## THEORY DERIVATION: ADAPTATION OF A CONTEXTUAL MODEL OF HEALTH RELATED QUALITY OF LIFE TO RURAL CANCER SURVIVORS

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#### ABSTRACT

For the growing population of cancer survivors, an obvious conceptual framework to guide the inquiry of health related quality of life (HRQOL) in rural cancer survivors has not emerged. In this paper, Walker and Avant's theory derivation procedures are used to adapt Ashing-Giwa's Contextual Model of HRQOL, the parent Model, to incorporate rurality into the Model's contextual dimensions. Rural cancer survivor relevant definitions and refinements are proposed for the macro (system) and micro (individual) level dimensions of the parent Model. This adaptation of the Ashing-Giwa HRQOL Model identifies concepts and components of a contextual model that must be included, measured, and accounted for to fully and deeply understand the HRQOL of rural cancer survivors.

## **INTRODUCTION**

The cancer survivor population, defined as individuals who have completed treatment for any type of cancer and currently have no apparent evidence of active disease, now numbers 11 million. A subset of this growing population is rural cancer survivors. With close to 25% of the U.S. population living in rural areas (Gamm, Hutchinson, Dabney, & Dorsey, 2003) one can estimate 2.5 million rural cancer survivors in the United States. It has been documented that people living in rural and remote areas suffer from health differentials including higher rates of mortality and morbidity such as poor health related quality of life (HRQOL). They are also more likely than urban adults to report having deferred care because of cost, with residents in remote counties least likely to have a personal physician (Bennett, Olatosi, & Probst, 2008; Hartley, 2004). Economic factors, cultural, social, and educational differences, lack of recognition by legislators and the sheer isolation of living in remote rural areas, impede rural Americans in their quest to lead a healthy life. Cancer survivors in rural settings report decreased HRQOL along with distinct needs linked to consequences of their cancer diagnosis and treatment (Aziz & Rowland, 2002; Weeks, Kazis, Shen, Cong, Ren, Miller, et al. 2004). Despite this documented health differential between rural and urban cancer survivors, an obvious conceptual framework to guide HRQOL inquiry of rural survivors has not emerged. Consequently, the purposes of this article are to: a) describe Ashing-Giwa's contextual model of HRQOL (2005) as the parent Model in guiding this inquiry and, b) use theory derivation procedures to present an adapted Model for use in rural cancer survivorship research.

#### THEORY DERIVATION PROCEDURES

Theory derivation procedures are useful when related concepts could benefit from a structural way to represent the relationships. It is also useful when insights about a phenomenon

have the potential to inspire further research (Walker & Avant, 2005). The process of theory derivation is iterative. This process involves cognizance of the level of theory development within ones area of interest via a keen knowledge of current literature leading to insights into possible new concepts and structures for theorizing. With the awareness and insight of a certain phenomenon from the literature (i.e. cancer survivorship), a parent theory is selected that as a whole (or in portions), offers a way to explain or predict the phenomenon of interest. Finally with creativity and thoughtfulness, the theorist borrows, modifies, and redefines relevant concepts and structures from the parent theory, to become meaningful within the context of the theorist's area of interest (i.e. rural cancer survivorship).

## PARENT MODEL: ASHING-GIWA'S CONTEXTUAL MODEL OF HRQOL

HRQOL is a commonly used framework to assess the impact of cancer and its treatment on cancer survivorship. Ashing-Giwa's (2005) Contextual Model of HRQOL (referred to as Model) provides a structure that expands traditional HRQOL frameworks by adding cultural and socio-ecological dimensions. The Model was informed by: 1) traditional HRQOL models (Cella, Tulsky, & Gray 1993; Gill, & Feinstein, 1994), 2) the biopsychosocial model, 3) qualitative and quantitative studies with cancer survivors, 4) the cancer and cancer survivorship literature, and 5) the multicultural and psychological literature. The Model is a "work in progress and under development" (Ashing-Giwa, 2005, p. 298).

The Model has eight dimensions, four macro or systemic level dimensions and four micro or individual level dimensions (Figure 1). The macro or systemic level includes selected contextual dimensions outside the individual, demonstrated to impact the survivorship experience. In contrast, the micro level contextual dimensions consist of individual level attributes and perceptions regarding the experience of cancer survivorship. Table 1 lists the corresponding components for each contextual dimension. Specifics of the Model will be briefly presented as a foundation for subsequent adaptation of the Model to rural cancer survivorship.

