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# <u>ARTICLES</u>

# Breast Cancer Survivorship: Are African American Women Considered? A Concept Analysis

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**Purpose/Objective:** To apply Rodger's (1989) evolutionary view of concept analysis to the term "cancer survivorship" with a heightened focus on breast cancer and African American women.

Design: Qualitative, concept analysis.

**Data Sources:** 50 references from the disciplines of nursing and medicine.

**Data Synthesis:** This analysis revealed that the concept of cancer survivorship is unique, evolving, and based on the meaning individuals give to a diagnosis of cancer and their experiences of living beyond the diagnosis.

**Conclusions:** The concept of breast cancer survivorship can be operationally defined as the process of living through the cancer experience beyond a breast cancer diagnosis. A crucial need exists to explore the meaning of cancer survivorship among African American women as a basis for culturally competent care.

Implications for Nursing: Nurses and other healthcare professionals must comprehend the meaning of breast cancer survivorship and its implications for cancer survivors. The meaning of cancer survivorship to African American and ethnic minority women must be explored. Culturally relevant cancer survivorship education and care should be provided for African American women and other cancer survivors of ethnic minorities as well as those involved in the women's social and healthcare world. Nurses and healthcare professionals must continue to advocate for health policies to improve the lived experiences of all cancer survivors.

There is life after breast cancer! But in going through treatment and all the things dealing with my breast cancer, some of the things I have learned are that I could not control all situations. I had to let go and allow God to take control. My spirituality, my faith was totally renewed.

—A breast cancer survivor, 1999

urvivorship" is a complex term that was introduced in the literature in the mid-1960s (Lew, 1967; Rogot, Goldberg, & Goldstein, 1966). The term initially referred to people who lived beyond catastrophic or traumatic events or the living family members of people who had died. As a biomedical term, it became associated with the length of time a person lives after a catastrophic event, such as cancer. Survivorship is defined by Random House Webster's College Dictionary (1999) as "the

# **Key Points . . .**

- When a concept such as cancer survivorship is developed or clarified inadequately, nurses have little direction to guide the construction of interventions for cancer survivors.
- Cancer survivorship is an evolutionary, dynamic, and multifaceted process that is unique, personal, and complex and involves people with cancer as well as those who support or care for them.
- ➤ Cancer survivorship is an individualized journey. The first step in providing culturally competent care is for nurses and other healthcare professionals to understand the meaning of this journey to cancer survivors.

state of being a survivor." A survivor is a person who exists despite adversity, one who continues to live after, or one who comes through, lasts, persists, pulls through, weathers, outlasts, and outwears. Survivor comes from the Spanish root word *vivir*, which means "to live." The concept of cancer survivorship applies to anyone diagnosed with cancer, regardless of prognosis or stage in the illness trajectory (Guillory, 1993; Mullan, 1985).

Survivorship emerged in the professional medical literature during the 1980s with major emphases on biomedical perspectives and length of survival, which was measured in five-year frames. With advances in cancer care and therapy, the number of survivors and the length of survivorship has increased. Survival rates have extended to 20 years and beyond. Likewise, the essence of cancer care has changed to include psychosocial and supporting health policies. These changes influenced the conceptualization of cancer survivorship. Definitions of cancer survivorship changed to not only include the length of time people live after being diagnosed with cancer but also to

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incorporate all the lived experiences of people with cancer, beginning with diagnosis and continuing for the remainder of their lives (Leigh, 1992, 1999; National Cancer Institute [NCI] Office of Cancer Survivorship, 2001; National Coalition for Cancer Survivorship [NCCS], 1986).

Several theoretical and conceptive views of survivorship are found in the literature; however, many views lack consensus and have not been operationally defined. Numerous related but equally abstract and complex concepts are used frequently to describe the characteristics of survivorship. These concepts include quality of life, coping, social support, the anomic (i.e., positive and negative) aspects of recovery from cancer, psychosocial issues, rehabilitation, consequences, and implications (Auchincloss, 1995; Dow, Ferrell, Haberman, & Eaton, 1999; Fredette, 1995; Lee, 1997; Leigh, 1999; Leigh, Boyle, Loescher, & Hoffman, 1993; Maher, 1982; Ott, 1997b).

