemed to facilitate greater emotional ease while building trust in the practitioner.

"I didn't have no problems at all, you know. Because I believed in him. Cuz he talked to me, he'd tell me what he's gonna do, how it was gonna be. And when I went to pre-op, for surgery, they took very good care of me. They told me, you know, step by step, what it's gonna be, how it's gonna be, how long it was gonna be."

"They stayed in my corner, they talked to me a lot. They always let me know what was going on at all times and now, any time I had a question or I wasn't sure about something, I could call.... "

"I appreciate them letting me know in advance, what I was to go through it, that I wouldn't be fearful when these things started happening. "

" I had a lot (of talking). And they gave me a lot of books to read, which I was grateful for because I started...I really went through 'em, cuz I wanted to know (laughs) what I was gonna have to face with it. "

"I think because it isn't particularly happening to them (the doctor) that they think, oh that's just a side effect; that doesn't matter. They (the doctor) know what's happening.... But it's important to the person who's actually going through it. Makes a difference."

"Yea, it would have been better if they had told me in the beginning; this is what's gonna happen. Sit down and tell people what's gonna happen to them. That's a much better way to do it."

In the instances where biomedical information conflicted with the woman's health belief system and the physician expressed this without regard for the importance of that system, there was a negative reaction from the patient.

"I feel that diet does have a lot to do with your care and the doctor was kinda saying--you know, food intake--he was kinda saying it doesn't. And so, you know, I kinda took offense to that."

This is not surprising. Blum (1983) predicts this occurrence when he writes, "In the face of a broader comprehension of health by the public, there is a predictable patient rejection of non-caring responses from such providers." In turn, Blum writes,

"...many of the providers see such holistic searchings as an expression of anti-intellectualism against medicine⁶."

Although the lack of racial concordance with the physician was not reported to be very important to any of the women, and most had good rapport with their doctors, the lack of cultural/ideological sensitivity damaged doctor-patient rapport .

"Well, I started to voice my opinion and kind of was cut off. And so, uh, I'm a fairly assertive person. But if I talk to you and I can see it's not gonna do any good, I won't continue on. Because we'd be arguing for...we wouldn't get anywhere, because we'd just be arguing."

Further, differences in conceptualization of health impeded the delivery of (psychological) health care. Comparison of the following clinical vignettes elucidate what happens when these concepts come into conflict. There was a difference in both the quantity and quality of interaction experienced by the respondents based on the degree of conceptual congruence.

Case 1

Subject 2, a 42 year old lawyer, presented with 2-1cm masses in the right breast; and a 1cm mass in the left breast. Her tumor was staged at IIa. The mammogram showed diffuse microcalcifications; and there was rapid cell growth by DNA indicators noted in the chart. This woman's doctor patient interactions were very high in quality.

"I had several doctors, and the lead doctor was very patient with questions...I didn't feel that I was railroaded or patronized I felt that they answered my questions when I had them, (it) didn't bother them that I sought a second opinion."

Here she elaborates on the interaction with her physician when she wanted to get a second opinion:

"They were very patient, they didn't push me. I mean the kind of cancer I have or had was an aggressive cancer. And so, it's not something you can wait 5 or 6 months because it may spread pretty quickly. So they didn't pressure me, but they did tell me that as soon as possible they wanted to have the surgery so, reduce the risk of death."

Overall, this woman had a high level of doctor patient interaction and was pleased with the service she received.

"They were caring, because, they answered my questions... I didn't feel that I was a number, I didn't feel that I was not respected. I just felt...they just made me feel that I was important and valuable and they were doing everything they could to help."

Important and valuable are ways everyone would like to feel as patients. She elaborates reasons why she felt respected:

"For example, when the pathology results came back about the lymph nodes, the doctor brought me a copy of it and let me read what the pathologist had to say. And told me, now these are my recommendations for you. They've taken out 28 lymph nodes... and 3 of them were cancerous. So we believe the cancer may have spread, we don't know how far and these are my recommendations."

With free access to information about her own case, it was not surprising that she felt:

"...that they did everything they could to make sure that I healed; (that) I was taken care of while I was healing."

Case 2

In contrast, subject 6, a 44year old, self employed janitor (at the time) who presented with an open wound in the right arm pit and a "fungating" 6x8cm mass, describes one of her initial doctor-patient interactions:

"I had started asking about my options but they kept coming back. They kept coming back at me, saying, well you know, your case is really a severe case right now. And, you know, you're taking a big chance to, to use the word 'stall'--I guess would be the best--any treatment that we suggest to you. Because, you know, you're looking at a life or death situation."

Doctor-patient interactions were consistently cold.

"They were kind of stones. Poker faces....But the doctors themselves it was like kinda this is old, this is just another everyday thing, you know. So they were kind of stone faces. They didn't comment on whether it was good or bad, they might have said something like, you're doing fine. But nothing came..."

Overall, she had very little interaction with her physician.

" He didn't really chat. He did ask me was I feeling any discomfort. He upped my medication--my pain medication--one time. Um, if I was doing okay, he didn't really stay to chat or anything. As long as I wasn't in any discomfort and things were going well as far as my recovery. He just came and made his u-turn."

Access to information was not uncommonly denied.

"Well there's different times when I would ask him different questions. You know, he had a nice bedside manner, but yet, he used it to kind of throw off questions, you know. Or maybe to answer you in a...like he was answering a child rather than an adult."

She did have a good interaction with one of the doctors, but of the rest she said:

"With all the other doctors: well we're gonna do this today. And once they said that, you're off. you know, he's gone. And if you had any questions you were gonna ask, you didn't have time to, because you were off. "

The irony here is that the woman who needed the most information, by prognosis and the most positive support got the least of both. It is difficult to say, exactly why it happened this way. One could speculate that the prognosis predicted by the biomedical frame influenced her physician's behavior. Maybe he felt there was no hope because he felt he was facing failure (stage IV breast cancer is generally untreatable); or the prospect of (her) death. Lack of positive interaction, denial of access to information and disrespect communicate more than just a busy schedule. The physician's ignorance about the patient's health frameworks diminished the quality of the interaction and lead to further miscommunication and misunderstanding.

" And, so they misread me, I suppose. And they were going to put a 24 hour suicide watch on me...He asked me...did I want to see a psychiatrist. And I said, yea, I'd like to see a psychiatrist. But it wasn't like I was going to kill myself or anything like that. It was just that I was feeling very...I mean it's a life or death situation. Naturally, you're gonna feel a little bit morbid, I guess. "

Obviously, the same doctor did not treat both of these women. However, in both cases, it appears that the physician's assessment of the gravity of the situation which influenced the quality of interaction. While the lawyer with a very poor

prognosis was told that the treatment would "reduce the risk of death," the janitor with an equally poor prognosis was told that she shouldn't "stall" because she was "looking at a life or death situation." It is possible that social class played a role in differential interactions. Lawyers and doctors belong to similar social classes in the US. Similar, (or perceived similarities in) constructions of the concept of health in these two groups may have facilitated the development of rapport in this relationship. On the other hand, differing conceptualizations (or perceived differences therein) contributed to a more adversarial relationship. The effect of this contrast is elucidated again in the degree and mode of delivery of information to each patient. While one woman was allowed to read her own pathology report, much of which would be incomprehensible to anyone but a pathologist and a surgeon, the other often could not get answers to her questions and felt as though she were spoken to like a child.