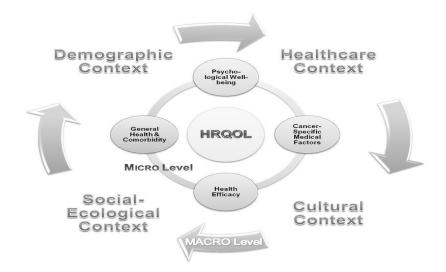


Figure 1. The contextual model of HRQOL. Adapted from Ashing-Giwa, K. T. (2005). The contextual model of HRQol: A paradigm for expanding the HRQol framework. *Quality of Life Research*, *14*, 297-307.

Level	<b>Contextual Dimensions</b>	Components
Macro/Systemic	Socio-ecological	socio-economic status (SES), life burden, and social support
	Cultural	ethnicity, ethnic identity, acculturation, interconnectedness, worldview, and spirituality
Micro/Individual	Demographic	chronological age and gender
	Healthcare system	access to health care, quality of health care, and quality of relationship
	General health & comorbidities	health status
	Cancer specific medical factors	cancer characteristics, age at diagnosis
	Health efficacy	motivation and know-how

Table 1. Parent Model Dimensions and Accompanying Components

## Macro Level Dimensions of the Parent Model

*Socio-ecological.* This contextual dimension of the parent Model is distinguished by the components SES, life burden and social support. All are implicated to "have more explanatory power" (Ashing-Giwa, 2005, pg. 299) in affecting HRQOL and survivorship outcomes than ethnic status alone. The Model proposes that low SES and associated experiences (i.e. diminished access to quality health care, lack of transportation, and unemployment that lead to marital instability and psychological stress) are barriers to health and risk factors for low HRQOL. Additionally, the life burden component of the socio-ecological dimension (living situation, role or functional strain, neighborhood resources/characteristics as well as overall day-to-day stressors) has been reported to be highly predictive of HRQOL (Ashing-Giwa, Ganz, & Petersen, 1999; Richardson, Wingo, Zack, Zahran, & King, 2008). Unlike the first 2 socio-ecological components that present risks to low HRQOL, the component of social support may mitigate the negative impact of cancer.

*Cultural.* The parent Model's cultural contextual dimension includes variables linked to culture that cancer survivors may draw from to deal with their cancer. The Model proposes that the relationship between culture and HRQOL outcomes is explicated via the variables of ethnicity, ethnic identity, acculturation, interconnectedness, worldview, and spirituality. For example, the cancer survivor's assessment of HRQOL is made through the variable of ethnicity (or cultural and ancestral origins) with its accompanying health beliefs and practices. Additionally, the variable ethnic identity or the degree to which cultural heritage is defined by the person (i.e. group vs. individual centered orientation in some cultures) influences how one behaves and relates to the environment (or context that they find themselves) and illness such as cancer (Ashing-Giwa, 2005). Level of acculturation describes how factors such as use of language, interaction with the media, and involvement in social networks from the same ethnic group modify behaviors learned in one's ethnic origin to support adaptation to the host country. The level to which these cultural adaptations occur influences HRQOL and survivorship outcomes through care-seeking and treatment decision-making processes (Ashing-Giwa, 2005). Similarly, the components of interconnectedness and how one views their well-being, and their

association with others such as family and social relationships or the more individual focused western view has the potential for both positive and negative influences on health practices and HRQOL. In the Model's cultural dimension, for example, a worldview such as fatalism, an outlook that is more common in ethnic minorities, affects both responses to cancer (e.g., treatment choices) and recovery of cancer survivors. Furthermore, the cultural factor of spirituality may mediate a worldview of fatalism in the appraisal of the cancer experience and HRQOL, if survivors feel strength from a connection to an omnipotent and omnipresent force in their lives (Ashing-Giwa, 2005).

**Demographic.** The variables of age and gender are identified as components in the demographic dimension of the parent Model. However, few studies focus on the impact of both variables in survivorship outcomes. In general, it is clear that age is commonly a factor in cancer survivorship. For example, advanced age is associated with an increased incidence and/or severity of disease and thereby is associated with decreased survival rates (Resorlu, Beduk, Baltaci, Ergun, & Talas, 2009). On the other hand, King, Kenny, Shiell, Hall, & Boyages (2000) reported that in a cohort of women undergoing surgery for early stage breast cancer, younger women fared worse than older women on a broad range of quality of life dimensions.

*Health care system.* This macro level dimension of the parent Model is composed of access, quality of care and quality of the physician-survivor relationship. Access to care for underserved persons with low SES is limited by costs, lack of insurance, language barriers and day to day competing demands related to access to care (e.g. transportation and child care). As a result, the quality of care received by minorities and underserved persons may be weakened and different than others. Needless to say situations such as these add a level of stress to the experience of cancer survivorship.

