“GOD WILL GET ME THROUGH”:
AFRICAN AMERICAN WOMEN COPING WITH BREAST CANCER
AND IMPLICATIONS FOR SUPPORT GROUPS

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This research examines the coping processes of African American women with breast cancer and how those processes relate to low usage of cancer support groups by these women. Prior coping research has utilized predominantly White samples. The limited research on African American coping responses is conflicting and characterized by small samples and non-probability sampling techniques.

In this study, 26 respondents from Central and North Texas metropolitan areas were interviewed, including 9 key informants, 9 African American breast cancer survivors, and 8 White survivors. The data suggest that African American and White women cope with breast cancer in significantly different ways. Culture appears to account for the differences. All African American breast cancer survivors identified faith as their primary coping strategy. In contrast, only half of the White survivors claimed faith as their primary coping strategy, but like the other White survivors, tended to rely on multiple coping strategies. The African American survivors conceptualized God as an active member of their support network. Most prayed for healing, and several attributed examples of healing to God’s intervention. The White survivors found God’s presence in the actions of other people. They prayed for strength, peace, and courage to endure the illness.

The use of faith as a coping strategy was the most significant difference between the African American and White breast cancer survivors, but different social support needs were also evident. White survivors readily disclosed the details of their illness and actively sought the
assistance of other people. African American women were much less likely to discuss their illness with other persons and expressed a greater inclination to rely on themselves.

This study indicates that cancer support groups must be structured to consider cultural coping differences for wider African American usage. Coping research conducted on primarily African American samples is necessary to develop interventions intended to serve African Americans.
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CHAPTER 1
INTRODUCTION

This research examines the coping strategies and resources of African American women with breast cancer and how they relate to the relatively low rates of utilization of cancer support groups by this segment of the population. Cancer support groups have proven to be an effective coping intervention. They have been linked with improved psychosocial functioning and reductions in self-reported physical pain (Fawzy, Kemeny, et al., 1990; Goodwin et al., 2001; Spiegel, Bloom, & Yalom, 1981) as well as with increased survival time for participants (Fawzy et al., 1993; Richardson, Shelton, Krailo, & Levine, 1990; Spiegel, Bloom, Kraemer, & Gottheil, 1989).

Breast cancer is the most frequently diagnosed cancer in women of all races and ethnicities in the United States. Currently, a woman in this country has a one in seven chance of developing invasive breast cancer in her lifetime. Approximately 211,240 new cases of invasive breast cancer are expected to occur nationally in 2005 (American Cancer Society, 2005). An additional 58,490 cases of in situ breast cancer (cancer confined to the duct) are also expected to be diagnosed. The incidence rates of this disease have continued to increase since 1980 as improvements in screening technologies have made possible the detection of breast cancers often too small to be felt.

Despite increased incidence of breast cancer, mortality rates have steadily decreased. From 1990 to 2000, mortality rates declined approximately 2.3% per year (American Cancer Society, 2005). Today, women diagnosed with localized breast cancer (cancer that has not spread to the lymph nodes) have a relative five-year survival rate of 98% compared with 72% in the
1940s. For women whose cancer has spread regionally, the current five-year survival rate is 80% (American Cancer Society, 2005).

The success in curing some breast cancers and in favorably improving the prognosis of those with more advanced disease has resulted in increased attention to the types and efficacy of coping strategies employed by women with this disease. Most of the research on coping with breast cancer, however, has utilized samples which consist largely of White, married, middle-class women (Glanz & Lerman, 1992). Far less is known about the coping needs and responses of African American women or why they seldom utilize cancer support groups. Differences in their disease experience and in their socio-cultural and historical experiences suggest that their coping processes also differ from those of White women.

Disease Experience

Research indicates that the breast cancer experience varies between African American and White women, presenting these groups with different challenges with which to cope. While White women have a higher incidence of breast cancer overall, African American women have a slightly higher incidence of invasive breast cancer before age 40 than Whites (Ries et al., 2003).

In addition, the prognosis for African American women tends to be poorer than for Whites. On a national level, mortality rates for African American women with breast cancer are 32% higher than for White women (American Cancer Society, 2004). In Texas, the divergence in mortality rates is even greater. Between 1997 and 2001, death rates for African American women were approximately 46% higher than for White women (American Cancer Society - Texas Division, 2004).

Differences in mortality rates are partly attributable to later stage at diagnosis among African American women. Over half (55%) of African American women diagnosed with breast
cancer are in a localized stage compared with 66% of White women; 36% of African American women are diagnosed in a regional stage of breast cancer compared with 29% of White women (American Cancer Society, 2004).

Even though African American women are more likely than White women to be diagnosed at more advanced stages of breast cancer, they tend to be treated less aggressively. A large-scale study of 7,781 women in treatment for breast cancer found that racial differences in care persisted even after controlling for insurance status, treatment location (public versus private hospital), and other demographics. African American women were less likely than White women to receive prognostic tests, radiation therapy in combination with mastectomy, and rehabilitation services (Diehr et al., 1989). A more recent review of the literature on racial disparities in the treatment and diagnosis of other types of cancer detected a similar pattern (Institute of Medicine, 2003).

Studies also indicate that African Americans with cancer receive less pain medication than Whites. Cleeland and his colleagues (1997) found that 65% of minority patients who had pain did not receive guideline-recommended prescription pain medication compared with 50% of White patients. Other research indicates that even after controlling for insurance status, African American women with breast cancer often receive less pain medication than White women (Payne, Medina, & Hampton, 2003).

The physician-patient relationship also differs between African Americans and Whites. African American patients have rated their visits as less participatory than Whites even after controlling for factors such as age, gender, education, and health status (Cooper-Patrick et al., 1999). Less interaction during visits may translate into more abbreviated sessions between
patients and their physicians. One study found that physician visits tended to be shortest between African American patients and White physicians (Cooper & Roter, 2003).

Socio-Cultural and Historical Experiences

The experiences of African American women with all major social institutions in the United States have also varied significantly from those of White women throughout most of the country’s history. Prior to the passage of civil rights protections in 1964, and for years afterward, many social institutions expressly excluded African Americans. Regardless of occupation or area of the country, African American men suffered from sporadic employment or underemployment. Compensation, for those who were employed, was significantly less than for their White counterparts (Jones, 1985). As a result, almost all African American women had to work either to supplement the family income, or to provide for the family when male relatives were unemployed. In addition to structurally-induced poverty, enforced segregation under Jim Crow laws restricted African American’s access to education systems, housing, public transportation and accommodations, stores, as well as health care.

The effects of racial oppression in the United States go beyond the often-examined impact on the socioeconomic status of African Americans. A history of abuse at the hands of health care providers has caused many African Americans to find it difficult to trust physicians or health care institutions. The Tuskegee Syphilis Experiment still lingers in the collective psyche of a number of African Americans. For forty years between 1932 and 1972, the U.S. Public Health Service conducted an experiment on 400 Black men who were in the late stages of syphilis. Most of these men were poor, illiterate sharecroppers from Macon County, Alabama who were not informed about the nature of their illness or of its seriousness. Physicians told them that they were being treated for “bad blood” but left them to degenerate with end-stage
syphilis long after penicillin became available in the 1950s as the preferred therapy (Brandt, 2000). An investigative panel appointed by the U.S. government in 1972 found the study to have been “ethically unjustifiable.”

The Tuskegee Syphilis Experiment was not an isolated incidence of medical abuse and racism. From 1960 to 1972, radiation experiments sponsored by the U.S. Department of Defense were conducted at Cincinnati General Hospital on mostly poor, African American patients (Rothman, 1991). The purpose of the study was to determine the effects that radiation exposure (e.g., from a nuclear blast) would have on soldiers in combat. The patients, however, were not told they were receiving deadly doses of radiation. Rather, physicians indicated that the radiation treatment was to relieve them from the pain of cancer.

In addition to distrust of medical institutions, long-term racial oppression may have had other effects on the coping resources and strategies of African Americans. For example, the African American church emerged as “one of the few indigenous institutions…built, financed, and controlled by Blacks” (Taylor & Chatters, 1991, p. 105), and religious faith became firmly embedded in the coping responses of African Americans. Further, African Americans families often evolved as extended network systems comprised of multiple households and characterized by a sense of reciprocal obligation. Members pooled money and information and provided mutual emotional support (Stack, 1974). Extended kinship networks also provided African American women, who for much of the twentieth century had little choice but to work long hours in very low pay jobs, assistance with caring for their own children, the elderly, and the sick.
Statement of the Problem

Experiences such as these may influence African American women’s perception of social support and of cancer support groups in particular. Therefore, it is significant and important to explore the ways in which cancer support groups, as an institutional extension of social support, are perceived by African American women.

Cancer support groups are a type of coping intervention intended to assist women with adjustment to their disease. Theoretically, a coping intervention should emanate from and be tailored to the group it is intended to serve (Folkman & Moskowitz, 2004). This research examines the coping processes of African American women diagnosed with breast cancer and how these processes relate to their use or nonuse of cancer support groups. It also suggests how this particular coping strategy might be designed or adapted to address the specific support needs of African American women.

This research focuses on the following questions:

1. How have African American women coped with the problems associated with breast cancer? How does this coping process compare with how White women cope with this disease?

2. How does the social-historical context influence the coping resources and strategies of African American women?

3. How do cancer support groups, as they are currently structured, relate to the coping strategies and resources of African American women? How could cancer support groups assist in the coping process?

4. What, if any, are the primary concerns of African American women with cancer support groups as they are currently structured?

5. How might cancer support groups be structured to benefit African American women?

6. What are the social support needs of African American women with breast cancer? How, if at all, do these women perceive that cancer support groups could effectively complement or supplement their existing social support system?
CHAPTER 2
REVIEW OF THE LITERATURE

Definition of Coping

The experience of breast cancer presents a woman with a number of demands with which to cope, including pain, physical disfigurement, changes in social relationships, treatment decisions, and fear and uncertainty about the future. The dominant theoretical framework used to examine how women cope with these challenges has been the contextual model of coping (Lazarus & Folkman, 1984). According to this model, coping is a process that is characterized by on-going behavioral and psychological efforts to manage “demands (external or internal) that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, p. 283). In other words, a woman’s coping responses to breast cancer are conditioned by her evaluation of the potential threats posed by the disease as well as her perception of the availability of psychological and social resources necessary to meet those threats.

Although the coping literature is substantial, little of it specifically examines the coping strategies used by African American women (Thoits, 1995) or the specific strategies used by these women when faced with breast cancer (Glanz & Lerman, 1992). Research that deals with the coping mechanisms used by women with breast cancer has typically relied on quantitative studies with samples consisting largely of White, married, middle-class, middle-aged women (Glanz & Lerman, 1992). Moreover, models that have guided much of the contemporary research on coping, including instruments intended to measure coping strategies, were developed and tested on predominantly White samples (Billings & Moos, 1981; Carver, Scheier, & Weintraub, 1989; Folkman & Lazarus, 1980, 1985). Therefore, the applicability of the findings from the coping research to African American women is largely unknown.
Identifying the coping strategies and resources of African American women with breast cancer and how they differ from those of White women has important implications. Certain ways of coping may be more effective in reducing distress for African American women than for White women. This information is essential for designing support groups to assist African American women to effectively address the challenges of breast cancer.

Types of Coping Strategies

In general, researchers distinguish between two major functions of coping. Problem-focused coping is aimed at eliminating or minimizing the stressor itself (i.e., problem, situation, or disease). In contrast, emotion-focused coping operates to manage the emotional responses that are often associated with a particular stressor (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Previous research has shown that people employ both forms of coping in almost every type of stressful situation (Folkman & Lazarus, 1980, 1985), including when they are specifically confronted with cancer (Bourjolly & Hirschman, 2001; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992).

Several types of problem-focused and emotion-focused coping strategies have been identified in previous research dealing with cancer patients (Bourjolly & Hirschman, 2001; Dunkel-Schetter et al., 1992; Reynolds et al., 2000; Stanton & Snider, 1993). Problem-focused forms of coping include seeking further information about the illness, deliberate analytic efforts to solve a particular problem, and personal advocacy directed at changing the stressor or situation. Emotion-focused forms of coping include seeking “moral support” from others, fantasizing, distancing (e.g., sleeping more than usual), and reframing the meaning of the threat in more positive terms.
In addition to problem-focused and emotion-focused coping strategies, some researchers distinguish between active and avoidant coping strategies (Billings & Moos, 1981; Carver et al., 1989). Behavioral or psychological attempts to deal directly with the stressor or how it is perceived are characterized as active coping strategies. Problem-solving and attempting to frame the stressor in more positive terms are examples of active coping strategies. Avoidant coping strategies involve some form of mental withdrawal or overt behavioral activity intended to distract the person from the stressor. Actions such as denial or alcohol abuse are considered avoidant strategies.

The manner in which a woman copes is an important factor in successfully addressing the emotional stress attendant to breast cancer. Theoretically, no coping strategy is inherently good or bad. The effectiveness of a coping strategy must be determined in the context in which the stressor occurs (Folkman & Moskowitz, 2004; Lazarus, 1993; Lazarus & Folkman, 1984). Research indicates, however, that avoidant approaches to a stressor such as breast cancer (e.g., denial, escape through sleep, alcohol abuse) are typically associated with poorer adaptation, whereas more engaged coping strategies lead to better adjustment (Carver et al., 1993; Dunkel-Schetter et al., 1992; Holland & Holahan, 2003; Stanton & Snider, 1993).

No clear consensus can be found in the literature regarding the comparative efficacy of problem-focused and emotion-focused coping strategies (Lazarus, 1993; Mattlin, Wethington, & Kessler, 1990; Thoits, 1995). However, Lazarus (1993) opines that “there is a strong tendency in western values to venerate the former and distrust the latter. Taking action against problems rather than reappraising the relational meaning seems more desirable” (p. 238).
Coping Resources: Social Support

In contrast to coping strategies which are a person’s active behavioral and/or cognitive efforts to deal with a particular demand, coping resources form a latent pool of available means out of which a person may draw to develop their coping responses (Thoits, 1995). Coping resources may be either psychological or social in nature (Pearlin & Schooler, 1978). Psychological resources consist of personality traits which reside within the self. Some commonly studied traits include a sense of control over life, self-esteem, and the level of optimism associated with an individual’s approach to personal challenges (Carver et al., 1993; Taylor, Lichtman, & Wood, 1984; Thoits, 1995).

In contrast, social resources are comprised of the interpersonal networks of family, friends, co-workers, neighbors, and voluntary associations of which a person is a part and which form a potential pool of support. Social support, the term most often used in the literature to refer to social coping resources, has both structural and functional dimensions. The structural dimension involves the type and number of relationships a person has as well as frequency of contact with other social network members (Berkman, 1985). Structural measures are typically concerned with the degree of a person’s social integration or isolation. In contrast, the functional dimension of social support involves either the receipt (actual or perceived) from various network members of emotional concern, information, instrumental aid (e.g., goods, services, money) or of appraisal (e.g., information important to self-evaluation) (House, 1981; House & Kahn, 1985).

The beneficial effects of social relationships on individual well-being were first noted by Durkheim (1951). Later, large scale prospective studies on social support and mortality confirmed his findings. These studies indicated that socially integrated individuals—those with
frequent social contacts and/or membership in organizations—tend to live longer than those who are more socially isolated (Berkman & Syme, 1979; Blazer, 1982; House, Robbins, & Hettzner, 1982; Schoenbach, Kaplan, Fredman, & Kleinbaum, 1986). Other research has shown that social support is linked with improved adjustment to a variety of types of serious and/or chronic illnesses (DiMatteo & Hays, 1981; Vogt, Mullooly, Ernst, Pope, & Hollis, 1992) and specifically to breast cancer (Bloom et al., 1991; Holland & Holahan, 2003; Waxler-Morrison, Hislop, Mears, & Kan, 1991).

Motivated by the potential health benefits of social support, early investigators urged the development of psychosocial interventions, including cancer support groups, to enhance social support networks. Sidney Cobb (1976) advocated that “we should start now to teach all our patients, both well and sick, how to give and receive social support” (p. 312). Researchers theorized that social relationships might be “more amenable to change than exposure to stress itself, or than other possible mediators like personality traits or coping styles” (Thoits, 1982; Wortman, 1984, p. 2339).

Cancer Support Groups as a Coping Intervention

Cancer support groups began to appear in the late 1970s. They typically consist of groups of six to twelve people who have been diagnosed with cancer and who are led by some type of health professional. In cancer support group meetings, members not only receive information, they share experiences. Gottlieb (1998) notes that, “[i]n principle, the combination of expert and experiential knowledge in the context of a supportive peer culture creates optimal conditions for improved coping and adaptation” (p. 636).

Cancer support groups are intended, among other things, to provide a resource for patients dealing with the interpersonal difficulties that often arise as a consequence of the
A diagnosis of cancer can often lead some members of the patient’s social network “to avoid the patient, to close off communication about difficult emotional topics, and to exhibit nonverbal signs of rejection stemming from uncertainty over how to respond” (Dunkel-Schetter, 1984, p. 81; Dunkel-Schetter & Wortman, 1982). Similarly, patients report that they sometimes feel uncomfortable sharing their fears about the disease with family and friends and seek to protect them by maintaining a positive affect (Dunkel-Schetter, 1984). In addition, cancer patients sometimes characterize as unhelpful the assistance offered by particular members of their usual social network (Dakof & Taylor, 1990; Dunkel-Schetter & Wortman, 1981). For example, some patients have reported that they dislike receiving information or advice about their illness from non-expert sources (Dunkel-Schetter, 1984).

Cancer support groups are intended to provide communities which complement the support given by their members’ natural support networks (e.g., family, friends, membership in organizations such as church) or which compensate for deficiencies in those networks created by the cancer (Gottlieb, 1998). In addition, they have been found to assist in reducing anxiety and depression (Fawzy, Cousins, et al., 1990; Goodwin et al., 2001; Spiegel et al., 1989), in reducing pain (Goodwin et al., 2001), and in facilitating improved communication with physicians and other health care professionals (Spiegel et al., 1981).

The most significant benefit of cancer support groups, however, would seem to be the increased survival times for participants in groups that provide emotional and/or informational support. In a landmark randomized clinical study, patients with metastatic breast cancer who attended weekly support group meetings for a year were found to have lived an average of 18 months longer than those in the control group (Spiegel et al., 1989). A support intervention for malignant melanoma patients also produced increased survival rates with statistical significance.
(Fawzy et al., 1993), and an educational intervention to improve compliance with therapy among patients with hematologic malignancies also had a positive significant impact on survival (Richardson et al., 1990).

Studies indicate that, of the persons who elect to use cancer support groups, a disproportionate number are White, middle- to upper-middle class women (Bauman, Gervey, & Siegel, 1992; Gordon et al., 1980; Taylor, Falke, Shoptaw, & Lichtman, 1986). Literature that deals with African American women’s nominal use of support groups is meager and consists largely of clinical speculation and anecdotal evidence (e.g., Barg & Gullatte, 2001). Understanding the disparity in usage between White and African American women necessarily entails examination of the coping strategies and resources commonly employed by these groups.

Coping Strategies of African American Women

The picture of coping for African American women with breast cancer is not clear. In addition to the research being scarce, it contains conflicting results. Some comparative research suggests that the coping processes of African American women with breast cancer are similar to those of White women while other studies suggest that the differences are greater than the similarities.

For example, results from one study on coping indicated that there was no difference in how African American and White women appraise their disease (Bourjolly, Barg, & Hirschman, 2003). These groups of women did not significantly differ in their evaluation of cancer as a threat to their health, safety, and physical well-being. Other anecdotal evidence suggests, however, that African American women at all income levels believe that breast cancer is a “White woman’s” disease (Guidry, Matthews-Juarez, & Copeland, 2003; Lythcott, Green, & Brown, 2003).
In addition, research indicates that many African Americans with cancer consider it to be only one of many life challenges. Potts (1996) notes that, in the accounts shared by his study participants, “cancer appeared as a subplot in greater life stories, which often included other life-threatening illnesses, and societal ‘cancers’ such as war and racism…” (p. 11). Content analysis of articles dealing with cancer in popular magazines with a predominant African American circulation (e.g., *Ebony, Jet, Essence*) supports this perspective. In these articles, Hoffman-Goetz (1999) found that “[t]he fight against cancer is…woven together with other fights, particularly those of social injustice” (p. 43).

Another comparative study found no significant differences in the coping strategies employed by African American and White women (Bourjolly & Hirschman, 2001). This quantitative study showed that the three most common coping strategies employed by both groups in order of frequency of use were seeking social support, positive focus, and “planful” problem-solving.

In contrast, Reynolds and her colleagues (2000) compared the coping strategies and survival rates of 442 African American and 405 White women with breast cancer and found that “Blacks appeared to use a substantially different constellation of coping strategies than Whites” (p. 942). African Americans were more likely than Whites to use positive focus, engage in wishful thinking, and suppress emotion. Whites were more likely than African Americans to problem-solve, use escapism, and express emotion.

*The Primacy of Religious Coping for African American Women*

Notwithstanding the limitations of the existing research on African American women coping with breast cancer, some trends have begun to emerge in the literature. At least one comparative qualitative study points to the primacy of religious beliefs and practices in coping
with breast cancer among African American women as compared with White women (Ashing-Giwa et al., 2004). Results from another study, which explored spirituality and its relationship to the cancer experience in 16 African American cancer survivors, indicated that prayer was the most important means of coping with cancer. Survivors gave it “the highest mean score for degree of helpfulness among all intervention items, including medical interventions” (Potts, 1996, p. 10). A handful of qualitative studies which specifically address the breast cancer experiences of African American women affirm the central nature of religious coping for these women (Ashing-Giwa, 1999; Ashing-Giwa & Ganz, 1997; Henderson, Gore, Davis, & Condon, 2003; Lackey, Gates, & Brown, 2001).

Definitive research on religious coping and its effects on health, however, is relative new and has been complicated by variance in conceptualization and measurement (Chatters, 2000; Levin & Chatters, 1998). For example, Pargament and his colleagues (1998) argue that religious coping cannot be subsumed under nonreligious forms of coping as it is on one commonly used instrument, the Ways of Coping (WOC) questionnaire (Lazarus & Folkman, 1984).

The WOC includes religious indicators in two of its eight coping scales: cognitive avoidance (e.g., I prayed), and positive focus (e.g., I found new faith). Another instrument frequently employed by coping investigators, the COPE, has a separate scale to measure religious coping strategies (Carver et al., 1989). This scale includes indicators such as seeking God’s help, putting trust in God, praying more than usual, and trying to find comfort in religion. Other social dimensions of religious coping, such as church attendance, asking for intercessory prayer of others, or seeking the counsel of clergy, are not considered in either instrument.

Only recently have researchers begun to address the role of religion and spirituality in coping with general stresses and with cancer in particular (Gall, 2000; Pargament et al., 1998;
Comparative research that employs instruments capable of measuring religious coping points to distinctive differences between African Americans and Whites. A few of studies found that African American women with breast cancer tend to use more religious coping than White women (Culver, Arena, Antoni, & Carver, 2002; Culver, Arena, Wimberly, Antoni, & Carver, 2004; Spencer et al., 1999). In other studies, African American survivors scored significantly higher than Whites on both public (e.g., participation in organized religious groups) and private (e.g., internal or solitary religious reflection) use of religion (Bourjolly, 1998) and reported greater spiritual and existential needs than Whites (Moadel et al., 1999). These studies, however, do not indicate the degree to which religious coping is used relative to other coping strategies. In addition, they are limited by the relatively small number of African American women in the samples and/or the lack of probability sampling.

Other research, however, using a large, national probability sample found that African Americans are more likely than Whites to engage in religious practices (e.g., attending religious services, watching religious television), to consider their religious beliefs important to their daily lives, and to seek spiritual comfort and support in the face of difficulty (Ferraro & Koch, 1994). Moreover, religious involvement of all types tends to be greater for African American women than for African American men (Ellison & Taylor, 1996; Lincoln & Chatters, 2003).

Longitudinal research on White women with breast cancer indicates they appear to employ religious coping less frequently than African American women. Carver and his colleagues (1993) found that religious coping was the third or fourth most frequently used coping method for White women across all measurement periods except at six months from diagnosis. Heim and his colleagues’ (1993) found that religious coping was reported as an important coping
response only by White women who were terminally ill. During the early hospitalization phase, it ranked twelfth in usage among coping strategies.

Although existing research has drawn some distinctions between the frequency of use of religious coping by African Americans and Whites, it has not differentiated to a significant degree between these groups in the manner in which religious coping is used. Little research exists on the content of the religious coping experience of African Americans and how that compares with Whites (Ellison & Taylor, 1996). For example, what differences, if any, exist between African Americans and Whites in their construction of the relationship with the divine or in their prayers? A handful of studies are suggestive of divergence between these groups.

Prayer and Healing

African American breast cancer survivors report that prayer, coupled with their spiritual beliefs, is an important religious coping strategy in dealing with cancer from discovery of the disease through treatment and recovery (Henderson, Gore et al., 2003; Lackey et al., 2001). Other research supports these findings. African Americans have indicated that prayer is the most effective means of coping in general with their personal problems (Ellison & Taylor, 1996; Neighbors, Jackson, Bowman, & Gurin, 1983) and is especially important when experiencing health-related problems (Ferraro & Koch, 1994). For African Americans, the tendency to seek spiritual comfort in the face of personal problems operates irrespective of socioeconomic status (Ferraro & Koch, 1994).

One study with a nationally-based representative sample of African Americans indicated that 78% of these adults reported praying nearly every day (Taylor & Chatters, 1991). Another 8% reported praying at least once a week. In addition, about 50% of African American adults reported requesting that others pray for them as often as daily to a few times a month.
In spite of the prior conceptualization of prayer as a form of “cognitive escape avoidance” in dealing with stress (Dunkel-Schetter et al., 1992), evidence exists that many African Americans with cancer consider the act of praying to be an active problem-focused coping strategy targeted at restoring their health (Potts, 1996). The importance of prayer as a means of coping with illness is deeply rooted in the belief among many African Americans that God is the source of healing both physically and spiritually (Ashing-Giwa & Ganz, 1997; Mathews, 2000; Potts, 1996). The Hoffman-Goetz (1999) content analysis of cancer-related articles (from magazines such as Ebony and Jet) supports the central nature of this belief for this culture. Sixty-four percent of the articles dealing with cancer mentioned the importance of prayer and faith in God for healing.

African Americans with cancer or other illnesses report that they pray to God to be cured (Abrums, 2000; Potts, 1996). However, respondents in one study reported that prayer also offered an “experience of healing and wholeness that did not rely on the experience of a cure” (Potts, 1996, p. 10). In contrast to African American cancer survivors, one qualitative study of the religious coping of predominantly White breast cancer survivors found that participants did not tend to rely on prayer for healing, but rather sought God’s assistance in understanding what was happening to them (Gall & Cornblat, 2002).

The effectiveness of African Americans’ use of religious coping when generally facing problems or difficulties, or specifically of African American women with breast cancer, has not been fully established (Ellison & Taylor, 1996). Most investigations on the efficacy of religious coping have analyzed data drawn from predominantly White samples (e.g., Gall, 2000; Pargament et al., 1998). This research indicates that religious forms of coping are helpful to those confronted with stressors considered uncontrollable (Pargament et al., 1998) and in the
reduction of depression associated with health-related problems (Mattlin et al., 1990). At least one study has specifically addressed the relationship between non-organizational religious involvement (e.g., prayer, devotional) and psychological well-being among African American women. Using a nationally-based sample, these investigators found that greater life satisfaction and happiness was positively associated with personal prayer and devotional activities (Lincoln & Chatters, 2003).

In spite of research that suggests the salutary effects of religious coping among African Americans, some investigators posit that this coping response may pose a barrier to the delivery of professional medical care. One researcher asserts that if “getting well or better is in God’s hands, not the [patients’]...patients may feel that any interference with the progression of their illness is not only an interruption of God’s work, but a demonstration of disrespect for them and their beliefs as well” (Pierce, 1997, p.7). Medical professionals serving as key informants in other studies report similar impressions (Ashing-Giwa & Ganz, 1997; Ashing-Giwa et al., 2004). They indicate that African American women “with strong religious beliefs perceive that their medical treatments are secondary to their spiritual therapy” (Ashing-Giwa & Ganz, 1997, p. 25). A negative relationship between religious coping and the actual use of health care by African American women, however, has not been demonstrated by research.

White Women Use Multiple Coping Strategies

The emphasis on religious coping by African American women with breast cancer that has begun to emerge in the literature is not found in coping studies that deal primarily with White women. Rather, White women have been found to employ multiple coping strategies to deal with the challenges associated with their disease (Carver et al., 1993; Dunkel-Schetter et al., 1992; Glanz & Lerman, 1992; Heim et al., 1993), and these strategies tend to change over time
(Carver et al., 1993; Epping-Jordan et al., 1999; Glanz & Lerman, 1992; Heim et al., 1993; McCaul et al., 1999; Stanton & Snider, 1993). One study reported that the median number of coping methods reported by cancer patients—42% of whom had breast cancer—was four (Dunkel-Schetter et al., 1992). Another five-year longitudinal study found that ten was the average number of coping modes used by breast cancer survivors (Heim et al., 1993).

One of the most frequently reported coping responses by White breast cancer survivors is seeking social support (Bourjolly & Hirschman, 2001; Carver et al., 1993; Dunkel-Schetter et al., 1992; Heim et al., 1993; Holland & Holahan, 2003; Stanton & Snider, 1993). This strategy includes activities such as talking with others to find out more about the illness, expressing feelings to another person, and seeking professional help.

White breast cancer survivors also employ acceptance as a coping mechanism during many phases of their illness (Heim et al., 1993). Examples of acceptance strategies include adjusting to the idea of having cancer, accepting the reality of the disease, and learning to live with the illness. Maintaining a positive focus is another coping mechanism frequently used by White women (Bourjolly & Hirschman, 2001; Carver et al., 1993; Holland & Holahan, 2003). This coping pattern includes specific strategies such as trying to grow as a person as a result of the experience and rediscovering what is important in life.