A third and final case demonstrates the breakdown in doctor-patient relationships when the hegemony of the somaticist health view attempts to dominate the broader conceptualization of health.

Case 3

Subject 3, a 66 year-old heavily involved church volunteer, mother of 10 and housewife presented with a 5.5x8 cm mass, assessed at stage III "atleast". Although she spoke of some high quality doctor-patient interactions, the one that colored much of the interview follows:

" He and I went toe to toe, and I tell you.... Oh yes we did. We had some words....he wanted me to still have the surgery and I said, I'm sorry! Every test that I've taken, since I had surgery, they tells me I don't need it.... I told him, no. I said, I'm sorry sir, I refuse to go through a surgery when the doctors had told me that I have no...no symptoms of nothing, evidence at all left in my breast....I said, now, if it should recur, I'll be glad to come back and have my breast removed. Ha! he didn't want to hear that. (The doctor said,) 'Well, we still say you need to go through surgery.' And then he went to so far to tell me, that if I was his wife or his mother, or his sister, he would demand it."

When she stood up for herself, the doctor's adversarial behavior escalated.

"I said, 'let that be the reason that I'm not your wife; I'm not your sister and you are not my brother, okay?' So therefore, I am not having a surgery. (He said.) 'Well, I tell you what, if you should have to come back, I refuse to operate you.' "

This physician's actions could have potentiated physical illness by inflicting serious emotional harm. The doctor felt comfortable behaving this way because he belongs to the social class which defines and controls health. Membership in this group lead him to believe that he had the power to administer it or withhold it . His position as a doctor and the shield of "good intentions" provided protection from scorn while the patient in this situation was labeled in her medical chart: "non-compliant."

B. Nurse-Patient Interactions

The women more overtly expected their nurses to address issues in the broader realms of health, than they did from their doctors. They wanted to feel special, like their nurses really cared and were not "just doing a job."

"Well the doctors, you know, they don't come in. They professional, you know. They don't...ain't gonna ask you how you doing...They gonna take care of you, but they not like the nurses. Because the nurses come in and they gonna talk, like, sit down and watch TV and visit for a minute or two..."

"The nurses were always there, if I wanted icewater, they made sure if I'm still in pain. They made sure that I wasn't in pain, or they'd give me my pain medicine. They always made sure I was comfortable...my diet...I had one nurse at night, I had a thing for chocolate cake and I had one nurse and she sneak downstairs and go get me chocolate cake and smuggle it up to the room. I was spoiled, right; you know and I loved it."

"She used to come check on me when she wasn't even working. And she would make sure I was getting my medicine and I was getting my meals. And that, you know, that made me feel good, you know. And that's, you know, that's what...counts."

"One of the nurses calls periodically, and I think he calls a lot of his patients that way. (Bill Shanks). he calls on a regular basis to find out how I'm doing....So if anything comes up, I can tell him when he calls or else, I can also page him. So I always have access to somebody who knows my whole history because he was there from the very beginning with the cancer.... I guess I would feel pretty cut off if he (Bill the nurse) didn't call and monitor me..."

" I know once Bill (the nurse) said to me, you can call me, beep me anytime, any hour."

"...he (Bill the chemo nurse) take so much pride in how he do his job. And he gets just say, personally involved with his patients, okay. If his patient is going through something that's making (them) depressed, he's gonna find out what it is...."

One might speculate that the women openly wanted this kind of care from nurses because they had more time than doctors. However, the comment that doctors are "professional" and therefore don't have time to really spend with a patient, again points out the impact of perceived class differences between the doctors and nurses; and between hospital staff and patients. It seems that the closer the social class of the provider to that of the patient, the greater the level of provider accountability. While some of the women felt comfortable to complain to an authority about bad nursing service, no formal actions were taken against any doctors; not even in situations where the treatment was incompatible with the provision of "health" care.

IV. Health and Social Support

The people who provided positive social support comprised partners/spouses, family, and friends, including church congregations and pastors. These people listened and talked openly with the women about their illness and they occasionally offered advice.

"I used to work as a volunteer at H in the nursery on the 9th floor and the coordinator of that program is a friend of mine and I think she and I talked about it as well."

"Mainly, just to let them (nurse friends at Highland) know what was going on with me, and what I decided to do and to get their input if they had any input. Cuz they're all in the health care business and if they had any input, just to get any input from them."

"I talked to my kids about it ,too. And they felt that the treatments was best for me to go ahead and, you know and do it."

Many people vowed to simply "be there" through the course of the illness.

"...with the care and help of my family and church family. Cuz I had a lot of support from them. Everything that I had to go through, they were there: my children were there, my sisters."

"My children and all of my sisters and we all came together and we talked about it and they promised to be there for me no matter what I had to go through. And my son and all of 'em prayed, and we prayed together "

"Well they were just there, I mean there at my fingertips. And that is most helpful when you know you have family support. If you have your family, you can make it though anything."

"But, going back and seeing different things that was happening to different people, I could see how it could, without positive influence, that you could be almost, really devastated. I just really thank God, because I really had a lot of support from outside source(s) and family."

In some instances, the entire church congregation prayed for recovery. These examples of positive social interactions are helpful because they support the woman's sense of coherence by increasing the perception of available resources for coping.

"Oh, (Pastor said) 'you'll be all right. You have to pray, you have to keep on prayin. Hold on.' "

"My pastor and his wife helped me a lot. And so did my pastor's son. He's a minister too. Matter of fact, my church members helped me a lot. I knew that they were praying for me. And this helps a lot....And when your church comes to your aid, you know that you are appreciated. And you know that you're missed."

Sometimes family members and partners accompanied the women to chemotherapy and radiation appointments; at times providing transportation and at other times providing uplifting and positive encouragement when the women felt they did not have the stamina to go on.

" Like some days I wouldn't be up to it you know and he (close friend) said, 'uh uh, can't have no downers, gotta see a smile on that face.' He'd get me pepped up you know, and then I go there and come out and I'd be all right."

"He (her husband) went with me (to chemo) unless he had to work and he was always there, and that's just one wonderful thing. Unless he had to be at work, he was always there for me. "

" I had my own car, and then my sister, like I said, she would always come and carry me. Even when I didn't want her too she would be here.

"We'd go to the hospital for treatment and everybody (all 5 siblings)...I say, y'all , y'all takin' up space for other patients. (they respond)...we don't care. We gonna be right here. Sometimes, I would feel so bad, everybody, all these folks with me just to go to the doctor. They said, 'oh no. We gonna see you through this.' And they did."