Differences in communication and perspectives of authority related to health care impact the physician-cancer survivor relationship (Ashing-Giwa, 2005). Obtaining health information and expressing concerns are influenced by some components described in the socio-ecological and cultural dimensions of the parent Model. Although active participation in one's health is associated with better quality of care and health outcomes (Phipps, Madison, Polansky & Tester, 2000; Speucha, Ozanne, Silvia, Partirdge & Mulley, 2007), ethnic minorities may not participate in their health care, or providers may not encourage their participation based on their perception that they lack interest in the process. Quality of care can be influenced by both access and the physician-survivor relationship, and can vary by facility (i.e. cancer center vs. local physician), and location (i.e. frontier vs. rural vs. metropolitan areas).

#### Micro Level Dimensions of the Parent Model

At the micro level of the parent Model, individual variables that may predict HRQOL include: general health and comorbidities; cancer-specific medical factors; health efficacy and psychological well-being (Table 1). In contrast to the macro dimensions of the parent Model that have a more global and less direct impact on HRQOL outcomes, the micro level dimensions influence HRQOL (an individual's evaluation of their current situation) directly.

*General Health and Comorbidities.* The general health dimension within the micro/individual level of contextual HRQOL can have a negative impact on HRQOL and survivorship outcomes. Similarly, severity and prevalence of comorbidities (that can vary among different ethnic and SES groups) can have a negative impact on HRQOL (Brooks, Chen, Ghosh, Mullin, Gardner, & Baquet, 2000; Garman, Pieper, Seo, & Cohenet, 2003; Schultz, Stava, Beck,

Vassilopoulou-Sellin, 2003). In a population-based study of 1,823 cancer survivors and 5,469 age-, sex-and education attainment matched control subjects identified from a 2000 National Health Interview Survey (Yarbroff, Lawrence, Clauser, Davis & Brown, 2004), cancer survivors were more likely to have multiple comorbid conditions than were control subjects.

*Cancer Specific Disease Characteristics.* Cancer survivors may experience various troublesome and unpleasant consequences stemming from either the type of cancer treatment, or other consequences from the cancer. Yabroff and colleagues (2004) reported burden (lost productivity, health and functional limitations, and overall preference or desirability of a state of health) of illness in cancer survivors to be linked with type of cancer (i.e. cancers with poor prognoses such as melanoma, lung, pancreatic cancer or multiple cancers) making them more likely to report fair or poor health and to have both physical and emotional limitations. Another example of the impact of cancer specific characteristics, Oh (2004) and colleagues found differences between women with recurrent breast cancer and disease-free breast cancer survivors in some areas of psychosocial adjustment. Domains that seem to be more directly related to the cancer experience (physical components of quality of life, cancer-specific stress, and vulnerability), comprised the majority of the differences between disease-free survivors and survivors who had a recurrence. Thus cancer-specific disease characteristics are relevant as a micro level dimension of HRQOL.

*Health Efficacy.* The parent Model proposes HRQOL outcomes are linked to health efficacy or one's ability to advocate on their own behalf by engaging in behaviors and health practices to maintain and promote health (Ashing-Giwa, 2005). This process is influenced by cultural contextual components at the macro level. These include perceptions of medical care, subjective norms for adhering to medical treatments and perceptions of support, all of which are important determinants of health practice and utilization and overall HRQOL for cancer survivors (DiMatteo, Hays, Gritz Bastani, 1993).

*Psychological Well-Being.* The last micro level dimension of the parent Model is psychological well-being, a well documented component of HRQOL. Research regarding cancer survivors has examined depression, anxiety, and self-esteem within the psychological well-being dimension (Deimling, Kahana, Bowman, & Schaefer, 2002; Pedro, 2001). In general, research findings support a positive relationship between psychological well-being and increased HRQOL.

## Summary and Critique of Parent Model

The Contextual Model of HRQOL provides an organizing structure to explore the complexities associated with understanding and measuring HRQOL. By adding cultural and socio-ecological dimensions to traditional multidimensional HRQOL frameworks and proposing interaction between macro dimensions and micro dimensions, Ashing-Giwa's Model provides a comprehensive structure for exploring HRQOL for cancer survivors. Furthermore, the parent Model proposes individual level variables that may be used to measure a specific dimension of HRQOL. Finally, the 4 macro level and 4 micro level contextual dimensions of the Model can be used to measure relevant assessment variables of cancer survivors' at risk for poor HRQOL and potential group disparity in HRQOL outcomes.