Problem-solving (e.g., considering what steps to take to deal with the problem, increasing efforts to address a concern, and considering how a problem might be handled best) (Bourjolly & Hirschman, 2001; Heim et al., 1993; Holland & Holahan, 2003) and distancing (e.g., sleeping more than usual, emotional containment, making light of the illness, or trying not to think about it) (Dunkel-Schetter et al., 1992; Stanton & Snider, 1993) are two other coping strategies often reported by White women dealing with breast cancer.
Social Coping Resources of African American Women

Examination of the coping resources of African American women indicates that they also differ from those of White women. A woman’s social support—the configuration of her network of family, friends, co-workers, and voluntary associations—forms a type of “social ‘fund’ from which she may access when handling stressors” (Thoits, 1995, p.64). Comparative research indicates that Whites tend to report higher levels of social support than African Americans (Ferraro & Koch, 1994). The particular structure of the social networks of African American women necessarily affects the how support is both delivered to and received from others in their networks.

Social network structure

The structural composition of the social networks of African American women differs significantly from those of White women. Proportionately, more White women are married than African American women. In 2000, 32% of all African American households in the United States consisted of married couples. In comparison, 50% of the non-Hispanic White households consisted of married couples (Fields, Casper, & U.S. Census Bureau, 2001). Similarly, African American women are also more likely to serve as single heads of households than White women. Of all African American households in 2000, 30% were headed by single women living with relatives (e.g., children, sister). Only 9% of White households were headed by women with relatives (Fields, Casper, & U.S. Census Bureau, 2001).

Married people tend to report higher levels of perceived support than those who are unmarried (Thoits, 1995). Thus, the lower marriage rates among African American women would seem to imply that these women might perceive that they receive less support. However, a study of 91 married and 183 non-married African American women found that having a spouse
had little effect on the number of socially supportive relationships (Brown & Gary, 1985). Married women indicated that their closest relationships included their family members, female friends, and husbands; non-married women pointed to their mothers, siblings, and children. Importantly, less than one-third of married women in this study indicated that their spouse was a source of emotional support.

Few studies have specifically examined the perceived social support needs of African American breast cancer survivors. A comparative study of women with early stage breast cancer found that African American breast cancer survivors reported receiving less social support from their spouse, children, and friends than White women (Bourjolly & Hirschman, 2001). However, it is not clear whether this finding is reflective of perceived support deficits by African American women or is indicative of a greater tendency on the part of White women to use social support as a coping strategy. Another possible explanation for this finding is the manner in which social support was measured. Support was conceptualized in the study as the receipt of emotional, informational, or concrete assistance. African Americans may conceive of support in another way. For example, Hamilton & Sandelowski (2003) found that African Americans with serious illness viewed themselves as active partners in relationships characterized by giving as well as receiving.

About half of the African American breast cancer survivors in another study reported experiencing isolation and a lack of social support (Ashing-Giwa & Ganz, 1997). These women were typically younger and single, did not have relatives nearby, or their nearby relatives had significant problems of their own. Research indicates that the size of the family and friendship networks of African Americans with a serious personal problem is associated with socioeconomic status (Chatters, Taylor, & Neighbors, 1989; Taylor, 1986). Larger informal
networks of friends and family were found among African Americans with greater levels of income and education. Women, and those reporting more frequent family contact, were also found to have larger informal networks.

*Extended Kin Networks*

Another way in which African American women’s social networks differ from those of White women is in the area of fictive family ties. Some scholars argue that as a structural response to poverty, high levels of unemployment, and segregation, African Americans have historically extended familial-like ties to those outside the family (e.g., Stack, 1974). Others trace the practice by African Americans of establishing fictive kinship ties to West African culture (e.g., Gutman, 1976). Irrespective of their origin, these extended kin networks were typically comprised of members from multiple households and were characterized by a sense of reciprocal obligation with members pooling money and information, and providing mutual emotional support.

These networks also served to provide African American women, who for much of the twentieth century had little choice but to work long hours in very low pay jobs, assistance with caring for their own children, the elderly, and the sick. Relative to African Americans, the practice of extending family networks to non-related members has been much less common among Whites (Chatters, Taylor, & Jayakody, 1994).

While many of the structural conditions which gave rise to extended kinship no longer exist, African Americans continue to accord family status to non-related others. Chatters and her colleagues (1994) found in their analysis of a large nationally representative sample of African Americans, that 66% reported fictive kin in their families. Moreover, there is evidence that the pattern of reciprocal obligation associated with extended kinship networks has also evolved into
a strong cultural pattern generally valued by most African Americans. McAdoo (1978) found that reciprocal obligation “continues to be a viable cultural component for the emotional well-being of Blacks at all economic levels, even when middle-class status has been maintained over several generations” (p. 775).

Because of their history of reciprocal obligation, African Americans may not envisage social support purely in terms of the receipt of instrumental, emotional, or informational support as it is often conceptualized in the literature. In a recent study of African Americans with cancer, Hamilton and Sandelowski (2003) found that participants did not consider themselves passive recipients of assistance even though they were ill. Rather, they considered themselves to be a part of two-way relationships characterized by a belief in a moral obligation to give back—either to those who had given to them, to others in their network, or even to strangers.

Research indicates that during times of illness and other stressful periods, a significant number of African Americans rely on their families and extended kinship networks for different types of support. Neighbors and Jackson (1984) found that 87% of the African Americans they surveyed consulted with a friend or family member about a problem. In another quantitative study, nearly 50% of the respondents indicated that they received help from their families either fairly often or very often (Taylor, 1986). Only 16% said they never received support while 27% reported they did not receive help very often. Respondents reporting the greatest level of support lived in close proximity to relatives, had frequent family contact, and had a perception of close family relationships, and had more income.

God as a Network Member

Growing evidence indicates that many African American women consider God to be an active part of their social networks. Feltey and Poloma (1991) argue that the development of
relationship with the divine is parallel to the development of other social relationships and that the divine may be incorporated into an individual’s cognitive personal network. Close to 25% of the African American breast cancer survivors in one study reported that God provided them with instrumental, emotional, and informational support compared with about 5% of White survivors (Bourjolly & Hirschman, 2001). African American breast cancer survivors reported receiving more support from God than did White survivors, even after controlling for marital status. Similarly, in a qualitative study of 43 African American breast cancer survivors, over half identified God as a more important source of support than either family or friends (Henderson, Fogel, & Edwards, 2003).

Contemporary African American literature also provides evidence of the conceptualization by African American women of God as a “real” social network member. Joan Morgan (1999), a journalist who is currently serving as Executive Editor of Essence magazine, asserts in her book *When Chickenheads Come Home to Roost,*

I’m going to make God the main man in my life….God reminds me that heartache is what tends to set in when a woman calls on a man to do the job that was intended only for Him….By giving God his proper place, I free my relationships from unreasonable expectations. And I free myself from fear—because I know somebody out there has got my back (p. 152-153).

**Nondisclosure**

In contrast to fictive family ties which tend to extend African American women’s social support system, there exists a communication attribute among African Americans that would appear to limit access to social support. Evidence exists of a practice by African Americans of nondisclosure of personal problems outside the family. An African American breast cancer survivor who participated in a recent qualitative study explained, “as Black women, we aren’t as outspoken as a lot of other women, we don’t share out problems with everybody. We keep it
within ourself or we keep it within a close-knit group of our own family…” (Ashing-Giwa et al., 2004, p. 414).

A theme which is evident in previous qualitative studies suggests that cancer is considered by some African Americans to be a private matter and not to be discussed, or mentioned outside the family (Ashing-Giwa & Ganz, 1997; Mathews, Lannin, & Mitchell, 1994; Moore, 1999; Wilmoth & Sanders, 2001). A 74-year-old African American breast cancer survivor in one study noted that “[w]omen just don’t talk about [breast cancer] with men, or other people, just doctors….Cancer is a private thing….The only one who needs to know is the doctor…” (Moore, 1999, p.46).

Historical literature sheds some light on the potential origins of this practice. Litwack (1998) recounts that slave parents instilled in their children a code of behavior intended to guide how they should act within their own family, with other Blacks, and with Whites. Black children learned early on that their physical safety often hinged on their ability to contain their innermost feelings and mask facial and other outward expression when they were in the presence of Whites. Slave children were taught to “act in a way just as though everything was all right…to do whatever the White man directed ‘em to do” and not to “voice their heart’s desire” (quoted in Litwack, 1998, p. 3).

Emancipation did little to eliminate the need to limit disclosure of personal information. The horrors of the Jim Crow era only served to reinforce the need for defensive secrecy developed by Blacks during slavery. In addition to masking personal problems, the practice of nondisclosure often extended as a matter of safety and necessity to cover positive achievements as well. African Americans understood all too clearly that their educational and professional aspirations and achievements challenged the claim of White supremacy by threatening an
existing social order dependent on a large pool of cheap, unskilled Black labor. Openly seeking an education often invited abuse. African American schools were burned, teachers were assaulted, and students were harassed. One means of coping with this dilemma was for Black school children to hide their books until they reached the school house (Litwack, 1998).

A similar type of privacy applied to matters of work and financial success. After emancipation, African Americans who were successful farmers or who ran successful businesses learned quickly to avoid or limit outward signs of prosperity in order to prevent sabotage or destruction of their success by resentful Whites (Litwack, 1998).

Thus, for African Americans, virtually no benefit accrued from disclosure of personal matters, especially personal problems. Prior to the passage of civil rights legislation in 1964 and to some degree afterward, African Americans had few avenues by which to address problems. For example, African Americans often could not get medical assistance, even when they could pay for it. There were few Black physicians, and White physicians often refused to treat Blacks. Blacks who were successful in procuring treatment often received substandard care. The extension of privacy to illness may be attributable to a desire among African Americans to avoid further marginalization. The potential for double marginalization, first as an African American and then as a person with some sort of problem, may have reinforced the practice of limiting disclosure of their illness.

Even though the practice of nondisclosure would appear to isolate African Americans and deprive them of social support, no research exists to confirm or refute such a conclusion.

*The Medical Establishment*

Physicians, nurses, and other health care workers are another part of a person’s formal support network and are an important resource during times of serious illness. Here again,
however, African Americans as a whole differ from Whites in their view of the support provided by the health care profession. Studies using predominantly White samples report that physicians and other health care providers are considered almost as important as family in dealing with cancer (Dakof & Taylor, 1990; Dunkel-Schetter, 1984). The patient and family depend on the health care providers for information and advice on how to deal with the disease and problems associated with treatment. However, many African Americans find it difficult to trust health care professionals. The horrors of the Tuskegee Syphilis Study and other medical research that abused people of color (e.g., the radiation experiments conducted at Cincinnati General Hospital on terminal cancer patients sponsored by the U.S. Department of Defense) (Rothman, 1991) have prevented many African Americans from developing confidence in health care providers. While legislation has subsequently addressed unethical human experimentation, racism in the medical community and discrimination by health care providers persist.

Distrust of health care providers does not stem only from past medical atrocities. Various African American health care professionals interviewed by Ashing-Giwa and Ganz (1997) “blamed the health care system for negative medical outcomes among African American women with breast cancer” (p. 25). They pointed to physicians who fail to comply with screening recommendations, problems with continuity of care, and a lack of careful attention to African American patients. Their concerns appear warranted. Studies indicate that African American women are less likely than White women to receive prognostic tests, radiation therapy in combination with mastectomy, and rehabilitation services (Diehr et al., 1989; McWhorter & Mayer, 1987). A more recent review of the literature on racial disparities in the treatment and diagnosis of other types of cancer detected a similar pattern (Institute of Medicine, 2003).
In addition, some studies have documented differences in pain management between African American and White cancer patients with African Americans receiving less pain medication even after controlling for insurance status (Cleeland et al., 1997; Payne et al., 2003). In a recent study of underserved minorities, Anderson and her colleagues (Anderson et al., 2000) found that 31% of African Americans with cancer received inadequate levels of pain medication. Physicians also underestimated the pain severity in 74% of African American patients and were more likely to underestimate the pain in females than males.

The dynamics of the physician-patient relationship also differs between African Americans and Whites. African American patients have rated visits with physicians as less participatory than Whites even after controlling for factors such as age, gender, education, and health status (Cooper-Patrick et al., 1999). Other research found that physician visits tended to be shortest between African American patients and White physicians (Cooper & Roter, 2003).

African American women suffering from breast cancer have reported dissatisfaction with their physicians. About half of the women who participated in one study reported experiencing problems with the care they received from their physicians, especially during follow-up (Ashing-Giwa & Ganz, 1997). These women had even more negative comments regarding their surgeons who, regardless of ethnic background “were described as insensitive, cold, and uncaring” (Ashing-Giwa & Ganz, 1997, p. 28). African American breast cancer survivors in other studies tend to describe their health care providers as unsupportive (Henderson & Fogel, 2003; Henderson, Gore et al., 2003). In a recent qualitative study, one African American breast cancer survivor asserted “the doctors don’t care. It’s either God or nothing” (Ashing-Giwa et al., 2004, p. 416).
Health Beliefs

Health beliefs can also have an impact on a woman’s interaction with health care providers because they affect when and from whom she might seek treatment, how she will describe her symptoms, and how she will comply with treatment. Various studies of African American beliefs about the origin of illness have found that many African Americans attribute illness to forces that are not always recognized by the medical establishment. One study, for example, found that many Blacks believe that illness has “natural” and “unnatural” causes (Snow, 1983). The failure to properly care for the body or sinful behavior was believed to result in natural illnesses while the antecedents of unnatural illness were traceable to the evil acts of others who used magic for their own purposes (Mathews, 1987; Snow, 1983).

In another study, African American women who presented to a clinic in rural, eastern North Carolina with advanced, late-stage breast cancer attributed some of their symptoms to impurities in the blood trying to get out. They believed that “blood can become dirty” and erupt into “lumps formed under the [skin] surface” (Mathews et al., 1994, p. 793). Mention of blood imbalances also occurred in about half of the accounts given by African American women with early- and middle-stage breast cancer but was not mentioned by any White patients.

According to another study, inappropriate conduct was thought by many African Americans to put them and others at risk of illness and even cancer (Mathews, 1987). Illness has also been viewed as punishment for failure to comply with God’s will (Ashing-Giwa & Ganz, 1997; Landrine & Klonoff, 1992) or as a test of one’s faith (Lawson, 1998). African American health care professionals interviewed as a part of another study indicated that many African Americans believe that breast cancer is caused by physical trauma or is contagious (Ashing-Giwa & Ganz, 1997). Still other researchers have found that many African American breast
cancer survivors believe that their cancer was related to unexpressed anger or the stress from emotionally traumatic events (Ashing-Giwa & Ganz, 1997; Lawson, 1998; Moore, 1999).

The extent to which factors such as age or socioeconomic status change some or all of these beliefs is not known. From their review of the literature, Landrine and Klonoff (1992) argue that while a few differences disappear when controlling for socioeconomic status “differences in health-related schemas and ensuing behavior remain even when social class and education are considered” (p. 270). How culturally specific health beliefs impact or coexist with a person’s knowledge of biomedical risk factors for breast cancer is also unknown. Studies indicate a lack of understanding of these risk factors (Ashing-Giwa & Ganz, 1997; Frisby, 2002; Lawson, 1998).

The Church

Another form of social support is found in membership in organizations. Among African Americans, church affiliation and attendance supplement the family and extended kin in their informal networks. Taylor (1991) found that African American women attended religious services and were more likely to be church members than African American men. Overall, church is an important organization in the informal network of African Americans of both sexes. Ninety-four percent of African Americans consider church attendance as very or fairly important and 70% report attending from once-a-day to a few times a month (Taylor, 1991).

Among older African Americans, regular church attendance has been found to be predictive of the receipt of social support from fellow members (Taylor & Chatters, 1986). Just over half of the respondents in this study reported receiving support from members either often or sometimes. Of those who reported receiving assistance, 58% reported receiving a lot of help while 29% reported some. The most prevalent type of support received was help during illness.
(32%) and included actions such as visiting and providing moral support. Prayer (17%) was the second most common type of support provided to fellow members.

The Impact of Socioeconomic Status

Financial resources are more than “an indicator of socioeconomic status, or when resources are scarce…an indicator of experienced chronic difficulty” (Thoits, 1995, p. 63). Sufficient monetary resources may act as a buffer against stress. For example, breast cancer survivors with sufficient financial resources may shield themselves from some of the stresses associated with managing various role responsibilities (e.g., childcare, home care) while ill by hiring assistance.

Higher socioeconomic status has also been found to have a positive relationship with certain psychological coping resources (Thoits, 1995). Those with higher income and education levels tend to have a greater sense of personal control—a characteristic believed to increase the use of effective coping strategies, and a lower sense of fatalism (Turner & Roszell, 1994). Socioeconomic status also impacts social coping resources such as the size of a person’s friend and family network.

In spite of significant gains since the passage of the 1964 Civil Rights Act, African Americans still tend to have fewer financial and educational resources than Whites. They are almost three times more likely to be poor than Whites. In 2001, 22.6% of African Americans lived below the official poverty line (Proctor, Dalaker, & U.S. Census Bureau, 2002). The median income of African American families in 2001 was $29,470 or about 64% of the median income of non-Hispanic White families (DeNavas-Walt, Cleveland, & U.S. Census Bureau, 2002).
Contributing to the disparity in income are higher rates of unemployment among African Americans and a higher proportion of single-parent families. In 2000, 44% of African American single mothers with children under the age of 18 lived below the official poverty line (Fields et al., 2001). African Americans are also less likely to have some form of medical insurance. Almost 19% of African Americans lack medical insurance compared with 10% of non-Hispanic Whites (Mills & U.S. Census Bureau, 2002).

African American women also tend to have less formal education than non-Hispanic White women. In 2000, slightly over one out of every five African American women ages 25 years and older had no high school diploma compared to 12% of White women of the same ages (Newburger, Curry, & U.S. Census Bureau, 2000). In terms of higher education, 17% of African American women ages 25 and older completed a bachelor’s degree or higher compared to one out of every four non-Hispanic White women.

The lower socioeconomic status of African Americans compared with Whites appears to contribute significantly to later stage diagnosis among African American women with breast cancer, to differences in treatment, and to a reduced period for obtaining medical information, including information concerning cancer support services (Eley et al., 1994). Some of the problems associated with lower socioeconomic status (transportation, childcare, inflexible work schedules) form obvious barriers to the use of coping interventions such as cancer support groups.

Cancer Support Groups

Studies indicate that, of the persons who elect to use cancer support groups—a type of coping intervention—a disproportionate number are White, middle- to upper-middle class women (Bauman et al., 1992; Gordon et al., 1980; Taylor et al., 1986). Although cancer support
groups were originally developed to enhance social support, it is not clear that their utilization is a product of a deficiency of social coping resources. Taylor and her colleagues (1986) found that cancer support group attendees were as likely as non-attendees to perceive their family and friends as being helpful in dealing with the cancer and to be able to discuss cancer openly with them. In fact, they found that cancer support participants used more social support of all types. These researchers speculated that use of “social support resources may reflect an underlying social orientation or, more specifically, it may reflect an underlying preference to solve problems through social means” (Taylor, 1986, p. 196). The sample utilized in this study was 93% White and 78% female. As a result of the skewed composition of the sample, the findings may not be generalized to African Americans, other minorities, or to men.

Literature that deals specifically with African American women’s nominal use of cancer support groups is meager and consists mostly of clinical speculation and anecdotal evidence (Barg & Gullatte, 2001). There is some indication that cancer support groups that are insensitive to the spiritually-based coping activities of African Americans may indirectly discourage their attendance. The resistance of African Americans to support groups that fail to incorporate prayer is also evident in a qualitative study of a breast cancer self-help group that was formed by two African American and two White women who were dissatisfied with the support groups provided by the local hospital (Mathews, 2000). These women named their group H.E.L.P—an acronym for Helping Everyone through Love and Prayer. What these women viewed as important in a support group was “a caring, supportive group whose members loved one another and reinforced that love through constant prayer and an ultimate faith that ‘God will restore our spirits’” (Mathews, 2000, p. 406).
Prayer and belief in God’s healing are obviously an important means of approaching or dealing with problems, including cancer, for many African Americans (Ellison & Taylor, 1996; Ferraro & Koch, 1994). It is not known whether the incorporation of prayer into cancer support group meetings would make these groups more attractive to African American women or is even feasible from a policy perspective. Many cancer support groups acknowledge the importance of spirituality, but avoid the use of any organized religious practices in their meetings (e.g., American Cancer Society). Anecdotal evidence suggests that cancer support groups which include prayer may be more successful in attracting African American women (Barg & Gullatte, 2001).

Not only may spiritual differences impede African American women’s use of breast cancer support groups, physical differences may be a barrier. An African American breast cancer survivor in one qualitative study voiced her concern over how African American women were treated in Look Good Feel Better, a group run by the American Cancer Society. The woman reported that the representative from that program “told us we should be happy with [the makeup] we could get, but all the colors were for light skinned complexions and not for brown or dark skinned Black women. Now why should we be happy with that” (Moore, 1999, p. 47).

More than basic matters of physical appearance or attributes, however, core similarity in cancer support groups appears critical to group cohesion and effective function. Gottlieb (Gottlieb, 1998) asserts that if members do not perceive one another as similar along certain valued dimensions, and if they do not have a common basis for comparing feelings, actions, and thoughts that arise out of their circumstances, then the group will have little appeal to them and could actually intensify the stress of the experience (p. 639).
A study of the attendees of Sisters Network—a national association of self-help groups for Black breast cancer survivors—found that their “searches for social networks were motivated by the need to talk about cancer in an African-American public sphere” (Moore, 1999, p. 46).

To begin to answer the question of why African American women use breast cancer support groups so infrequently, one must first understand how African American women cope with breast cancer. The dearth of literature on this subject, however, indicates that little is really known about African American coping strategies or resources and that most coping research is based on White samples. Folkman (2004) asserts that “an important motivation for studying coping is the belief that within a given culture certain ways of coping are more or less effective in promoting emotional well-being…and that such information can be used to design interventions to help people cope more effectively…” (p. 753).

Because the majority of the problems with which people cope “are persistent hardships experienced by those engaged in mainstream activities within major social institutions” (Pearlin & Schooler, 1978, p. 3), it is reasonable to assume that African American women may cope very differently than White women. The normative experiences of African American women with major social institutions in the United States have varied significantly from those of White women throughout most of the country’s history. The length of time associated with these divergent experiences and the degree of the disparity suggests that African American women may have been socialized to cope with life’s normal stresses in distinctive ways and it follows that their approach to dealing with an unusual stressor such as breast cancer would also vary.
CHAPTER 3

METHODS

Procedures

Twenty-six semi-structured interviews were conducted in two overlapping phases with respondents from metropolitan areas in Central and North Texas. In the first phase, 9 key informants answered questions about their experiences with African American women with breast cancer. In the second phase, 9 African American breast cancer survivors and 8 White survivors were interviewed.

Recruiting Assistance

In May 2002, I approached the Dallas, Texas, offices of the American Cancer Society (ACS) for assistance in exploring the use of support groups as a coping strategy for breast cancer survivors. This office reacted favorably to assisting in my proposed research effort, but indicated that the research effort would be limited to quantitative methods and would not permit any face-to-face interaction between me and any ACS-sponsored participants. Concerned with client confidentiality, Dallas ACS initially proposed to distribute a questionnaire or some type of survey instrument to their support group attendees and collect the completed instruments from the women who ultimately chose to participate in the study.

After three meetings, the Dallas ACS staff arranged an appointment for me with senior staff from the state offices in Austin, Texas. The state office was interested in the research project, but was specifically concerned about low participation rates in their breast cancer support groups by African American women and other minorities. We agreed to narrow the research to examine the coping strategies of African American women, and the way in which these strategies relate to use or non-use of support groups. We also discussed the need for face-
to-face contact with African American survivors in order to explore the coping strategies they employed with various challenges associated with breast cancer as well as their thought regarding the usefulness of support groups.

In March 2003, after a preliminary review of the literature, I met with senior staff at the ACS offices in Austin to discuss more specifically the research and methodology. I also sought the input of the Austin ACS personnel in structuring the project. One staff person inquired what ACS would do if I concluded that support groups were not a viable coping strategy for African American women. The answer by other Austin staff was brief: “The results are what they are.”

ACS agreed to actively provide assistance after I had received Institutional Review Board approval. For their assistance, I agreed to present the findings to the state office of ACS at the conclusion of the study.

During the course of the study, I visited with the Austin office staff on several occasions to advise them of my progress in the research.

*Key Informants*

The first phase of the research consisted of interviews with key informants. Key informants were initially recruited with the assistance of the state offices of the American Cancer Society. They provided names and addresses of individuals who would serve as key informants since a number of health professionals, social workers, and ministers from Texas volunteer on ACS committees. Potential informants received an email from ACS requesting assistance with a research project. The email described the project, provided background of the study, and requested that the subject respond if he or she were interested in participating. ACS provided the names, telephone numbers, and email addresses of those who consented. I contacted these
informants by telephone and asked them to participate in a face-to-face, audio-taped interview, lasting from 1-2 hours.

The interviews of key informants recruited with ACS assistance yielded the names of additional potential informant contacts. If the person agreed to take part in the study, I contacted the person by telephone and asked him or her to participate in the same type of one-hour, face-to-face, audio-taped interview. All key informants whom I contacted agreed to participate.

Inclusion Requirement: To obtain a broader range of perspectives on the coping strategies employed by African American women with breast cancer and how these strategies relate to their use or nonuse of support groups, I recruited a variety of professionals. I selected African American women and men who were actively working in their profession, had at least five years experience providing some type of care or support to cancer patients, and were older than 25 years of age. Key informants were recruited from healthcare delivery professions (e.g., physicians, nurses), social work, and non-profit organizations committed to providing services to cancer patients. Ministers were also recruited as key informants because the literature suggested the importance of religion as a coping mechanism for African Americans.

Exclusion Requirement: Non-English speaking persons were excluded from the study as were persons who were retired from a profession which had contact with cancer patients.

Breast Cancer Survivors

The second phase of the research consisted of interviews with breast cancer survivors. The first breast cancer survivors interviewed were also recruited with the assistance of the offices of the American Cancer Society in Dallas, Texas. ACS has contact with a number of breast cancer survivors through its support groups, its pool of volunteers, and its community ties.
Sample Selection: Breast cancer survivors who serve as ACS volunteers were contacted by telephone by local staff and asked if they would participate in a research project. The staff member briefly described the project and sought verbal permission to give the survivor’s contact information to the researcher. ACS staff subsequently provided me with names and telephone numbers of those who agreed to participate. ACS staff members did not disclose the number of calls they initiated or the refusals they received.

I contacted the breast cancer survivors by telephone and asked them to participate in a 90-minute, face-to-face, audio-taped interview. The interviews of breast cancer survivors recruited with ACS assistance and key informant interviews yielded the names of additional survivors. Still other survivors were recruited through my friends and associates. The recruitment process seemed to be facilitated by the fact that nearly one in seven women in the United States will be diagnosed with breast cancer in her lifetime, and most people have friends or family who are survivors (American Cancer Society, 2005). The women in the second group of potential survivor participants were first contacted by the referral source. If the survivor agreed to take part in the study, I contacted her by telephone and asked her to participate in a 90-minute, face-to-face, audio-taped interview.

Sample Inclusion: To observe a broad range of coping experiences, I recruited women of different ages and survivorship lengths. Survivors were chosen who were between the ages of 25 and 80 years old with a self-reported confirmed diagnosis of breast cancer. Because coping strategies change over time, women were recruited who had survivorship lengths of between eight months and fifteen years. However, more emphasis was placed on recruiting survivors who had been diagnosed with breast cancer for less than five years. I assumed that those within this survivorship frame would still be actively coping with either breast cancer itself or some other
repercussion associated with the disease. Efforts were also made to include survivors who were active support group attendees.

The literature suggested that differences in socioeconomic status might also affect the coping resources and strategies of women with breast cancer. Therefore, to achieve some variation in social class, survivors were recruited from differing parts of the greater Dallas-Fort Worth area.

Sample Exclusion: Women older than 80 were excluded from the study because they often have additional health problems, which combined with advanced age, might have altered their approaches to coping. Also excluded from the study were women with survivorship lengths of longer than 15 years because I assumed that they were no longer coping actively with breast cancer or its related issues. Non-English speaking survivors were also excluded from the study.

Data Collection

Prior to formal collection of data, I interviewed two social workers who were employed by one of the county hospitals in the Dallas-Fort Worth area. While neither of these social workers had responsibilities directly related to cancer patients, both had extensive experience working with African Americans in a health setting. These preliminary interviews provided me with another layer of insight on topics to explore in the interviews with key informants and breast cancer survivors. These interviews also afforded me the opportunity to inquire about issues that I might need to consider as a White researcher talking to African American women about a deeply personal and stressful period in their lives.

Even with the assistance and sanction of the American Cancer Society and affiliated organizations such as Faces of Survivors, I recognized that “entry” into the research setting was important. I understood that my perspective as a White, well-educated, middle-class woman
would vary from that of many of the survivors I planned to interview—especially the African American survivors. In an effort to improve my understanding of African Americans, I immersed myself in African American history. I read works which addressed slavery and the Jim Crow era. In keeping with Mills’ (1959) notion of the intersection of biography and history, however, I focused on familiarizing myself with a more recent period in history (1950 – 1965), and on work which specifically addressed race relations in the North Texas area. Some of these works included Leon Litwack’s *Trouble in Mind: Black Southerners in the Age of Jim Crow*, Taylor Branch’s (1988) *Parting the Waters: America in the King Years 1954-1962*, and Jim Schutze’s (1986) *The Accommodation*—a book which specifically addressed racial tension in Dallas, Texas in the 1950s. I also read contemporary works such Joan Morgan’s (1999) *When Chickenheads come home to Roost* and listened to the music of popular African American gospel artists such as Michelle Williams. This process significantly increased my ability to view issues from the perspective of African Americans and improved my credibility with the key informants and breast cancer survivors that I interviewed.

Interviews with key informants and breast cancer survivors were conducted over a ten-month period which started in July 2003 and was completed by April 2004. Data from these interviews were triangulated with participant observation and historical research.

*Key Informant Interviews*

The purpose of the key informant interviews was to gain insight from community health professionals and advocates into the coping mechanisms and social support needs of African American women with breast cancer and to verify the validity of issues raised by the literature review (Bernard, 2002). These semi-structured interviews were also intended to elicit the perspectives of these professionals on the viability and potential benefits of cancer support
groups for African American women. All key informants were African American, and worked in Austin, Dallas, or Fort Worth, Texas.