"In fact, every chemo session, every chemo session, he (boyfriend) went with me. He took off from work and uh, so I had the support. He was always there."

"...say, at home, when I was getting ready to go, I'd tell my boyfriend, I don't know if I can take it anymore, you know. Cuz, I mean you really feel sick. And my boyfriend (would say), you can take it, you can do it, I'll be right there, you know. You know, so, he would start joking, whatever. And that would get me to the hospital."

"Oh if I needed to be taken somewhere, he (husband) would. Or either somebody else would do it."

Occasionally, these supporters acted as advocates at the hospital.

"He used to tease them, talking about, 'now y'all give her a good shot now, I don't wanna hear any hollerin'.' you know and he used to have the doctors cracking up, have 'em laughing."

" In fact, he saved me a couple of times. Because they made a couple of mistakes, in the hospital. Like, one time, they were telling me to come back too soon for my next treatment. And he goes, (to the scheduler) 'no, no she's not.' And they said, 'yes she is.' And he said, 'no she's not.' And then he went through--she's off 8 days and blah, blah, blah...' (and they said) 'that's right, that's right.' And then another time--the nurse was gonna give me the wrong thing."

The positive effect of social networks is well documented in the psychosocial literature. Marshall and Funch (1983) showed the extent of social networks and the depth of involvement directly impacted the clinical course of breast cancer^{24,46}. These interactions were sharply contrasted in the interviews with negative support. Negative social support happened in situations when people acted like they felt sorry for the women.

"They were like, 'oh V., I'm so sorry.' I said, 'you know what, I don't want to hear no tears, I don't to hear no (inaudible).' I said, 'I'm the one who's got to go through it. All I want you to do is just be here for me when I come home.'"

"I didn't pay 'em no attention. I'm the one supposed to been...you know, breast cancer. Not them. And they gonna look pitiful."

"They felt sorry for me. And I told 'em I don't want you to feel sorry for me. Because I don't feel sorry...I didn't feel sorry for myself. All I wanted them to do is love me and show me support, that's all."

"...being a very independent and strong person, I didn't want to hear things from people like, 'oh, I'm sorry to hear that.' Because I would hear things like that that would make me sad and make me feel like I really didn't wanna deal with it."

The expression of pity seemed to undermined the women's belief in her personal efficacy and ability to heal herself. It was as if those who felt pity for the woman felt that she were going to die. This questioned the women's sense of manageability. The aversion to pity was as consistent for family members as it was for friends.

"They reacted like the sisters and brothers, oh, V. I'm sorry and what do you want me to....What the hell is you gonna do? Ain't nothing you can do. I said, 'go'on on, makin' me crazy.' I just...just leave me alone."

"but I didn't tell the whole family...and like I said, I don't want anybody feeling sorry for me. No, I don't need that."

"Of course they (her children) wasn't doing me no good, cuz they was feeling sorry."

"I didn't tell nobody but my children. And (they said): Momma we can't believe this done happened and blah, blah, blah. I said, well, I'm not helpless. I'm not paralyzed or nothing you know."

"My son was more worried than I was, made me sick! Ooh, and he made me, you know, he's the one (that) made...I felt sorry for, instead of feeling sorry for myself. He probably musta thought I was gonna die."

"You know, they might (say), well, she ain't gonna get well, you know she gonna die. And this. You know, a lot of people think that way."

Stigmatization reactions were another example of negative social support from both friends and family/partners.

"There was a man who is an evangelist and he's pretty close to us and um, lets see after the chemotherapy, I had...I ended up losing my hair and so I had on a wig. and so he asked me and my husband, he says 'why would your wife cut off all her hair?' and I said 'oh no it wasn't that, it was I lost it to the chemo and this is a wig.' and he backed off and he looked really uncomfortable and it made me uncomfortable...."

"We started getting along real bad then; when I told him I had cancer. He started treating me like I had some kind of plague, okay."

"And he would tell me that, didn't nobody want me cuz I was old and ugly. And I told him, he would come here--he wouldn't even step close to me. I told him, I said, if you think I got something you gonna catch, you don't need to be in my house."

"I had to just sever ties. I couldn't talk to my mother anymore. My mother was, uh, said she was gonna call the hospital and take me out of there. And (she said) why did I let those people cut on me, and all that kind of stuff. I told my sister, I can't deal with her, I can't talk to her, I can't, you know. I just left them alone."

"...very dominating type parents. That, this was something my mother didn't want me to do, so I had to almost disassociate myself with her. Because I would probably all these adjectives: feel guilty; feel saddened that she wouldn't accept my opinion; feel like a little girl, that I would have to do what she wanted me to do....And knowing how aggressive my mother would be about her decision, or her thought regarding me not having the operation, I just didn't want to hear it."

"And at this particular time, I was going through problems with (pause) a man; that was living in my house (laughing). I wanted to say something else but I'm gone be nice, okay? And I think what really made me have such a hard time going through my treatment is that he turned his back on me when I was ill."

The consequences of these types of interactions are potentially quite harmful. In many cases, they resulted the practice of secrecy, isolation and depression.

"I didn't talk about the cancer to too many people on the outside because although it doesn't bother me, it seems to make people uncomfortable."

"For example, at my church , I didn't talk to too many people about it. Because I didn't want...I felt that it was just a health problem that, for me to go through and I didn't want anyone feeling sorry for me and looking at me as though gee, you're going to die or there's something seriously wrong with you because I don...I didn't feel that way. "

"So rather than having to deal with their reactions, I just didn't discuss it unless it was someone I felt comfortable with or felt wouldn't react that way."

"To me, unless a person is a health care professional or going through it, to me, people don't want to talk about it."

"I was. I used to sell candy, and serve the homeless at the church. But I don't do none of that. I don't have...I don't have...I just don't feel up to doing it. I just don't."

"You know, peoples that don't know, I don't want them to know. You know. Look like you scare people away or something--oh she has...oh gosh. So who knows knows, who don't...but really nobody but my family."

"Cuz to me, that's your business; your private thing. And (if) everybody know, some people kind of scorn you if you got certain...just like the AIDS, Cancer. Oh you just don't want to be around 'em. "

This maybe important for two reasons. First, social isolation during the course of illness has been shown to negatively correlate with health and breast cancer outcome^{4,24,46}. The second reason is that the emotional damage caused by secrecy and isolation may be particularly prevalent in this population. As one woman stated:

Q: Do you think that black people have/keep secrets?

A: "I think so. I think they can hold secrets better than any other race."

V. Health and Follow-Up Care

There was only one type of person that all of the women said they would feel safe to talk to about their illness. These were other women who had been through the experience themselves.

"But my friends, no. I ain't told nobody. I wouldn't dare unless I find someone that has been through the experience and I would share that."

