

Cancer Survivorship in Rural and Urban Adults:

A Descriptive and Mixed Methods Study

By

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## Abstract

Title: Cancer Survivorship in Rural and Urban Adults: A Descriptive and Mixed Methods Study

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Cancer survivors are living longer, growing in number as the proportion of older adults in the population increases, and are now recognized as being at risk for decrements in health and well-being due to cancer and cancer treatment. Effects of treatment may persist many years after diagnosis and new treatment-related problems can appear years after treatment is completed. Challenges that confront survivors are not simply a continuation of experiences that occur during the cancer treatment phase; they are unique problems in the cancer illness trajectory, as the person treated for cancer transitions from the acute to the chronic phases of the illness. Persistent effects include physical and psychological symptoms, and social and spiritual impact.

Rural-dwelling survivors are viewed as having higher levels of risk for decrements in health and well-being due to decreased access to healthcare, specialty services, and support resources. The purpose of this descriptive and mixed methods design study is to explore and compare the impact of cancer in rural and urban-dwelling adult cancer survivors in two regions of the Pacific Northwest, Alaska and Oregon. The majority of

areas in the state of Oregon are considered rural but there is road access to all the inhabited areas of the state and the weather is not as severe as that of Alaska. Rural Alaskans live in some of the most remote and isolated regions of the United States with extreme geographical and weather challenges and high travel costs.

The convenience sample (N=132) included adult survivors of all cancer types who had completed cancer treatment and were cancer-free. Participants were recruited through distributing emails and flyers to cancer survivorship programs, support group leaders, oncology and primary care providers, and networking strategies. Data was collected via a web based survey (88%) and survey completed on paper and mailed (12%). The sample was predominantly middle aged, with a mean age of 58, and included 84% women. Time since treatment was completed ranged from 3 months to 36 years (mean 6.7). The most common types of cancer reported by the sample included breast (54%), gynecologic (9%), lymphoma (8%), head and neck (7%) and colorectal (5%).

Measures included the Impact of Cancer, version 2 (IOCv2) and the Memorial Symptom Assessment Scale short form (MSAS-SF). Means and standard deviations for the major variables from the total sample were IOC positive impact scale ( $M = 4.09$ ,  $SD = .65$ ), IOC negative impact Scale ( $M = 2.67$ ,  $SD = .82$ ), employment concerns ( $M = 2.60$ ,  $SD = 1.11$ ), relationship concerns partnered ( $M = 2.71$ ,  $SD = .74$ ), relationship concerns non-partnered ( $M = 2.72$ ,  $SD = 1.3$ ), MSAS-SF

physical symptom scale ( $M = 1.21$ ,  $SD = .61$ ). Comparison across the regions showed statistically significant differences in body concerns [ $F(1, 132) = 4.08$ ,  $p < .05$ , worry  $F(1, 132) = 4.98$ ,  $p < .05$ , negative impact  $F(1, 132) = 4.38$ ,  $p < .05$ , and employment concerns  $F(1, 132) = 18.48$ ,  $p < .05$ ]. Overall, the Alaska rural group reported the most positive outcomes.

A subsample of 19 cancer survivors were interviewed and qualitative findings revealed a temporal pattern of late survivorship, with major post-treatment themes identified as reconciling, cancer/life perspective, survivor identity, and long-term impact. Themes reflecting rural/urban differences included access to healthcare, travel, care coordination/navigation, connecting and community, thinking about death and dying, public/private journey, and advocacy. Three profiles of intensity and impact also emerged from the qualitative data.

The results of this study challenge prevalent assumptions about rural-dwelling cancer survivors and their risk for negative outcomes. Findings provide insight into the differences and similarities between rural and urban cancer survivors. From the qualitative findings, a preliminary framework of survivorship emerged, which extends into later stages of survivorship. Unique themes, not previously described as rural/urban differences, were discovered, and a profile of rural survivorship emerged, with a common thread being community. Access to healthcare may not be the driver of the survivorship experience. Symptoms have a strong

impact. There is an opportunity to influence healthcare providers and develop programs serving this growing population with their complex issues, building on the strengths of both rural and urban living, and the engagement of the cancer survivor community.

## Acknowledgement

Doctoral study and the dissertation experience is an incredible, once-in-a-lifetime, and transformational journey. Spanning several years, there are so many family, friends, faculty and colleagues to thank, more than can be named.

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## Table of Contents

Chapter 1 INTRODUCTION AND PURPOSE OF THE STUDY	1
Cancer Survivorship in the Pacific Northwest and Rural Settings	4
Gaps in Knowledge	8
Study Purpose and Specific Aims	9
Significance to Nursing	10
Chapter 2 REVIEW OF LITERATURE	14
Overview of Cancer Survivorship	14
Methodological Challenges in Cancer Survivorship Research	24
Survivorship Models and Frameworks	28
Quality of Life and the Four Domains of Survivorship	36
Physical Well-Being and Symptoms	42
Psychological Well-Being	49
Social Well-Being	54
Spiritual-Existential Well-Being	68
Survivorship as a Chronic Illness	72
Health-Related Behavior Change after Cancer	77
Myths and Social Perceptions of Cancer	77
Survivorship Issues in Older Adults	79

Survivors of Multiple Cancers	81
Health Disparities in Cancer and Survivorship	82
Survivorship in Alaska Native and American Indian People	87
Survivorship in Rural Settings	92
Rural and Frontier Descriptions of Alaska and Oregon	95
State of the Science: Gaps Addressed by This Study	101
Specific Aims	102
<b>Chapter 3 RESEARCH DESIGN AND METHODS</b>	104
Overview and Rationale	104
Participants and Sampling Plan	111
Data Collection Procedures	117
The Impact of Cancer Instrument	120
Data Analysis	125
Scientific Rigor in Qualitative Methods	129
Power Analysis: Quantitative Strand	132
Sample Size Determination: Qualitative Strand	133
Potential Limitations	133
Ethical and Regulatory Requirements	135
<b>Chapter 4 RESULTS</b>	137
Aim #1 and Its Associated Findings	137
Aim #2 and Its Associated Findings	149
Quantitative Findings	151

Aim #3 and Its Associated Findings	156
Qualitative Subsample	158
Qualitative Methods	158
Qualitative Findings	167
Diagnosis and treatment experience	169
Post-Treatment	197
Profiles of Intensity and Impact	221
Comparison of Quantitative and Qualitative Findings	226
Summary	229
Chapter 5-DISCUSSION	231
Quantitative findings	231
Qualitative Findings, Constructs Revealing Rural/Urban Differences	244
Rural Urban Health Assumptions	254
Survivorship Frameworks	259
Profiles of Intensity and Impact	260
Implications	262
Study Limitations	264
Additions to the Body of Knowledge	265
Recommendations for Future Studies	266
Summary	268
REFERENCES	270

## APPENDIXES

315

## LIST OF TABLES AND FIGURES

## Tables

Table 1	Institute of Medicine Recommendations	23
Table 2	Ethnicity in Alaska and Oregon	116
Table 3	IOC Subscales	120
Table 4	Phase I-Data Analysis	126
Table 5	Phase II-Data Analysis	127
Table 6	Most Successful Recruitment Strategies	139
Table 7	Region and Location	139
Table 8	Sample Characteristics	143
Table 9	Age, Age at Diagnosis, and Time Since Treatment	144
Table 10	Cancer Diagnosis	145
Table 11	Second Cancer Diagnosis for Those with Multiple Cancers	145
Table 12	Treatment Modalities and CAM	147
Table 13	Co-morbidities	148
Table 14	Cancer Impact on ADL, Self-rated Health, Access to Healthcare, Satisfaction With Healthcare, Summary of Cancer Treatment	149
Table 15	Descriptive Statistics-Outcome Variables-Mean	153

## Scores by Region and Locality

Table 16 Reliability Statistics	154
---------------------------------	-----

Table 17 Correlations Between Age, Time Since	155
---	-----

## Treatment, Physical Symptoms, and the IOC Outcomes

### Variables

Table 18 Follow-up Tests, Post Hoc Comparisons	157
--	-----

Table 19 Qualitative Subsample-Age, Age at Cancer	159
---	-----

### Diagnosis and Time Since Treatment

Table 20 Qualitative Subsample: Characteristics	160
---	-----

Table 21 Qualitative Subsample: Cancer Diagnosis	161
--	-----

Table 22 Qualitative Subsample: Cancer Treatment	161
--	-----

### Modalities and CAM Usage

Table 23 Qualitative Subsample: Co-morbidities	162
--	-----

Table 24 Qualitative Subsample: Cancer Impact on ADL,	163
---	-----

### Self-rated Health and Healthcare, Satisfaction with

### Healthcare, Summary of Cancer Treatment

Table 25 Descriptive Statistics for Profile #1	223
--	-----

Table 26 Descriptive Statistics for Profile #2	224
--	-----

Table 27 Descriptive Statistics for Profile #3	226
--	-----

Table 28 Comparison of Quantitative and Qualitative	227
---	-----

### Findings

## Figures

Figure 1 Estimated Number of Cancer Survivors in the US from 1971 to 2002	15
Figure 2 The Cancer Control Continuum	31
Figure 3 Quality of Life Model Applied to Cancer Survivors	32
Figure 4 Biopsychosocial Model of Cancer Survivorship	34
Figure 5 The Tribal Healthcare System in Alaska	98
Figure 6 Urban and Rural Areas in Oregon	100
Figure 7 Conceptual Triangulation	111
Figure 8 Recruitment and Sampling Plan, Phase 1	115
Figure 9 Recruitment and Sampling Plan, Phase 2	116
Figure 10 Location of Alaska Participants by Borough	141
Figure 11 Number of Participants from Oregon and Neighboring Areas by Location	142
Figure 12 Years Since Treatment Completed	144
Figure 13 Comparison of Means by Region and Location of Selected IOC Outcome Variables	157
Figure 14 Framework of Cancer Survivorship: Moving Forward	168

## **CHAPTER 1**

### **INTRODUCTION AND PURPOSE OF THE STUDY**

Approaching estimates of 13.7 million, cancer survivors are substantially increasing and currently represent 3.5% of the United States (US) population (American Cancer Society (ACS), 2012). Within this group, 2.8 million survivors are living in rural settings (Weaver et al., 2013). In 2012 the number of new cancer cases is expected to be over 1.6 million, and the number of deaths is expected to be 577,190 (Siegel, Naishadam, & Jemal, 2012). The number of diagnosed cancer cases in the US is expected to double by the year 2050 as the population ages and increases in size (Edwards et al., 2002). The majority of cancer survivors (64%) have survived at least 5 or more years since diagnosis, and 15% have survived at least 20 or more years (ACS, 2012).

Approximately 66% of those diagnosed with cancer can expect to survive beyond 5 years after diagnosis (ACS, 2008b). With continued advances in early detection and effective treatments, the number of people living years beyond a cancer diagnosis will continue to increase (Aziz & Rowland, 2003). Cancer survivorship is a significant public health challenge in the US especially with regard to maximizing the long-term health and well-being of survivors (Feuerstein, 2007a).

Cancer survivors (CSs) may experience lasting adverse effects of treatment, regardless of disease status, and may continue to experience



health decrements many years after diagnosis (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). CSs are likely to face co-morbid illness, functional limitations, long-term and late effects, difficulties with returning to work and other role transitions, uncertainty, fear of recurrence, barriers to quality healthcare, and psychosocial, emotional, cognitive, physical, spiritual and economic sequelae that significantly complicate their lives (ACS, 2012; Aziz & Roland, 2002; Ganz, 2006; Haylock, 2006; Hewitt, Greenfield, & Stovall, 2006). The long-term effects of cancer treatment may lead to premature mortality and morbidity, and interventions found effective, whether therapeutic or lifestyle-related, must be developed, examined, and disseminated (Aziz & Rowland, 2003).

Current thinking suggests that the challenges that confront CSs are not simply a continuation of experiences that occur during the cancer treatment phase: they are unique problems in the cancer illness trajectory, as the person treated for cancer transitions from the acute to the chronic phases of the illness. The problems are characterized as multifaceted and dynamic (Feuerstein, 2007b). Challenges with transitions and notions of abandonment are experienced by cancer survivors (Hewitt et al., 2006). The end of the acute treatment phase is one of the most stressful aspects of the cancer experience (Harvard Medical School, 2006), yet many health impairments may go unrecognized (Grant, Economou, Ferrell, & Bhatia, 2007). Side effects of treatment may persist, as well as the onset of late

effects, which may occur months or years into survivorship (Hewitt et al., 2006).

Some cancer patients will have visible effects and disfigurement that will continue such as a limp due to limb amputation from sarcoma or changes in speech related to cancer of the larynx. However, often times the visible signs of cancer treatment disappear (e.g., hair loss from chemotherapy); therefore, it can be difficult for others to understand that residual effects may remain for a long time (Jenkins, 2006).

Approximately 75% of CSs have health deficits related to their cancer treatment (Aziz & Rowland, 2003), 54% have chronic pain, 72% have experienced depression at some time during their treatment or survivorship, and 33% have faced infertility (Lance Armstrong Foundation, 2004a). A survey conducted by the Lance Armstrong Foundation (LAF) with 1,024 self-identified cancer patients also revealed that the healthcare system did not meet 50% of the survivors' "non-medical" needs and that healthcare providers did not offer guidance in coping with survivorship issues. Non-medical needs were identified as infertility, sexual dysfunction, depression, fear of recurrence, difficulty with relationships, and financial or job insecurity. Despite this apparent burden, 62% were experiencing "good health," 47% indicated that dealing with cancer made life better, and 70% would volunteer to assist in survivorship activities (LAF, 2004a; Wolff, 2007).

Cancer survivorship research is a new and emerging field. Historically, it has come under the rubric of the specialty of oncology, and more recently,

it is developing into a specialty of its own. In fact, an evidence-based and standardized definition has yet to emerge (Feuerstein, 2007b). Most studies utilize a specific timeframe to identify the sample being studied, (i.e., post-acute treatment, greater than two years post-treatment, greater than five years post-treatment, etc.). Many studies combine survivors with those in acute treatment, which can make it difficult to sort out issues unique to survivorship from the acute side effects of treatment (Golant, Altman, & Martin, 2003; Shepherd et al., 2006). This study focuses on CSs who are cancer-free and who have completed primary treatment.

### **Cancer Survivorship in the Pacific Northwest and Rural Settings**

Oregon experiences a slightly higher incidence of cancer than the general US population, and it is second highest in the nation for incidence of breast cancer in women (Oregon Partnership for Cancer Control, 2005). Cancer is the leading cause of death for Oregonians, and mortality rates from cancer are higher than the national rates (Oregon Partnership for Cancer Control, 2005; Siegel et al., 2012).

Based on the Rural Urban Commuting Area (RUCA) system, the rural population of Oregon is 29.1% of the state population and the area defined as rural occupies 86.3% of the land in the state (Oregon State University, 2007). People living in the eastern part of the state may be over 100 miles from cancer screening or treatment facilities. There are 26 cancer treatment programs in Oregon that are certified by the American College of Surgeons, and none are located in the eastern half of the state (American College of

Surgeons, 2012; Oregon Office of Rural Health, 2010). In addition, there are 12 rural hospitals in the central and eastern regions of the state, and only five offer any type of cancer care services. No oncologists are identified east of the city of Bend (Oregon Society of Medical Oncologists, 2012).

The Oregon Cancer Control Plan, prepared by the Oregon Partnership for Cancer Control, has addressed survivorship as a key area of needed improvement. Their goal is to improve the quality of life (QOL) of Oregon CSs by addressing the physical, emotional, social, and vocational challenges of cancer survivorship. In addition, their goals for CSs include (a) increasing the numbers of cancer survivors, significant others, and health professionals who utilize CS resources, and (b) increasing the numbers who are informed and participate with their provider in their long-term follow-up health plan (Oregon Partnership for Cancer Control, 2005). Currently, there are estimated to be 175,460 CSs living in Oregon (ACS, 2012).

Alaskans have unique needs regarding the cancer survivorship experience. Alaska has a higher percentage of rural population than the rest of the United States (US Census Bureau, 2006), and 52.3% of the state's population live in frontier areas (National Network of Libraries of Medicine, 2007). Additionally, Alaska contains more frontier land than any other state (National Center for Frontier Communities, 2007), is over twice the size of Texas (City-Data, 2007), and encompasses 20% of the land mass of the US (Alaska Experience Project, 2007). Furthermore, Alaskans face geographical challenges not present in any other state, such as limited road access into

rural areas and harsh weather patterns. Travel by air is required to reach the remote areas, which make up the greatest portion of the state. This level of extreme remoteness and challenges with access make Alaska different from any other state in the US in this regard. Many healthcare services that would be considered standard care in other states are unavailable in rural and remote Alaska (GAP Report, 1995).

Cancer treatment is often provided far from home, either in one of the larger cities in Alaska or in one of the contiguous lower 48 states. In Alaska there are multiple systems of healthcare required to provide care for a diverse population. A cancer patient may need to access these multiple systems of healthcare as only certain systems and locations provide specialized oncology care. These challenges create a significant disruption in their lives, as these cancer patients are unable to fulfill their role obligations and are separated from their support system. CSs may return to their communities and families after having been away for extended periods of time. Rural-dwelling cancer survivors may be at risk due to decreased access to healthcare and specialty services as well as fewer support resources (Angell et al., 2003). In addition, mental health disparities have been identified with rural CSs showing poorer mental health outcomes than urban CSs (Burris & Andrykowski, 2010).

Access to oncologists in Alaska is limited to the urban areas of Anchorage and Fairbanks (ACS, 2012). Furthermore, cancer is now the leading cause of death in Alaska (State of Alaska, Public Health Statistics,

2007) and the second leading cause of death in the US (ACS, 2008).

Alaskans have a higher incidence of cancer than the US average (Siegel et al., 2012). For Alaskan CSs, anecdotal accounts have shown that travel costs are substantial and can be a financial burden for treatment and follow-up. Rural and remote areas are more extreme, with even less access if CSs do not live on the road system.

Rural-dwelling CSs may also be faced with lack of symptom management, lack of access to psychosocial interventions, isolation, and decreased coping with regard to their cancer experience, and they are particularly vulnerable to being lost in transition (Hewitt et al., 2006). One study in Australia, utilizing a national cancer registry, compared rates of survivorship between rural and urban residents to determine if there was evidence for a rural-urban differential for cancer risk. They found overall cancer survival rates to be similar; however, when they analyzed individual types of cancer, they found significantly lower cancer survival rates in rural settings when compared with urban settings in ten specific types (Wilkenson & Cameron, 2004). More recently, Singh, Miller, Hankey, and Edwards (2011) found that rural residents have a higher cancer mortality with the largest risk being for lung, colorectal, prostate, and cervical cancers.

Studies are lacking that compare QOL between rural and urban CSs, and recent studies are yielding inconsistent results. Some studies are finding poorer outcomes in rural CSs (Burris & Andrykowski, 2010; Lyons & Shelton, 2004; Weaver et al., 2012), some are finding better outcomes in rural CSs

(Schultz & Winstead-Fry, 2001), and some are showing mixed findings (DeSipio et al., 2010) or no differences (Andrykowski & Burris, 2010).

It is estimated that there are currently approximately 30,000 CSs living in Alaska (ACS, 2012). Overall mortality rates are higher in Alaska than in the US as a whole (Alaska Cancer Registry, 2008). In Oregon, cancer death rates are slightly higher than the US average (Siegel et al., 2012).

### **Gaps in Knowledge**

Most of healthcare research related to cancer has focused on the acute and treatment stages of the illness. In the literature there is a strong suggestion that more research is needed during the post-treatment stages of survivorship. According to an Institute of Medicine (IOM) report, this phase of the cancer trajectory has been relatively neglected in advocacy, education, clinical practice, and research. CSs are considered an understudied population (Hewitt et al., 2006) who may be lost in transition. Aziz and Roland (2003) provided an overview of relevant cancer survivorship research and identified the issues encountered by cancer survivors in rural communities as an area in need of research. They also emphasized the need to study the psychosocial effects of cancer among CSs in rural settings. It is currently unclear which types of interventions are most effective in the cancer survivor population. The evidence in the literature is inconclusive as to what type of intervention to develop geared toward CSs, especially in rural communities. Although there is strong evidence that traditional cancer support groups are effective in patients during the acute

phase of cancer treatment (Zabalegui, Sanchez, Sanchez, & Juando, 2005), less is known about how to effectively meet the needs of long-term CSs, especially those living in rural and frontier settings.

The present study is the first of its kind in these regions. The findings will contribute to the body of knowledge of cancer survivorship, specifically uncovering knowledge of the experiences and symptoms of urban and rural CSs. The study focuses, in part, on an underserved population: rural dwellers.

### **Study Purpose and Specific Aims**

The purpose of this descriptive and mixed methods design study is to explore the impact of cancer in rural- and urban-dwelling adult CSs living in two regions of the Pacific Northwest. A mixed methods design allows for a quantitative and qualitative exploration of the phenomenon, including comparisons within and between regions. The first phase of the study was quantitative exploration of the impact of cancer, and the second phase utilized a qualitative approach, following up on the quantitative findings obtained from Phase 1.

The specific aims for this study were as follows: (a) to explore the impact of the cancer survivorship experience and symptom experience in rural- and urban-dwelling adult CSs in two regions of the Pacific Northwest (quantitative), (b) to compare the cancer survivorship experience in rural- and urban-dwelling adult CSs within and between two regions of the Pacific Northwest (quantitative), and (c) to explore and compare the physical



(including symptoms), psychological, social, and spiritual-existential aspects of cancer survivorship in rural- and urban-dwelling adult CSs within and between two regions of the Pacific Northwest (qualitative).

The conceptual framework guiding the study design was the quality of life model applied to cancer survivors developed by Ferrell, Dow, Leigh, Ly, and Gulasekaram, (1995). It includes four domains of quality of life: (a) physical well-being and symptoms, (b) psychological well-being, (c) social well-being, and (d) spiritual well-being. The qualitative strand of the study fills a gap in the literature as there has been very little qualitative exploration of the survivorship experience. The qualitative descriptive approach was utilized. The quantitative strand of the study measured several domains of the cancer survivorship experience as identified by Zebrack, Ganz, Bernaards, Petersen, and Abraham (2006) and Crespi, Ganz, Petersen, Castillo, and Cann (2008). Aspects of survivorship measured included altruism/empathy, health awareness, meaning of cancer, positive self-evaluation, appearance concerns, body change, life interferences, worry, employment concerns, and relationship concerns. The symptom experience was also measured. All measures were compared between the urban and rural participants.

### **Significance to Nursing**

This study is congruent with one of the major priority areas for cancer survivorship research as identified by the National Cancer Institute, Office of Cancer Survivorship (OCS). The OCS supports exploratory level research

and theory-based descriptive and analytical studies that examine the physiologic, psychosocial, and economic effects of cancer and its treatment on survivors' quality of life, functioning, and health. In addition, this study fits three of the seven areas of particular interest to the OCS: (a) health disparities; (b) economic outcomes, patterns of care, and service delivery; and (c) healthy lifestyles and behaviors (US Department of Health and Human Services, National Institutes of Health, National Cancer Institute, 2007).

This study meets two of the purposes of the LAF and the Center for Disease Control and Prevention's National Action Plan for Cancer Survivorship: Advancing Public Health Strategies initiative: "minimizing preventable pain, disability, and psychosocial distress for those living with, through and beyond cancer," and "supporting cancer survivors in accessing the resources and the family, peer, and community support they need to cope with their disease" (LAF, 2004b, p. 1).

The international research priorities for cancer survivorship have been summarized by Girgis and Butow (2009) and include recommendations from the United Kingdom, the US, and Canada. Priorities identified include the development of instruments for use in survivorship research; development of effective care models and interventions; and researching the long-term effects of cancer diagnosis and treatment on patients, their families, and caregivers, and needs and characteristics of unique or disadvantaged populations.

The findings generated from this study will assist in determining if rural dwellers in Alaskan and Oregon are at risk for negative sequelae associated with their cancer experience, when compared with urban-dwelling survivors in the same region. In addition, they will inform the process of developing health promotion interventions. Findings will potentially increase access to resources for this population. The findings will also provide insight for healthcare providers caring for this population, especially primary care providers, which may include physicians, nurse practitioners, and physician's assistants. In addition, the community and mental health aides in the village settings in Alaska will benefit as they are most often providing healthcare for Alaska Native survivors who live in the remote villages of Alaska.

The findings will also be utilized by nurses, oncology practitioners, healthcare navigators, social workers, and support group/community group leaders so that they may prepare their oncology patients during the acute/treatment phase for what to anticipate in the survivorship phase as well as encouraging them to emphasize aspects of survivorship in their cancer care programs. Nurses play a critical role in identifying and managing many of the ongoing sequelae of cancer and its treatment (Curtiss, Haylock, & Hawkins, 2006). In addition, this study's results will raise awareness about the significant and unique challenges and experiences that CSs face living in urban and rural settings. It provides an opportunity to influence emerging programs as they develop within this new field of cancer survivorship. Lastly, cancer touches everyone and is not the domain of any one healthcare

discipline or practice setting; therefore, the results of this study will reach beyond nursing and into all of the disciplines that interact with cancer survivorship.

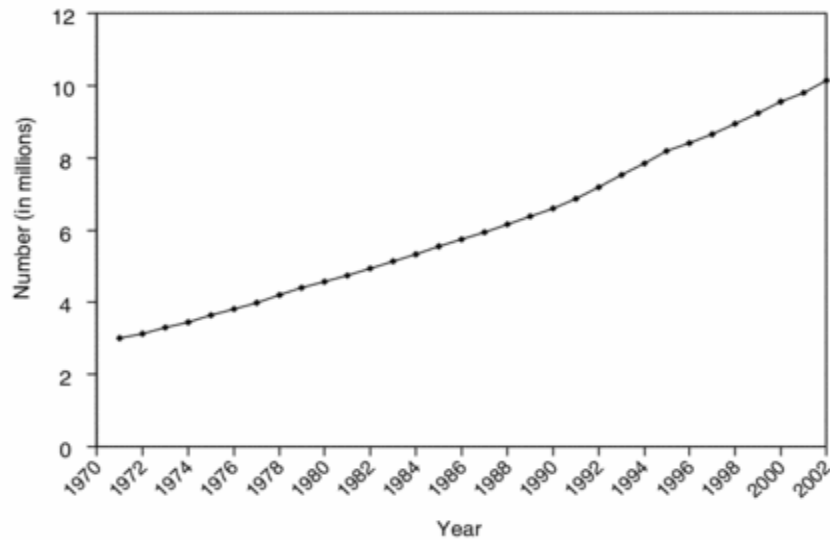
## **CHAPTER 2**

### **BACKGROUND AND SIGNIFICANCE**

#### **Overview of Cancer Survivorship**

Despite great advances in cancer care, knowledge of cancer survivorship issues and survivorship care are still emerging. With the aging and increasing US population, CS numbers are expected to increase in the future. As shown in Figure 1, the number of survivors has increased from approximately 3 million in 1970 to approximately 10 million in 2002 and is now estimated at over 12 million (ACS, 2012; National Cancer Institute, 2008). Contributing to this increase is the aging of the baby boomer generation, an increase in effective cancer screening, and improvements in treatment. Half of all men and one-third of all women in the US will develop cancer at some point in their lifetime, and the public views cancer as the most important health issue facing the nation (Hewitt et al., 2006). There has been a dramatic rise in rates of survivorship today as compared to 40 years ago, with rates increasing by as much as 50%.

The three most common sites for invasive cancer among survivors is breast cancer in women (22%), prostate cancer in men (18%), and colorectal cancer (10%). Reaching beyond the numbers, the importance of quality of life (QOL) for cancer survivors (CSs) is paramount. Cancer has



*Figure 1.* Estimated number of cancer survivors in the US from 1971 to 2002 (Hewitt et al., 2006).

recently surpassed heart disease as the leading cause of death among those under 85 years of age in the US (Hewitt et al., 2006). Those who make it through the challenge of diagnosis and treatment may continue to experience problems. Late and long-term effects persist long after the cancer leaves the body. Some people may remain cancer-free for long periods, some live with intermittent periods of active disease or persistent or progressive disease, and some continue to live after expected death (Welch-McCaffrey, Hoffman, Seigh, Loesher, & Meyskens, 1989). There is a growing group of survivors who have experienced cancer more than once (Mariotto, Rowland, Ries, Scoppa, & Feuer, 2007). These categorizations may be overlapping. All of these factors make cancer survivorship a significant public health issue.

Survivors face a multitude of issues, and healthcare is just beginning to formally address them. Survivorship as a distinct specialty is in its infancy (Feuerstein, 2007a). Conceptualizations of survivorship are still underdeveloped (Leigh, 1992), and survivorship was considered a “new movement” as recently as the early 1990s (Leigh, 1994). Historically, past perceptions of survivors as family members who were left behind from those who died from cancer has progressed to those living greater than five years post-cancer treatment (Leigh, 1994). Current accepted definitions include survivorship beginning “from the time of diagnosis and for the balance of life” (National Coalition for Cancer Survivorship-NCCS, 2013) and include the period of diagnosis and treatment, and early survivorship. This study focused on survivors who are cancer-free and who have completed primary treatment.

More exploration of experiences of life after cancer treatment is needed (Gilbert, Miller, Hollenbeck, Montie, & Wei, 2008; Tritter & Calnan, 2002). There is evidence that the needs of CSs are not being met (Wilson et al., 2000). The interrelated experiences of adverse medical, psychosocial, and economic issues faced by CSs puts them at great risk for physical and psychological morbidity (Alfano & Rowland, 2006).

Research to decrease health disparities in cancer survivors is lacking, and sources of these disparities have not been completely explained. Aspects of race and culture are poorly studied in cancer survival (Oseni & Jatoi, 2007). Consistent disparities in incidence, mortality, and

survival by race and ethnicity have been identified (Hewett et al., 2006). Minorities and rural dwellers are less likely to be represented in survivorship research (Smith et al., 2006). Rural-dwelling CSs may be particularly at risk and may experience lack of symptom management, isolation, lack of provision of psychosocial care, decreased coping, and decreased access to healthcare and specialty services; and they are particularly vulnerable to being lost in transition (Angell et al., 2003; Hewitt et al., 2006). Rural CSs are more at risk than urban counterparts for psychological distress (Koopman et al., 2003). A preliminary study conducted in Kentucky found that rural CSs experience poorer mental health outcomes than urban CSs, when adjusted for education and physical functioning. The sample included both genders and survivors of three cancer types: breast, hematologic, and colorectal. Specifically, rural CSs reported poorer mental health functioning ( $p=0.02$ ), greater symptoms of anxiety ( $p=0.01$ ) and depression ( $p=0.02$ ), greater distress ( $p=0.04$ ), and more emotional problems ( $p=0.02$ ). Furthermore, they may be displaced from their communities during cancer treatment and face many challenges when they return. Compounding these issues, their healthcare providers may not be aware of the unique needs of CSs (Grant et al., 2007).

As mentioned above, a study in Australia, utilizing a national cancer registry, compared rates of five-year survivorship between rural and urban residents to determine if there was evidence for a rural-urban differential for cancer risk. They found overall cancer survival rates to be similar; however,



when they analyzed individual types of cancer, they found significantly lower cancer survival rates in rural settings when compared with urban settings in ten specific types of cancer. Reasons for the differences were not explored as part of the study; however, some potential contributing factors were discussed such as higher smoking rates among rural populations and less access to healthcare (Wilkenson & Cameron, 2004). A literature review of the breast cancer experience of rural women found four overarching themes: “access to treatment and treatment type, medical providers and health information, psychosocial adjustment and coping, and social support and psychological support services” (Bettencourt, Schlegel, Talley, & Molix, 2007, p. 875). Some of the findings from this review included the fact that rural and urban women receive different primary treatments for breast cancer, rural women may have greater difficulty negotiating their usual gender roles during and after treatment, they want greater health-related information about breast cancer, and they have less access to psychological therapy. In fact, in eight studies reviewed, rural women were less likely to have breast-conserving surgery than urban women (Bettencourt et al., 2007). Differences in care may be due to a number of factors, which include decreased access to healthcare and specialist care, and fewer support resources (Angell et al., 2003).

In a small study situated in the mid-western region of the US, Reid-Arndt and Cox (2010) found that increased rurality was associated with lower QOL ( $p = .03$ ), lower functional well-being ( $p = .06$ ), and an increase

in breast cancer (BC) specific symptoms ( $p = .04$ ) in BC survivors within one month after completing chemotherapy. The researchers recommended studying the nuances of the rural communities that could impact these findings.

Oregon has a very high level of rurality (Oregon State University, 2007). Metropolitan areas are clustered in the western regions of the state, and the majority of the eastern part of the state is rural and/or frontier (Crandall & Weber, 2001). Rural communities are heavily impacted by the problems facing the healthcare system. Issues include traveling long distances for services, difficulties in recruiting and retaining healthcare providers, increasing poverty levels, increasing numbers of older adults, and difficulties in accessing quality healthcare (The Oregon Story, 2012)

Alaska has an extreme level of remoteness and contains much more frontier land than any other state: 31.11% as compared with its closest neighboring state, Washington, which has a rate of 1.59%. The state with the second highest percentage of frontier land is Texas with 7.42% followed by Montana at 6.26%. In contrast, California has 2.46% and Oregon has 2.25% (National Center for Frontier Communities, 2000). Limited road access and harsh weather patterns create challenges in the delivery of healthcare (GAP Report, 1995). Alaska also has a higher percentage of rural population than the rest of the US states (US Census Bureau, 2006). Cancer treatment in Alaska is often provided far from home and creates a significant disruption in people's lives.

Many healthcare services that would be considered standard care in other states are unavailable in rural and remote Alaska (GAP Report, 1995). Minimal resources and specialists are available for cancer survivors. For example, Alaska has fewer physicians per capita than most states, and oncologists are not available outside of urban centers. More specifically, 23% of CSs are survivors of breast cancer who are at risk for lymphedema. According to the National Lymphedema Network, there is only one lymphedema specialist in the state of Alaska and she is located in an urban community. In Oregon, there are three listed and two are located in urban areas (National Lymphedema Network, 2011). In a recent study of geographic access to cancer care in the US, Alaska was excluded because much of the travel is not road-based (Onega et al., 2008).

Brems & Johnson (2010) conducted a needs assessment of 309 Alaskan breast cancer survivors. One of the first studies in Alaska, this cross-sectional, descriptive study begins to uncover the needs and experiences of CSs in both urban and rural settings, with emphasis on how to improve healthcare services. While findings showed that most women were satisfied with their healthcare, a number of improvements were recommended in the areas of patient/provider communication, advocacy and policy-making, and hospital and treatment service facilities. Experiences of cancer survivors in Alaska, and the impact of cancer on their lives and health are just beginning to be explored.

Broadly defined, cancer survivorship encompasses the entire cancer continuum from the time of initial diagnosis through the remainder of the survivor's life. Specifically, it focuses on the distinct phase after completion of active or acute cancer treatment. In the post-acute treatment phase, the range of issues experienced by survivors include physical, mental, and social aspects of the experience, which can be a substantial burden (Gilber, Miller, Hollenbeck, Montie, & Wei, 2008). Survivorship care includes these issues broadly as well as monitoring for late and long-term effects related to treatment, assessment of health-related quality of life (HRQOL), and maintenance of general overall health. Screening and surveillance for recurrence of cancer and new diseases are also critical. In addition, management of the psychosocial aspects of cancer recovery and reintegration into normal daily life are issues paramount to survivors. The survivorship experience is dynamic, and its transitions create particular times of stress, such as the transition from acute treatment to long-term follow-up (Ganz, 2003). Some scientists have suggested the need to transition from a focus on cancer control to a perspective inclusive of post-treatment surveillance, recovery, and rehabilitation in order to meet the long-term needs of survivors (Gilbert et al., 2008). A greater investment is needed to learn about the management of late effects. In addition, as treatment regimens evolve, what is known about cancer survivors today may change (Hewitt et al., 2006). Many of these needs have previously gone unrecognized; are frequently unknown to the healthcare community

including those working both within and outside specific cancer specialties (Grant et al., 2007); and are poorly understood (Aziz & Rowland, 2003).

There is a need to focus on all stages of cancer survivorship, ranging from when patients are newly diagnosed to the time when they have been living cancer-free for many years (Feuerstein, 2007a). QOL research and survivorship experiences are interrelated, because both are measures of how patients treated for cancer function and experience life after treatment. Health issues that extend beyond the immediate post-treatment period and into the survivorship period have recently become more relevant and have been the focus of several advocacy groups, including the LAF and the National Coalition of Cancer Survivorship (Gilbert et al., 2008). Measures of QOL in survivorship are more developed than measures of experiences and cancer impact (Alfano & Rowland, 2006). In addition, only one published concept analysis was found in the literature, and it focused only on the implications for African American (AA) breast cancer survivors (BCS) (Farmer & Smith, 2002).

A landmark report published by the IOM provided an overview of the state of the science of cancer survivorship (Hewitt et al., 2006). The main purpose of the report was to ensure the best possible outcomes for CSs. Other purposes included (a) raising awareness of the medical, functional, and psychosocial consequences of cancer and its treatment; (b) defining quality healthcare for survivors and identifying strategies to achieve it; and (c) improving the QOL of CSs through policies to ensure access to

psychosocial services, fair employment practices, and health insurance. The report also outlines the four essential components of survivorship care: prevention, surveillance, intervention, and coordination. The recommendations from the IOM report are summarized in Table 1.

Table 1

*Institute of Medicine Recommendations*

<b>Number</b>	<b>Recommendation</b>
1	Raise awareness of the needs of cancer survivors, establish survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate care for survivors.
2	Provide a comprehensive care summary and follow-up plan (survivorship care plan) that is adequately explained to all patients completing active cancer treatment.
3	Use systematically developed evidence-based clinical practice guidelines, assessment, and screening instruments to help identify and manage late effects of cancer and its treatment.
4	Develop measures for quality of survivorship care and implement quality assurance programs to monitor and improve the care received by all cancer survivors.
5	Test models of coordinated, interdisciplinary survivorship care in diverse communities and across healthcare systems.
6	Develop comprehensive cancer control plans that include consideration of survivorship care, and promote the implementation of and improvement of existing state cancer control plans.
7	Develop and promote educational opportunities for healthcare providers to equip them to address the healthcare and QOL issues facing survivors.
8	Act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors who experience short-term and long-term limitations in the ability to work.
9	Act to ensure that all cancer survivors have access to adequate and affordable health insurance with the assistance of insurers and healthcare payers.
10	Increase funding support of survivorship research and expand mechanisms for research to influence improvements in survivorship care

Source: Summarized from Hewitt et al., 2006.

The purpose of this descriptive and mixed methods design study is to explore the impact of cancer, in rural- and urban-dwelling adult cancer survivors living in the Pacific Northwest. This study of the cancer survivorship experience in Alaska addresses 5 out of the 10 IOM recommendations. Specifically, it raises awareness of the needs of cancer survivors, determines the degree in which patients have survivorship care plans in place, identifies late effects of cancer treatment, provides a basis to educate healthcare providers, and addresses healthcare access issues with a focus on rural populations in Alaska and Oregon.

The remainder of this chapter reviews the methodological challenges in survivorship research, compares and contrasts different models of survivorship, and reviews the current literature focusing on quality of life of the cancer survivor. Additional topics pertinent to this proposal include survivorship as a chronic illness, health-related behavioral change after cancer, myths and social perceptions of cancer, survivorship issues in older adults, survivors of multiple cancers, health disparities in cancer survivorship, survivorship in Alaska Natives and American Indians, survivorship in rural settings and in Oregon and Alaska, and a description of the rural and frontier settings in the two regions.