Nine key informants participated in the study. All informants were African American, 30 years of age or older, and had some type of help-giving or advocacy experience dealing with people who have cancer. This group included nurses, a physician, a social worker, a minister, and professionals from cancer-related organizations (e.g., American Cancer Society, community-based groups). A tenth key informant was interviewed but was disqualified because she had negligible experience with cancer patients.

All key informant interviews were audio-taped except in one case in which the informant requested that the interview not be recorded. Three other key informants requested that I stop the tape while they recounted a particular incident. In all of these cases, the incident related dealt with some form of racial discrimination which they had personally experienced and did not want tape recorded. In one instance, for example, the key informant had experienced a problem at work and did not want to risk being identified in a tape recording.

Interviews with key informants ranged in length from 60 minutes to nearly three hours. The average interview length was 90 minutes. All key informant interviews were conducted at the offices of the respondents. Overall, the key informants expressed a strong desire to participate in the study. For example, one physician readily rescheduled his interview after having had to cancel the first appointment. Most informants made time during their busy professional schedules to accommodate the interview.

The initial key informant interviews were guided by topics covered in the review of the literature. Questions in later interviews were modified based on information received from previous informants (Strauss, 1987). These semi-structured interviews addressed the role of
culture as a factor in coping and included open-ended questions dealing with topics such as religion, health beliefs, physician-patient relations, family/friend support, the impact of socio-cultural and historical experiences on coping styles, and the use of cancer support groups. Examples of questions posed are: “What part does prayer and spirituality play in the lives of African American women with breast cancer?” and “If you were to design a cancer support group for African American women, what would you include and why?” A complete list of the questions that guided the key informant interviews are set forth in Appendix A.

Establishing rapport with most key informants was fairly straightforward. In additional to their professional experiences in dealing with cancer patients, most of the key informants are actively involved as volunteers in improving some aspect of healthcare delivery to African Americans. For example, one key informant who is a registered nurse established a support group for African American survivors. Another informant, a minister, serves on a state level committee for the American Cancer Society in Austin. All of the informants expressed interested in the research project and were very willing to provide information.

*Breast Cancer Survivor Interview Guide*

Seventeen breast cancer survivors participated in this study. The purpose of these semi-structured interviews was to elicit personal narratives directly from survivors about their cancer experience, coping strategies, support needs, and thoughts about support groups. To compare more effectively the coping strategies and support needs of survivors, both African American and White survivors were interviewed. All breast cancer survivors were English-speaking, born in the United States, and lived in North Texas in the greater Dallas-Fort Worth area.

Questions which guided the breast cancer survivor interviews were formulated based on a literature review. The questions in these semi-structured interviews were open-ended and dealt
primarily with the survivors’ reactions to various aspects of their cancer experiences. The topics covered with African American breast cancer survivors were modified based on information gained from the key informants. Moreover, questions also changed somewhat as a result of information gained from breast cancer survivors as these interviews progressed.

The first question was an invitation to the survivor to describe her cancer experiences and was generally posed as follows: “One of the most stressful experiences a person can have is to be diagnosed with cancer. Can you tell me when you first learned about your illness and what went through your mind after you learned your diagnosis?” This invitation to the survivor to begin telling her story generally elicited detailed information on her experiences with breast cancer and was the basis for many follow-on probes for both African American and White breast cancer survivors. All of the survivors told their stories in chronological order starting with the discovery of their breast cancer and related their experiences to the present. If a survivor did not mention an area of specific interest (e.g., role of spiritual beliefs in coping, support from family, friends, medical profession), I asked a specific, but open-ended question which addressed it. Questions used to direct the survivors’ interviews are listed in two separate guides in Appendix A: one for survivors who have attended cancer support groups and the other for survivors who have not attended these groups.

The Interviews

Interviews with breast cancer survivors were conducted at a location of their choosing. Interviews were conducted in various locations, including survivors’ homes, public locations such as restaurants or libraries, and at the offices of different cancer services organizations.

Allowing the survivor to choose the location and time of the interview appeared to be helpful in establishing basic rapport and trust. My telephone calls to survivors to arrange the
interviews often lasted over 15 minutes. These initial conversations gave survivors an opportunity to form an impression about me before meeting me in person. In these calls, I gave a brief explanation of the purpose of the study and answered questions. Most survivors shared some aspect of their cancer experience during the initial phone call. For example, one survivor told me that she got the results of an abnormal mammogram right before the end of her spring semester. She reported that she asked the physician if she could follow up with the biopsy at the end of the semester and that physician agreed. Consequently, when we met in person, we first talked about her coursework and conversation came fairly easily.

In general, breast cancer survivors were comfortable with being audio-taped. Discomfort or self-consciousness over being audio-taped appeared to dissipate soon after the survivor became engrossed in telling her story. The survivors were informed prior to the interview that the taping could be stopped at any time. I frequently stopped the tape during interviews to allow for breaks, telephone interruptions, or to allow a survivor to collect herself if she cried. One survivor requested and was provided a transcribed copy of her interview.

Because of the nature and sensitivity of the interviews, I focused on making these interviews less formal and more conversational. As a result, I seldom took notes during interviews, and when I did, I made every effort to be unobtrusive. At the beginning of each interview, I often exchanged pleasantries with the survivor for a few minutes. If I had arrived first at the planned meeting place, I already had out in plain view two tape recorders (one was for backup), a note pad, the questionnaire, and the consent form. If we arrived at the same time, or if I arrived later, I removed these items from my brief case immediately. After the initial exchange, I formally explained the research project and the consent form. I also indicated that the interview and/or recording could be stopped at any time. The participant signed the form, and I placed it in
my file. Although I always gave the interviewees an opportunity to ask questions at this point, there rarely were any. I always asked the survivor if she was ready to begin before turning on the tape recorders. At the conclusion of the interview, when I was certain that the participant was ready to end, I turned the recorders off.

In four cases, the interviews took place with family members nearby. In each case, the participant and I moved to a location that was physically separated from the family members and was private. In two of these cases, I temporarily stopped the interview process to accommodate interruptions from family members. The interruptions were brief and never lasted more than five minutes.

The taped interviews of breast cancer survivors were usually delivered to the professional transcriptionist within two days following the interview, and transcripts were generally returned to me within 10 days. All survivors gave permission to contact them following the interview if I had additional questions. I called three survivors subsequent to their interviews to ask additional questions or to request clarification. In addition, three other survivors called me following their interviews to follow-up.

*Afriean American Survivors*

Nine African American breast cancer survivors participated in the study. Two additional survivors agreed to be interviewed, but were disqualified from the study, one for refusing to sign informed consent, and the other for refusing to supply her surname on the informed consent. Three of the breast cancer survivors served in a dual capacity as key informants because of their experiences in forming cancer support groups for African American survivors. However, they are counted only among the African American breast cancer survivors.
All of the African American survivors reported that they were pleased to participate in the project. They indicated a willingness to share their experiences with breast cancer in order to educate other African American women about the disease, its treatment, and the resources available to help women through the process. One survivor is a Reach to Recovery volunteer with the American Cancer Society, and another founded an organization to provide support services to African American cancer survivors.

The African American women were proud of their survivorship and believed that sharing their experiences was a form of personal testimony—a means of crediting God for taking them through the experience of breast cancer. They were also pleased to offer their thoughts on support groups and how they might be better structured to address the specific needs of African American women.

Most interviews with African American survivors were conducted in a single session. However, two sessions were required for two of the survivors due to the time constraints of the survivors. The length of each interview ranged from one hour and 15 minutes to over 3 hours. The average interview length was approximately one hour and 45 minutes.

White Survivors

Eight White breast cancer survivors were interviewed. An additional White survivor was contacted and agreed to be interviewed, but subsequently failed to appear at the interview or respond to a follow-up telephone call from the researcher.

White breast cancer survivors also seemed enthusiastic about their participation in the project. Most of these survivors indicated that the experience of breast cancer had taught them many important things and welcomed the opportunity to share their experiences with others. Two of the survivors actively kept friends and family apprised of their illness through email
distribution lists. One survivor kept a “Breast Blessing Book” to chronicle her experiences which she brought to her interview.

Two of the White survivors are currently Reach to Recovery volunteers with the American Cancer Society and actively work with women newly-diagnosed with breast cancer.

All of the interviews with the White survivors were conducted in a single session. The length of each interview ranged from 55 minutes to just over 3 hours. The average interview length for White survivors was approximately one hour and 30 minutes.

Participant Observation

During the ten months that interviews were conducted, I was able to supplement data collected through that process by participating with African American women in a variety of events and settings. I attended meetings, went to social events, had lunch with survivors, and attended cancer specific events.

Early in the interview process, I attended a dinner meeting sponsored by the Church Connection. This organization was formed through a collaborative effort with the American Cancer Society in Fort Worth, Texas, and local African American churches. The mission of the Church Connection is to reduce cancer mortality rates among African Americans by providing education about cancer prevention, detection, and treatment. It consists of ACS volunteers who are also members of local African American churches. These volunteers disseminate information they receive at meetings to their churches.

The Church Connection meeting was an early opportunity for me to observe meetings run by African Americans for African Americans. At the request of the leadership, I was able to briefly describe my research to those in attendance. In addition to the informal conversations I had with others at the meeting, the formal sanction of my research by the Church Connection
leadership had the effect of broadening my contact base in Fort Worth with the African American community.

As a result of this meeting, I established connections with Faces of Survivors (FACES), a non-profit organization with headquarters in Fort Worth, Texas, which provides education and support services to African American cancer survivors and their families. I walked with the FACES team of African American survivors and their families in the 2003 Susan G. Koman Race for the Cure. Participation in this event gave me the opportunity to have informal discussions with several African American survivors and their families, and to clarify themes from the formal interview process. I also participated in several meetings at FACES, all of which were predominantly attended by African Americans. In some of these meetings, I was the only White person in attendance. These meetings gave me, as a White person, a better sense of the dynamics in groups which are predominantly African American. I was also able to observe firsthand the common practice of prayer and reference to God in secular meetings.

Analysis

Taped interviews were transcribed verbatim. I transcribed most of the key informant interviews, but I employed a professional to transcribe the interviews with breast cancer survivors. Over 2,200 pages of transcripts were generated from interviews with key informants and breast cancer survivors. The transcribed text was analyzed using grounded theory, an approach which is useful for identifying concepts, variables, and for generating hypotheses (Strauss, 1987).

The initial stage of analysis consisted of reading the transcripts and noting in the margins the themes, patterns of attitudes, beliefs, and behaviors discussed by each survivor and key informant. My supervising professor also read and similarly annotated many of the transcripts.
We subsequently compared our notes for similarities. Over 50 themes, attitudes, beliefs, and behaviors were jointly reviewed, labeled, and assigned code numbers. Segments of text which supported a particular theme were then labeled with the appropriate code number.

In the second stage of analysis, the codes were compared and similar ones were grouped into categories. For example, many survivors indicated that they prayed as a means of coping with their breast cancer. They variously indicated that they prayed for healing, strength, their doctors, and other matters. Codes dealing with prayer for various issues or people were grouped together into a category labeled “what people pray for.” This second level of coding produced 17 basic categories. These categories included items such as healing, somatic concerns, medical personnel, and guidance.

Questions or ideas naturally arose in the process of making distinctions between categories (and subcategories) and served to direct future inquiry in the analysis. These questions or ideas were recorded in the form of “memos,” and assisted in making connections between categories. For example, it became apparent during analysis that African American survivors often pray to God for healing more than White survivors. This realization led to further analysis of transcripts looking for answers to the question: “What do faithful White survivors pray for?”

Interviews were also analyzed for the presence or absence of certain words or phrases, as well as for the number of times a particular word or phrase was used. This process was useful in determining the importance or emphasis placed by the survivor on a particular topic. A survivor might mention, for example, that she does not attend church regularly; however, her transcript might reflect a high usage of words such as “God,” “Lord,” or “faith.” In this case, the survivor may rely on her faith to cope, but not on the church.
After the codes were categorized, individual transcripts were compared with the categories to determine common patterns among African American survivors as a group and White survivors as another group. Next, the two groups were compared for similarities and differences. The comparisons between the groups provided especially valuable insight. For example, previous studies have suggested that African Americans with cancer cope religiously more than Whites (Culver et al., 2002; Culver et al., 2004). However, these studies provided no information on how the faith-based coping strategies of African American and White survivors compare. Use of intra- as well as inter-group comparisons revealed that African American and White survivors differ in their respective use of faith as a coping strategy. Moreover, this process of comparison also indicated that African American survivors and White survivors who cope spiritually construct their faith in different ways.

The constant comparison of categories led to the development of concepts and basic research themes. Through the identification of concepts and the relationships which appear to exist between them, basic theory was generated which addressed African American survivors’ support needs and how they might or might not be met within the context of a cancer support group. Thus, the concepts, linkages, and subsequent theory were “grounded” in the data collected during the two phases of interviewing.

Ethical Considerations

Approval for the study was obtained from the University of North Texas Institutional Review Board prior to its commencement. All participants gave written informed consent prior to their interview. The consent forms used for key informants and breast cancer survivors are included in Appendix B. Respondents were assured that the information they provided would be
confidential and that their anonymity would be preserved in any written results by eliminating comments or other contextual material that might be traceable to a particular individual.

Interviews conducted with key informants drew on the professional experiences of the participants and posed them no harm. The breast cancer survivors interviewed, by virtue of their gender, race (for some), and illness, are considered a vulnerable population. However, the breast cancer survivors did not suffer harm by voluntarily describing their personal experiences with breast cancer. The information provided in these interviews differed little from that exchanged in a normal social context. Some of the breast cancer survivors cried when talking about their experiences; however, almost all survivors indicated that they felt better after the interview and that they appreciated the opportunity to share their experiences. This reaction is consistent with research that suggests that telling one’s story is a healing experience (Pennebaker, 1990).

Limitations

The primary means of data collection for the breast cancer survivors was semi-structured interviews designed to elicit personal narratives about their cancer experiences. This methodology required that breast cancer survivors retrospectively report on the stresses they faced and how they coped with those stresses from periods ranging from a few months to several years prior to the interview. There are two basic concerns associated with retrospective narrative accounts. The first is the accuracy of recall by survivors of specific thoughts, feelings, or behaviors which occurred at some period in the past. Several survivors addressed this problem by keeping journals, sending regular emails to others about their experiences, or by keeping a file. Two survivors kept a journal of their experiences and one of these provided regular email updates to friends and family. Another survivor who did not journal also sent regular email updates. One survivor brought a file to her interview that contained information relevant to her
breast cancer. Most survivors however, appeared to clearly recall the date and circumstances surrounding their diagnosis, their reactions, and their subsequent treatment.

Another concern with retrospective accounts is the potential for distortion as the breast cancer survivor attempts to construct a coherent narrative of her experiences or find meaning in the event (Folkman & Moskowitz, 2004). Some thoughts or behaviors may have been omitted in the absence of some form of coping inventory. However, having to recall and reconstruct events without the assistance of a checklist eliminates the bias associated with prompting and has the potential to uncover ways of coping not included on inventories.

A number of breast cancer survivors interviewed had experience relating their story to others. Three survivors are active Reach to Recovery volunteers and another has received training in that program. The experience of these survivors of talking to and mentoring other women recently diagnosed with breast cancer may serve to sharpen the memory of their own experiences. Five other survivors have formally talked about their breast cancer experiences either to their church or to other civic organizations. The expressed or unexpressed attempt by survivors to find meaning in the construction of their personal narrative is not necessarily a limitation. It simply reveals another form of coping.

This study also has limitations common to qualitative research. The small number of participants and the use of a non-probability sample selection method preclude generalization of findings to a larger population. While every effort was made to recruit as diverse a sample as possible in terms of age, socioeconomic status, and length of time since diagnosis, sample participants were largely drawn from metropolitan areas in North Texas. The coping strategies of African Americans and Whites from this area may not be consistent with those living in rural areas or in other parts of the state of Texas, or with those in other parts of the United States.
Although qualitative research is sometimes conducted with small teams of researchers, it is often conducted by a single researcher (Neuman, 2000). In this study, I conducted all of the interviews. While this approach tends to increase the reliability and consistency of the interview process between participants, it also has limitations. For example, socio-economic biases attendant to my status as a White, middle-class, female may have affected data collection and interpretation. My personal characteristics, especially my ethnicity, may also have acted as a barrier for some respondents or introduced bias into the sample (Frankfort-Nachmias & Nachmias, 2000). For example, the African Americans who agreed to interviews with me may have been more comfortable speaking to Whites. Moreover, my demographic characteristics may have resulted in response bias because parts of this research project touched on racially sensitive issues (e.g., distrust of healthcare providers). As a result, participants may have been less spontaneous, or felt less comfortable reporting their attitudes on these issues to a researcher of a different race. Key informant interviews were intended, in part, to address some of these issues by acting as “cultural guides.”

Racial and cultural differences between a researcher and the study participants are not, however, necessarily without advantage. These differences may contribute to an enhanced perceptiveness on the part of the researcher (Frankfort-Nachmias & Nachmias, 2000). In my case, the racial difference may actually have increased my access. Some African American respondents expressly welcomed the opportunity to share what they have learned from their illness experience with a White person.

Justification for Qualitative Methods

While the coping literature is fairly substantial, relatively little is known about the coping strategies employed by African American women with breast cancer and how these strategies
relate to support groups. Early quantitative studies which dealt generally with coping often failed to report specifically on African Americans (e.g., Pearlin & Schooler, 1978), or had no African Americans in the sample (e.g., Folkman & Lazarus, 1980; Mattlin et al., 1990). Studies such as these provided the framework for the development of instruments intended to measure the use of coping strategies (e.g., Folkman & Lazarus 1980; Lazarus & Folkman, 1984). Dunkel-Schetter and her colleagues (1992) adapted one such instrument for use with a sample of 668 cancer patients. The sample was 93% White, but the researchers did not report separately by race or ethnicity. The effect of much of this early research was to develop a theoretical framework which is primarily reflective of White coping strategies and devoid of African American influence.

Later quantitative studies have targeted how women cope with breast cancer, but like earlier coping research, these studies tend to have insufficient numbers of African American women in the sample to report by race (e.g., Stanton & Snider, 1993) or fail to report specifically on African American women (e.g., Bloom et al., 2001; Epping-Jordan et al., 1999).

Recently, some quantitative research has been directed at uncovering the coping strategies employed by different minority groups with breast cancer. However, these studies are also characterized by samples having relatively few African Americans and by the use of non-probability sampling techniques (Bourjolly & Hirschman, 2001; Culver et al., 2002; Culver et al., 2004; Spencer et al., 1999). Sample sizes of African Americans in these studies ranged from N=8 (Culver et al., 2002) to N=41 (Bourjolly & Hirschman, 2001).

The small sample sizes in recent quantitative studies on minorities coping with breast cancer, coupled with an absence of probability sampling techniques, have resulted in non-representative findings. Moreover, while the results from these studies are suggestive, they lack the richness of qualitative data. For example, Culver and her colleagues (2004) found that
African American women with breast cancer use more religious coping than White women. However, they do not indicate what religious coping involves. In addition, implicit in their findings is the notion that religious coping is roughly equivalent for African American and White women—an assumption worthy of further exploration.

Qualitative methods are appropriate when no suitable sampling frame exists and when problems are present in recruiting sufficient numbers of participants for a quantitative study. Thus, while the American Cancer Society sponsors a number of professionally led breast cancer support groups statewide and would appear to be a source for a sampling frame in this research, it does not keep records on the racial makeup of the groups.

Research concerning the coping strategies of African American women with breast cancer necessarily involves the examination of the illness episodes which form a specific unit of social context and are appropriate for qualitative analysis (Lofland & Lofland, 1995). Qualitative methods are invaluable for uncovering and describing the culturally-specific meanings associated with the illness experience and associated coping processes because of the importance placed on understanding the patient’s frame of reference (Marshall & Rossman, 1989). They also facilitate the discovery of key themes, concepts, and behavioral patterns related to coping. In addition, the inductive processes which are characteristic of qualitative methods are a more effective means of identifying the issues which either encourage or impede cancer support group attendance by African American women.
CHAPTER 4

RESULTS

Sample Characteristics

*Characteristics of Breast Cancer Survivors*

Of the 26 respondents interviewed for this study, 17 were breast cancer survivors. The breast cancer survivors were English-speaking, born in the United States, and between 18 and 65 years old. Fifty-three percent (9) of the sample of breast cancer survivors were African American and 47% (8) were White. One African American survivor had one parent of Caribbean origin.

Forty-four percent of African American and 75% of White breast cancer survivors were married. Forty-four percent of African American breast cancer survivors had college degrees compared with 50% of White survivors; 22% of African American survivors and 25% of White survivors had advanced degrees (see Table 1).

Sixty-six percent of African American breast cancer survivors were employed full-time, compared with 38% of White survivors. All of the White breast cancer survivors were covered by private insurance compared with 78% of the African American survivors. Twenty-two percent of the African American sample received disability benefits while none of the White sample received such payments.

On average, the African American breast cancer survivors were diagnosed at a younger age than White survivors (see Table 2). Forty-four percent of the African American breast cancer survivors were 40 years or younger when their cancer was first detected in contrast to only one White breast cancer survivor who was as young as 40 at diagnosis.

The proportion of African American breast cancer survivors diagnosed at later stages of the disease was higher than Whites. Forty-four percent of the African American breast cancer
survivors were diagnosed with non-localized breast cancer compared with 25% of White breast cancer survivors. National data indicate that, on average, 43% of African Americans with breast cancer are diagnosed in non-localized stages compared with 33% of Whites (American Cancer Society, 2003).

Table 1

*Survivor Demographic Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>African American Survivors (n=9)</th>
<th>White Survivors (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>66% (6)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Part-time</td>
<td>11% (1)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Retired</td>
<td>22% (2)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Not Employed</td>
<td>0% (0)</td>
<td>25.0% (2)</td>
</tr>
<tr>
<td><strong>Private Insurance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>78% (7)</td>
<td>100% (8)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advanced Degree</td>
<td>22% (2)</td>
<td>25% (2)</td>
</tr>
<tr>
<td>College Degree</td>
<td>44% (4)</td>
<td>50% (4)</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>33% (3)</td>
<td>25% (2)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>22% (2)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Married</td>
<td>44% (4)</td>
<td>75% (6)</td>
</tr>
<tr>
<td>Divorced</td>
<td>33% (3)</td>
<td>25% (2)</td>
</tr>
<tr>
<td><strong>Average Number of Children Per Survivor</strong></td>
<td>1.33</td>
<td>1.25</td>
</tr>
</tbody>
</table>

White breast cancer survivors may have been treated more aggressively for their disease than African American survivors. Twenty-five percent of White breast cancer survivors diagnosed with localized breast cancer had double-mastectomies. In contrast, none of the African American breast cancer survivors received this treatment. All of the White survivors reported receiving radiation, chemotherapy, or both. One African American survivor did not receive either chemotherapy or radiation treatment after her mastectomy in 1997, nor did she report that
it was recommended by her physician. Only after she suffered a recurrence on the same side in 2000 did she receive both therapies.

Table 2

*Disease and Treatment Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>African American Survivors (n=9)</th>
<th>White Survivors (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Age at Diagnosis</strong></td>
<td>44 years</td>
<td>49.3 years</td>
</tr>
<tr>
<td><strong>Percent 40 years or younger</strong></td>
<td>44% (4)</td>
<td>12.5% (1)</td>
</tr>
<tr>
<td><strong>Percent older than 40 years</strong></td>
<td>56% (5)</td>
<td>87.5% (7)</td>
</tr>
<tr>
<td><strong>Disease Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Localized (Stage I)</td>
<td>44% (4)</td>
<td>75% (6)</td>
</tr>
<tr>
<td>Non-localized (Stages II – IV)</td>
<td>56% (5)</td>
<td>25% (2)</td>
</tr>
<tr>
<td><strong>Surgical Procedure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>22% (2)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>78% (7)</td>
<td>25.0% (2)</td>
</tr>
<tr>
<td>Double Mastectomy</td>
<td>0% (0)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td><strong>Adjuvant Treatment Received</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation only</td>
<td>11% (1)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Chemotherapy only</td>
<td>44% (4)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Radiation and Chemotherapy</td>
<td>22% (2)</td>
<td>25.0% (2)</td>
</tr>
<tr>
<td><strong>No Adjuvant Therapy</strong></td>
<td>22% (2)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td><strong>Reconstruction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>44% (4)</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>No</td>
<td>33% (3)</td>
<td>25.0% (2)</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>22% (2)</td>
<td>37.5% (3)</td>
</tr>
</tbody>
</table>

Overall, African American survivors were sicker than the White survivors, often had fewer financial resources, and received less aggressive cancer treatment than White breast cancer survivors.

Profiles of the individual African American survivors are located in Table 5; White survivors are located in Table 6, in Appendix C. In order to protect the identity of the survivors, the names listed in these tables are pseudonyms.
Characteristics of Key Informants

In addition to the breast cancer survivors, nine key informants were interviewed for the study. The key informants were professionals who had experience working in some capacity with cancer patients. Eight key informants were African American. One key informant was half-Black (Caribbean origin) and half Mexican. The group included two nurses, a physician, a social worker, a minister, three professionals from non-profit agencies which serve cancer survivors, and a board member of a faith-based agency dedicated to disseminating health-related information to the local African American community. Seven of the key informants were women and two were men. The median age of this group was approximately 45 years old with combined experience with cancer patients of over 50 years. All key informants who received requests agreed to participate in the study. One key informant was disqualified due to a lack of experience with cancer survivors.

Cultural Differences in Coping with Breast Cancer

The data indicate that distinctive differences exist in the coping responses of African American and White women with breast cancer in North Texas. A woman’s use of certain coping strategies is shaped by social factors as well as by individual personality and psychological profile. People with serious illness tend to want others in their social network to respect how they manage the physical and emotional effects of their disease (Register, 1987). For example, a woman must decide how much to talk to others about her illness. Too much discussion may invite the unwanted pity of others, while too little may suggest to others that she is in denial about her illness. The boundaries of any coping strategy, including the discussion of illness, are socially and culturally defined.
An unstated assumption in much of the literature on coping is that African American and White women currently share the same culture in the United States. While this is true in part, culture “is not a fixed condition but a process: the product of interaction between past and present” (Levine, 1977, p. 5). The socio-cultural experiences of African American and White women have varied significantly for most of the country’s history.

Cultural differences borne out of divergent socio-historic backgrounds appear to account for the differences in the coping strategies of the women in this study, especially in the way in which faith influences response to the illness and in the use of social support. The variance in these coping strategies has significant implications for the design of cancer support groups for African American breast cancer survivors. This chapter discusses some of the differences found in the coping strategies of African American and White women breast cancer survivors who reside in the North Texas area. The major themes discussed are set forth in Table 3.

Personal Faith as a Coping Strategy

Without exception, the breast cancer survivors interviewed—both African Americans and Whites—professed a belief in God. The data indicate that personal faith was a dominant coping mechanism among all of the African American breast cancer survivors. The importance of African American spiritual beliefs has previously been documented by a number of researchers (Ferraro & Koch, 1994; Lincoln & Chatters, 2003). Ellison and Taylor (1996) specifically reported that prayer is an essential coping response by African American women with personal health problems. In contrast, personal faith appeared to be less important to the White participants in this study. This finding is also consistent with that of previous studies (Ashing-Giwa et al., 2004; Bourjolly, 1998; Culver et al., 2004).
Previous research, however, generally fails to examine how African American and White cancer survivors who use their faith as a coping strategy vary in their respective approaches to that faith. Data from this study show that, as groups, African American and White breast cancer breast cancer survivors differed in their views of God, and also in the manner in which, as well as the extent to which, they drew support from their religious faith.

*The Importance of Faith in Coping for African American Survivors*

Each African American breast cancer survivor accorded major significance to God’s assistance in her coping with cancer. Without exception, African American survivors indicated they would advise other newly diagnosed women that faith in God is essential. For example, Bernice, who was age 60 at the time of her diagnosis and who is active in the American Cancer Society’s Reach to Recovery program, knows that as a volunteer, she must be careful talking about God to the women she visits. She asserts, “The first thing I would tell them, if I could, is pray. And lean on the Lord for everything. And ask for his direction.” Bernice also offers follow-up advice: “And then be positive about everything else.” Likewise, Sheila, age 38 at diagnosis, would urge others “to be positive and always keep God in your life and in your thoughts and prayers.” Terri, who was 37 years old when she was diagnosed with inflammatory breast cancer in stage three and who struggled through months of treatment complications, would offer similar counsel. She states, “The most important advice that I would give to anyone diagnosed with cancer would be to maintain a positive outlook…And trust God.” These comments reflect a sense of optimism that involves the belief that, when life is devastating, these survivors will triumph through their faith in God either on earth or in Heaven.

For African American breast cancer survivors, a positive attitude is predicated on faith in God. Comments from Kimberly, who was age 48 when she was diagnosed with breast cancer,
demonstrate that positive attitude is a manifestation of the strength derived from her faith. She explains, “First of all, I would tell them never give up. Keep the faith. Keep hope alive….My faith and the hope that I have gives me the strength to get up and fight another minute, another day.”

The optimism expressed by African American women in this study is consistent with at least one prior study which documented optimism among African American women coping with breast cancer (Henderson, Gore et al., 2003). That study, however, did not relate optimism to spiritual strength. The unfaltering faith and strong religious orientation of the survivors in this study appears to be reflective of the reliance on faith that has emerged out of the historical experiences of African Americans in the United States as they have dealt with racial oppression (Hill, 1972; Nobles, 1972).