These people were valued because they had the capacity to understand the experiences the women were having over the course of the illness. It was widely held that women who understood the experience first hand would act and communicate in ways which validated the subjects' experiences. Further, women with experience could shed new light on the meaning of the illness in the woman's life and encourage her to tap her internal resources.

"I would like to have to talked to someone... one type who was going through it because that's something I can share with someone who knows what it's like, and knows what it's like at that time. But also someone who had already been through it and could give me some insight to help me see the light at the end of the tunnel. "

"Yea, I met a whole lot of nice people there (at the radiation treatments)...and you know, we were like a little family: We'd meet everyday, go in the dressing room and change our clothes and talk about, like 'well so and so got one more week, countdown time.' you know and you know, that's inspiring."

"The lady that helped me through the medication and...she was very helpful because she had went through the breast surgery she had to have hers taken..."

"...if they never gone through that, they won't understand how you feel, you know. But if a person that's sitting at the desk that have gone through what I have gone through, then they can be more sympathetic to you. "

"Yes if you're going through something and you can get some names and telephone numbers of someone that has been through this, this will build up your esteem. And this will help you, a lot."

The women in the study valued first hand experience more than medical knowledge for its roots in practical reality.

Q: Did you ever feel like no one else could understand what you were going through?

A: "Yes. You know. I don't think you do unless you been through it. Can you understand? It's just like a woman had a baby."

"You don't know. A person can tell you all day. You're gonna do this. But once you experience it, you know."

Q: If you had a choice between someone who has been through it and a doctor...

A: "I prefer the one that been through it. Cuz, see he only done... just cut it off and sew you up or whatever. But she can tell you how she feel and she relate to you, you know. He could, too. But see, nothing like experience."

While a medical text or a doctor could predict theoretical outcomes of disease and treatment, only someone who had first hand experience could share strategies for coping with physical disfigurement, the effects of chemotherapy and radiation therapy; and feelings about breast reconstruction.

"Now, that would be fine...to see what her feelings are, you know. Another patient that have had that."

"I would like to meet new people to see what their reaction is....To see how other women...you know, have they cut out any of their activities or whatever."

"If I could have talked to a woman that had this before. Yeah. It would have made me more comfortable, you know, going through with it."

"And so, I think talking to patients that have had chemo and maybe saying, you know, what did you feel is important for somebody else to know so they don't get scared and say, you know, what's happening, what's happening."

"She said, don't look at the part about I'm going to die. God is going to cure me, you know. This is the way she brought it to me. And it helped me a lot. It helps a lot to sit down and talk with someone that has experienced breast cancer. I experienced uterus cancer, not breast cancer."

With this desire to talk to and the great value placed on the input of women with experience, it was surprising to notice a trend of refusal or disuse of the services

offered as follow up in the Satariano-Harness study of 1994. These services included breast cancer survivor support groups, and in home care. In the current study, the women said they refused services for a number of reasons. From access issues;

“If I have the time. I'm very busy. And I work everyday, so. I just didn't have the time. I didn't go out to the studies (at Highland) because I couldn't fit it in.”

to preexisting social networks.

“Well, they (hospital staff) offered me a lot of services that I could have had going through this. But like I told the lady, I said, you know what, that wouldn't be fair because you could take this and use it for someone who's really in need. I don't need it, I said, my family's been right there.”

“...at that time, I could take care of myself. And my daughter was living her then. I had plenty help.”

“ My daughter help me with that. That's fine. See, I don't drive and she have a car. And she take me around to places.”

Some were proud and felt that accepting the services would cause them to feel as if they were handicapped or needy.

“F. (the interviewer from last time) told me that, and I didn't think I needed it, cuz I didn't want to feel like I was, you know, I was handicapped.”

“I wanted to do it myself. You know after I felt better...let me see, how old was I then? I was like 69 or seventy. I said, shute, I ain't that old. I'm old, but I ain't that old (that) I can't get around and do something myself. Cuz I don't like to feel handicapped.”

“So I would come home after treatments and uh, do what I had to do. Come in and cook, and do whatever else I had to do. You know, so. I didn't need no one. I stood...(laughs) just stood strong. I didn't need nobody. I didn't even think about it. No. No. That didn't even enter into my mind.”

Q: If there were more survivors around, would that had made a difference?

A: “Most definitely. I think it makes a difference. I think where the problem would come in is whether I would use it or not....I know everybody's not like me, but I'm the type of person, I wouldn't necessarily seek help out. Because I would always be trying to deal with it myself and because I'm a closed person.... I wouldn't necessarily come to you and say, I feel bad, I feel like I'm dying, will you come talk to me for a minute, you know.”

“I did things for myself. I'm not a person that depend on somebody else to do something for them. I wasn't raised that way.”

"That's the way I was raised. My mother raised me not to depend on nobody but myself. (That's) how I was raised."

This pride, or the desire not to be treated as an "ill" person is consistent with the finding that subjects who expressed a fierce sense of independence were often the ones who were the most eager to be of service to others.

"For my benefit, I wouldn't need it, but, if it was for someone else, I wouldn't mind being there."

"But if it was necessary, I mean for to benefit to someone else, to share or something like that, then I wouldn't mind it. But for my own self, I don't feel that I need it right this...at this time."

"I wish I could help them because.... The girl and I tried to get a quilting class going on. Cuz some of those girls probably feel sorry for themselves. We could sew and stuff like that and be successful in something. We could be doing something, you know, make 'em feel better. It might make 'em feel better."

Q: Did you ever want help?

A: "Uh-uh. That's funny, huh? But I didn't. Cuz I didn't feel that sick you know. That's funny, but I sure do want to help somebody. Cuz I don't want to feel like I'm that, you know, that sick that I need...."

Although they did not directly mention the utility of breast cancer support group, the women discussed the utility of sharing their experiences. These comments suggest that the women felt that through sharing their own experience, they would be able to help others.

"Oh, I talk about it all the time because it's very important that women learn to take mammograms. And I talk about it constantly because that's what saved me. "

"If you can share your experience with someone else, you're helping this person. You haven't experienced it. But, I feel like I can help you, if you get breast cancer."

"I hope they put my name on the list. Maybe I can be a help or a pillar of strength for somebody else. Cuz I've been there. And I know what you're going through. It's hard to explain because if you really haven't experienced it yourself, you don't know how it feels."

"They said, you of all people, why did this have to happen to you. I said, why not? I said, the lord knows for what reason I'm going through this. Maybe it's not just for (me), (it's) to be an example for somebody else down the road further."

The subjects thought sharing could help them by counteracting isolation; helping them come to terms with their illness; and by imparting meaning to their experience.

“And I thank god for the interview that you have that maybe this will be an enlightenment for some other woman that's going through that they may feel they're not able to cope with it or face it, but they can.”

“ I never did come to a conclusion on your question, 'how do I feel about talking about it.' Is, it helps me to open more and even though it's still within a selected group. But it helps me to talk about it and explore within my mind, actually how I feel when I'm talking to you about it. I know feelings come up.”