Cancer survivorship is in need of rigorous conceptual development (Leigh, 1992; Rendle, 1997). Conceptual development, a preliminary step in formal investigation, allows researchers to clarify a concept (Rodgers & Knafl, 1993). Clarification of the survivorship concept can substantively increase knowledge in nursing. Conceptual clarity is imperative to develop interventions that improve outcomes for cancer survivors. With conceptual clarity, the discipline of nursing can develop interventions to support individuals spiritually, psychologically, emotionally, socially (Rendle), and culturally.

The purpose of this article is to describe the application of Rodgers' (1989) evolutionary view of concept analysis to the term "cancer survivorship" with a heightened focus on breast cancer and African American women. A dearth of literature on African American women and cancer survivorship exists. Is this because African American women have such a low survival rate? Compared to other American ethnic groups, African American women have the lowest breast cancer five-year survival rate (American Cancer Society [ACS], 2002; Joslyn & West, 2000; Yood et al., 1999). Whereas the incidence rate is lower for African American women than for European American women, African American women are three times more at risk for dying from breast cancer than European American women. The five-year survival rate is 87% for European American women and 72% for African American women (ACS). Breast cancer mortality rates have decreased for European American women; however, they have remained virtually unchanged for African American women, whose mortality rates are 44% higher than those of European American women (Shinagawa, 2000). Shinagawa stated that an excess burden of breast cancer exists among minority and medically under-

Exploring the meaning of survivorship to African American women as a basis for developing appropriate support and care is crucial. Because cancer survivorship is perceived by many as the lived experiences from a diagnosis of cancer to the end of a person's life, one may question whether the lived experiences of African American women cancer survivors differ from those of other ethnic groups. Rodgers (2000) emphasized that a concept must be understood in the context of its setting. In this situation, the sample is African American women with breast cancer and the setting is the culture of African American women. Exploration of the meaning of cancer survivorship to African American women through

concept analysis can provide valuable information for healthcare providers, health policy makers, and others involved in providing quality-of-life care for African American women.

# Evolution of Definitions of Cancer Survivorship

The professional literature on cancer survivorship has shown a gradual emergence from a biomedical, static focus to a comprehensive, dynamic perspective. Table 1 contains selected definitions that reflect the evolution of the definition of cancer survivorship from a static perspective to a dynamic viewpoint.

The meaning of cancer survivorship in the professional literature has evolved, over time, from focusing on people living beyond a diagnosis of cancer for a set number of years to a dynamic process that encompasses a holistic view of experiences for the balance of people's lives. Cancer survivorship is described as challenging, ongoing, tumultuous, "a balancing act," and a concern of all who interact with people diagnosed with cancer. Although the concept of cancer survivorship has evolved over time, it remains abstract. This concept is in need of rigorous conceptual clarification to enable planning of appropriate interventions for cancer survivors. With the concept of survivorship developed inadequately, nurses have little direction from which to base interventions for long-term survivors (Wyatt & Friedman, 1996). Concept development of cancer survivorship through concept analysis will contribute to the emerging knowledge base in nursing and facilitate clarity of concept use. Conceptual clarity of cancer survivorship will advance effective and culturally appropriate interventions to enhance the lives of cancer survivors.

## **Concept Analysis**

Whitley (1997) purported the continuing need to identify and validate concepts used to describe phenomena pertinent to nursing through descriptive theory development and clinical validation. Walker and Avant (1995) stated that concept development is a critical, but often neglected, approach to theory development in nursing and affirmed that the basis of any theory depends on the identification and explication of the concepts. Walker and Avant (1995) further asserted that concept development is necessary when one of three situations exists: (a) few or no concepts are available in the theorist's focal area of interest; (b) concepts already are available in the area of interest, but they are unclear, outmoded, or unhelpful; or (c) a great deal of theoretical literature or research on the topic of interest exists, but it does not match. The situations respectively require concept derivation, concept synthesis, and concept analysis.