### **Methodological Challenges in Cancer Survivorship Research**

Ganz (2003) provided a compelling argument for how and why to study cancer survivors: (a) a growing numbers of survivors, (b) late effects of treatment are not known, (c) studying later experiences will help in future

choices of primary treatments, (d) little is known about the interaction of cancer treatments and co-morbidities, and (e) the aging cancer population and the emergence of a new specialty of geriatric oncology. Ganz (2003) also described some of the methodological challenges in studying survivorship: (a) challenges in identifying survivors, (b) non-participant bias, (c) the majority of survivors do not have ongoing contact with oncology specialists as they age, (d) many different cancer sites and treatments, and, (e) treatment strategies are evolving.

Some of the additional methodological issues in this field of research include (a) inadequate representation of minorities and those of lower socioeconomic status (Angell et al., 2003; Bellizzi, Miller, Arora, & Rowland, 2007; Foley et al., 2005; Koopman et al., 2001; Lauver, Connolly-Nelson, & Vang, 2007; Lee, Schover, Partridge et al., 2006; Matthews, 2003; Pedro, 2001; Schultz, Klein, Beck, Stava, & Stellin, 2005; Tomich & Helgeson, 2002); (b) most studies are cross-sectional and do not capture the dynamic and temporal nature of the survivorship experience (Bellizzi et al., 2007; Bowman, Deimling, Smerglia, Sage, & Kahan, 2003; Foley et al., 2005; Ransom, & Pagano, 2007; Hewitt, Rowland, & Yancik, 2003; Mellon & Northouse, & Weiss, 2006; Pedro, 2001; Reid-Arndt & Cox, 2010); (c) models and instruments are in the developing stages (Alfano & Rowland 2006; Feuerstein, 2007b; Zebrack et al., 2006); (d) inconsistent measures are utilized across studies and most studies utilize self-report (Garman et al., 2003; Mathews, 2003; Stewart, 2001); (e) concern regarding survivor



bias (Ashing-Giwa et al., 2003; Braun, Mokuau, Hunt, Kaanoi, & Gotay, 2002; Foley et al., 2005; Garman, Pieper, Seo, & Cohen, 2003; Smith et al., 2006); (f) the influence of co-morbidities and aging as confounders (Garman et al., 2003; Gotay, Ransom & Pagano, 2007; Schultz et al., 2005); (g) the use of retrospective reporting, which is not always accurate (Bowman et al., 2003; Foley et al., 2005; Gil et al., 2004; Hewitt, Breen, & Devesa, 1999); and (h) treatment status is often not reported (Breaden, 1997; Burman & Weinert, 1997; Golant et al., 2003; Jim & Andersen, 2007; Matthews, 2003; Saegrov, 2005).

In terms of sampling issues, convenience sampling may not capture the diversity of survivors (Ashing-Giwa et al., 2003), and some samples mix newly diagnosed patients with survivors (Foley et al., 2005; Golant et al., 2003; Shepherd et al., 2006). There are variable inclusion and exclusion criteria across studies. Inconsistent and mixed sampling strategies make it difficult to study aspects specific to survivors and present challenges when comparing across studies.

Many studies are cancer-site specific, and many are broad and include all cancer types. Breast cancer is highly represented in this body of research. Having a site-specific or broad approach is neither a strength nor a limitation; it is a different perspective. In addition, symptoms are often not prominently featured in the research, and they may be blended with QOL measures (Ferrell et al., 1995; Foley et al., 2005; Ganz et al., 2002; Golant et al., 2003; Gotay & Pagano, 2007; Stewart et al., 2001).

In the rural cancer studies, there is little rural versus urban comparison and many of the samples have low levels of rurality that do not approach those of Alaska (Angell et al., 2003; Burman & Weinert, 1997a, 1997b; Celaya et al., 2006; Gil et al., 2004; Reid-Arndt & Cox, 2010). Few studies stated that they included rural dwellers in their samples (Matthews, 2003). Most often, if rural dwellers are included, they are not analyzed as a separate group (Braun et al., 2002; Gil et al., 2004). Several studies focusing on rural aspects were found from Australia and are discussed below.

More recently, a growing number of studies have conducted rural/urban comparisons in QOL of CSs, and results are inconsistent. Some studies are finding poorer outcomes in rural CSs (Burris & Andrykowski, 2010; Lyons & Shelton, 2004; Waldmann et al., 2007; Weaver et al., 2012), some are finding better outcomes in rural survivors (Schultz & Winstead-Fry, 2001), and some are showing mixed findings (DeSipio et al., 2010) or no differences (Andrykowski & Burris, 2010).

There is little qualitative work done in this area. Only eight qualitative studies pertaining to cancer survivorship were found in the literature (Ashing-Giwa et al., 2003; Braun et al., 2002; Breaden, 1997; Dow, Ferrell, Haberman, & Eaton, 1999; Foley et al., 2005; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Nelson, 1996; Pelusi, 1997; Wilson, Andersen, & Meischke, 2000). Additionally, only two mixed methods design

studies were found in this area of inquiry (Ferrell et al., 1995; Lauver et al., 2007).

### **Survivorship Models and Frameworks**

Currently there is no widely used, acceptable framework or model used to guide cancer survivorship. QOL is often included and is considered a key outcome (Smith et al., 2006). Models and conceptualizations described by Mullan (1985), Welch-McCaffrey et al. (1989), Ferrell et al. (1995), and Feuerstein (2007c) are discussed here as well as definitions of the cancer control continuum and a discussion of cancer trajectory definitions. A further comparison of current models and frameworks is included in Chapter 5.

Mullan (1985) is considered the first to describe cancer survivorship as a concept and his classic essay is heavily referenced in the literature. It is a poignant description of a physician's personal experience with cancer yet has profound professional recommendations, many of which are still relevant nearly 30 years later. He describes the three "seasons of survival" (p. 271): acute, extended, and permanent, each stage with its unique concerns. Acute survival begins with the cancer diagnosis, and the focus is diagnostic and treatment efforts. This stage is associated with fear and anxiety. In the extended survival phase, basic treatment has terminated and the patient goes into remission. This stage is associated with watchful waiting and is dominated by a fear of recurrence. Diminished strength and significant physical challenges are associated with this phase. Many

symptoms and effects may have started in the acute stage, but now the survivor must endure them without all of the attention from healthcare providers that is associated with the acute phase. The survivor is now coping at home, in the community, and in the workplace. The permanent survival phase is associated with a “cure”; however, the experience and its effects remain with the survivor. According to Alfano and Rowland (2006), there is worry about late effects, and being disease-free does not mean being free of the disease, a concept described by one cancer survivor as “it ain’t over when it’s over” (p. 432). Mullan further described the multifaceted aspects of survivorship:

Survival is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be a part of their immediate, and to some extent, long-term future (p. 271).

Mullan’s vision continues to be influential today and his work is enhanced by his own personal experiences as a survivor, as well as his biomedical perspective as a pediatrician. He was very influential in framing the early work of survivorship research and advocacy. In fact, Mullan is one of the founders of the National Coalition of Cancer Survivorship (NCCS).

Welch-McCaffrey et al. (1989) further conceptualized survivorship framed by potential trajectories: (a) living free of cancer for many years; (b) living long cancer-free but dying rapidly of late recurrence; (c) living cancer-free (first cancer) but developing a subsequent primary cancer; (d) living

with intermittent periods of active cancer; (e) living with persistent cancer; and (f) living after expected death. Some view breaking the experience down into stages as promoting studying isolated fragments, and that this loses sight of survivorship as a whole process (Breaden, 1997). This is a potential limitation of both the work of Mullan and Welch-McCaffrey, who each conceptualized survivorship in stages. However, it is difficult to articulate and capture the dynamic and fluid aspects of survivorship without considering stages, especially as the timeframes for cancer survivorship are evolving. Defining the stages is the challenge.

Specific patterns of survivorship have yet to emerge in the literature. Further complicating the picture is that confusing and interchanging terminology is often used referring to cancer trajectories, phases, and stages as well as the cancer continuum. The Cancer Control Continuum, as defined by the National Cancer Institute (NCI), is depicted in Figure 2. Survivorship is considered a stage in the continuum and was recently added due to the growing numbers (NCI, 2007). Within the survivorship stage, health promotion has become a rapidly expanding area of inquiry (Rowland, 2008). For the purposes of this study and consistent with the IOM report, the phase of study is the period of survivorship that “follows primary treatment and lasts until cancer recurrence or the end of life” (Hewitt et al., 2006, p. 60). See Appendix A for definitions pertinent to this study.

## THE CANCER CONTROL CONTINUUM

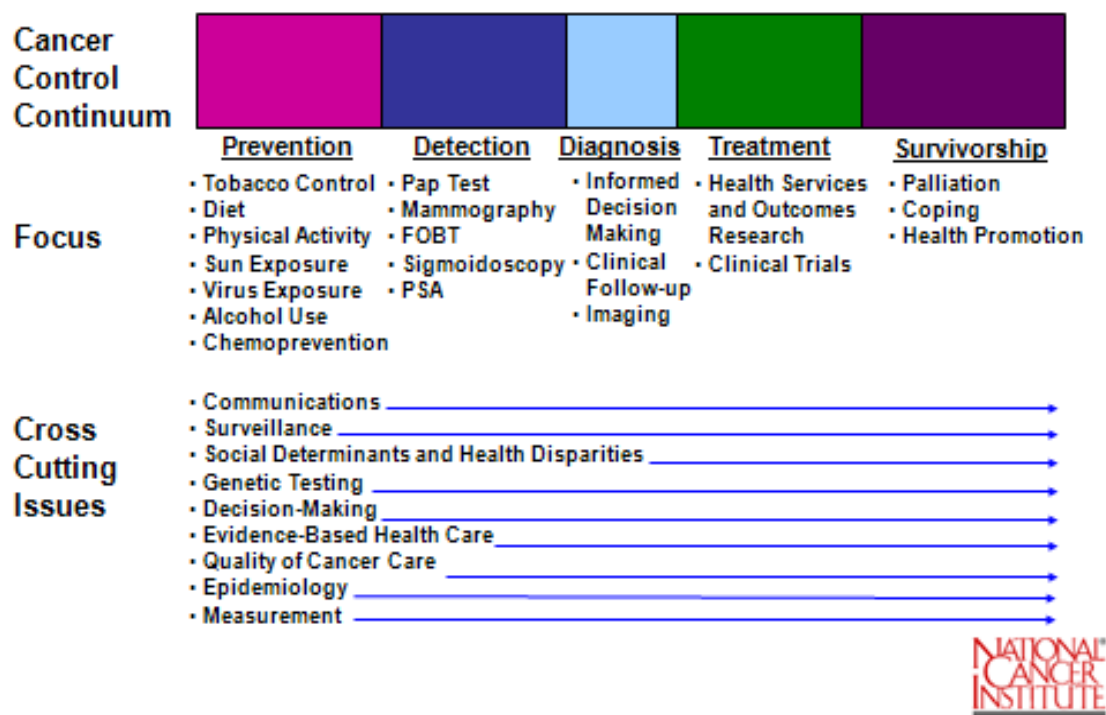
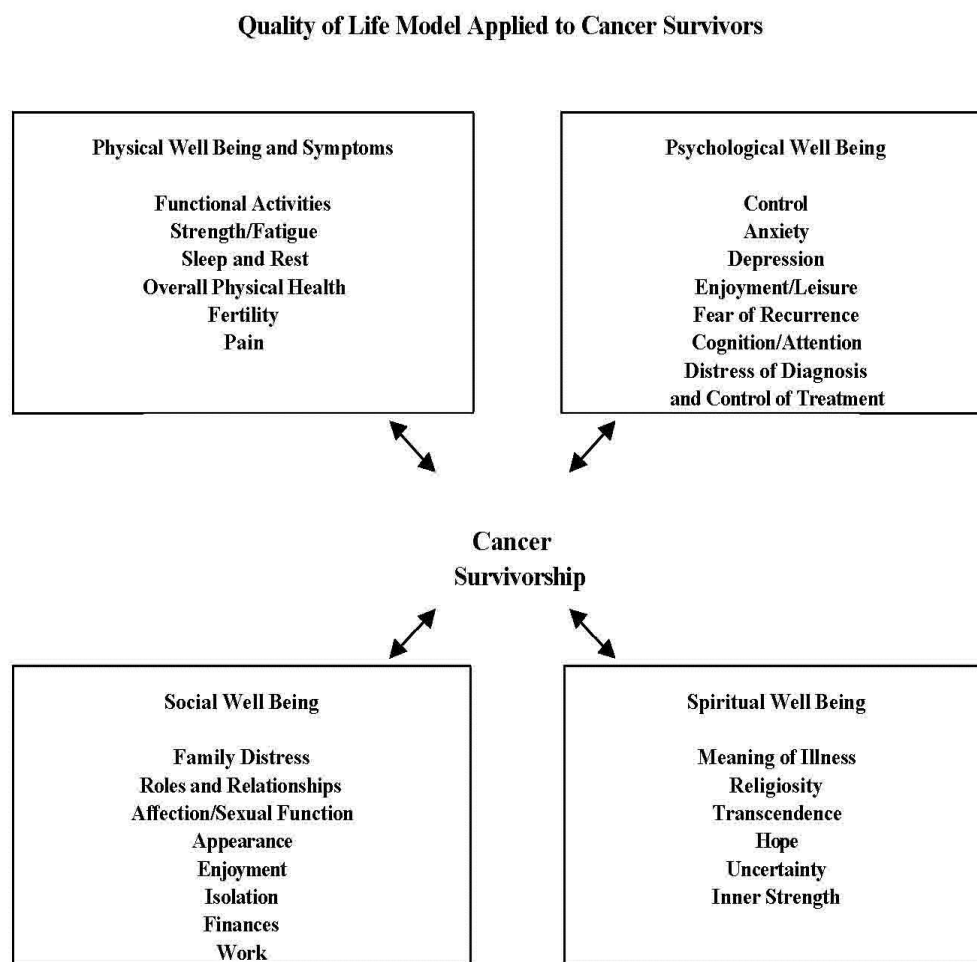


Figure 2. The Cancer Control Continuum (NCI, 2007).

Ferrell et al. (1995) developed a conceptual framework based on a QOL model applied to CSs (see Figure 3). This framework originated in research conducted in cancer pain management (Ferrell, Wisdom, & Wenzel, 1989) and later was modified based on QOL research conducted with bone marrow transplant survivors (Ferrell et al., 1992a, 1992b). The framework identifies 4 domains of QOL including physical, psychological, social and spiritual well-being, which are consistent with the predominant views of what encompasses the major dimensions of QOL in the literature. The domains are the foundation for an instrument that measures QOL in



*Figure 3. Quality of Life Model Applied to Cancer Survivors (Ferrell et al., 1995).*

cancer survivors: the Quality of Life, Cancer Survivorship (QOL-CS). This QOL framework was discussed in the IOM report, was described in a literature review (Leigh & Clark, 1998) and was used to inform several studies reviewed here (Ferrell et al., 1995; Cimprich, Ronis, & Martinez-

Romas, 2002; Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Dow et al., 1999; Stewart et al., 2001). It has been modified since the 1995 publication and is available on the Internet (City of Hope, 2006).

A limitation of the framework is that it does not include explicit cultural aspects, although it does address meaning of illness. The concepts listed under each domain do resonate with the descriptions of cancer survivorship in the literature. The domains are multi-dimensional; however, they do not capture the dynamic aspects of cancer survivorship over time. The domains are inter-related and changes in one domain can influence perceptions in another. For example, a disruption in physical well-being due to uncontrolled symptoms can affect psychological or social well-being (Ferrell & Dow, 1997). There is disagreement in the literature regarding the dimensions and attributes related to QOL; however, there is general agreement on the major domains as conceptualized in the Quality of Life as Applied to CSs framework (Hewitt et al., 2006; Pedro, 2001).

More recently, Feuerstein (2007b) has proposed an example of a stage-based framework, the biopsychosocial model of cancer survivorship, which is based on his work as a physician (see Figure 4). In his book chapter, Feuerstein (2007b) proposed an assessment of the literature, his personal experience as a cancer survivor, and his clinical stages of diagnosis, treatment, acute, sub-acute, chronic and end-stage, which are influenced by medical, sociocultural, individual, and environmental factors. He emphasizes the importance of the temporal nature of survivorship and suggests that this



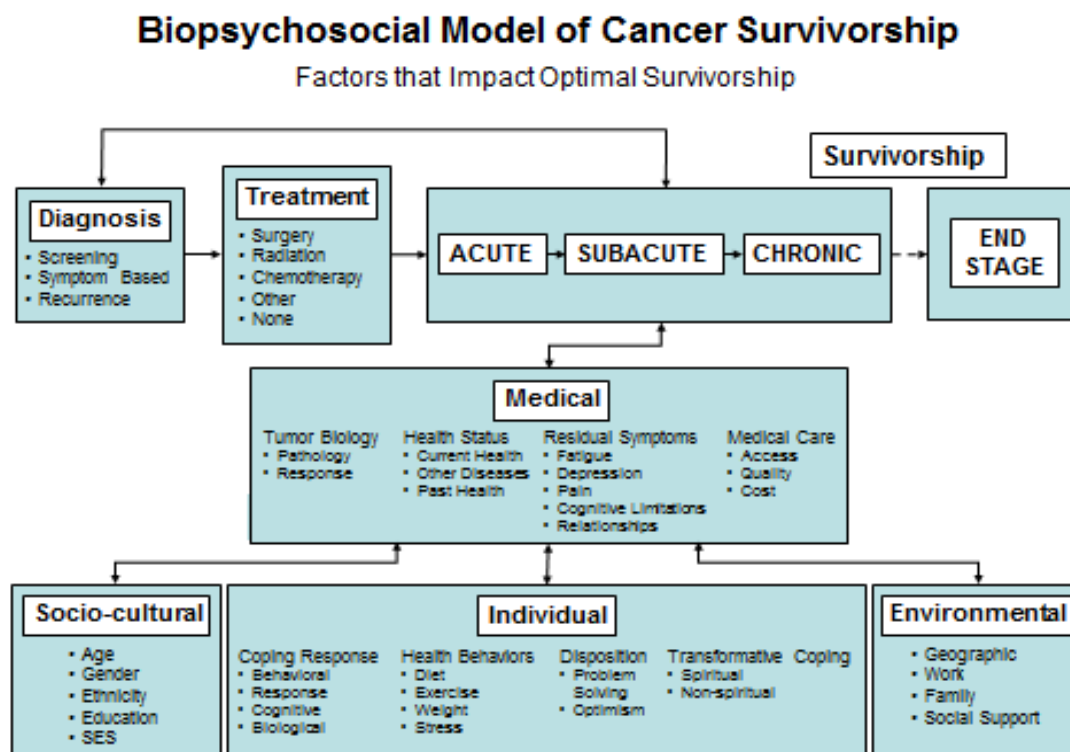


Figure 4. Biopsychosocial Model of Cancer Survivorship (Feuerstein, 2007b).

conceptual framework should be used to help organize research and thinking in this area (Feuerstein, 2007c). This framework has not yet been found in published studies. It does show promise; however, because it reflects the survivorship experience over time, in stages, is multi-dimensional and reflects the complexity of the phenomenon. It is the only framework found that identifies geographic issues which are included as a part of environmental aspects. It also includes aspects of medical care (access, quality and cost) under medical aspects.

In summary, there is no accepted, comprehensive model for cancer survivorship. Some models capture the dynamic aspects of survivorship

(Feuerstein, 2007b; Mullan, 1985) and some are relatively static (Ferrell et al., 1995). None of the models address the specific cultural aspects thoroughly and they need to be further tested in ethnic minorities. Several models and conceptualizations have been described, compared, and contrasted. There is no standardized model for cancer survivorship in the published literature. Once models utilized are consistent, further research will increase the understanding of the strengths and weaknesses of the models.

In this study, the model developed by Ferrell et al. (1995), the quality of life model applied to cancer survivors, was used to guide the inquiry. This model was chosen because it best depicts the multi-dimensional aspects of cancer survivorship, has been tested to the greatest extent, has been effectively used to design educational programs related to cancer survivorship (Grant et al., 2007), and has been used to develop instruments specific to survivorship (Ferrell et al., 1995; Zebrack et al., 2006). In addition, it is the best fit for a descriptive study of survivorship and influenced the approach to this inquiry. It provides the most in-depth analysis and description of the cancer survivorship phenomenon. Unlike other models, the spiritual aspects are well developed. The Impact of Cancer (IOC) instrument was the basis for the quantitative arm of this study and is based on the QOL model. The 4 domains of QOL were used to frame a section of this chapter as well as the interview questions for the qualitative arm of this study. This provides theoretical congruency throughout both the quantitative and qualitative arms of the study.

### **Quality of Life and the Four Domains of Survivorship**

Much of cancer survivorship research utilizes QOL measures for the outcome variable and crosses several domains. There is no consistency in QOL measures (Ferrell et al., 1995; Ganz et al., 2002, Hassey Dow, Ferrell, Haberman, & Eaton, 1999; Heidrich, Egan, Hengudomsub, & Randolph, 2006; Mellon, Northouse, & Weiss, 2006, Smith et al., 2006; Stewart et al., 2001). Some researchers have used generic QOL instruments such as the Short Form -36,(SF-36) which may not capture specific attributes unique to the cancer survivorship experience. The QOL-CS is more suitable for studying cancer survivors earlier in the survivorship trajectory, as the individual items may not be as relevant to long-term survivorship (Zebrack et al., 2006). For example, symptoms such as nausea and vomiting rarely extend into long-term survivorship. Relatively little is known about the long-term impact of cancer and there are few measurement tools that have assessed well-being and adjustment in long-term cancer survivors who are five years or more post-treatment (Zebrack et al., 2006). The Impact of Cancer (IOC) developed by Zebrack et al. (2006) attempts to measure the constructs that are unique to late survivorship. The items reflect more of a “moving forward” concept, and less emphasis is placed on diagnosis and treatment experiences, as is the case with the QOL-CS. In this study the survivorship experience was measured using the IOC.

Much of the cancer survivorship research crosses all four domains of survivorship, is multidimensional, and reflects the complexity of the survivorship

phenomenon. Ferrell et al. (1995) utilized a descriptive approach to describe the QOL of long-term survivors in a large sample that was 81% female and averaged 6.7 years since cancer diagnosis. The sample was predominantly survivors of breast cancer, lymphoma, ovarian cancer, and Hodgkin's disease. Based on a scoring of 0 (worst) and 10 (best), CSs' mean QOL subscale scores were psychological well-being (5.88), spiritual well-being (6.59), social well-being (6.62), and physical well-being (7.78). Evidence of active disease had a significant negative effect on physical well-being, female gender had a significant negative effect on physical and psychological well-being and a significant positive effect on spiritual well-being. Living with a spouse/partner had a positive significant influence on fatigue and aches and pains. Living with a spouse/partner had a negative influence on initial diagnosis distress, fear of recurrent cancer, family distress, and the importance of spiritual activities, and positive influence on life purpose. Living with children had a significant positive influence on psychological and spiritual well-being. Surviving longer than five years since diagnosis and income greater than \$40,000 had a significant positive influence across all four domains. All significance levels were  $p < 0.05$ . These investigators also found that emphasizing the positive outcomes such as hopefulness, having a purpose in life, improving personal relationships, and feeling useful, happy, and satisfied can outweigh the potential negative outcomes overall.

In a large longitudinal study of long-term BCSs, Ganz et al. (2002) measured QOL outcomes in survivors who were between one and five years

post- diagnosis, and later those who were more than five years post-diagnosis and disease-free. That study found that the survivors' emotional well-being was excellent, energy level and social functioning were unchanged, and that symptoms such as hot flashes, night sweats, vaginal discharge, and breast sensitivity were less frequent then when measured at baseline. However, symptoms of vaginal dryness and urinary incontinence were increased. Sexual activity with a partner declined significantly (from 65% to 55%,  $p = 0.001$ ) between the two assessment periods. Survivors who had received systemic adjuvant chemotherapy had lower QOL than those who did not. In a multivariate analysis, a history of receiving chemotherapy was a statistically significant predictor of a poorer current QOL ( $p = .003$ ). However, long-term, disease-free BCSs reported high levels of functioning and QOL many years after primary treatment. Quality of social support received by survivors who have received chemotherapy is an important predictor of improved QOL. The investigators suggested that psychosocial interventions aimed at social support beyond the acute phase of treatment should play a vital role in the ongoing care of BCSs.

Yabroff and colleagues (2004) focused on a large national, population-based sample, stratified by tumor site and time since diagnosis and matched with a healthy control group. In estimating the burden of illness in CSs, they found that the participants had poorer outcomes across all burden measures, had higher levels of lost productivity, and were more likely to report their health as fair or poor. CSs reported statistically significantly higher burden than the

healthy control group across tumor sites and across time since diagnoses (health utility,  $p < .001$ ; lost productivity,  $p < .001$ ; general health,  $p < .001$ ). The health decrements were found in patients many years following their reported time of cancer diagnosis. The researchers suggested a need to increase research in the area of indirect and intangible components of the cancer burden, and improved measures of long-term burden of illness and lost productivity.

Stewart et al. (2001) found that 89% of ovarian CSs regarded their health as good or excellent, but 53.5% of the total sample had current pain or discomfort. Despite the symptoms, these women reported better mental health and equivalent energy levels to the general population. However, women under the age of 55 reported a greater sense of loss about sexual function and fertility. Most women reported that their ovarian cancer experience had changed their views on life and relationships in a positive way (Stewart et al., 2001). Several studies and literature reviews show that there are both positive and negative effects of cancer (Alfano & Rowland, 2006; Bellizzi & Blank, 2007; Ferrell et al., 1995; LAF, 2004a; Pelusi, 1997; Stewart et al., 2001; Tomich & Helgeson, 2002, 2004; Wilson et al., 2000; Zebrack et al., 2006). Survivors have reported a renewed enthusiasm with their approach to life, life outlook changes, reprioritization of values, growth in self-confidence, and strengthened spirituality (Zebrack, 2000). In addition, many CSs make positive changes in their health habits (Alfano & Rowland, 2006).

In a sample of 307 adult CSs recruited from a community cancer center, Schlairet, Heedon, and Griffis (2010) found that the most frequently experienced needs were fatigue (83%), fear of recurrence (78%), and sleep disturbance (75%). In a small phenomenological study, Pelusi (1997) uncovered nine themes related to surviving breast cancer: a future of uncertainty, abandonment, sanctuaries along the way, self-transcendence, finding resolution to the financial cost of cancer, mediating expectations of others, survivors' lifelines, circle of influences, and the journey. BC is an experience of facing the unknown and experiencing many losses. At the same time, this journey evolves into one of growth and enlightenment, providing the woman with many unexpected and new opportunities. In searching for the meaning of the journey (which changes over time), one grows and finds comfort and challenges in the midst of uncertainty. The journey affects not only the women themselves but also those around them. The researcher asserted that survivorship must be viewed less as a period of acute symptoms and more as a dynamic, life-long process (Pelusi, 1997). This is consistent with the recommendations of Breaden (1997), who suggested that if survivorship is studied in fragments, it is possible to lose sight of the whole process.

Numerous interventions have been tested to improve symptom management and QOL in survivors. In a small pilot interventional study, Golant and colleagues (2003) developed an intervention based on an empowerment model. The intervention was designed to foster optimal symptom management and was proposed to improve psychological and physical functioning through

the proactive integration of medicine with mind and body techniques. The study was conducted on a mixed sample of survivors and cancer patients (varying sites) during the acute phase and also included caregivers. The intervention was implemented through an educational conference and emphasized mind-body techniques. Psychometrics were measured the day of the intervention and subsequently 30 days later. From baseline to follow-up, patients reported significant decreases in depressive symptoms ( $p < 0.05$ ) and problems with work ( $p < 0.01$ ). Some improvement in health and well-being were greater for those who had not experienced fever or infection, those without children, and those who were working. A limitation of this study is that it didn't provide information on sample demographics such as where the patients were at in their cancer treatment regimen. Additional factors were not identified and accounted for that could have impacted the outcomes in the study, such as completing cancer treatment. With regard to working, findings from this study were consistent with several studies that suggest that QOL is improved when survivors continue to work or is lower when they do not work (Bowen et al., 2007; Golant et al., 2003; Schultz et al., 2005).

The lack of standardization of measures and criteria for samples makes it difficult to compare across studies. This problem has been recognized by the ACS, and researchers are incorporating longitudinal and cross-sectional methods in three large studies that are currently underway. The longitudinal design will study survivors as they move through the continuum of survivorship. The study design will survey at the points of two, seven, and



twelve years post-diagnosis to identify predictors of QOL (Smith et al., 2006). These studies are utilizing multiple measures of QOL: the SF-36, the Satisfaction with Life Domains Scale - Cancer, the Cancer Problems in Living Scale, and the Modified Rotterdam Symptom Checklist.

In summary, the survivorship literature focusing on overall QOL indicates that CSs continue to have multiple symptoms that are bothersome, experience positive and negative aspects, and may view themselves as healthy despite their challenges. In addition, more interventions are needed to improve QOL and symptom management. Findings support the need to focus on symptoms in survivorship research and suggest that decreasing the symptom burden should have a positive effect on QOL.

### **Physical Well-Being and Symptoms**

Several studies show that the symptom experience is an issue for survivors. A descriptive cross-sectional study in Norway studied health and QOL in persons with cancer and compared these data with a sample that had not been diagnosed with cancer. Self-reporting on the SF-36, participants reported feeling drained of energy long after their cancer treatment ended, when compared with the population as a whole. Across age groups and cancer sites, mean scores for SF-36 were lower in 31 out of 40 subgroups (Saegrov, 2005). Despite enjoying good physical, psychological, social, and spiritual health, many survivors still reported bothersome symptoms.

Janz et al. (2007) studied the symptom experience and QOL of women following treatment for BC in a descriptive cross-sectional study. The mean

number of symptoms reported was 6.8, with the five most common being systemic therapy side effects (87.7%), fatigue (81.7%), breast symptoms (72.1%), sleep disturbance (57.1%), and arm symptoms (87.7%). Younger age and poorer health status at diagnosis were associated with a worse symptom experience. Fatigue had the greatest impact on QOL, and higher levels of fatigue were associated with a substantial reduction in QOL across multiple domains.

In CSs more than five years post-treatment, Schultz, Beck, Stava, and Vassilopoulou-Sellin (2003) found that the most common health effects were arthritis/osteoporosis (26% of respondents). Survivors of Hodgkin's disease reported that 33.8% had thyroid and lung problems. Prior history of lymphoma was associated with frequent mention of memory loss (14.7%). This group of survivors reported generally good health but outlined multiple lasting medical problems.

In a study of long-term BCSs, the purpose was to describe the relationship between menopausal symptoms, physiological health effects of cancer treatment, and the physical contributors to QOL. In this cross-sectional, descriptive study, 69% reported hot flashes as a problem (similar to other studies), 40% had osteoporosis, 63% had painful intercourse, 87% reported an inability to concentrate, 93% reported fatigue (39% reported severe fatigue), 90% reported problems with sleep, 34% reported lymphedema (slightly higher than other studies), and 53% reported that they were unhappy about how things turned out for them. Survivors who were most unhappy were also more likely to

perceive cancer as having an overall effect on their health. Symptoms of breast cancer and menopause may be similar and are difficult to sort out (Schultz et al., 2005).

Kornblith and colleagues (2003) studied survivors 20 years after adjuvant chemotherapy for breast cancer. Utilizing phone interview and a descriptive, cross-sectional design, only 1-6% reported conditioned nausea and vomiting, 29% reported sexual problems attributed to their cancer, 39% reported lymphedema, and 33% reported persistent numbness. This is similar to the findings of Schultz et al. (2005).

### **Physical Activity**

There is growing evidence to support the hypothesis that some cancer rates are increasing due to increased weight and decreased physical activity. While incidence of the most four common cancers (lung, colorectal, breast, and prostate) has decreased, cancers associated with excess weight have increased (pancreas, kidney, and esophagus). Excess weight is a concern for decreased quality of life in CSs and may worsen prognosis for several cancers (Eheman et al., 2012).

Schmitz et al. (2005) conducted a meta-analysis research of controlled physical activity in CSs. They found that physical activity improves cardio-respiratory fitness during and after cancer treatment, improves symptoms and physiological effects during treatment, and vigor post-treatment. Physical activity is generally well tolerated by CSs, but the literature did not allow conclusions to be drawn regarding adverse events from exercising. More studies are needed to

establish definitive guidelines for physical activity and to identify the positive effects on CSs.

More recently, Cramp and Daniel (2008) conducted a systematic review of exercise for the management of cancer-related fatigue in adults. The objective was to evaluate the effect of exercise on cancer-related fatigue both during and after cancer treatment. The review included 28 randomized controlled trials and a total of 2083 participants; however, only six of the studies covered the survivorship period, and only two were conducted in long-term CSs. There were several methodological issues identified, including low statistical power, inconsistent measures, lack of variety of types of cancer in the samples, systematic bias effecting control groups, and interventions being too short. The review suggested that exercise appears to have some benefit in decreasing fatigue, both during and after cancer treatment and should be considered as a management strategy. Further work is needed to determine the most effective specific exercise regimens (type of exercise, length and frequency of sessions, and the level of intensity). Stevinson et al. (2009) studied the associations between physical activity and health-related outcomes in 357 ovarian CSs and focused on the dose-response relationship. Ovarian CSs who were meeting guidelines for physical activity were found to have improved outcomes of fatigue ( $p < 0.001$ ), peripheral neuropathy ( $p < 0.001$ ), sleep dysfunction ( $p < 0.001$ ), and psychosocial functioning ( $p < 0.001$ ). More studies with long-term follow-up are needed, and a range of types of cancer and disease stages need to be studied (Cramp & Daniel, 2008).

## **Specific Symptom Review and Summary**

In this next section, the most common physical symptoms experienced by cancer survivors are briefly reviewed and summarized. It is important to note that symptoms vary according to populations at risk, the cause of the symptom, and the level of knowledge and research base on assessing, preventing, and managing the symptom (Nail, 2001).

**Fatigue.** Fatigue is one of the most pervasive and debilitating lingering effects of cancer and may persist several years post-diagnosis and treatment (Lawrence et al., 2004). Varying rates of fatigue prevalence in CSs are reported in the literature; 17-56% (Lawrence et al., 2004), 19-82% (Prue, Rankin, Allen, Gracey, & Cramp, 2006), and 76-99% (Ng, Alt, & Gore, 2007). It is a significant problem for over one-third of BCSs, five to seven years post-diagnosis, and is predicted by depression, cardiovascular problems, and treatment with both chemotherapy and radiation (Alfano & Rowland, 2006). Cancer-related fatigue is differentiated from exercise-induced fatigue in that it is of greater magnitude and persistence, it remains after periods of rest, and it is more severe and distressing than exercise-induced fatigue. It is multidimensional, can include behavioral and physical dimensions (Ng et al., 2007) and is seen in all age groups (Nail, 2004). Receiving a bone marrow or stem cell transplant is a risk factor for persistent fatigue. Causes of treatment-related fatigue include anemia, infection, declines in hormones, muscle mass loss/physical de-conditioning, cytokine release, and sleep disruption. Fatigue is a major contributor to QOL and its effects extend to the family, particularly for long-term survivors of bone marrow transplant, as

fatigue can persist and interfere with their abilities to assume pretreatment roles in family care, work, and the community (Nail, 2004).

Historically, fatigue has been underappreciated by the medical community, even though the vast majority of cancer survivors experience this symptom (Ng et al., 2007). Reinertsen and colleagues (2010) found that BCSs from Norway may experience fatigue up to 10 years after multimodal breast cancer treatment, and the authors estimated that 33% have chronic fatigue and 25% have persistent fatigue. They found that current psychological distress ( $p < 0.001$ ), discomfort in the treatment area ( $p < 0.001$ ), and high body mass index ( $p < 0.001$ ) were associated with chronic fatigue and also predicted persistent fatigue.

Physical activity is one of the most promising interventions to address this symptom (Alfano & Rowland, 2006) although the reasons for this, particularly for cancer treatment-related fatigue, are unclear (Woods et al., 2008). Other interventions being investigated include psychosocial interventions and the use of stimulant medications. Longitudinal studies are needed to examine the time course of fatigue in CSs (Lawrence, Kupelnick, Mill, Devine, & Lau, 2004), and more study is needed on the relationship between fatigue and other symptoms (Nail, 2004).

**Pain.** Pain is very common in advanced and metastatic disease; however, it is also common in cancer survivors without evidence of disease and may be due to incisional pain, paresthesia, edema, and phantom limb sensations (Ferrell & Dow, 1997). Post-treatment pain syndromes may be caused by chemotherapy, radiation therapy, or surgery. One common example is painful peripheral

neuropathy due to common chemotherapy drugs (Burton, Fanciullo, Beasley, & Fisch, 2007). While not highly recognized in the cancer survivorship research, clinical experience suggests that pain in CSs can be as debilitating as it is in cancer patients experiencing treatment. Studies may not focus specifically on pain; however, studies in various groups of CSs have shown relationships between pain and decreased QOL, decreased function, as well as other symptoms. Pain syndromes may vary by cancer site and type of treatment. Patients who are younger, have lower socioeconomic status (SES), and are within five years after primary treatment are at increased risk for experiencing pain (Chang & Sekine, 2007). It is estimated that the prevalence of chronic pain in BSCs is 50% (Burton et al., 2007).

### **Infertility Issues**

Of CSs, 5% are in their primary reproductive years (Hewitt et al., 2006). CSs treated as young adults are likely to have concerns about infertility. In survivors treated for Hodgkin's disease, testicular cancer, and patients experiencing bone marrow transplant, there is a link to increased distress related to infertility (Alfano & Rowland, 2006). Infertility-related distress may be experienced by CSs who were childless before cancer; who have poor sexual self-image, body image, or self-worth; who received chemotherapy with retroperitoneal lymphadenectomy; and those of lower SES. In addition, systemic treatments for cancer can also contribute to sexual dysfunction (Ronson & Body, 2002). Recent attention has been paid to this issue, and guidelines for fertility preservation have been developed by the American Society of Clinical Oncology

(ASCO). It is recommended that oncologists discuss the possibility of infertility as a risk of cancer treatment as early as possible (Lee, Cohen & Edgar, et al., 2006).

## **Psychological Well-Being**

### **Cognitive Dysfunction**

Problems with cognition can extend beyond the acute treatment period. Commonly referred to as “chemo brain” or “chemo fog” (Alfano & Rowland, 2006, p. 433), decline in cognitive performance has been associated with direct treatment to the brain as well as the administration of high doses of chemotherapy. Symptoms are generally subtle and not detected by common screening methods. Patients may experience problems with concentration, short-term memory, and problem-solving. Studies have shown impairments in verbal and complex information processing, concentration, and visual memory (Nail, 2001). A certain subset of patients receiving chemotherapy may be at risk or more vulnerable to the neuropsychological or cognitive effects of chemotherapy.

Other factors that may be associated with neuropsychological impairment include depression, anxiety, fatigue, sleep disturbance, and estrogen levels. An accurate picture of the etiological causes of cognitive dysfunction in this population is yet to be developed. Interventions are currently being tested in CSs and include cognitive remediation and cognitive behavioral management (Ferguson, Riggs, Ahles, & Saykin, 2007).



## **Psychological Distress and Post-Traumatic Stress Disorder**

Psychological distress is a common challenge for CSs with prevalence rates ranging from 5-50% (Kornblith & Ligibel, 2003). As many as 30% of BCSs will experience persistent psychosocial distress (Hewitt et al., 2006).

Psychological distress in CSs often stems from multiple sources: fear of recurrence with accompanying dysfunction, dependency, facing a possible early death or possible disfigurement, fears of abandonment by family and friends if the disease progresses, emotional disturbance triggered by stimuli that remind them of their cancer experience, cancer-related sexual problems, long-term medical sequelae, and cancer-related insurance and employment problems (Kornblith & Ligibel, 2003).