Although the parent Model provides a comprehensive, practical structure to assist culturally responsive research, in its current developmental state it possesses shortcomings as a framework for research. One drawback of the Model is its lack of specificity. For example, an operational definition to clearly differentiate the macro from the micro level dimensions of HRQOL is lacking. Conceptualizations for each dimension are offered, yet not fully validated (Ashing-Giwa, 2005b, 2007). Testing is needed for clarity and specificity of the Model. Furthermore, the weighted importance of each contextual dimension within the macro and micro level dimensions is lacking. For example, if only one or two of the individual level dimensions are accounted for, how will this impact the macro level dimensions and vice versa? Must all four dimensions on either the macro or micro level be included in the measurement of cancer survivor's HRQOL? Are some Model dimensions essential or core and therefore always measured in the assessment of HRQOL? If so which dimensions are they? Or can one assume that all eight dimensions have equal weight in the assessment of HRQOL in cancer survivors?

In spite of these shortcomings, the contextual Model of HRQOL has organizational merit in integrating knowledge regarding relevant contextual dimensions and specific components that impact cancer survivorship into a single, unified schema. The Model is conceptually useful in describing the "lived experience" of cancer survivors by acknowledging the influence of both the external (macro) and internal (micro) contexts on HRQOL. The inclusion of culture as a contextual dimension provides a mechanism for examining not only the complex nature of HRQOL but also culture in its broadest terms (i.e. rurality as culture) and its relationship to HRQOL. The formulation of effective survivorship interventions requires isolation of actual and potential sources of differences and similarities in outcomes of care among survivors. This requires examining multiple influences (i.e. demographics, healthcare context, and cancerspecific medical factors). A Model such as the contextual Model can advance this objective. Further operationalization and specificity of the macro and micro dimensions that comprise the contextual Model, as well as alternate conceptualizations of all or selected dimensions, could facilitate the measurement of factors contributing to poor HRQOL.

## ADAPTATION OF PARENT MODEL FOR RURAL CANCER SURVIVORS

Adaptation of the Contextual Model of HRQOL to rural cancer survivors is conceptualized as a comprehensive, evidence-based framework to guide cancer survivorship HRQOL research. Adaptations to the parent Model offer a framework with rurality as a defining factor. This offers the potential for concept clarification and subsequent standardization of HRQOL assessment factors for rural cancer survivors. The adaptation of the parent Model will facilitate conducting cancer survivorship research that is theoretically grounded and responsive to cultural and socio-ecological dimensions including survivors living in a rural culture. Ashing-Giwa's Contextual Model of HRQOL, the parent Model, has at its core three key statements or assumptions. Table 2 lists these next to the author's derivations for rural cancer survivors.

Conceptually, the parent Model views culture as a "way of life". Additionally, the Model posits that a relationship exists between HRQOL and culture. Adaptation of the parent Model to a rural setting is proposed by expanding the macro dimension of culture to include rurality, thus making the Model relevant to a rural population. The terms rural and rurality have been differentiated by some researchers with *rural* referring to a particular kind of geographic setting and *rurality* a particular behavior style associated with an individual from a rural area (Hoggart, 1990). If culture is defined as a way of life in a group of people with shared values, behaviors, and meanings that stem from learned and accumulated experiences, rurality could be viewed as culture. For purposes of this paper, rurality will be defined as a culture and the parent Model will be adapted to explicate the rural dimension of cancer survivorship to the formerly culturally

Table 2. Assumptions of Parent Model and Adaptation for Rural Cancer Survivors

Assumptions in Parent Model	<b>Author Derivations</b>
The Model is trans-ethnic and trans-cultural	Rurality is a defining factor of HRQOL for rural cancer survivors at the macro and micro level
Predictors of HRQOL vary across ethnicities	Predictors of HRQOL may vary across levels of rurality
Ethnic culture is a mediating variable to negative health outcomes	Rurality as culture mediates negative and positive health outcomes

based Model. Furthermore, it is postulated that rurality can mediate negative health outcomes and will precipitate variations in predictors of HRQOL. For the population of rural cancer survivors, the parent Model also adds relevant dimensions to facilitate full exploration of the risk factors for poor HRQOL and disparities in rural HRQOL outcomes.

The remainder of this article illustrates theory derivation by expanding culture to include rurality and adapting concepts from the parent Model to add meaningfulness to the inquiry of HRQOL and rural cancer survivorship (Table 3 and 4). The discussion focuses on the adaptation and/or refinement of components within the macro and micro levels of the parent Model based on the derived assumption that rurality as a culture, is a defining factor of HRQOL. The focus in the adapted Model is on those contextual dimensions that are primarily experiential in rural cancer survivorship and an embodiment of rurality in physical or psychosocial states of health and well-being. Concepts or components from the parent Model will be evaluated for their value in fully understanding and measuring HRQOL for rural cancer survivors, accompanied by documentation from the literature for proposed adaptations of the Model. The ultimate goal of the adapted contextual HRQOL Model for rural cancer survivors is to facilitate development of

## Adaptation of the Parent Model's Macro Level Dimensions for Rural Cancer Survivors

Macro level dimensions consist of contexts primarily outside of an individual and not necessarily manipulable by the individual yet which may directly influence an individual's HRQOL. The following section describes adaptation of the macro level dimensions in the parent Model for rural cancer survivors (Table 3).