*Faith and the Coping Strategies of White Survivors*

While faith was a primary coping strategy identified by all African American respondents, it was not uniformly recognized as such by White breast cancer survivors. Thirty-eight percent of the White survivors did not mention either faith or prayer in the advice they would offer to someone newly diagnosed with cancer. For example, Linda, who was 52 years old when she was diagnosed, advises that “you have to listen to what your body tells you. Don’t keep trying to do everything yourself. There are other people out there who love you, who would gladly do whatever it is you need them to do.” Linda, who describes herself as independent and strong-willed, found it personally challenging to ask others for help. She acknowledges, however, the importance of the assistance provided by her “inner support core”—her husband and two grown daughters.
### Table 3

**Major Coping Themes**

<table>
<thead>
<tr>
<th></th>
<th>African American Survivors</th>
<th>White Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faith as a coping strategy</td>
<td>• Primary strategy</td>
<td>• One of many strategies</td>
</tr>
<tr>
<td></td>
<td>• Source of positive attitude</td>
<td>• Connected with social support</td>
</tr>
<tr>
<td>View of God’s presence</td>
<td>• Immediate personal presence</td>
<td>• One step removed</td>
</tr>
<tr>
<td></td>
<td>• Actual member of support network</td>
<td>• Manifests care through other people</td>
</tr>
<tr>
<td>View of God</td>
<td>• Healer</td>
<td>• Source of emotional support</td>
</tr>
<tr>
<td></td>
<td>• Deliverer from earthly difficulties</td>
<td></td>
</tr>
<tr>
<td>Prayer</td>
<td>• Request healing</td>
<td>• Requests for strength, peace, courage</td>
</tr>
<tr>
<td></td>
<td>• Problem-focused coping strategy</td>
<td>• Emotion-focused coping strategy</td>
</tr>
<tr>
<td>View of Physicians</td>
<td>• God’s instruments</td>
<td>• Responsible for curative care</td>
</tr>
<tr>
<td>Relationship with Physician</td>
<td>• Worked to achieve level of comfort</td>
<td>• Expressed trust</td>
</tr>
<tr>
<td></td>
<td>• Sought information on illness</td>
<td>• Sought best physician for treatment</td>
</tr>
<tr>
<td>Social Support</td>
<td>• Good support from family, extended family, and friends</td>
<td>• Good support from family (especially husband), friends</td>
</tr>
<tr>
<td>Illness Appraisal</td>
<td>• One of many difficult life challenges</td>
<td>• Most difficult life challenge</td>
</tr>
<tr>
<td></td>
<td>• “God will get me through.”</td>
<td>• “Why me?” or “Why not me?”</td>
</tr>
<tr>
<td>Request for assistance</td>
<td>• Personal reserve or nondisclosure</td>
<td>• Disclosure to others after firm diagnosis</td>
</tr>
<tr>
<td></td>
<td>• Ethos of personal strength</td>
<td>• Sought the support of others</td>
</tr>
</tbody>
</table>
Another example is Carol, a divorcée who was 56 years old when she was diagnosed. She found that her experience with breast cancer pointed to “what a narrow life [she] was leading.” She decided she needed to reach out more to other people and started attending a local support group; she indicates she would advise others to do the same. Mary, whose doctor initially misdiagnosed her cancer, recommends that a newly-diagnosed woman “seek out women who have survived the experience….Seek out the information about your particular condition….As much as you can arm yourself with knowledge so you can approach it in a knowing way….” The advice that each of these survivors would offer is not uniform, but rather appears to be directly related to specifically addressing what each perceived to be her greatest challenge with the illness.

To the extent that White breast cancer survivors acknowledged their faith as a coping strategy, they described a faith experience different from that of African American breast cancer survivors. It was often described as one ingredient among many used to cope with breast cancer. Marie, for example, advises:

I would talk to [survivors] from every angle that helped me: one, your friends—somebody you love, somebody who loves you, that can touch you and be physical with you. Animals are good for healing—they are—prayer, your faith, deep breathing, yoga, meditation, trying to live in the present. I don't know. It’s not a cake box recipe....

Marie’s statement that “it’s not a cake box recipe” is an acknowledgement that there is no uniform approach to coping. If her cancer returns, she speculates, “I don’t know how I am going to respond to it again.” Previous research indicates that Whites who have cancer tend to use several different coping styles rather than adhering to one primary coping strategy (Carver et al., 1993; Dunkel-Schetter et al., 1992).
Only half of the White breast cancer survivors pointed directly to their faith as the most important strategy in coping with their cancer, but even as they did so, they tied their faith to other coping resources such as the support of family and friends. Two White survivors, who both underwent a double mastectomy and reconstruction, indicated that they found their personal faith invaluable along with the help and guidance from breast cancer survivor friends. Jennifer, who was age 40 when she learned she had breast cancer, would advise other newly diagnosed women to put their illness in perspective. She asserts, “It’s not about you, but it’s all about you. And that encompasses the whole idea that this is so much bigger than you, [and] that God will use it….” However, she adds that “as much as I hate it, I did love that somebody encouraged me because as you struggle…a friend just talks to you about how suffering isn’t punishment.” Jennifer’s faith is very important to her; however, she needed her friends to help her through the crisis in faith brought about by her illness.

Susan, age 54 at the time of her diagnosis, reflects, “Everybody comes at faith differently, but to me the faith was the most important. But on a real practical level, talking to somebody that’s had the exact same cancer is real important, in the same age group and the same kind of cancer.” Previous research supports the value of Susan’s experience with other cancer survivors. Taylor and her colleagues (1988) found that the support of other cancer survivors can reduce distress in those who are newly diagnosed with the disease.

For two other survivors, the importance of faith relative to social support as coping strategies is evident in how they structure the guidance they would offer others newly diagnosed with breast cancer. Cathy, who was age 41 when she was diagnosed, first comments on the need for positive support from family and friends, but then restates her advice: “I’d put faith, family and friends…. Similar counsel was offered by Wanda, who was diagnosed at 48 years old. She
asserts, “I would say first to find all the support that you can get. You know, open up with everybody.” She adds that, for women she knows personally, she would counsel, “First you’ve got to turn it over to God.”

The hesitation to offer faith first as a coping strategy or to render such advice to strangers points to a difference between African American and White women on the primacy as well as the privacy of their faith. For Wanda, talking to others about her faith in God as a coping strategy depends on personal relationship. White women who value their faith do not necessarily assume that other White women hold it in similar regard. African American women, in contrast, expect that other African American women will look to their faith and are less hesitant to discuss faith with each other. Their approach is related, in part, to the role of the church in African American social life. Historically the church is “one of the few indigenous institutions…built, financed, and controlled by Blacks” (Taylor & Chatters, 1991, p. 105). As a result, religious expression has been shaped by social norms and expectations and characterized as semi-involuntary (Ellison & Sherkat, 1995).

In addition to the church, White women in the United States have historically had access to broader networks of social support. The dual significance White survivors place in their faith and in the assistance they receive from family and friends is reflective of their socio-cultural and historical experience and is a key difference between faithful White and African American survivors. This variance between African American and White survivors who place value on faith as a coping mechanism is connected to their respective views of God.

*African American Survivors View God as a Personal Being*

The faith referred to by the African American breast cancer survivors in this study was consistently characterized by belief in a God who was consistently experienced as a being with
whom one could have a human-like relationship. Some African American breast cancer survivors described their experience with God as explicitly as Elizabeth who simply stated, “I have a relationship with Him,” or Kimberly who asserted, “I was born again in 1980”—a statement which is representative of personal affinity with Christ.

For most of the African American breast cancer survivors, however, evidence of their sense of relationship with God was apparent in the context of their interviews which are often suffused with references to “God,” “the Lord,” “faith,” and “prayer.” It was also manifest in the rather routine way in which these references occurred in the interviews. Repeatedly, African American survivors relayed their prayers or conversations with God, in much the same way that friends report to each other their conversations with the significant people in their lives. For example, Bernice relates the following exchange after learning her diagnosis: “‘Lord’, I said, ‘Well, if it’s breast cancer, it’s breast cancer.’ And my mother had had breast cancer. I said, ‘Lord, if she survived it, I can too.’” This frequent, routine mention of God reflects a belief in the immediate presence of a God with whom the survivor often engages in active dialogue.

African American breast cancer survivors not only talk to God, they report receiving answers. In some cases, the response is considered an answer to a specific question. Sheila agonized over whether to have a lumpectomy or mastectomy after her diagnosis. Her doctor presented both as options but favored a mastectomy. She reports, “I kind of listened to other people and then kind of based my decision off of that and what God said to me.” Sheila’s comments suggest relationship with a personal God who provides her with informational support and guidance.

In other cases, survivors indicated that God spoke to them even when his direction was not specifically sought. For instance, Terri was employed and working on her master’s degree
when she was diagnosed with breast cancer. She claims that God warned her about her condition months before receiving a formal diagnosis. She recalls, “I was getting ready for work and the Lord says, ‘Check your breast. You’re going to need a normal picture of them, so get a film of them.’ And I thought, well, that’s kind of strange.” Terri went to the doctor immediately, but reports that the examination and subsequent mammogram did not uncover any abnormality. She remembers her doctor saying, “There’s nothing there; all the tests have proven that.” Six months later, however, her breast swelled to three times its normal size, and Terri received chemotherapy to shrink the tumor prior to a mastectomy. For Terri, this experience demonstrated God’s power to directly influence her behavior to seek preventive screening.

An account by Paulette is similar to Terri’s. Paulette, who was 50 when she was diagnosed with breast cancer, recalls:

I was standing at my sink fixing dinner and this inner voice says, “Go get a mammogram.” And I was shocked, and I said, “Huh?” And again it said, “Go get a mammogram.” I recognized the voice as being that of the Holy Spirit, and immediately I knew, right then, that I had breast cancer.

Paulette had a mammogram which revealed early stage breast cancer. She remembers the doctor saying that her cancer was so small that she “probably would not have felt it for another year and a half, or two years.” Paulette and Terri’s accounts are demonstrative of a faith connection derived from a sensory experience of God. Neither survivor referred to these episodes as miraculous.

African American survivors sensed God’s immediate presence as a “normal” occurrence. Moreover, God is understood by them as a being who directly intervenes to support them or deliver them from harm. These reactions are consistent with research which indicates that African American religious traditions make little distinction between the physical and spiritual world. Levine (1977) maintains that slaves “extended the boundaries of their restrictive universe
forward until it fused with the world of the Old Testament, and upward until it became one with the world beyond” (p. 33). Slaves taught their children about the God of the Old Testament—a personal God who would deliver them just as Moses delivered the Israelites from bondage in Egypt.

*White Women View God as “One Step Removed”*

White breast cancer survivors who attribute importance to their faith as a coping mechanism describe a less direct experience of God. For them, God is often present through the actions of other people. Jennifer refers to this phenomenon as “the body of Christ”—a way of being loved and cared for by God through other believers. She indicates that complications from a double-mastectomy and reconstruction taught her more “about God’s provision.” She adds, “The body of Christ people came around, helped us, and encouraged us.” Jennifer’s comments suggest a belief that God’s presence and support in her life is manifested through her family and friends.

Susan also expresses the belief that God works through others in her life. She reflects, “I think people were there for me for certain reasons just by the grace of God.” The people Susan refers to are friends who are breast cancer survivors and who acted as mentors during her treatment. She explains, “People were put before me that had good experiences, and I went through it thinking, ‘Oh, it’s a piece of cake.’ So if they said it was a piece of cake, it was going to be a piece of cake.” Susan believes her ability to maintain a good attitude throughout her treatment is attributable to the positive role models given to her by God.

Similarly, Wanda views the help received from the parents of a child who attends the preschool where she works as evidence of God’s assistance. Because both of these parents are physicians, she called them to seek advice about where to receive treatment. Wanda recalls one
of them saying, “You’re going over here. It’s hard to get in, but I will get you in.” She reports receiving a call the following morning advising her of an appointment they had scheduled for her. Wanda asserts, “So I just felt like from that point that just kind of like God took over.” Wanda credits God for the direction provided by these doctors.

This theme of God’s support coming through other persons is consistent with the findings in another recent qualitative study of breast cancer survivors. Utilizing a predominantly White sample, the investigators in that study also observed that “support was seen by some as a manifestation of God’s presence and a channel through which God helps the survivor…” (Gall & Cornblat, 2002, p. 529).

In another example showing a more indirect experience with God, Carol described circumstances rather than the actions of people as a manifestation of God’s assistance. Carol wanted to quit her job and start her own business, and as a result had begun application for separate insurance. At the same time, she went in for her annual check-up. Her mammogram indicated an irregularity that doctors ultimately determined was early stage breast cancer. She claims, “I believe that the way we found out about breast cancer was definitely divinely inspired.”

References by White breast cancer survivors to prayer, to God, and to God’s work also depict a God who is more removed from the physical world than he is for African American survivors. Like African American survivors, White survivors report that they talk with God; however, these conversations have a quality of being contained and one-way. Jennifer, for example, recounts her response to a difficult day during her treatment. She remembers, “And I just began to pray, and I just talked to God, I mean, out loud….” Twice during her interview, Jennifer makes this differentiation. Apparently her prayers were most often offered silently.
Cathy’s approach to prayer was also very private. She reports that, after her diagnosis, she would often return home from her part-time job and retire to her sunroom to spend time alone with God. She recalls, “I’d pray, and I’d cry, and I’d moan, and I’d come home and set out here in the sunroom and visit. We’d talk—you know, I’d talk or moan and groan, and I’d be done.” None of the White survivors reported receiving direct communications from God.

The differing views of how God manifests in this world, that is, directly or indirectly, likely also affect how African American and White breast cancer survivors seek help from God. In this study, just as they perceived God’s presence differently, African American and White women differed in what they actively asked of God.

**African American Survivors Pray for Healing**

Seventy-eight percent of the African American breast cancer survivors reported that they prayed for healing. These requests often followed receipt of the diagnosis and were not appeals of last resort that occurred only when conventional medicine failed to produce the desired result. The prayers were based on a belief that God is the healer. After learning she had cancer, Bernice reports, “I claimed my healing, right then and there.” In another case, Sheila recalls, “I asked him to heal me, and I said that ‘I know you can do that, because I know you have the power.’”

The belief in God as healer overrides expressions of doubt. Elizabeth, who was diagnosed with advanced stage two breast cancer, recalls having “prayed, and … asked God to heal my body.” She confided in her minister, however, that “‘Satan keeps telling me, he’s not going to do that for you.’ I said, ‘I know I trust and believe in God, and I know he’s going to do what I’ve asked him to do, because he said: Whatever you need, just ask.’ And I truly believe that.” Elizabeth’s faith was apparently bolstered by conversations with her pastor.
The conviction that God heals is also reinforced by accounts of miraculous healing. Some African American breast cancer survivors and key informants reported either knowing someone who had been the recipient of this type of healing or having had their own experience with this phenomenon.

Two African American survivors indicated they had personal experience with miraculous healing while in regular medical treatment for their disease. Terri suffered a stroke from complications associated with her treatment. The stroke affected her right side and she was unable to walk or use her right arm. She describes her own miracle:

Wednesday, before I leave going to rehab, I just get this feeling of peace and then I get this feeling of warmth coming all over me, and warmth shoots through my legs and everything….I felt like God was all over me, and he was all in the room, I knew that’s what was going on….I got up and walked to the bathroom, pushing my IV pole, yeah.

Terri was still transferred to a rehabilitation unit because she was unable to use her right arm. However, she credits God with healing her right leg and enabling her to walk. In her testimony, written three years after her diagnosis, she declares, “Miracles are not a thing of the past, but of the present, and do occur daily!”

Sherry, a school teacher, relates a similar experience in which she believes that God provided her palpable physical comfort as well as emotional support. After her surgery, she experienced internal bleeding and reactions to morphine which caused her considerable pain and discomfort. Her doctor told her he would have to do surgery again to correct the problem. Sherry, who reports that she is “not a good patient” and is afraid of pain recalls,

And for a brief moment, it was like my body was awake, and I felt as if I was just kind of sinking into the bed. And then—and there’s no explanation, other than I felt like God just kind of lifted me up and said, it’s going to be okay. I’ve got you. Because I was literally just like sinking, and then I just was, okay, let’s go.
She firmly believes that God relieved the pain, the itching caused by the morphine, and her despair over facing another surgery.

Alice, a breast cancer survivor who has regular contact with other African American breast cancer survivors in her work, asserts, “A woman will go into a doctor’s office—and I’ve seen it happen, and I can’t explain it—will have a lump in her breast, won’t take any medication, and will just intensely pray, pray, pray, and all of a sudden the lump is gone. I’ll say this—I would not advocate it.”

Similarly, Shirley, an ostomy nurse and key informant, reports knowing a woman who claims to have experienced a miraculous healing. She recounts, “One lady at our church said the doctors told her she had breast cancer and when they got ready to go in, there was nothing there. And that was her testimony about how the Lord healed her.” Neither Alice nor Shirley denies the existence of miracles and both claim to believe in healing—including miraculous healing. Both also strongly encourage active medical care in addition to faith healing. Their acceptance of both types of healing is consistent with previous research which indicates that most Americans view faith-based healing and medical treatment as complementary (Bearon & Koenig, 1990).

*White Survivors Pray for Strength, Peace, and Courage*

In contrast to African American women, White breast cancer survivors did not mention miraculous healing, nor did they tend to pray for healing. Only two White survivors (25%) offered that they prayed for their health—one for healing and the other that “the treatment would all work.” Another White survivor specifically recounts that she did not ask God to cure her of breast cancer. Cathy says, “I didn’t ask for healing. I just asked for him to get me through it.”

Like Cathy, other White survivors who employed faith as a coping strategy tended to ask God for emotional support rather than healing or help with somatic concerns. For Cathy, “get me
through” was a request for assurance. She explains, “If you’re up against adversity, you tend to cry out. That’s who I went to for my comfort.”

Jennifer prayed for strength. Her doctor informed her that she had cancer after she regained consciousness from her surgery. She reports, “And right after [the doctor] walked off I just looked at my husband and I said, ‘Pray right now that we’ll walk strong through this.’” Jennifer recalls that, a few days later, God gave her Psalm 73:26: “Your health may fail, and your spirit may grow weak, but God remains the strength of my heart. I will make the sovereign Lord my shelter, and I will tell everyone about the things that he does for me.” She says this verse with its message of God’s provision of internal strength became her “battle cry” throughout her treatment; however, she did not request, nor does she credit God with, an effort to cure her physically.

Other White survivors indicated they sought peace and courage through prayer and their faith. Susan reflects, “Whenever I would have fear I would sing praise songs or pray. In the shower when I was taking chemotherapy I would sing, ‘Onward chemo soldiers, marching on to war.’” She maintains that her prayers and singing gave her a feeling of peace. Susan never indicated that she prayed specifically for healing; however, she reported that she “read a lot of inspirational poems or Bible phrases that talked about healing.” Another White survivor, Marie, who was learning the value of prayer during her struggle with cancer notes, “So my psyche was working very hard on all of these issues of how to not be overrun by anxiety and fear. And that probably greatly aided me—my faith, and trying to stay focused.”

The divergence in the content of the prayers of White and African American breast cancer survivors reflects different frames of reference regarding the healing process and God’s
role in that process. These different perspectives extend to formal medical institutions and attitudes toward physicians in particular.

Faith and the Medical Profession

*African American Survivors Believe Doctors are God’s Instruments*

African American women clearly believe that God has the power to heal and will intervene to heal. This belief is not doctrinaire, however, but rather operates on a continuum. Jean, a key informant, explains that “some people go to the extreme and think that means that you don’t need to go to the doctor, and some people see that God has given the doctors gifts, and the skill and the knowledge, and the medication to be able to help you.” Failure to seek any medical care and placing faith exclusively in God comprises one end of the continuum, while seeking the help of the medical establishment coupled with an absence of faith is the other.

In this study, even as they prayed for healing, all African American survivors, irrespective of socioeconomic status, actively and aggressively sought medical care for their condition. These women evidence a belief that God’s healing may come either through formal medical treatment or miraculously through divine intervention. Kimberly’s comments are illustrative:

I prayed and asked the Lord to take that [the cancer] from me. He didn’t, so he must have another way. If he’s ready to call me home, then so be it. If not, he’ll heal me the conventional way. Either way healing is healing, and I received healing, and so whichever way he decides to heal me, if it’s miraculously or through by way of medicine, all is His healing.

Kimberly clearly indicates a belief that only God has the power to heal, and that doctors are merely the instruments through which God works—a commonly observed belief among African Americans (Abrums, 2000; Ashing-Giwa & Ganz, 1997; Potts, 1996). Moreover, Kimberly’s acknowledgement of God’s power and control over her health and ultimately her life is not
fatalistic. This belief did not abnegate her use of preventative care or her pursuit of aggressive treatment. In fact, Kimberly, who is a woman with limited economic means, was diagnosed based on her annual mammogram—a regular practice for her for over 18 years.

A deep belief in God’s healing power coupled with an active approach to treatment is also evident in the advice Elizabeth would give others newly diagnosed with breast cancer. She offers, “I would first and foremost tell them to trust in God….And to make sure that they actively, not passively, take part in their treatment.” Elizabeth was out of town on a business trip when she first detected a problem with her breast. She called her gynecologist when she returned but he was on vacation. She then called his replacement, but still could not get an appointment. She remembers thinking, “Do you either wait a couple of weeks until he gets back from vacation, keep trying to contact his replacement, or do you just do what you know you do best, take matters in your own hands? So I called and made an appointment and set up my own mammogram.” Elizabeth continued to be proactive during her treatment by researching her condition. During a visit with her plastic surgeon, she indicated, “I just need to do my own research, and I’m not doubting what you’re saying, but I just need to go home and think about what I’m going to do.”

In previous research, African Americans have rated their physician visits as less participatory than Whites (Cooper-Patrick et al., 1999). However, the African American breast cancer survivors in this study often investigated their disease independently and carefully questioned their physicians. For example, Alice believes that she was offered the opportunity to participate in a clinical trial because she was well-informed and asked questions during visits with her oncologist. She asserts, “I was utilizing the resources, asking questions, kind of knew what questions to ask….I was my own advocate.” Bernice also believes in learning about your
illness. She reports, “I had read all the books I could put my hands on chemo and radiation.” As a result, she chose to have a mastectomy rather than lumpectomy. Bernice also believes in being prepared for visits with her doctors. She claims, “When I would go in, I would have a whole list of things—a whole page full of stuff. They [the doctors] couldn’t come lightly and then go right out. I would take my folder.” These comments are indicative of personal advocacy and active efforts to participate in treatment decision-making.

The combination of faith in God for healing and the active use of medical science by the African American breast cancer survivors suggest a different view of prayer as a coping mechanism than is sometimes portrayed in the literature. For example, Singer and Baer (1995) have described praying as “compensatory and accommodative rather than corrective” (p. 295) while others have labeled it as “cognitive escape avoidance” (Dunkel-Schetter et al., 1992). Both of these characterizations appear to derive from a perception that prayer and active problem-solving are mutually exclusive. Neither of them accurately reflects the attitudes and approaches of the African American breast cancer survivors in this study. Their experience mirrors that of many African Americans who find that prayer serves as an active force in healing and as resistance to dominant ideology (Abrums, 2000). For them, prayer shifts control over the healing process away from a predominantly White health care profession and into the hands of a trustworthy God.

_African American Survivors’ Comfort with Physicians_

Even though African American breast cancer survivors in this study were active participants in their medical treatment, they did not repose trust in their doctors. When these women used the words “trust” or “faith,” it was almost always in reference to God. Carl, a
physician who practices at a large urban hospital, explains that African Americans do not tend to expect to feel much connection with doctors. He maintains,

There’s an acceptance of a certain level of—I’ll use the term ‘non-relationship.’ I believe when people go to the doctor, they don’t expect a whole lot….They expect you to be competent, and they expect you to not be mean and nasty, but they only expect you to kind of do your job.

Consistent with Carl’s comments, data from the interviews suggest that African American breast cancer survivors approach medical care in a different manner than White survivors.

This difference may be explained by the abuses African Americans have suffered historically from the medical establishment (Rothman, 1991). Gamble (1997) argues that the legacy of the Tuskegee Syphilis Study “endures, in part, because the racism and disrespect for Black lives that it entailed mirror Black people’s contemporary experiences with the medical profession” (p. 1776). Indeed, recent research indicates that African Americans continue to receive substandard medical treatment for a broad range of illnesses. Moreover, the disparity in treatment persists even after adjusting for health insurance coverage, socioeconomic status, stage and severity of the disease, and type of medical facility (Institute of Medicine, 2003; Williams, 2002).

Instead of “trust,” African American breast cancer survivors most often used the word “comfortable” to characterize their relationship with their physician. This word suggests a relationship free of stress or of discernible discriminatory behavior. A state of comfort was achieved when a physician demonstrated a willingness to spend time carefully answering any question the survivor had regarding her condition. Alice recounts, “My comfort level with that doctor was because he was just so comfortable with the human body. And the way he described the surgery, it was just very comforting.”
For Elizabeth, the doctor’s willingness to answer questions as well as his demeanor was important in making her comfortable. She states, “The surgeon examined me, very nice, very mannerable—I just got a good feeling from him. So it’s like, okay, fine, I’m comfortable with this guy….And he explained to me what was going to happen during the lumpectomy.” Sherry, who expresses regard for her physicians, indicates she would advise others who are newly diagnosed with cancer to “make sure that you feel comfortable with your doctors. Definitely, make sure you feel comfortable.” However, she goes on to add, “It’s hard for me to say that it was all the doctors and not just I knew I had given it over to God.”

Sherry’s distinction about who was truly responsible for her sense of comfort is telling. Even when African American breast cancer survivors became comfortable with their physicians they seldom used the word “trust” or other synonyms such as “confidence” in reference to those relationships even if they came to hold their doctors in high regard. Elizabeth, for example, claims, “My oncologist was wonderful. I love him to death. I told him that the other week.” However, her usage of the word “trust” was almost completely confined to references to God.

Kimberly, who was treated at a county hospital, also expressed appreciation for her physicians. She recalls that her doctors “talked to me about any questions and concerns….As a matter of fact, I miss them. I don’t want to be over there getting treatments, but I miss the attention they gave me. They made me feel like a human being.” Kimberly does not use the word “trust” at all in her interview; however, she makes numerous references to her faith in God.

Unlike Elizabeth and Kimberly, Sherry uses the word “trust” in reference to her surgeon, but only with qualification. She declares, “I have to at some point trust her experience, trust her education, and trust God to, you know, make sure that she’s doing the right thing by me.” So, ultimately, even for Sherry, the trust that the doctor will perform to the best of her capability is
reposed in God. Importantly, not one of the African American breast cancer survivors indicated that they distrusted their doctors, and all but one said they were generally satisfied with their treatment. Only one African American survivor reported a problem with a physician.

The tendency by African American women to approach clinical encounters with some level of reserve, even when they believe they are receiving proper medical treatment, may be tied to current physician attitudes and behavior. Van Ryn and Burke (2000) studied 618 patient encounters, the majority of which (84%) involved White physicians. They found that physicians tend to perceive African American patients as less intelligent, less likely to comply with treatment, and more likely to engage in destructive behaviors than White patients.

Several other studies have indicated that some African Americans have beliefs about cancer which may impede their willingness to seek formal medical assistance (Ashing-Giwa & Ganz, 1997; Landrine & Klonoff, 1992; Mathews, 1987; Mathews et al., 1994; Snow, 1983). The only respondent in this study, however, to mention such a belief was Rhonda, a registered nurse and African American survivor. She indicated that she has some older family members (60-70 years of age) living in rural Louisiana who have inaccurate notions about cancer. She reported their belief is that “if you have cancer and you get cut on, that you’re going to die because the cancer is open to the air.” Rhonda claims this belief “irks me to no end” because some of her older relatives and other African Americans “don’t understand that cancer can be treated.” No African American survivor in this study reported personally holding this type of health belief.

White Survivors’ Trust in Doctors

The language used by White breast cancer survivor when speaking of their doctors sounded very similar to the language used by African American breast cancer survivors in referring to God’s healing power. White survivors who point to their faith as a coping strategy
appear to rely on their doctors for healing more than African American survivors. For White women, physicians are responsible for providing curative care in the temporal realm, while God primarily provides spiritual assurance and different forms of emotional support. Among White breast cancer survivors of faith, this duality is not considered an affront to God’s power or a lack of belief.

For example, Cathy claims that her doctor’s “whole attitude was not like death….It was just like we can do this, it’s going to be okay, and I just put my faith in the medical field and him being a surgeon…..” Similarly, Wanda asserts, “I’m very religious, and I basically said, ‘Okay, here you go, God.’ You said to give me your problems, and I said, ‘Here it is.’” But, at the same time, Wanda sought assistance from doctors. After her mastectomy, she waited anxiously for the results of the lymph node biopsy to determine if the cancer had spread beyond the breast. She recalls, “…I remember sitting at home one day thinking, well, I can still handle it, even if it turns out [cancerous]. I can handle it, because the doctor said we can handle it.” Confidence that doctors can “handle it” is perhaps reflective of a belief by many White breast cancer survivors of faith that God’s healing services are not generally required until the illness is deemed incurable by the medical establishment.

Indeed, for most White women, the medical establishment has been a reliable source for the cure of a great many physical illnesses. Moreover, advances in medical science are regularly heralded in the media. For example, a recent article in *Time* magazine, entitled “Surviving Cancer,” proclaims that new drug therapies that will ultimately replace chemotherapy and radiation, “are transforming cancer from a deadly disease into a chronic condition that can be managed indefinitely” (Park, 2004, p. 59). Positive experiences with the medical establishment coupled with consistent media messages announcing miraculous breakthroughs in treatment,
may fuel the consciously or subconsciously held beliefs of many faithful Whites that God typically does not need to intervene in the earthly sphere to provide healing.

Confidence in the medical establishment is evident in the word choice of White breast cancer survivors. These women tended to use the word “trust” in reference to their physicians, in contrast to African American breast cancer survivors who used it almost always in relation to God. This usage does not indicate a lack of confidence by Whites in God so much as it reflects a great confidence in doctors and their ability to actively treat illness. For example, Marie, a White breast cancer survivor who recommends prayer and faith as a coping strategy, declares, “The only thing I know is that I went through it [cancer] once—I went through it. I trust in my doctors.” Similarly, Cathy asserts, “I trusted the doctor. I trusted my OB/GYN who hadn’t seen [my surgeon] in nine years, but knew he was a good physician. He knew he was a great surgeon, and that made all the difference in the world.” Mary’s trust in her physician was due to his professional status. She asserts, “So I trusted him...because I knew he was the head of the breast center.”