Post-traumatic stress disorder (PTSD), a qualitatively different type of distress, is also common among cancer survivors with prevalence ranging from 5-38% (Amir & Ramati, 2002; Deimling, Kahan, Bowman, & Schaefer, 2002; Hampton & Frombach, 2000; Hodgkinson et al., 2006; Jacobsen et al., 2002; Kangas, Henry, & Bryant, 2005; Kornblith et al., 2003; Kwekkeboom & Seng, 2002; Mundy et al., 2000; Palmer, Kagee, Coyne, & DeMichele, 2004). Related symptoms are numerous, such as depression, anxiety (Hodgkinson et al., 2007), and acute stress disorder (Kangas et al., 2005). PTSD is also associated with diminished physical, mental, and social functioning and decreased QOL (Hampton & Frombach, 2000); and it may negatively impact the survivor's follow-up care (Kwekkeboom & Seng, 2002). In addition, longer survivorship periods are not necessarily associated with reduced distress (Hodgkinson et al., 2006).

In one study focusing on older CSs, the strongest predictor of both depression and hyperarousal associated with distress was current cancer-related symptoms. Individuals who continue to experience sequelae of cancer are more likely to be depressed and have problems such as impaired concentration or sleep disturbance. Cancer survivors are known to be vigilant and have a heightened monitoring of symptoms (Deimling et al., 2002). At what point does this increased vigilance become distress for the survivor? In contrast to the findings of Hodgkinson et al. (2006), Nezu and Nezu (2007) reported in a literature review that the symptoms of distress appear to dissipate over time, as fear of recurrence diminishes.

According to Vachon (2006), only 10% of cancer survivors receive any psychotherapy, despite the prevalence of psychological distress, and there are no strong recommendations about the effectiveness of psychosocial interventions for cancer patients. In the cancer survivorship PTSD research, there is considerable variability in stage of illness, survivorship, and type of cancer (Smith, Redd, Payse, & Vogl, 1999). It is also thought that PTSD may be under-represented in cancer survivor studies because of the tendency for people with PTSD to exhibit avoidance behavior (Jacobsen et al., 2002).

Certain groups of CSs are at risk for psychological distress or PTSD. Some groups include women (Jacobsen et al., 2005), younger adults, Whites (Bowman et al., 2003), lung cancer patients (Zabora et al., 2001), rural CSs (Koopman et al., 2001), and CSs with lower SES, income, and educational status (Kangas, Henry, & Bryant, 2002). Also associated are greater fear of recurrence

(Black & White, 2005), the belief that diagnosis and treatment causes greater family distress (Bowman et al., 2003), high perceived intensity of treatment (Hampton & Frombach, 2000), and negative appraisals (Bowman et al., 2003). CSs with prolonged physical sequelae, such as lymphedema or numbness, and reduced physical functioning have worse psychological adjustment when compared with survivors who do not have physical sequelae (Kornblith & Ligibel, 2003). CSs with high avoidance and low social support (Jacobsen et al., 2002) and poor social functioning (Kangas et al., 2002) as well as those with greater dissatisfaction with medical care are at risk (Kornblith et al., 2003).

Protective factors include emotionally supportive relationships, strong social support; active coping strategies such as problem-solving, positive reappraisal, and emotional expression (Stanton, 2006); and being post-menopausal (Bowman et al., 2003). While there has been a growing number of research studies conducted in cancer survivors focusing on PTSD, empirically based guidelines specific for PTSD and cancer are lacking (Kangas et al., 2002).

### **Depression**

Estimates of the prevalence of depression in CSs range from 0% to 38% for major depression and from 0% to 58% for depression spectrum syndromes. Rates may vary among cancer sites (Alfano & Rowland, 2006). Even when the most stringent criteria are utilized, 5% to 15% of patients with cancer meet the criteria for major depression and another 10% to 15% present with less severe depression symptoms. One of the challenges is that symptoms related to responding to cancer treatment may overlap with the symptoms of depression.

The Beck Depression Inventory for Primary Care and the depression subscale of the Hospital Anxiety and Depression Scale are suggested for clinical use as they demonstrate acceptable internal consistencies (Vachon, 2006). A major challenge is that self-report instruments are unable to diagnose depression, and instead provide information related to the severity of the depressive symptoms. Another limitation in the depression studies is that structured clinical interviews have historically been the gold standard for diagnosing depression, yet the interview strategy may not be used in the studies (Nezu & Nezu, 2007).

A higher level of physical disability, advanced disease, experiencing pain, and certain treatments/medications are factors associated with a greater prevalence of depression. Risks for depression include pre-morbid coping skills, social isolation, close family members with a history of cancer and depression, a personal history of depression, a personal history of substance abuse, and socioeconomic pressures (Nezu & Nezu, 2007). Compounding the concern with depression is that it is progressive in nature and has been associated with decreased cancer survivorship. The importance of early diagnosis and treatment is paramount (Vachon, 2006).

### **Stress and Coping**

Lauver and colleagues (2007) studied the stressors experienced and the coping strategies used by women CSs at the end of cancer treatment, using a descriptive, mixed methods and longitudinal design with open-ended interviewing. Their results showed that the primary stressors at the end of treatment included feelings of uncertainty about treatment, follow-up, symptoms,

physical concerns, difficulty concentrating, attitudes about body, and dealing with mortality. Participants used acceptance, religion, and distraction as primary coping strategies, and the number of stressors experienced decreased over the four-month period post-treatment.

### **Social Well-Being**

Hewitt, Breen, and Devesa (1999) explored the composition of the CS population as well as the social implications of a cancer diagnosis in a nationally representative sample of over 1,500 self-identified CSs. Data were analyzed from the 1992 National Health Interview Survey (NHIS) and some of the characteristics of the CS population included the following: (a) the most common type of cancer was female reproductive (27.8%) followed by female breast cancer (20.4%), prostate and male reproductive organ cancers (9.5%) and colorectal cancer (9.1%); (b) there were more CSs that were women (69.8%); (c) nearly half (46.2%) were age 65 or older; (d) 76.4% were first diagnosed with cancer at age 35 or older and the majority (52.4%) were diagnosed at ages 35-64; (e) most CSs had lived five or more years post-diagnosis (63.3%) and 9.9% have been CSs for more than 25 years. They found that 55.7% had obtained a second opinion, 58% had received patient education materials from a healthcare provider, only 14.2% had received counseling or participated in a support group, and only 5% reported participating in research studies. Information about the makeup of this population, medical care experiences, and social implications is just beginning to be explored.

## **Employment and Economic Impact**

Over one-third of CSs are working age (Hewitt et al., 2006). According to Hewitt et al. (1999), 10.7% of CSs had been denied health or life insurance coverage because of their cancer, and 18.2% of those who continued to work experienced employment problems due to their cancer. In addition, 4% were either fired or laid off due to their cancer. Working survivors may experience what is known as “job lock,” which is the inability to change jobs because of a fear of loss of health insurance or due to privacy issues. Survivors may stay in a job that they do not like due to fear of losing employment and benefits (Alfano & Rowland, 2006; Bradley & Bednarek, 2002). There are positive and negative aspects of the employment and economic situation for survivors portrayed in the literature. Recent studies show that the majority of employment age survivors continue to work (> 62%), and they may work more hours and have higher earnings than their non-cancer colleagues. This picture is more encouraging and is being impacted by increased numbers of survivors, increased survival rates, the increase in people working beyond age 65, and lack of mandatory retirement (Main et al., 2005). In addition, several federal laws have been implemented to provide CSs with some protection against employment discrimination. These include the Americans with Disabilities Act, the Family and Medical Leave Act, the Employee Retirement and Income Security Act, and the Federal Rehabilitation Act.

In contrast, Bradley, Bednarek and Neumark (2002), in a descriptive study comparing BCSs with non-survivor controls, found that overall, breast cancer has

a negative impact on employment. Survivors were employed less (53.8%) than women without breast cancer (64.18%) ( $p < 0.01$ ).

It is reported that inadequate reimbursement for cancer care results in an increased economic burden for cancer patients and their families (Alfano & Rowland, 2006). Cancer care is very costly and is one of the three most expensive diagnoses in the US. In addition, as many as one in five cancer patients who are working at the time of diagnosis are unable to work one to five years later from cancer-related limitations. Those with jobs that require physical labor are more likely to have difficulties returning to work after cancer treatments. Furthermore, half of those with limitations are unable to work at all. Compounding this, the uninsured often do not receive the care that they need, have poorer health, and are more likely to die than the insured (Hewitt et al., 2006). High-income CSs also enjoy better QOL (Short & Mallonee, 2006).

In a large matched control study of adult survivors (Yabroff et al., 2004), CSs were less likely than control subjects to have had a job in the past month, were more likely to be unable to work because of health, and had lost more days of work in the last 12 months (all  $p < .001$ ). Unfortunately, for a subset of CSs, an estimated 16.8% of working-age survivors are unable to work because of a physical, mental, or emotional problem. In addition, 7.4% of those who are able to work are limited in the kind or amount of work they can do. This sample consisted of 24% younger than age 50, 25% between the ages of 50-64, and 50% aged 65 or older. Given that this is an older sample, the findings may not

reflect the experiences of younger adults and those in the earlier years of their work life (Yabroff et al., 2004).

In a cross-sectional descriptive study of long-term CSs between the ages of 35 and 75, 65% were employed five to seven years after their initial diagnosis. Reasons for stopping employment included retiring (54%), poor health or disability (24%), quit (4%), or other reasons (9%). Of those working, participants identified that between 11% and 26% of the time, they perceived that cancer interfered with tasks at work. This study stratified by gender, marriage, and cancer site, however, did not stratify between age groups. Overall, 84% of the employed long term survivors worked full time. Of the respondents, 33% employed prior to their cancer diagnosis were no longer employed. The majority of them had retired; however, 50% indicated that their retirement was not related to their cancer. The researchers concluded that the employment opportunities for cancer survivors seem optimistic and speculated that some of the myths regarding the cost of cancer and impact on the workplace may be beginning to be dispelled (Bradley & Bednarek, 2002).

Mody et al. (2008) studied childhood survivors of acute lymphoblastic leukemia and compared them with the general population. At the more than 20-year follow-up, and in survivors between the age of 25 and 49, rates of marriage, college graduation, employment, and health insurance were all lower when compared with sibling controls ( $p < .001$ ). The survivor age group of 25-44 is less likely to have health insurance (Hewitt et al., 2006).



In a retrospective study with a large sample of adult CSs, Short and colleagues (2005) found that a greater percentage (75%) quit working after the first year when they had stopped working during treatment and returned, then when they continued to work throughout treatment (50%). They also concluded that survivors of central nervous system, head and neck, and stage IV blood and lymph cancers had the highest risk of either quitting work or going on disability.

In summary, negative impacts on economics, earnings, health insurance, and work experiences have been described in the literature. These studies have shown that negative factors can reduce employment (some due to physical disability). Employment is impacted by lack of control over schedules, need for transportation, and discrimination on the part of employers. In contrast, the alternative view of a more positive status of employment and economics is also portrayed. Some of the findings in these studies include CSs working more hours and earning higher wages, and the studies show that the overall impact of cancer on employment status is not as severe as once thought. Perhaps a change in this picture has been influenced by several new laws implemented in recent years that are designed to protect and advocate for CSs (Hewitt et al., 2006). In addition, two recommendations in the IOM report are related to employment and health insurance (see Table 1), which may influence positive economic and employment outcomes. In terms of methodology, many of these studies do not compare with control groups, do not use national samples, and may not control for correlates that can influence employment. Future longitudinal research is needed in this area as well (Bradley et al., 2002).

## Family Caregivers

Research on family caregivers (CG) has, like other aspects of cancer, mainly focused on the acute treatment phase of cancer. Family CGs of survivors have been shown to have lower QOL ( $p = 0.03$ ), higher fear of recurrence ( $p = 0.001$ ), lower social support ( $p = 0.02$ ), and lower family hardiness ( $p = 0.002$ ) than the survivors that they care for (Mellon et al., 2006). Mellon and colleagues (2006) defined family CG/significant other as someone whom the survivor identified as having been through the cancer experience with him or her and who had been his or her main source of support. CGs were self-selected by the survivors. In this descriptive study, female CGs reported the lowest QOL of all the groups when compared with male and female survivors and male CGs (Mellon et al., 2006).

Mathews (2003) compared CSs and their CGs in terms of role and gender differences in cancer-related distress. Sampling strategies were similar to Mellon et al. (2006) as the CS was asked to identify his or her CG. Congruent with Mellon et al. (2006), CG means on overall psychological distress were significantly higher than those shown for survivors ( $p < 0.012$ ). Mathews' study suggested that gender-specific, dyad-tailored cancer support services are needed. Mathews, Baker, and Spillers (2003) in another article described the demographics of the CGs in the same study. Most of the CGs were spouses (68%), with 44% being husbands and 24% wives. Other CG relationships included mothers (7%), adult children (7%), friends (5%), siblings/other (8%), and partners (7%). The role of "informal cancer care" (p. 2557) is described by Kim

and Given (2008) and includes multidimensional aspects such as treatment monitoring, symptom management, emotional financial and spiritual support, and assistance with personal and instrumental care.

Kim and Given (2008) conducted a literature review focusing on the QOL of family CGs across the trajectory of cancer and survivorship. They found that the QOL of family CGs varied along the illness trajectory. Specifically for the middle to long-term phase of survivorship, associated with remission, there are few family-based interventions developed with demonstrated efficacy. Some interventions that have been studied include a problem-solving skills intervention and an intervention aimed at improving psychosocial function in CGs who were older adults. The researchers concluded that little research in this area is theoretically and methodologically rigorous, and that family-based interventions across the trajectory are needed.

Caring for the caregiver remains a challenge, not only in cancer care-giving, but across other chronic and acute illnesses. In a recent review of the general care-giving literature, several unresolved issues and gaps have been identified including when and how support is best provided, what the intended goals are, as well as who the perceived beneficiary is. Another gap identified is that there is little evidence of the effectiveness of this activity. More optimistically, there is a growing body of evidence that show positive and rewarding aspects to care-giving, including fostering enhanced relationships, increased social esteem, and a sense of personal satisfaction and moral fulfillment (Payne, 2007).

## **Life Developmental Stage**

Another important aspect to survivorship that influences QOL is the life developmental stage of the survivor (Leigh & Clark, 1998). Within each adult life stage, individuals encounter unique physical, psychological, psychosexual, and social tasks. This has been recognized as a significant factor in children and very young adults (Cimprich et al., 2002). The needs and experiences of a young adult survivor with small children is likely to be very different from a survivor who is approaching retirement. Those in college or starting a new career are going to have unique challenges. Lazarus and Folkman (1984) hypothesized that certain events, such as a cancer diagnosis, are considered “off time” (p. 116) and that they may be more stressful and traumatic since they are unexpected.

In one of the few studies that addresses a life-stage perspective, Cimprich and colleagues (2002) studied age at diagnosis and QOL in BCSs who were more than five years post-diagnosis. In that descriptive study, they found that long-term survivors of BC who were diagnosed at an older age ( $> 65$ ) showed significantly worse QOL outcomes in the physical domain ( $p < 0.05$ ). Those who were diagnosed at a younger age (27-44) showed worse QOL outcomes in the social domain than the other age groups ( $p < 0.03$ ). Additionally, there is evidence that CSs report difficulty integrating back into society and their previous roles (Leigh & Clark, 1998; Yabroff et al., 2004).

Foley and colleagues (2005) studied the meanings ascribed to the cancer experience through semi-structured interviews of 58 long-term CSs who had experienced cancer at various sites. Through systematic content analysis,

themes were identified as personal growth, that's life, relinquishing control, and resentment, and they were then analyzed by cancer type, gender, and age. Older survivors were more likely to be classified as *that's life*, and younger survivors as *personal growth*. Older CSs had difficulty differentiating between the late effects of cancer and treatment, and just plain aging. In contrast, survivors at younger ages often referred to cancer as a life-changing event that reshaped their outlook on life, and that often led to changes in work or personal relationships.

In a small qualitative study in Australia, Thewes, Butow, Girgis, and Pendelbury (2003) explored the psychosocial needs of BSCs who were 6-24 months post-acute treatment. The qualitative analysis compared younger and older survivors. The concerns of the younger survivors included (a) concerns about fertility, (b) needing emotional support after treatment ended, and (c) needing age-relevant information after treatment. Older women were less likely to participate in support groups and overall reported fewer needs. Younger women discussed limitations that they felt their cancer experience had placed on their lifestyles and careers. Other studies have reported that cancer had altered survivors' progress or priorities at work (Stewart et al., 2001) or reduced personal ambition (Joly, Espie, Marty, Heron, & Henry-Amar, 2000).

**Adolescent and young adult survivors.** Recently, the younger cancer population has been identified as an area of need. The adolescent and young adult (AYA) population is defined as those diagnosed with cancer between the ages of 15 and 39 years. The NCI and the LAF have recently partnered to examine issues unique to this age group. AYAs have seen little to no

improvement in cancer survival rates for the last several decades. Findings from a progress review group have made recommendations to improve cancer care and research in this age group, including survivorship care. The report identified several factors that have contributed to lack of improvement in outcomes in this population. The AYAs have the highest uninsured rate of any other age group. Issues with health insurance in AYAs include transitioning from school to employment (or unemployment) or “aging out” of parent’s coverage. As students, or early on in their careers, they may be priced out of adequate coverage or may forgo coverage due to competing expenses for QOL (US Department of Health and Human Services, 2006).

In addition, AYAs may see themselves as invulnerable to serious disease, which may cause delays in seeking medical care and treatment. They may “fall through the cracks” in healthcare, and they typically have low participation in clinical trials. Furthermore, there is a lack of treatment guidelines and limited psychosocial resources for this population. Peer relationships may be challenged as they navigate the illness and survivorship experience. AYA survivors face significant challenges that are distinct from other age groups. The report concludes that more research is needed to further understand survivors’ life-stage development and developmental characteristics across the intellectual, interpersonal, emotional, practical, existential/spiritual, and cultural domains, which will impact clinical outcomes and QOL (US Department of Health and Human Services, 2006). In a review focusing on long-term survivors diagnosed with cancer as children, Schwartz (1999) found that those treated for cancer in

childhood may have significant cognitive deficits that may result in poor academic achievement. Over time, intellectual development may lag behind the expected progression.

### **Roles and Relationships**

Interpersonal relationships form the basis for social functioning, which is widely regarded as a critical minimum component of health-related QOL assessments. The presence of a positive partner relationship is a key component of successful adaptation to most aspects of the cancer experience (Thornton & Perez, 2007). Living with a spouse or partner predicts a positive response to QOL (Ferrell et al., 1995). Maintaining “normal life roles” can be protective for psychological distress (Alfano & Rowland, 2006). The majority of people diagnosed with cancer report high levels of relationship quality over the course of survivorship, although partners of cancer patients may experience significant decrements in physical, emotional, and social functioning that appear to mirror the patient’s own response to cancer. Most studies focus on partners and less on family and friends (Thornton & Perez, 2007) although a range of individuals contribute to the survivors’ social network and include spouse or partner, family and friends, health professional, and social support groups (Flanagan & Holmes, 2000). Family support is key for all ethnic groups (Ashing-Giwa et al., 2003).

Marital adjustment and cancer have received some attention in the literature. Despite common perceptions, divorce does not necessarily increase after a diagnosis of cancer, although relationships are likely to be strained. Many studies show stronger interpersonal relationships (Alfano & Rowland, 2006). Of

all the forms of support, the most important aspect of emotional support is the availability of a confidant. Spouses become even more important in the patients' social support series due to their centrality in patients' lives. Partner support may decline over time during the survivorship period and survivors may report that their spouse does not understand what they have been through (Kornblith & Ligibel, 2003). Relationships that are perceived as unsatisfactory early on in the cancer trajectory are at risk for future psychosocial dysfunction. Couples who are able to maintain open communication throughout the cancer experience report better marital adjustment than those who report communication problems (Thornton & Perez, 2007). When treatment ends, interpersonal relationships may be strained because new patterns of interaction and functionality need to be negotiated, and most likely will be different than the acute phase (Leigh & Clark, 1998).

Changes in identity may affect the way that the survivor carries out his or her roles and responsibilities and his or her new role as a cancer survivor. Cancer can disrupt social roles such as parent, employee, student, or spouse. Low QOL may be associated with the LTS's difficulty in successfully achieving tasks associated with particular social roles. Level of engagement in role activities has been recognized as important in influencing QOL (Zebrack, 2000). Many CSs describe their new identity as a survivor as "the new normal" (Alfano & Rowland, 2006).

In terms of social interaction, the literature describes three forms of socially constrained behaviors that may cause the cancer patient to feel



misunderstood or alienated: criticism, avoidance, and withdrawal. Social constraints are associated with poorer illness adjustment and relationship distress in patients with cancer (Thornton & Perez, 2007). Conversely, increased social support has shown a survival benefit (Alfano & Rowland, 2006).

Rural BSCs may be especially concerned about role disruption because their social roles as caregivers are more central to their lives. Being away from home disrupts social roles. Roles may be more difficult to maintain in rural settings due to limited resources. Many survivors find relief when others help with traditional gender role demands (Bettencourt, Schlegal, Talley et al, 2007).

### **Sexuality**

Sexual dysfunction in CSs may be caused by various factors and include biological changes from cancer or treatment. Some of the treatments that may be a problem include pelvic surgery or radiation, hormonal manipulations, and chemotherapy. In addition, the CSs psychological response to cancer can influence sexuality (Alfano & Rowland, 2006). In BCSs, 20-30% develop sexual problems including general sexual disruption, decreased frequency of intercourse, and difficulties reaching orgasm. These issues can persist for 20 years post-treatment (Kornblith et al., 2003). Additional risk factors include those with pre-existing relationship problems and those who undergo hormonal changes from chemotherapy (Kornblith & Ligibel, 2003). Men treated for prostate, bladder, and testicular cancers are at high risk for erectile dysfunction. Prostatectomy, radiotherapy, and androgen blockade treatments are associated with risks of 43-66% (Alfano & Rowland, 2006). Reduced sexual interest and

decreased sexual functioning can impact CSs of any site, with prevalence rates reported at 18-40% (Ronson & Body, 2002).

A huge issue with regard to sexuality is the failure of healthcare providers and survivors themselves to raise the issue. Standard treatments include educational interventions, pharmacologic treatments, and psychotherapeutic methods although studies specific to CSs are uncommon. Promising interventions focus on treating both the physical and psychological factors (Alfano & Rowland, 2006).

### **Body Image**

Body image concerns are associated with poor psychosocial adjustment and decreased sexual activity and functioning across cancer types and sites. Body image concerns are common among BCSs, including those who receive breast-conserving surgery. Interventions based on research are lacking in this area, although physical exercise has been shown to improve body image in CSs (Alfano & Rowland, 2006). Ashing-Giwa et al. (2003) found that body image concerns were common among all ethnic groups in their qualitative study focusing on the breast cancer experiences of African Americans, Asian Americans, Latinas, and Caucasians.

### **Psychosocial Adaptation and Interventions**

Two factors in particular are associated with positive psychosocial adaptation: perceived social support (especially from the spouse or partner) and coping style (those with a positive and active coping style do well). Additional protective factors include optimism, expression of emotions, finding a positive

meaning from the cancer experience, maintaining self-esteem and customary roles, and strong spirituality (Alfano & Rowland, 2006). Lim and Zebrack (2006) found that the use of supportive care services, satisfaction with social support, network size, and reliance on formal and informal social ties affect QOL for long-term survivors of leukemia and lymphoma. Using hierarchical regression, these variables accounted for 52.4% of the variance in QOL. Enhancing support networks, both formal and informal, may improve QOL for survivors.

In their review of recovery in cancer survivorship, Alfano and Rowland (2006) outlined important take-home points with regard to this body of research: (a) patients who receive interventions aimed at their function or well-being do better than those without the interventions; (b) support groups are the most common type of intervention studied; (c) there is limited generalizability of most interventional studies; and (d) use of these types of programs aimed at decreasing the aftereffects of cancer remains sparse. According to Nezu and Nezu (2007), the interventions can be grouped into the categories of educational, cognitive-behavioral, and group therapy. They also reported that group therapy programs that focus predominantly on peer support and shared feelings are less effective than either educational interventions or those that teach coping skills.

### **Spiritual-Existential Well-Being**

#### **Uncertainty and Fear of Recurrence**

According to uncertainty in illness theory, uncertainty is created when components of illness, treatment-related stimuli, and illness-related events possess the characteristics of inconsistency, randomness, complexity,

unpredictability, and lack of information in situations of importance to the individual (Mischel et al., 2005). In BCSs, events triggering uncertainty and fear of recurrence are intrusive, occur randomly, and are often unpredictable and sudden. The survivor may be uncertain about how these events will impact his or her life and future. Uncertainty, and the associated cognitive and behavioral responses, can lead to poorer decision-making, poorer psychosocial adjustment, decreased QOL, and characteristics of post-traumatic stress responses (Mischel et al., 2005).

Uncertainty and triggers of uncertainty have been studied a great deal in CSs. Specific triggers include new bodily or functional changes, medical checkups, media events about cancer, or news of another survivor having a recurrence of cancer (Gil et al., 2004). Gil et al. (2004, examined the triggers of uncertainty about recurrence of cancer in a sample of Caucasian and African American BSCs, using descriptive methods. The findings indicated that the most frequent triggers were news of someone else's cancer; new aches and pains; environmental sights, sounds, smells; information from the media, and annual medical exams. The most frequent symptoms were fatigue, joint stiffness, and pain. Illness uncertainty persists long after diagnosis and treatment, and most BSCs have multiple triggers of uncertainty.

In a randomized controlled design study, Mishel and colleagues (2005) tested the efficacy of a theoretically based uncertainty management intervention delivered to older long-term BCSs (5-9 years post-treatment), used in a mixed sample of Caucasians and African Americans (AAs). The intervention was based

on the earlier work of Mishel (1997, 1998, 1999), which focused on the theory of uncertainty in illness. Participants in the intervention group were taught cognitive-behavioral strategies to manage uncertainty about recurrence, based on the thought that knowledge and information are the primary resources for managing uncertainty. Women averaged two triggers per month. Calming self-statements were used most frequently for coping with triggers, followed by distraction and relaxation. Imagery was the least commonly used and was reported as less helpful than the other strategies. Of the participants, 80% found that using a self-help manual for symptoms was helpful and there were significant differences over time for the treatment groups when compared with the usual care control group. Training in uncertainty management resulted in significant positive improvements in cognitive reframing (for AAs only) ( $p = 0.03$ ), cancer knowledge ( $p = 0.001$ ), patient-healthcare provider communication ( $p = 0.001$ ), and a variety of coping skills ( $p = 0.001$ ).

### **Meaning of Life and Spirituality**

Dow and colleagues (1999) studied the meaning of QOL in cancer survivorship and found that it was multifaceted and complex. Over-arching themes included struggle between independence-dependence, balance, wholeness, life purpose, reclaiming life, having control, altered meaning of health, multiple losses, and surviving cancer from a family perspective. Existential distress is often thought to be a ubiquitous part of the cancer experience. In a mixed sample of newly diagnosed cancer patients and survivors, Lee, Cohen, Edgar et al. (2006) developed an intervention for meaning making,

which consisted of individualized sessions, acknowledging losses and life threats, examining critical past challenges, and plans to stay committed to life goals. Following the intervention, the participants significantly improved in self-esteem ( $p = 0.003$ ) and reported a greater sense of security in facing the uncertainty of cancer ( $p = 0.03$ ).

Meraviglia (2006) studied the effects of spirituality (meaning in life and prayer) on a sense of well-being among women who have had breast cancer, and who are in various stages of early and long-term survivorship. Meaning in life was positively related to psychological well-being ( $r = 0.66$ ) and negatively related to symptom distress ( $r = -0.27$ ). Prayer was positively related to psychological well-being ( $r = 0.36$ ) but not significantly related to symptom distress. Women with higher prayer scale scores reported lower education levels, less income to meet their needs, and closer relationships with God. Meaning in life mediated the impact of BC on physical and psychological well-being. Strong relationships exist among spirituality and personal and cancer characteristics. The findings support the need for healthcare providers to encourage BCSs to explore their spirituality as an effective resource for dealing with the physical and psychological responses to cancer.

Tomich and Helgeson (2002), in a cross-sectional study of BCSs, examined the relation of beliefs about the world and the self, meaning in life, and spirituality to the QOL of both cancer survivors and healthy controls. In both groups, a continued search for meaning in life had a negative impact on QOL. The strongest and most consistent correlate of QOL for both survivors and

healthy women was having a sense of purpose in life. The investigators suggested that future research is needed to identify a subgroup of women who sustain lasting difficulties. Several studies found that spiritual beliefs and practices are central to coping and a prominent piece of the survivorship experience (Ashing-giwa et al., 2003; Braun et al., 2002; Breaden, 1997).

### **Survivorship as a Chronic Illness**

Feuerstein (2007b) discussed how cancer is viewed in many countries (other than the US) as “another chronic illness” (p. 5) and the term *cancer survivor* is not often used. For the most part, in the US it remains distinct from chronic illness, although there are both similarities and differences. While many of the experiences of CSs are similar to those with chronic illness, there are unique aspects to living with cancer and beyond cancer. Similarities include that it can be disabling, cause intense pain, cause embarrassment, and be stigmatizing (Tritter & Calnan, 2002). However, the prevailing thought is that there are more differences than similarities. Some of the differences include the following: (a) cancer covers a range of different diseases based on categorization at the cellular level; (b) there are complexities in cancer treatment; and, (c) periods of chronic illness are interspersed with acute episodes (although this aspect is similar to heart failure) and it usually begins acutely (Tritter & Calnan, 2002). Naus, Ishler, Parrott, and Kovacs (2009) proposed the cancer survivor adaptation model, which is based on a disability model and conceptualizes cancer as a chronic illness; it emphasizes adaption over time through goal appraisal and change. While the model may not be based on research, it does

seem to be a theme identified in the literature that despite having aspects in common with other chronic illnesses, cancer is distinctive. Moreover, there is overlap and many CSs experience other illnesses and co-morbidities (Garman et al., 2003; Gotay, Ransom & Pagano, 2007; Schultz et al., 2005), which impacts their treatment as well as their experiences.

One of the most striking differences between cancer and other diseases is the associated visible changes in appearance. Common physical changes associated with cancer and treatment include surgical scars, loss or change in a body part, weight loss or gain, hair loss, puffy face, and swelling in the limbs (Cancernet.com, 2006). These changes are noticeable and contribute to changes in body image and are in contrast to heart disease and diabetes, which are by and large invisible. A survey of women revealed that cancer was the most feared disease, even though the most common cause of death in women is cardiac disease (Women's Health Research, 2005).

Hewitt et al. (2003) focused on age, health, and disability of CSs in a large and diverse sample that included survivors of a variety of cancer sites and ages, and years since diagnosis ranging from less than two to greater than 20. Compared with individuals without a history of cancer or other chronic disease, CSs were significantly more likely to report being in fair or poor health (odds ratio-OR, 2.97); having a psychological disability (OR 2.18), three or more other chronic medical conditions, psychological problems, one or more limitations of activities of daily living (ADLs) or instrumental activities of daily living (IADLs) (OR, 2.22); and having one or more functional limitations. Participants under the



age of 65 were unable to work because of their health (OR 3.22). The likelihood of poor health and disability was much higher among participants who also reported co-morbid chronic conditions. In fact, in older adults, disability is predominantly caused by chronic illness (Hewitt et al., 2006).

Thorne and colleagues have conducted a review and synthesis focusing on the chronic illness experience and shifting images over time (Thorne & Paterson, 1998; Thorne et al., 2002). These researchers asserted that conceptualizations of individuals with chronic illness have shifted from a focus on loss and burden toward images of health within illness, transformation, and normality. In addition, healthcare relationships have shifted to client-as-partner (Thorne & Paterson, 1998). In this review, seven studies focused on cancer were included in the synthesis. Cancer studies focused on maintaining a health perspective (Coward, 1990; Kagawa-Singer, 1993; Moch, 1990), dealing with uncertainties of cancer and cancer recurrence (Rawnsley, 1994), and symptom management (Smith, Holcombe, & Stullenbarger, 1994).

More recently, Rowland (2008a), based on a review of the literature and experiences with the Office of Cancer Survivorship, proposed that the survivorship sector of the cancer control continuum needs to be revised to more fully consider health promotion. The author cited seven reasons why health promotion has become an issue of great interest and importance: (a) there are growing numbers of CSs, (b) survivors can expect to live long lives, (c) the majority of CSs are older and at risk for co-morbidities, (d) cancer treatment can compromise health in a number of ways, (e) interventions to reduce co-

morbidities are needed, (f) CSs are demanding help in reducing morbidity and mortality, and (f) cancer may provide a “teachable moment” (p. 365) for many who are diagnosed.

Comparing illness trajectories can illustrate the similarities as well as the differences between cancer survivorship and other chronic illnesses. For CSs who are free of cancer, there may be perceptions that the cancer is “gone” or “cured” although there is commonly fear of recurrence. In comparison, with heart disease and diabetes, once diagnosed, there may not be an expectation of a “cure,” but goals are established for control and minimizing progression of disease. However, there is generally not a perception of a “new” heart failure or a “new” diabetes, as there would be with a cancer recurrence or second cancer. The impact of other chronic illnesses and their progression and cancer survivorship may intersect with the experiences of late effects associated with cancer and cancer treatment. Both chronic illness and late effects may be unpredictable and variable; however, the progression of chronic illness may be more predictable in certain diseases (Wellard & Beddoes, 2005). Diabetes progression and symptoms are affected by how well glycemic levels are controlled and heart disease may be impacted by lifestyle changes, in contrast with cancer, which comes and then often leaves the body if treatment is effective or goes into remission. Complicating the picture, cardiac disease is one of the potential late effects associated with cancer treatment. It usually develops within several months after chemotherapy but may develop years later (Hewitt et al., 2006).

Many symptoms common to survivors are also common to other chronic health conditions and may be attributed to aging. It may make it difficult to determine what is attributed to cancer, what is attributed to aging or other chronic illnesses, and what may be late effects. Cancer can be considered a chronic disease in part due to the potential devastating impact of late effects, although the degree of risk of late effects to individual patients cannot be predicted. Adding to this, untrained healthcare providers may miss the presentation of late effects as they may be subtle, and they may not have received training specific to cancer survivorship issues (Hewitt et al., 2006). In the present study, it is difficult to sort out symptoms related to cancer late effects versus other chronic illness. Data were collected on co-morbidities as well as symptoms and other manifestations that may actually be late effects.

In a small, descriptive, correlational study, 18 participants with BC were compared with 24 participants without BC. The researchers found that the symptom experience and QOL of older breast cancer survivors are similar to those of older women with other chronic health problems. In addition, beliefs about symptoms influence QOL in older women. More specifically, not knowing the cause of symptoms was significantly related to poorer social functioning, less energy, poorer mental health, lower purpose in life, and higher levels of depression and anxiety. Also, symptom distress was significantly related to believing that symptoms were caused by chronic illness ( $p < .05$ ) (Heidrich et al., 2006). For cancer survivors, the relatively high incidence of co-morbidities, ADL limitations, and functional limitations poses challenges to the survivors and those

providing survivorship care, and it suggests a need for integrated care models which integrate chronic care and rehabilitation (Hewett et al., 2003). In relation to the present study, there is some evidence that the rates of chronic illness are increasing in rural Alaska (GAP, 1995) and it is considered a critical health issue.

### **Health-Related Behavior Change after Cancer**

Cancer survivors are known to make positive health-related behavior changes. The life-threatening experience of cancer diagnosis and treatment can serve as a catalyst to make such changes. Unhealthy behavior changes are less studied than positive changes. In a large cross-sectional study of CSs with various types of cancer and stages of survivorship (3 to 11 years), Hawkins and colleagues (2010) found that CSs were more likely to make positive than negative behavior changes; 88% reported at least one positive behavior change, and the mean number of positive changes was 3.9 out of a possible 15 behaviors. Also, 60% of CSs reported no negative behavior changes since being diagnosed with cancer. Survivors with physical health limitations often face the greatest challenges in making positive health behavioral changes.

### **Myths and Social Perceptions of Cancer**

Myths and social perceptions of cancer are prevalent in society and contribute greatly to the experience of cancer patients and survivors. According to Flanagan and Holmes (2000), cancer “holds a special mystique and is imbued with socio-cultural meanings, which extend far beyond the rational, scientific, and biological facts of the disease” (p. 740). These researchers conducted a literature review to examine the impact of cancer on social relationships. Some of the

themes they found included (a) the importance of the social relationship, (b) stigma and cancer, (c) avoidance-behavior and the non-materialization of support, and (d) overprotective behavior and its impact on the social relationship. The discussion of stigma is particularly pertinent, as it can lead to a process of social disruption that can significantly impact the person with cancer. In addition to stigma, excessive fear and dread may cause family and friends to exhibit avoidance or overprotective behaviors and the person with cancer may, as a result, perceive that his or her social support is inadequate (Flanagan & Holmes, 2000).

One of the common myths is that cancer is an automatic death sentence, and despite advances and improved survival rates, it is still associated with death (Leigh, 1992). Cancer fatalism has been shown to be a barrier to participation in cancer screening, prevention, diagnosis, and treatment (Gansler et al., 2005). There are also perceptions that the patient causes the disease from either their psychological state, what they eat, or their personal habits. Another common perception is that cancer is contagious, when, in fact, it is not. A frightening misperception is that all people with cancer will die in pain. Additional inaccurate perceptions include these: (a) it is better for someone not to know he or she has cancer, (b) positive thinking will cure cancer, (c) the medical establishment is hiding a cure for cancer, (d) cancer surgery causes tumors to spread, (d) some people may be too old for cancer treatment, and (e) sugar causes cancer to grow faster (Cancernet.com, 2005).

Gansler and colleagues (2005), in a descriptive study of people without cancer, found that the most prevalent misconception was “treating cancer with surgery can cause it to spread throughout the body” (p. 653), and this item was endorsed by 41% of the sample. The second most prevalent misperception was “the medical industry is withholding a cure for cancer from the public in order to increase profits,” which was identified as true by 27% of the sample. Identifying and dispelling myths and misperceptions are important as they may affect adherence to treatment regimens (Gansler et al., 2005).

### **Survivorship Issues in Older Adults**

More than 60% of CSs are over 65. Cancer prevalence rises steadily with age, and for the age group between 80-84, the prevalence is 19% (Hewitt et al., 2006). The highest incidence occurs in women aged 75-79 (Ries et al., 2002). Older adults with cancer are more likely to have co-existing co-morbidities and decreased functional status, and they may be at a higher risk for developing long-term sequelae from cancer-related therapies (Rao & Demark-Wahnefried, 2006). Older CSs are particularly vulnerable due to the impact of treatment, the impact of cancer on the risk for co-morbidities, and the effects of co-morbidities on cancer care (Aziz & Belizzi, 2008). With the growing number of CSs living five or more years beyond their diagnosis, the focus of cancer care must extend beyond the limited focus on cure to one that fosters health promotion and minimizes physical dysfunction or disability after illness. Rowland and Yancik (2006) noted that “new knowledge must be generated at the cancer-aging

interface” (p. 505). Guidelines for managing older adults who have cancer have been developed (Balducci, 2003).

Sweeney et al. (2006) compared older women who had a cancer diagnosis and survivors at follow-up with a cohort who had never been diagnosed with cancer. Women who were CSs for less than two years reported the most functional limitations, but long-term (five or more years) CSs remained more likely than those who had not had cancer to report that they were unable to do heavy household work (42% of the 5-year CSs as compared with 31% of those who had never had cancer). The increased prevalence of functional limitations was apparent for 5-year survivors of several types of cancer. This study revealed the importance of targeting older adults with cancer for interventions to maintain or regain physical function.

Heidrich and colleagues (2006) found that older adult women both with and without breast cancer attributed the cause of their symptoms to aging, chronic illness, or unknown but rarely to breast cancer. Beliefs about symptoms in older women influence their QOL. Bowman et al. (2003) studied the appraisal of the cancer experience by long-term older survivors in AAs and Whites. There was some evidence that the longer survivors live with cancer and encounter other life events, the more they may incorporate it into their lives and regard it as part of their living experience. In this study, a more stressful appraisal was associated with the belief that the diagnosis and treatment caused greater family distress, being younger, and being White.