When the definition or attributes of a concept are unclear, the ability of the concept to assist in fundamental tasks is impaired greatly. In other words, identifying an instance of a particular concept and distinguishing such an occurrence from one that is not an example of the concept is difficult. Differentiating between the concept of interest and other related concepts also is difficult (Rodgers, 1989). Survivorship is an unclear concept; therefore, concept synthesis and analysis are necessary to clarify the term. Concept analysis is a strategy that allows researchers to examine the characteristics of an attribute or term (Walker & Avant, 1995).

Table 1. Definitions of Survivorship Reflecting the Evolutionary Meaning of the Concept

Source	Definition
Mullan, 1985	Survivorship is an evolution of survival beginning with diagnosis that includes three phases: acute (revolves around treatment), extended (constitutes remission or cessation of basic and rigorous treatment), and permanent (exists when cancer is unlikely to recur or neoplasm activity has decreased).
National Coalition for Cancer Survivorship, 1986	Survivorship is not only about long-term survival or cure; rather, people with cancer are survivors from the time of diagnosis through the remainder of life.
Quigley, 1989	Survivorship endpoints vary from time since diagnosis to time since cessation of treatment; patients are included in some studies despite the presence of active disease.
Carter, 1989	Survivorship is the experience of living through cancer, which includes individuals with cancer, their families, significant others, care providers, and others in the social setting.
Leigh, 1992	Cancer survivorship is a continual, ongoing process rather than a stage or component of survival; it is the experience of living with, through, or beyond cancer.
Leigh, 1994	Survivorship is seen as a dynamic and ongoing process instead of a specific outcome or stage of survival. It is living with, through, or beyond cancer and is about personal experiences and individual journeys.
Ferrell & Dow, 1996	Cancer survivorship is a tumultuous experience of balancing the elation of surviving life-threatening illness with the demands of chronic health concerns and altered life meaning.
Clark & Stovall, 1996	"Cancer survivorship" is a term used to represent the state of living with the challenges of the cancer experience.
Leigh, 1996	Survivorship is the experience of living with, through, or beyond cancer.
Leigh, 1998	Survivorship can be characterized as a continually changing process rather than a static outcome or cure.
Leigh, 1999	Survivorship, as a continuum, begins at the moment of diagnosis and extends for the balance of life.
National Cancer Insti- tute Office of Cancer Survivorship, 2001	An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. Family members, friends, and caregivers also are affected by the survivorship experience and are, therefore, included in this definition.

#### Framework for Concept Analysis

According to Rodgers (1989), "a concept is considered to be an abstraction that is expressed in some form, either discursive or nondiscursive" (p. 332). Rodgers' (1989) approach to concept analysis addressed contemporary concerns valuing dynamism and interrelationships within reality and asserted that a concept continually is subject to change and developed through significance, use, and application. Rodgers (1989) emphasized that this approach to concept analysis differed from traditional approaches in that it emphasized that the analytic process used to clarify a concept of interest is nonlinear and involves a series of eight overlapping phases (see Figure 1). Although each phase depicted in Figure 1 is distinct, Rodgers (1989) indicated that the phases overlap.

The **attributes** of a concept constitute the way it is perceived, not its dictionary definition. Attributes are the primary characteristics of a concept. **Antecedents** are the events of the phenomena that generally are found to precede an instance of a concept. **Consequences** are occurrences that follow a concept. Rodgers (1989) stated that the identification of antecedents and consequences provides further clarity of a concept and that concept analysis should be conducted in a linguistic manner. Identification of **surrogate terms** comprises an essential step in concept analysis. Surrogate terms are ways of expressing the concept other than the word or expression selected for study. These terms serve as a manifestation of the concept and relate its

philosophical position, which may be expressed in different ways. Surrogate terms are used interchangeably with the concept of interest and either are stated or implied. Attention to **related concepts** helps to position the concept being studied within a repertoire of concepts that bear some connection. Related concepts have some relationship to the concept of interest but do not share the same set of attributes.