*Socio-Ecological.* The parent Model describes the socio-ecological context using selfreported household income, highest level of education completed, life burden i.e. the level of stress associated with various aspects of life such as finances, employment, family, and community relations (Ashing-Giwa, 2007), and social support. The following adaptation of the parent Model's socio-ecological context to rural cancer survivors is offered: *The rural socioecological context consists of common, shared effects of systems and processes in the rural setting that contributes to social cohesiveness that shapes the HRQOL for the cancer survivor.* A rural socio-ecological context pertains to the social arrangements and behaviors amongst people distanced from points of concentrated population or economic activity. Two studies, one by Craig (1994), and another by Leiper and Reutter (2005), illustrate this proposed definition in the adaptation of the socio-ecological context. In an ethnographic study with rural elders, Craig (1994) studied "What is the culture of rural community life for elderly residents?" and "What are the dynamic processes of rural community life that have links with health of elderly residents?" The author identified relationships, especially reciprocal relationships, as key in understanding the life of rural elders. Reciprocal relationships expressed by elders included: they felt they "belonged" to increased feelings of obligation toward each other and to the community as a whole. For example, when an elder who was well known in the community became terminally ill, the community readily offered emotional and instrumental support, which in turn was received willingly by the rural elder, allowing them to fulfill their desire to die at home. Additionally, rural elders in the study were more likely to accept a referral for health care if it came from individuals with whom they had relationships, such as family or older friends in the community with similar health conditions. Findings from this study are illustrative of social arrangements and shared effects of systems and processes contributing to social cohesiveness that occur in rural settings.

Leipert and Reutter's (2005) study using feminist grounded theory methods, examined how women maintained their health in geographical, social, political, and economically challenged contexts in a northern rural region of Canada. This study identified components of the socio-ecological context (also found in the parent Model) that may be applicable to rural cancer survivors. Findings from three separate interviews with twenty five women of diverse backgrounds revealed that the women experienced vulnerability to physical health and safety risks, psychosocial health risks, and risks of inadequate health care. The women addressed their vulnerabilities by developing resilience through "making the best of the north" (Leipert & Reutter, 2005, p. 57). "Making the best of the north" meant that women developed and used resources and opportunities available in the community that enabled them to address and sometimes reduce their vulnerabilities and risks. The decision to use available resources and opportunities was influenced by their economic circumstances, educational backgrounds, interests and values. For example, women with lower income and education used more resources by seeking available (although limited), education and information to manage their vulnerabilities. They sought education and information from community colleges, community education programs, nurses, physicians (although few in number), and distance education. This education helped to change their attitudes and provided additional job opportunities which in turn made them able to manage their vulnerabilities. A secondary benefit of educational opportunities such as classes and seminars was the discovery of other women who shared and appreciated their circumstances and who, over time, provided a rich resource for emotional, instrumental, and affirmational support. Similarly, this network of support was seen in the majority of rural breast cancer survivors in Heishman's (1999) study which cited friends as more supportive than family members. These two studies illustrate the impact socio-ecologic components in the parent Model and rurality can have on HROOL.

Socio-economic status, life burden and social support in the context of rurality impacts the HRQOL of rural cancer survivors (Koopman, Angell, Turner-Cobb, Kreshka, Donnelly, & McCoy, et. al, 2001). Rural women have been reported to be especially concerned about role disruptions as a result of a cancer diagnosis and treatment because their role as caregivers are central to their lives (McGrath, Patterson, Yates, Treloar, Oldenburg, & Loos, 1999a; McGrath et al., 1999b). Interruption of this role influences their self-evaluation as valued members in their rural communities (Lopez, Eng, Randall-David, & Robinson, 2005) and may be a source of "burden" which in turn impacts HRQOL. In contrast with non-rural women, rural breast cancer survivors may need to reside away from home for long and/or multiple periods of time for follow up care which is often not available in the rural communities. This can be disruptive to the family unit. In some rural settings services (e.g., community services such as child care or home health care) are limited and/or less accessible; therefore rural women cancer survivors have reported needing help with physical and daily living needs. Additionally, rural breast cancer survivors report significant relief when they received help with the demands of their traditional gender roles (Bettencourt, Schlegel, Talley, & Molix, 2007).