### **Survivors of Multiple Cancers**

Mariotto et al. (2007) using data from the Surveillance, Epidemiology & End Results (SEER) database, estimated the number of and described the pattern of disease among US cancer survivors living with a history of multiple malignant tumors in the US. An estimated 756,467 people in the US have been affected by cancer more than once between 1975 and 2001, representing almost 8% of the current cancer survivor population. In that time period, women whose first primary cancer was BC represent 25% of the survivors with multiple cancers, followed by men and women (15%) whose first primary cancer was colorectal and men (13%) whose first primary site was prostate. Of those studied, 74% had two or more cancers of different primary sites, and 26% were diagnosed with two or more tumors of the same site. Findings have important implications for public health practice. With individuals diagnosed with cancer living longer and the aging of the US population, the number who will develop multiple malignancies is expected to increase. As a consequence, there is a growing need to promote effective cancer screening along with healthy lifestyles among these at-risk populations to ensure optimal physical and psychosocial well-being of these long-term CSs and their families. Efforts to design and evaluate effective, efficient, and equitable approaches to surveillance and treatment plans for second malignancies will be critical in reducing the national burden of cancer.

Utilizing a case control design, Gotay, Ransom & Pagano (2007) studied the QOL in survivors of multiple primary cancers compared with CS controls. QOL was compared between 487 CSs of second-order and higher-order primary



cancer diagnosis, and a matched group of 589 survivors of a single cancer diagnosis. Survivors of multiple primary cancer diagnosis had significantly lower global QOL ( $p < .001$ ), vitality ( $p < .001$ ), and existential well-being ( $p < .01$ ), and higher intrusive stress symptoms ( $p < .05$ ). Controlling for demographic, medical, and trait-like psychosocial characteristics (e.g., optimism and resilience), having multiple primary cancer diagnoses explained small but significant variances on global QOL ( $R^2 = 0.04$ ;  $p < .001$ ), vitality ( $R^2 = .01$ ;  $p < .05$ ), and existential well-being ( $R^2 = 0.01$ ;  $p < 0.05$ ). Patients in the multiple primary cancer group scored worse on all of these measures. Results suggest that survivors of multiple primary cancer experience modest but lasting QOL deficits when compared with CS controls. The experience of cancer can have long-term effects, and the experience of multiple cancers may compound this risk. This coupled with co-morbidities, and an aging population, influences treatment and follow-up strategies (Balducci, 2003). Data on more than one cancer and recurrence were collected in this study.

### **Health Disparities in Cancer and Survivorship**

Sources of health disparities in cancer have not been completely explained, but it is well known that minority groups are underrepresented among cancer survivors, and this is, in part, due to relatively poor access to primary healthcare and effective screening and treatments for cancer. Consistent disparities in incidence, mortality, and survival by race and ethnicity have been identified (Hewitt et al., 2006). Individuals who are of low socioeconomic status (SES) and who are medically underserved are less likely to be represented

among CSs. Minorities are more likely to be diagnosed at later cancer stages, to have worse treatment outcomes, and to experience a shorter life expectancy (IOM, 2003). Consequences of treatment disparities include more frequent recurrence, shorter periods of disease-free survival, and higher mortality rates (Hewitt et al., 2006).

Lower SES is often associated with poorer outcomes and is a stronger predictor of outcomes than race (Hewitt et al., 2006). Poverty is a key determinant of poorer outcomes (Freeman, 2002). The poverty rate in Oregon is estimated to be at 15.8%. and has risen in recent years. This is thought to be due to the recession (Oregon Center for Public Policy, 2011). The majority of the population of rural Alaska is at the poverty level or below with the highest areas of poverty ranging from 13.5% to 26.2% (Ecanned, 2007). The poverty rate for American Indians and Alaska Natives in Alaska is 20.2% although the average poverty rate for Alaska is 9.5%, compared with the US rate of 13.8% (DHHS, Office of Minority Health, 2012).

Across all racial and ethnic groups, the five-year survival rate is more than 10% higher for persons who live in affluent census tracts (where less than 10% of the population is below the poverty line) than for persons who live in poorer census tracts (those with more than 20% below the poverty line) (Singh et al., 2003). According to the US Census Bureau (2005), the official poverty rate in 2010 was 15.1%. The economically challenged are less likely to be insured, have less access to healthcare, and are less likely to be informed about their health status and risk of disease. In addition, minorities may present with cancer at later

stages than Whites. However, some studies have shown that even when access is equal and SES is accounted for, differences in cancer survival between racial groups remain (Oseni & Jatoi, 2007).

Some examples of well-documented treatment disparities related to cancer include (a) women receiving less breast-conserving surgery and radiation when they reside in poorer census tracts, (b) AA's with lung cancer being less likely to receive recommended surgery, (c) AAs being more likely to go unstaged and receive no treatment for cervical cancer than Whites, and (d) Whites being more likely than any other racial/ethnic group to receive aggressive treatment for colon cancer. The complex interplay between social, economic, and cultural factors as a cause of health disparities has been widely discussed in the literature. Most of the studies have focused on screening, reactions to diagnoses, and early interventions, and there is not as much in the literature about health disparities in cancer survivorship. Other factors identified that contribute to disparities in cancer include tumor biology and co-morbidities. Race and culture may be intertwined, yet culture remains very poorly studied in cancer survival (Oseni & Jatoi, 2007).

Even less is written about rural survivorship and most studies regarding disparities in rural survivorship come from Australia. In Australia, it is estimated that one-third of the approximately 350,000 diagnosed each year with cancer reside in rural settings (Kenny, Endacott, Botti, & Watts, 2007). Perhaps the most well-documented disparities in rural settings are in the provision of psychosocial

care with several studies documenting this to be inadequate in rural settings (Buehler & Lee, 1992; Burman & Weinert, 1997; Turner et al., 2005).

In a large qualitative study of BCSs from various ethnic groups, Ashing-Giwa and colleagues (2003) determined that Asians and Latinas were more likely to receive mastectomy than lumpectomy, while AA BCSs were least likely to receive adjuvant therapies, including radiation and chemotherapy. The prevailing concerns among all women included overall health, moderate physical concerns, cancer recurrence or metastases, psychosocial concerns related to worry about children and burdening the family, and body image and sexual health concerns. Additional challenges include lack of knowledge about BC; medical care issues such as insurance, cost, and amount of time spent with physician; cultural sensitivity of provider, language barriers, cultural factors related to beliefs about illness, gender role, and family obligations (e.g., self-sacrifice). These BCSs, particularly the women of color, identified their spiritual beliefs and practices as central to their coping (Ashing-Giwa et al., 2003).

Bowen et al. (2007) studied the ethnic and socioeconomic correlates of functioning in long-term BCSs. AA women reported significantly lower physical functioning (PF) when compared with White and Hispanic women ( $p = 0.01$ ) but higher mental health scores ( $p < 0.01$ ). In the final model, race was significantly related to PF, with blacks reporting poorer PF than Whites ( $p < .01, .05$ ). Not working outside the home, being retired or disabled, and being unemployed were associated with poorer PF when compared with those who were employed ( $p < .01$ ). This study did not focus on the American Indian/Alaska Native (AI/AN)

population and did not differentiate rural versus urban in the demographics, although it did include participants from a wide range of socioeconomic levels.

Braun et al. (2002) studied the Native Hawaiian population concerning the impact of fatalistic attitudes, access to healthcare, and culturally linked values. Findings were similar to CSs of other ethnicities. The following themes were identified: success in accessing healthcare information, professionals, facilities, and insurance; the ability to overcome the barriers confronted; and proactive health behaviors regarding screening, diagnosis and treatment. Native Hawaiian traditions helped sustain them, such as helping others, gaining strength from Hawaiian spiritual beliefs, and relying on family for personal support. Participants did not respond passively to the cancer diagnosis, and they expressed few fatalistic attitudes. Participants did give numerous examples of other Native Hawaiians who did not seek screening or treatment for cancer because they lacked insurance, had poor access to care, or felt alienated by Western healthcare. Several barriers perceived by rural participants were described, such as feeling disregarded by their physicians (Braun et al., 2002).

As noted previously in this chapter, ethnic minorities are generally underrepresented in survivorship research, and this must be rectified in order to make progress with health disparities in this specialty area. Smith and colleagues (2006) have been attempting to overcome this by over-sampling minorities in the ongoing studies of survivorship conducted by the ACS. They are also addressing the issue of respondent bias. Many groups considered disadvantaged are less likely to respond to research surveys. Groups least likely to respond are the

elderly, males, and nonwhites, survivors of bladder cancer, cohorts at longer periods post-diagnosis, and those in poor health (Smith et al., 2006). This raises the concern that the voices of all survivors are not present in the current body of knowledge, thus contributing to participant bias.

### **Survivorship in Alaska Native and American Indian People**

Just less than 20% of the population in Alaska is Alaska Native (US Census Bureau, 2006). The Alaska Native people residing in Alaska have unique problems as CSs. These may include difficulty and expense of traveling long distances to access care, community members fear of getting cancer themselves, inability to hunt and fish as before, difficulty maintaining a subsistence lifestyle and providing food for their families, and the lack of support groups in the villages, which are the most remote Alaska Native settlements (Alaska Experience Project, 2007; Alaska Native Tribal Health Consortium [ANTHC], 2006).

Cancer has been the leading cause of death in Alaska Native people since the early 1990s. While the overall cancer death rate has declined in the United States, the cancer death rates in Alaska Native people have increased. Alaska Native women have the highest cancer death rate of all racial and ethnic groups, while Alaska Native men rank third after African American and Hawaiian men. Alaska Native people are 40% more likely to die of lung cancer and have higher death rates for several other smoking-related cancers such as cancers of the kidney, bladder, head and neck, and cervix (ANTHC, 2004). Alaska Native people are among the racial groups with the highest mortality rates for all

cancers combined in comparison with all other racial groups. Cancers occurring disproportionately in Alaska Native people include lung, colorectal, cervix, prostate, kidney, and stomach (Intercultural Cancer Council, 2001).

While the death rates are significant, the stories of the survivors are very compelling. “It is important to remember that cancer in Alaska Natives is more than numbers and statistics. It is about people and lives affected during the cancer journey. Stories are about loss, hope, culture, reaching out and sharing. They tell the real story of cancer in Alaska Natives” (ANTHC, 2004, p. 2).

Nationally, access to healthcare is a major barrier for cancer diagnosis and treatment in Alaska Native and American Indian people. Alaska Native and American Indian people are second only to Hispanics in lacking health insurance. The Indian Health Service (IHS) is the primary/only source of healthcare and is only able to meet approximately 40% of the healthcare needs for American Indian and Alaska Native patients (Intercultural Cancer Council, ICC, 2004). In addition, studies conducted in the “Lower 48” states show that more than half of those eligible do not use the IHS services (Burhannsstipanov & Olsen, 2004). Since 1998, the US Census Bureau has not counted IHS eligibility as health insurance coverage. Contrary to the popular opinion that the IHS provides adequate healthcare for all American Indian and Alaska Native people, the IHS is grossly underfunded. Healthcare for American Indian and Alaska Native people in Alaska is tribally owned and managed, with some funding from the IHS. The tribally managed healthcare services that are provided in Anchorage are the

most sophisticated and extensive of any other regions in Indian Country in the lower 48 states.

High cancer mortality rates among some American Indian women residing in the Lower 48 states is attributed to late detection of the disease and underutilization of available treatment (Glanz, 2003). Furthermore, American Indian people are not benefiting from the reduced cancer incidence rate as documented for Whites, indicating a significant health disparity for this population (Satter et al., 2005). American Indian/Alaska Native cancer statistics are thought to be underreported due to racial misclassification and incomplete information related to diagnosis on death certificates (Burhansstipanov & Olsen, 2004), suggesting that the disparities may be even greater than what is reported. However, efforts have been underway to improve methods in cancer surveillance in American Indian and Alaska Native people (Espey, Wiggins, Jim, Miller, Johnson, & Becker, 2008)

Complicating the picture, Alaska Native people residing in Alaska have the highest smoking rates in the US (Management Sciences for Health, 2003). American Indian and Alaska Native women have adult cigarette smoking rates of 38.6% and an overall smoking rate of 27.4% compared with 23% for adult White females and 25.7% smoking rates for White males. In contrast, the lowest smoking rates are found in female Asian Americans at 7.9%. In addition, adult American Indian and Alaska Native females have the highest obesity rates at 43.2% (Ward et al., 2004).



The importance of storytelling of health, healing, and survivorship in American Indian/Alaska Native people is described by Pelusi and Krebs (2003). Twelve themes were identified through an educational activity/gathering with 125 American Indian/Alaska Native people residing in the Lower 48 states. The themes expressed in terms of story were cancer journey, responsibility to self and community, getting beyond the diagnosis, cancer lessons-cancer gifts, the strength of our stories, being connected, prospering through cancer, pain is more than a word, survival is an attitude, spirituality and cancer, specific cancer issues, and understanding our ways. It is common for American Indian and Alaska Native people to blend traditional healing and spiritual practices in conjunction with biomedical care.

In an overview of Native American cancer survivorship, Burhansstipanov and colleagues (1999) identified the pertinent aspects of history as well as some of their perspectives regarding survivorship. Canales and colleagues (2010), through a community-based participatory and ethnographic approach, are developing an archive of cancer survivorship stories from Native Americans in Connecticut. The first of its kind to document survivorship stories in this manner, the researchers have identified this as a major way to problem-solve and educate both current and future generations about the survivorship journey.

In a community-driven research and education project, Burhansstipanov and colleagues (2012) developed the Native American Cancer Education for Survivors (NACES). Based on the social, cognitive theoretical model, participants in the study completed measures of QOL and physical ability, and were

compared along the continuum of survivorship. Results indicated that co-morbidities were prevalent (high blood pressure, arthritis, and diabetes), and numerous CSs were experiencing side effects from cancer treatments. This was the first study to report outcomes specifically for Native American BCSs residing in the Lower 48 states.

Ethnic minorities are overrepresented in the cancer burden yet underrepresented in cancer research (Ashing-Giwa, 2005). For Alaska Native people, there is little, other than anecdotal experience, informal stories, and statistics to guide clinicians in providing holistic care for those experiencing cancer. There are a multitude of individual belief systems within the American Indian and Alaska Native people. Examples of the perceptions of cancer from Native American cancer survivors residing in the Lower 48 states concerning cancer diagnosis include the following: (a) “cancer is a White Man’s Disease” (Burhansstipanov & Olsen, 2004, p. 183), (b) cancer is punishment for you or your family members’ actions, (c) to protect members of one’s community, the person with cancer “wears the pain” (p 183), (d) cancer is part of one’s natural path, (e) cancer results from a curse, and (f) the “cancer spirit” (p 183) is contagious. Hearing from the Alaska Native people themselves is necessary to incorporate culture and the meaning of the illness experience, which will assist in guiding care. In this study, there was targeted recruitment in Alaska to ensure that American Indian and Alaska Native people were included in the sample (see Chapter 3).

## **Survivorship in Rural Settings**

### **Alaska**

Survivorship in rural Alaska presents unique challenges due to a number of factors. Alaska has a higher percentage of rural population than the rest of the United States (US Census Bureau, 2006). In addition, there are geographical challenges not present in any other state, such as limited road access to rural areas and harsh weather patterns. Travel by air is required to reach most rural and frontier towns and villages in the state. Cancer treatment is often provided far away from the home (ANTHC, 2006). In rural and remote Alaska, there is lack of access to an oncologist. This scenario means traveling from a village in bush Alaska to an urban area in the state, or temporary relocation to a cancer center in the “lower 48.” Patients are often separated from their families and support systems during these times, and they incur excessive costs.

The researcher (McNulty, 2007) conducted a community profile focusing on Soldotna, Alaska, a rural community on the road system. All four healthcare providers interviewed identified cancer care as a significant need. Oncology services are provided on a limited basis at the local hospital; however, there is no practicing oncologist in the area. Patients often travel to Anchorage for treatment, which is a three-hour drive away. Two of the interviewees felt that the cancer survivors were “silent” in the community. One interviewee’s husband was a recent survivor, and she stated “nothing is available to assist you in returning to your life.” The profile also revealed that many people are either uninsured or under-insured in this community, and there were no local resources for survivors

(McNulty, 2007). This profile is thought to be typical of rural communities in Alaska, with remote areas having even less access.

Resources for cancer survivors in Anchorage, the largest city in Alaska, include the Survivorship Program based out of Providence Alaska Medical Center (PAMC) and the Alaska Cancer Care Alliance. The ACS has an office in Anchorage, and the LAF funds a small grant for a survivor program at PAMC. The local ACS chapter hosts conferences geared toward survivors. In addition, the Alaska Comprehensive Cancer Partnership (2012) has a committee that focuses exclusively on survivorship issues.

## **Oregon**

Oregon also has a very high level of rurality, especially in the eastern part of the state. As described previously, cancer treatment centers are non-existent in these rural regions, although several rural hospitals do provide chemotherapy infusion services. Typically, though, cancer patients must travel long distances for treatment, frequently over mountain passes, and resources for survivors may be sparse (American College of Surgeons, 2012; Oregon Office of Rural Health, 2010). During treatment, support is available from the Susan G Komen for the Cure's Oregon and Southwest Washington affiliate and the ACS to assist with travel and lodging costs for breast cancer patients in this situation (Susan G Komen for the Cure Oregon and SW Washington, 2012). For survivors living in eastern Oregon, services in metropolitan Idaho may be closer than services in metropolitan Oregon (Cancer Care, St Luke's Mountain States Tumor Institute, 2012). It is estimated that there are 8,500 cancer survivors living in Central and

Eastern Oregon, which covers a 32,000-square-mile service area. A well-developed survivorship program is in place in Bend, located in central Oregon, which provides services such as a cancer support volunteer partnership program, cancer support groups, educational programs, and special events (St. Charles Medical Center Cancer Survivorship Program, 2012).

In the Portland, Oregon metropolitan area, there are several cancer survivorship programs including the Providence Cancer Survivor Program, the HEROES program at Compass Oncology, and the OHSU Knight Cancer Institute's Adolescent and Young Adult Program. Some of these programs provide outreach to the rural areas of the state. In addition, there are 21 communities in the state that provide various types of cancer support groups, some focusing on survivorship. However, only a handful of support groups are offered in the rural areas of the state (Susan G Komen for the Cure Oregon and SW Washington, 2012).

Rural-dwelling survivors may experience lack of symptom management, lack of access to psychosocial interventions, isolation, and decreased coping with regard to their cancer experience, and they are particularly vulnerable to being lost in transition (Hewitt et al., 2006). In a recent review of literature of psychosocial interventions for cancer survivors, rural populations have been minimally studied, and the evidence is not conclusive as to what type of intervention to develop for a rural community. Although there is strong evidence that traditional cancer support groups are effective in patients during the acute phase of cancer treatment (Zabalegui et al., 2005), less is known about the

needs of psychosocial interventions for CSs, especially those who are rural dwellers.

Howat, Veitch, and Cairns (2006) compared health attitudes of urban and rural oncology patients in Australia. Rural patients scored significantly higher for internal belief and belief in chance. No statistically significant differences were evident between rural/urban patients by gender, nor social support scores. Hope levels were generally high with no significant difference between urban/rural patients, regardless of treatment intent. The researchers identified the concept of “rural connectedness” (Howat et al., p. 4) where the participant may identify with or see himself or herself as being rural., even though he or she no longer lives in a rural setting. In this study, patients identified with their rurality and this may not coincide with their current residence. CS experiences in Alaska may be more similar to those in Australia than to those in any other state in the US. The levels of rurality may be similar, as well as the prominence of an indigenous population. Another similarity is that 80% of cancer care in the US is provided outside of specialist facilities and many are managed in rural settings. A similar picture exists in Australia but may not be well documented (Kenny et al., 2007).

### **Rural and Frontier Descriptions of Alaska and Oregon**

#### **Alaska**

Alaska is designated as a frontier state. Frontier is defined as “a population density of less than 6 per square mile and driving time to a hospital of either 60 minutes or severe geographic and/or seasonal climatic conditions” (Buehler, Malone, & Majerus-Wagerhoff, 2006, p. 130). Rural communities have

a population of less than 1,000 people with fewer than 400 people per square .4 miles. Rural remote communities are 49-248 miles or 1-4 hours transport in good weather from a major regional hospital. Rural isolated communities are more than 248 miles or four hours transport in good weather from a major regional hospital (Leipert, 2006). The “road system” refers to the corridor that stretches through the center of the state. Except for Juneau and communities in southeast Alaska, all of the state’s larger urban communities are located on this limited road system. Most importantly, the vast majority of the state is not on the road system.

The Alaska healthcare system uses a regional approach to the organization of healthcare delivery. The categories include level I—village, level II—sub-regional center, level III—regional center, and level IV—urban center (Alaska Experience Project, 2007). The most remote and isolated communities in Alaska are the Alaska Native villages, which may be accessible only by limited air or marine travel. The villages have challenges that are similar to developing areas such as inadequate housing, poor sanitation, limited school systems, political inequities, high unemployment rates, and cultural issues (GAP report, 1995). Healthcare is provided by community health aides (CHAs), who are lay people from their residing village who are provided special training. Emergency medical technicians and itinerant public health nurses also provide healthcare services in these most remote areas (Alaska Experience Project, 2007).

The level II sub-regional centers may have a health center or clinic, and they typically serve a population of approximately 1000 residents. Level III regional centers may have a small hospital with a minimal level of services. Level

IV urban centers would include hospitals in Anchorage and Fairbanks, the two largest cities in the state. This is where the specialty care is provided (Alaska Experience Project, 2007). An example of the various levels of care is the tribal health system in Alaska. The levels of care are depicted, with the “hub-and-spoke” patterns of referrals, starting with the villages, and the highest level of care in Anchorage. See Figure 5.

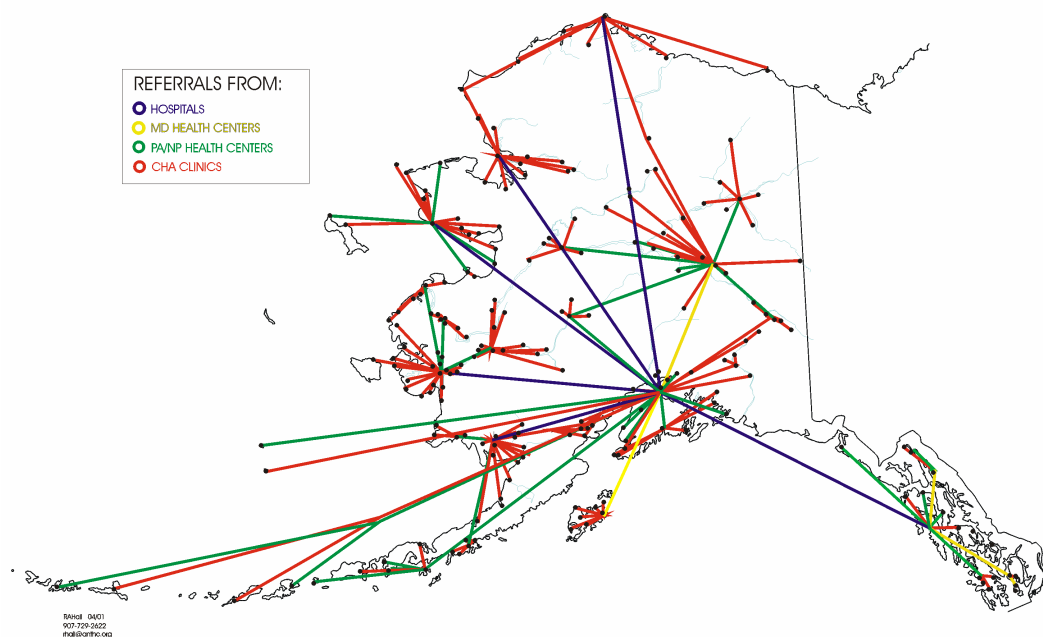
There is also evidence that people are leaving the villages and relocating to regional and urban areas in Alaska. The rates of relocation have accelerated during the last few years, increasing from 1,200 migrations a year between 2002 and 2005 to 2,700 in 2006-2007. Reasons for this have been cited as rising fuel costs, lack of jobs, lower quality of education, housing shortages, and alcohol and drugs (Alaska Department of Labor, 2008).

One study, conducted as part of the Cancer Education for Community Health Aides Program in Alaska, evaluated the CHAs’ comfort level with providing cancer education in their communities. Approximately 50% of the CHAs reported feeling “OK” when providing information about cancer risk factors, cancer screening, surviving cancer, and providing care and support. CHAs reported feeling less comfortable with discussing cancer diagnosis, treatment, pain and loss, and grief (Cueva, Lanier, Dignan, Kuhnley, & Jenkins, 2005). A new role has recently been developed in the tribal HC system and at the village level: the community mental health aide. Both the CHAs and mental health aides have the potential to influence cancer survivorship care in the most remote and isolated settings of Alaska.



# THE ALASKA NATIVE HEALTH CARE SYSTEM

## Typical Referral Patterns



*Figure 5.* The Tribal Healthcare System in Alaska. Source: Alaska Native Tribal Health Consortium, 2004

In this study, participants from the major cities in Alaska (Anchorage, Fairbanks, Juneau and the Matanuska Valley) were considered urban. Rural communities may be on the road system in Alaska, or they may be reached by boat or plane access only, within 1-4 hours. Remote and isolated communities are greater than 4 hours from a major regional hospital. Major hospitals are only located in the urban areas of the state. However, there are six remote tribal facilities that serve villages in their regions. In the statistical analysis, rural and remote dwellers were grouped together, as there were an insufficient amount of

CSs living in remote/isolated areas to be analyzed as a separate group. See Appendix A which provides definitions for rural utilized in this study.

## **Oregon**

Oregon is the ninth most extensive and the 27<sup>th</sup> most populous of the United States. It consists of coastal areas, valleys, and mountainous regions. The largest city is Portland, and the majority of the urban areas are located in the Willamette Valley area. There are also smaller urban areas in the central and southern regions of the state. Of the population, 22.2% is considered rural (USDA Economic Research Service, 2012). The urban and rural areas are depicted in Figure 6. There are several different definitions for rural designations. This map shows the Office of Rural Policy Classification, which is based on distance from an urban community. *Rural* is defined as a geographic area that is at least 30 miles by road from an urban community (Crandall & Weber, 2005).

There are 116 hospitals in Oregon, of which 32 are rural. In addition, there are approximately 61 rural ambulatory care clinics (Agapecenter, 2012; Oregon Office of Rural Health, 2012). Of the 32 rural hospitals in Oregon, only 14 are in the eastern most rural part of the state and they are very spread out. Major healthcare systems in Oregon include the Providence Health System and Samaritan Health Services although there are many others. Oregon Health and Science University is the only major academic medical center in the state, and the OHSU Knight Cancer Institute is the only cancer center in Oregon designated

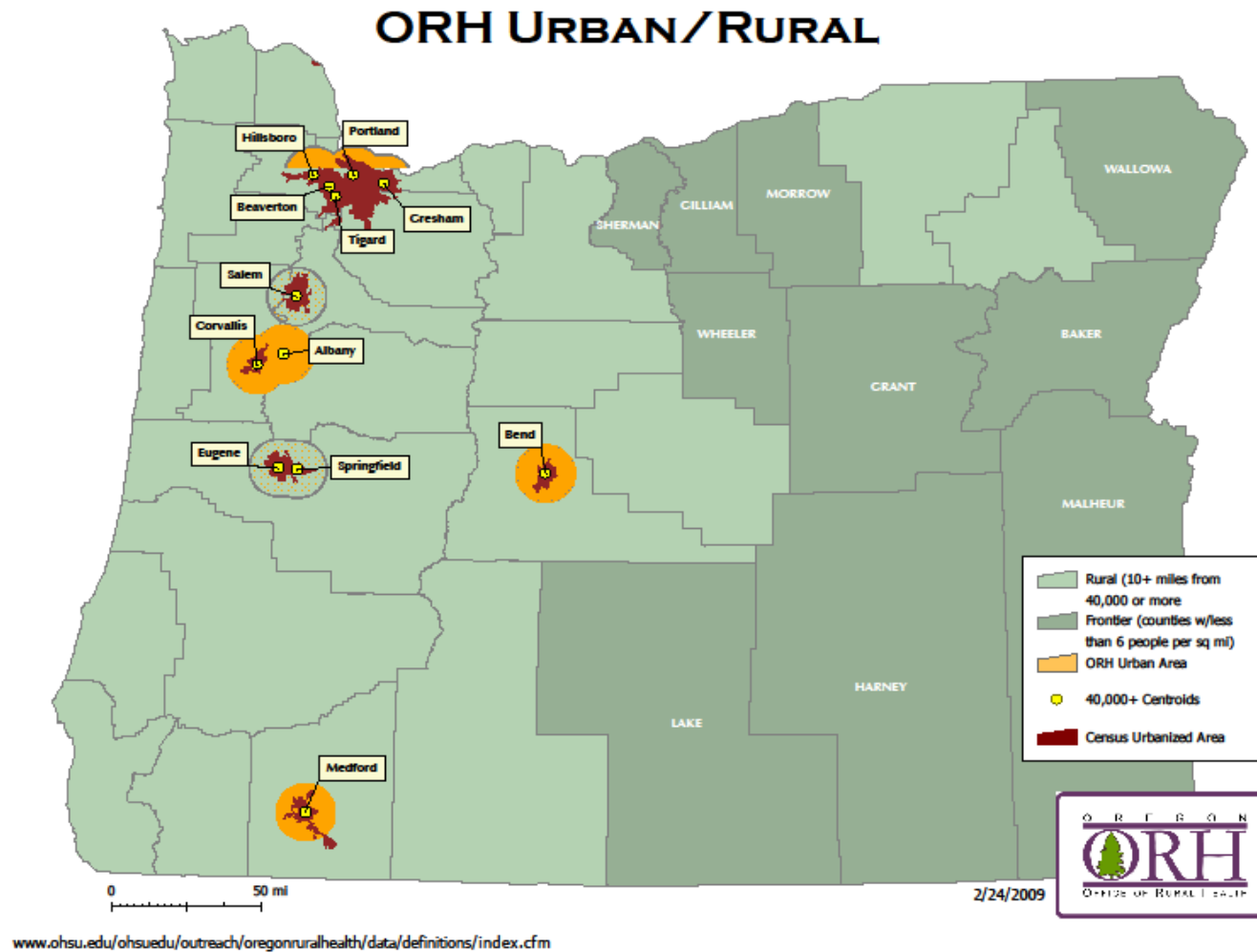


Figure 6. Urban and Rural Areas in Oregon (Oregon Office of Rural Health, 2009).

by the National Cancer Institute (OHSU Knight Cancer Institute, 2012). Both of these are located in Portland.

### **State of the Science: Gaps Addressed by This Study**

A multitude of issues related to cancer survivorship have been discussed. There is a strong suggestion in the literature that more research is needed during the post-treatment stages of survivorship, especially long term (Hewett et al., 2006). CSs are considered an understudied population, and QOL and experiences during survivorship, including symptom experience and management, are worthy of attention. Numerous physical, psychological, social, and spiritual aspects of survivorship have been identified. Health disparities in cancer survivorship have been outlined. Survivors living in rural communities have been identified as an area of needed emphasis (Aziz & Rowland, 2003). Prior to this study, little was known specifically about cancer survivorship in Alaska and Oregon, and very little about rural CSs. The purpose of this descriptive, exploratory, and mixed methods study was to explore the impact of cancer in rural- and urban-dwelling adult cancer survivors living in two regions of the Pacific Northwest. The mixed methods design allowed for a quantitative and qualitative exploration of the phenomenon, and comparison within and between regions. The conceptual framework guiding the study design was the quality of life model applied to cancer survivors developed by Ferrell et al. (1995). Utilization of a broad sampling plan in this study resulted in a heterogeneous sample with respect to cancer diagnoses and treatment regimens

experienced by the participants. In addition, this ensured heterogeneity of persistent long-term and late effects across the sample.

### **Specific Aims**

The specific aims for this study of cancer survivorship are as follows:

*Aim #1: Explore the impact of the cancer survivorship experience and symptom experience in rural and urban dwelling adult cancer survivors in two regions of the Pacific Northwest (quantitative).* The impact of cancer was measured with the IOC and the symptom experience was measured with the Memorial Symptom Assessment Scale. Participants with high and low scores falling in the upper and lower quartile ranges of the IOC were determined to identify who is doing well and who is struggling in their survivorship experience. These participants were explored more in depth in aim #3.

*Aim #2: Compare the cancer survivorship experience in rural- and urban-dwelling adult cancer survivors within and between two regions of the Pacific Northwest (quantitative).* We proposed main effects for region and urban/rural status and a region by urban/rural status interaction based on the differences in access to care between the regions and population groups. These hypotheses should be viewed as exploratory because of the limited information available about CS experiences in adults in both regions.

*Hypotheses:* Urban dwellers will have more positive scores on study instruments than rural dwellers, Oregonians will have more positive scores than Alaskans, and there will be an interaction between region and urban/rural status such that urban-dwelling Oregonians will have more positive scores than urban Alaskans, and rural Oregonians will have more positive scores than rural Alaskans.

*Aim #3: Explore and compare the physical (including symptoms), psychological, social and spiritual-existential aspects of cancer survivorship in rural and urban dwelling adult cancer survivors within and between two regions of the Pacific Northwest (qualitative).* Various aspects of the cancer survivorship experience were elicited and described through interviews with participants identified in aim #1. Underlying patterns and themes were identified. Results from aim #3 were utilized to help explain the results from aims #1 and 2.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODS**

#### **Overview and Rationale**

This descriptive and mixed methods study explored the impact of cancer in rural-and urban-dwelling adult cancer survivors (CSs) living in Alaska and Oregon. The specific aims for this study were to (a) explore the impact of the cancer survivorship experience and symptom experience in those cancer survivors in two regions of the Pacific Northwest (quantitative), (b) compare the cancer survivorship experience in those survivors within and between the two regions (quantitative), and (c) explore and compare the physical (including symptoms), psychological, social, and spiritual-existential aspects of cancer survivorship in those same survivors (qualitative).

A mixed methods design was chosen for this study, in part, because survivorship is a new and evolving phenomenon, and the models and instruments are not well developed (IOM, 2004; Feuerstein, 2007b). In addition, multiple perspectives and types of data ensure that this complex and multidimensional phenomenon and health issue is explored fully (Happ et al., 2006). The major strength of mixed methods studies is that they “allow for research to develop as comprehensively and completely as possible” (Morse, 2003, p. 195). Additional strengths include the following: (a) words and narratives can be used to add meaning to numbers, (b) numbers can be used to add precision to narratives, (c) such a study can answer a broader and more

complete range of research questions, (d) it allows for the strengths of both qualitative and quantitative methods to be capitalized upon, (e) it can provide stronger evidence for a conclusion when convergence and corroboration of findings are achieved, (f) it can add insight and understanding that may be missed with the utilization of only one method, (g) it can be used to increase generalizability of the results (h) and it provides for more complete knowledge to inform theory and practice (Johnson & Onwuegbuzie, 2004). A possible weakness of mixed methods research is that it could be challenged as less rigorous than if a multi-method design were used (Morse, 2003). Additional weaknesses include the following: (a) it may be difficult for one researcher to carry out the research with more than one approach, (b) the researcher must learn about both approaches and understand how to mix them appropriately, (c) there may be criticism from “methodological purists” (d), it is possibly more time-consuming and expensive than a shorter single methods design, and (d) there may be details that are not fully worked out including problems of paradigm mixing, how to mix quantitative and qualitative data, and how to interpret conflicting results (Johnson & Onwuegbuzie, 2004).

Mixed methods are evolving (Tashakkori & Creswell, 2007). The following is a definition of mixed methods according to John Creswell (cited in Johnson, Onwuegbuzie, & Turner (2007): “mixed methods research is a research design (or methodology) in which the researcher collects, analyzes, and mixes (integrates or connects) both quantitative and qualitative data in a



single study or multiphase program of inquiry” (p. 119). Johnson et al. (2007), through a synthesis of the current literature on mixed methods, offered the following definition, from the perspective of the social sciences, which takes the description a bit further: “mixed methods research is an intellectual and practical synthesis based on qualitative and quantitative research; it is the third methodological or research paradigm (along with qualitative and quantitative research)” (p. 129). This powerful third paradigm provides the most informative, complete, balanced, and useful research results. Mixed methods research (a) partners with the philosophy of pragmatism; (b) follows the logic of qualitative or quantitative research; (c) relies on qualitative and quantitative viewpoints, data collection, analysis, and inference techniques, combined to answer the research questions; and (d) is appreciative of broader sociopolitical issues (Johnson et al., 2007).

Creswell and Plano Clark (2007) in their original text on conducting mixed methods research offered the following definition, which is the definition this study design was based on:

Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process. As a method, it focuses on collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone (p. 5).

More recently, Creswell and Plano Clark (2010) have identified a definition of core characteristics of mixed methods research that incorporates more diverse points of view. They are;

- Collects and analyzes persuasively and rigorously both qualitative and quantitative data (based on research questions).
- Mixes (or integrates or links) the two forms of data concurrently by combining them (or merging them), sequentially by having one build on the other, or embedding one within the other
- Gives priority to one or to both forms of data (in terms of what the research emphasizes)
- Uses these procedures in a single study or in multiple phases of a program of study
- Frames these procedures within philosophical worldviews and theoretical lenses
- Combines the procedures into specific research designs that direct the plan for conducting the study

Mixed methods are justified further in a critical review of the literature related to cancer survivorship and QOL, offered by Zebrack (2000). That review emphasizes the importance of a multi-method approach to survivorship research, which utilizes both a quantitative and qualitative assessment of QOL. These multi-method approaches provide an opportunity to best understand the meanings and interpretations that survivors attribute to their life experiences, which in turn make up the quality of their lives. Research designs relying only on quantitative instruments do not adequately capture the total essence of an individual's QOL (Anderson, Bush, & Berry, 1986), and there is support in the literature to provide an opportunity for survivors to report additional concerns not covered in quantitative instruments when possible (Gotay & Muraoka, 1998). Qualitative studies of CSs tend to elicit descriptions of a process by which they

adapt to the illness (Carter, 1993; Pelusi, 1997), which may not be uncovered with quantitative data collection methods alone. Strategies such as probing interviews assist in obtaining accurate QOL data and provide more comprehensive explanations of QOL outcomes (Zebrack, 2000).

In this preliminary mixed methods study, the quantitative data were collected first within each state, followed by the qualitative data. Specifically, Phase 1 of the study consisted of recruiting participants and administering the Impact of Cancer (IOC) instrument and the symptom-focused checklist, and obtaining demographic data. The IOC scales were computed to identify outlier participants with both high and low scores on the IOC positive and negative impact scales. These participants were then recruited to participate in an in-depth interview. This captured the experiences of those survivors who were doing well and those who were not, with the goal of elucidating the most variation in the experience. Examining those doing well is important to understand factors that might promote positive adaptation, rehabilitation, post-traumatic growth, and continued employment (Alfano & Rowland, 2006). On the opposite end of the spectrum, exploring those not doing well identifies their struggles and challenges and uncovers strategies and interventions that might be needed. Creswell described this method as exploring outliers and can provide insight about why these participants diverged from the quantitative sample (2003).

In addition, a comparison of rural and urban survivors was made from the qualitative findings. By combining the quantitative and qualitative findings, the goal is a better understanding of the experience of cancer survivorship. In this study, the quantitative and qualitative data were given equal priority. However, the quantitative strand is slightly more dominant since it occurred first. The quantitative data explored many different aspects of the cancer survivorship experience, the impact of cancer, and the symptom experience, and provided for the rural/urban comparison. The qualitative data explored the physical, psychological, social, and spiritual-existential aspects of cancer survivorship, and it included rural and urban participants for comparison. Valuing the uniqueness of individual experiences of cancer survivorship, and viewing participants as active in the management of their experience, makes it essential to incorporate their subjective voice to illuminate the cancer survivorship experience (De Vito Dabbs et al., 2004). The analysis process works back and forth between an inductive and deductive process (Johnston, 2004).