In some cases, the White survivors had so much confidence in their physicians that the women sought little other information regarding their disease or its treatment. Wanda reports that she told her doctor, “Tell me what you want me to do, how you want to handle it.” She added, “I’m not one of these to get on the Internet and look up all the stuff.…I just did what they told me to do.” Likewise, Cathy who looked for information on the Internet immediately after her diagnosis, quickly abandoned the effort because it was “too mind-boggling.” She mentioned it to her doctors who she reports “advised me not to really read information on the Internet…because that can really confuse you....” Similarly, Marie asserts,

My belief is that [the doctors] have studied it their whole lives, and that I was not, in a 24-hour period, by standing in front of some books in Barnes and Noble,
going to become knowledgeable about this….I had enough information and the
faith and trust in my surgeons and my team to make the decision.

For these survivors, seeking additional information about their disease was not helpful. They trusted their doctors to control treatment efforts.

Further evidence of the trust reposed in the medical establishment was an inclination of many White breast cancer survivors to shop for the best doctors to treat them. Three White breast cancer survivors who professed a deep faith in God searched for highly regarded physicians while another was already in treatment with a highly reputable surgeon practicing at a research hospital. In contrast, none of the African American breast cancer survivors indicated that they looked for a surgeon or oncologist beyond the referrals provided by their regular physicians.

Shirley, a key informant who is currently a manager in a home health care agency, sums up the essential difference in perspective between African Americans and Whites suffering from an illness such as cancer:

The difference is that with the majority of African American people,…the first thing that they are going to do is call on their pastor or somebody in the church to pray for them….I mean they are going to seek treatment, but it is going to be faith-based. Whereas, typically with a White person, they are looking for the best doctor who’s going to treat them.

For the African American breast cancer survivors in this study, faith in God and use of the medical services go hand in hand as they cope with their disease, but the ultimate power to heal belongs solely to God.

Faith and Social Support

In much the same way that the African American women and White women in this study differed in their reliance on their faith as a coping strategy for dealing with breast cancer, they differed in how they viewed their need for social support and in how they satisfied that need.
Personal faith plays a role in this aspect of coping also. White women wondered about their illness and actively sought the support of other people. African American women appeared to take the illness more in stride and were content to rely on God and their own personal strength.

White Survivors Often Ask “Why Me?”

A common theme among White breast cancer survivors was the question, “Why me?”—a question regularly raised by those suffering from serious illness (Register, 1987). For the White survivors in this study, breast cancer was the most difficult experience they have ever faced. Jennifer was shocked when the small lump she found while in the shower turned out to be cancerous. A person of deep faith, she reports that she felt like God was punishing her. She recalls, “You know, you’re asking those hard questions, like, I-can’t-believe-you’ve-done-this-to-me kind of questions….But you just think about all those things. What have I done?” Jennifer also grappled with other possibilities. Perhaps her suffering was not punishment, but abandonment by God.

After listening to treatment options at her surgeon’s office she recalls asking, “Where is God in this?” Over the course of her treatment, which sometimes resulted in serious complications, Jennifer worked at resolving the question. She concluded that “suffering isn’t punishment. It’s discipline, and discipline isn’t bad. Discipline is training.” She ultimately addressed her feeling of being punished by coming to embrace the notion that her suffering served a positive spiritual purpose.

Linda suffered from a similar nagging sense of being singled out for suffering. She nearly died from pneumonia brought on by chemotherapy. When she had trouble sleeping nights during a three-week hospital stay, she recalls, “I kept trying to figure out what it was all about, why? There had to be something. And then you think about, you know, I’m not a bad person. I’m a
good person. Why do bad things happen to good people?” Linda concluded that she was not being punished by God and that the question is essentially a conundrum. She asserts that “there’s not an answer. It’s not because you’ve done something wrong, it just happened.” Linda resolved the “why me” question for herself in a slightly different manner than Jennifer by concluding that suffering is random.

Two other White breast cancer survivors who claimed not to have considered the question “why me” acknowledged that they had, in fact, considered and discarded it. They had already determined that suffering occurs randomly and is not necessarily connected to behavior. Marie volunteers that she “never had that problem or issue, ‘why me?’ This is life. Somebody walks out and gets hit by a truck. Somebody is in the Twin Towers on September 11th and somebody isn’t.” For Marie, death or suffering may simply be the result of being at the wrong place at the wrong time, but she also believes that a divine plan governs what might otherwise appear as random events. She reports, “So my faith was simply that the outcome would be as it should, and then I would try to cope with it as best I could….”

Similarly, Susan, a woman with a deep sense of faith, states, “I never got upset or wondered ‘why me,’ because we’ll just deal with this…you don’t know if your life is going to be short or long, and you could walk out and slip on the ice and crack your head and die.” These survivors’ comments suggest that they do not believe that God actively punishes people through suffering in this world.

In one case, friends posed the question “why me” for the survivor’s consideration. Wanda, who was determined to be positive after her diagnosis, recalls that her oncologist told her that a good attitude is important to recovery and that focusing on “why me” is counter-productive. She decided to avoid that type of rumination; however, that determination did not
shield her from dealing with the question. Wanda reports that her friends protested, “I just don’t understand this. You’re a good person. Why did God let this happen to you?” Wanda, whose faith is very important, reports having responded to her friends by saying, “God didn’t let this happen to me. This just happened, but the second it happened he was there to get me through it.” Wanda, like Marie and Susan, does not believe that God directly intervenes in the temporal sphere to punish; nor does she believe that God intervenes to protect.

*African American Survivors Believe “God Will Get Me Through”*

The “why me” question was largely missing from interviews with African American survivors. Two mentioned the question, saying that they had not asked it. The others did not discuss it at all. Over half of the African American breast cancer survivors pointed to experiences they considered more difficult to deal with than their breast cancer. Potts (1996), who detected the same basic theme in his research on spirituality and the experience of cancer among African Americans, referred to this phenomenon as “cancer as a subplot.” In addressing all of these adversities, a dominant theme in the interviews with African American survivors was that God would get them through their problems.

Without exception, the African American breast cancer survivors interviewed credited God with bringing them through their illness. Alice simply states, “I have to honestly say my spirituality, that’s what got me through it. That’s really what got me through it.” Rhonda, a thirteen-year breast cancer survivor and registered nurse, uses more specific images when she credits God with getting her through cancer. She maintains

I believe that the Lord brought me through all of this. There is a song out there that was my motto during cancer treatment: *If It Wasn’t For the Lord By My Side Where Would I Be?* If it wasn’t for the Lord taking care of me, walking me through, because he walked me through every step of this, I wouldn’t be here.
In addition to being a healer, God is perceived to be a very present guide, companion, and caretaker. It is clear that these women consider God to be an active member of their social network. This perception by African American breast cancer survivors has been documented by at least one quantitative study (Bourjolly & Hirschman, 2001).

For African American breast cancer survivors, crediting God with getting them through the illness affirms God’s presence and support for the survivor as she suffers with the difficulties associated with the illness. The data indicate, however, that the belief that “God will get you through” was not an expression of blind optimism. It involved personal reflection and active coping. Terri recalls that God told her, “I am going to heal you very quickly of the cancer, but the road to recovery is going to be a long and difficult one, so prepare yourself. And the road to recovery is what has been a long and difficult one.” After completing her treatment, Terri indicates that she still finds the periodic check-ups challenging. She reflects,

I have had to stop and think about the fact that God brought me through all of the other, so he’s going to get me through this. He promised me he would….So then I’m leaning on my faith, and I’m choosing to believe that every single checkup is going to be a good checkup….

Terri, who was in stage III at diagnosis, actively chooses to engage in positive thinking in spite of the severity of the disease and the complications associated with her treatment.

Bernice’s approach is also demonstrative of active coping. After receiving word that her mammogram was abnormal, she recalls praying, “Whatever it is, Lord, you’re going to take me through it.” After it was confirmed that she had cancer, Bernice prayed for healing and then reports saying to God, “Well, Lord, I don’t want to have a hard time.” I said, ‘I’m going to do everything that I can through you to help give me strength and to keep my strength.’” Even though Bernice trusted God to take her through her illness, she actively worked on trying to regain her health.
Central to the belief that “God will get me through” is the notion that God does not abandon those in need. African American breast cancer survivors fervently believe that God is there to support them. Elizabeth had just started a new job when she was diagnosed with breast cancer—advanced stage II with lymph node involvement. She had not accrued enough sick leave, and had to take off without pay in order to have a mastectomy. Elizabeth is divorced and could not rely on any form of spousal support. Complications from treatment and metastasis to another part of her body ultimately forced her to take disability. Because of financial strain, she lost her house and moved in with her mother. She recently returned to work. In spite of her many struggles, Elizabeth maintains, “God takes you through to get you to where you need to be..., and I’ll tell people quick, He hasn’t gone off and left me.”

Sheila’s assessment of her situation was similar to Elizabeth’s. Sheila was first diagnosed with breast cancer in 1996 and had a mastectomy along with reconstructive surgery. Three years later, she found a lump on the side of her reconstructed breast. She subsequently had a lumpectomy followed by chemotherapy and radiation. She maintains, “What I had to go through to get back to being a survivor was probably the most difficult part, the chemo, from a physical standpoint. Once I knew that I had God on my side, He never left me…..” Sheila’s illness was not the only difficulty she faced. Shortly before her second diagnosis of breast cancer, she lost both her mother and her older sister to cancer.

The abiding belief among these cancer survivors that God has not abandoned or failed them is described by Carl, a key informant, as a by-product of the African American cultural experience. According to Carl, among African Americans, faith “plays a huge role” in the process of coping. He explains that “it’s about people’s belief system, it’s about how they were
raised, and how they saw their parents, grandparents, everybody else deal with illness, deal with conflict, deal with racism, whatever….”

Carl points out that this system of beliefs is taught to African American children by their families and other African Americans and is actively modeled as a means of dealing with individual problems or suffering as well as with a broader adversity. The lyrics from contemporary African American gospel music reflect this dynamic: “You can make it, stop complaining. There’s a purpose for your life. Mama’s been where you goin’…it’s gonna be alright. He’ll [God] never put more on you than you can bear…” (Williams, 2004). Indeed, for African Americans, suffering is understood as both an individual and a collective condition. Jean, another key informant, appears to refer to this collective condition when she explains, “What we believe is that we have to have faith that God will take care of you.…”

The collective nature of this belief is evident in Terri’s comments. She had numerous visits from friends and family to offer their support in the days after she learned she had breast cancer. She remembers their support and encouragement. She recalls, “The one thing they all said is, ‘You know God has not failed you. You will make it through this, right?’”

Although 63% of the White breast cancer survivors also credited God with helping them through their illness, their characterization of God’s assistance often included the support of significant others. For example, Cathy indicates, “Sure, I did pray after I got the news….It will be okay, we’re going to get through it, and so we did” (emphasis added). Similarly, Jennifer explains that she and her husband “became more dependent on God through the process because we just couldn’t do it alone.” In another case, Wanda emphasizes, “For me, God was a big part of getting through this….” However, in discussing her volunteer efforts with breast cancer survivors she reports, “…I couldn’t have imagined getting through without my husband.” Wanda
and other White survivors credit God and others with getting them through the difficulties associated with breast cancer.

The Culture of “Keeping it to Yourself”

The belief among African Americans that God, more than human others, will get them through their illness also reflects a difference between African American and White social networks in the delivery of social and emotional support. Carl, a physician and key informant, asserts that because African Americans were historically denied access to institutions capable of providing assistance, there was no place to take problems apart from God. He explains, for example, that medical problems were not discussed outside “the confines of the house, and the immediate family. And so no one talked about it. You personally didn’t talk about it. Family members didn’t go out and talk about it.” Carl refers to this practice as “the culture of keep it to yourself and take it to the Lord in prayer.”

Because African Americans were often powerless to offer certain kinds of assistance to each other, Carl believes they found little use in discussing the problem. He paraphrases this dynamic as “I really don’t know how to help you. You know, why talk about it?...I’m in no better position to help you than you are to help yourself.” Thus, the lack of discussion functioned to dissociate both parties from the severity of the problem as well as from the sense of helplessness which accompanied it.

African American breast cancer survivors indicated an awareness of the cultural practice of “keep it to yourself” but offered differing explanations than Carl for its usefulness. Elizabeth, a 55-year-old survivor, views it as form of protection from a hostile, outside world. She reflects that it is “something that’s learned....I was taught that the less people know about you, the better off you are.” Terri, a 41-year-old survivor, understands nondisclosure as cultural reaction to
marginalization. She observes that “it was taboo for us to discuss anything negative outside the home….You didn’t want anybody to think badly of you or look down on you, so you pretended that everything was always okay…even if it wasn’t.”

The practice of keeping certain matters private appears to be most pronounced among older African Americans. Betsy, a key informant, observes that the tendency is most prevalent among those who are ages 70 and older. Terri has a similar impression and notes that “if you find someone older than [my mother], say, like 70, you may not get any answers out of them. They may not talk to you.” This practice also appears common throughout African American culture, irrespective of socioeconomic background. For example, both Jean, a key informant in her mid-thirties with health education experience, and Alice, 46-year-old breast cancer survivor, have parents with advanced degrees. Both report the practice of nondisclosure in their families.

While illness is generally a private matter among African Americans, the subject of cancer is even more secret. Alice, a breast cancer survivor who founded a non-profit agency that provides services to African American cancer survivors, has encountered women who will not name their illness. She reports that there are women “in our group that will call and some of them don’t even say the word ‘breast cancer.’ They’ll say, ‘Oh I have that—you know what I have.’ And, I’ll say to them, ‘breast cancer.’ And they’ll say, ‘Yes, that’s it.’”

Like other personal matters, older African Americans are especially private about cancer. Rhonda, a 47-year-old registered nurse who battled breast cancer over 14 years ago, reports that “you didn’t talk about the ‘big C’ in the older generations. Oh, no, that’s a faux pas.” Paulette, age 64, recalls, “I don’t know of one single person when I was growing up that I knew had breast cancer. I never heard it, no one ever said it, and I recognize that they probably did, but no one said anything about it.” Reverend Jones, a 58-year-old prostate cancer survivor and key
informant, had a similar experience. He recounts that, when he was younger, “you did not hear in
the Black community as much about cancer as you do today. And I’m sure that there was as
much of it going on back then as there is now. But, it just wasn’t discussed and talked about.”

The privacy surrounding cancer in particular appears to be linked, in part, to the belief
that this disease is stigmatizing, or a source of shame. Paulette explains that for many African
Americans, cancer is “something that you shouldn’t have…that devalues you, or something that
makes you less than who you are.” Similarly, Kimberly asserts that “there is such a stigma that
goes along with cancer. I have felt stigmatized before by telling people.” She reports that, after
telling an associate about her illness, “from that point on he was standoffish.” Her experience is
not uncommon. Many cancer patients report that friends or associates treat them different after
learning about their cancer diagnosis (Wortman, 1984). For Kimberly, however, the sense of
ostracism associated with her cancer only served to underscore the validity of the cultural
practice of “keep it to yourself.”

Most African American survivors in this study chose to live openly with their disease.
Elizabeth asserts, “What’s the point? Why hide?” She believes that her attitude and example of
openness have probably “made more people at church come out of the closet than you would
ever imagine.” Rhonda, who is a registered nurse, also elected to be open with others about her
breast cancer even though discussion of cancer in her family remains taboo. She exclaims, “I tell
everybody, you know, what’s wrong with you? I’ve got breast cancer.”

For many survivors, the choice to override the cultural bent toward limited disclosure of
one’s illness appears fueled by a desire to help others and an understanding that the cultural
silence can have adverse consequences for those with the disease. Terri recalls that her mother
“couldn’t understand why I would not be quiet and hide and pretend it was not there. I told
everybody. I blabbed to the world….It finally helped her to understand...that me talking educates people.” Like Terri, Elizabeth has also tried to educate people by speaking to various groups about her breast cancer experiences. This willingness to share her experience with others started early in her illness. She recalls that “each time before surgery I consented for it to be filmed, or for students to watch, if necessary. I don’t have a problem with that…if it will help somebody else.”

Bernice, who was 60 when she was diagnosed, was one of two survivors interviewed who kept knowledge of her illness largely confined to her immediate family. She reports that she did not tell fellow church members until three years later—long after she had successfully completed treatment. In spite of her inclination to be private about her cancer, however, she offered to have her mastectomy filmed. Bernice’s attitude regarding disclosure has continued to change in the three years since her initial diagnosis. After learning that a fellow church member had breast cancer, Bernice approached her privately and reports having told her, “Well, look at me, I’ve had it….When I was sick that time, that’s what it was. And, I’ll walk you through this if you want me to.” Today, Bernice is a Reach to Recovery volunteer for the American Cancer Society.

The commitment to help others exhibited by Bernice and other survivors is reflective of a difference in emphasis in the African American conception of social support. Even as they acknowledged needing and receiving support from their social networks, most African American survivors believed they have an obligation to give back. African Americans historically have engaged in forms of reciprocal obligation. Recent research on cancer patients supports the continuation of this practice (Hamilton & Sandelowski, 2003).
“Grunt and Go On”

Closely related to the cultural practice of nondisclosure is recognition of personal strength. Carl explains that his mother identified this inner fortitude when she admonished, “‘You grunt and go on.’” He elaborates that this was “what she taught everybody” as he was growing up. “[I]t’s basically you don’t complain and you don’t talk about [problems] and you simply grunt to yourself and you go on and make it work however you need to make it work….it’s really about internalizing and just managing it to the best of your personal abilities.”

The expression “grunt and go on” is similar to “John Henryism,” a phrase coined by Sherman James and his colleagues (1983) to refer to the stress that results from coping with persistent social and economic oppression. The dynamic of inner strength evidenced by the phrase “grunt and go on” is not unlike the extraordinary physical strength and stamina demonstrated by John Henry who, legend holds, was placed in a drilling contest between himself and a steam-powered machine. Henry, an ex-slave, won the match, but lost his life in the enormity of the struggle.

A sense of inner strength was evident in many interviews with African American breast cancer survivors. Paulette asserts, “[Y]ou’re supposed to be able to take care of it, and if you can’t take care of it…. you are not supposed to go out there and tell everybody else about your problem.” Thus, the act of nondisclosure, of simply handling problems without complaint, is an external manifestation of internal strength. The pity of others is an affront to that sense of inner fortitude. Bernice, who had a mastectomy five years ago, explains that she didn’t tell many people outside the family “because I didn’t want anybody coming up feeling sorry for me….I just wanted to just stay happy.” This phrase refers to maintaining an acceptable public face. For
Bernice, disclosing her cancer to others meant potentially jeopardizing how they might see her—a burden she was unwilling to bear in addition to her illness.

While the practice of nondisclosure is no longer universally endorsed among African Americans, the strength often associated with this practice is. African American women point to this attribute as a positive part of their group identity. Betsy, who provides assistance to cancer survivors, remarks that “African American women are not wimpy women.” Strength is also a quality that African American women expect of each other. Jean, a key informant, believes that among African American women “there is a stigma associated with not being strong enough.” She maintains that “they see themselves as stronger than needing to have outside help.”

Rhonda, a nurse and breast cancer survivor, believes that African American women are stronger than White women. In her opinion, “White people fall apart when they’ve been diagnosed with breast cancer….” Paradoxically, “Black women get their strength. They get strong.”

White Survivors Spread the News

For the White breast cancer survivors, only pre-diagnosis activities were associated with nondisclosure. Marie’s comments typify the attitude held by the White survivors. She explains, “I didn’t want to alarm anybody….I just felt that I wanted to be private about the biopsy until I had the information—I had no reason to alarm anybody.” After receiving a firm diagnosis of breast cancer, however, White survivors either notified family, friends, and coworkers of their illness or they told a few friends or family members with the expectation that the news would be spread to others.

Cathy, for example, first told her husband and immediate family, but then notified friends and co-workers. She recalls, “Of course, the girls at work knew, and then Sandra told friends.
We are real, real close, and she told her mom, and her mom told Suzanne. I’m sure that’s how the word got out. I really didn’t say she could or she couldn’t.” Marie, a divorcee, found it difficult to tell others about her cancer, but still wanted others to know. She explains, “I tried to tell the few closest friends and gave the go ahead to tell the other friends.”

Two other survivors used email to notify others about their diagnosis or to update them on their condition. After telling her family and closest friends, Susan sent an email to several of her co-workers telling them about her diagnosis. Jennifer took a more formal approach than Susan and decided to begin an “email bank” to update friends as a form of Christian witness. Jennifer asserts, “I just was brutally honest and told people how I felt, and it was cathartic. It was good for me and the Lord.”

Other White survivors also indicated that it was good for them to share their cancer experiences with others. Wanda reports that her physician encouraged her to talk with others about her cancer. She says the doctor told her that “you can bring two people and put them in a room and the diagnosis is just the same, but the one that shares it with her friends and family and lets them help her through it just always seem to do better than the one that says I don’t want anybody to know…. ” Some research supports the salutary effects of openly sharing the illness experience with others (Spiegel et al., 1989).

For White survivors, disclosure of their illness with others was connected to the receipt of various forms of emotional support. Cathy remembers that people sent her a lot of cards. Jennifer, who sent regular email updates on her condition, reports “I’d get lots of good responses. It became fun for me and encouraged me.” Susan, who also sent emails, felt comforted by the knowledge that others were praying for her. She recalls, “I had a lot of people email me or send me notes and say they were praying for me.”
Wanda was touched by the concern expressed for her by a fellow church member who read about her condition in the church bulletin. On her first Sunday back at church after her surgery, she recalls “I did really good with everybody, and everybody was so good, and when we got ready to go to Sunday School class, this guy came over and he started crying….But he was really showing how he felt. Not many men will….But that was a big thing for me….”

Jennifer, more than any other White survivor, talked to friends about her cancer experience and received a great deal of support in return. She recalls that when she arrived at the hospital for her double-mastectomy, “four of my very dearest friends were there with a hot pink fleece blanket. And they had embroidered ‘breast buddies’ on the blanket, and all four of us got in this blanket, and they said, ‘We are here to wrap you in our love and to send you off just knowing that we are here to pray for you….”’ This image of vulnerability stands in stark contrast to the operative style of African American women who pride themselves on personal strength.

Chapter Summary

The data from this study strongly suggest that African American and White women in North Texas cope with breast cancer in different ways. Faith was identified by all African American breast cancer survivors as their most important coping strategy. Only half of the White survivors made this claim, but their reliance on faith appeared tied to another strategy—the assistance they received from family and friends. The African American survivors reported a very present relationship with God, characterized by conversation-like prayer and a sense of God’s personal, direct involvement in their illness. A majority prayed for healing, and several reported accounts of miraculous healing which they attributed to God’s intervention. The White women viewed God’s presence more indirectly and as manifest through the love and care of other people. They prayed for strength, peace, and courage to endure the illness experience.
Although African American breast cancer survivors actively sought the benefits of conventional medical treatment, they trusted in God for healing. White survivors, in contrast, trusted their physicians for healing.

African American breast cancer survivors also expressed different social support needs than Whites. White survivors often wondered, “Why me?” and worked to resolve the question for themselves. They also actively sought the support and assistance of other people as they readily disclosed the fact and details of their illness. African American survivors simply believed, “God will get me through.” This belief, along with the practice of nondisclosure and an ethos of personal strength, appear to emanate from African Americans’ historical experience with racial oppression. African Americans did not discuss problems with other people because nothing could or would be done for them. God was the only being on whom African Americans could rely. The practice of nondisclosure appears to be waning as racial oppression is lifting, but confidence in being able to overcome adversity with God’s help persists.

These results have significant implications for the development of coping interventions. The following chapter explores some of those implications as they relate to breast cancer support groups.
CHAPTER 5
IMPLICATIONS FOR CANCER SUPPORT GROUPS

Cancer Support Groups as Interventions

Theoretically, cancer support groups, as coping interventions, should be developed and tailored to the coping strategies and resources of the group they are intended to serve (Folkman & Moskowitz, 2004). In practice, however, they were designed and developed based on the coping needs and social support resources of Whites with the assumption that they would be helpful to anyone. Aware that this reasoning is erroneous, Carl, a key informant and physician, observes that the medical establishment sometimes believes that because it is “important to us, we assume that it is important to somebody else.” He adds, “And we also don’t speak the language in a way that people understand….So until we start to understand the belief system, it’s hard to create appropriate interventions.” Shirley, another key informant and nurse, concurs. She comments that “most of the support groups I think are geared toward Caucasians as far as thinking and talking.” She adds that she believes that most African Americans also “think that the support groups are for White people and support groups are not for African American people.”

A perceived lack of outreach specifically to African Americans by major providers of cancer services may fuel the notion that cancer support groups are primarily for Whites. Jean, a key informant with several years experience providing services to cancer patients, indicates that she does not recall much effort to “really target or reach out to African American women to get them to come to the support groups.”

Findings from this study indicated that coping attributes distinctive to African American breast cancer survivors have major implications for the design of support groups (see Table 4).
These attributes, coupled with existing support group design and the perceived appeal to Whites, appear to be impediments to support group usage by African Americans.

Cultural Specificity

The data from the interviews with African American breast cancer survivors and key informants suggest the importance of establishing more support groups designed specifically for African American women and led by African Americans. The primary impetus for directing efforts at forming such groups is culture rather than color. Gottlieb (1998) argues that support group composition is of “paramount importance” and asserts that if members “do not perceive one another as similar along certain valued dimensions, and if they do not have a common basis for comparing the feelings, actions, and thoughts that arise out of their circumstances, the group will have little appeal for them…” (p. 639) (emphasis added).

At least one qualitative study supports the conclusion that problems associated with negotiating cultural consensus can occur in cancer support groups. In that study, Mathews (2000) found that traditional cancer support groups, “premised on the biomedical model of the disease process, may be quite effective in meeting the needs of patients who embrace such a view.” However, she also found that these groups do not appeal to “those whose beliefs and values conflict in key ways with the biomedical model” (p. 410-411).

An understanding of the need for culturally specific support groups was evident in several interviews. Harriet, a key informant, encounters African American breast cancer survivors not only in her work as an oncology research nurse, but also as a facilitator of a support group specifically for African Americans. She is aware of an express desire among African American women “to be in an environment that they look like other people, have religious beliefs and cultural beliefs as other women around them through this fight of cancer.”
Table 4

**African American Survivor Coping Attributes and Implications for Support Groups**

<table>
<thead>
<tr>
<th>Coping Attributes</th>
<th>Implications for Support Groups</th>
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<tr>
<td>Personal faith as primary coping</td>
<td>• Incorporate prayer—especially intercessory prayer for healing&lt;br&gt;• Use testimonials&lt;br&gt;• Seek endorsement from churches or church leadership&lt;br&gt;• Greatest perceived cultural difference by African American survivors</td>
</tr>
<tr>
<td>strategy</td>
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<tr>
<td>Perception of cultural difference</td>
<td>• Form support groups primarily for African American women&lt;br&gt;• Address appearance concerns (hair, make-up, prosthetics, keloid scars)&lt;br&gt;• Differences in support networks (more single or divorced African American survivors)&lt;br&gt;• Advertise support groups through churches and African American media outlets&lt;br&gt;• Hold meetings at locations readily identifiable as predominantly African American</td>
</tr>
<tr>
<td>Relationship to medical establishment</td>
<td>• Hold support groups away from hospitals or physician offices&lt;br&gt;• Use African American facilitators&lt;br&gt;• Use African American professionals (nurses, physicians, social workers) as speakers&lt;br&gt;• Provide information on important questions to ask treating physicians</td>
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<tr>
<td>Nondisclosure &amp; ethos of personal</td>
<td>• Emphasize dissemination of practical information about the disease&lt;br&gt;• Deemphasize disclosure of fears or feelings in the group setting&lt;br&gt;• Ask prominent African Americans with cancer to give personal testimony&lt;br&gt;• Institute a “buddy system” to facilitate private exchange&lt;br&gt;• Emphasize strength through mentorship of other survivors&lt;br&gt;• Change the name of “support group” to “survivor group”&lt;br&gt;• Develop brochures that profile survivorship rather than recount mortality statistics</td>
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<tr>
<td>strength</td>
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<td>Reciprocal obligation</td>
<td>• Emphasize opportunities to help other survivors or their families&lt;br&gt;• Provide opportunities to take information to others in the community: churches, places of employment, sororities, community centers, etc.&lt;br&gt;• Encourage group participation in breast cancer events such as “Race for the Cure,” and “Relay for Life”</td>
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Rhonda, a registered nurse and breast cancer survivor who started and then facilitated a support group for African American women for several months, has similar comments. She indicates that African American breast cancer survivors want someone who “looks like them in the support group. African-American people have different values and different systems that they look at. The way we were raised and our values and our cultures are different.”

Reverend Jones, a key informant and prostate cancer survivor who attended a predominantly White support group, states, “[C]ultural likeness—yes, that’s a plus for a support group. Because you have the same things that you can talk about—you don’t talk just about your cancer….”

The expressed desire to be with others who share similar values and appearance may also be connected with a wish to be in a social milieu which is devoid of the possibility of racially-based hostility. No African American survivor in this study who attended a mixed support group mentioned a bad experience with other White group members; however, several African American survivors described other unpleasant encounters with Whites which they perceived were racially oriented.

In addition to providing an environment with cultural similarity, predominantly African American groups would be better able and possibly more motivated to address issues that arise out of cosmetic differences between African Americans and Whites. These issues include such things as applying makeup, acquiring wigs, and getting appropriately colored prosthetic devices (Wilmoth & Sanders, 2001). Some scholars have mentioned cosmetic differences as impediments in mixed groups (Mathews, 2000; Moore, 1999). Physical recovery from surgery also varies in some respects between African American and White women. For example, Wilmoth and Sanders (2001) found in their study that African American women who were
treated surgically for their disease were concerned about keloid formation at the surgical site. Keloids, or enlarged scars, are significantly more common among dark-skinned people.

To the extent that cultural similarity is an important consideration in the composition of cancer support groups, that similarity should extend to support group leadership. In this study, several key informants commented on the need for African American facilitators for support groups. For example, Reverend Jones maintains, “[T]he leader of that support group ought to be the person who has the most cultural relationship with the members of that group. I think that’s an important factor.” Shirley explains that “to have a non-Black person come and lead a support group for Blacks” would be problematic for those in attendance. She speculates that the participants’ response would be to ask, “How do you know what I am sowing and what I am doing?”