- 1. Identify the concept of interest.
- 2. Identify an appropriate setting and sample.
- Collect data regarding the attributes of the concept: surrogate terms, references, antecedents, and consequences of the concept.
- 4. Identify related concepts.
- Analyze data regarding the attributes of the concept: surrogate terms, references, antecedents, consequences, and related terms.
- 6. Conduct interdisciplinary or temporal concepts.
- 7. Identify a model case of the concept, if appropriate.
- 8. Identify hypotheses and implications for future development.

#### Figure 1. Phases of Rodgers' Model for Concept Analysis

Note. Based on information from Rodgers, 1989.

## **Methods**

This concept analysis of cancer survivorship uses Rodgers' (1989) evolutionary view. Of the numerous methods of conducting concept analysis (Chinn & Jacobs, 1983; Chinn & Kramer, 1991; Rodgers, 1989; Sartori, 1984; Schwartz-Barcott & Kim, 1986; Walker & Avant, 1983), Rogers' (1989) model was selected because in this model, concepts are developed using an inductive method that develops over time with attention to methodologic rigor.

This analysis involved a literature review of Ovid bibliographic records that included six databases: MEDLINE® (1966–2001), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982–August 2001), PsychInfo (1984-May 2001), CancerLit (1975-August 2001), Health-STAR (1975-September 2001), and Premedline (October 2001) computer searches. In addition, references were identified through a manual search of the literature and a descendancy approach (i.e., tracing citations through the reference lists of retrieved articles).

To narrow the list of more than 50,000 references on survivorship, the terms "cancer survivorship" and "English" were entered into the search. This search netted 192 references: 25 in CINAHL, 46 in Medline, 20 in PsychInfo, 53 in CancerLit, 46 in HealthSTAR, and 2 in Premedline. To be included in the criteria for this analysis, references must have included cancer survivorship in the title or the text and referred to women who were diagnosed with cancer. A total of 30 references from the computer search, 11 secured through manual search of the literature, and 9 obtained with the descendancy approach met inclusion criteria. The final sample was 50 references from nursing and medical journals and books. For concept analysis, Rodgers (1993) advocated using at least 30 references from each discipline or 20% of the total literature available on a concept.

Data collection was performed through the initial reading of each article, chapter, or book to capture the general inflection of the writing. Next, verbatim passages were recorded on data collection sheets. Themes then were identified and attributes were extrapolated from the themes. These data were organized into specific categories: attributes, consequences, references, surrogate terms, and related concepts.

# **Findings**

The first finding reflected paucity of literature on breast cancer survivorship and African American women. However, African American women are beginning to emerge in the literature on cancer survivorship. In a dissertation study, Guillory (1993) initiated defining the meaning of breast cancer survivorship to African American women. Almost no additional work has been conducted in this area. A recent study by Moore (2001) approached survivorship from stories of African American women's experiences beyond a breast cancer diagnosis. The data from these two studies are too limited to be generalized as the meaning of breast cancer survivorship to African American women.

The second finding was a definition of the concept of cancer survivorship that was expressed as its attributes or characteristics. The characteristics or attributes of cancer survivorship are its antecedents, consequences, surrogate terms, and related terms (see Table 2).