According to Johnstone (2004), the main reasons to use mixed methodologies include triangulation and complementarity. Data triangulation involves reviewing and analyzing evidence from multiple sources, and utilizing an inductive process in the analysis, which integrates the quantitative and qualitative findings. The strength of data triangulation is that it results in a “thick description” and deepened insights of the phenomenon of interest that would otherwise not be possible with fewer data collection strategies. *Complementarity*

means that overlapping and diverse aspects of a phenomenon may emerge, and the mixed methods add scope and breadth to the study. In addition, participants are involved in the study in more than one way. Risks of mixed methodologies include theoretical and conceptual confusion, method dominance when not intended, too much data to be synthesized and presented well, false presumption of completely investigating a phenomenon, unknowingly capturing more than one phenomenon, and difficulty of the researcher in questioning from more than one paradigm (Creswell, 2003; Johnstone, 2004). Utilization of the QOL framework (Ferrell et al., 1995) provided theoretical congruency through all phases of the study.

A model based on the work of De Vito Dabbs et al. (2004) was used in this study to guide conceptual triangulation. Cancer survivorship is a complex and multidimensional phenomenon. This model ensures that multiple dimensions are considered and that the findings are integrated into one model of cancer survivorship, as depicted in Figure 7. Creswell (2003) offered a checklist of questions and strategies for designing a mixed methods study. These included having (a) a basic definition of mixed methods, (b) a clear strategy and criteria for choosing mixed methods, (c) a visual representation of the study design with proper notations, (d) a process of data collection and analysis as they relate to the model, (d) a description of sampling strategies for both the quantitative and qualitative data collection, (e) procedures for validating both types of data, and (f) a narrative structure that relates to the type

of mixed methods strategy being utilized. All of these elements are included in this proposal. A stronger design would be experimental/interventional; however, it is unclear, based on the state of the science at this time, what intervention would be the most effective for CSs living in rural and urban settings in Alaska. This descriptive study is needed first.

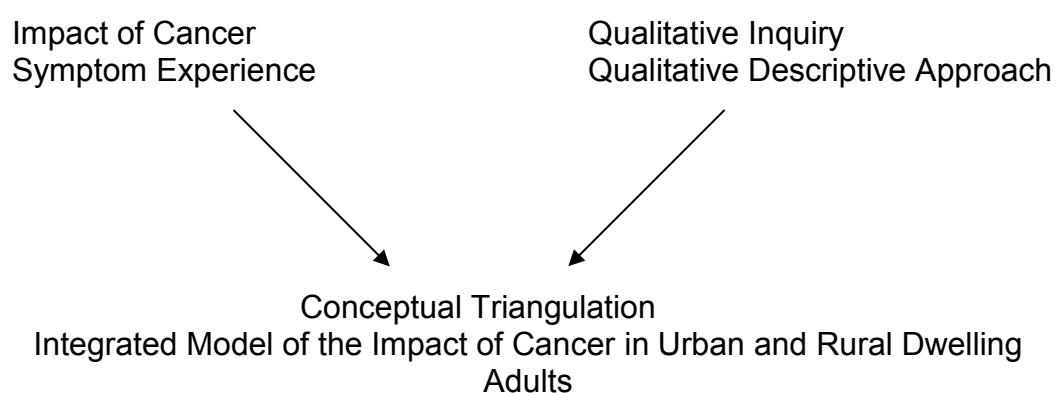


Figure 7. *Conceptual Triangulation* (based on De Vito Dabbs et al.,2004).

### **Participants and Sampling Plan**

The sampling strategies for this study were broad and inclusive. They included adult CSs who had lived with any type or site of cancer, who were cancer-free at the time of the study, who were at least 18 years of age, who were at least 18 years of age when diagnosed, and who had completed acute cancer treatment. This purposive sample reflected the continuum of survivorship, including early and late stages; included both genders and a variety of cancer diagnoses; and provided heterogeneity in the experiences of the survivors as well as the persistent and late effects.

Participant inclusion criteria consisted of no active cancer treatment such as cytotoxic chemotherapy, radiation therapy, or cancer surgery within the past 8 weeks. Long-term therapy, such as hormone manipulation for breast cancer or prostate cancer or long-term targeted therapy for CML, was allowed. Additional inclusion criteria included no recurrence of cancer, no significant or obvious cognitive impairment that would prevent them from fully participating, any gender or race/ethnicity, and being from urban, rural, and remote settings in Alaska and Oregon. Participants were able to speak, read, and write English were without severe cognitive deficits. Those with non-melanotic skin cancer were excluded from the study. Purposive sampling was utilized to ensure that equal numbers of rural/remote and urban participants were enrolled in the quantitative strand of study. Once identified from Phase 1 of the study, participants with high and low scores on the IOC, and a mixture of those from urban and rural settings were invited to participate in Phase 2. Purposive sampling for this group was utilized to obtain cases deemed information-rich for the purposes of this study, to explore the physical, psychological, social, and spiritual-existential aspects of cancer survivorship.

Historically, there has been much emphasis placed on female patients in cancer survivorship research, as much of the research has been done in breast cancer survivors (Kangas et al., 2002). This study utilized a broad sampling approach and included all cancer types, both genders, and crossed all adult age groups. Volunteer participants were recruited from the community utilizing the

following strategies: (a) networking through formal survivorship programs; (b) posting on web sites and listservs of various non-profit organizations and employee bulletins; (c) networking through cancer support group leaders; (d) networking through nurse practitioners, primary care physicians, and oncologists; (e) professional contacts; (f) newspaper ads; (g) personal contacts; (h) community events focused on survivorship; (i) postings on the OHSU campus; (j) Facebook networking; (k) flyers sent to participants in other studies, (l) mailing to GYN database in Alaska, (m) postings at an oncology rehabilitation clinic; (n) posting at the Alaska Native Medical Center clinics and acute care areas; and (o) presentations to professional and community groups. Snowball sampling was utilized to recruit additional participants. During recruitment in Alaska, the investigator did not use her position as NURSE DIRECTOR at the Alaska Native Medical Center to recruit participants. In Oregon, participants from neighboring states (such as southern Washington and northern California) who met study criteria were allowed to participate, as cancer survivors frequently seek treatment and services across state borders. These participants were included in the Oregon sample. Newspaper ads in regional areas were utilized to target recruitment of rural CSs. See Appendix B for a recruitment flyer and a lay information handout.

A pre-enrollment screening questionnaire was utilized to determine eligibility for the study (see Appendix C). The goal for the sample was to obtain maximal variation and heterogeneity in the survivorship population. The goal for



the final quantitative sample was 25 in each group to allow for statistical comparison within and between geographic locality groups and regions; that goal was based on a power analysis.

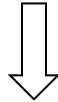
Nineteen participants were interviewed in the qualitative strand of the study. The qualitative sample consisted of participants with high and low scores on the IOC, as well as a mixture of urban- and rural-dwellers. A smaller sample size than would be considered in a standalone qualitative study is acceptable, because the qualitative strand of this study is less dominant; therefore, it does not have to be a complete study within itself (Morse, 2003). See Figures 8 and 9 for an overview of the recruitment and sampling plan for the study. Phase 1 study participants received a \$10 gift certificate and Phase 2 participants received a \$25 gift certificate. Gifts were funded by the investigator's personal financial resources.

Attempts were made to enroll participants who reflect the ethnic/minority demographics of each state (see Table 2) and represented both genders. The Alaska Native Medical Center (ANMC) in Anchorage was a recruitment site for Alaska Native participants. American Indians/Alaska Natives represented 10.3% of the Alaska sample. In addition, 7.3% of the Alaska sample reported their ethnicity as mixed race. The total percentage of ethnic minorities included in the Alaska sample was 17.7%. Ethnic diversity was not captured in the Oregon sample. In the analysis and description of the sample, race, ethnicity, and gender were compared for each geographic group (see Chapter 4).

## Phase 1: Quantitative Strand

### *Recruitment strategies:*

Recruited adult CSs through multipronged approach (online networking, postings at healthcare agencies, networking through cancer support group leaders, professional and personal networking, newspaper ads, etc.).



### *Sampling strategies:*

Stratified convenience sampling: (to obtain mixture of urban and rural participants and various sites, ages, gender and ethnicity)  
Snowball sampling  
Over-sampling of men and minorities



Conducted pre-enrollment screening questionnaire to determine study eligibility.  
Obtained written informed consent.  
Continued to recruit until at least 25 participants from each group had completed the quantitative instruments.  
Final sample reached: Alaska urban 42, Alaska rural 26, Oregon urban 34, Oregon rural 30 = total quantitative sample 132.



Participants completing the quantitative instruments were asked if they were willing to participate in an interview.  
100% of the participants indicated they would be willing to conduct an interview.  
Contact information was maintained for later contact (only accessible by local investigator and was destroyed after data analysis completed).



Participants scoring in the upper and lower quartile on the IOC are identified for qualitative sub-sample in Phase 2.  
\$10 gift certificate provided to participants in Phase 1.

*Figure 8. Recruitment and sampling plan, Phase 1.*

## **Phase 2: Qualitative Strand**

Recruited for interviews from above sub-sample.  
Study eligibility reconfirmed.  
Conducted in-depth interviews with 19 participants.  
Alaska urban-5, Alaska rural-5, Oregon urban-4, Oregon rural-5 = total qualitative sample 19.  
\$25 gift certificate provided to interview participants.

*Figure 9. Recruitment and sampling plan, Phase 2.*

Table 2

### *Ethnicity in Alaska and Oregon*

<b>Ethnicity</b>	<b>Alaska</b>	<b>Oregon</b>
White	70%	78.5%
African-American	4%	1.7%
Alaska Native/American Indian	18%	1.1%
Asian	5%	3.9% (includes Pacific Islanders)
Native Hawaiian/Pacific Islander	1%	
Hispanic (any race)	4%	11.7%
Multiracial		2.9%
Other	2%	

*Sources:* Alaska Department of Labor (2000), US Census Bureau (2010).

## **Participation of Children**

Children were not included in this study because this study is only exploring the cancer survivorship experience in adults. Cancer survivorship in children and their families is an important health issue; however, it is a unique

experience. Aspects of treatment and healthcare delivery systems are particularly unique to the pediatric cancer population (Hewitt et al., 2006). The focus of this study is specifically on adults, ranging from young adults to older adults.

### **Data Collection Procedures**

#### **Quantitative Strand**

Because the IOC is a relatively new instrument and has not been used in Alaska, a brief pilot was conducted to determine the practical utility of the instrument. Five CSs recruited from cancer support groups and personal contacts in Anchorage completed the instrument and then discussed it with the investigator. For a complete description of the pilot and the results, as well as reliability statistics for the IOC, see Chapter 4.

Based on feedback from the pilot, the participants who contacted the investigator and were determined to be eligible were given a choice of completing the instruments via a Survey Monkey web format or on paper mailed to their homes. Follow-up phone calls and emails were sent to remind the participants to complete the instruments. Informed consent was obtained when the instruments were completed.

#### **Qualitative Strand**

The method utilized in the qualitative strand of this study is qualitative description. Qualitative description draws from the general tenets of naturalistic inquiry and provides for straight description of a phenomenon. According to

Sandelowski (2000), qualitative description is categorical, is less interpretive than other qualitative methods, does not require a conceptualization of highly abstract rendering of those data, and stands alone as its own qualitative method.

Participants who scored in the upper and lower quartile on the IOC, and a mixture of rural and urban participants, were recruited to participate in in-depth interviews. Using the same sample for both strands of the study minimizes threats to internal validity. Participants were asked on their demographic information data sheet submitted with the quantitative instruments if they would be interested in participating in a follow-up interview. Those who met the criteria were contacted by the researcher and arrangements were made for an interview. Participants in the Anchorage area were given a choice to be interviewed in person or by phone. Rural participants from Alaska and participants from Oregon were interviewed over the phone. Interviews were audio-taped and transcribed verbatim by the researcher. Interviews lasted between 40 and 105 minutes, with the average being approximately 60 minutes.

### **Demographic Data**

The following demographic data were collected: age, gender, ethnicity, racial category, type of cancer, cancer site, type of treatment regimen, time since diagnosis, time since primary treatment completed, type of medical care currently receiving (including adjuvant cancer treatment), marital status,

employment status, type of health insurance coverage, educational level, address, how long resided at current location (if they had relocated, previous locations and timeframes), and phone number.

In addition, co-morbidities were assessed. Co-morbidities have been found to influence functional status particularly in older CSs. In fact, Garman et al. (2003), using a multivariate analysis, found that co-morbidity, not survivorship of cancer, relates to functional status, when controlling for age, race, sex, education, marital status, depression, and cognitive status. Another central issue is the challenge in distinguishing between late effects and long-term impact in survivorship is discerning how much of the experience is due to cancer or cancer treatment and how much is due to natural aging (Foley et al., 2005; Shultz et al., 2003). In addition, participants were asked if they have a survivorship care plan in place, which is consistent with the IOM recommendations. This was asked as “Do you have a summary of your cancer treatment available to you that a healthcare provider could use to see exactly what treatment you had?” In addition, they were asked if they have had cancer more than once. See Appendix D for the demographic participant data collection form.

### **The Impact of Cancer Instrument**

The IOC instrument is designed to measure the unique aspects of long-term survivorship (five years or more post-diagnosis). Original testing was conducted on an 81-item version of the instrument, which originally had six

subscales and, after factor analysis, was revised to have 10 subscales. The most recent version (IOCv2) has two higher order scales, a positive impact scale and a negative impact scale, each consisting of four subscales. See Table 3 for a list of the subscales.

Table 3.

*IOC Subscales*

<b>Positive Impact Scale Subscales</b>	<b>Negative Impact Scale Subscales</b>	<b>Other</b>
Altruism/empathy	Appearance Concerns	Employment Concerns
Health Awareness	Body Change Concerns	Relationship Concerns (partnered)
Meaning of Cancer	Life Interferences	Relationship Concerns (unpartnered)
Positive Self-evaluation	Worry	

Source: Crespi et al., 2008.

Individual items included in the IOC are worded to indicate level of agreement (*strongly agree, agree, neutral, disagree, and strongly disagree*). It was developed by extensive qualitative interviewing of CSs and underwent a robust process of establishing content validity by utilizing an expert panel of CSs, researchers, and clinical practitioners. One of its biggest strengths is that it attempts to be more specific to long-term survivors and measures distinct and relevant constructs related to this stage. Its limitations include minimal data to support estimates of reliability, and further work is needed on confirming the

factor structure. In addition, it still needs evaluation of responsiveness over time (Zebrack et al., 2006). Further psychometric work was conducted on the IOCV2 to provide additional evidence for validity, in a large sample of BCSs 5 to 10 years after diagnoses (Crespi et al., 2008). The language in the individual items is more consistent with the long-term survival phase of survivorship and has more of a feeling of “moving forward” and not as much focus on the earlier diagnosis and treatment experiences as is the case with other instruments. The IOCV2 used in the present study is included in Appendix E.

### **Comparison with Other Instruments**

An alternative instrument, the Quality of Life-Cancer Survivors (QOL-CS), was also considered for this study. QOL is a very common outcomes measure in cancer survivorship research (Ferrell et al., 1995; Ganz et al., 2002; Hassey Dow et al., 1999; Heidrich et al., 2006; Mellon et al., 2006; Smith et al., 2006; Stewart et al., 2001). However, in the literature, there is no standardization of instruments utilized and many are not well described. Some researchers use generic QOL instruments such as the SF-36, which may not capture specific attributes of the cancer survivorship experience. The QOL-CS, while specific to survivorship, has not been widely used. In addition, the individual items may not be distinct to later survivorship (Zebrack, 2006).

Another commonly used instrument is the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-CORE 30 (EORTC QLQ-C30). This 30-item instrument is well established and measures



physical, role, emotional, and social functioning, as well as disease-specific symptoms, financial impact, and global QOL; it has been used extensively in cancer patients (Howat et al., 2006; Victorson, Cella, Wagner, Kramer, & Smith, 2007); however, it is not specific to survivorship.

A shorter instrument, the Brief Cancer Impact Assessment (BCIA), is based on the IOC and is showing promise in cancer survivorship research. This less comprehensive instrument may be more practical for clinical trials; however, it appears to measure different aspects of the impact of cancer in survivors than the longer version of the IOC (Alfano et al., 2006). The BCIA is also being utilized in clinical practice settings. The IOC was ultimately chosen as the quantitative measure for this study because of the comprehensiveness of the instrument, the various dimensions of the impact of cancer that it measures, and the fact that it is most likely to fully elucidate the phenomenon under study and capture the uniqueness of the survivorship experience, including the long-term experience. While aspects of the physical domain are somewhat lacking in the IOC, this was accommodated by supplementing with a symptom measure. In addition, it is based on the work of Ferrell et al.(1995), which provides congruency between the quantitative and qualitative strands of the study. See Appendix F for a chart that summarizes the psychometric properties of the IOC, the QOL-CS, the EORTC QLQ-C30, and the BCIA.

## Symptom Measure

The Memorial Symptom Assessment Scale Short Form (MSAS-SF) was administered, and measures 32 symptoms and their associated frequency and distress. It is a multidimensional symptom assessment instrument that rates physical and psychological symptoms, has demonstrated validity and reliability in the cancer population, and is considered easy to use (Chang et al., 2000); it captures multiple symptoms common in cancer survivors. Participants rate each symptom from 0 to 5, 0 indicating symptom not present and 5 indicating symptom caused very much distress. In addition to the total score, there are three subscales: a global distress index, physical symptom distress, and psychological symptom distress. In this study, the physical symptom distress subscale was used.

The MSAS-SF has been used in studies focusing on the acute phases of cancer as well as during survivorship. One study reported a Cronbach's alpha of 0.85 (Thompson, 2007), and another reported Cronbach's alphas for the subscales ranging from 0.76 to 0.87 (Chang et al., 2000). The MSAS-SF has also demonstrated evidence for convergent and criterion validity (Chang et al., 2000). There is conceptual overlap between the IOCV2 subscale, body change concerns, and the MSAS-SF. One item on the body change concerns subscale inquires about energy not returning to pre-cancer levels, in contrast to the symptom of fatigue as measured on the MSAS-SF. See Appendix G.

### **In-Depth Interviews**

Interviews were semi-structured and used open-ended questions. The main interview questions were as follows: (a) what is it like to have experienced cancer? (b) what is it like to be a cancer survivor? (c) how has the experience of having survived cancer affected you? (d) what has helped you as a survivor? (e) what has not been helpful? and (f) how do you think living in a rural (or urban) area has impacted your experience? Additional questions for the interviews emerged from the analysis of the quantitative data. Particular attention was paid to cultural issues as this has been identified as a gap in the literature (Oseni & Jatoi, 2007), and Alaska is extremely culturally diverse.

Follow-up and probing questions were employed as necessary and to elicit the richness and depth of data desired in order to fully explore the phenomenon. Examples of probing questions included can you tell me a little bit more about that?, or can you give me a specific example? or “can you tell me a story about that? As the interviews progressed, questions such as these—tell me about your experience of getting cancer and becoming a survivor? what were you thinking about? what’s that like for you? and has anything surprised you?”—were effective in eliciting rich responses. An interview guide was used in conducting the interview. See Appendix H for the detailed interview guide.

## **Field Notes**

In addition to the interviews, field notes, describing what the researcher observed, experienced, and reflected upon during the interviews, was utilized. Field notes were completed after every participant interview, to encourage reflection, creativity, and understanding of the experience of collecting the data and interacting with participants. Information such as where the interview took place, who was present, a description of the setting, social activities, and interactions were recorded. In addition to the observations, the field notes included the researcher's feelings and reactions to what was being observed, and any insights and interpretations. Field notes help provide a complete picture of the phenomenon and assist the researcher in moving through the data analysis process (Patton, 2002).

## **Data Analysis**

Specific data analysis conducted for both the quantitative and qualitative strands of the study are summarized in Tables 4 and 5.

### **Quantitative Strand**

**Analysis for study aim #1.** Descriptive statistics were obtained from the demographic data and instruments. Means, SDs, frequencies for each item, variable, and subscale of the IOC were computed, as well as the total score. Reliability was evaluated by examining the internal consistency of the instrument subscales. For the IOC, the method described by Zebrack and

colleagues (2006) was followed. For the MSAS, the method described by Chang et al. (2000) was used to calculate internal consistency of the subscales. As part of the exploration of the impact of cancer, zero order correlations were calculated between age, the time since diagnosis, and the symptom scale and the major outcome variables of the study.

Table 4.

*Phase I-Data Analysis*

<b>Aim</b>	<b>Variables</b>	<b>Measure</b>	<b>Analysis</b>
<b><i>Phase I</i></b>			
Aim #1-Explore the impact of the cancer survivorship experience	Impact of Cancer  Symptom Experience	IOCv2  MSAS-SF	Descriptive Statistics  Zero order correlations between time since treatment and outcome variables
Aim #2-Compare the cancer survivorship experience in rural and urban adults within and between two regions of the Pacific Northwest	Impact of Cancer  Symptom Experience	IOCv2  MSAS-SF	2 x 2 ANOVA  2 x 2 ANOVA

Table 5-

*Phase II-Data Analysis*

<b>Phase II</b>	<b>Interviews</b>	<b>Data transcription</b>	<b>Analysis</b>
Aim #3-Explore and compare the physical, psychological, social and spiritual-existential aspects of cancer survivorship in rural and urban adults	Various aspects of the cancer survivorship experience are described	Interview transcripts, transcribed verbatim	<p>Content analysis and constant comparison analysis</p> <p>Underlying patterns and themes identified</p> <p>Rural and urban perspectives compared</p> <p>Experiences between and within the two regions compared</p>
Data Integration			<p>Inductive and deductive approach between all types of data</p> <p>Quantitative and qualitative findings were compared and contrasted.</p>

**Analysis for study aim #2.** A 2 x 2 analysis of variance (ANOVA) was conducted to allow for the four individual groups to be compared as well as the

two regions. The ANOVA test was chosen for this exploratory study as the best way to compare within and between groups because each group is independent, and all samples come from populations having the same continuous distribution. SPSS version 17 software was utilized.

### **Qualitative Strand**

**Analysis for study aim #3.** The product of a qualitative analysis is a rich description of a process or phenomenon. Data analysis is continuous and occurs simultaneously with data collection. The researcher was immersed in the data. The methods of analysis were qualitative content analysis and constant comparative analysis.

### **Content Analysis**

Qualitative content analysis is an analysis strategy in qualitative descriptive studies. It is the least interpretive of the qualitative analysis approaches in that the goal is to represent the data just as it is, while answering the who, what, and where of people, places, and activities (Sandelowski, 2000). Content analysis is a more deductive qualitative analysis method and is a way to confirm the descriptions of patterns and themes uncovered in the data (Lincoln & Guba, 1985). It involves summarizing the informational content from multiple data collection methods and assumes that the patterns and themes of interest have been previously revealed and described (Denzin & Lincoln, 2005; Sandelowski, 2000).

The data were read and coded by conceptualizing underlying patterns and themes. Data files were created and organized, and simultaneous memos regarding the data were written throughout the coding process. The data were sorted into patterns and themes, focusing on key events, descriptions of symptoms and experiences, and interactions. Patterns and themes were identified, coded, and continually revised throughout the analysis phase of the study.

### **Constant Comparative Analysis**

The process of constant comparative analysis guided the conceptualization of the patterns of experiences with cancer survivorship. The purpose of this design is to generate conceptual and descriptive categories from the data (Kendall, 1999). N Vivo qualitative software was utilized. Field notes and participant observations were incorporated into the analysis, and data were sorted into patterns and themes.

### **Scientific Rigor in Qualitative Methods**

Qualitative reliability and validity criteria suggested by Creswell and Plano Clark (2010) was utilized in this study. Checking for qualitative validity involves evaluating whether the information obtained through qualitative data collection is accurate and reflects the perspectives of the participants. More than one strategy is recommended. Strategies utilized in this study to ensure validity included member checking, data triangulation, and additional



researcher data analysis. Strategies for inter-coder agreement were utilized to ensure reliability. See Chapter 4 for the procedures followed to ensure validity.

### **Member Checking**

Once data were analyzed, participants were asked to give feedback on the key ideas that emerged from the data analysis. They were asked if the ideas resonated with their experiences as a cancer survivor, and if they were an accurate reflection of their experiences.

### **Data Triangulation**

This involves gathering data from several individuals with varying cancer survivorship experiences, as described in the recruitment and sampling plan for this study.

### **Additional Researcher Data Analysis**

Peers and faculty from OHSU participated in qualitative data analysis of several interviews and compared analysis with the researcher. During data collection, the researcher engaged an expert qualitative researcher who reviewed initial transcripts to ensure that there was not a biased line of questioning being used with the participants.

*Inter-coder agreement.* Peers and faculty from OHSU who were familiar with qualitative analysis techniques coded transcripts generated from this study and determined if they arrived at the same codes as the researcher.

Additional strategies utilized to facilitate qualitative data analysis and to decrease bias included a reflexivity journal. A reflexivity journal is a way for the

researcher to reflect on his or her biases. The process for field notes has been previously described. The reflexivity journal, in conjunction with the field notes, assisted the researcher in examining her feelings and biases as she progressed through the research process, and they provided a continual process of self-reflection. A decision audit journal was maintained and included the rationale for any decisions made during data collection and analysis.

### **Integration of results**

Final analysis of the quantitative and qualitative data occurred together to generate the overall findings from this study. Findings were compared, contrasted, summarized, and brought together into one narrative (see Chapter 5). According to Bryman (2007), “in genuinely integrated studies, the quantitative and qualitative findings will be mutually informative” (p. 21). The researcher utilized both inductive and deductive analytic techniques and went go back and forth between the two, as suggested by Johnstone (2004). A comparative matrix was utilized to compare, contrast, and integrate the quantitative and qualitative findings. Findings from the interview transcripts were compared with item responses on the IOC to clarify perceptions.

Several authors have reported challenges with truly integrated findings. Some of these challenges include (a) intrinsic aspects of quantitative and qualitative research, (b) challenges with audiences and publications, and (c) methodological preferences of the researcher (Bryman, 2007). In this study,

equal weight and priority were given to the quantitative and qualitative results; however, the quantitative strand is slightly more dominant as it occurred first. Data triangulation was achieved by comparing different sources of data and findings. Triangulation strengthens a study by combining methods. This study accomplished methodological and data triangulation (Patton, 2002).

Mixed methods research offers an opportunity to pay attention to both data analysis and interpretation (Creswell & Plano Clark, 2010). It is also vital to note the importance of defining validity in a mixed methods context and the overall importance of the ability of the researcher to draw meaningful and accurate conclusions from all of the data in the study. This reinforces the idea of “inference quality,” which is the accuracy with which the researcher draws inductive and deductive conclusions from a study (Teddle & Tashakkori, 2003, p. 36).

### **Power Analysis: Quantitative Strand**

The sample size was large enough to compare the rural- and urban-dwelling participants between and within regions using the 2 x 2 ANOVA test. Bettencourt and colleagues (2007) in an extensive literature review of the breast cancer experience of rural women found that most studies that have compared rural and urban residents have utilized large national databases. In the non-database studies, about two-thirds of the studies had relatively small sample sizes (100 or less with a range of 6-100), and 78% of these studies did not utilize an urban comparison group. In the studies that compared rural and

urban samples, the sample size ranged from 24-451 (Bettencourt et al., 2007).

This is a preliminary and exploratory study and achieved a sample size of 132.

The original sample size target was 25 in each group ( $4 \times 25 = 100$ ).

This is based on a Pass 2011 ANOVA power analysis, which establishes the sample size of 25 per group for the interaction effect at an effect size of 0.3 and an alpha of 0.05 (Neter, Kutner, Nachtsheim, & Wasserman, 1996; Winer, 1991). The estimated effect size is based on the fact that this is a preliminary study, and it is unknown what the effect size is due to a lack of similar studies to base it on.

### **Sample Size Determination: Qualitative Strand**

As previously discussed, the sample size for the qualitative strand was determined by the results of the quantitative strand. Interviews revealed rich data, and researcher saturation was achieved after conducting 19 interviews (see Chapter 4).

### **Potential Limitations**

Response bias is commonly reported in cancer survivorship research and is a limitation for this study. Are certain types of individuals more likely to respond to questionnaires and are they different from than those who do not respond? (Yabroff et al., 2004). A second limitation is that the data for the quantitative strand of the study were obtained through self-report measures. The qualitative strand of the study compensated for this to some agree, by further elucidating the survivorship experience in more detail. Conversely, a

third potential limitation is that the data from the qualitative strand, since it is follow-up data and not as complete as the quantitative strand, could be viewed as less than comprehensive. If the supplemental data are less comprehensive than what would be obtained in a complete study, it could be considered thin. One way to compensate for this weakness is to ensure that both methods are fully described, as well as the way that less saturated data sets and complimentary relationships between data sets are verified (Morse, 2003). These limitations have been addressed in the data analysis section. The intent of the study is exploration/description and follow up to the quantitative data, not to conduct a stand-alone comprehensive qualitative study. In addition, explicit criteria for validity for both strands of the study have been described, as well as the statistical and qualitative analysis conducted.

Creswell and Plano Clark (2010) identified several possible threats to validity in sequential mixed methods designs with regard to data collection: (a) selecting the same or different individuals for the qualitative and quantitative data collection, (b) using the same sample sizes for both strands, (c) not choosing participants for follow-up who helped explain significant results, and (d) not designing an instrument with sound psychometric properties. In this study, specific sampling strategies have been described that outline the specific purpose for the qualitative and quantitative strands of the study. Specific criteria from the IOC results were utilized to choose participants to

interview in-depth. In addition, the IOC has been previously tested and has shown sound psychometric properties in CSs (Appendix B).

Creswell and Plano Clark (2010) also identified several threats to validity with regard to data analysis issues: (a) choosing weak quantitative rules to follow up on qualitatively, (b) choosing weak qualitative findings to follow up on quantitatively, and (c) not addressing validity issues. The methods in this study that have been identified for quantitatively identifying who participated in the qualitative strand are sound and have been justified by previous studies (Alfano & Rowland, 2006) as well as by mixed methods experts (Creswell, 2003). In addition, strategies to address validity issues for both the qualitative and quantitative strands of the study have been described. Lastly, since the study was conducted only in two states in the Pacific Northwest, and there is a relatively small sample size, generalizability outside the region is limited.

## **Ethical and Regulatory Requirements**

### **Protocol Review**

The research protocol and procedures for protecting the rights of human subjects were reviewed and approved by the Oregon Health & Science University Institutional Review Board, the OHSU Knight Cancer Institute Clinical Research Review Committee, and the Alaska Area Institutional Review Board. Tribal review and approval was conducted by the Alaska Native Tribal Health Consortium and the Southcentral Foundation.

**Informed Consent**

Participants were recruited from survivorship programs and hospitals and clinics located in Alaska and Oregon and through the community. Newspaper ads and web postings in regional areas were utilized to ensure adequate participation from remote and rural sites. Those who were interested in participating in the study contacted the researcher by telephone or email, and a brief description of the study was given including a review of the eligibility criteria. All those who were eligible and willing to engage in an interview or complete study questionnaires gave written informed consent. See Appendix I for the IRB-approved informed consent.

## **CHAPTER 4**

### **RESULTS**

This chapter summarizes the results of the study. It is organized into seven sections: a) a description of the overall sample characteristics, including how the participants were recruited into the study, the participants' geographical locations of residence and demographic and cancer-specific characteristics; b) the results of the brief instrument pilot; c) the quantitative findings, which include correlations and comparison of study outcomes across the four geographical groups; d) a description of the qualitative sub-sample; e) the qualitative findings, which includes a framework of survivorship, an exploratory description of cancer survivorship, and a comparison of the rural and urban cancer survivors' experiences; f) a description of profiles of intensity and impact of survivorship experiences; and g) a comparison of the quantitative and qualitative findings.

The purpose of this descriptive and mixed methods study was to explore the impact of cancer in rural- and urban-dwelling adult cancer survivors (CSs) living in two regions of the Pacific Northwest. The three study aims are presented sequentially, followed by findings associated with each aim.

#### **Aim #1 and Its Associated Findings**

Aim #1: Explore the impact of the cancer survivorship experience and symptom experience in rural- and urban-dwelling adult CSs in two regions of the Pacific Northwest (Quantitative).



## **Quantitative Sample**

**Recruitment.** Participants were recruited utilizing stratified convenience sampling and they consisted of CSs living in urban and rural settings of Alaska and Oregon. A summary of the recruitment strategies and numbers of participants successfully recruited into the study from each strategy are included in Table 6. Because of the variety of recruitment strategies utilized, it is unknown how many people were actually recruited into the study and declined to participate. Therefore, it is not feasible to calculate an overall response rate. Once potential participants contacted the researcher for information about the study and were screened for eligibility, 70% of this group completed the study questionnaires. Participants were given a choice of method for survey administration. The large majority, 88.6% of the participants, completed the survey via a web-based Survey Monkey format, and 11.4% completed paper surveys. All of the participants were willing to participate in an interview.

**Demographics.** The descriptive data for the sample were obtained from the demographic data collection form (see Appendix D). The descriptive statistics are depicted according to the four naturally occurring groups (Alaska urban, Alaska rural, Oregon urban, Oregon rural) as well as the total sample. Table 7 shows the number of participants by region and location.

Table 6

*Most Successful Recruitment Strategies*

<b>Recruitment Strategy</b>	<b>Alaska</b>	<b>Oregon</b>	<b>Total</b>
Formal survivorship programs- emailed flyer		28	28
Web based postings on Listervs	23		23
Support group leaders	5	11	16
Networking through NP's	10	5	15
Newspaper ads	10	2	12
Professional contacts	7	4	11
Posting at OHSU		5	5
Community events	4		4
Personal contacts	4		4

Note: NP=nurse practitioner, OHSU=Oregon Health & Science University

Table 7

*Region and Location (N = 132)*

<b>Region</b>	<b>Location</b>		<b>Total</b>
	Rural	Urban	
<b>Alaska</b>	26	42	68
<b>Oregon</b>	30	34	64
<b>Total</b>	56	76	132

**Geographic Locations.** The locations where participants resided at the time of the study are shown in Figures 10 and 11. In Alaska, participants were from the three major urban centers of Anchorage, Fairbanks, and Juneau. The rural participants represented the majority of regions of the state, from as

far north as Barrow, as far west as Nome, and as far south as Petersburg. Rural participants included those living in remote and isolated areas as well as rural communities on the road system. In Oregon, urban survivors from the Portland, Salem, Corvallis areas participated, with a particularly large participation from Bend. Rural participants lived in most regions of the state, including the coastal areas, southern Oregon, and as far east as Pendleton and Burns. A small number of participants were from the neighboring states of Washington and California, and they were included with the Oregon sample. Ten percent of the sample changed their location of residence within one year of completing cancer treatment.

**Demographics.** The majority of the sample were female, white, married, employed, well-educated, and insured, and on the average they were middle-aged. The average time since cancer treatment was completed was 6.7 years (see Tables 8 and 9).

Figure 12 shows the time since treatment completed by timeframe ranges. For survivors of more than one cancer, time from the most recent cancer treatment completion was calculated. The sample represents a mix of early and late CSs.

**Specific cancer characteristics.** Table 10 shows the cancer diagnosis profile for the sample. Breast CSs represented more than half of the sample (56.1%). Just under 17% of the total sample had experienced cancer more

than once, with approximately 1/3 of this group having a recurrence of the same cancer type (see Table 11).



*Figure 10.* Location of Alaska participants by borough



Table 8

*Sample Characteristics by Region/Location*

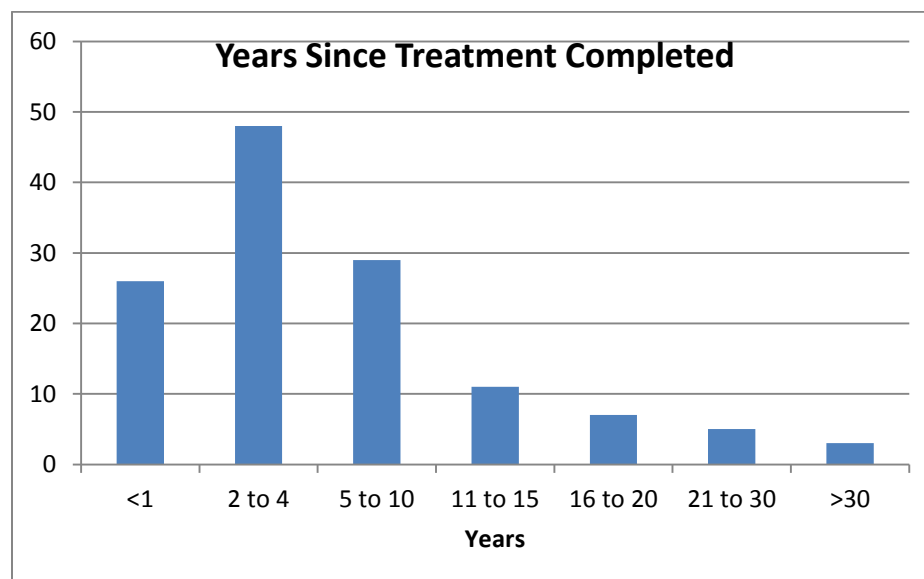
	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=42	n=26	n=34	n=30	N=132
	%	%	%	%	%
<b>Gender</b>					
Female	85.7	96.2	70.6	86.7	84.1
Male	14.3	3.8	29.4	13.3	15.9
<b>Employment</b>					
Full-time	57.1	46.2	44.1	16.7	42.7
Part-time	21.4	30.8	17.6	16.7	21.4
Not employed	21.4	23.1	38.2	63.3	35.9
Missing				3.3	
<b>Education</b>					
High school	20	7.7	24.2	20	18.6
Some college	12.5	19.2	12.1	33.3	18.2
Associate's	7.1	15.4	6.1	10.0	9.1
Bachelor's	17.5	26.9	36.4	23.3	25.0
Graduate	40.5	7.7	21.3	13.3	21.2
degree					
Missing	2.4	23.1			7.9
<b>Marital status</b>					
Married	66.7	80.8	79.4	60.0	71.2
Not married <sub>a</sub>	19.0	11.5	17.6	30.0	19.7
Never married <sub>b</sub>	14.3	7.7	2.9	10.0	9.1
<b>Race/Ethnicity</b>					
Alaska Native	11.9	3.8			4.6
American	2.4				0.8
Indian					
>One race	2.4	15.4	5.9		5.3
White	83.3	79.9	94.1	100.0	88.6
Missing		.9			0.7
<b>Health insurance</b>					
Medicaid				3.3	.8
Medicare	9.5	11.5	20.6	60	24.2
IHS/Tribal <sub>c</sub>	14.3				4.5
Private	76.2	84.6	73.5	36.7	68.2
No coverage		3.8	5.9		2.3

HS=high school, a = Not married or partnered, b = Never married or partnered,  
c = Indian Health Service/Tribal healthcare beneficiary

Table 9

*Mean Age, Age at Diagnosis, and Time Since Treatment in Years*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=42	n=26	n=34	n=30	N=132
<b>Age</b>					
Mean	56.31	54.27	58.71	64.57	58.40
SD	7.78	9.38	7.92	11.35	9.67
Min	39	33	44	27	27
Max	68	67	73	79	79
<b>Age at Cancer Diagnosis</b>					
Mean	49.63	46.19	51.47	54.07	50.44
SD	9.72	10.27	11	14.83	11.82
Min	28	21	26	20	20
Max	69	61	71	73	73
<b>Time Since Treatment</b>					
Mean	5.72	5.89	6.29	9.20	6.70
SD	6.52	6.38	6.82	10.55	7.71
Min	.75	.25	1	.33	.25
Max	26	20	36	36	36



*Figure 12. Years Since Treatment Completed.*

Table 10

*Cancer Diagnosis*

	AK Urban	AK Rural	OR Urban	OR Rural	Total
	n=42	n=26	n=34	n=30	N=132
	%	%	%	%	%
Breast	69	61.5	38.2	53.3	56.1
Gynecologic	4.8	11.5	11.8	10	9.1
Lymphoma	4.8	11.5	11.8	6.7	8.3
Head and neck	7.1	3.8	11.8	3.3	6.1
Colorectal	4.8	3.8	11.8		5.3
Melanoma	4.8	3.8	5.9	3.3	4.5
Prostate	4.8		5.9	3.3	3.8
Lung				13.3	3
Leukemia/ Hematologic		3.8	2.9		1.5
Testicular				3.3	.8
Multiple myeloma		3.8			.8
Bladder				3.3	.8

Table 11

*Second Cancer Diagnosis for Those with Multiple Cancers*

	AK Urban	AK Rural	OR Urban	OR Rural	Total
	n=9	n=4	n=6	n=3	N=22
	%	%	%	%	%
<b>Second Cancer Type</b>					
Breast	37.5	50.0			22.7
Melanoma	12.5		50	33.3	22.7
Gynecologic			16.7		5
Prostate	12.5		16.7		9
Colorectal				33.3	5
Lung	12.5				5
Testicular	12.5				5
Kidney	12.5				7
Bladder		25.0			7
Other			16.7	33.3	1.5
Missing	12.5	25.0			10.1
<b>Recurrence of same cancer type</b>	44.4	50.0	16.7	33.3	36.4



**Treatment modalities.** Cancer treatment modalities were most commonly surgery (80.3%), followed by chemotherapy (62.9%) and radiation (53.8%). The number of treatment modalities that each participant received was pretty evenly spread between one (34.8%), two (34.1%), and three (31.1), respectively. Approximately a quarter of the participants (26.5%) were currently participating in some sort of complimentary or alternative medicine (CAM) therapies, with just under half of this group receiving more than one type of CAM. The most common types of CAM utilized were acupuncture, supplements, and massage (see Table 12 for cancer treatment modalities and CAM).