“ I mean if I'm in a...some type of setting where there's discussions, then I might bring it up, just to work my way through in how that the Lord healed me of it. You know, I was delivered, so, I don't mind talking about it. “

“But it doesn't bother me to talk about it. If anything, it gives you relief. If you can share your experience with someone else, you're helping this person.”

Conclusion

With respect to breast cancer epidemiology, American Black women live in a paradox. They have an overall lower incidence of the disease than white women, but their mortality rates are relatively higher. The body of work which attempts to explain these differential outcomes is essentially a literature of victim blaming. There is little or no attention to the impact of psychosocial issues, doctor patient interactions, or access issues on survival; and there is very minimal contribution to the works by black women breast cancer survivors themselves. The danger in the limited nature of this body of research is that as the dominant source of information, it influences the way physicians approach medical care and it serves as the basic philosophy for the development of breast cancer intervention for this group. The goal of the present research was to share the experiences of a group of black women breast cancer survivors so that they might have the opportunity to exert equal influence on physicians and the development of appropriate health interventions.

The goals of intervention are both to encourage early detection of breast cancer and to increase the length and quality of survival. Audre Lorde, a black poet and one time breast cancer survivor wrote: "Survival isn't some theory operating in a vacuum. It's a matter of my everyday living and decision making."⁴⁶ If biomedicine is to address this period of 'everyday living and decision making,' it must derive a deep understanding of what it means for this group to survive/secure health. Further, it must apply this understanding to the creation of breast cancer interventions and treatment.

In contrast to the narrow definition provided by biomedicine, the women in this study held a broader view of health. For them, this concept extended beyond the realm of physical well being and into the realm of psychological well being. In their definition, physical and psychological well being have equal impact on each other and cumulatively determine self assessed health status. This speaks to the social construction of health since low income black women living in a calssist, racist and

sexist society will need more than just physical strength to overcome the daily stresses of living and decision making in addition to the added stress of the illness condition. This articulation of health has been corroborated in the writings of contemporary black female authors and community activists. The importance of psychological well being in achieving health after breast cancer has also been validated in some biomedical circles by the work of Marshall and Funch (1983) and Spiegel (1989).

The women in the current study have been able to maintain this sense of health through the course of their illness by various means. One means is the internalization of what Antonovsky called Sense of Coherence (SOC). The SOC is a global orientation to events in the world which allow a person to cope with various life stressors. The components of the Sense of Coherence are comprehensibility, manageability and meaningfulness. Many of the women in the study achieved a SOC through faith in God/destiny. This helped them to make sense of their illness (comprehensibility/God's will/universal order); to perceive that they had ample available resources to get through the illness (manageability/God as social support); and to find that they were able to gain something from the experience (meaningfulness/life enrichment/awakening). Many of the women placed all control over the course of the illness in God's hands. Some, in biomedicine might say that these women feel powerless and that their attitudes are fatalistic. This is a mislabeling which results from different perceptions of what it means to live and from the social construction of the concept of control. These women are not fatalistic, but experience life as a gift, only temporarily one's own. Further, the women discussed control in terms of their own emotional stability and the degree to which they participated in maintaining health; rather than in the ways that they, through human actions could change the course of God's will on earth.

Good doctor-patient interactions were those in which the physician tried to address the broader aspects of health. They were able to do this by freely distributing information, answering questions patiently and respecting the woman's personal health

belief system. When good rapport was established, doctors in the SOC frameworks were tools of God and contributed to the woman's sense of manageability. When doctors were unable to abide by the woman's broader definition, and could only see the somatic side of health, doctor patient interactions deteriorated. At times, this was further complicated by class issues between the doctor and patient.

Poor doctor patient interactions were potentially harmful in two ways. The first was that these interactions could have contributed to psychological harm. Psychological harm in the definition of health put forth by the respondents might decrease the woman's ability to heal physically. Second, adversarial interactions between doctor and patient could easily contribute to what doctors call "non-compliance."

In interactions with nurses, the women talked overtly about the desire for emotional care and service beyond the call of duty. This discussion again brings up issues of social class (and hospital rank). While physicians were never really held accountable for unsupportive actions, the women felt free to hold their nurses accountable for care which did not support psychological well being. This suggests that the women were (consciously or unconsciously) aware of and accepted the socially prescribed limitations and approval afforded deeply entrenched members of the dominant biomedical group (doctors).

Positive social interactions included those with family and friends that bolstered the woman's sense of coherence. This was accomplished by increasing her sense of manageability (augmenting available resources). Negative interactions, such as reactions of pity or stigmatization from other people (friends or family) undermined the woman's sense of self efficacy and introduced negative thought. Many of the women avoided such reactions through secrecy and isolation. This is an issue to be dealt with since secrecy and isolation have been implicated in poor health, depression, and decreased breast cancer survival.

As has been revealed in other narratives of women with breast cancer, this study showed that survivors would most likely be willing to break the code of secrecy in the presence of other survivors. Talking with other survivors, and having the opportunity to share experiences added meaning to these women's illness experiences and provided emotional relief for some. These findings have obvious implications for the conceptualization and development of follow up and home care services.

The previous quantitative study showed that follow-up services were generally refused when offered to these women at the time of their treatment. In this study, reasons for refusal were elucidated. Some women refused the services because they felt they had strong extant social networks, some had access issues, and still others felt that by accepting the services, they were admitting to some internal inadequacy. At the time of this survey, some were interested in or involved in follow up services through Highland Hospital. This change in attitude regarding these services over time also has obvious implications for the administration of follow-up care.

Caveats

First, the discussion of overall well being is not meant to perpetuate the same ideas that Bernie Seigal advocates. This study is not meant to give the impression that if a woman just keeps a good attitude that everything will be okay; the cancer will go into remission. This kind of simplistic thought has driven some to self blame for contracting the disease and the inability to recover ⁶⁸. But rather, I am trying to call attention to the relevance of psychological well being in an effort to avoid causing psychological harm and potentially negatively impacting health outcomes.

Second, critics of qualitative research may also suggest that this work is limited by its small sample size and lack of generalizability⁸. This is less significant in this study since Highland hospital saw a total of 40 cases of breast cancer in 1992; 3 fewer than the previous year ³¹. Of the 10 women interviewed in this study, 4 were diagnosed and treated in 1992. With black women representing 36% (or about 14) of the case of breast cancer in that year³¹, this study included a significant representation of the black, breast cancer patient population in 1992. Similar analysis may obtain for cases in 1993 and 1994. This lends weight to the significance of the theories resulting from the current study.

Further, work in the qualitative *phenomenologic* methodology has as its goal the development of potentially impactful theory derived from many sources. So the theories developed here are not limited to inputs from the ten subjects participating in this study. Other sources such as contemporary literature; recent and past cancer narratives; and community experience were consulted in order to help confirm, negate and ultimately fortify the theories derived from this work. This study, by uncovering new information through interviews with a small sample represents a beginning and an impetus for further exploration.