#### Table 2. Attributes of Survivorship Attribute Characteristics Antecedent (condition Cancer diagnosis that precedes survivorship) Consequences (events **Physical** that follow the diagno-• Cancer treatment and sequelae sis of cancer) of treatment and disease process, body image changes, reproductivity and sexuality issues, family burden issues, death Psychosocial • Fear of recurrence of cancer, emotional vulnerability, adjustment, adaptation, genetic counseling, concept of self, altered interpersonal relationships, uncertainty Spiritual • Strengthened spirituality, hopefulness, more focused goals, greater appreciation for life, strengthened intrapersonal relations, strengthened family relationships and creative expressions Socioeconomic • Employment and insurance discrimination, limited access to health and life insurance, excessive long-term treatment costs Surrogate terms (used Survivor, sufferer, exceptional painterchangeably with tient, cancer outcomes, all lived

survivorship)

Related items (bear some relationship with survivorship but do not share the same set of attributes)

experiences

Quality of life, coping, cure, adaptation, adjustment

#### **Antecedents**

Antecedents are the phenomena that generally are found to precede an instance of the concept. A consensus exists in the literature that a diagnosis of cancer is the antecedent of survivorship. In this analysis, cancer was the precipitating event and people must have survived that diagnosis or traumatic event to be survivors. Whereas some researchers felt that individuals must live for more than five years after being diagnosed with cancer before being classified as a survivor (Carter, 1989; Fredette, 1995), others stated that survivorship begins with the diagnosis of cancer (Arnold, 1999; Breaden, 1997; Dow & Lafferty, 2000; Ferrell & Dow, 1996; Leigh, 1999; Mullan, 1985).

#### Consequences

The consequences of survivorship that follow a cancer diagnosis are varied and influenced by the medical parameters of the disease, intrapersonal factors, sociocultural factors, availability of emotional and tangible support, and access to resources (Payne, Sullivan, & Massie, 1996; Pozo-Kaderman, Kaderman, & Toonkel, 1999). Psychologically, people with cancer are challenged because of the emotional vulnerability of the diagnosis and a life with uncertainty (Auchincloss, 1995). This uncertainty is amplified by fear of recurrence and death (Northouse, 1991). Survivors often encounter depression, body image changes, and sexuality concerns. Individuals and family members face adjustments and adaptations to every physical, social, psychological, emotional, economical, and spiritual aspect of their lives (Breaden, 1997; Loescher, Clark, Atwood, Leigh, & Lamb, 1990).

The review of literature on psychological responses to breast cancer by Shapiro et al. (2001) revealed that about one-half to two-thirds of breast cancer survivors deal well with the psychological aspects of the disease. Herold and Roetzheim (1992) described the psychosocial sequelae of a cancer diagnosis as a period of "watchful waiting." The uncertainty that follows a cancer diagnosis is referred to as the Damocles syndrome, which is described in this story.

In Greek mythology, Damocles was invited to the king's banquet for dinner. Once there, he found himself seated beneath a sword suspended over his head by a single horsehair. Damocles was happy to be at the king's feast, but any movement by him while reaching for food or drink might knock the sword loose and spell a quick death. Such is the predicament and vulnerability of the cancer survivor, thankful to be alive but fearful of recurrence and the risk of second malignancy. (Herold & Roetzheim, p. 780)

Family members and breast cancer survivors experience similar psychological responses to the diagnosis of breast cancer. Pervasive fear, anxiety, and uncertainty may affect interpersonal relationships, social roles, and the quality and quantity of social support provided. Socioeconomic status also may be altered. Spirituality may be challenged. In essence, the family members, as well as women with breast cancer, are survivors.

Physical challenges of survivorship may include the sequelae of the disease and its treatment that cause pain and sleep disturbances and affect survivors' sexuality and reproduction, physical functioning, role functioning, and general health. In their five-year follow-up study of disease-free survivors of breast cancer, Ganz et al. (2002) found that physical functioning was unchanged from the baseline survey. However, declines from baseline were found related to frequency of hot flashes, night sweats, vaginal discharge, breast sensitivity, stress incontinence, vaginal dryness, weight gain, and frequency of sexual activities.