#### **Co-morbidities, health and healthcare ratings, and lifestyle**

**impact.** Just under half of the participants reported having 1 to 2 co-morbidities. The most common co-morbidities reported were high blood pressure, depression, and arthritis (see Table 13). Over 40% reported that cancer had had an impact on their ADLs. The largest proportion of the sample rated their health as “very good” (45.7%), their access to healthcare as “excellent” (47.3%), and their satisfaction with healthcare as “excellent” (46.9). These ratings reflected perceptions of their overall healthcare, not just cancer care. The majority (64.1%) reported possessing a summary of their cancer treatment (see Table 13).

Table 12

*Cancer Treatment Modalities and CAM*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=42	n=26	n=34	n=30	N=132
	%	%	%	%	%
<b>Modalities</b>					
Chemotherapy	59.5	73.1	70.6	50	62.9
Radiation	38.1	57.7	32.4	63.3	53.8
Surgery	88.1	88.5	70.6	73.3	80.3
<b>Number of Modalities</b>					
One	26.2	26.9	44.1	43.3	34.8
Two	38.1	26.9	38.2	30	34.1
Three	35.7	26.2	17.6	26.7	31.1
<b>CAM (at time of study) N=35</b>	45.7	11.4	31.4	11.4	35
<b>CAM Type</b>					
Acupuncture	68.7		27.3		40
Supplements	43.8	100		75	40
Massage	50		45.5		37.1
Meditation	18.8			50	14.3
Diet	6.3	100			14.3
Chiropractic	6.3		36.4		14.3
Reiki		25	18.2	50	14.3
Imagery	12.5	50			11.4
Naturopath	18.8		9		11.4
Yoga	12.5	25	9	25	11.4
Other			18.2	50	11.4
Healing Touch	12.5		9		8.6
Traditional or holistic healing	18.8				8.6
<b>Percentage using more than one CAM type</b>	25	75	45.5	75	43

Table 13

*Co-morbidities*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=42	n=26	n=34	n=30	N=132
	%	%	%	%	%
<b><i>Number of co-morbidities</i></b>					
Zero	14.4	30.8	19.42	7.7	17.9
One to two	3.8	30.8	52.9	36.6	43.2
Three to four	28.6	23	17.6	13.3	23.5
Five or more	9.5	7.6	12.9	20	9.8
<b><i>Co-morbidity type</i></b>					
High blood pressure	42.9	15.4	14.7	46.7	31
Depression	26.2	7.6	14.7	20	18.2
Arthritis	11.9	15.4	5.8	33.3	15.9
High cholesterol	14.3	3.8	14.7	16.7	12.9
Asthma	7.1	11.5	11.7	10	9.8
Thyroid disease	14.3	11.5		10	9.8
Heart disease	9.5	7.6	5.8	7.7	7.5
Osteoporosis	7.1	7.6	2.9	3.3	5.3

Table 14

*Cancer Impact on ADL, Self-Rated Health, Access to Healthcare and Satisfaction With Healthcare, Summary of Cancer Treatment*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=42	n=26	n=34	n=30	N=132
<b>ADL Impact (yes)</b>	42.9	34.6	41.2	40	40.5
<b>Health Rating</b>					
Excellent	14.3	25	24.2	6.7	17.1
Very Good	50	54.2	36	43.3	45.7
Good	21.4	12.5	24.2	40	24.8
Fair	11.9	8.3	12.1	10	10.9
Poor	2.4		3		1.6
<b>Access to Healthcare</b>					
Excellent	54.8	48	47.1	36.7	47.3
Very good	28.6	24	44.1	43.3	35.1
Good	14.3	16	2.9	13.3	11.5
Fair	2.4	8	5.9	6.7	5.3
Poor		4			.8
<b>Satisfaction With Healthcare</b>					
Excellent	47.6	25	24.2	50	46.9
Very good	45.2	54.2	36.4	33.3	41.5
Good	7.1	12.5	24.2	10	8.5
Fair		8.3	12.1	6.7	2.8
Poor			3		.4
<b>Summary of Cancer Treatment (yes)</b>	57.1	73.1	73.5	55.2	64.1

### **Aim #2 and Its Associated Findings**

Aim #2: Compare the cancer survivorship experience in rural- and urban-dwelling adult CSs within and between two regions of the Pacific Northwest (quantitative). Main effects were proposed for region and urban/rural status and a region by urban/rural status interaction based on the

differences in access to care between the regions and population groups.

These hypotheses should be viewed as exploratory because of the limited information available about CS experiences in adults in both regions.

*Hypotheses:* Urban dwellers will have more positive scores on study instruments than rural dwellers, Oregonians will have more positive scores than Alaskans, and there will be an interaction between region and urban/rural status such that urban dwelling Oregonians will have more positive scores than urban Alaskans, and rural Oregonians will have more positive scores than rural Alaskans.

### **Instrument Pilot**

Prior to this study, the Impact of Cancer version 2 (IOCv2) instrument had not been utilized in Alaska; therefore, a brief pilot of the instrument was conducted. CSs who met study inclusion criteria were recruited from Anchorage cancer survivor support groups. Five CSs meeting the study inclusion criteria participated in a brief instrument pilot of the IOCv2 and the participant demographic form, to determine the practical utility, readability, and comprehension of these instruments. This group consisted of 3 survivors of breast cancer, 1 prostate and 1 melanoma, 4 women and 1 man, with ages from 45 to 68. Time since treatment completed ranged from 2 years to 25 years. Four CSs were from an urban setting, and one was from a rural area. Pilot participants found the instruments to be clear and understandable. No concerns were raised regarding the IOCv2 instrument. Feedback was given

regarding the question about health insurance coverage on the participant demographic data collection form. Various types of coverage were added as options to make it clearer for the participants. Four of the pilot participants completed the survey on paper, and one utilized the web-based Survey Monkey format. All of the participants indicated that they would be willing to complete the survey either on paper or via the web-based program, which confirmed the researcher's plan to allow participants to choose the method that would work best for them.

## **Quantitative Findings**

### **Outcome Variables**

The two instruments utilized in the study were the Impact of Cancer Scale version 2 (IOCV2) and the Memorial Symptom Assessment Scale (MSAS), a physical symptom subscale (see Appendixes E and F). The IOCV2 is divided into 11 subscales, and two higher-order subscales, which are the positive and negative impact subscales. Individual items are worded to indicate level of agreement (strongly agree = 5, agree = 4, neutral = 3, disagree = 2, and strongly disagree = 1). The subscales included in the positive impact scale are *altruism/empathy, health awareness, meaning of cancer, and positive self-evaluation*. For the positive impact constructs, a higher number indicates more positive impact. Subscales included in the negative impact scale are *appearance concerns, body change concerns, life interferences, and worry*. Additional subscales of the IOC are employment

concerns and relationship concerns (partnered and not partnered). For the negative impact constructs, employment concerns and relationship concerns, a higher number indicates more concerns. For the physical symptom measure, a higher score indicates a worse symptom experience. Means, standard deviations, and sample size for the outcome variables are included in Table 15. Reliability statistics were conducted on this sample for the IOC and are compared with the findings from Crespi et al. (2008). Cronbach alphas were similar across the variable between the two samples. Two exceptions were positive self-evaluation and relationship concerns (partnered). See Table 16.

### **Correlations**

Pearson correlations were conducted between age, age at diagnosis, time since treatment, and the study outcome variables as measured in the IOCV2 and the MSAS instruments. Correlations were also conducted between the physical subscale of the MSAS and the IOCV2 outcome variables.

There were no statistically significant correlations between age at diagnosis and the outcome variables. There were no statistically significant correlations between age, time since treatment, and physical symptoms with the IOCV2 subscales of altruism/empathy, health awareness, meaning of cancer, positive self-evaluation, positive impact, and appearance concerns. Statistically significant correlations are reported in Table 17.

Table 15

*Descriptive Statistics-Outcome Variables-mean scores by region and locality*

	AK Urban		AK Rural		OR Urban		OR Rural		Total	
	n	M (SD)	n	M (SD)	n	M (SD)	n	M (SD)	n	M (SD)
Altruism/empathy <sup>a</sup>	42	3.91 (.64)	26	3.94 (.87)	34	3.97 (.66)	30	4.05 (.60)	132	3.96 (.68)
Health awareness <sup>a</sup>	42	4.07 (.56)	26	3.95 (.72)	34	3.93 (.66)	30	3.93 (.72)	132	3.98 (.65)
Meaning of cancer <sup>a</sup>	42	3.10 (.76)	26	3.25 (.86)	34	3.27 (.83)	30	3.14 (.82)	132	3.18 (.81)
Positive self-evaluation <sup>a</sup>	42	4.07 (.62)	26	4.13 (.65)	34	4.00 (.69)	30	4.20 (.67)	132	4.09 (.65)
Positive Impact Scale <sup>a</sup>	42	3.79 (.47)	26	3.81 (.59)	34	3.79 (.57)	30	3.83 (.54)	132	3.80 (.53)
Appearance concerns <sup>b</sup>	42	2.78 (1.02)	26	2.54 (1.21)	34	2.50 (.99)	30	2.52 (1.13)	132	2.60 (1.07)
Body concerns <sup>b</sup>	42	3.02 (1.25)	26	2.42 (1.15)	34	2.91 (1.09)	30	2.99 (1.25)	132	2.87 (1.20)
Life interference <sup>b</sup>	42	2.32 (.83)	26	2.03 (.90)	34	2.12 (.76)	30	2.05 (.76)	132	2.15 (.81)
Worry <sup>b</sup>	42	3.34 (.95)	26	3.01 (1.10)	34	2.80 (.94)	30	3.09 (1.17)	132	3.08 (1.04)
Negative Impact Scale <sup>b</sup>	42	2.86 (.81)	26	2.50 (1.10)	34	2.58 (.75)	30	2.66 (.88)	132	2.67 (.82)
Employment concerns <sup>b</sup>	33	3.07 (.99)	18	2.02 (.93)	18	2.07 (.94)	13	2.92 (1.22)	82	2.60 (1.11)
Relationship not partnered <sup>b</sup>	11	2.92 (1.13)	4	2.33 (1.63)	5	2.07 (1.59)	11	2.70 (1.29)	31	2.72 (1.30)
Relationship partnered <sup>b</sup>	30	2.80 (.74)	22	2.73 (.66)	24	2.81 (.72)	15	2.37 (.86)	91	2.71 (.74)
Physical symptoms <sup>b</sup>	42	1.21 (.63)	25	1.24 (.68)	28	1.09 (.45)	25	1.30 (.68)	120	1.21 (.61)

<sup>a</sup>Higher is positive (better outcome)<sup>b</sup>Higher is negative (poorer outcome)



Table 16

*Reliability Statistics*

	Cronbach's $\alpha$ Statistic	
	Crespi et al., 2008	McNulty, 2013
<b>Summary Scales &amp; Subscales</b>		
<i>Positive Impact Summary Scale</i>	0.79	0.75
Altruism/empathy	0.82	0.81
Health awareness	0.80	0.74
Meaning of cancer	0.87	0.83
Positive self-evaluation	0.79	0.69
<i>Negative Impact Summary Scale</i>	0.78	0.79
Appearance concerns	0.82	0.82
Body change concerns	0.82	0.84
Life interferences	0.81	0.82
Worry	0.89	0.92
<i>Employment concerns</i>	0.76	0.76
<i>Relationship concerns (not     partnered)</i>	0.78	0.74
<i>Relationship concerns     (partnered)</i>	0.80	0.62
<b>Sample Characteristics</b>		
Mean age	66.3	58.4
Mean years since diagnosis	7.4	
Mean years since treatment completed		6.7

Table 17

*Correlations between Age, Time Since Treatment, Physical Symptoms, and the IOCV2 Outcomes Variables*

	HA	BC	LI	WY	NI	EMP	RP
<b>Age</b> N=132	-218*	-.183*	-.184*	-261**	-.252*		
<b>Time Since Treatment</b>		-.197* N=131					-.230* N=91
<b>Physical Symptoms</b>		.315** N=120	.432** N=120	.295** N=120	.327** N=120	.337** N=79	

Notes: HA = health awareness, BC = body concerns, LI = Life interference, WY = worry, NI = negative impact, Emp = employment concerns, RP = relationship partnered concerns

\*correlation is significant at the 0.05 level (2-tailed)

\*\*correlation is significant at the 0.01 level (2-tailed)

### **Comparisons between Location (rural/urban) and Region**

#### **(Alaska/Oregon)**

Univariate analysis of variance (ANOVA) was conducted to compare the study outcomes variables between the urban and rural CSs and between the Alaska and Oregon CSs, controlling for age. No statistically significant or meaningful differences were found with either comparison.

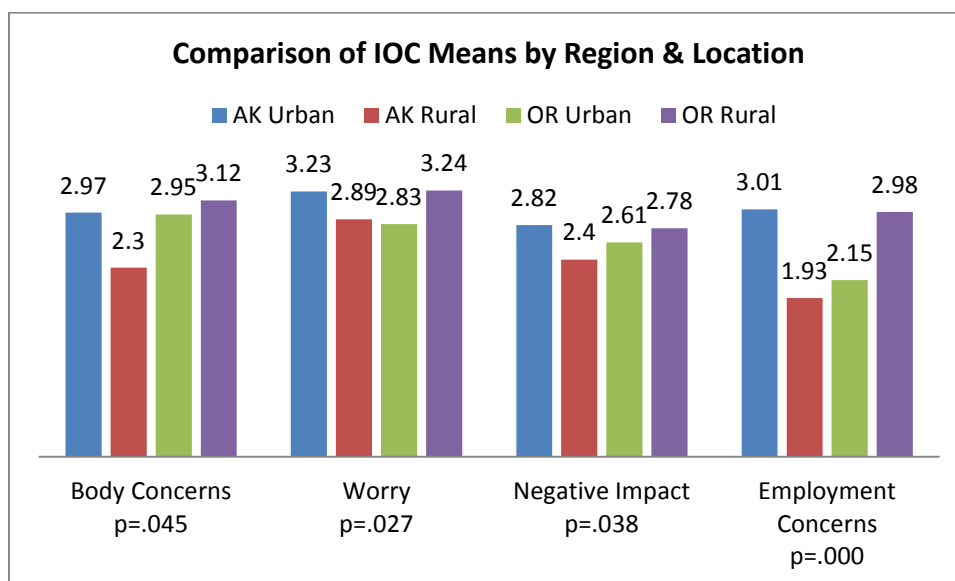
### **Comparisons across the Four Geographic Groups**

A univariate 2 x 2 ANOVA was conducted to compare the study outcomes across the four groups, controlling for age. No significant main effects were found. Significant interaction between region and location was found for body concerns [(F (1, 132) = 4.08,  $p < .05$ , partial  $n^2 = .031$ , worry, F (1, 132) = 4.98,  $p < .05$ , partial  $n^2 = .038$ , negative impact, F (1, 132) = 4.38,

$p < .05$ , partial  $n^2 = .033$ , and employment concerns  $F(1, 132) = 18.48$ ,  $p < .05$ , partial  $n^2 = .194$ ]. Figure 13 shows the differences and patterns between the outcome variable means for each group. The Oregon rural group had the highest body concerns, followed by Alaska urban, Oregon urban, and Alaska rural being the lowest. For worry, the Oregon rural group had the highest concerns, followed by the Alaska urban and Alaska rural groups, with Oregon urban having the least worry. The negative impact was the greatest for the Alaska urban group, followed by Oregon rural; Oregon urban and the Alaska rural group reported the least negative impact. The Alaska urban group had the highest employment concerns, followed by Oregon rural, Oregon urban and the Alaska rural group reporting the least amount of employment concerns. Follow-up tests were conducted to determine which differences were statistically significant and are shown in Table 18.

### **Aim #3 and Its Associated Findings**

Aim #3: Explore and compare the physical (including symptoms), psychological, social and spiritual-existential aspects of cancer survivorship in rural and urban dwelling adult CSs within and between two regions of the Pacific Northwest (qualitative).



Note: Significant interaction effects when controlling for age

*Figure 13.* Comparison of Means by Region and Location of Selected IOCv2

Outcome Variables.

Table 18

*Follow-Up Tests, Post Hoc Comparisons*

Comparison	Mean Difference	Significance	Hypothesis Supported?
<b>Body Concerns</b>			
AK Urb higher than AK rur	.658	.025	no
OR Urb higher than AK rur	.630	.041	no
OR rur higher than AK rur	.894	.008	no
<b>Worry</b>			
AK urb higher than OR urb	.461	.048	yes
<b>Negative Impact</b>			
AK urb higher than AK rur	.413	.037	no
<b>Employment concerns</b>			
AK urb higher than Ak rur	1.150	.000	no
AK urb higher than OR urb	.940	.002	yes
OR rur higher than AK rur	1.055	.005	no
OR rur higher than OR urb	.850	.021	yes

Note: urb=urban, rur=rural

## **Qualitative Subsample**

### **Description of Qualitative Subsample**

To ensure that a broad range of survivor experiences and impacts were captured participants with the highest and lowest scores on the IOCV2 positive impact scale and negative impact scale were recruited to participate in an in-depth interview. An attempt was made to ensure that rural and urban CSs were evenly represented in the sample. Nineteen interviews were conducted and participants included 10 CSs from Alaska (5 urban and 5 rural) and 9 CSs from Oregon (5 urban and 4 rural). A description of the qualitative subsample is included in Tables 19 through 24.

## **Qualitative Methods**

### **Data Collection**

A qualitative descriptive approach was utilized to explore the experiences of cancer survivors and the impact of cancer from diagnosis to the present. The interviews began with the researcher asking the CSs in more general terms about their experiences, and moved into more specific probing questions concerning the impact. The interview guide is included in Appendix H. Three interviews were conducted in person, and 16 were conducted over the phone. After obtaining informed consent, all were tape recorded and transcribed verbatim. The researcher conducted all of the transcription, which allowed her to be immersed in the data, and assisted in generating emergent insights.

Table 19

*Qualitative Subsample-Age, Age at Cancer Diagnosis and Time Since Treatment*

	<b>AK Urban</b> n=5	<b>AK Rural</b> n=5	<b>OR Urban</b> n=5	<b>OR Rural</b> n=4	<b>Total</b> N=19
<b><i>Age at Time of Study</i></b>					
Mean	56.8	58	58.6	66.5	59.6
SD	4.6	6.3	5.6	3.79	6.06
Min	54	51	53	61	51
Max	65	66	67	69	69
<b><i>Age at Cancer Diagnosis</i></b>					
Mean	53.4	49.8	55.8	57.5	54
SD	5.20	6.02	.54	13.20	7.84
Min	48	42	49	39	39
Max	62	58	65	67	67
<b><i>Time Since Treatment</i></b>					
Mean	3	5.4	2.8	5.8	4.2
SD	4.7	3.9	.8	7.5	4
Min	1	1	2	1	1
Max	7	11	4	17	17

Table 20

*Qualitative Subsample: Characteristics*

	AK Urban n=5 %	AK Rural n=5 %	OR Urban n=5 %	OR Rural n=4 %	Total N=19 %
<b>Gender</b>					
Female	90	100	40	100	78.9
Male	10		60		21
<b>Employment</b>					
Full time	40	20	40		26.3
Part time	40	40	20	25	31.6
Not employed	20	40	40	75	42.1
<b>Education</b>					
High School	20	20	40	25	26.3
Some College		20		25	10.5
Associate Degree	40		20		15.8
Bachelor's Degree		20	20	25	15.8
Graduate Degree	40	40	20	25	31.6
<b>Marital Status</b>					
Married	100	100	90	100	94.7
Not married <sup>a</sup>			10		5.2
<b>Ethnicity</b>					
>One Race		20			5.2
White	100	80	100	100	94.7
<b>Health Insurance</b>					
Medicaid				25	5.2
Medicare	20			25	10.6
Private Insurance	80	80	100	25	73.7
No coverage		20			5.2
Missing				25	5.2

Notes: a = Not married or partnered

Table 21

*Qualitative Subsample: Cancer Diagnosis*

	<b>AK Urban</b> n=5	<b>AK Rural</b> n =5	<b>OR Urban</b> n=5	<b>OR Rural</b> n=4	<b>Total</b> N=19
	%	%	%	%	%
Breast	60	100	20	25	52.6
Gynecologic				25	5.3
Lymphoma			20	25	10.6
Head and neck			20		5.3
Colorectal	20		20		10.5
Prostate	20		20		10.5
Lung				25	5.3
Second Cancer Type					
Melanoma			20		5.3
Bladder		20			5.3

Note: No second cancers were recurrence of same cancer type

Table 22

*Qualitative Subsample: Cancer Treatment Modalities and CAM Use*

	<b>AK Urban</b> n=5	<b>AK Rural</b> n=5	<b>OR Urban</b> n=5	<b>OR Rural</b> n=4	<b>Total</b> N=19
	%	%	%	%	%
<b>Modalities</b>					
Chemo-Therapy	60	100	40	50	63.2
Radiation	90	40	20	75	52.6
Surgery	100	100	90	50	84.2
<b>Number of Modalities</b>					
One	20		60	50	31.6
Two	20	60	40	25	36.8
Three	60	40		25	31.6
<b>Receiving CAM</b>	40	20	20		21.1
<b>CAM type</b>					
Supplements	40	20			15.8
Acupuncture		20			5.3



Table 23

*Qualitative Subsample: Co-Morbidities*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	n=5	n=5	n=5	n=4	N=19
	%	%	%	%	%
<b>Number of Co-morbidities</b>					
Zero		20	20	50	21
One to two	40	40	40	25	37
Three to four	40	40	40	25	37
Five or more	20				5
<b>Co-morbidity Type</b>					
High BP	60		20	75	36.8
Arthritis	40	40	20	50	36.8
Depression	60				15.8
Heart Dis	40			25	15.8
Asthma	20	40			15.8
High Chol	20		20	25	15.8

Notes: BP=blood pressure, Dis=disease, Chol=cholesterol

**Qualitative Analytical Process**

Steps in the qualitative analytical process included line-by-line coding and content analysis, creation of a codebook, sorting and synthesis of codes into categories and major themes, and identifying exemplar quotes to support themes and categories identified. The reflective process was facilitated through memoing. Methods to ensure rigor included additional researcher data analysis/inter-coder agreement, and member checking (Creswell & Plano Clark, 2010). A decision journal was maintained throughout the process.

Table 24

*Qualitative Subsample: Cancer Impact on ADL, Self-Rated Health and Healthcare, Satisfaction with Healthcare, Summary of Cancer Treatment*

	<b>AK Urban</b>	<b>AK Rural</b>	<b>OR Urban</b>	<b>OR Rural</b>	<b>Total</b>
	<b>n=5</b>	<b>n =5</b>	<b>n=5</b>	<b>n=4</b>	<b>N=19</b>
	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
<b>ADL impact (yes)</b>	60	20		25	26.3
<b>Health rating</b>					
Excellent		20	30		15.8
Very good	60	80	30	50	57.9
Good	20		20	25	15.8
Fair	20			25	10.5
Poor					
<b>Access to Healthcare</b>					
Excellent	20	40	20	50	31.6
Very good	80	40	60	25	52.6
Good		20	20	25	15.8
Fair					
Poor					
<b>Satisfaction with healthcare</b>					
Excellent	20	40	20	75	36.8
Very good	80	60	60	25	57.9
Good					
Fair					
Poor			20		5.3
<b>Summary of cancer treatment (yes)</b>	60	40	100	100	73.7

**Coding and content analysis.** The researcher utilized content analysis to analyze the data. She began by reading each transcript from beginning to end, and subsequently read each one carefully and conducted

line-by-line coding as well as coding passages of data. The researcher utilized Atlas.ti software. Coding techniques utilized were descriptive, process, emotion, versus, and in vivo as described by Saldana (2009), capturing the experiences and impact of having had cancer on the survivors.

**Codebook creation.** After coding seven interviews, the researcher created a preliminary standardized code book to ensure consistency and coherence. When analyzing the remaining 12 interview transcripts, she used these codes as well as new codes that did not fit into the existing codes.

**Sorting and synthesis of codes into categories and themes.**

Thematic analysis techniques were utilized, and sub-categories were identified and combined into categories and overarching themes/high-level categories that depicted the survivorship experience. As the analysis progressed, particular attention was paid to the differences between region and locality, dichotomies, and contrasts and dualities emerging from the data as well as profiles of intensity and impact across the participants. The researcher returned to the data over and over again, to make sure that the categories and explanations made sense and to ensure that they reflected the nature of the cancer survivorship experience. Mind maps were created to depict each theme with supporting categories, to identify redundancy and areas of overlap and to clearly identify the rural and urban differences. Saturation was achieved after coding and analyzing 17 interviews, and no new codes or themes were seen in the data from the last two interviews.

**Identification of exemplar quotes.** Exemplar quotes were selected to illustrate the rural and urban cancer survivorship experience and impact, providing for thick description, as suggested by Sandelowski (2000). Quotes were modified slightly at times to correct for grammatical errors and improve readability. During this quote identification process, one major theme was reorganized and a few categories were also combined and consolidated. The final framework and themes were verified by three non-participant CSs.

### **Rigor**

**Memoing and reflection.** Throughout the analysis process, reflection was enhanced by memoing. Memoing for each interview transcript was completed in Atlas.ti, and memoing across interviews was completed in Word with a template created by the researcher. The template was based on the approaches of Miles and Huberman (1994) and Saldana (2009) of questioning during qualitative analysis. The researcher engaged in an ongoing process of questioning to guide interpretation and reflection about how to improve the interview process. Self-reflection is critical to the qualitative analysis process since the researcher is the instrument of analysis (Patton, 2002).

Through the writing process, reflection included processing what was going on with the researcher and how it might be impacting the data analysis. The researcher brought her clinical background as a nurse as well as her personal experiences with cancer and healthcare to the research process.

For example, the researcher is not a cancer survivor herself; however, she is married to a cancer survivor. While this aspect is a potential source of bias, it also results in the potential for increased understanding and empathy. The researcher is a resident of Alaska; therefore, the connection established with the Alaska participants was slightly different than with the Oregon participants; however, the common ground was interest in cancer survivorship. The researcher took the stance of empathetic neutralizer as described by Patton (2002). In this approach, the researcher attempts to be perceived as caring by the participants yet neutral about what is shared by the participants. Through the reflection process, the researcher acknowledged these perspectives and biases and disclosed her stance to the participants when appropriate. Being aware of these perspectives and observing how these interactions may impact data collection and analysis are paramount. Feedback on the interviewing and analysis process was obtained from qualitative research colleagues and a qualitative research mentor throughout the process of prolonged engagement with the data.

#### **Additional researcher data analysis/inter-coder agreement.**

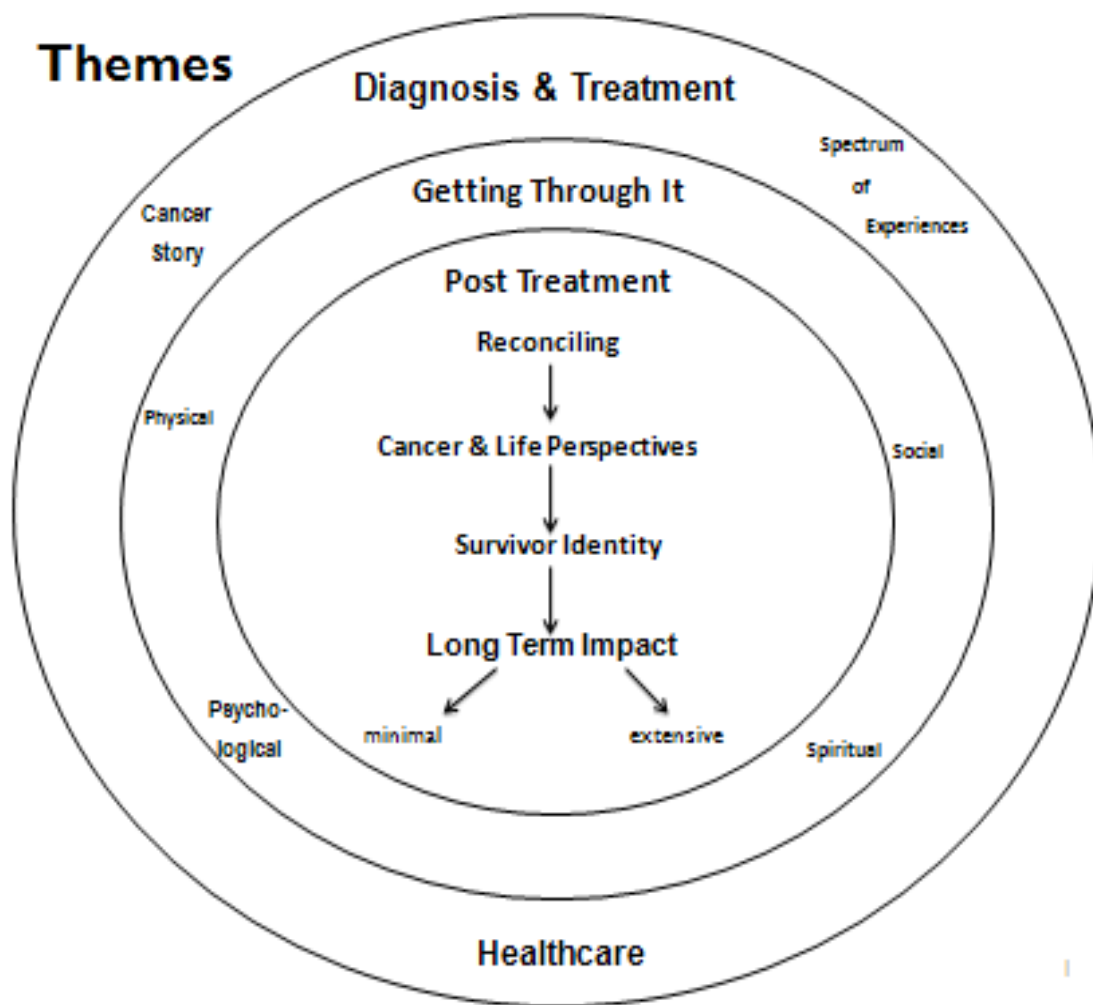
Consultation was obtained from qualitative research colleagues (peers and faculty) throughout the analysis process. During initial coding, transcripts were reviewed, simultaneous coding was conducted among several researchers, and coding strategies were discussed and agreed upon. If codes emerged that were not identified by the researcher, she followed up on the

line of questioning and analysis. Group discussions also occurred later during the synthesis and identification of major themes.

**Member checking.** Member checking was conducted with 3 interview participants and with 3 colleagues who are CSs who did not participate in the study. The mind-mapping format was utilized to clearly elucidate the themes and categories. Short descriptions and definitions of each category were shared, using short phrases from the survivor interview data and synthesized impressions. Participants and colleagues were asked if the themes and categories made sense and if they resonated with them as individuals. No significant changes were made in the findings as a result of the member-checking process. Minor revisions in the naming and organizing of categories were made. The overarching themes were maintained during this process, and the overall depiction of the survivorship experience was supported.

### **Qualitative Findings**

Figure 14 shows the overarching themes as a framework for the qualitative findings. The themes of diagnosis and treatment, getting through it and healthcare, are depicted in a circular pattern, setting the context for the post-treatment phase of survivorship, which was the focus of this study. The themes included in the post-treatment phase, depicted in a temporal pattern include (a) reconciling, (b) cancer perspective/life perspective, (c) survivor identity, and (d) long term impact (minimal and extensive). Rural/urban differences were found within all of the themes except for reconciling. Specific



*Figure 14.* Framework of Cancer Survivorship: Moving Forward.

constructs that revealed rural/urban differences were healthcare access, care coordination/navigation, community and connections, thinking about death and dying, and public/private journey. See Appendix J for mind maps which depict each theme, sub-theme and category that emerged from the qualitative data.

## **Diagnosis and Treatment Experience**

**Discovering cancer.** Survivors described how they discovered their cancer, whether it was finding a lump on their own or during routine medical screening. One 4-year survivor described finding a lump on her breast, “One night I was staying up late and I was on the computer playing Mahjong and I felt this pulsing in my breast, and I started feeling of it, and it was really pulsing, I went to bed and I kept feeling it....I woke up my husband...I knew something was wrong”

**News of cancer.** Participants shared how they received the news that they had cancer as well as how they shared the news with the people in their lives. Some described “the call” and being in shock from the news as well as surprised. The experience of receiving the news from a healthcare provider was described as both a positive and negative experience, similar to the perceptions of the overall healthcare experience, which are described later. One survivor described his experience as being quite traumatic, yet he still described moving forward:

He looks in my throat and he says well, you know it could just be a little swelling, but he put up his fingers in parentheses (gesturing the letter C) and he said it could be the big one. And I thought, you did not just do the big one on me, I was sitting there in shock already....my wife was the one that called me while I was at home and told me that I had cancer, so I had a good cry, and she came home and tried to console me, and then she went back to the office to get some antidepressants, and we kind of started the process from there.



Several survivors felt that the providers were too cavalier when sharing the news of cancer, and they didn't appreciate being told when they were still sedated and recovering from anesthesia in a public setting. One survivor described being shaken by this experience:

I went into surgery pretty confident that this was going to be okay, and the doctor walked back only minutes after surgery and I was just barely waking up and he pretty bluntly said, 'well, you've got lymphoma, you've got non-Hodgkins lymphoma,' he said something about it being the good kind or the bad kind, and we understand now we totally misunderstood what he said because it wasn't very clear, but it was pretty shocking, and he was pretty cavalier about it and we were very angry about the delivery that we got with our diagnosis because, basically, he was telling me that I had cancer, but he seemed to be in way too good a mood, he seemed to be doing it off-handedly.

Survivors described the early experiences as being very overwhelming and how they thoughtfully chose to share their news with their loved ones. It was particularly challenging to share the news of cancer to children, especially if they were away at college or living in another part of the country. It was important for this survivor to reassure her children:

Like my children, so you have to call them and tell them, and that's always difficult and with two of them living 3,000 miles away, so the first, the first one I talked to was the one who lives here, and we talked briefly....And then our next daughter when we called her, she was obviously upset, and I said, the only way I know how to put it to you, when I got up this morning and this was how I felt, and then he called me this afternoon he told me I have cancer. I said, I don't feel any different, you know physically I don't feel any different. So I said things are not going to change dramatically just because there was a diagnosis of cancer. We're just going to look at the positive part of it and find out what we can do

**Sudden.** The transition from being healthy to having cancer and receiving treatment was described as being sudden and fast. As one survivor described, “It was just like being on a freight train.” Other survivors expressed similar experiences: “And here I was healthy, no problems and the next thing I know I’m having surgery and stage III cancer.”

**Others’ reactions.** Survivors were often worried about the decision to disclose their cancer or not, and about the potential reactions of others. Responses to communicating the news of cancer varied; some were described as exaggerated reactions, some as supportive, and some as pulling back. This long-term rural survivor describes how one of her best friends pulled back:

A lady that had been my best friend when our kids were little, she moved away, and she came back, I’m sorry, I just can’t see you looking like that, and so she wouldn’t even come see me. And I thought, well, that wasn’t much fun. I also realized she couldn’t deal with it. It was her problem and was not mine.

This survivor was also concerned about being treated differently: “When people know you have cancer, it’s like, hey, they think it might be contagious...But I didn’t tell anybody for the longest time, I didn’t want people to look at me differently.”

Another response was described as “sympathy overdrive” by a survivor with a low intensity experience:

I have been somewhat taken aback by other people’s attitudes at times, maybe it’s societal or cultural., or maybe something else, but it seems like a lot of people expected me to be devastated and crushed by this experience. It’s as if other people took this

much more seriously, but then they didn't have the information that I had. I knew I wasn't in any particular danger from it, but people hear the word *cancer* and immediately go into sympathy overdrive, like I should be disabled or have post-traumatic stress or you know some sort of lingering emotional trauma involved, and frankly I wasn't particularly upset at the time. But some people seem to think that you ought to be really traumatized to have cancer.

Several female survivors described their husbands and fathers as having a tendency to minimize: "I hate to stereotype a lot of men...I'm just gonna say neutral. He's like a lot of men. He just keeps it inside, kind of the denial thing, stick his head in the sand and it's gonna go away, and if I don't talk about it, it's gonna go away.

**Travel.** Travel was a common experience, whether it was from rural to urban settings or from Alaska to the lower 48 states for treatment. Rural survivors planned their travel around their response to chemotherapy, and batched appointments to decrease travel: "My husband drove us to Anchorage every 3 weeks (7-hour drive). After I had the chemo, I knew that I would have a good hour and a half, 2 hours before things kind of hit me, so we would go out to lunch, do any last-minute shopping and then we'd just hit the road because 3 hours out, I was passed out." And sometimes they made treatment decisions based on travel factors ("I decided to just have a mastectomy because I didn't have to have radiation. I didn't have to move to town") or relocated temporarily for treatment:

I moved over there [to Bend] and got an apartment, and went back and forth to the radiation treatments, which were about 5 miles away...I rode my bike back and forth, and then I would

come home on weekends and then go back and stay the week there...then I had to go to Portland for 3 weeks because they had a more specific piece of radiation equipment...

Travel represents a significant expense, especially for the rural survivors. However, it was important for rural survivors to be in their homes and communities as much as possible, and they were willing to travel long distances for treatment and then return. They considered this a trade-off, and one rural survivor reported, "I just wanted to be miserable in my own home."

I've always been so far away so that's normal. We raised our kids here and we always knew that if anything happened...So you always live your life knowing that it just takes you a while to get to medical care, you know, so you sort out what is an emergency and what isn't an emergency, so you go from there. So I don't think the distance bothered me, other than I didn't want to have to leave home....

It's a very different experience for survivors from urban areas who decide to receive treatment close to home: "No I didn't have to travel at all. I'm probably less than 10 minutes from both the chemo and the radiation, because they were like right across the street from each other, maybe 5 minutes. I drove myself to every one of my appointments."

**Traumatic/misery.** Most survivors suffered during their chemotherapy experiences and some descriptors included the following: "chemo is torture, "chemo misery" and "chemo was excruciating." This is how one urban survivor of prostate cancer described his initial experience with chemotherapy:

When I went in there for the first treatment...after the IV first went in, I started feeling shocks in all of my joints, starting with my

neck and my back, in my hips and elbows and everything, and it kept on going and going, it felt like I was in an automobile or truck accident....it was very traumatic when I was going through it....