Third, while black feminist thought in interview methodology allowed an opportunity for black women to define their illness experience in their own terms, it is

important to remember that the results of this study are not the views held by all black women. Understanding of cultural conceptualizations of health, or anything else, cannot be accomplished by checklist. The only solution to cultural incompatibility in doctor-patient interactions is for the physician to ferret out the patient's social constructed definition of health and health belief systems and discover a way to work with it. This study reaches peak utility when all physicians become cognizant of the complexity and diversity of personal health beliefs, and begin to purposefully, systematically, and analytically incorporate this knowledge into medical practice. If doctors are working to serve the patient's best interest, that is, to provide them with health, they must aspire beyond their own notions of health to create a therapeutic partnership to address that patient's sense of health as well. It is only then that physicians and institutions can optimize breast cancer care for this and all populations.

Recommendations

1. Further Epidemiological Studies

A. Qualitative Study: Larger Sample Size

If biomedicine hopes to design interventions to impact breast cancer outcomes for African American women, it is crucial to begin to understand, in depth, socially constructed health beliefs in these communities.

The qualitative method of research will help to uncover context and hidden meaning in responses elicited by quantitative research. The contribution of black feminist thought in the approach to qualitative interviews will also allow black women to begin to articulate perceptions of their own social environment as well as their experience with illness within that environment. The results must be derived, expressed and critiqued by other black women. This will provide the opportunity for the women who are affected to have input into the design of appropriate therapeutic intervention and may increase utilization of such interventions.

To develop these interventions on a large scale, we must perform qualitative studies of larger sample size. This will take an incredible amount of time, but future benefits will exceed this drawback. Larger sample size will increase the generalizability of resulting theories. Further, population based theories will gain greater acceptance and begin to influence physician's approaches to health provision and the appropriateness health care of solutions.

The sample sizes do not have to be nationwide. Large (primarily county) hospitals may benefit from performing their own qualitative interviews, since they are usually community based. There is reason to believe that surrounding communities, particularly if they are low income, will share common threats to health and thus derive similar goals in their health belief systems. Hospitals undertaking this task may eventually tailor care provision appropriately for their specific communities.

It might be suggested that quantitative interviews in the form of needs assessment could serve the same purpose, in both faster and thus, more cost efficient ways. The drawbacks are two fold. First, the survey instrument would likely be prepared by a trained researcher or institution. This will confine possible responses from participants and only truly uncover the places where the both interviewer and subject overlap in their thinking about health and health care services. Second, the irony of needs assessment as we currently know it, is that it proposes to discover community needs, while offering limited choices of available resources. The services offered may not be needed; while what is chosen by respondents may only be "needed" relative to the other choices. Through qualitative studies, we can begin to ask a community, "what are the forces you are up against?" and "what assets do you already have to combat these forces?" The difference between the two questions is true "needs" assessment.

B. Qualitative Studies: Comparative

In this study, the potential impact of racism on the doctor-patient interaction was not explored. In general, the women said that the race of their provider did not make a difference in their interactions and most of them were able to develop good rapport. It is difficult to believe, however that the environment of the hospital shields those inside, from the forces outside; of which, racism is one.

To better assess the impact of racial incongruence in the doctor-patient interaction, it would be interesting to compare the differences in breast cancer experiences of white women and black women, with specific questions about the doctor patient interaction. Issues of comparison might include, as was undertaken in this study regarding class, the amount of information provided, the level of doctor-patient interaction, and the kinds of options offered to the women for treatment. It is clear that these studies would have to control for stage of breast cancer at the time of diagnosis, so as to avoid the effect of good versus poor prognosis on physician behavior.

The same type of comparative study could be performed to assess the role of physician gender in the interaction.

2. Optimize Breast Cancer Care: Focus on Wellness

Breast cancer care, specifically for African American women should be pursued by a dual therapeutic approach. It should be pursued both medically and in terms of psychosocial issues and wellness. Highland General hospital is unique in that it has the capacity to do both. The idea for this program is not unique. Alta Bates Comprehensive Cancer Center also provides psychosocial support to women survivors and their families. However, the difference at Highland lies in the ability to house the majority of both types of services in the same building.

A. Before Diagnosis: Outreach Strategies

The psychosocial care should start before diagnosis, with the Alameda County Breast Cancer Early Detection Partnership Program (BCEDP). Qualitative interviews should be conducted with Highland breast cancer patients to determine approaches to outreach for the promotion of early breast cancer detection and cancer education. Since these women have been through the experience, they may be better equipped to articulate the ways in which outreach can be the most effective. Both breast cancer survivors and trained lay health workers from the same community should do outreach.

B. At Diagnosis and Entering the System: Cancer Navigation

Q: Would it have made a difference if someone had gone with you to the appointments?
"That might have been nice. But I didn't have anybody to go with me. So I had to do it myself."

After diagnosis, the women enter into a completely new culture of the medical system. This is a time when psychosocial intervention will also be useful. Highland General Hospital hosts two of only three cancer navigators in the state. Cancer navigation is a means by which women can obtain advocate-style help in getting

through the health care system. The current navigators accompany people to appointments, help them to understand procedures, research health related questions and advocate for them with doctors and in the coordination of medical care.

Because of the demands of the job and the small number of navigators at Highland, it might be helpful to expand the cadre of navigation workers. This might be accomplished by scaling down the duties of the navigator so that breast cancer survivors who live in the community may also participate. Pared down navigational duties might include accompanying women to appointments, openly discussing experiences with different treatments, answering experiential questions and providing emotional support when possible.

C. During Treatment: Recommendations for Doctors

"Yea, it would have been better if they had told me in the beginning; this is what's gonna happen. Sit down and tell people what's gonna happen to them. That's a much better way to do it."

Physicians should be aware that not black women may not know a lot about breast cancer. This has been documented in the biomedical literature. It is interesting that the literature fails to discuss one of the most important misconceptions that black women may hold about breast cancer: that this is a white woman's disease. Dr. Susan Love, a premiere breast surgeon at the University of California, Los Angeles partially acknowledges the role of biomedicine in this misperception when stating, "...society needs to find ways to recognize breast cancer as a health problem for black women; most commercials and public service announcements about breast cancer...use young white women as models."⁶⁵ This lack of information may lead to what some doctors perceive as passivity or non participation in the interaction around treatment decisions.

Q: So they just said, we're going to take your breast off?

"Yea. That we got to remove it. And I said well couldn't you give me some medicine or something? He said, no. But see, they didn't explain to me that you could take a portion off. They didn't explain..."

The decisions the women make are limited by the options they perceive. Furthermore, the options they perceive are directly influenced by the degree of information furnished by their physician. Physicians should entertain a goal of maximally open communication in order to provide as much information as possible. If they are unable to provide anything more than reading materials, they should refer the woman to a cancer navigator or an experienced breast cancer survivor.