Socioeconomic outcomes may include discrimination when applying for or changing employment, limited access to health and life insurance because of preexisting condition clauses in policies, excessive costs of cancer treatment that exceed the upper limits set by many insurance companies, and costs of other therapeutic modalities that may not be covered by insurance (Herbst, 1995; Hewitt, Breen, & Devesa, 1999). Findings from the 1992 National Health Interview Survey indicated that 11% of cancer survivors were denied health or life insurance coverage because of a cancer diagnosis (Hewitt et al.).

In addition to the challenges that follow a diagnosis of cancer, many survivors encounter positive changes in their lives. One of the major changes may be a strengthened spirituality that promotes finding greater meaning and purpose in life. Individuals may become more open to giving and receiving love

and discovering hope and creativity (Herold & Roetzheim, 1992; Utley, 1999). Some individuals describe their new focus as having control, balance, and a greater appreciation for life (Dow et al., 1999). Others express their love by engaging in community and volunteer activities. Many survivors state that relationships with family and friends are strengthened.

#### **Surrogate Terms**

Surrogate terms that are used interchangeably with survivorship include being a survivor (Dow et al., 1999; Leigh, 1998), a sufferer (Breaden, 1997), and an exceptional patient (Fredette, 1995). Abbey (1997) suggested that survivorship and cancer outcomes are the same concept. Other concepts found in the literature are coping, cure (Herold & Roetzheim, 1992), adjustment, and adaptation (Somerfield, Stefanek, Smith, & Padberg, 1999).

#### **Related Concepts**

Related concepts bear some relationship to the concept of interest but do not share the same set of attributes. They help to position the concept within a repertoire of concepts that bear some connection to the concept of interest. Quality of life is the most frequently cited concept related to survivorship (Dow et al., 1999).

#### **Attributes**

Several themes related to cancer survivorship were extracted from the literature. Table 3 lists the primary characteristics of the attributes, along with themes of cancer survivorship. The six broad characteristics of cancer survivorship extracted from themes in the literature were that it is complex, individualized, a process, unique, relational, and dynamic. Themes related to **complexity** included trajectory of disease, all-encompassing, multifactorial, and a phenomenon of human existence. Individualized themes included personal journey and subjective process. **Process** was described as nonlinear quality of healing, dynamic, and ongoing, and not a stage or static condition but a process. Unique was characterized as personal change and unique for each person. The term **relational** implied that when one family member has cancer, the entire family experiences the turmoil. **Dynamic** was characterized by changing, tumultuous, evolving, and life changing.

#### **Discussion**

This analysis helped to identify a definition of the concept of cancer survivorship. Cancer survivorship is a multidimensional concept that includes the experience of living through or beyond the illness and is a process, not a stage or a component, of survival (Leigh et al., 1993). Survivorship is individualized, dynamic, unique, complex, multifaceted, interdependent, and uncertain. Particularly significant in this analysis is the use of the term cancer survivorship "from the time of diagnosis to the remainder of an individual's life" (NCCS, 1986). Because cancer survivorship is a dynamic concept, people with cancer are faced with ongoing change, even when they are considered cured. The results of this study support the definition of a cancer survivor as living with, through, and beyond cancer; therefore, survivorship is the process of individuals' lived experiences.

Another finding was that survivorship is multifactorial (Carroll, 1998). It includes the spiritual, psychological,