One survivor felt that she just couldn't go on during treatment:

So by April I still had another month left, I said to my doctor, 'I just cannot do this anymore, I'm so miserable, my toes are numb and sensitive, my fingers are numb and sensitive, I can't see out of my eyes, my face is all puffed out because of the steroids and stuff.' And he looked at me and he said, 'the doctors who prescribed these trials are a lot smarter people than me, and they know what they're doing.... it's only one more month,' and I said, 'one month to you goes by fast, for me, it's 24/7 torture, I'm so miserable, my stomach is almost like an acid indigestion feeling from the chemo because I've been on it for so long, I'm miserable my fingers are numb, my toes are numb, the neuropathy, I can't even get into bed the sheets, I can't even touch my feet with the sheets and stuff like that.' So he convinced me to stay on it for another month

**Scary.** Survivors described the scariest times as in the beginning when newly diagnosed, when waiting and planning for surgery knowing that they had a tumor, and during procedures and reactions from chemotherapy.

Some accounts included: "It was scary in the beginning knowing that I have cancer." "I just wanted to flee the minute I sat down in that green recliner." They described lack of control as being scary, and the early periods after completing chemotherapy when there was uncertainty as to the outcome of the treatment. All survivors thought that the experience of cancer was less scary over time; however, a few survivors experienced setbacks after their treatment was completed, such as a scare with recurrence or a complication. Experiences and emotions associated with recurrence are included later

under the long-term impact section. This account is from a male survivor just after completing treatment: "I had a lot of anxiety. I was on antidepressants, I was on sleeping pills, 'cause I'd wake up in the middle of the night, just wide awake. Then I'd wander around the house, so it was pretty scary there for a while. I had no, I had no normalcy in my life."

In contrast, negative experiences with chemotherapy were not universal, and a survivor of lymphoma felt that his experience was "not as bad as he expected."

**Defining moments.** Survivors reported vivid remembrances along their journey, including when their cancer was discovered, losing their hair, when they developed a particular symptom such as losing their sense of taste, or receiving the news of cancer on a holiday or a birthday. They often knew the exact dates of what they considered to be milestones, such as when they heard the news, when they started or completed treatment, or when they had a scare with recurrence. As stated by one survivor, "It's funny how when you're a survivor you know all the exact dates of everything." "I finished my chemo on Pearl Harbor day. That always has some significance to me. I'm not sure why but it does."

Some examples of what the survivors described as "low points" include (a) complications after treatment completed, (b) having a mastectomy on a wedding anniversary, (c) receiving cancer news while still sedated from procedure, and (d) waiting to hear if disfiguring surgery would be needed.

One survivor described the time period after receiving the news as being a “very dark time.”

For this survivor, one of his low points was when he lost his sense of taste due to radiation:

I remember the exact day I lost my taste buds, because radiation just burned me up. It was the first week-end in August because we have a county fair here and I told my wife, I’m going to lose my taste buds so I want to go the fair and get some fair food. “We went on a Saturday, and I got a big plate of teriyaki chicken noodles and it tasted like copper.”

One hopeful defining moment for a rural survivor, was her vivid memory of when she was able to start thinking about the future again:

It wasn’t until probably a year after I was done with my treatment that I had gone up to Fairbanks to my daughter’s graduation, which I never thought I would see, and when we were driving home, it was the first time in 2 years that I really thought about having a future, that I could plan for more than just for a few weeks ahead.... I remember the exact moment when I actually thought, wow, I can actually think about the future without, maybe one day retiring and those types of things, and of course, any one of us at any moment, we don’t know if we have a future or not. You just never know when your next breath is your last, but that was the moment that it was like a whole big wave of, um, excitement came over me, that, wow, I actually have a chance of living for a few more years. You come up with those realizations.

**Cancer story.** While it was not a specific question on the interview guide, most of the survivors launched into a detailed description of how they discovered their cancer, their medical workup, and treatment experiences. Often it was in typical “day in the life of” fashion, especially when describing their treatment experiences. For this rural survivor of cervical cancer, travel and commuting for treatment and work was the frame for her story:

I knew I had to do it. I think chemo started at about 9 o'clock, 4 hours, and radiation was always at 11. I drove myself to radiation every day, and then, so it was like an hour and 15 minutes to get to my radiation appointment, which was about 5 minutes, and then I would drive an hour and a half to 2 hours to get to work, and then I work until about 5, then I would drive home, I'd fix dinner, my husband and I would have dinner together, then I would go to bed. I'd get up at 5, I'd leave here at 6, I'd drive back to Salem for an hour and a half, then I'd drive another hour and half to 2 hours to work. And one day a week, I stayed at a house near the treatment center so I could have the treatment in the late afternoon, and then have another treatment first thing the next morning, so that would save me one trip.

Survivors often compared their experiences to those of others and were eager to share their cancer story as well as the stories of others. In addition, they found it validating to hear the stories of others. Some survivors described feeling validated when completing the IOC questionnaire, and through the process of responding to the questions, they realized that others had similar experiences. During member-checking discussions, one survivor shared that being a participant in the study felt empowering, and for another, it was therapeutic and validating to review the preliminary results and compilation of others' experiences. The various cancer stories also revealed that there was variation or a spectrum of experiences.

**Spectrum of experiences.** Survivors described emotional responses to cancer and treatment that ranged from extremely emotional to matter of fact, often reflecting the level of intensity of the experiences. They reported that while many experiences were similar across survivors, many were also different. Many contrasting views were identified throughout the



interviews, such as experiences of aging. One female survivor felt that cancer had aged her prematurely: “I’ve always looked younger than I am, by about 10 years, but after I had chemo, I looked 10 years older, so I aged 20 years in a 6-month period.” This was in contrast with a male survivor who shared that he felt younger than ever since he recovered from cancer treatment and chose to participate in a support group for young adults. “We have a young adult survivor group for people that were diagnosed before the age of 40. But since I feel 40 now, but I’m going to be 54 next month, but I feel that young that I want to go to the younger group.”

Both of these survivors had intense treatment experiences; however, the survivor who felt younger had minimal long-term impact and the survivor who felt that she had aged prematurely experienced a significant impact due to cognitive decline. This decline caused her inability to work and sense of loss of self, and she experienced a high level of stress and anxiety. She went from being a math teacher to being unable to balance her checkbook or fill out a work timesheet correctly, and she was still experiencing this impact four years after treatment was completed.

Some survivors reported being very emotional during chemotherapy, terrified to be alone, and experienced significant “ups and downs.”. In contrast, one survivor reported that “chemo was not as bad as I thought it would be.” Comments from these survivors show their views on the variation in responses to the experience: “I have worked with clients that pretty much

had the same condition that I had who were totally devastated.” “A lot of people think it’s all the same. Everything is so different. Just from going to the support group I found out that there’s such a continuum of severity, and it isn’t helpful when people think they know.”

## **Healthcare**

The interface between the survivors and healthcare was particularly strong during diagnosis and treatment, and getting through it.

**Navigating/coordinating own care.** Care coordination was identified as a particular challenge, especially for the rural survivors. This rural survivor pushed to receive chemotherapy closer to home:

The doctor asked me if there was anything that would help with my treatment, and I said, well, is it possible for me to take the chemo in Glennallen, which, at that time they did not do, and so I took the remainder of the treatments there, and that’s just like I said, but I could go to Glennallen for an hour and a half and take my treatment and come home and feel bad in my own house as supposed to a 5 or 6-hour ride.

Alaskan survivors thought that the care coordination was better in the “lower 48”:

I went to a navigator, because that was one thing that came up at the group that really bothered me, that I thought I could use help with. Lots of people in the group decided to go out of state, and they would say, in California they have one person that you deal with all the time as you’re going through everything, or in Canada, there’s one person that deals with you. They would talk about a lot of different places, but one person to help guide you through it, and that’s kind of what the navigator is, they check in with you at the beginning, but after that you’re really on your own, like when things come up.

One urban Alaska survivor had a multitude of problems with care coordination, which included going to the “lower 48” for a second opinion, having delays with scheduling surgery (over a period of several weeks and having a very aggressive cancer type), a doctor moving away, and several changes in plans for treatment regimens.

**Access.** Rural survivors talked about the cancer care services in their communities (or lack of them) and the challenges with traveling. While they were sometimes envious of the resources available in urban settings, this was not enough to relocate. “You can’t support a specialist, the town is too small.....and that’s true with, with a lot of rural areas, if you’re a specialist you cannot survive in a town of 10,000.”

But it’s a small community, and you do the best you can, just being out here, in the sticks, you know, you have to, something has to be fairly wrong to get a referral to go across the desert, and both of us have been back and forth so much, you know, the distance and the expense, and so that is kind of a problem

One survivor from a remote area in Alaska felt that her workup progressed quickly because she was from “the bush.” An urban survivor described access to healthcare as “like cutting butter.” This urban survivor spoke very positively about the close proximity to healthcare and other programs.

I didn’t have to travel, and the support groups are all really close, too, the activities, we have some, lots of support activities around here by survivors and others who provide events everything is really local, so it’s very close, and very easy to, you know I’m 5 minutes from the clinic and the hospital, and the

hospital and the clinic are side by side so that makes things very simple. When I couldn't drive, the bus goes there, so I didn't have to worry about getting to appointments when I wasn't supposed to drive after the surgeries, and I think that helps.

**Disappointed in healthcare.** There were a variety of situations described that revealed concerns about suboptimal healthcare. This survivor did not feel that he was included as part of his healthcare team:

Nobody's really on your team, and I found that to be a problem. That's how I really felt, is that nobody's on my team and they say that they work in a collaborative way and nobody's a specialist in anything, but it felt a little bit like they were a team, and I wasn't so much a part of that team. I wanted someone to be on my team.

Several medical mistakes were described, and these included mistakes in mammogram reports and errors in communicating correct information. This survivor experienced a significant medical mistake: "There was one little glitch. They had gotten a new radiation machine, and they had recalibrated it from sea level. So there were a number of us that were overdosed.

For this survivor, the biopsy and placement of a chip procedure felt very forceful and she viewed it to be unnecessary:

Right before she's going to do this, she says 'oh by the way, we're going to put a titanium chip in you,' and I said, 'why would you do that, because the doctor said that if the biopsy is positive, her recommendation is a mastectomy.' She said, 'well, if you're not going to let us do it, then we won't do it' (raised her voice), real mean, like I was interfering with my treatment, and so I said okay, and, they almost didn't do it because the pain was so bad I was almost screaming, and I said, 'can't you put a local in there or something, because when I had my other biopsy when you just lay on the table they put a local in there.'

She said, 'no, we can't do that, for this one it's different.' Well they're poking in there and I said 'can't I try a different position,' and she said, 'we're not going to be able to do it because it's just too painful for you', and I said 'just try one more position,' and they tried another position and they put that titanium chip in me and the biopsy was negative, so now I have a chip in there. You're not going to be able to feel it and it won't hurt. I can feel it and it hurts. I went back to the doctor and I said, 'they put that in there for no reason, I want it out,' and she said, 'oh you don't want to do that, that's surgery,' and she said that she hadn't heard of any side effects or anything from those.

Teaching about lymphedema was considered to be lacking by several survivors:

Not one person at the hospital, not one nurse or doctor or anyone, knowing I was from a remote community, said one thing about that compression sleeve. I found out about that at the support group. And I'm so glad, because you can have all kinds of complications if you don't do that when you fly.

**Mistrust in the healthcare system and providers.** Medical mistakes, being given wrong information, having information withheld, receiving mixed messages, misdiagnosis, and disappointments in healthcare often led to skepticism and mistrust, both in the healthcare system and in the providers.

This rural survivor felt that her mammogram results were mishandled by the local clinic, which would have resulted in her slipping through the cracks if she was not on top of it:

When I went to the clinic here, had my mammogram, they didn't notify me, so a month into it, I called them and they said well they lost it, so I said you probably should return my money and I'll have it done somewhere else because of my history. I hung up and they call me right back. The clinic is a needed thing for stabilizing people and getting them out of here.....so that was the thing that annoyed me in the very beginning, is that they were sloppy, and I don't trust this clinic now.

This survivor was misdiagnosed several times:

I was probably misdiagnosed with pneumonia, probably 6 or 7 different times, it was just a matter of, you have pneumonia and they would treat it and it never seemed to get any better. And I eventually went to see a pulmonologist and he told me that he did not think I ever had pneumonia, that it was a misdiagnosis, but it bears watching because I don't know what it is, and we want to make sure that we watch it carefully, so every 3 months I would go in and have a CT scan done, and he would review it with me.

**Positives in the healthcare system and providers.** Despite the negatives, survivors also shared positive stories about their healthcare experiences and providers. This survivor describes the personal attention that she received from her oncologist and receiving the results from her PET scan the same day that she had the test:

I can't tell you how much I appreciate everything he did for me. He was there for everything. He would go down and make the appointments with me, to make sure he was gonna be there when certain things happen. So I went in at noon for the PET scan and he called me that night. He said, 'I just didn't want to think about you spending all weekend worrying. That's all we see is that one thing that we've been looking at all along, and I do think it warrants doing a biopsy,' but, he said, 'we'll schedule that when the office is open.' It was really nice, it was nice that personal part of it, that he was so supportive

This survivor appreciated the humor from her oncologist: "I think a lot of it had to do with my oncologist. He's such a great doctor, and I have a lot of faith in him. He just really was, kind of the light of my life. He was just always there, and he made me laugh when I didn't feel like laughing."

This survivor chose a community to retire in, partly based on the healthcare that was available: “Most of the time we’re very sure about what they’re telling us, the best way to go, and we’ve just been very happy with what they have to offer up here.”

### **Getting Through It**

The subcategories identified within getting through it, physical, psychological, social, and spiritual, fit with the a priori categories reported by Ferrell et al. (1995) in their survivorship framework and previously described in Chapter 2.

**Physical.** The main physical impact described was due to symptoms.

***Impact of symptom/managing symptoms.*** Symptoms have a huge impact on survivors, and eight out of 19 participants reported a significant long-term impact. Symptoms with the biggest long-term impact included fatigue, chemo brain, lymphedema, neuropathy, incontinence, and sexual dysfunction. One survivor described a long-term physical disability due to lymphedema:

About 2 years after treatment, I developed lymphedema and that’s been a pain in the butt ever since, but I deal with it and I receive treatment, and I wear a compression garment, and I also have a bit and piece that I put on at night, it looks like a sumo wrestler outfit but it keeps the fluids from building back up. My husband does a lymphedema massage on me every night. My arm is pretty much immobile from having been affected for so long, and it’s not like it hasn’t had exercise. When I started working at the school, and you’re on your feet for about 7 hours a day and the fluid started building more and more, and I noticed that uh I was getting more and more immobile. Couldn’t type with both hands, and just kind of gone downhill since then, although

when I do water aerobics, I can move from my shoulder, and so it kind of floats around in the water. And that's about all the mobility I have.

Several survivors offered descriptions of the long-term impact of “chemo brain.” It sometimes played out during the interview, when the survivor would lose his or her place or become forgetful or express random thoughts that were not cogent: “I can’t get things in the right order, like my words to kind of come out to say the way I want it to say, so I’m sounding kind of disjointed and, but that’s part of what my brain is at the moment.”

Survivors described many approaches to symptom management including taking power naps at work, exercising, adjusting exercise due to neuropathy, using guided imagery to decrease stress and increase concentration, and planning for hot flashes.

**Psychological.** Subthemes under psychological included (a) emotional responses, (b) losing and gaining control, (c) adapting and growing (leading to the “new normal”), (c) and fighting spirit/kicking cancer in the butt.

One survivor felt that others expected her to be emotional, but she was not. Another 17-year survivor described the early experiences as “panic and naked fear.” For this four-year rural survivor, it was still very emotional to discuss her cancer experiences:

I need to warn you that I get emotional when I talk about it...I know that I make people uncomfortable when I cry, but I cry when I talk about it and I’m not sad. It just has an emotional button that it pushes to talk about it... I don’t think I’m depressed, I think I have certain buttons that take me to a place that was really hard....



This 3-year survivor describes feeling of lack of control:

You know that's probably the worst thing about any disease, but cancer in particular, because you don't have any control. I mean you have treatments, you have people tell you you can do this and this might happen and we can do that, and that might happen. But it's all in someone else's hands. You have no way of doing anything about what's wrong with you, or stopping it, or controlling it, none... This is what they think is gonna happen if I don't have the treatment. It is a very control thing when you think about it, because you can't, it's like flying, the whole fear of flying, it's the fact that you get up at 38,000 feet, you're not in control, and there's nothing you can do to change that. And with cancer, there's nothing you can do to change that. I just feel like I'm, I'm at their mercy, those cancer cells, whatever they want to do to me, they're going to try to invade me forever or however, and I can't stop them. That's a scary feeling. But it's another thing that you can't dwell on.

One urban survivor gained a sense of control through medical monitoring: "My wife has been cancer-free, we're both in remission, so it's just part of life I guess, and if it comes back, it's going to come back. I don't see that there's anything I can do either way, except monitoring it, have people monitor it, see what's happening..."

It was also common to try to gain control over improving their health through exercising and improving dietary and health habits. ("It's what I can do.") One survivor reported feeling back in control when she could drive again, after being unable to drive during chemotherapy.

Survivors described many trade-offs, adaptations, and growth experiences, both emotionally and physically, and were often surprised

where they ended up. For this male survivor of lymphoma, it was returning to his “pre-diagnosis personality”:

It didn't seem like the darkness that it was at first. Even while I was uncertain about the outcome, I seemed to adapt to the whole idea really fast, and I was surprised by that, because I thought it was going to be like crossing over a line and you'd never be back over on the other side to your pre-diagnosis personality or outlook on life.

It is challenging yet important to accept new limitations and learn to pace yourself: “Not like it used to be. There are a lot of limits to what I can do. Those are probably some of the hardest things to accept, is your limitations.....it's the things you learn to live with and it's good to be able to know that you can. A lot of people can't.”

This five-year rural survivor was required to adapt to physical changes that impacted her approach to dressing:

Basic dressing in summer months is a challenge. In the winter, I do okay. I always have a vest on. I know that I'm not symmetrical and so I am forever layering. When we go to visit my parents in Florida, it's very uncomfortable for me, because I can only strip down to a certain level where I'm comfortable, so I suffer mightily without air conditioning.

Survivors described needing to go into the “cancer-kicking mode” and likened it to going to war or facing battle: “Right after I was diagnosed, my friend told me, just put your cancer kicking boots on and be done with it.” Another survivor said, “That was kind of my attitude through the whole thing. I just knew that I was gonna kick it in the butt, and it was going to be hard, but you know we were going to go through it and be done with it and we did. And it's all in the attitude.”

It was important to not allow cancer to have too much power over them, as described by one survivor's statement: "Don't ever spell cancer with a capital C. It gives it too much power."

**Social.** Subthemes under social included (a) financial impact, (b) work impact, (c) seeking and providing information, (d) support and networks, (d) connecting, (e) community, (f) support group—love it or leave it, (g) intimacy challenges, and (h) relationships.

For the most part the survivors reported minimal impact on finances from the cancer experience, as the majority had what they considered to be good health coverage. Some of the challenges included the cost of gas for commuting to treatment and watching the bills pile up during treatment. Several different types of support from non-profits were described including gas cards and insurance co-pays and were very much appreciated. Most survivors described very supportive work environments, and often it was an important part of their support system. One rural survivor described a group of employees that prepared customized meals depending on what type of day she was having:

The company I work for was very supportive. They got me a laptop computer so I could do stuff at home, you know cause that's our income and that's where my insurance is through. I couldn't not keep my job. That was a big worry that I would be so sick that I would lose my job and lose my benefits because my husband wasn't working at the time. They were very supportive. I would go do my chemo on Thursday afternoons and I would come to work on Friday because you don't really get sick 'til the 3<sup>rd</sup> day, and everyone there they would make me different types of food that was good for chemo days or good for low white

count days or good for nausea days. They all got into it and were coming up with recipes out of the cooking for cancer book, and we'd freeze it and so I'd have my lunches right there at work and I could choose.

However, there were workplace challenges such as not being allowed to use company email to update co-workers, and being downsized from a job shortly after treatment was completed.

Survivors discussed the benefits of continuing to work including "getting back to normalcy through hard work," and they shared that it was a good diversion, kept them motivated, and it was beneficial to stay active. They were proud of not missing work during treatment. Some work challenges were described as dealing with fatigue and hiding the effects of treatment. One survivor who is a construction worker described his initial challenges just after treatment was completed and he had lost a considerable amount of weight. Initially he could only work a few hours and he gradually got his energy back to be able to resume physical labor.

It was very important for survivors to receive information for themselves and to share information with other survivors or those newly diagnosed. It was common for the survivors, both urban and rural, to be avid readers and Internet searchers. Urban survivors described the support groups as being important sources of information for them. One survivor described needing to know all of the details in the beginning, but over time, as his survivorship experiences progressed, it was less important to know the details, and the information was often conflicting. Lymphedema recognition

and management was a common topic for learning and teaching for the breast cancer survivors.

Support was much needed for the survivors to get through it and it came from family, friends, neighbors, and community groups such as church and other survivors. For one rural survivor, it was important for her not to have to ask for something but for her support person to “just do something”:

A neighbor came over and said she'd type work projects for me, and she'd bring lasagna casseroles over, and I would be reading in my book. That when you wanted to help someone, don't say what can I do, just do something. And that's what she did. It was like she had read the book, but she didn't. She just knew how to be. It was the things like that; random acts of kindness were always surprising.

There were many examples of spousal support, which came in the form of physical and emotional encouragement. This topic elicited emotional reactions from several female survivors:

He's been like my support system all my life. And he hasn't changed whatsoever with the cancer; he has no qualms about. If he did, he never showed it to me. I don't think he ever had any qualms about how it would impact our lives, but for the most part, you just have to take what comes along and learn to live with it, and that's his attitude about everything, and it was great for both of us that he is like that.

Survivors felt the need to connect with other survivors who had been through similar experiences, someone they could relate to. Some were involved in formal programs, and some connected on their own individually, and often there was mentoring occurring from the experienced survivor to

the newer survivor. This urban survivor connected through a formal program:

There's this group called Cancer Hope and they match you up with people like myself, with a gentleman that just either found out that they have prostate cancer or if they're going to be having surgery, what's to expect, or what's the best way to go. I've talked to a gentleman out of state, I did the same thing when I found out about mine, so I got to talk to four gentlemen and see what they went through, and that was good, and now in turn, I can share what I went through, my treatment...it makes them feel good, and it makes me feel good.

Survivors also connected through friends, church, neighbors, and exercise programs. Rural survivors described being more connected with their neighbors informally. One rural survivor described it as "they just showed up on my doorstep." For this rural survivor it was at church daycare:

Any time I hear of someone with cancer, we talk. There's a little boy in the daycare next door to me who had cancer of the eye. And we talk, and I said did you know that we had something in common? And I just said I'm a cancer survivor, too, and he just thought that was so cool.

Rural survivors felt that in urban settings they would not have as strong a connection to others: "The cities don't have that; everyone is so anonymous. A lot of people don't even know who their neighbors are." Urban survivors talked about their communities: "We have a community here in the downtown...there's no isolation, like I couldn't get around, I was never out of commission ..." but not as strongly as the rural survivors. For this rural survivor, it was like the town was one big support group.

We have a gigantic support group in this town. If a house burns down, and this happens, we get together and we furnish all of the

house. For those 2 with Lou Gehrig's here we rebuilt houses for them. For the time they had left, we had food, we had work days, we had 60 people come out on any given work day that we had going.....guys from the community, electricians fixed us up with electricity...that's the way this community is. We all know each other, it's such a support group, the whole community. You can be at odds with one another on issues, because it is a small community, but the next time if you have a problem, those same people, we are all drawn together.

Both urban and rural survivors participated in support groups. While some survivors found support groups to be beneficial, others did not appreciate hearing about the "horror" stories:

Oh it was just one horrible story after another, and I just thought I don't know. I don't think I can do this, and they got around to me, and I was last, and I said, I can talk right now but I can't listen, and I felt so bad, because that's the name of the group because they have someone to listen to you, but I just couldn't listen. And they said it's okay, and so I got so I could listen to other people, but I was a basket case when I came out of there the first time because of all the other stories.

This survivor appreciated being able to get information quickly and connecting to another survivor on an individual basis:

But we found out a lot of information really fast, by hooking into the leukemia and lymphoma support group, and that made it easier, and there have been many events over the course of the almost 3 years now that we've known about through them, we've gotten help from them, and so I'm really grateful that they're there, and I would recommend connecting with them, and they set us up with a mentor right from the beginning, someone who had a similar lymphoma, someone who I could talk to on the phone who had been through the experience, and you know that was a good thing, too.

In a few rural communities, the support groups had faded away, and a few survivors had tried support groups, but they did not find them beneficial, “It just wasn’t for me but I know they do help some people.”

Challenges with sex and intimacy were common. Some were mechanically related (such as cervical dysplasia from chemotherapy and impotence from surgery). Some challenges were more related to a decreased sex drive, possibly due to aging, with one survivor referring to herself as a “eunuch.” This survivor described her intimacy challenges:

When I was on chemo, they told us to flush the toilet twice whenever I went to the bathroom because those chemicals can hurt other people, and, he was afraid to touch me, and it was really hard, because of those chemicals... and then, the chemicals forced me to go through menopause, and so that made sex harder, so we’ve had to deal with that, and, intimacy is really hard. And it makes me feel more distant from him, but he’s really, I mean, he’s caring and he, he’s affectionate, but, we’ve just been through a lot in 3 years...our relationship has changed a lot. We were, we were always all over each other, (laughs) so it was a big change. Really, we’ve been together for over 30 years, and we’ve been through so much and it’s changed.

Survivors talked about relationships becoming closer but also being challenged due the emotional toll. “My husband and I are closer, I think, it was a very sobering situation, and you realize your mortality a little more quickly, and so I think it has drawn us closer together.” “All of those things have taken an emotional toll on both of us really. It feels like okay we’re due for a winning streak here, but as far as our relationship, it is good, as solid as ever, but there’s also the fact that it’s been a difficult time, and to be going through a difficult time even when you’re close is a difficult thing.”



One urban survivor found it frustrating to deal with a daughter with special needs during treatment, especially since her daughter could not understand what she was going through during chemotherapy. Another rural survivor felt that her relationships were more meaningful, and she chooses to spend time with her closer circle of friends, rather than spending time with acquaintances and those she viewed as more superficial relationships.

**Spiritual.** Subthemes under spiritual included (a) positive attitude, (b) spiritual journey/gaining strength, and (c) finding your own journey. Having a positive attitude was an absolute must for these survivors and really helped in getting through it.

My doctor shared with my husband that my attitude was good, and my thought was, well, if this is the time I have left, I'm not gonna sit around and mope about it. I did the things that I wanted to do to the best of my ability and I think that's important. Other folks have told me that it is, too. Every year the Komen has the breast cancer issues conference in Portland, and you hear the same things from those folks: attitude is important.

So I didn't think about negative things, I just thought about positive things. Okay, that's one week down, four weeks to go, you know, okay I'm half-way.....I have a really good outlook and I think that's what got me through it....I need to be all that I can be.

Survivors drew extensively from their spirituality, whether it was through formal church and prayer networks, or through nature and pets. "I think nature is my healer, and my dogs, being with them." A few survivors shared that their faith had been renewed since experiencing cancer:

My spiritual life has deepened, but it's hard for me to say if that's just a factor of my age or if that's the cancer. I certainly didn't feel like God abandoned me by giving me cancer, I did not feel like

God inflicted me with cancer. I feel like it's just a part of what happened in my life, and my faith in God is very deep and it's very important to me. And I have had a bit of renewal in that.

One huge piece is my faith. My faith is definitely, has been brought to the forefront with this experience of my being diagnosed...I've reconnected with a church that I started attending years ago. I felt really drawn to it when things were totally out of my power and grasp, it felt like such a cliché, I might die therefore find God, but it has been a source of strength, a source of comfort, and brought me a whole nesting network of friends and support, and so now I'm very active in the church and very happily so.

Spirituality was a great source of strength for survivors: "I think God knew I was strong enough to deal with it and I did....I had a really good church family who prayed me through every part of it. My pastor came to see me at every step, so it was very good." "I felt like God was with me all the way, and I had these devotions that I did every day and it was weird because they would be exactly what I was worrying about or thinking about at the time."

It just gives you the courage, every day, to know that you're not alone, even though you have family, and friends, and that network, you have someone that, but you can draw a lot of strength from spirituality. Having a relationship with God, there is strength in that. It's something that I can actually feel.

For one survivor it was something that couldn't be explained:

I found the strength through family and friends, and my own inner strength to get through it. I'm pretty sure that somebody was there on my shoulder, just kind of helping me through it, even though I didn't hear it, I could tell that somebody was helping me get through it.

One survivor found that in rural settings, people were more comfortable praying in public and discussing the spiritual aspects. The survivors also described different personal responses to cancer:

Everyone is different and they have to find their own journey, and treatments have changed, too. I find myself questioning and suspicious if people are suffering from chemo. I kind of wonder, well, I was very fortunate, I didn't, I had a relatively good tolerance to the chemo, so when I hear of people suffering mightily, I fret, well, why aren't people more on top of that? I'm very judgmental.

This urban survivor talked about her healthcare journey in terms of "riding the wave":

Well at first it was like a wave, of just okay, I'm gonna do what they tell me to do, you know, the doctors and professionals and such. I always felt that I could do it here in Alaska. Some people from some of the support groups and stuff say, you know recommend going outside, and maybe getting some outside second opinion. You know anyone that I was recommended I always felt confident with them; they seemed to know what they were doing, and so I rode the wave.

This rural survivor is still trying to find a balance of what she can handle in terms of working and/or volunteering.

I'm having trouble finding a balance of what I can handle, and what I can't handle, because I'm not like I used to be, but I'm recovered, and so I'm trying to find a balance. I don't want to be full time because I didn't know what I could handle, and they made the position  $\frac{3}{4}$  time, but I still found myself diving into it and just making my job consume me, so I'm trying to find a way that I can find meaning, but not hurt myself. I don't want to have something that's gonna make me stress out and gain weight and be at the computer too much, but, still be able to help and find meaning, so I haven't found that balance yet.

## Post-Treatment

### Reconciling

**Body.** A common area for physical reconciling for survivors was trying to determine if symptoms are related to cancer recurrence, a late effect from cancer treatment, a new health issue, or just plain aging.

Then I just have to sit myself down and focus on something. You know you get kind of a, what you would think would be ADHD where you'd just zipping from one thing to another, and your thoughts just whip out, but how much of that also is just what you would go through in menopause and that type of thing, too. It's hard to distinguish which is which. I think it just kind of makes it more prominent .....how much of it is old age and how much of it is caused from the chemo or the cancer

**Mind, spirit.** Survivors spent time reconciling their faith and beliefs, and putting them in the context of the cancer survival experience. They were reflecting, questioning, and working through emotions toward mental well-being.

I am a Christian, and at the time that I got cancer, I was reading through the Bible, and I was doing Job. And there is a particular verse in there, that says, though he slay me... I praise him, my hope is in him. And I thought, do I have that belief? And I thought, yes I do. Well it wasn't too long before I was tested, and yes I do. And I think that that helped me to come to terms with a lot of things because I know that events in my life are father-filtered and nothing happens to me that he hasn't allowed it, so it's up to me to glean the good things from that experience.

It's pretty powerful when it forces you to, doesn't force you, but I chose to, I can honestly say, that I'm living, that when it's time for me to leave this earth, I will be leaving with very few regrets. Because I've been able to deal with some unresolved stuff, re-finding my faith, and that's a pretty fabulous place to be in. Actually, I've often said, if it weren't other than the fact that it

could ultimately kill me, I'd say cancer's the best thing that ever happened to me.

Survivor's guilt can be a struggle for some, although they are trying to live "normally":

I find I'm less aware of the cloud hanging over my head, until something will trip me up. I find I take it extremely personally, whenever I hear of another person diagnosed, not just breast cancer, any kind of cancer. I have survivors guilt, often find myself questioning why I am here while others aren't.

**Choices.** Although survivors realized that they are not going to find the perfect answers, they are for the most part happy with their treatment choices and realize that they have made the best choices for themselves.

I mean it was really a shock when I found out that I had it, and worried about taking care of it, but it's just knowing that it was cured, and I can live my life like I still want to. I feel that I don't like anyone to have cancer, but just to be able to take care of it, at that time, and not worry about how many years you've got, it's just beneficial and I'm glad I got it done.

And I started asking more questions about what I was doing, and finding out that everything they tell you at the doctor isn't necessarily what everyone experiences and isn't necessarily what you have to choose. I started realizing that I had choices, and then I started feeling like, even though what happened to me was really fast, and maybe I wouldn't have picked that, but it was the best for what I was, for what I had.

For this survivor of prostate cancer, it was about choosing to live, even though the long-term side effects of treatment have a huge impact: "I made the decision to live, it's better to be alive, than not being alive... I couldn't, no, I wouldn't do anything differently, because things are working out fine, I'm alive..."

It was important for the survivors to know that they had done everything:

And I also know, that if I get breast cancer again, and I could, I'm very realistic about it, and people always say, oh you won't, well I don't know that I won't and they don't know that I won't, I might, and if I do, I'll just deal with it, as it comes, and I don't ever have to get out of the bed in the morning and say, why didn't I have both breasts removed? And why didn't I have my ovaries removed? Why didn't I, why didn't I, I never have to say that because it's all done. I can't think of anything else that I could do to reduce my risk.

Cancer helps you to prioritize and determine how you want to spend your life:

I think you hear other people say this. Once you've had it, you say to yourself, how do I want to spend the rest of my life? So it's caused me to maybe focus a bit more. I said to myself, how do I want to spend it? I thought about it. The very first thing that came into my mind was I want to see my children, I want to see my grandchildren every single day.

Sometimes the choice is an attitude, such as "you can get bitter or you can get better." One rural survivor regretted not seeing a counselor, which was one of the few regrets shared by the survivors.

**Relationships.** Most survivors shared that they had no regrets regarding relationships: "I'm almost 70 years old, and I think that I have led a very good life. I've had, I've done all the things that I want to do. I don't have grandchildren that I'm waiting for to grow up, none of that." One long-term rural survivor went to great lengths to heal family conflicts:

When school is out every year we have what we call cousins days, and everyone comes for 3 days of just camping. We live on a lake and we just play games and work and just lay aside

everything else. And everybody really looks forward to it. My kids look forward to it, my grandkids look forward to it, and even the grown grandkids look forward to it. It's just a fun thing, and kind of a unique family holiday for us, and it grew out of, I guess I decided I wanted to do it because there were some hard feelings in the family and there were some blaming going on. We just need to lay this all aside, and we did.

It was important for one rural survivor to keep her promises to a friend who was going through a terminal cancer experience, and this turned out to be a life-changing experience for her.

My friend who passed away in October, it was an amazing life-changing event for me. When she was first diagnosed, we actually had quite a troubled history together; when we reconnected, I think it was four years ago, at that point, she had been diagnosed with stage III colon cancer, and I love that I seem to be a go-to person. If someone is diagnosed, I am called a lot, as a reference, as someone to talk to, and I like that, but anyway, we reconnected over her colon cancer. She got better, or so we thought, and that was just one less regret that I could check off my list, and then, she had been clear for three years, and I hadn't seen her for probably for over a year, and when she called last June, newly diagnosed with the stage 4 pancreatic cancer, and so we connected again, and at that point, she was panicked because she had friends that were turning away from her, and I foolishly told her that I'll be the friend that holds your hand 'til the very end, and I was able to keep that promise, and I tell you what, I've never watched anyone die, and it was pretty life-changing, but the fact that I still get, obviously I still get choked up about it, but the fact that I was able to do that, for her, is just phenomenal.

### **Cancer Perspective/Life Perspective**

**Why me/why not me.** Several survivors talked about how important it was to them not to question "why me?" "Some people say why me, and pretty much why not me. It could be anything, why not me, why isn't it me going through this? Because we all go through something. This is just the

battle that I'm sent out to do. "I never went to that point of 'why me.' You know, what are you doing to me, God?" Survivors were concerned that by asking "why me" they might be wishing the cancer experience upon someone else.

People say that. I've never said that. "Why not me?" Am I saying that I'd rather see somebody else you know? Why not me? My mother said it one time, and I found it very annoying, and, that's just what I said to her, "why not you?" Is there somebody that you would prefer to have this, mother? And that was the last that she said of that, and you know, I explained to her that she wasn't singled out to get this. It's a random thing, by genetics or environment, or whatever happens.

This survivor described another survivor's experience sorting through the "why me/why not me" aspect and considered it a sign that she was doing well:

I always think of my husband's niece and she was diagnosed with breast cancer, and was very upset, but a year later when I talked with her and I said, 'How's it going, Cindy?' and she said, 'You know, it's great,' but she said that first beginning part of it is awful, and I said, yah, it is awful. She was seeing a psychiatrist and she leaned over and said to me so, "What did you think when they told you you had breast cancer? Did you say, why me? And she said she looked at her, I didn't say why not you? She said, you know, so many people out of so many people are going to be diagnosed with breast cancer. I happened to be the one in that little parameter of people. Why would I wish that on someone else? I don't want it, but I don't want anyone else to have it either. I thought that's why you're doing so well...

**Moving forward.** Moving forward is perhaps the essence of the cancer survivorship experience, working through it, putting it behind you, yet keeping it part of who you are. This survivor of a less intense cancer experience wonders if this made it easier for her to put it behind her.



And the fact that it was easy makes it sort of easier for me to put it behind me and move on, and had it been less easy, perhaps it would have been less easy for me to leave it, because you know, I don't think about it all the time, I didn't rewrite my life. I didn't make big changes based on the experience, but it is certainly part of the life experience that is who I am.

This survivor felt it was really important to work hard to “do cancer right”:

After a couple of weeks, I started to think, okay, I've got this, this is what I've got to do, and my wife is disappointed with me when I say this, but having cancer has been like another thing you do in life. Okay, we did this and okay now we have to do cancer. Let's see how good a job we can do, let's do this really good, and do it right. So you work really hard to do cancer right. It's something else you do and it's all going to come to an end at some point

Survivors definitely feel that having had cancer is part of who they are, yet it is important to leave it in the past and move on. “Take every day for all the good there is in it, and leave the stuff of yesterday. “Well, I can't even think about how it has changed, you know, when I was going through it, it was definitely traumatic. There's no doubt about it, but, after a while, it's just been in the past.” “If the news is relative good how quickly you can move past it. I mean you know it raises its head probably every 3 or 4 months. I'll think about it, I've got this cancer thing you know.”

**Prepared/building on past experiences.** Survivors felt that they were prepared for cancer. One survivor felt that God had prepared him: “A friend of mine and I, we were working out 3 days a week, so I was basically in the

best shape of my life. I think God was grooming me for this to be perfectly honest with you.”

One survivor approached cancer in the same manner that she had approached any other crisis in her life, in a systematic way: “I know that I pretty quickly came to terms with it. This is what it is and this is how I’m gonna deal with it. If this doesn’t work, this is the next step, and that’s pretty much how I approach any crisis in my life. Okay this is what it is, this is what we can do, this is what we can’t do.”

This survivor drew on her experiences as a single parent, which helped her to be independent and to “keep going” through the cancer treatment experience.

As a single parent, I had to face a lot of challenges, so I was prepared for any challenges. By that point, I was not getting child support for a while, and I had to make sure my kids were fed, I had to go to work, I had to pay day care, I had to do a lot of things, and I did them by myself, so when it comes to this, I guess I’ve become very independent and I realize you know, this isn’t going to keep me from going to work. I’m just going to have to keep going and do what I did like I did when I was a single parent.