Differences in Faith

Besides group composition and leadership, this study indicates that the use of faith as a coping strategy would be a critical consideration in designing cancer support groups intended to serve African Americans effectively. This strategy is the single most significant difference identified in comparing the coping responses of African American and White breast cancer survivors. The data suggest that, in group settings consisting of both African American and White breast cancer survivors, this difference alone would impair the ability of members to identify with one another.

Although the White survivors did not articulate a recognition of this difference, the African American breast cancer survivors clearly perceived a difference. They expressed an understanding that Whites do not generally share the same belief in God’s healing or place the same value on faith as a coping strategy. For example, after sharing her diagnosis with fellow
employees at a large bank, Elizabeth was approached by some White coworkers who “were very into religion” and wanted to put her on the prayer list at their church. She appreciated their gesture and adds, “I’m probably on a lot of prayer lists in several White churches, which is fine. You know, as far as I’m concerned there is one God, there is one faith, you know.” However, even though by her own admission, she shares the same faith with religious Whites, she is aware of an important difference. She asserts, “They believe in God, but I don’t know if they really trust him. Because when I tell you that my body is healed, I truly believe that.” For Elizabeth, there is little use in putting the name of an ill person on a prayer list if you do not believe in God’s healing power.

The experience of talking with White women with breast cancer during chemotherapy treatments increased another African American breast cancer survivor’s awareness of differences between African Americans and Whites in the exercise of their personal faith. Terri, a social worker who understands the usefulness of support groups, was determined to find an all-African American support group after these exchanges. She indicates, “When I would talk to some of the [White] ladies, some of them said, ‘Well, I’m just not very religious.’ Or some would say, ‘Well, although I believe in God, I have more faith in my doctor.’” Terri found that she did not value the same things as White breast cancer survivors in terms of coping with illness. She notes, “I needed somebody with the same cultural background that I had, as far as my religious beliefs, because my religion is how I made it through, my trust and belief in God.”

Paulette, an African American breast cancer survivor who attended a support group composed primarily of White survivors, stopped attending because the values and priorities of the other members did not match hers. At one support group meeting, Paulette was approached by a White survivor who suggested that she buy a wig before starting chemotherapy. Paulette
declined to do so stating, “To go get a wig is to say that I don’t believe in God—that he can take care of it and that my hair won’t come out.” After learning her diagnosis, Paulette had prayed to keep her hair during treatment. When her doctor informed her that her chemotherapy regimen would not result in hair loss, she viewed that as an answer to prayer. Consistent with her faith and culturally-endorsed notions of God as healer, Paulette credits God with keeping her hair and not the use of a particular chemotherapy agent.

Incorporating the Faith Component into Support Groups

The importance to African Americans of faith as a coping strategy and their feelings about how their faith differs from that of Whites strongly indicate that a faith component is essential for cancer support groups intended to serve African Americans. The incorporation of this component might be most effectively accomplished by offering opportunities during a group meeting for prayer. All of the African American survivors in this study reported regular, frequent personal prayer. Group and intercessory prayer opportunities may also be helpful.

In addition to prayer, consideration should be given to incorporating “testimonials” into support group meetings. Harriet, who has conducted support groups for African American cancer survivors, explains that “the testimony is the story of your life—actually, the good things that have happened and the bad things and how the good things have overshadowed the bad things.” In the context of cancer support groups, a woman’s story of survivorship is the testimonial. Betsy, a key informant, reports that in these testimonies, in addition to the difficulties associated with the illness, survivors “would tell you some of the conversations they had with God, and how he brought them through, and how they were at ease before they even went to surgery.”
The Potential Role of African American Churches

Using African American churches to host cancer support groups would also obviously facilitate the incorporation of the faith element into those groups. The importance to African Americans of faith as a coping strategy, coupled with the central nature and influence historically associated with the African American church, has led some scholars to suggest that church-sponsored support groups would be an effective means of attracting African American participants (Barg & Gullatte, 2001). This notion is fueled by the success of programs to increase screening and early detection that have been sponsored by African American churches (Powe & Weinrich, 1999). It may also be supported somewhat by church attendance statistics. In Taylor and Chatters’ 1991 study, 94% of African Americans considered church attendance as very or fairly important and 70% reported attending from once-a-day to a few times a month (Taylor & Chatters, 1991). Although attendance numbers may not now be as high, especially among younger African Americans, church attendance was important to all African American survivors interviewed for this study.

Several key informants and breast cancer survivors in this study pointed to the church as a logical location for support group meetings. Laura, who has over 10 years experience in providing services to cancer patients, argues that it is important “to provide a support group in an environment where people feel it’s a natural environment for them to seek support.” For African Americans, the church has historically been such an institution (Caldwell, Green, & Billingsley, 1992). Shirley, a nurse, clearly believes that the church would willingly sponsor support groups. She asserts,

If ACS (American Cancer Society) or somebody were to go to all of the African American churches and say, ‘We are going to start a support group…and we want to train somebody to be the leader of this group. We will give you all the tools
you need to do this, and you are going to have it here in your church.’ It would happen. They would get somebody to do it.

Carl, a physician and key informant, agrees and believes that such an approach would work because ministers are “the grass-roots”—the people of influence in the African American community and as such are the logical people to initiate support groups. Organizations from outside the community may recognize a need for the delivery of service, but do not know how to implement the program. He explains that “a lot of people pretend to know what’s going on in the community but they are not rooted in there.”

In addition to the influence of most African American ministers on their congregants, other advantages accrue to church-sponsored support groups. Churches may also be considered a logical place to implement formal support groups because of their history of providing services to members. Harriet, a key informant and oncology nurse, indicates that African American churches are increasingly aware of the problems that breast cancer poses for its members and have developed their own in-house support. She asserts, “More members of churches have some type of support system from the church base itself. And often times, there are special ministries in the church. Our church has a special ministry.” Similarly, Paulette, a breast cancer survivor, pointed to an informal support program for cancer survivors in her church. She reports,

> When we find out that ladies have cancer…we go to support that particular person….It is not a formal group that we meet every so often and have bylaws….It’s not anything like that. It’s just a group of us who have already had it, and we just go and help the sister get through hers.

These programs provide emotional as well as spiritual support.

In spite of the apparent advantages of using churches to sponsor African American cancer support groups, disadvantages also exist. Informal groups such as the type described by Paulette may lack connection to the medical resources and information that are offered by more formal
organizations such as the American Cancer Society. Support group sponsorship by churches may also narrow their outreach. Alice, a breast cancer survivor and founder of a support organization for African American cancer survivors, argues that, even though the church is central to the lives of most African Americans, “[T]here are folks who don’t go to church.” Moreover, Reverend Jones believes that church influence may be waning among younger African Americans. He observes that they “have so many other things to attract them.” He reflects that “at one time, you know, you came to church. Everybody was at church and we did whatever was going on in church….[It] doesn’t work that way anymore.”

Sponsorship of support groups in churches may narrow appeal in other ways. Alice asserts that some people “won’t enter into another church. They have their own home church and that’s the only church they’re going to go to.” She continues, “If you have a support group in a church and it’s a good support group…the person from Church B is not going to come over to Church A.”

Betsy, a key informant who provides services to cancer patients, has experienced the proprietary approach of churches to their members. She reports that she was contacted by a church who requested support group facilitator training. She recalls, “They just wanted us to come in and tell them how to do a support group….They just wanted it for their church members. They were very adamant about that.”

Another drawback to church-sponsored support groups is described by Shirley. She asserts that African American church members “are usually at church all day.” She goes on to explain, “Having a Sunday support group would never work in the Black community because they go to Sunday School, they go to church, they have evening services, they have night service. And they are caught up into that.” Church activities for faithful members are not limited to
Sundays. Shirley adds that “they have Wednesday night church, they have choir rehearsal on Tuesdays and Thursdays,” and that it is hard “to actually find a time and to have one that’s going to benefit and support what they do....”

One survivor’s experience with facilitating a support group in a church may be a case in point. Rhonda, a registered nurse reasoned that if she “started the support group and had it at a church, people would come out. It would be centrally located, and I was trying to gear it towards the African-American people, so I went to the area where the people were.” Rhonda advertised the group by distributing brochures to the county hospital and other private hospitals. Her meetings initially had 10 to 15 survivors in regular attendance at the monthly Saturday meeting. She found however, that attendance “eventually just dwindled down.”

Even if formal cancer support groups are not sponsored by or located in churches, however, it appears from this research that they should be endorsed by the African American religious community and in any event should be held in locations that are recognized as predominantly African American. Churches, along with African American media outlets, could also provide effective advertising for cancer support groups.

Nondisclosure Concerns

In addition to the role of faith in African American coping, the historical practice of limiting disclosure of personal information is a feature distinctive to African American culture having potentially important implications for cancer support groups is. As currently conceived, support groups may be antithetical to the coping styles of many African American women, especially those over 70 years of age, for whom the idea of wide disclosure of personal matters, especially illness, is anathema. Support group attendance alone may constitute a form of disclosure sufficient to discourage if not preclude participation by older African Americans.
Moreover, as Shirley, a key informant, explains, the disclosure characteristic of support groups conflicts with this “cultural thing of privacy.” This conflict arises because support groups are predicated, in large part, on the disclosure of personal problems, fears, and doubts to others in the group in an effort to collectively solve problems (Gottlieb, 1998).

To honor the culturally ingrained sense of a need for privacy with respect to personal issues, cancer support groups might be designed to deemphasize disclosure and to emphasize the dissemination of practical information about the disease. Paulette apparently appreciated that the support group she attended “gave you information, a lot of excellent information on, you know, eating, health concerns, of course, the smoking thing, how to take care of yourself, also where to find various products that you can use like prostheses and things like that.” Alice agrees and adds that support groups are also invaluable settings for the promotion of more active dialogue with physicians. She observes that newly diagnosed cancer patients learn things from other survivors that doctors may not have discussed. She cites, as an example, care for the mouth during chemotherapy. She explains that “then through that conversation with a lay person who has been through that, you now can go back to your doctor, and have a more enhanced conversation with him or her.”

Rhonda, a breast cancer survivor, believes that African American breast cancer survivors want practical information related to their personal appearance. She maintains that “We want to know how to take care of ourselves everyday….What do we need to do to get our hair washed...[and] can we get our nails done?” Previous research indicates a need for this type of information by African American women (Lackey et al., 2001).

A de-emphasis on disclosure would appear to extend, in particular, to discussion in support groups of personal feelings. If a support group focuses too much on feelings or on what a
perceived as negative behaviors or thoughts, African American women may stop attending. Paulette stopped going to the support group after three visits because “they kept talking about this depression that women have after they go through breast surgery, and I guess that many women do have that, but I just didn’t buy it.”

Indeed, research indicates that a common reason given by those who elect not to attend support groups or who quickly drop out, is that they do not want to expose themselves to the problems and distress of others (Gottlieb, 1998). African American women, in particular, believe that it is important to maintain a positive attitude. In one study, African American breast cancer survivors reported that they avoided negative people as a means of coping with the disease (Henderson, Gore et al., 2003). The researchers observed that “[p]articipants felt strongly that negative people did not make them feel positive about their situation and tended only to bring down their spirits” (Henderson, Gore et al., 2003, p. 644).

Notwithstanding a possible need to reduce emphasis on disclosure, this study indicates that specific opportunities for disclosure in the form of testimonials ought to be available in African American cancer support groups. All of the African American survivors in this study readily disclosed many intimate details of their illness experiences and expressed willingness to provide this testimony to others. They believed their stories would help others by giving them more information on the disease, as well as by encouraging others to believe that they could survive their illness. Finally, they expressed intentionality in overriding the practice of nondisclosure in hopes that others would follow suit. The use of more prominent African Americans, possibly persons who were not members of the group, to give their personal testimonies at support group meetings would provide further examples of this openness while preserving the privacy of group members.
Personal Strength

The sense of personal strength possessed by African American women is an attribute that appears to be sourced, in part, in the practice of nondisclosure. It is also an attribute that potentially affects the design of cancer support groups. Jean, a key informant, observes, “I think African American women are very, very, proud and they are proud of the fact that they don’t feel the need to go to a shrink or to a support group. I’ve heard for years, ‘Oh, you don’t need no shrink, you know, sisters, they can work it out.’”

The phrase itself, “support group,” strongly suggests that those who attend are somehow in need of outside assistance from others in coping with the disease. Many of the African American survivors in this study did not identify with this notion of support. For example, Sheila, a 45-year-old recurrent breast cancer survivor, indicated that she felt no need for a support group, even after her mother was diagnosed with brain cancer during her own illness. She explains, “I felt like, okay, I’ll handle this. I’m not whining about it. I’m not depressed about it. I’m not stressed out about it.” Sherry, a public school teacher, also reported never wanting to attend a support group. She says, “It kind of got to be a joke….My friends would say, ‘No, she ain’t going to go to see a group because she’s just going to make them feel bad. You’re here, you’re alive….What’s your issue, you know?’”

For some survivors, their sense of personal strength was linked to self-esteem. In spite of Kimberly’s nearly solitary walk through treatment, she notes, “I found that I helped myself, and that made me feel better.” Bernice also acknowledges the benefits of her personal strength. She reports that her attitude regarding her illness was “whatever I have to do I’ll do it….I’m very strong, I’m very strong.” This sense of personal power and vigor is a valuable asset for any woman confronting the rigors of treatment.
Changing the name from “support group” to something such as “survivor group” might help dispel concerns African American women have that these groups consist largely of needy women. The word “group” may also be associated with a lack of psychological fortitude and may need to be changed to something like “club” that has positive connotations for African American women. Terri has attended support groups and sees value in them, but acknowledges that many African American women have “stereotypical” ideas about the kinds of women who attend. She asserts that, for the most part, support group attendees are “not crazy, needy people who have no hope.” Terri’s comments suggest the value of normalizing the function of support groups for African American women.

Support groups may be more successful in attracting African American women when outreach expressly appeals to their sense of personal strength. For example, Paulette reports that her surgeon asked her to attend a support group because she was coping so effectively. She states that the surgeon “wanted me to go to the support group because I was handling it. That’s the word he used, you know how to handle it, and we need people who know how to handle it.”

Offering opportunities to give testimonials in support group meetings would also appeal to the strength of African American women. Another way would be through the development of brochures that emphasize survival rather than mortality statistics. Alice, who has worked with support groups explains, “We’re not saying Mary Lou could be one out of five people that gets breast cancer….We say this is a woman who has had breast cancer and has lived beyond her diagnosis. We present it in a positive way….It is not a bunch of statistics.” The emphasis, for African Americans, is on strength and survivorship.

Rhonda, a nurse by profession, believes that a reason African Americans tend to be private is the need to maintain a positive personal image. She reports that when she recommends
that her patients “meet with a social worker and talk about things, they’ll say, ‘Well, I’m not crazy. I don’t have any problems.’” This statement may not be a denial of the existence of personal problems. Indeed, most African American survivors were clear about the problems they faced. Rather, it may be an indicator of the cultural emphasis on personal capability and strength, or it may reflect a reservation about professional assistance.

Reciprocal Obligation

The historical tradition of reciprocal exchange which has characterized African American extended kinship networks (Hamilton & Sandelowski, 2003) should also be considered in the design of cancer support groups that are culturally specific for African Americans. Encouraging African American women to come to support groups in order to help others casts the attendee as a capable giver and is a natural extension of this tradition. Elizabeth tried a support group and continued going because she liked being able to do things to help others. She explains that she does whatever needs to be done, including volunteering to work distributing information on breast cancer for a local hospital’s “survivor day.”

A year after she was diagnosed, Bernice was invited by an African American nurse to attend a support group meeting. Bernice indicated that she felt no need for support but says, “I went so that maybe something I could do or say something that would help the others that were there.” She now encourages other African American women to come to the support group “and get involved with helping others.”

To capitalize further on the practice of reciprocal obligation while honoring desires for privacy, support groups might consider instituting a “buddy system.” New members in the group could be paired with longer-term survivors who could act as mentors. These dyads would allow for the dissemination of practical information about the disease and for the possibility of
discussion of feelings in a more private context. Rhonda, a breast cancer survivor who has facilitated a support group for African American women, believes the buddy system would be an extension of support groups. She asserts, “That would be an ideal situation, you know, where you don’t feel like you’re out there alone, and if you can’t wait until the next support group meeting, you can always call that person up and say, ‘Hey, I just need to talk.’” Alice, who also has experience facilitating support groups for African American women, agrees that giving back is important. She believes that support group members “are going to take something away from it but eventually are going to feel that you have to give something back.” She adds, “I can say that every person that has been a part of the support group gives back through volunteerism, through connecting with another survivor—even if it’s volunteering just with one person….”

Support groups could also encourage group participation in cancer research fund raising events such as the “Race for the Cure” and the “Relay for Life.” Facilitating opportunities among support group members to operate as personal envoys in the larger community, providing information on cancer detection, treatment, and survival to other groups, would also capture the spirit of reciprocal obligation.

Relationship to the Medical Establishment

Another cultural attribute that should be considered carefully in structuring cancer support groups is the perspective of African Americans toward the medical establishment. They live with knowledge of the history of abuse suffered by African Americans at the hands of White health care providers, and they know or suspect that African Americans still experience racial discrimination in medical treatment. Although the African American survivors in this study actively sought medical treatment, they did not exhibit the same level of trust in their physicians as White survivors. This difference suggests that cancer support groups for African Americans
might be more effective if they were distanced from the formal medical establishment. For example, they might be held in places other than hospitals or physicians’ office. Physicians could be invited to support groups as speakers. In addition, it would probably be more effective to utilize African American, rather than White, medical experts to bring information to support groups.

Finally, it should be recognized that many support groups sponsored by health care establishments or by organizations such as the American Cancer Society avoid spiritual practices such as prayer and testimonials. The absence of these spiritual practices would appear to fundamentally reduce the appeal of these groups to African Americans.

Conclusion

Establishing more support groups which are primarily for African Americans may seem counter-intuitive in the context of a society at large that continues to struggle with issues of social integration, and that increasingly views as preferential, efforts aimed at improving participation in programs by minority groups. However, forming groups that cater primarily to the cultural needs of African Americans does not imply exclusion of people of other races or cultures from these groups. Nor does it suggest that groups composed primarily of White women exclude African American women who find those groups useful. Rather, forming groups that appeal primarily to African American women would acknowledge the existence of African American culture and honor its differences from other cultures.

One recent study found that African American and Latina breast cancer survivors “welcomed and actively participated in support groups that were culturally and linguistically appropriate” (Ashing-Giwa et al., 2004, p. 425). Establishing effective support groups for African Americans requires further study and increased attention to their coping strategies and
resources. It also requires an investment on the part of organizations dedicated to providing cancer services. Rhonda, who once founded and facilitated a support group for African American women, observes, “I think it requires a lot of time to get it going very well. I think it requires a lot of work—you’ve got to have some backers to get that going.” The potential return is improved quality of life for African American cancer survivors and a reduction in mortality rates.
CHAPTER 6
THEORETICAL CONSIDERATIONS

Findings from this research indicate distinctive differences in the coping behaviors and resources of African American and White women with breast cancer in North Texas. Faith in God was identified by all African American breast cancer survivors as their most important coping strategy while only half of the White survivors made this claim. This finding was not surprising. Historical literature has long pointed to the importance of both the church and faith to African American culture (Levine, 1977). In addition, empirical studies using data from the National Survey of Black Americans (NSBA) have also found that religious responses—particularly the use of prayer—are common among African Americans when addressing personal problems (Ellison & Taylor, 1996; Taylor & Chatters, 1991). While the NSBA was not specifically designed to examine coping behaviors, findings from studies using this data clearly suggest a pattern in how African Americans deal with the stress in their lives.

Moreover, studies using other large nationally-based samples have found that African Americans tend to report higher levels of prayer and other types of private religious activities (e.g., reading the Bible) than Whites (Roof & McKinney, 1987) and that they are also more likely than Whites to seek spiritual support in the face of problems (Ferraro & Koch, 1994).

Even though these studies point to differences between African Americans and Whites in dealing with stress, research which specifically examines the coping responses of African Americans generally, or of African American women coping with a stressor such as breast cancer, in particular, is thin.

Social influences, including culture, as important variables in coping have been underemphasized by scholars or overlooked altogether (Folkman & Moskowitz, 2004). This lack
of attention is attributable in part to the circumscribed perspective of psychology, the discipline from which much of the coping literature emanates (Landrine & Klonoff, 1992). Pearlin (1989) observes, “Because interest in coping was rooted initially in clinical concerns, researchers tend to think of a person’s coping repertoire as representing a clinical profile unique to the individual and to ignore the shared, normative basis of individual coping” (p. 250). As a result, coping research has examined individual responses without much, if any, consideration of broader social or cultural patterns or influences.

Emphasis on Personal Agency

The dominant theoretical framework used in coping research has typically approached coping processes from an individualistic perspective. Within this framework, an individual’s coping responses are conditioned by her evaluation of the threat posed by the stressor as well as her perception of the availability of psychological and social resources necessary to meet the threat (Lazarus, 1993). The presumption in this model is that individuals are activists who operate independently of one another and are capable of exerting influence on their environment (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998; Riger, 1993; Thoits, 1995).

Little consideration has been given to the direct effect that social or structural influences might have on an individual’s appraisal of a stressor or her subsequent selection of coping strategies. Within the dominant model of coping, social influences are viewed only as factors that affect coping decision-making processes indirectly through their impact on psychological and social coping resources (See Figure 1).

Influence on Psychological Coping Resources

Among identified psychological coping resources, a sense of mastery over life and self-esteem are the most commonly recognized and studied by researchers (Thoits, 1995; Turner &
A sense of mastery over life is defined as “the extent to which one regards one’s life-chances as being under one’s own control in contrast to being fatalistically ruled” (Pearlin & Schooler, 1978, p. 5). Feeling less mastery is associated with a sense of powerlessness and tends to occur when a person feels unable to achieve certain ends or objectives. Structural constraints such as inadequate resources, restricted opportunity, and employment in jobs in which a person has little control over the work or how to do it also contribute to a sense of powerlessness (Wheaton, 1985). In the context of the cancer experience, mastery may deal with a woman’s belief in her ability to gain control over her disease (Taylor, 1983).

**Figure 1**

Contextual model of coping.
Self-esteem, another commonly studied psychological coping resource, is “the evaluation which the individual makes and customarily maintains with regard to himself or herself: it expresses an attitude of approval or disapproval toward oneself” (Rosenberg, 1965, p. 5). The formation of self-esteem involves three basic components. The first, *reflected appraisal*, deals with how an individual perceives she is viewed by others. *Social comparison* is the second component of self-esteem. This process occurs when there is an absence of objective information about one’s self or one’s situation. Under these conditions, individuals make judgments about themselves on the basis of comparisons with others. The third component of self-esteem, *self-attribution*, involves drawing conclusions about the success or failure of one’s own actions or efforts (Rosenberg, 1986).

The stability and level of a person’s self-esteem are believed to be “determined by the nature and consistency of one’s cumulative experiences of reflected appraisals, social comparisons, and self-attributions” (Turner & Roszell, 1994, p. 191). An individual’s social resources are obviously implicated in the development and on-going maintenance of self-esteem. Social resources, in turn, are believed to be affected by a person’s level of self-esteem (Thoits, 1995; Turner & Roszell, 1994). Little attention, however, has been paid to the interaction between social and psychological resources.

Evidence exists that the distribution of self-esteem and sense of mastery is linked to an individual’s position in the social structure, that is, to her social status. Women and members of minority groups, unmarried people, and persons with lower income and education, have been observed to have a lower sense of self-esteem and mastery (Turner & Roszell, 1994). Because studies indicate that higher levels of mastery and self-esteem buffer the negative effects of stress, researchers posit that individuals with greater psychological resources choose to use more
effective coping strategies (Thoits, 1995; Turner & Roszell, 1994). This link, however, has not been definitively established (Thoits, 1995).

**Influence on Social Resources**

In addition to psychological resources, an individual’s coping resources include her family, friends, neighbors, and other voluntary associations. Social support, the term most often used in the literature to refer to this network of family and friends, has both structural and functional dimensions. The structural dimension is concerned with the type and number of relationships a person has as well as frequency of contact with these relationships (Berkman, 1985). However, the most basic structural measure of social support is less concerned with number or type of relationships, but rather with whether or not a person has some form of intimate relationship. This type of relationship has been linked to reductions in stress (Cohen & Willis, 1985).

The functional dimension of social support involves either the receipt (actual or perceived) from various network members of emotional concern, information, or instrumental aid (e.g., goods, services, money) or of appraisal (e.g., information important to self-evaluation) (House, 1981; House & Kahn, 1985). The *perceived* availability of social support has been demonstrated to have a stronger positive effect on mental health than the actual receipt of support (Thoits, 1995).

Coping researchers have also noted some of the effects of social status on perceived support. Women, persons who are married, and persons of higher socioeconomic status tend to report higher levels of perceived support (Thoits, 1984, 1995). Network size and contact between members also varies by social status. It is positively related to socioeconomic status and negatively related to age (Thoits, 1982). Men tend to have “more ‘extensive’ but less ‘intensive’”
networks than women (Thoits, 1995, p. 65). Few studies have examined the effect of perceived or received support on an individual’s choice of coping strategies. Results from those which have are inconsistent (Thoits, 1995).

Social Resources Treated as Latent

Within the existing coping literature, social resources are conceptualized as latent. That is, they are viewed as “a potential source of crucial support” from which an actor may choose to draw when dealing with a particular stressor (Pearlin & Schooler, 1978, p. 5). The conceptual emphasis is on an active individual who freely draws on social and psychological resources in order to orchestrate a response to a given stressor.

Scant consideration has been given to the direct pressures exerted on the actor by other members in her network to influence coping choices. This theoretical omission has drawn criticism from some scholars who quip, “Even the Lone Ranger had Tonto” (Dunahoo et al., 1998, p. 137). Indeed, a woman’s social network is also impacted by her diagnosis of breast cancer as the members of that network must also respond to the illness. Interaction with others in her social network helps frame her understanding of the illness and its severity, and is a critical component in decision-making processes (Pescosolido, 1992).

Nor has much attention been focused on how an individual’s place in the social structure might affect her appraisal of a stressor or choice of coping strategies. If social class is considered from the perspective of Bourdieu (1986), it is logical to assume that it would impinge on coping processes. He argues that an individual’s social class is predicated upon her relative possession of four different kinds of resources or capital. Economic capital refers to her financial status (income, assets) and also includes employment benefits such as health insurance and paid sick leave. Social capital involves both familial and extra-familial connections. It also includes
membership or affiliation with formal organizations (e.g., church) or clubs. Bourdieu (1989) defines the third type of capital, symbolic capital, as “the form that various species of capital assume when they are perceived and recognized as legitimate” (p. 17). For example, a medical degree is symbolic of the recognition of doctors as legitimate healers in American society. Other types of healers lack this symbolic recognition. Finally, cultural capital refers to such things as educational credentials, linguistic style, and manners.

Bourdieu’s (1986) multi-faceted approach to class is a useful tool for examining the impact of various forms of capital in shaping a woman’s choice of coping strategies. For example, lower quantities of economic capital pose real barriers to the receipt of treatment and also affect how the disease is experienced. Moreover, interaction between the health care provider and the patient may be impaired if each possesses different quantities of cultural capital.

The Absence of Cultural Considerations

The coping literature has also ignored the role of culture in shaping an individual’s coping behaviors as well as her interaction with others in the process of coping. Again, the possibility of a connection appears logical, and Bourdieu provides a framework for examination of the relationship. For Bourdieu (1990), culture is more than one form of capital. It is also connected with “habitus,” a concept which provides the linkage between the structural properties associated with social class and those of individual cognition and agency. He argues that the experience of operating for long periods within an objective class location in the social world has the effect of producing in the individual “schemes of perception, thought and action” which he refers to as habitus (p. 54). Those who occupy basically the same social positions (hold similar forms and quantities of capital) tend to have similar habitus.
Habitus, however, is not a deterministic concept. According to Bourdieu (1990), it is both a “structuring structure” and a “structured structure” (p. 53). That is, habitus is formed through an individual’s interaction with the social world. But individual action, suggested by habitus, serves to recreate the social world.

Habitus conditions an individual’s approach to life and decision-making in such a way that acting is more a matter of routine behavior than rational decision-making. It provides guidelines by which people make choices and is manifest in an individual’s manner of speech, dress, tastes in food, and other practices. By extension, it would also affect a woman’s choice of coping strategies.

Swidler (1986) takes Bourdieu’s argument on culture farther. She posits that culture’s influence on action is not merely the result of the psychological proclivities of habitus or value orientations. Rather, she opines that culture influences individual action directly by providing a “tool-kit” of habits, skills, and beliefs which “people may use in varying configurations to solve different kinds of problems” (p. 273).

Toward a Social Model of Coping

The data in this study indicate that Swidler and Bourdieu’s notions on the role of culture in shaping individual action amplify the current model of coping processes (See Figure 2). Results from this study suggest that cultural influences more than any other factor account for the variance in the coping strategies of African American and White women diagnosed with breast cancer. The data also point to the importance of social influences on coping for both African American and White women. These findings suggest that cultural and social factors are important variables that shape individual action in every stage of the coping process. These influences are apparent in how African American women and White women appraise a stressor
such as breast cancer and in how they activate strategies to deal with the various threats associated with the disease.

Figure 2

Social model of coping.

The Social Context of Primary Appraisal

Cultural and social influences both appeared in this study to affect the respondents’ appraisal of their diagnosis. A stressor such as the receipt of a diagnosis of breast cancer is not just an exigency that a woman confronts as an isolated incident. It is a major life stress occurring
in relation to, and converging with the other stresses she currently faces and has faced in the past. Pearlin (1989) observes that it is difficult to examine a stressful life event in isolation because “stressors typically surface as groups or constellations of stressors, some primary and others secondary, that blend events with more durable strains” (p. 254).

A life event stressor such as breast cancer requires immediate adjustment for a relatively short period of time. The more “durable strains” to which Pearlin refers are chronic, persistent demands which require adjustment over much longer periods of time (Thoits, 1995). The types of chronic strains which people typically experience vary according to their social status (Pearlin, 1989; Pearlin & Schooler, 1978). Thus, women tend to be exposed to different chronic strains than men, African Americans to different strains than Whites, and so on.