"Well, I started to voice my opinion and kind of was cut off. And so, uh, I'm a fairly assertive person. But if I talk to you and I can see it's not gonna do any good, I won't continue on. Because we'd be arguing for...we wouldn't get anywhere, because we'd just be arguing."

For provider communication reflecting the importance of sociocultural sensitivity, Berlin, et al (1983) recommends following the acronym: L.E.A.R.N. This stands for: **L**isten with sympathy and understanding the patient's perception of the problem; **E**xplain your perception of the problem; **A**cknowledge and discuss differences and similarities; **R**ecommend treatment; **N**egotiate agreement⁵. These guidelines will help the physician begin to understand how the woman is coping with her disease and how to work with her to support this.

"...if I feel that the staff doesn't care, why should I go back."

Including the patient's concerns and concepts in setting and achieving the goals of health care delivery will help develop a therapeutic partnership and may contribute to a decrease in "non-compliance."

Breast cancer and all other cancers are diseases with very strong emotional components and socially constructed definitions of health. This is particularly relevant to the group of women in this study. Doctors may do harm by denying access to information and ignoring the patient's contribution to healing. In severe cases of breast cancer, the doctor should treat the disease aggressively, not the patient.

D. Follow-Up Care: Support Groups and Peer Referral

“Yea, I would have liked to talk to other women. Hear their side, and let them hear mine. That would have been really good...Yea, I would love that; exchange stories with other women.”

Breast cancer support groups can provide a source of strength for women and their families. Highland Hospital currently has a number of breast cancer support groups running. Special attention, however need be paid to the scheduling of these groups, since most of the women who were interested but never attend gave time conflict as the main barrier to participation.

Q: If there were more survivors around, would that had made a difference?

A: “Most definitely. I think it makes a difference. I think where the problem would come in is whether I would use it or not....I know everybody's not like me, but I'm the type of person, I wouldn't necessarily seek help out. Because I would always be trying to deal with it myself and because I'm a closed person. Um, that I wouldn't necessarily come to you and say, I feel bad, I feel like I'm dying, will you come talk to me for a minute, you know.”

It is crucial that follow up services be offered because many proud women would not voluntarily ask for help. It's also important to pay attention to the way follow up is offered to these women.

“I didn't think I needed it (follow-up support), cuz I didn't want to feel like I was, you know, I was handicapped.”

Some may feel insulted or that the person offers is judging them to be too sick to take care of themselves. Therefore, offers of support group and peer counseling should be shared in a positive light. It should be offered in a way which exposes the benefit for both or all persons involved, not just the benefit to the woman who is newly diagnosed. Facilitating these connections helps maintain focus on the idea that surviving breast cancer is a long term process. It does not end with the removal of the breast or the breast mass, but continues on through the remainder of life. Maintaining contact throughout the survival period may also increase the use of follow up services since at least 2 of the women in this study changed their minds about the use from the

time of hospitalization to the present. This may correlate with age at the time of the interview.

Some women who feel shy about sharing in group setting might find the peer referral system easier to use.

"But it doesn't bother me to talk about it. If anything, it gives you relief. If you can share your experience with someone else, you're helping this person."

"I hope they put my name on the list. Maybe I can be a help or a pillar of strength for somebody else. Cuz I've been there. And I know what you're going through. It's hard to explain because if you really haven't experienced it yourself, you don't know how it feels."

The creation of a breast cancer survivors peer referral system will help survivors help others while simultaneously helping themselves. bell hooks points out the importance of experienced women sharing survival wisdom: "It would be useful to black women to hear more from one another about the ways we change our lives to reduce and/or eliminate stress.³⁴" This type of system has already been created by the Women's Cancer Resource Center, in Berkeley. Peer referral forms require a phone number and some detailed information about the survivor including religious disposition, thoughts on the causes of breast cancer and feelings about alternative therapies. The purpose of the detailed information is to appropriately match newly diagnosed women with survivors who hold similar beliefs. The registry would also serve as a referral tool for physicians and survivor network for the drafting of outreach workers.

Highland General Hospital is unique in that it has the capacity to optimize breast cancer care for this group of patients. Hospital administrators acknowledged the need to address breast cancer issues in this population in the 1993 annual report. "The problem of breast cancer is especially acute for minority, low income, underinsured or indigent patients. For example, African American women...have a higher probability of dying of this disease than white women in every situation analyzed; all age categories, all stages of disease at diagnosis, and all treatment

modalities.³¹" The higher probability of dying regardless of treatment modality suggests that biomedicine is failing in its attempts to correct this problem. This study has suggested a means by which biomedicine can expand its approach and redirect its goals toward meeting the patients' concepts of health.

The integration of psychosocial intervention into the routine medical regimen will serve both the doctor and patient's individual concepts of health. The psychosocial parallel to medical treatment should begin with the BCEDP, cancer navigation program, peer referral system and follow up with support groups. In a well coordinated program including all of these elements, survivors who are willing and able may re-enter the system to help themselves and other women to achieve health, well being and ultimately survival.

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Appendix A: Survey Instrument

PART A: GENERAL INFORMATION AND INTRODUCTION

I. INFORMED CONSENT PROCEDURE

II. INTRODUCTION

Thank you for agreeing to be part of my special health study of women who have undergone treatment for breast cancer in their lifetime.

Your participation is of course voluntary. Should we come to any question that you do not want to answer, just let me know, and we will go on to the next one.

I will be asking some very general questions and I want you to feel free to tell me anything and everything that you want.

I want to emphasize that all of the information obtained in this study will be kept confidential. No one will be identified by name.

You have the right to end the interview at any time.

III. BACKGROUND

1. General

When is your birthday?

_____/_____/_____

So, tell me about yourself.

Are you married?/ divorced?/ widowed/ living with someone?

How long have you been ()?

Who lives with you right now? (no names, just relationship gender and ages)

Did you grow up in the Bay Area?/ Where did you grow up?

Did you go to high school around here? (in the Bay Area?)

Did you go on to college? Where did you go?

Do you belong to any clubs, church groups, organizations?

How long have you been involved?

What do you like to do for relaxation/fun?

Do you work? What do you do?

Do you enjoy what you do?

2. Feelings Today

How are you feeling today?

How do you feel about sharing your experience with breast cancer?

3. Breast Cancer Status

When did a doctor or nurse tell you that you had breast cancer?

Were there any other times?

Are you currently in remission?/(Do you currently have breast cancer?)

(When did you get the diagnosis of this cancer?)

When were you treated for breast cancer?

4. Employment and Insurance

Were you working during that time?

What was your job?

Please tell me briefly what you did at that job.

How long were you at that job?

Did you enjoy your work?

Did you have health insurance benefits (thru job or other)?

Tell me all the types of health insurance you had at the time.