Although on the surface this finding may not seem very different from the challenges of any woman, they have implications for the conceptualization and accurate measurement of the socio-ecological dimension in the adapted Model that integrates rurality as described in the rural cultural context in the next section. For example rural breast cancer survivors may need to purposely anticipate their needs and requests for help with daily living needs due to geographical distance between other women who could serve as resources as opposed to more spontaneous requests for help and subsequent assistance when the day doesn't go as planned. These implications can inform rural health research strategies to ensure study approaches are designed to be meaningful and responsive to needs of rural cancer survivors.

*Cultural.* Culture is the way of life in a group of people with accompanying values, behaviors, and meanings (Kagawa-Singer, 2000) that stem from individuals learned and accumulated experiences. In the parent Model, self-reported ethnicity was utilized as a proxy for the dimension of cultural context (Ashing-Giwa, 2007). In the adaptation of the Model to rural cancer survivors, rurality (a lifestyle associated with people living in a rural region) is added and expands on the cultural components described in the parent Model. Byrd and Clayton (2003) define culture as "The accumulated store of shared values, ideas (attitudes, beliefs, and norms), understandings, symbols, material products, and practices of a group of people. Culture has material and non-material aspects" (p. 522). Additionally Purnell and Paulanka (2005) define culture as "the totality of socially transmitted behavioral patterns, arts, beliefs, values, customs, life ways, and all other products of human work and thought characteristics of a population of people that guide their worldview and decision making" (p. 2).

Based on these broad definitions of culture, a conceptualization of the rural cultural context in an adapted Model includes a lifestyle with attitudinal and structural elements arising from a rural worldview and leading to a creative, dynamic existence to manage the vulnerability (e.g., dependence on others, geographic inequities) associated with living in a rural setting. As a rural resident, one's ethnic culture or way of life requires integrating the "life way" of rurality. Consequently the interactions between one's inherent ethnic culture and situational rural culture must be considered in the adaptation of the cultural dimension of the parent Model of HRQOL for rural cancer survivors. Since the 2000 passing of the Minority Health and Health Disparities Research and Education Act, federal funding agencies have required that researchers address culture. If meanings of health are contextually constructed, then culture must be defined broader than race and ethnicity. Culture mediates health outcomes; therefore the assessment and measurement of HRQOL in rural cancer survivors must include rurality or the lifestyle associated with being rural residents as part of the cultural context in an adapted Model. Rurality as culture within the cultural dimension of HRQOL is perhaps indirectly supported and illustrated via the documentation of high rates of accidents and injuries and risk-taking behaviors in rural populations (Dixon & Welch, 2000; National Center for Health Statistics, 2001). It has been suggested that an attitude that does not encourage preventative health behaviors is prevalent in rural areas, as is the attitude emphasizing independence or self-sufficiency (Elliot-Schmidt & Strong, 1997; Leipert & Reutter, 2005). Attitudes such as self-reliance, independence, and a reluctance to seek help, also are displayed in rural cultures (Eberhardt & Pamuk, 2004; Harju,

Wuensch, Kuhl, & Cross, 2006). These attitudes are linked to income and educational level described in the socio-ecological context of the Model and are purported to impact HRQOL. The attitude of preventative health as a low priority juxtaposed with the higher priority of work and stoicism seem at odds with each other yet illustrates the realities of rurality. Given this "way of life", rural cancer survivors and their health care providers face unique challenges related to "culture" that impact rural cancer survivorship and development of cancer survivorship treatment plans.

Leipert and George (2008) report a study of rural women's health in Canada. According to participants in this study, "rural culture maintains aspects of conventionality expressed in traditional gender roles and circumscribed opportunities for women" (p. 215). The expectations and practices stemming from a rural culture can both hinder and empower rural women. For example, women described how traditional role expectations limited their ability to make decisions and be independent. However, these women also described rural community-oriented culture as positive from the standpoint of familiarity with one another that led to an awareness of each other's needs. These factors contributed to a culture of support that had the potential of fostering women's health. A similar phenomenon was reported by Leipert & Reutter (2005) where the rural culture was supportive of women if they subscribed to cultural norms established within the rural community. Implied in these exemplars of rural cultural context are rural community values and processes, both of which are fundamental elements in the concept of culture and more specifically rurality in the adapted Model of HRQOL.

**Demographic.** On the surface, labeling a dimension on the macro level of the Model as demographic seems redundant to the concepts embedded at the individual level of the Model. However, in the adaptation of the Model for rural cancer survivors, two potential macro level demographic components are relevant because of their ability to shed light on, or mediate the relationships among variables impacting HRQOL for rural cancer survivors: 1) type of employment and 2) years of residence in a rural setting.