Varying experience with chronic strain indicates a direct effect on how a diagnosis of breast cancer is appraised by African American and White women. Over half of the African American women (55%) in this study pointed to stressors in their life that they considered more difficult to deal with than their breast cancer. For most of these survivors, their more stressful experiences emanated from intimate relationships with men. For example, Terri has battled stage three breast cancer for the last four years and has experienced a myriad of complications, including a stroke. She reflects, “Looking back on it now, I don’t think it was anymore difficult than some of the other things I’ve had to deal with….I still think mentally and emotionally, my divorce was harder than the cancer.” Terri was married for a year to a man who was abusive and claims that experience left her feeling like she had failed.

Similarly, Sheila points to her marriage as the most significant challenge in her life, in spite of the problems she has experienced with her cancer. She was first diagnosed at age 38 and had a mastectomy along with reconstructive surgery. However, about three years later, she had a
recurrence in the reconstructed breast and had to undergo a lumpectomy and more chemotherapy. She asserts, “I don’t know that the cancer was the most difficult part. My life before cancer was difficult….,” Sheila, who has been married for over twenty years, claims the real challenge for her has been her relationship with her husband. They fight frequently over how to discipline their children. Sheila’s husband is also emotionally abusive. He never believed that she really had breast cancer and encouraged her to discontinue chemotherapy treatments.

Even though Alice was diagnosed with stage two breast cancer at age 40 and required a mastectomy, she asserts that “the relationship with my mother was the most difficult thing I have ever faced in my life. We had differences over decisions I made regarding my son.” Alice was single when she became pregnant with her only son. She and the child’s father decided not to marry.

That relationships with men may register as more difficult for many African American women than their struggle with cancer would appear to be reflective of the social context in which they live. In 2000, about 35% of African American women ages 18 and older were married and living with a spouse compared with 58% of White women. In this same age group, over two times as many African American women (39%) as White women (17%) reported that they had never been married (Fields et al., 2001). While roughly similar percentages of African American women (12%) and White women (11%) in this age group are divorced, the rate of divorce for African Americans is considerably higher than for Whites.

In contrast to the appraisal of most African American survivors, almost all White survivors viewed their breast cancer as the most difficult experience they had ever faced. For the most part, the White survivors described lives that were freer of generalized stressors than did the African American survivors. For example, Susan, reports that her cancer “is probably the
most difficult thing I’ve ever had to deal with.” She was diagnosed in stage one, but her cancer was a particularly aggressive type, and as a result she had double-mastectomy and reconstruction. Susan has been married over 25 years and has two grown children. She works part-time, but she and her husband are very comfortable financially.

Jennifer, a stay-at-home mom, and her husband are also comfortable financially. She recognizes that her life prior to her breast cancer was not particularly difficult. She explains,

Being 40 in a community like ours, we have a lot—everything we need. It’s very, upper middle-class, and people just haven’t been through a lot of difficult things in life really, for the most part….And so my cancer was, like, the first big hit in the community of believers that I’m in….

Jennifer saw her life before breast cancer as similar to that of her friends—relatively easy. Other less affluent White breast cancer survivors also considered their life “easy” before their diagnosis. Wanda, who is married with two grown children and works part-time teaching preschool, had a mastectomy followed by chemotherapy four years ago. She indicates “…for me this has been the most difficult. Up until then I thought my life was pretty easy.”

The difference in appraisal of a diagnosis of breast cancer by African American and White survivors evident in this research may appear to conflict with the finding of Bourjolly and her colleagues (2003) who reported no difference in appraisal between groups. Those researchers conceptualized breast cancer as a single clinical stressor, and both African American and White women appraised the cancer as a potential threat to their health or physical well-being. When the socioeconomic status of the study’s respondents is examined, however, a difference in appraisal by the respective groups is suggested. The African American survivors in that study had significantly fewer financial resources than the White survivors but viewed the threat of their cancer as being of the same magnitude. The failure of African American women to view breast cancer as more threatening in the face of access to fewer economic resources, may be evidence
of a cultural distinction in appraisal. However, Bourjolly and her colleagues (2003) do not reach such a conclusion.

When social context is specifically examined, as it was in this study, the potential importance of social characteristics in the appraisal of stressors becomes apparent. Even though a stressor such as breast cancer may be similar (e.g., stage, treatment), the women appeared to appraise it differently based on their position in the social structure.

*Cultural Capital and Choice of Coping Strategy*

The coping strategies which are mobilized to deal with a stressor such as breast cancer appear also to be directly affected by social characteristics. Depending on her position in the social structure, a woman may draw on varying quantities of economic, social, symbolic, and cultural capital to cope with her disease. The direct impact of social structure—especially as reflected in cultural capital—on a woman’s choice of coping strategies is evident in the patterned differences identified in this study between African American and White survivors’ coping responses.

African American survivors tended to rely on one primary coping strategy to deal with their illness compared with White women who employed multiple coping strategies. For African American survivors, faith that God would get them through the illness was identified as the most important way to deal with their cancer. The faith expressed by these survivors was characterized by conversation-like prayers with God and a sense of God’s personal, direct involvement in their illness. A majority of these survivors prayed for healing, and 33% reported accounts of healing which they attributed to God’s intervention. African American culture seems clearly evident in this choice of strategies and the importance accorded it.
Religious practices are central features of African American culture. Empirical studies substantiate the importance of prayer and of the church to African Americans. They have indicated that prayer is the most effective means of dealing with their personal problems (Ellison & Taylor, 1996; Neighbors et al., 1983) and a substantial number (78%) have reported praying everyday (Taylor & Chatters, 1991). Regular church attendance is another element of these practices (Taylor & Chatters, 1991).

Through years of racial oppression, African American ministers have used their pulpits to empower and spiritually uplift members of their churches. Their sermons have been, and continue to be, targeted at providing direction for dealing with the unique chronic strains which confront African Americans (Hamlet, 1994). Ministers specifically teach the efficacy of prayer in responding to personal problems, including health-related concerns (Abrums, 2000).

Empirical evidence indicates that 62% of African Americans believe in the healing power of prayer (Klonoff & Landrine, 1996). This belief cuts across socioeconomic lines. Neither the practice of seeking God’s assistance in the face of problems nor this demonstrated belief in the healing power of prayer is associated with socioeconomic status (Ferraro & Koch, 1994; Klonoff & Landrine, 1996). The pervasiveness of these spiritual attributes among African Americans provides evidence that spiritual coping is a form of cultural capital.

In contrast, spiritual practices tended in this study to be less important coping tools for White breast cancer survivors. Only half of the White survivors indicated that faith was their most important coping strategy. For those who did claim to rely primarily on this strategy, they did so in a manner different from African American survivors. They tended to pray for strength, peace, and courage to endure the illness experience rather than healing. For curative care, White survivors reposed trust in their physicians.
Further, findings from this research suggest that African American and White survivors who rely on their Christian faith as a primary coping strategy do so in different ways. The data also suggest that this variance is linked to differences in cultural capital derived from dissimilar socio-cultural and historical experiences. However, none of the interviews with African American or White survivors included specific questions regarding denominational preference. The beliefs people hold about God, the nature of God’s character (e.g., deliverer, judge, healer, creator, etc.), God’s accessibility, and other issues obviously vary considerably by denominational preference.

Unfortunately, the religious coping literature, like the more general coping literature, has tended to ignore culture as an important variable. Many studies have used samples that were predominantly White (e.g., Gall, 2000; Pargament et al., 1998) or tended to collect data on race/ethnicity for control purposes (e.g., Pollner, 1989). To assume that the religious coping strategies of African Americans are similar to Whites, or to fail to examine specifically these strategies, is to neglect the potential effect of structural forces on individual action.

The Cultural Context of Social Support

Cultural differences would also appear to explain differences in the use of social support by African American and White survivors. White women have historically tended to have access to a greater array of institutional support and larger support networks. This access is a part of their culture and may account for their greater use of the social coping resources available in that culture. One area of social support in which this differences appears most evident is in White survivors’ reliance on their husbands.

Indeed, the husbands of White survivors figured prominently in their coping processes. Immediately after diagnosis, husbands tended to encourage problem-focused coping by
participation in treatment decisions. Jennifer’s husband, for example, encouraged her to see a
doctor after she found a lump on her breast. When the treating radiologist recommended
delaying six months before doing a biopsy, her husband directly intervened. Jennifer recalls,  
“being in the healthcare business, he found a top surgeon and sent me there. He went with me  
with my films….”

Susan’s husband also encouraged active problem-solving by going with her to buy books  
about breast cancer. She asserts, “My husband and I went out and bought a lot of the books that  
were recommended, read, and gathered a lot of information.” In a similar vein, Linda’s husband  
actively participated in formulating questions for doctor’s visits. She reports, “So I just made my  
list of questions. And, [my husband] would add to it, and so between the two of us we figured  
out all of the questions we wanted to ask, and he wrote down the answers to all of them.”

In contrast to the White survivors, 75% of whom were married, over half of the African  
American survivors in this study were either single or divorced. Those who were married did not  
report active problem-solving by their husbands. The reason for this difference also appears  
connected to culture. African American husbands are likely to operate with cultural tool-kits that  
are similar in many respects to those of their wives. For example, Sherry, an African American  
survivor, describes her husband as “phenomenal.” She reports that after her biopsy, “we went in  
to talk to [the surgeon] so she could say, okay, here are your options, and that sort of thing. And  
pretty much, my initial, response at that point was to immediately just pray.” She explains that  
“the doctor was positive, so we were positive, and we know God is in control” (emphasis added).

Culture also seems implicated in the differences evident in the social networks of African  
American and White survivors. The White survivors in this study viewed God’s presence rather  
indirectly and as manifest through the love and care of other people. African American survivors
tended to conceive of God as a member of their social support networks, just as real as any person and equally or more capable of exerting influence and providing direct support. The potential importance of non-human network members has been suggested in previous research. Pollner (1989) observes that there is evidence that “divine relationship may approximate concrete social relationships in intensity” (p. 92). He found that participation in this type of relationship was positively related to psychological well-being.

African American breast cancer survivors reported regular conversations with God. In some cases, survivors indicated that God spoke to them even when his direction was not specifically sought. The stated belief of the African American survivors that God would get them through their illness suggests a different form of empowerment or personal mastery. Such a belief may increase the individual’s perception that daily stress, chronic strain, and major life stresses such as cancer are more manageable through an alliance with a more powerful force. Indeed, most African American breast cancer survivors in this study would consider their faith in God as a problem-focused coping strategy.

In the past, psychologists have been uncomfortable with this form of empowerment because they believed it undermined an individual’s sense of personal efficacy and active problem-solving. Only recently have researchers begun to address the role of religion and spirituality in coping with general stresses and with cancer in particular (Gall, 2000; Pargament et al., 1998; Stefanek et al., 2004).

The faith in God expressed by the African American survivors in this study did not impede their use of medical care. African American survivors actively and aggressively sought medical treatment for their breast cancer. However, their belief in God as the ultimate healer would appear reflective of different institutional relationships. African Americans have been
historically victimized by the medical establishment. Even today, research indicates that they often receive substandard treatment for a range of physical conditions, even after controlling for socioeconomic status and coverage by private insurance (Institute of Medicine, 2003; Williams, 2002). Conceiving of God as healer and the doctor as God’s instrument has the effect of shifting power away from the predominantly White, and historically abusive, medical establishment and onto the side of the faithful believer (Abrums, 2000).

White survivors, irrespective of the quality of their faith, expressed trust in their physicians. This view is consistent with their cultural experience. Hence, faith in doctors as a coping response would be as much a part of the cultural tool-kit of White survivors as faith in God is for African Americans.

Selection of Tools from the Cultural Tool-kit

In addition to faith that God would get them through the illness, other tools were evident in the cultural tool-kit of the African American breast cancer survivors. One such tool is the practice of keeping personal matters such as illness confined to the family or very close friends. This theme was mentioned by almost all African American breast cancer survivors and the majority of key informants. However, the practice was not followed by the majority of the African American survivors in this study.

The distinction between awareness of a cultural practice (e.g., keep it to yourself) and the decision-making process of determining whether or not to use it, has important implications for the manner in which culture may influence action. Swidler (1986) argues that a “culture is not a unified system that pushes action in a consistent direction” (p. 277). Rather, an individual’s cultural tool-kit consists of varying prefabricated links of actions that she may elect not to use in constructing strategies of action. This process of election points to the means by which
individuals in a given culture construct new practices or keep older ones. It also demonstrates that cultural tools can function at a cognitive level and are not merely subconscious influences.

For African American women with breast cancer, faith and prayer appear to be indispensable means in their cultural tool-kits. Other tools such as the practice of not disclosing personal matters, while available, appear less important as a result of ongoing change in the larger culture in which African Americans reside. According to Swidler (1986), people do not “build lines of action from scratch, choosing actions one at a time as efficient means to given ends. Instead, they construct chains of action beginning with at least some pre-fabricated links” (p. 277). Culture provides those links.

Social and Cultural Influences on Coping Outcome

Coping outcome is the end product of an individual’s action(s) to deal with a particular stressor. Outcome is also viewed as the manner in which a person expresses her reaction to stress. Although this study did not specifically explore the outcome aspect of coping, Pearlin argues (1989) that social and cultural characteristics may be involved in how the outcome to a stressor is manifest. For example, depression may be a more typical outcome or expression of stress among women, while abuse of alcohol may be more typical among men.

Differential patterns of mental illness between African American and White women suggest that culture plays an important role in the expression of stress. Even though it is widely acknowledged that African American women tend to experience greater levels of chronic strain, research indicates no significant differences in the prevalence of major depressive disorder between African American and White women (Brown & Keith, 2003). However, other differences in the social patterns of mental disorders are apparent. For example, African American women are more likely to have agoraphobia and post-traumatic stress than White
women but are less likely than Whites to experience drug or alcohol dependence (Brown & Keith, 2003).

It is reasonable to assume culture may also shape the outcome an individual expects to experience from employing a given coping strategy. This expectation is shaped by an awareness of the outcomes others in their social networks expect of their coping efforts. African American women are subject to “double-consciousness”—an awareness of the expectations of their own networks as well as that of the dominant White culture (DuBois, 1969). A sizeable proportion of coping research has utilized outcome measures reliant on various self-reported indicators psycho-social well-being (Lazarus, 1993). An important question is what these indicators are actually measuring.

Cultural and social influences are also apparent in the research bias expressed over outcome efficacy. Researchers in the behavioral, social, and health sciences are less religious than the general population (Chatters, 2000; Dossey, 1993). Moreover, their belief systems may influence research design and interpretation of findings (Chatters, 2000). For example, Dunkel-Schetter and her colleagues (1992) in their study of the coping patterns of cancer patients, conceptualized prayer as an indicator of “cognitive escape avoidance”—a pattern of coping associated with poor outcomes.

More disturbing is the racial bias evident in coping research. African Americans have long drawn on their faith as a means of dealing with life stress. Simple logic would imply that specific study of the coping processes of populations which have faced higher levels of stress would yield fruitful information. However, not only does the general coping literature tend to ignore African Americans (and other minorities), the more recent religious coping literature does as well. Lincoln and Chatters (Lincoln & Chatters, 2003) observe that “[o]nly a few studies
examine the relationships among religion, stress, and well-being among African Americans” (p. 227). Findings from those studies indicate that their faith is positively associated with psychological well-being (Bearon & Koenig, 1990; Ellison & Taylor, 1996; Lincoln & Chatters, 2003).

In this research, African American breast cancer survivors emphasized the importance of faith and prayer as a means of coping with their illness. Almost all indicated a fervent belief that God not only provided emotional comfort, but actively healed their bodies. They pray because they believe it is effective. In her testimony, Terri tells others of God’s healing powers. She exclaims, “Miracles are not a thing of the past, but of the present, and do occur daily!”

A growing body of research substantiates that spiritual coping generally has salutary effects on mental health (Ellison, 1991; Pollner, 1989; Seybold & Hill, 2001), is an effective means of dealing with uncontrollable situations (Pargament et al., 1998), and provides important emotional support in coping with breast cancer (Feher & Maly, 1999; Gall & Cornblat, 2002). Empirical research has also begun to demonstrate the beneficial effects of religious coping and prayer on physical health (Chatters, 2000; Dossey, 1993; Levin & Vanderpool, 1992; Seybold & Hill, 2001). The data suggests that African Americans have long understood the value of what empirical research has only recently begun to demonstrate.
Irrespective of race or ethnicity, breast cancer presents a woman with a number of demands with which to cope, including pain, physical disfigurement, treatment decisions, and fear and uncertainty about the future. From a purely medical perspective, the nature and extent of these challenges obviously vary by the stage and severity of the disease. Compared with the White survivors in this study, the African American survivors tended to be diagnosed in later stages of breast cancer, a finding consistent with previous research (American Cancer Society, 2003). Thus, for the African American survivors, the physical threats posed by the disease tended to be more serious than they were for the White survivors.

The African American survivors were also more likely to have to face their illness with fewer economic resources than the White survivors. Only 44% of the African American survivors were married at the time of their diagnosis compared with 75% of the White survivors—marriage patterns that are fairly consistent with national data (Fields et al., 2001). The resulting lack of a second income for most of the African American survivors translated into fewer financial resources and a need to work full-time while facing the rigors of treatment. Sixty-six percent of the African American survivors were employed full-time when diagnosed compared with only 38% of the White survivors.

Even though the African American survivors tended to be diagnosed at later stages and had fewer resources with which to address the disease, over half of these women (55%) pointed to stressors in their life that they considered more difficult to cope with than their breast cancer.
Almost all of the White survivors, in contrast, appraised their breast cancer as the most difficult experience they had ever faced.

Not only did African American and White women tend to appraise the relative difficulty of their breast cancer in different ways, they chose to activate different coping strategies. Faith that God would get them through the illness was identified by *all* African American breast cancer survivors as their most important coping strategy irrespective of socioeconomic status. White survivors employed multiple coping strategies to deal with their disease, a finding that is consistent with previous research (Dunkel-Schetter et al., 1992). Only half of the White survivors indicated that their faith in God was their most important coping strategy. Even so, this strategy for Whites was closely connected with social support, another coping strategy commonly employed by the White survivors.

How faith was utilized as a coping strategy also differed between the African American and White survivors. The African American survivors reported a very present relationship with God, characterized by regular, conversation-like prayer and a sense of God’s personal, direct involvement in their illness. In addition, a majority of African American survivors indicated that they prayed for healing, and several reported accounts of healing which they attributed to God’s intervention. The White survivors viewed God’s presence more indirectly and as manifest through the love and care of other people. They prayed for strength, peace, and courage to endure the illness experience.

African American breast cancer survivors also expressed different social support needs than Whites. White survivors readily disclosed their illness to other people and actively sought their support and assistance. African American survivors simply believed that God would see them through their illness and tended to be more reserved than White survivors in discussing
their illness with other persons. Although African American breast cancer survivors actively sought the benefits of conventional medical treatment, they trusted in God for healing. White survivors, in contrast, trusted their physicians for physical cure.

The differences evident in this study between African American and White survivors in their coping responses to breast cancer suggest significant implications for cancer support groups. If such groups are to be effective for African Americans, this study indicates that they must be designed specifically for African Americans. The results suggest that such support groups should be comprised primarily of African American participants and be led by African American facilitators. Prayer is indicated as an essential component of such groups. In addition, the groups may need to change their emphasis from providing assistance to providing some opportunities to render assistance.

Moreover, this study suggests that socioeconomic status alone cannot be treated as determinative of cancer support group attendance among African American survivors. The ranking of religious coping as primary by the African American breast cancer survivors held constant in this study without regard to socioeconomic status. The virtual absence in the structure of many cancer support groups to express that mode of coping must also be viewed as a potential cause of low attendance. Further, it is possible that religious coping completely displaces the value historically attributed to cancer support groups.

On a fundamental level, the differences evident in this study between the African American and White survivors in the appraisal of their breast cancer and in their reliance on coping strategies suggest that social and cultural factors have a profound effect on coping processes. Such an explanation is logical.
An illness such as breast cancer is not experienced by an individual as an isolated stressor. It necessarily occurs in the context of the individual’s experience with other chronic strains or even other major life challenges. The chronic strains in the life of an individual, in turn, are affected by her social status. Thus, women tend to confront different chronic strains than men, and African Americans encounter different chronic strains than Whites. In the United States, the experience of being Black has historically resulted in persistent difficulties with almost every major social institution except the church.

Likewise, few individuals experience the various stressors in their lives in utter isolation. An individual’s experience with stress and strain often spills over on others in their social networks. Indeed, a major life stressor such as breast cancer is experienced as a threat not only by the woman who receives the diagnosis, but also by her closest family members and friends. It is not an extraordinary stretch to conclude that the reaction of the network to the illness, or the patient’s expectation of what that reaction might be, might also affect her reaction to the illness. The findings from this study indicate that members of a woman’s support network are actively involved in efforts to influence the choice of her coping strategies after a diagnosis of breast cancer.

Moreover, the clear pattern of spiritual coping by all African American survivors implicates culture in choices of coping response. Over 15 years ago, Pearlin (1989) argued that coping is “of sociological interest because important elements of coping may be learned from one’s membership and reference groups in the same ways as other behaviors are learned and internalized” (p. 250). I have argued that Swidler’s (1986) notion of a cultural tool-kit is an effective framework for examining how certain beliefs and prefabricated lines of action directly influence individual coping choices.
Some of the African American survivors in this study indicated an awareness of certain cultural practices but did not use them in the context of their cancer experience. For example, the demonstrated awareness of the cultural maxim to “keep it to yourself,” but the decision by many African American survivors not to employ it, points to the interaction between structure and agency. Structure provides the boundaries for certain choices, and yet the choices people make determine future boundaries. Culture, as a particular arrangement of social structures, is not static.

In addition, the findings from this study suggest that culture is more indelible than some previous research indicates. For example, a recent publication by the American Cancer Society states that “within racial and ethnic groups, there is substantial cultural and socioeconomic variation,” but goes on to assert that “more affluent and educated members of racial and ethnic minorities may have a cancer experience similar to that of the generally more affluent White population” (American Cancer Society, 2004, p. 24). Equivalent socioeconomic status may make the resources necessary to access medical care and treatment more similar; however, the data in this study suggest that the experience of coping with the disease may still vary significantly.

Scant research exists regarding cultural and social effects on coping. As a result, the coping processes of African Americans and members of other races and ethnicities in this country have remained largely invisible. This study indicates that more research on this subject is needed. It also indicates that, in addition to examining cultural differences among respondents, the researcher must also take into account her own cultural background.

Race and the Researcher

I began this research project just over two years ago with few consciously preconceived ideas about the coping processes of African American women with breast cancer or why so few
of these women use support groups. The psychological literature on coping had very little to offer. Most research from this discipline had utilized samples consisting primarily of White, married, middle-class women. The sociological and anthropological literature pointed to the importance of the church and of prayer for African Americans facing life problems, but provided scant information on how African American women cope with a stressor such as breast cancer. The medical literature evidenced an awareness of African American beliefs regarding healing, but tended to regard these beliefs as potential obstacles to early detection efforts or compliance with treatment regimens.

As a White researcher, I recognized that I could not draw on my own cultural experiences to inform what little I gleaned from the literature regarding African American coping processes. While I have friends who are African American, the majority of my closest relationships are with other White people. Prior to this research project, I had rarely been in situations in which I functioned as a minority—at least from a racial perspective. But, even though my own cultural background provided little in the way of assistance, I believed I could draw to some degree on my education. As a sociologist, I had been trained on the intersecting issues associated with race, class, and gender. However, as I would learn, education without praxis remains largely sterile.

Of course, it would not be accurate to suggest that I began this research as a “blank slate.” I started as a well-intentioned researcher who is a part of the dominant culture in the United States. Kimmel and Messner (2001) have astutely observed that “the mechanisms that afford us privilege are very often invisible to us. What makes us marginal (unempowered, oppressed) are the mechanisms that we understand, because those are the ones that are most painful in daily life” (p. x). As a White person, I carry an “invisible knapsack” of unearned social assets which I regularly cash (McIntosh, 2002). Part of that privilege involves being a part of a
group that sets social standards. Whites do not typically see themselves as having “race.” Rather we learn to think of our lives as “normative, and average, and also ideal, so that when we work to benefit others, this is seen as work which will allow ‘them’ to be more like us (McIntosh, 2000, p. 98).

My initial approach to this investigation was to view the lack of attendance by African American women in cancer support groups as a problem. My reasoning was as follows: African Americans are an underserved and vulnerable population who have higher breast cancer mortality rates. Support groups have proven to be beneficial interventions. Therefore, African Americans would benefit from these groups if I could learn why they choose not to use them. In other words, my thought processes were reflective of the views expressed in most health care research—that is, that African Americans are “problem people” (West, 1995). It did not initially occur to me that African American women might not see themselves as “vulnerable” or that they might have effective coping processes that would preclude their need for a support group.

Fortunately for me, the respondents in this study were wonderful teachers. All of the breast cancer survivors—African American and White—were interested in sharing their experiences with me with the hope that by doing so they might help others. For the African American survivors, I believe the desire to help others cut through some of the barriers that might otherwise have reduced their willingness to work with a White researcher. These women were kind, open, and very patient with my efforts at developing verstehen.

It quickly became apparent to me in the first interviews with key informants and African American breast cancer survivors that, to understand fully their coping processes in the face of critical illness, I would need to develop a better understanding of what they cope with on a day-to-day basis. My race has not been a problem for me, and I did not have enough close African
Americans in my social network to help make me sufficiently knowledgeable about the issues that race creates for them. Therefore, I immersed myself in history and read works which addressed slavery and the Jim Crow era. I also focused on familiarizing myself with the history of the period leading up to the passage of civil rights legislation in the 1960s. Finally, I read material that specifically addressed race relations in the North Texas area.

I was surprised at how little I really knew about the extent of the racial oppression in this country—especially in the post-Civil War period—or of its unspeakable cruelty. The works which addressed the civil rights era were particularly helpful, because that was a period of “lived history” for many of the African American survivors and key informants that I interviewed.

As my understanding of racial oppression in this country increased, I began to view myself and White culture in a whole new light. I found that I needed to examine more closely the racial conceptions and prejudices in my own cultural tool-kit. Although I approached the research thinking of myself as a somewhat enlightened human being, I had to acknowledge significant deficits in my true levels of personal understanding. Once, during the course of this research project, an African American woman asked me if I had ever noticed the different circumstances of African Americans and Whites when I was growing up in Houston in the early 1960s. Embarrassed, I affirmed that I had. I explained that my family had an African American housekeeper, and that my mother used to drive her home at the end of the day. I would often ride with my mother to take her home.

Our housekeeper lived in a poor, segregated area about 4 miles from my home. I do not recall any explanation for her poverty or for segregated neighborhoods. Nor did it occur to me then to seek an explanation. Rather, my silent acceptance of her circumstances was a product of the aggregate of my interactions with other Whites. White attitudes and beliefs about African
Americans are a part of my cultural tool-kit. Those beliefs and attitudes have adjusted with closer interaction with African Americans.

Perhaps those that I interviewed later on, both African American survivors and key informants, sensed my willingness to try to leave my cultural tool-kit at the door and to learn, not only about their experiences with cancer, but also first-hand about the other significant challenges they endure. Several recounted very personal, racially-related incidents in their lives which ranged from insults from coworkers to the assault of a 10-year-old African American girl (the daughter of a key informant) by her White male school mates. Hearing these personal experiences put “faces” on the history I had been reading.

Over the course of the project, I developed an enormous appreciation for the coping processes of the African American breast cancer survivors in this study. As they struggled with their cancer, they reported more stressful circumstances than the White survivors. The majority of the African American survivors continued to work while they suffered through chemotherapy. Two survivors with metastatic breast cancer, who were covered by private insurance, were forced to take disability and experienced significant financial disruption.

In spite of their challenges, however, the African American survivors generally maintained a positive tone in their interviews. They did not tend to see themselves as victimized by this disease or by their other life challenges. Rather, they viewed themselves as survivors. They were optimistic and indicated a strong belief that God would see them through.

I do not mean to imply that the African American survivors had a “Pollyanna” approach to their illness or to their faith. Most of these women clearly described their suffering and the efforts they made to address it. Some survivors mentioned struggles they had with their faith. However, it was apparent that all of these women believed that God could and would deliver
them from the difficulties associated with their breast cancer. It was also evident that they conceived of God as an actual, functioning member of their support network. According to Thomas’ (1966:1931) theorem, “Situations that are defined as real are real in their consequences” (p. 301). Pollner (1989) extends this notion by asserting that “others defined as real are real in their consequences” (p. 102). The African American breast cancer survivors in this study clearly view God as real.

In reporting the results of this research, I have struggled to maintain balance. My appreciation of African American coping processes is not meant to imply a lack of appreciation for those employed by the White survivors. Nor should my admiration of the coping skills of the African American survivors be construed as my belief that they were better than those of the White survivors. The White survivors also had important information to share about how to cope with breast cancer. What they tended to report, however, has been described before.

Often, during the course of this project, White friends and associates would ask me what I was finding. I would report on the primacy of spiritually-based coping for the African American survivors and attempt to articulate how that coping style compared with the White survivors who used a similar strategy. Some of those who inquired have strong religious beliefs. They were most often impressed by the coping responses of the African American survivors and wished to emulate those responses in their own faith journeys.

In qualitative interviewing, the researcher is the measuring instrument. As the research instrument in this project, I can certainly report that I evolved through the research process. I became more educated on the coping responses of African American women with breast cancer as well as African American culture as a whole. I also became more cognizant of the tools in my cultural tool-kit some of which I hope that I have been successful in discarding.
The findings from this research suggest that culture is an important variable in shaping action—my own, and that of others. Much remains to be learned about culture and coping. In my experience, that is best achieved by starting with an appreciation of difference.

Implications for Future Research

Consideration of the impact of culture on coping cannot be accomplished by research which uses samples consisting predominantly of Whites, or by research that captures race or ethnicity purely for control purposes. Future research should be directed at specifically studying the coping processes of African Americans as well as other racial and ethnic groups in the United States. Moreover, to the extent that these groups are compared with Whites, the comparison should be directed at uncovering differences, not to assigning value to the difference. This objective may be easier said than done. Too often, the health behaviors of Whites form a value-laden standard by which other racial and ethnic groups are measured.