Table 3. Attributes and Themes of Cancer Survivorship

Attribute	Themes
Complex	The experience of cancer (Arnold, 1999; Ferrell & Dow, 1996) Critical events in the trajectory of cancer (Ferrell & Dow) Involves physical, psychological, and spiritual well-being (Ferrell & Dow) Wide range (Auchincloss, 1995) Multifactorial (Carroll, 1998) Long-term psychosocial adjustment (Carter, 1989) Five areas of life are affected during the survivorship process: physical, psychological, sexual, social, and spiritual (Pelusi, 1997). Survivorship is all encompassing and deals not just with physical survival within a time frame or cure and does not imply needing or receiving therapy but deals with quality of survival on and off therapy, cured or not cured (Leigh et al., 1998). A phenomenon of human existence (Breaden, 1997) Many aspects of rehabilitation (Otto, 1994) Positive and negative experiences of being cured (Maher, 1982)
Individualized	Personal journey (Breaden)  "My battle with cancer" (Ferrell & Dow) Uniquely and personally perceived by each individual (Ferrell & Dow)  "Their cancer treatment" (Ferrell & Dow) Subjective process (Carter, 1989) Enduring sense of vulnerability (Dow, 1990)  "Their cancer experience" (Utley, 1999) Ways of coping with cancer are highly individualized (Krause, 1991). "A cancer survivor;" "her story" (Pelusi)
Process	Going through the cancer experience (Carter, 1993) Survival is a whole process; it is a process of survival (Breaden). Nonlinear quality of healing (Clark & Stovall, 1996) Dynamic and ongoing process (Leigh, 1994) A process of adaptation (Dow, 1991) Trajectory of cancer (Dow, 1990) An ongoing process that begins at the time of diagnosis (Dow, 1990; Gambosi & Ulreich, 1990) A process, rather than a stage, which involves a continuum of events (Clark & Stovall) Survivorship movement (Leigh, 1994) A changing process rather than a static outcome or cure (Leigh, 1999) A process, not a stage or a component, of survival (Leigh et al., 1993) The search for meaning and reclaiming life is an ongoing process (Dow et al., 1999). The evolution of the process of survival by the National Coalition for Cancer Survivorship (Leigh et al., 1998)
Unique	Personal change (Bushkin, 1993; Harrell, 1972) Feelings of self-consciousness (Loescher et al., 1990) Search for meaning (Dirksen, 1995) Unique to each person (Ferszt & Waldman, 1997) Uncertainty (Auchincloss)
Relational	Surviving cancer from a family perspective (Dow et al.) Social support may favorably affect survival (Lee, 1997). The cancer experience is felt by all; it is a family disease and a friend disease (Pelusi). When one family member has cancer, the entire family experiences the turmoil (Ott, 1997a).
Dynamic	Survivorship is a dynamic concept (Clark & Stovall).  A continuing, changing process (Leigh, 1999)  A tumultuous experience of balancing the elation of surviving a life-threatening illness with the demands of chronic health concerns and altered life meaning (Ferrell & Dow)  The cancer experience is life changing (Auchincloss).  The evolving meaning of cancer (Utley)

physiologic, sociological, vocational, and sexual dimensions of cancer survivors' lives (Ferrell & Dow, 1996; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Hoffman, 1989; Mayer, 1992; Ott, 1997b; Wyatt & Friedman, 1996). Cancer survivorship encompasses the whole person, the person's relationships, and the totality of the individual's lived experiences, including physiologic, sociological, spiritual, psychological, vocational, and sexual aspects.

An additional finding of this study was that a paucity of research exists on ethnic minorities, especially African American women. The authors began by questioning whether African American women are considered in survivorship literature. This study found that the cancer survivorship literature does not address survivorship from ethnic and cultural perspectives. Culture influences how people see the world and interact with others. Culture affects the cancer experience; it influences "pri-

ority setting, level of trust, behavior in different situations, and perceptions of the relationship between behavior and health outcomes" (Ott, 1997a, p. 31).

The paucity of empirical studies on cancer survivorship and the limited disciplines from which data were derived for this study limit the validity of any conclusions that can be drawn. However, the results of this study provide a foundation for additional analyses of survivorship, especially with African American and other ethnic minority women.

# **Implications**

The research on cancer survivorship and African American women fails to provide nurses and other healthcare providers with the necessary information needed to provide the culturally competent care vital for survivors' personal journeys. Following Rodgers' (1989) model, the eighth phase of the evolutionary view calls for setting forth some hypotheses. The authors propose that the following hypotheses be tested with African American women cancer survivors.

- Cancer survivorship will be perceived differently by African American women and other culturally and ethnically underrepresented groups compared to European American women who are cancer survivors.
- African American women from low socioeconomic levels will differ from African American women from middle socioeconomic levels in their descriptions of cancer survivorship.