Leipert and Reutter (2005) described rural women "making the best of the north" by coping with financial and work issues that illustrates how the demographic of employment may fit as a macro level component of the demographic context. Survival in the north meant these women had to be resilient, and had to have adequate and secure finances which sometimes necessitated full and part-time employment. The women's choices were restricted by the community's need to limit the amount, type and quality of work options in order to provide some work to as many as possible. In smaller northern communities, women with advanced education found it difficult to find appropriate employment and would engage in part-time employment in a variety of work situations including farming, ranching, retail, and foster parenting. Travel risks going to work outside their communities, were associated with the climate and terrain; therefore, these rural women would assume part-time employment locally to maintain control in their lives, while others started their own businesses or sold produce grown on their farms to remain locally.

A second demographic component that may impact the HRQOL of rural cancer survivors, and thus the necessary inclusion in an adapted Model of HRQOL, is years of residence in a rural setting. It stands to reason that choosing to live and remain in a rural setting long-term, contributes to or affirms fundamental values and attitudes of rurality. Choice of residence is described in the theme "choice" that emerged from a qualitative analysis in a study by Lee and Winters (2004). Choosing to "come to" live and stay in a rural setting was associated with generational and family ties or choosing to leave a more densely populated area, as stated by one rural resident: "I feel our quality of life here is as good as any place in the state" (Lee & Winters,

2004, p. 57). Arbuthnot, Dawson, and Hansen-Ketchum (2007) reported on rural older women who desired to remain in their own home and community despite the challenges of rural life. The realities of aging in a rural community (distant family members, loneliness, chronic transportation difficulties, and limited access to social resources) were only one aspect of their life as rural dwellers and "ordinary life circumstances of the women were inextricable from their overall sense of happiness and well-being" (p. 44).

Health Care System. The health care context as adapted for rural cancer survivors can be described as the experience of, and access to a range of healthcare strategies. These include formal and informal providers in collaboration with paid or volunteer rural cancer survivors that facilitate rural health determinants and minimize health risks. This dimension of health care in the parent Model includes access and quality of health care. This dimension is not only relevant in the assessment of the rural cancer survivor's HRQOL, but may be more significant than in the non-rural environment. Access to health care for rural cancer survivors may mean planning ahead and working with family and individuals in the community to coordinate trips to local or distant specialists or appointment times with the availability of telehealth professionals. The difficulty with healthcare access also may be due to disruption of family life and employment (Davis, Williams, Redman, White, & King, 2003). Bettencourt and colleagues (2007) suggested that rural breast cancer survivors have distinct experiences and challenges, some of which may best be addressed by "insiders" or health care providers in the community. Bettencourt's review identified rural (vs. urban) women desirous of greater health related information about breast cancer. This implies the need for information sharing and cooperation among oncologists and general practitioners in rural areas to stay knowledgeable about both the needs of cancer survivors and current recommended treatments. These studies support the adaptations made to the components of the health care system dimension from the parent Model.

Parent Model		Author Derivations	
Contextual Dimension	Components	+Added Component *Refined Component	
Socio-ecological	Socio-economic status Life Burden/stress Social support	+Affirmational support	
Cultural	Ethnicity Ethnic identity Acculturation	*Prominent Ethnicity of rural regions	
Culturul	Interconnectedness Worldview Spirituality	+Rural cultural attitudes, Resilience, Definition(s) of health, Community values & processes	
Demographic	Chronological age Gender Relationship status	+Type of Employment, Years and choice to live in rural setting	
	Access to health care	+ Use of confidence building strategies	
Health care system	Quality of health care Quality of doctor/patient relationship	* Preference for "insiders", Individualized communication style	

Table 3. Adaptation of the Parent Model's Macro Level Dimensions for Rural Cancer Survivors

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## Adaptation of the Parent Model's Micro Level Dimensions for Rural Cancer Survivors

The micro or individual level of the parent Model includes four contexts: general health, cancer-specific medical factors, health efficacy, and psychological well-being (Table 4). These describe individual level attributes and perceptions regarding cancer survivors' HRQOL.

General Health & Comorbidities. Within the general health and comorbidities dimension, the addition of number of co-morbidities and level of functional status are essential in the refinement of the parent Model for rural cancer survivors. Rural survivors in general are less likely to access health care regularly and thus are often diagnosed with later stage cancers (Weeks, Wallace, Wang, Lee, & Kazis, 2006). Additionally they may experience complications or exacerbation of their comorbidities that contribute to decreases in function. As a result, the number of comorbidities and functional status are essential components to add in the adaptation of the Model.