Did you have:

Medi-Care Medi-Cal Medi-Gap Blue Cross/Blue Shield
Kaiser Other: _____

5. Overall Well Being

Would you say your overall health is:

Excellent Good Fair Poor No answer/DK

What's your definition of "healthy?"

What does it mean for you to be healthy?

PART B: VIGNETTES
I. MEDICAL ENCOUNTERS
1. Lump Discovery

When did you first think you might have cancer?

Why did you think that?

Specific Questions

How were you feeling?

What does the word 'cancer' make you think about?

Were you worried about insurance?

Were you worried about where you would get health care?

Did you have any other specific worries at that time?

2. Diagnosis

Take a moment to think about the day when a doctor or nurse told you that you have cancer.

Do you remember that day?

What do you remember most about that day.

Specific Questions

What were the more important things going on your life at that time?

Was anyone with you at that time--like a friend or family member?

How were you feeling?

What was it like to talk to the doctor?

Was it your regular doctor?

What race was the person who told you the news?

Did that make any difference to you?

3. Treatment

Now, we've talked about when you found out the news. What happened next?
Did you go home and think about it?

What kind of medical treatment did you get for breast cancer?

How was that treatment decided on?

Did someone at the hospital talk to you about treatment options?

When did you talk to this person about choices and decisions?

Was it the same day as when they first told you about the cancer?

What was it like to talk to that person?

Specific questions

Were the options explained clearly? Did you understand them?

Were you offered the option of a second opinion?

Did you have specific worries you wanted to discuss with the doctor at that time?

Did you ask those questions?

Why not?

Were you able to get answers to your concerns?

Did you feel respected? Listened to? Like your opinion counted?

Further questions

How long was it before you decided what to do?

Did someone at home, or a friend help you make the decision?

Who did you talk to about it?

Was that person helpful?

Did anyone talk to you about breast reconstruction (plastic surgery)?

4. Post Surgery I

**Now let's talk about what happened after your treatment
(If Surgery...)**

Did you stay in the hospital following surgery?

Did the doctor stop by to see you?

Who (else) stopped by?

Who stopped by the most?

When did you first see the doctor?

What was it like? Did he seem interested in you?

Specific Questions

Did he make you feel like everything was going to be alright?

Did you have specific questions you wanted to ask him?

Were you able to ask?

Why not?

Further

What was your greatest concern after treatment?

Were you able to talk to someone about this concern?

Did you get what you needed/get answers?

4a. Post Surgery II

Were there any other interactions with medical staff after surgery that you'll never forget?

Specific Questions

With social workers?

With therapists/counselors?

5. Chemotherapy/Radiation

Now let's talk about chemotherapy and radiation treatments. Did you have chemotherapy at Highland?

Did you have radiation therapy at Highland?

What was that like?

Specific Questions

Was it difficult to keep appointments?

Why? transportation? job? kids?

Did you have bad side effects of the drug?

Were you prepared for those effects?

Who helped you prepare?

Were you able to talk to someone about the bad side effects?

Were your concerns listened to?⁷³

Did you see your doctor at all during this time?

Were they helpful?

Who was the most helpful to you at that time?

Did you feel comfortable going for appointments?

Did anyone go with you to the appointments?

Would it have made a difference if someone had gone with you?

Why/Why not?

6. Follow Up I

When did you finish your chemotherapy/radiation therapy?

After chemo/radiation, did you talk with or visit your doctor at Highland?

How did that happen?

Specific Questions

Did anyone call you to remind you about appointments?

Would that make a difference in whether or not you came?

Did someone talk to you about getting a prosthesis?

Was that stressful?

6a. Follow up II

At the time of your breast surgery or treatment, did anyone talk to you about support or home care services?

Did you get them?

Why/Why not?

Specific Questions

Were you satisfied?

II. SOCIAL NETWORKS

1. Family Relationships

Now let's talk about your relationship with your family at the time.

How many relatives/family members do you feel close to?

In general were you close to these same folks over the period of time we've talked about?

2. Telling the Family

Did you tell anyone in your family the news?

Who did you tell?

Specific Questions

How did they take it?

How did you feel?

Were the family members that you told helpful to you at all during this time?

How were they helpful?

3. Family at the Hospital

Did your family have any contact with the hospital or staff during the process?

Can you recall any experiences when a family member spoke with your doctor or other hospital employees?

Was it helpful?

In what way?

Specific Questions

Were the doctors or any other medical staff willing to talk to your family and answer questions about breast cancer?

Did someone in your family help you get what you needed at the hospital ?

4. Relationships with Friends

How many close friends do you have, who are not family?

Were you involved with any church groups, clubs or support groups during this time?

5. Telling Friends

Did you tell any of your friends/group members the news?

Specific Questions

How did they react?

Was it helpful to talk to them about it?/why--why not

How did their reaction make you feel?

Have you maintained those relationships until now?
Did any of those relationships change?

6. Friends at the Hospital

Did your friends have contact about your case with the hospital or staff during the process?

Was it helpful?

In what way?

Specific Questions

Were the doctors or any other medical staff willing to talk to your friends and answer questions about breast cancer?

Did any of your friends help you get what you needed at the hospital?

III. BROAD VIGNETTES

1. Sources of Strength

Was there something that kept you going during that time?
Can you identify what that was?

Specific Questions

Was it your family? friends? belief in God? medical treatment?
support group?

2. Voice /Woman's Perspective

Looking at this process overall,

Did you feel like your concerns were listened to at the hospital?

Who was the best listener?

Did you feel like they respected your opinion?

Did you feel like you could rely on/trust the medical staff?

Who did you trust/like/confide in the most?

Did you feel in control of the situation?

What does control mean to you?

Did you feel you could achieve these things?

Who was the most supportive at helping you do this?

Specific Questions

Please rate how each of the following people helped you achieve ():

Doctor	very helpful	not helpful	no difference
Nurses	very helpful	not helpful	no difference
Friends	very helpful	not helpful	no difference
Family	very helpful	not helpful	no difference

What did they do that made them helpful to you?

3. Personal Saviors

Looking back over this experience, what got you through it?

4. Recommendations I

Were some parts of your experience with breast cancer more difficult than others?

What was the hardest part of your experience?

What could have made it better or easier?

Specific Questions

Did you need help getting to the hospital for appointments--like transportation or childcare?

Was it difficult to deal with doctors? nurses? social workers?

Did you ever feel like no one else could understand what you were going through?

Did race play any part in that?

Did male/female sex play any part?

4a. Recommendations II

Is there something about your experience that you think every African American woman should know?

Is that everything?

If other women were getting together to talk about how they were coping after treatment for breast cancer would you be interested in participating?

4b. Recommendations III

Is there something about your experience that you think every doctor, nurse or hospital worker should know?

Is that everything?

PART C: CLOSURE

Would you like a copy of the final report from this research?

Do you have any questions for me?

Please feel free to call me if you recall something you think would be important to know or if you want to add something to what you've already said.

Thank you very much for your bravery, time and energy.