The literature that includes African American women either has so few individuals that testing a subsample is not feasible or the explorations of cancer survivorship fail to examine its meaning from the perspective of African American women. The literature on the related concept of quality of life and African American women (Ashing-Giwa & Ganz, 1997; Ashing-Giwa, Ganz, & Petersen, 1999; Northouse et al., 1999) revealed the existence of within-group variations based on socioeconomics, age, and education. For example, middle-income, college-educated African American women's assessments of their quality of life was very similar to their European American counterparts (Ashing-Giwa et al.). Researchers can question whether these findings carry over to cancer survivorship.

Clinical implications related to African American women are four-fold: (a) nurses and other healthcare professionals must have a greater understanding of the definition of cancer survivorship and its meaning and implications for cancer survivors; (b) a need to explore the meaning of cancer survivorship to African American and ethnic minority women exists; (c) culturally relevant cancer survivorship education and care should be provided for African American women, other cancer survivors of ethnic minority, and people involved in the women's social and healthcare world; and (d) nurses and healthcare professionals must continue to advocate for health policies to improve the lived experiences of all cancer survivors.

Because cancer survivorship is an individualized journey, the first step in providing culturally competent care is for nurses and other healthcare professionals to understand the meaning of this journey to individual cancer survivors. The variables that might affect and personalize their journeys, such as age, socioeconomic status, culture, social support systems, access to health care, work environment, and psychological responses to a diagnosis of cancer, must be under-

stood. Women from low socioeconomic levels frequently have lower levels of education and income. Access to health care and healthcare utilization can be relevant. The frequently encountered discrimination in care and resources within the healthcare system and among insurance providers can be major sources of stress and conflict. Cancer survivors need assistance and support in navigating the healthcare system and in knowing their rights as patients and cancer survivors. Healthcare utilization is affected greatly by cancer survivors' understanding of the healthcare delivery system and available community resources.

A need exists for more research on cancer survivorship and women from diverse ethnic and cultural groups. Findings from the research can help healthcare professionals to better understand the meaning of cancer survivorship to these populations and develop culturally appropriate interventions. Enhancing cancer survivorship should be a multidisciplinary, collaborative activity. However, nursing should take the lead in the development of culturally appropriate interventions that represent the best practice. Nurses can assume leadership roles in educating survivors about and encouraging enrollment in clinical trials and research studies designed to test cuttingedge and quality-of-life care across the continuum of survival; encouraging agencies to keep updated registries of cancer survivors for networking, consulting, and advancing knowledge and expert testimony; and advocating changes in health policies that meet the multidimensional needs of cancer survivors and their families. Organizations such as NCCS, the NCI Office on Cancer Survivorship, and other groups of survivors have done and are doing much to link survivors with each other and the public. In addition, these organizations and offices serve as sources of referral.

Provision of culturally competent care should be comprehensive, individualized, and focused on the continuum from diagnosis to the end of cancer survivors' lives. Healthcare providers can educate cancer survivors and their community and serve as links between survivors and valuable resources. Connecting cancer survivors to applicable services, informing them of the Patients' Bill of Rights, and promoting holistic health are a few clinical strategies that will promote the quality of life for cancer survivors and quality of their support systems.

Finally, socioeconomic factors must be considered for high quality cancer care. Policies are needed at agency, organizational, and societal levels that promote access to care, prevent discrimination in employment and insurance, and encourage ongoing early detection and prevention. Advocacy for and with cancer survivors continues to be a significant need.

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## For more information . . .

- ➤ Black Healthnet www.blackhealthnet.com
- ➤ Celebrating Life: African American Women Speak Out About Breast Cancer www.celebratinglife.org
- ➤ Intercultural Cancer Council: African Americans and Cancer Frequently Asked Questions http://iccnetwork.org/cancerfacts/cfs1.htm

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.