Researchers should also consider the effect of other social characteristics on coping processes. For example, prayer is widely employed by African Americans as a response to serious personal problems; however, Ellison (1996) found that the odds of turning to prayer as a means of coping are over two times higher for African American women than African American men. This gender gap held after controlling for multiple dimensions of religiosity (e.g., church attendance). More information is needed, therefore, on how African American men specifically, as well as men from other racial and ethnic groups, cope with a serious stressor such as cancer.

Findings from this study indicate that the majority of African American survivors did not consider breast cancer their most difficult life challenge compared with White survivors who uniformly appraised it as the most difficult challenge they had ever faced. This finding underscores the importance of social context in the appraisal of a stressor. Previous research has
recognized the importance of context in the individual’s appraisal of the stressor; however, “context” has been limited to the situation or condition that is considered threatening (Folkman & Moskowitz, 2004). More information is needed on how African American women with breast cancer appraise their illness relative to other chronic strain in their lives.

More study also needs to be directed at how culture influences an individual’s selection of coping strategies after appraisal, including how African American coping responses compare with those of Hispanics, Asians, as well as Whites. Findings from a few studies indicate that African American and Hispanic women with breast cancer are more likely to employ religious coping (Ashing-Giwa et al., 2004; Culver et al., 2002; Culver et al., 2004) and to report greater spiritual and existential needs (Moadel et al., 1999) than White women. However, as results from this study indicate, African American and White survivors who used religious coping did so in different ways. The results also suggest that variance in socio-cultural and historical experiences account for the difference in religious coping between African Americans and Whites.

An interesting follow-on question is whether the coping processes of other racial and ethnic groups in the United States are as distinctive as those of African Americans, or whether the coping processes of other non-White groups are more similar to those of Whites. The duration and intensity of racial oppression directed at African Americans in this country suggest that their coping processes may be particularly distinctive from those of other groups. Yancey (2003) argues that “the special type of alienation African Americans experience will persist” while “other racial minority groups are undergoing an incorporation into the dominant society that escapes Blacks” (p. 164). If he is correct, the coping processes of other non-White groups may more closely mirror those of Whites. Longitudinal research is required to determine how the
coping resources and strategies of African Americans evolve as the effects of racial oppression shift.

Coping strategies that are religious or spiritual in nature have only recently begun to receive serious attention from researchers. A new theoretically-based coping measure has recently been developed to measure the range of religious coping strategies (Pargament et al., 2000). Unfortunately, the religious coping literature, like the more general coping literature, has tended to ignore culture as an important variable. Many studies have used samples that were predominantly White (e.g., Gall, 2000; Pargament et al., 1998) or tended to collect data on race/ethnicity for control purposes (e.g., Pollner, 1989). There is a need for research which specifically examines the religious coping responses of African Americans. In addition to prayer, more information is needed on other aspects of their religious coping. For example, one African American survivor drew inspiration by comparing her experiences with stage three inflammatory breast cancer to the many trials endured by the Old Testament character Job. Future research should examine what scriptural passages, or what hymns or other religious activities, are most meaningful or comforting to persons confronting serious personal illness or other major life stressors.

None of the interviews with African American or White survivors in this study included specific questions regarding denominational preference, although occasionally a survivor would offer that information. The beliefs people hold about God, the nature of God’s character (e.g., deliverer, judge, healer, creator, etc.), God’s accessibility, and other issues obviously vary considerably by denominational preference. What is not known from this research is how the various aspects of religious coping of African American women would compare with White
women from a denomination which has expressed beliefs regarding physical healing (e.g., Pentecostal). This area could also bear further exploration.

In addition, researchers should explore the outcomes associated with various forms of religious coping among African Americans. A few studies on cancer patients measure efficacy of religious coping in terms of reduction in distress (e.g., Culver et al., 2004). Other studies have examined the effects of various dimensions of religious coping on self-esteem and personal mastery (e.g., Ellison, 1993) or on psychological well-being, an index measure consisting of self-reported life-satisfaction and happiness (e.g., Lincoln & Chatters, 2003). Not only are multiple outcome measures warranted, future researchers should examine the meaning associated with outcome measures such as “life-satisfaction” or “happiness” (Keith, 2003). What do such phrases mean to African American women? What does personal mastery mean to those who have strong beliefs about God’s presence in their immediate support network? Questions such as these consider the social and cultural implications associated with coping outcomes.

Results from this study suggest that cultural and social factors also account for the way in which social support is given and received by African American women coping with breast cancer. African American survivors perceived of God as member of their support networks while White survivors, if married, tended to look more to their husbands for support. Findings from this study suggest that relationships with men may pose a special form of chronic strain for African American women. More information is needed on the extent and composition of this type of strain, and its impact on the receipt of support by African American women who are experiencing serious or chronic illness.

Until we have a more complete understanding of the coping processes and resources of African Americans, it is difficult to develop effective interventions. Cancer support groups
appear to be a logical extension of the coping processes of White women who employ social support as a regular part of their coping arsenal. However, faith that God would get them through their illness was a primary means of coping for the African American survivors. Clearly cancer support groups need to be tailored for this difference if they are to be effective in serving the needs of African American women. It may well be that interventions other than cancer support groups would more effectively address the needs of African American women who are confronted by the stresses of breast cancer. Future research should examine the efficacy of support groups or other interventions which are specifically designed to meet the needs of African American women.

African American survivors may be wholly comforted in their reliance that God will get them through their illness; however, it is important to explore the kinds of coping assistance other people or institutions might also provide. Moreover, further study should start from the perspective of African American women and not from models predicated on White notions of coping or social support. Future research in this area can also be informed and enhanced by thinking that is akin to the traditional African American process of reciprocal obligation. That is, it can seek to determine how best to serve African American breast cancer survivors and it can seek to learn from African American breast cancer survivors so that other survivors can be better served.
APPENDIX A

QUESTIONNAIRES
Key Informants
Semi-Structured Interview Guide

Instructions

Thank you for taking time to participate in this study. The information you give will help to understand how to serve the needs of breast cancer survivors. There is no right or wrong answer to the questions. We are only interested in your opinions. First, I would like to tell you about this study and what it involves. After I explain it, I will ask you to sign a consent form that states that I have told you about the study, that you understand the study and your part in it, and that you have agreed to participate.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if cancer support groups might be helpful to them. What we know about cancer support groups is that they are used mostly by White, middle-class women. We would like to hear from people who are involved in addressing the cancer needs of Black women. Your personal and professional insight regarding these issues will be very helpful. You are a part of the first phase of the research. The second phase will involve interviews with breast cancer survivors.

I expect this interview will last from 45 minutes to one hour. You may choose not to answer any question and you may also terminate the interview at any point. With your permission, I would like to audio-record this interview. Your name will not be on this recording and your answers will remain confidential. After the recording is transcribed, it will be destroyed. Would you mind if I took notes?

In order to keep your identity private, the consent form will be separated from the interview transcript and stored in a locked file. Do you have any questions? Would you like to look at a copy of the interview guide? Would you please sign the consent form?

1. Tell me what a typical day is like for you.

2. There are a number of cancer support groups sponsored by the American Cancer Society. As you know, often Black women do not attend. Can you think of reasons why this may be the case?

3. If you were to design a cancer support group for Black women, tell me what you would include?
   a. Probe: Do you think that cancer support groups for Black women should only focus on information?
   b. Probe: Do you think that cancer support groups for Black women should focus only on providing emotional support?
   c. Probe: If so, why?
4. Considering the social history of Black women, do you think that cancer support groups should be structured differently?
   a. Probe: If so, how do you think they should be changed?

5. Take a second and think about the history of Black women, slavery, segregation, and discrimination. How do you think that their coping styles may be different because of this history?

6. As you know, prayer, church attendance, and spirituality has played a major role in the history of Blacks. Tell me how you think that prayer and spirituality play a part in the lives of Black women with cancer. Can you describe specific experiences or incidents?

7. A lot has been written about the extended kinship networks of Blacks and mutual reciprocity. How does this work in times of a serious illness like breast cancer?
   a. Probe: Do you think most Black women get as much support from family and friends as they need to deal with their breast cancer? If not, what could be done to supplement that support? What would be the best source to provide that support?
   b. Probe: How would you say Black women with breast cancer prioritize their needs as a result of the illness as against the needs of their family?

8. Outside of family and close friends, where do Black women go to receive support (e.g., church, clubs)? What is the nature of that support?
   a. Probe: Do you think most Black women get as much support from these other sources as they might? If not, what could be done to improve on or supplement this type of support?

9. How do you think most Black women feel about the support they receive from the doctors most responsible for treating their disease?
   a. Probe: Have you heard any horror stories relating to Black women and health care providers? If so, would you share them?
   b. Probe: Do you think most Black women get as much support from health care professionals as they need to deal with their breast cancer? If not, what could be done to improve that support?

10. Other types of counselors sometimes play a role in assisting those suffering from serious illnesses. In your experience, do Black women tend to seek support in dealing with the emotional aspects of their illness from some type of counselor (e.g., psychologists, social workers, ministers)? If yes, which type of counselor? What is the nature of that support?
    a. Probe: Do you think most Black women get as much support from counselors as they need to deal with their breast cancer? If not, what could be done to improve this type of support?

11. In your experience, what do Black women believe are the causes of breast cancer? Do these beliefs affect how they deal with the cancer? If so, how?
    a. Probe: Tell me how you think Black women view breast cancer survivorship?
12. When diagnosed with cancer, how in your experience, do most Black women view their chances of survival? How does this view affect how they deal with cancer?
   a. **If support group leader:** Tell me your role in helping Black women deal with their fears?

13. How much control do you believe that Black women feel they have over breast cancer or preventing its recurrence? How does this play into their coping with the disease?

*Thank you for your time and your insight.*

14. Is there anything that I have failed to ask you, but that you would like to add?

15. Is there anything that you think I need to ask in future interviews with other professionals such as yourself?
   a. What about with breast cancer survivors?

16. Is there anything that you would like to ask me before we close?

17. Do you know of other professionals who have information about these topics and who would be willing to talk to me about them? If so, may I use your name as a means of introduction?

18. Do you know any breast cancer survivors who might be willing to be interviewed? If yes, may I use your name as a means of introduction?

*Thank you so very much for your willingness to share your experiences. They have been very helpful and I know they will help others.*
Breast Cancer Survivors
Semi-Structured Interview Guide

Instructions

Thank you for taking time to participate in this study. The information you give will help to understand how to serve the needs of breast cancer survivors. There is no right or wrong answer to the questions. We are only interested in your opinions. First, I would like to tell you about this study and what it involves. After I explain it, I will ask you to sign a consent form that states that I have told you about the study, that you understand the study and your part in it, and that you have agreed to participate.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if cancer support groups might be helpful to them. What we know about cancer support groups is that they are used mostly by White, middle-class women. We would like to hear from Black women. Your personal experiences with this disease will be very helpful. You are a part of the second phase of the research. In the first phase, we interviewed various professionals who help people with breast cancer.

I expect this interview will last at least one hour. You may choose not to answer any question and you may also terminate the interview at any point. With your permission, I would like to audio-record this interview. Your name will not be on this recording and your answers will remain confidential. After the recording is transcribed, it will be destroyed. Would you mind if I took notes?

In order to keep your identity private, the consent form will be separated from the interview transcript and stored in a locked file. Do you have any questions? Would you like to look at a copy of the interview guide? Would you please sign the consent form?

Before we talk about your experiences with cancer, it would be helpful to get some basic information from you. Would you mind completing this questionnaire?

1. Take a second and think about the last couple of days. Tell me what a typical day is like for you.

2. One of the most stressful experiences a person can have is to be diagnosed. When did you first learn about your illness?
   a. Probe: Tell what went through your mind when you were diagnosed.
   b. Probe: How did you know that something was wrong?
   c. Probe: How did you decide what to do? (e.g., talk to a family member, consult a friend)
   d. Do you know how the illness had progressed when the doctor found it?
3. Tell me about the kinds of treatment that you have received.
   a. Probe: Are you currently in treatment?

4. I would like to hear about the reactions from your family and friends since you were diagnosed.
   a. Probe: Do you have family living nearby?
   b. Probe: Would you say you are close to your family?
   c. Probe: Do you see or talk to them often?

5. Many people who have this illness come up with ideas about how they got it. Would you mind sharing your thoughts with me about this if you have any?

6. Tell me what, if anything, you believe will prevent the progression of your illness?
   a. Probe: What kinds of things do you do to keep it from coming back?

7. As you know, cancer is rampant in the Black community. Tell me about your experiences, if any, of people you know who have had cancer.

8. What has been the most stressful aspect of your illness? Has there been more than one thing?

9. Tell me how you have coped with that stress?
   a. Probe: Which strategy have you used the most?
   b. Probe: When do you tend to use [this strategy] the most?
   c. Probe: Would you say this is way your family tends to deal with stresses?
   d. Probe: How does [this strategy] make you feel afterwards?

10. What is the most important advice you would give to a person who is dealing with this disease?

11. Tell me how your spiritual beliefs have helped you cope with your illness.
   a. Probe: What about activities in your church? Are there any specific activities in your church that has helped you to cope with your illness?
   b. Probe: Are you involved in organizations or social activities apart from the church (e.g., sororities, Eastern Star) that have helped you to cope with your illness? How have they helped you?

12. Some people think that cancer is a private matter and should not be discussed. Tell me your thoughts about that.
   a. Probe: Who, if anyone, do talk to about your illness?
13. Could you describe the support you have received from family or friends in dealing with this illness?
   a. Probe: Do you get as much support from your family and friends as you need?
   b. Probe: What could they do to be more helpful?
   c. Probe: What advice would you give to a family member or friend of someone suffering from this illness?

14. Who else helps you to deal with your illness outside of your family?
   a. Probe: In what ways do you receive support from them?
   b. Probe: Do you get as much support from this source as you need?
   c. Probe: What could this source do to be more helpful?

15. How would you describe the support you have received from the doctors most responsible for treating your cancer?
   a. Probe: Did you have a regular doctor before you were diagnosed?
   b. Probe: Do you get as much support from your doctors as you need?
   c. Probe: What advice would you give to a doctor who is treating a person with your illness?

16. What about the nurses or social workers? How would you describe the support you have received from them?
   a. Probe: Do you get as much support from these health care workers as you need?
   b. Probe: What could they do to be more helpful?

17. Some people find talking to a professional such as a minister, social worker or counselor when they are ill. What are your thoughts about that?

18. People receive information about their illness from different sources. Where have you gotten the most information about your illness?
   a. Probe: What has been the best source of information?
   b. Probe: Knowing what you know now, what kind of additional information would have been helpful?

19. I would like to ask you about cancer support groups. Has anyone ever talked to you about professionally led cancer support groups?
   If yes:
   a. Probe: Who talked to you or gave you information about cancer support groups (doctor, nurse, social worker, friend, etc.)?

   If no:
   b. Cancer support groups are made up of about 6-12 people who share the same diagnosis and get together to talk about their disease and give mutual support. These groups are usually led by a health care professional who also shares information on how to deal with cancer. Cancer support groups are often offered by hospitals or are sponsored by groups like the American Cancer Society. Cancer support group meetings are usually free of charge.
c. Probe: Given your experiences with breast cancer, do you think cancer support groups would have been helpful to you? Why or why not?
d. Probe: Do you think other Black women might find cancer support groups helpful? Why or why not?
e. Probe: White women tend to attend cancer support groups more than Black women. Tell me why you think this is the case.

*We are just about finished with this interview.*

20. Is there anything that I haven’t asked you, but that you would like to tell me, about your experiences?

21. Is there anything that you think I need to ask in future interviews with breast cancer survivors?

22. Do you know other breast cancer survivors who might be willing to be interviewed? May I use your name as a reference when contacting that person?

23. Is there anything you would like to ask me?

*Thank you so very much for your willingness to share your experiences. They have been very helpful and I know they will help others.*
Breast Cancer Survivors – Cancer Support Group Attendees
Semi-Structured Interview Guide

Instructions:

Thank you for taking time to participate in this study. The information you give will help to understand how to serve the needs of breast cancer survivors. There is no right or wrong answer to the questions. We are only interested in your opinions. First, I would like to tell you about this study and what it involves. After I explain it, I will ask you to sign a consent form that states that I have told you about the study, that you understand the study and your part in it, and that you have agreed to participate.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if cancer support groups might be helpful to them. What we know about cancer support groups is that they are used mostly by White, middle-class women. We would like to hear from Black women. Your personal experiences with this disease will be very helpful. You are a part of the second phase of the research. In the first phase, we interviewed various professionals who help people with breast cancer.

I expect this interview will last at least one hour. You may choose not to answer any question and you may also terminate the interview at any point. With your permission, I would like to audio-record this interview. Your name will not be on this recording and your answers will remain confidential. After the recording is transcribed, it will be destroyed. Would you mind if I took notes?

In order to keep your identity private, the consent form will be separated from the interview transcript and stored in a locked file. Do you have any questions? Would you like to look at a copy of the interview guide? Would you please sign the consent form?

Before we talk about your experiences with cancer, it would be helpful to get some basic information from you. Would you mind completing this questionnaire?

1. Take a second and think about the last couple of days. Tell me what a typical day is like for you.

2. One of the most stressful experiences a person can have is to be diagnosed. When did you first learn about your illness?
   a. Probe: Tell what went through your mind when you were diagnosed.
   b. Probe: How did you know that something was wrong?
   c. Probe: How did you decide what to do? (e.g., talk to a family member, consult a friend)
   d. Do you know how the illness had progressed when the doctor found it?
3. Tell me about the kinds of treatment that you have received.
   a. Probe: Are you currently in treatment?

4. I would like to hear about the reactions from your family and friends since you were diagnosed.
   a. Probe: Do you have family living nearby?
   b. Probe: Would you say you are close to your family?
   c. Probe: Do you see or talk to them often?

5. Many people who have this illness come up with ideas about how they got it. Would you mind sharing your thoughts with me about this if you have any?

6. Tell me what, if anything, you believe will prevent the progression of your illness?
   a. Probe: What kinds of things do you do to keep it from coming back?

7. As you know, cancer is rampant in the Black community. Tell me about your experiences, if any, of people you know who have had cancer.

8. What has been the most stressful aspect of your illness? Has there been more than one thing?

9. Tell me how you have coped with that stress?
   a. Probe: Which strategy have you used the most?
   b. Probe: When do you tend to use [this strategy] the most?
   c. Probe: Would you say this is way your family tends to deal with stresses?
   d. Probe: How does [this strategy] make you feel afterwards?

10. Tell me how your spiritual beliefs have helped you cope with your illness.
    a. Probe: What about activities in your church? Are there any specific activities in your church that has helped you to cope with your illness?
    b. Probe: Are you involved in organizations or social activities apart from the church (e.g., sororities, Eastern Star) that have helped you to cope with your illness? How have they helped you?

11. Some people think that cancer is a private matter and should not be discussed. Tell me your thoughts about that.
    a. Probe: Who, if anyone, do talk to about your illness?

12. Could you describe the support you have received from family or friends in dealing with this illness?
    a. Probe: Do you get as much support from your family and friends as you need?
    b. Probe: What could they do to be more helpful?
    c. Probe: What advice would you give to a family member or friend of someone suffering from this illness?
13. Who else helps you to deal with your illness outside of your family?
   a. Probe: In what ways do you receive support from them?
   b. Probe: Do you get as much support from this source as you need?
   c. Probe: What could this source do to be more helpful?

14. How would you describe the support you have received from the doctors most responsible for treating your cancer?
   a. Probe: Did you have a regular doctor before you were diagnosed?
   b. Probe: Do you get as much support from your doctors as you need?
   c. Probe: What advice would you give to a doctor who is treating a person with your illness?

15. What about the nurses or social workers? How would you describe the support you have received from them?
   a. Probe: Do you get as much support from these health care workers as you need?
   b. Probe: What could they do to be more helpful?

16. Some people find talking to a professional such as a minister, social worker or counselor when they are ill. What are your thoughts about that?

17. People receive information about their illness from different sources. Where have you gotten the most information about your illness?
   a. Probe: What has been the best source of information?
   b. Probe: Knowing what you know now, what kind of additional information would have been helpful?

   **We have just about reached the end of our first interview. In our next interview, I would like to talk with you about cancer support groups. Before we close I would like to ask another question.**

18. What is the most important advice you would give to a person who is dealing with this disease?

   **Thank you so much for taking the time to talk with me today. This has been very helpful and I know your answers will help others. Could we schedule our next meeting?**
Breast Cancer Survivors – Cancer Support Group Attendees
Semi-Structured Interview Guide
Second Interview

Thanks for agreeing to meet me for this second interview. I expect this interview will last about one hour. There is no right or wrong answer. We are only interested in your opinions. You may choose not to answer any question and you may also terminate the interview at any point.

Before we begin, do you have any questions from our last session or other thoughts that you would like to share?

1. I would like to ask you about cancer support groups. I know you attend (have attended) a cancer support group. Who talked to you or gave you information about cancer support groups (doctor, nurse, social worker, friend, etc.)?

2. What made you decide to attend a cancer support group?
   a. Probe: What would you say is the most important reason you attend?
   b. Probe: Which group do you attend?

3. I would like to hear about your group. Would you tell me about who attends?
   a. Probe: What is the racial mix?
   b. Probe: Does the racial mix make a difference to you?
   c. Probe: What about the marital status of the attendees? Does that make a difference?
   d. Probe: How about the length of illness of the attendees. Does that affect your feelings about the group?

4. How often would you say you attend your group?
   a. Probe: How long have you been attending?

5. Based on your experience, when in the course of the illness would you say it is most important to attend a cancer support group? Why?

6. What happens at your cancer support group meetings? Would you describe one?
   a. Probe: What is it about the group meetings that you find satisfying?
   b. Probe: What is it about the group that you don’t like or that you find less satisfying?
   c. Probe: Is there anything you would change about the group meetings, and if so what?
   d. Probe: Is there anything that makes it hard for you to attend? If so, what?

7. Do you think other Black women might find cancer support groups helpful? Why or why not?
8. White women tend to attend cancer support groups more than Black women. Tell me why you think this is the case.

*We are just about finished with this interview.*

9. Is there anything that I haven’t asked you, but that you would like to tell me, about either your experiences with your illness or with cancer support groups?

10. Is there anything that you think I need to ask in future interviews with breast cancer survivors?

11. Do you know other breast cancer survivors who might be willing to be interviewed? May I use your name as a reference when contacting that person?

12. Is there anything you would like to ask me?

*Thank you so very much for your willingness to share your experiences. They have been so helpful and I know they will help others.*
APPENDIX B

CONSENT FORMS
CONSENT FOR PARTICIPATION IN RESEARCH STUDY

“Coping and Cancer Support Groups”

Key Informant

I, ________________________, agree to take part in a research study on coping and cancer support groups as a part of Brenda McCoy’s doctoral dissertation, under the direction of Dr. Erma Lawson at the University of North Texas.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if and/or how cancer support groups can be helpful to them. I understand that I am being asked to participate in this study because I am a professional with expertise in breast cancer (e.g., doctor, nurse) or in providing some type of assistance to women suffering from this disease (e.g., social worker, minister, breast cancer advocate). I understand that participation in this study is strictly voluntary. The study personnel may choose to stop my participation at any time. I understand that no guarantees or assurances can be made as to the results of the study.

This study will begin in July, 2003 and end no later than May, 2004. I consent to participate in one face-to-face interview which will last approximately one hour and will occur at an agreed location. I agree to have this interview tape recorded. Only the primary investigator, Brenda McCoy, her supervising professor, Dr. Erma Lawson, or persons responsible for transcription will have access to this taped interview. I understand that the taped interview will be stored in a locked cabinet when not in use by the research team and that it will be destroyed when the study ends. I understand that my name will be kept in confidence and that I will not be personally identifiable in the results of this study.

I understand that I am being asked to answer questions based on my professional experiences in dealing with women with breast cancer and that there are no known risks associated with this. However, I understand that I can withdraw from this study at any time without consequences.

I understand that I should contact Dr. Erma Lawson at the Department of Sociology at the University of North Texas at [redacted] or Brenda McCoy at [redacted] if I have further questions or any problems related to this study.

This research study has been reviewed and approved by the University of North Texas Committee for the Protection of Human Subjects. I understand that if I have any questions or concerns regarding this study, I can also contact this committee at (940) 565-3940.
I voluntarily consent to participate in this study. I certify that I have had this research study explained to me and had ample opportunity to ask any questions. All questions on my mind have been answered to my satisfaction. I have read, understand, and have been told that I will receive a signed copy of this consent form.

Participant: __________________________________________ Date: ___________________

I certify that I have explained the study and research procedures to the participant signing above. I have explained the known benefits and risks of the research. It is my opinion that the participant understood the explanation.

Investigator: _________________________________________ Date: ___________________
CONSENT FOR PARTICIPATION IN RESEARCH STUDY

“Coping and Cancer Support Groups”

Breast Cancer Survivor

I, ________________________, agree to take part in a research study on coping and cancer support groups as a part of Brenda McCoy’s doctoral dissertation, under the direction of Dr. Erma Lawson at the University of North Texas.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if and/or how cancer support groups can be helpful to them. I understand that I am being asked to participate in this study because I am a breast cancer survivor. I understand that participation in this study is strictly voluntary. The study personnel may choose to stop my participation at any time. I understand that no guarantees or assurances can be made as to the results of the study.

This study will begin in July, 2003 and end no later than May, 2004. I consent to participate in one face-to-face interview which will last approximately one hour and will occur at an agreed location. I agree to have this interviews tape recorded. Only the primary investigator, Brenda McCoy, her supervising professor, Dr. Erma Lawson, or persons responsible for transcription will have access to this taped interview. I understand that the taped interview will be stored in a locked cabinet when not in use by the researcher and that it will be destroyed when the study ends. I agree to complete a basic questionnaire about things such as my age, marital status, and employment. This questionnaire will be stored in a locked file when not in use by the research team and will be destroyed when the study ends. I understand that my name will be kept in confidence and that I will not be personally identifiable in the results of this study.

I understand that the procedures used in this study are without significant risk. However, I understand that I can withdraw from this study at any time without any consequences. Some people find answering questions about their disease stressful. I understand that I may be at risk of experiencing stress or emotional discomfort and that, if I do, no form of compensation is available. If I seek any medical treatment, I will pay for it myself or seek payment from my health care insurer (e.g., Medicare, Medicaid, Blue Cross/Blue Shield) which may or may not provide coverage. If I have questions, I should contact my insurer.

I understand that I should contact Dr. Erma Lawson at the Department of Sociology at the University of North Texas at [redacted] or Brenda McCoy at [redacted] if I have further questions or any problems related to this study.

This research study has been reviewed and approved by the University of North Texas Committee for the Protection of Human Subjects. I understand that if I have any questions or concerns regarding this study, I can also contact this committee at (940) 565-3940.
I voluntarily consent to participate in this study. I certify that I have had this research study explained to me and had ample opportunity to ask any questions. All questions on my mind have been answered to my satisfaction. I have read, understand, and have been told that I will receive a signed copy of this consent form.

Participant: _______________________________ Date: ________________

I certify that I have explained the study and research procedures to the participant signing above. I have explained the known benefits and risks of the research. It is my opinion that the participant understood the explanation.

Investigator: _______________________________ Date: ________________
CONSENT FOR PARTICIPATION IN RESEARCH STUDY

“Coping and Cancer Support Groups”

Breast Cancer Survivor: Cancer Support Group Attendee

I, ______________________, agree to take part in a research study on coping and cancer support groups as a part of Brenda McCoy’s doctoral dissertation, under the direction of Dr. Erma Lawson at the University of North Texas.

The purpose of this study is to discover how Black women with breast cancer cope with this disease and if and/or how cancer support groups can be helpful to them. I understand that I am being asked to participate in this study because I am a breast cancer survivor. I understand that participation in this study is strictly voluntary. The study personnel may choose to stop my participation at any time. I understand that no guarantees or assurances can be made as to the results of the study.

This study will begin in July, 2003 and end no later than May, 2004. I consent to participate in two face-to-face interviews which will last approximately one hour each and will occur at an agreed location. I agree to have each of these interviews tape recorded. Only the primary investigator, Brenda McCoy, her supervising professor, Dr. Erma Lawson, or persons responsible for transcription will have access to this taped interview. I understand that the taped interviews will be stored in a locked cabinet when not in use by the research team and that they will be destroyed when the study ends. I agree to complete a basic questionnaire about things such as my age, marital status, and employment. This questionnaire will be stored in a locked file when not in use by the research team and will be destroyed when the study ends. I understand that my name will be kept in confidence and that I will not be personally identifiable in the results of this study.

I understand that the procedures used in this study are without significant risk. However, I understand that I can withdraw from this study at any time without any consequences. Some people find answering questions about their disease stressful. I understand that I may be at risk of experiencing stress or emotional discomfort and that, if I do, no form of compensation is available. If I seek any medical treatment, I will pay for it myself or seek payment from my health care insurer (e.g., Medicare, Medicaid, Blue Cross/Blue Shield) which may or may not provide coverage. If I have questions, I should contact my insurer.

I understand that I should contact Dr. Erma Lawson at the Department of Sociology at the University of North Texas at [contact information] or Brenda McCoy at [contact information] if I have further questions or any problems related to this study.

This research study has been reviewed and approved by the University of North Texas Committee for the Protection of Human Subjects. I understand that if I have any questions or concerns regarding this study, I can also contact this committee at (940) 565-3940.
I voluntarily consent to participate in this study. I certify that I have had this research study explained to me and had ample opportunity to ask any questions. All questions on my mind have been answered to my satisfaction. I have read, understand, and have been told that I will receive a signed copy of this consent form.

Participant: __________________________________________ Date: ___________________

I certify that I have explained the study and research procedures to the participant signing above. I have explained the known benefits and risks of the research. It is my opinion that the participant understood the explanation.

Investigator: _________________________________________ Date: _________________
APPENDIX C

BREAST CANCER SURVIVORS
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<th>Treatment</th>
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### Table 6

**White Breast Cancer Survivors**

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REFERENCES