*Cancer-Specific Medical Factors.* Cancer specific characteristics are *the distinct cancer diagnosis and treatment related variables that individually or in combination elucidate actual and potential health risks for the rural cancer survivor.* With this proposed definition in the adaptation of the parent Model, along with the dynamic described in the general health and comorbidities context above, it is important to add three components to this micro level dimension. These are new and/or secondary cancers, recurrence of primary cancer, and type of treatment(s).

*Health Efficacy.* Health efficacy is not a concept confined to individuals in a rural setting, but has implications for health literacy and health promotion practices. The health efficacy micro dimension adapted for rural cancer survivors describes the *adaptable state of mind that stems from immersion and identity with a rural lifestyle that informs navigational (i.e. problem-solving, resource assessment/evaluation), relational (i.e. neighbor, family, HCP), and* 

Parent Model		Author Derivations	
Contextual Dimension	Components	+Added Component *Refined Component	
General health	Health status (disease status, co-morbid illnesses) Role limitations	* Number of Co-morbidities, Functional Status	
Cancer specific medical factors	Cancer characteristics Age at diagnosis Stage of cancer Time since Diagnosis Type of surgery Adjuvant Therapy	+ New and/or secondary cancers, Recurrence of primary cancer, Type of treatment(s)	
Health efficacy	Motivation and know how Health practices utilization Perceived health efficacy Medical adherence	+Health promotion practices, Health literacy, Expectation of ruggedness & self-reliance, Resilience *Confidence	
Psychological well- being	Level of functioning Emotional well-being	* Self-reliance, Positive "Can-do" attitude	

Table 4. Adaptation of the Parent Model's Micro Level Dimensions for Rural Cancer Survivors

personal (i.e. communication, psychomotor) skills necessary to thrive in a rustic, country setting and to create viable solutions in the presence of few resources. In the process of theory derivation this proposed definition of health efficacy for rural cancer survivors can inform the research concerning rural cancer survivors.

*Psychological Well-Being.* Psychological well-being in the adaptation of this micro level dimension is an *individual's degree of mental and emotional functioning that facilitates HRQOL*. Refinement of the components of this micro level context would include focusing on self-reliance and a positive attitude (Arbuthnot, Dawson, & Hansen-Ketchum, 2007; Elliot-Schmidt, & Strong, 1997). Measurement of these two refined components from the parent Model must occur to have an accurate and relevant understanding of HRQOL for rural cancer survivors.

## SUMMARY

Using a theory derivation process, the author adapted the macro and micro dimensions of the parent Model, Ashing-Giwa's contextual Model of HRQOL, by expanding the Model's cultural contextual dimension and refining and/or adding to all dimensions in order to make the parent Model relevant to the rural population. The adapted parent Model provides the necessary structure for the design of rural health research regarding the complex, multidimensional nature of HRQOL for rural cancer survivors. At the macro level, rurality within the adapted culture and social-ecological dimensions must be included in the assessment and measurement of HRQOL in the rural cancer survivor population. Additionally at the micro level, all four adapted dimensions are essential to comprehensively address HRQOL for rural cancer survivors. The adapted Model for HRQOL in rural cancer survivors derived from the parent Model can serve to identify the factors and mechanisms contributing to rural cancer health disparities. Theoretical adaptations have been described in this article with the goal of ensuring a comprehensive, context-relevant approach to the assessment and measurement of HRQOL for rural cancer survivors. Additionally it is anticipated that a broader knowledge of HRQOL that elucidates the macro level rural cultural dimension will facilitate health practitioners' ability to advocate for the needs of this sub population of cancer survivors.

Directions for future nursing inquiry and theory development may stem from this initial adaptation of the contextual Model of HRQOL. Ashing-Giwa's research questions in the evolving development of the parent Model are: a) What are the predictors of HRQOL in a multiethnic sample of breast cancer survivors and b) Do predictors have similar associations with HRQOL for each ethnic group (African-, Asian-, Latina-, and European American)? The same questions stemming from the adaptation of the Model to rural cancer survivors, might include: a) what are distinctive predictors of HRQOL in rural cancer survivors? And b) do predictors have similar associations with HRQOL for varying levels of rurality (i.e. rural vs. frontier) or rural geographic regions (i.e. south vs. mid-west)? Finally, viewing rural cancer survivorship from the perspective of a contextual model of HRQOL holds much promise for future research, practice, and health policy initiatives. There remains a paucity of research on how culture becomes manifest in clinical encounters as experienced by rural cancer survivors. This adaptation of the parent Model is a step towards addressing the goal of culturally responsive research to address rural health needs of cancer survivors.

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