Another drew on experiences with past medical problems and a background as a nurse:

For me, it was more straightforward because I had been through some medical issues in the past, so I had already gone through sort of the rearranging of your life and making sure that you are living the way you want to. And I think a lot of people get that from cancer, they look at their lives and sort of re-prioritize...perhaps I was more prepared than some people going in, because I do also have a background as a medical provider, and so I had enough medical background that I don’t feel totally

alien to that world. The terminology comes more easily, I'm able to grasp some of the procedural stuff more quickly, because I'm familiar with it. I speak the language, so I think that made it a lot easier. I had less confusion, and I was never overwhelmed. There's a lot of information.

For this survivor, cancer was "just a bump in the road," and advice from her grandmother and seeing her brother-in-law survive cancer convinced her that she could be a survivor:

My grandmother always told me that you can do anything if you want to. And having been the first grandchild to go to college and become a professional has just made a real difference in my life. Cancer was just a bump in the road for me. You know a lot of people, they hear cancer and it's doomsday. For me it was, I can get through this, it didn't matter what I had, I knew I could get through it. I had a brother in law who had non-Hodgkin's lymphoma, way back when that wasn't very treatable, and they did a lot of experimental stuff with him and he was a survivor, so I know that I can be.

**Compounding factors.** There were a variety of circumstances and past life experiences that further compounded the cancer experience. For one survivor it was the downturn of the economy: "Around the time that I was diagnosed, the bottom of the market dropped out. So when all the contractors were trying to figure out what they were doing, I was getting ready to go through cancer treatment."

This survivor's mother had had a long-term experience with terminal cancer: "And my mother's cancer was so bad. I mean she had leukemia and she knew that eventually she was going to get another form of cancer. And to see something like that all of your life, it's hard." For this survivor, two friends died when she was going through treatment: "During all of this going

on with my treatment, I had two close friends that I worked with, and they were going through cancer at the same time that I was, and they were younger than me. They both died when I was in the process of getting my chemo, that was really hard.”

One survivor was dealing with her mother’s progressive dementia and the fact that her mother was obsessed with what caused her cancer:

I explain this every time to my mom, and finally I said, ‘Mom, I wish you would not ask me that anymore because it, it’s emotional for me, and I don’t know why I got it, and I have no risk factors, and this is what I think, but I know now, it’s nothing that I did,’ cause it’s almost like she wants to blame me.

**Catalyst for change.** Sometimes the cancer brought on other life changes, whether it was going back for a degree or changing jobs to reduce stress or giving up their own business. “It was after breast cancer. I went ahead and completed and got my bachelor of science. That was one thing that I might not have done if I hadn’t had cancer.”

Work is a good diversion, I had my own consulting business, and I was really thankful that it happened then, only because I was able to work my hours around it and was able to work from home, so it didn’t impact as much. But I will say after that experience that was also a key factor for wanting to stop my business. I had my own business for 8 years, and that was a very key decision for wanting to stop having my own business and be a regular employee again because I wanted more of that 8 to 5 consistent schedule.

**Thinking about cancer/reminders.** Thoughts about cancer do emerge for survivors, sometimes spontaneously, and sometimes there are

triggers such as hearing someone else's story, or a physical reminder such as lymphedema or dealing with a prosthesis.

I think about it more when I work with someone that is newly diagnosed as a volunteer, and you know they are sort of asking the questions that I asked, and going through the information search that I went through. I think about how easy it was for me when I work with somebody who's having a particularly difficult time.

I think a lot of it has to do, too, with me thinking about recurrence, the fact that I have this arm to remind me all the time. Sometimes it swells up depending on what I eat, or if it's hot, whatever, so it's always a reminder to me, but that's life.

But things like that will trip me up, because I'll go along and think everything's fine and then something simple like a wardrobe malfunction will trip me up, and I'll be like, I'm different than everybody else.

Even though several survivors shared that they didn't think about it that much, there were those who felt that "it is always in the back of my mind," especially if they were concerned about recurrence. In contrast, this survivor described not thinking about it, but through the interview he realized that he thought about it more than he realized: "I don't even think about being a cancer survivor. I haven't even thought about that in such a long time, it affected me when I went through it, when I went through the chemo, and, hormone therapy and the radiation, but I don't' even think about it.

**Thinking about death and dying.** Thoughts of death and dying were common. This survivor thought about where she wanted to die.

It also made me think about what do I want to when, if I have any heads up before I leave this world, how do I want to manage that? Do I want to be at home, do I want to be at the hospital? Do

I want my family to see me in the throes of this or not. It's definitely not pretty.

This rural survivor felt that dying in her rural town would feel more normal and comfortable. "I also felt like if I died, that it was just normal, and I would have people around me and I would feel good, even if I was gonna die. I didn't feel that here."

This survivor felt that religion makes death more scary:

There are some religions that make death a very scary thing and I think that's too bad. We should be worried more about life than about death, and so that's sort of the spiritual foundation that I draw on. I'm more concerned about life and quality of life, than with staying alive forever.

Several survivors expressed that it would be more difficult to watch their spouse die than to die themselves. And another survivor joked, "None of us are getting out of here alive."

**Cancer is everywhere.** Survivors are concerned about the magnitude of cancer." My wife works in the medical field, and before I was diagnosed, we had never even heard about cancer. And now that I've gone through it, it seems like it's everywhere, we see it all the time."

It's made me more aware of people who have had cancer, especially since my wife had cancer. Seemed like half of her friends had breast cancer, it's so ridiculous just how many people have cancer. And I've had some friends who've had testicular cancer and prostate cancer, you know, and it's more prevalent because I know about it now>

There are so many people in the world with cancer right now. I am one of the most fortunate ones because I am a survivor and because I am able to function and enjoy life and there are many people who can't because of cancer. It's just something that is

there, and I don't know if it will ever go away, for anybody, no matter how early the detection is, there's still no cure. The treatments are getting better, but there's still is no cure and no cause. And that to me is one of the scariest things about cancer, it just keeps getting worse, it's so prevalent. There's so many different kinds, there's so many different kinds of treatment, and some are successful, some are not. It's just something that you have to learn to live with, because you can't get away from it. Pretty depressing, isn't it?

**Appreciative.** This was a prevalent and strong view across the survivors who are grateful for having survived and to be able to continue to live life and experience all it has to offer.

What surprises me the most is that people are still dying from this thing and I feel very lucky...I feel like a kid, literally, I have a second lease on life..... I just feel so fortunate, literally, I just burst at the seams because I am so happy to have my life back, and then some.

I am just so grateful for the 17 years since then. I've seen grandchildren born and great grandchildren. Although cancer is bad, I think it gives you an appreciation for what really matters in life, like people, and you don't care so much about the politics of family life, all the little quarrels and things are not important. It's a double-edged sword. It was pretty hard, but there certainly are gifts of appreciation that you gain from having experienced it.

One of the hardest things was being semi-comatose on your 29<sup>th</sup> wedding anniversary, just giving up a breast, you know, it's like, okay, this is not a high point in life. But then you appreciate, and that anniversary comes around again, and you think, oh wow, here we are all these years later and we've had numerous grandchildren that are an immense blessing to our life, and you think well if I had perished back then, I wouldn't have known that person and that person.

I have a friend and every morning she wakes up and says thank you God for another day, and that's what I do....one of the books I read said to list 5 things that you're thankful for every day, I've done that for 3 years, I have pads that are full, and I still do that, every night I do that.

**Pride.** Survivors expressed being extremely proud for getting through treatment and being a survivor. Some displayed visual reminders, “I wear my band proudly.”

While I’m not a competitive person athletically, I take great pride in that when I did my chemo and they gave me my schedule, I was determined I was not going to miss one chemo, not that you have any control over that, that was my only, really bad crash and burn, after only my second treatment my white count crashed, and they said, ooh, we cannot give you chemo if it’s like this, and it boomeranged back up. I was good, but it’s such a sense of pride, because I did all 8 rounds and didn’t miss one.

**Admiration.** Admiration was both expressed about others as well as received:

She was in 7<sup>th</sup> grade when she got cancer, and I knew her then, and we prayed for her, she was just a dear. I told her just a couple of weeks ago, you were my hero, I said, when I got cancer, I can do this, because you did it, and she goes, oh, I didn’t know I touched anybody’s life, and I said oh yeah, you touched a lot of people’s lives. Because here she was in 7<sup>th</sup> grade, with cancer. What a horrible thing!

I’ve had friends come up to me and say because of you I’ve changed my life. They realized how short life can be, and here I was healthy, no problems and the next thing I know I’m having surgery and you know stage III cancer. I actually had a friend tell me that, she told me, Katy, I’ve never told you this, but I’ve always admired you, and the other thing is that you changed my life. When you got cancer, I talked to my husband and we went out and bought this cabin out along the highway, which we always wanted to do, and we started doing the things that we always said we were going to do and we didn’t do. I’ve had a lot of people come up and tell me how much they admire me, which is good, great support, too, because you know that they know what you’ve been through



**Giving back.** Most of the survivors were engaged with volunteering, giving their time generously, and were quite enthusiastic about it. Some are working to improve healthcare in their communities, especially the rural survivors. “I would rather be part of the solution and not part of the problem. So I serve on the patient and family advisory committee at the hospital.” In addition, they reached out to other survivors:

I enjoy being as much help as I can. As a matter of fact, when I was going through chemo, my doctor, uh, called me and said, well, if you wouldn't mind, I'd like to refer some folks to you so you can talk to 'em, and tell 'em how you've dealt with, and probably 7 or 8 ladies I've talked to, and I've told 'em, you know, and it just helps, to talk about stuff.

I'm actually a mentor. I'm mentoring a guy now who went through the same kind of cancer that I did. Because when my wife and I went through it, we didn't have anyone to talk to, we didn't even know who to call...I'm in this mentor program and once in a while they'll match me up with someone that's got throat cancer, and I'll just call 'em up and share my experiences with 'em. And this last guy that I got hooked up with, I went over to their house and probably talked with them for an hour and a half, and just answered every question they had, and I told him, call me any time if you have any questions, and he's actually called me a couple of times you know for advice, for questions, or just somebody to talk to before he started into treatment....so I am absolutely excited to help people who don't know who to talk to, to ask questions, stuff like that....it's kind of my way to give back because we didn't have any support.

One survivor started beading groups for survivors living in remote settings of Alaska: “People who didn't know each other were interacting at the beading group so it had really good results, and it was therapeutic.”

This survivor served as a resource for her rural community: “My number is at the clinic, and they know anybody can come by or call me. They can stop by. We all know where everybody lives, too. It’s not like being in a city.”

Since I survived it, I’m going to do what I can to make sure others get through it with being there, just a listening ear for others and such, because so many people listened to me when I was “what am I going to do now” and, “will you explain to me why I have to do this and this and this?”

### **Survivor Identity**

**Public or private journey.** Survivors shared how public or private they wanted to be about sharing their cancer journey. The dichotomy of knowing/not knowing emerged in both urban and rural survivors, yet one rural survivor preferred to keep it concealed, especially to her work clients. One rural survivor indicated that “everyone knows,” and this was described as a “double-edged sword” in that sometimes in a small community, you can’t get away from it.

Sometimes I was exposed more than I wanted to be as far as being out in the community. I mean everyone knows I’m a cancer survivor, but sometimes I just want to quietly write a check to the American Cancer Society, I don’t want to go through all the hoopla of the fundraising and the socialness of a team, and yet sometimes, it’s really cool to do that survivors walk...everyone knows what you’re going through, it’s a positive and they can lift you, but it’s a negative because you can’t escape it.

Yet this urban survivor also experienced a small community within her urban setting:

I’ve already had my name in the *Daily News* and my picture, when they did a thing a thing on cancer survivors several years ago. I gave an interview, so it’s not anything that people don’t know. Everybody knows about me, everybody knows what I went

through and, it's a small town. When you work in the media and when you know each other from working here and there, it's no secret.

One rural survivor felt that she was less of a survivor when she travelled to an urban setting, where no one knew her versus being in her home community where "everyone knows.". This survivor also described her public journey and how it inspired her with the strength to go on:

I was in school, and I had a very public journey because I was teaching, and so my third graders were aware of what was going on, their parents were aware of what was going on, and of course it was very reinforcing to present a strong front because I had an audience. And so they were very inspiring for me to get through stuff

This survivor would go back and forth between a remote/rural and an urban setting and she was uncomfortable praying in a public place initially but received caring in both places:

When I went back, every time I saw somebody they would hug me and tell me they had been praying for me at their church, and, even when we saw people here in Anchorage, they would grab me and say, 'let's say a prayer,' and I've never had anybody do that with me in my whole life, so it was kind of uncomfortable at first, but how much caring that is, just being able to do that in a public place here

**Cancer club.** Most of the survivors were connected to cancer-related community activities and routinely spent time with fellow survivors. Events included fundraisers, awareness events, seminars, and volunteer groups. They described experiencing camaraderie over survivorship events and shared having positive as well as negative experiences with these events.

One survivor who participated in a cancer retreat described how interacting with other survivors was surprisingly beneficial for him:

I felt like I could be as forthcoming as I needed to be. I felt like I'm gonna go to this cancer retreat because my wife thought it was a good idea to. I feel like I don't need a lot of support, and that was the way that I felt before I went, and somehow when I got there, I felt like I really did belong there and though I didn't need support, I felt like I was getting something that I didn't know I needed.

One survivor described it as a “fraternity” and the visual identification of the “yellow bands”: “And to be honest with you, it feels like kind of a fraternity. I see people with yellow bands, and I don't have any problem walking up to them and saying so are you a survivor? Or are you supporting someone?”

And this rural survivor called it a “sisterhood” and exhibited the strong attachment to survivors and survivor groups, and conveyed that there is benefit to both parties in giving and receiving support:

The various cancer support groups and all the volunteers and caring individuals that are everywhere, if a person can figure out where to seek them out, are an integral part of survival during the cancer experience and certainly are very much needed after the sense of calm returns. I have not met a breast cancer survivor that is not willing to listen, share, and assist anytime anywhere, if they are told they are needed in some way. I think most cancer survivors want to be needed by others going through the cancer experience because maybe it helps resolve issues of their own? Plus, people just want to feel needed and feel that what they have gone through is important to someone else and that there is a sisterhood out there that they are part of now.

**Minimizing.** Survivors who experienced a less intense journey tended to minimize their experiences. One survivor even referred to herself as a “phony”:

There were so many people that were much sicker than me, with shaved heads and implanted porta caths, so I don’t know, I guess I am a survivor, but there are so many other people that have survived terrible things...I actually feel like a phony sometimes.

Survivors with less intense experiences (minimal symptoms or impact) universally shared that “others have it so much worse” and felt that their experiences were easier when compared to others.

I guess the thing is, knowing I had the cancer, and going to these dinners once a month, and seeing people that are in much worse shape or going through much worse than what I did, I just feel very, not blessed, just confident, that I’m just there. I’ve got my problems, but others are having more problems.

Another survivor with a less intense experience commented that she needed to be careful about how she communicated this to others: “Certainly when I go to the support groups and I’m trying to share my experience, with people, in a way that’s not too cavalier, because it is a big deal for people that are going through the active phases.”

Survivors with more intense experiences (i.e., severe side effects from treatment, significant prolonged symptoms with negative impact) did not minimize their experiences. However, survivors with intense treatment experiences but minimal long-term impact tended to minimize. Even a survivor with an intense treatment experience and significant impact

minimized her situation, when comparing it with other diseases which she considered to be more challenging.

I know people that have multiple sclerosis or Lou Gehrig's disease and Alzheimer's and their journey is so much tougher than mine, even when I was fighting, battling cancer, their journey is daily, always. And their inspirations to me, how they, you know, just continue everyday living, and doing the best they can with a joyful spirit and it's just amazing to me, so I live with cancer. I'm not dying from cancer, I live with it. That's how you have to look at it.

**I'm more than cancer.** All of the survivors felt that cancer did not define or describe them as a person. "Person first, cancer second" and "cancer doesn't define me" were strong themes. Several survivors did not want to be known for having cancer, and they felt that it was extremely important to know who you are, before and after cancer, and to not lose focus about who you are. This was expressed by an urban survivor:

I'm interested lately in the theme of survivorship. Once you have had it, everybody is appalled, and once you're a survivor, it becomes a definition, and for me it's not a very good definition because I don't fit any of the categories. It will be nice to see survivors used in sort of a broader sense because the cancer has not defined me and neither does survivorship define me...it's a very small part of, in terms of my total identity.

And this from a rural survivor:

I don't want to be known as the breast cancer survivor, or the woman that had breast cancer. I, if somebody wants to come and talk about it, they want to see my scars, the word is out there, with our little cancer group here, because they have the walks and everything here, they know that anybody can call me any time, I'm very open about all of it, but I don't want to be known as the woman that had cancer, you know, I'm still me. I haven't changed. My body has changed a bit, if you get me

without my clothes, but since I wear a prosthesis, you would not know to look at me. But I'm very candid about it.

I'm the type of a person, I'm not afraid to talk about things. I'm not afraid to talk about dying and death, and so on, so everybody is always comfortable around me with things like that, so I'm still me, and my daughter, we talked it over, and we all, that's the way we want it, very open, but let's not focus, don't lose focus on who I am.

### **Long-Term Impact**

**Survivor.** The long-term impact on the survivors varied, but most would agree that "it's just part of my life now." While some survivors had minimal physical impact, those with a higher intensity cancer treatment experience shared that they were concerned about premature aging, chemo brain, physical disability, ongoing symptoms, and they had learned to live with lasting bodily changes. For these survivors, the long-term impact was extensive.

**Health/health monitoring.** Survivors focused extensively on perceptions of their health, their health habits, and how they monitored their health.

***Health within cancer/healthier after cancer.*** Survivors considered themselves healthy before and after cancer, and sometimes during cancer treatment. "But the idea that I have all this healthcare going on around me and I still get cancer...I've always felt healthy, even through this whole process, I've never felt sick."

Several survivors described very active lifestyles:

I can't say I forget, because I have the mastectomy and I always have the breast form there, but, I think I'm in better health and in better shape than prior to my diagnosis. We love to walk, lately, we haven't because we have ice and snow, but my knees have been hurting, but my husband and I will walk in the afternoon, check the mail, just do errands, and walk back, and I love that.

***Focus on wellness.*** Focusing on wellness and improving physical and mental well-being was crucial to the survivors. "It's very easy to concentrate on an illness, easier than it is to concentrate on your wellness. You have to work hard to concentrate on your wellness."

I'm eating better, I'm walking more. I hit the farmers market instead of the grocery store. I have an acupuncturist in the family so I'm going to her regularly. I recently made an appointment with a naturopath, but I haven't been there yet, so just sort of trying to broaden my perspective on healthcare because there's more than one mode and they're not mutually exclusive. I should probably avail myself of all of the options that I can.

This survivor described the rural lifestyle that kept her very active, out of necessity:

I make an effort to exercise some every day, but our lifestyle is such that you exercise whether you want to or not, like we cut wood and we have a garden and we have animals, so I think I live a pretty physical lifestyle. When I realize I'm not doing physical things, I'll walk, and in the winter time I ski but I have a pretty physical life, I don't know, I know I'm stronger and more physical than the rest of the women that are my age around here. I just have a more active lifestyle that's required of me.

***Vigilant about monitoring health and symptoms.*** All of the survivors participated in regular medical monitoring:

Every 3 months I go back and they verify my PSA, and I've been doing it every 6 months now, and it's been 2 years, so now I



have to go I guess once a year I have to go now, just to make sure there's no readings whatsoever, and everything's zero now.

Sometimes, a new symptom launches an investigation:

It's just like okay, let's investigate, see what it is, even if it is cancer, you've caught it early, and I mean that's the whole thing is to try to catch it early as you can and it doesn't give you a life sentence by any means, so I think it has changed my view of, of cancer. I mean it's still something that you want to be very careful about, but it doesn't mean that oh, you're gonna die.

**Concern for children.** Survivors expressed concern for their children's risk of getting cancer: "So my son has to of course watch for prostate cancer, but doubly so because we have prostate cancer and breast cancer. And my daughter has to be aware now of course because of both." There is frequently concern for the child's anxiety over the parent having cancer:

It was really sad. My daughter was a senior in high school. I told her one time, let's go to Salem and get piercings, side by side piercings, and she said what, you, Mom? You'd let me have a piercing? And I knew that's what she had wanted, so I said sure, and we had our noses pierced, and it was kind of a little connection thing we did. When I was younger, my dad got cancer, and I was just a basket case, and I did not want her to think I was gonna die, and that I wouldn't be around for her.

**Circle of family and friends.** Survivors shared the view that the experience impacted not only themselves, but everyone in their lives. "The one thing that I learned I guess out all of this, is that it's a physical experience, but it's also an emotional and spiritual experience for not only you, but all the people around you in your world." "I did observe how it affected the people in my life, and not only did I have to deal with the

situation, but that they had to deal with it. I guess I learned it's not all about me. I thought it was all about me, but it's not all about me."

**Uncertainty.** Uncertainty originated from the unpredictability of the disease and response to treatment. The survivors found the "unknowns" to be very stressful. While there was a great deal of uncertainty for the survivors, they consistently tried to put this in perspective. "The oncologist told me that should the cancer reappear for me, I don't know if we can treat you again, that might not be an option. Well, that means that I have to take more advantage of everything we have. But I think I can accept that."

There's always the little twinges and tweaks, the longer you get out from your original cancer, the less that they play with your brain. You're always thinking, is that another tumor, did it metastasize? What is that? Those are those automatic negative thoughts that you have to crush and get those good images back in your brain, and just go on, and try not to dwell on those types of things. I would imagine that at this stage in my life I could die of heart disease, just as easily as cancer, that's what both of my parents died from, so, we just don't know. I could choke on a chicken bone this afternoon, you don't know, you can't sit and worry about it.

**Recurrence.** Concerns and worry about cancer recurrence is a very prevalent theme for survivors, and it is always in the back of their minds. For the most part they don't dwell on it; however, they are still watchful.

You know it's fine, everything looks the same. There's not any changes and there's no new tumors, so that in itself is always a great thing to hear, but you always live with that, you always know in your mind that any time that that could still be there, or it could be growing.

For this survivor with a high risk of recurrence, she thinks about it every day:

I go and look and see because of the thought that it, that every day it's going to come back and if it does, I'm screwed. But it keeps me on my toes as far as you know, my habits of eating because of that chance, too, so it makes me aware, more aware. Don't go there, you don't want it to come back.

While this survivor has fear, she feels that if it comes back, it will be caught early again:

It's always in the back of your mind, there's a chance of reoccurrence, there's that increased chance of uterine cancer because of the Tamoxifen that I'm on, so, that fear is there, and any time, you know they were seeing this spot, and they were double checking it and doing extra ultrasounds on it and stuff, and it was, here we go again. But it turned out to be nothing, so it's always that fear, but I really don't think I'm gonna die from it. I've been lucky enough that they found it early and got it out, and I do my regular checkups you know...I see those doctors on a regular basis and so that they can monitor it and if anything comes up, hopefully they can catch it early again.

For this long-term rural survivor, the fear of recurrence diminished over time:

"When you go for your first mammogram in those first few years, you have kind of a naked fear that you're trying to suppress. You know it could always come back, but I don't think you don't have that same stark terror that you did before."

**Advocating for self and healthcare services.** Survivors advocate for themselves and others. "I've heard so many stories from so many people all over, that it just seems like the medical profession in general that you have to be your own advocate, no matter where you are." The rural survivors were especially committed to improving healthcare in their

communities, such as advocating for lymphedema therapists in their town or encouragement for the local clinic to be more patient-centered:

If you're going to be a healthcare facility, then you think about your patients before you think about yourself. And I went to the city and I had a little meeting with people, and this is what I said, 'You think about your patients first and not yourselves, you have to either be in the business of caring for people medically, or get some jobs where you can be in politics.'

This survivor of lung cancer showed great courage when she confronted a physician after he referred to lung cancer as being hopeless when giving a talk.

For breast cancer and for colon cancer, there's so much more awareness for those diseases. And he said, 'Unlike lung cancer where you just go "oh well".' Afterwards, I thanked him for all the information he gave us, and I told him, I didn't write my death sentence yet so you probably shouldn't either, 'cause I'm a lung cancer survivor, and he apologized.

### **Profiles of Intensity and Impact**

The qualitative analysis of participant interviews revealed three clear patterns of intensity of experiences and level of prolonged impact. The profiles are (a) less intense treatment experience/none or minimal prolonged impact (n=7), (b) intense treatment experience/minimal prolonged impact (n=5), and (c) intense treatment experience/extensive prolonged impact (n=7). Rural and urban CSs were included in each of the three profiles. Tables 25 through 27 show the descriptive statistics, study outcome means and a case profile for each group. Chapter 5 discusses these profiles and how they compare with the study outcome variables.

### **Profile #1-Less Intense Treatment Experience/Minimal Prolonged Impact**

Case exemplar: Carol is 54 and in a committed relationship. She is a four-year survivor of breast cancer, lives in an urban setting, and works full time. She underwent two different mastectomies, first to remove the cancer, and the second electively to achieve a symmetrical physical appearance. She recovered quickly. She found the surgeries to be “easy,” without much pain or any complications. The only impact for her was missed work and the temporary inability to drive. She has no long-term symptoms due to cancer or treatment, is proactive about her health, and has adopted a more natural approach to health management. She is active in survivorship programs. She shared that people expected her to be devastated from her cancer diagnosis, but she wasn’t and she considered many people to be in “sympathy overdrive.” When volunteering and working with people who are newly diagnosed, she is careful not to come across as too cavalier as she realizes that there is a range in responses to cancer. A summary of descriptive statistics for the CS’s identified to be profile #1 is included in table 25.

### **Profile #2-Intense Treatment Experience/Minimal Prolonged Impact**

Case exemplar: Carl is 53 and a 3.5-year survivor of throat cancer, who lives in a rural setting, approximately 60 miles from a major medical center. He is married and works full time in a job that requires physical labor.

Table 25

*Descriptive statistics for profile #1, N=7*

Categorical Variables	
Location	Count
Rural	3
Urban	4
Mean age (years)	58.86
Mean time since treatment completed	4.43
Diagnosis	
Breast	4
Prostate	1
Colon	1
Lymphoma	1
Cancer Treatment	
Cancer more than once	0
Number of treatment modalities	1-2
Continuous Variables	
Variable	
Mean number of co-morbidities	2.29
IOC mean positive impact score	3.30
IOC mean negative impact score	1.99
Mean MSAS-physical symptoms	.60

He underwent radiation, having to relocate temporarily. During diagnosis and treatment, he experienced significant weight loss, depression, anxiety, fatigue, and he lost his sense of taste. He required a feeding tube to prevent further weight loss and maintain nutrition. After radiation was completed, for several months, there was still some uncertainty as to the potential need for disfiguring surgery. This was eventually determined to not be necessary. Prior to cancer, he was in very good physical shape, but it took months to get to the point where he could even work for a few hours a day. He gradually

resumed exercise and working, and he got to the point where he exercised vigorously. He now feels that he is in the best shape of his life, and he feels younger than he did prior to having cancer. He is maintaining a good weight, and he is proud of the fact that he has maintained a very positive attitude throughout his experience. The one long-term impact that he has is a diminished sense of taste, which he describes as being at about 25% of normal. He serves as a cancer mentor and provides support to other throat cancer survivors. See table 26.

Table 26

*Descriptive statistics for profile #2 N=5*

Categorical Variables		
Location		Count
Rural		3
Urban		2
Mean age (years)		58.60
Mean time since treatment completed		3.50
Diagnosis		
Breast		2
Colon		1
Lymphoma		1
Throat		1
Cancer Treatment		
Cancer more than once		0
Number of treatment modalities		1-3
Continuous Variables		
Variable		
Mean number of co-morbidities		.8
IOC mean positive impact score		4.33
IOC mean negative impact score		1.83
Mean MSAS-physical symptoms		.81

**Profile #3-Intense Treatment Experience/Extensive Prolonged Impact**

Case exemplar: Melissa is 56, and a 6-year survivor of breast cancer who underwent mastectomy, chemotherapy, and radiation. She lives in an urban setting and travelled to a different state for her surgery and returned for the remaining treatments. She has genetic components to her disease and breast cancer susceptibility gene 2 (BRCA 2). She was newly married at the time of cancer diagnosis, works full time, and worked throughout most of her treatment experience. She describes significant lingering effects such as lymphedema, chemo brain, and neuropathy. She has very strong worry and anxiety about recurrence and reports that she “thinks about it every day,” especially since her doctor has told her that she is at high risk for recurrence. She is an avid seeker of information on the Internet, and she frequently researches new symptoms, wondering if it is related to a cancer recurrence, cancer spread, or due to another disease or aging. She feels that this process increases her worry, but she likes to prepare questions for her physicians. She feels that she has lost her protection after being off the aromatase inhibitor. She has become more aware of improving her health habits and is determined to avoid cancer causes. She volunteers for a cancer survivorship non-profit. She did not minimize her symptoms or experiences. See table 27.



Table 27

*Descriptive statistics for profile #3, N=7*

Categorical Variables	
Location	Count
Rural	5
Urban	2
Mean age (years)	61.14
Mean time since treatment completed	4.37
Diagnosis	
Breast	4
Prostate	1
Cervical	1
Lung	1
Cancer Treatment	
Cancer more than once	3
Number of treatment modalities	2-3
Continuous Variables	
Variable	
Mean number of co-morbidities	2.29
IOC mean positive impact score	3.76
IOC mean negative impact score	2.75
Mean MSAS-physical symptoms	1.40

### Comparison of Quantitative and Qualitative Findings

A comparison of the quantitative and qualitative findings is outlined in Table 28. It is important to note where the findings potentially converge and diverge (Creswell & Plano-Clark, 2010). Different questions were asked in each strand of the study. The qualitative findings were more exploratory and not framed by the analysis of the quantitative findings. Therefore, there was not an opportunity to clarify or explain the quantitative findings, which could have occurred if quantitative data were analyzed first. However, there

Table 28

*Comparison of Quantitative and Qualitative Findings*

<b>Quantitative findings</b>	<b>Qualitative findings</b>
Urban/rural differences found on study outcome variables. <i>Body concerns.</i> AK urban higher than AK rural. OR urban higher than AK rural. OR rural higher than AK rural.	Urban/rural differences emerging from interview data. Discussed as concerns about symptoms, wardrobe challenges with breast prosthesis, etc. No differences identified between rural/urban survivors.
<i>Worry</i> AK urban higher than OR urban.	Worry manifested itself in the themes of recurrence and uncertainty, but no differences were identified between rural/urban CSs.
<i>Negative Impact</i> AK urban higher than AK rural.	Interwoven throughout the CSs experiences but not predominant. Best described in the profiles of intensity/impact.
<i>Employment</i> AK urban higher than AK rural. AK urban higher than OR rural. OR rural higher than AK rural.	Work impact discussed, but mostly positively.
No statistically significant differences in self-reported health, satisfaction with healthcare, and access to healthcare. Elements in the positive impact scale that revealed no differences. Not measured items related to CS identity. Not measured items measure worry about the future. Elements in the positive impact scale that revealed no differences.	Access and care coordination (urban more positive).  Community/connecting (rural more positive). Public/private journey (neutral).  Thinking about death and dying (neutral). Advocacy (rural more positive).
<b>Alaska Oregon Differences</b>	
No statistically significant	Care coordination—Alaskans

differences in study variables when compared between the two states. felt that care coordination/navigation was better in the lower 48 states. Formal survivorship programs—more developed in Oregon than Alaska.

### **Findings from correlations**

Constructs that contribute to the negative impact scale on the IOC are more significantly correlated with age, time since treatment, and physical symptoms than the positive impact scale of the IOC.

As time passes after cancer treatment, there are diminishing body concerns and relationship concerns in the survivors that are partnered. Symptoms are an important influence on the impact of cancer and quality of life well into late survivorship, and may also impact employment.

Relationships were impacted and reconciled but in a positive way. Concerns with sexuality were predominant, but no rural/urban differences found. All interview participants discussed symptoms, their impact, and how they were managing them. Some were hugely impactful, contributed to significant disability for the survivors, and contributed greatly to the profiles of intensity and impact identified. Symptoms with the greatest impact identified were paralysis due to lymphedema, cognitive decline due to chemo brain, and sexual dysfunction.

### **Intensity and Impact Profiles**

Patterns of symptom scores were consistent with the profiles identified

Symptoms are a big influence in the intensity and impact profiles.

IOC scores reflected the intensity and impact of long-term survivors, and the differences between those with intense treatment experiences and those with less intense experiences.

Case exemplars developed for each profile.

was an opportunity to clarify individual responses on the study instruments during the interviews. The quantitative and qualitative findings were similar in that the rural/urban differences were not pronounced. Differences identified in the two phases of study emerged in different constructs. In the quantitative findings, there were no major differences identified between Alaska and Oregon experiences. The Alaskan interview participants reported that lack of care coordination was an issue, and they perceived that care coordination was better in other states as well as Canada. The Oregon CSs were more engaged with survivorship in general and participated in more formal survivorship programs. Formal survivorship programs in Alaska seem to be sparse, especially in the rural and remote settings.

### **Summary**

Quantitative comparisons between the rural and urban groups showed no statistically significant differences. Comparisons across region and locality showed significant differences in body concerns, worry, negative impact, and employment concerns. Overall, the Alaska rural group experienced the most positive outcomes.

Qualitative findings revealed a temporal pattern of late survivorship, with major post-treatment themes identified as reconciling, cancer/life perspective, survivor identity, and long-term impact. Themes reflecting rural/urban differences included access to healthcare, travel, care

coordination/navigation, connecting and community, thinking about death and dying, public/private journey, and advocacy. Three profiles of intensity and impact also emerged from the qualitative data. The three profiles identified were (a) less intense treatment experience/minimal prolonged impact, (b) intense treatment experience/minimal prolonged impact, (c) intense treatment experience/extensive prolonged impact. Comparison of quantitative and qualitative findings reveals that each phase of the study is tapping into different and unique constructs.

Chapter 5 compares the findings from the present study with findings in the literature. Implications and limitations of the study, and recommendations for future research is also discussed.

## CHAPTER 5

### DISCUSSION

This chapter presents an analysis and discussion of the key findings and compares the findings from the present study with previous studies in the literature. The quantitative findings are discussed first, followed by the themes that emerged from the qualitative data. The third section of the chapter discusses the findings within the context of existing literature on rural and urban similarities and differences relevant to healthcare. The framework of survivorship that resulted from the present study is then compared with other published cancer survivorship frameworks. The implications of the findings related to intensity and impact profiles is then discussed, and the chapter concludes with a discussion of limitations, a description of the overall implications of the study, additions to the body of knowledge made by this study, and suggestions for future research.

#### Quantitative Findings

##### Responses to the Impact of Cancer (IOCv2)

The IOCv2, which is described in Chapter 3, consists of 11 subscales. Four subscales (*altruism/empathy, health awareness, meaning of cancer, and positive self-evaluation*) are combined to create an overall positive impact score. The overall negative impact score is based on responses to four subscales (*appearance concerns, body change concerns, life interferences, and worry*). Three additional subscales (employment

concerns, and a relationship concerns subscale with versions for those who are partnered and not partnered) provide information about issues relevant to CSs but do not contribute to positive or negative impact scores.

The IOCV2 is a relatively new instrument has only been found in one published study. Crespi and colleagues (2008) examined the reliability and validity of the IOCV2 in a large sample of long term BC and non-Hodgkin lymphoma (NHL) survivors. Mean IOCV2 subscale and higher order scale scores were fairly consistent between the present study and the Crespi et al. (2010) study. They are most similar between the present study and the BC group in the Crespi et al. (2010) study. The present study showed slightly higher relationship concerns and negative impact than both the BC and NHL groups in the Crespi et al. (2010) study.

### **Patterns of Correlations**

**Age and outcomes.** Age at time of study showed small to moderate negative but statistically significant correlations with health awareness, body concerns, life interferences, worry, and negative impact. Similar patterns of relationships between age and individual subscale scores were reported by Zebrack, Petersen, and Ganz (2008) in a study of 5- to 10-year survivors of breast cancer, prostate cancer, colon cancer, and lymphoma. Compared to the current study, Zebrack et al. (2008) found a weaker negative and non-significant correlation between age and negative impact ( $r = -0.06$ ) when compared with the present study ( $r = -.252$ ).

Results of previous studies examining age (both at the time of diagnosis and at the time of study) as a predictor of survivorship outcomes have suggested that younger CSs experience higher levels of mental health issues such as post-traumatic stress disorder than older CSs (Bellizzi et al., 2004; Geffen, Blaustein, Amir, & Cohen, 2003; Widows, Jacobsen, Booth-Jones & Fields, 2005; Zebrack et al. 2008). Furthermore, in their multivariate analysis model, Zebrack et al. (2008) found that age was a significant predictor of physical health, mental health, and QOL. Being an older CS was associated with better mental health and QOL, but being a younger CS was associated with worse physical health. Similarly, Cimprich et al. (2002) found that younger breast cancer survivors (BCSs) exhibited worse QOL outcomes in the social domain and better QOL outcomes in the physical domain than older BCSs. Also consistent with the results from the present study, Mullens, McCaul, Erickson, and Sandgren (2004) found that younger age was associated with more worry and anxiety in short- and long-term colon cancer survivors. In the present study, worry had the strongest statistically significant, negative correlation with age ( $r = -.261$ ) of all of the IOCV2 subscales.

Studies show that the concerns of CSs may vary by age, with younger CSs having more concerns about disrupted work, fertility, and child-rearing issues than older CSs. There is growing evidence that older CSs may have improved their lives as a result of having had cancer, and they may have a



positive orientation toward being a CS, thus developing coping strategies that may contribute to successful aging (Deimling et al., 2007).

Worry may have a positive or negative impact on CSs. A positive aspect of worry identified in the literature is that it can motivate interest in adopting protective health behaviors (Mullens et al., 2004). While this response may be common in CSs diagnosed with cancer as an adult, survivors of childhood cancers may respond by engaging in risky behaviors. In the Childhood Cancer Study, Zeltzer and colleagues (2009) found that psychological distress predicted poor health behaviors including smoking and alcohol use as well as fatigue and sleep problems in survivors of childhood cancer. Younger CSs may be at higher risk for worry and other outcomes associated with the negative impact scale such as body change concerns. Zebrack et al. (2008) found that worry predicted positive as well as negative outcomes in a sample of long-term survivors of breast cancer, prostate cancer, colorectal cancer, and lymphoma. They also found that CSs having a lower income or co-morbidities (as measured by a co-morbidity index), experienced worse physical functioning. Utilizing a general linear model, Zebrack et al. (2008) found that younger age at diagnosis was significantly associated with a higher score on the IOC positive impact scale, although type of cancer was not.

The construct of fear of recurrence (FOR) often overlaps with the construct of worry. Across studies, the measurement of worry may be limited

to worry in general, FOR, separate measures of both worry in general and FOR, or a single measure that contains general items and FOR-specific items. On the IOCV2, 2 of the 6 items on the worry subscale address FOR, but the main focus is worry about health and the future. The IOCV2 is not designed to produce a separate score for FOR.

The subscales of body change concerns, life interferences, worry, and the higher-order negative impact scale on the IOCV2 were more significantly correlated with age than the positive impact scale of the IOCV2. This is consistent with the early development work that was conducted with the IOC (Zebrack et al., 2006). In the IOCV2, the worry subscale has more items than the other subscales (7 as compared to 3 to 5), and the negative impact scale has more items than the positive impact scale (20 compared to 17). This could contribute to the stronger endorsement of the negative impact subscales.

**Time since treatment and outcomes.** Time since treatment showed a small to moderate negative and statistically significant correlation with body change concerns and relationship concerns (partnered). There are few studies that report the associations between time since treatment and survivorship outcomes. Body change and appearance concerns are important for CSs as well as those who have not experienced cancer as the outward presentation of the body has become very influential in defining identity (Lawler, 1997). A similar construct, body image, has been widely

studied in BCSs (Alfano & Rowland, 2006; Pelusi, 2006). Evidence suggests that changes in body image after breast cancer treatment may have an impact on sexuality and relationships. There is also evidence to suggest that there are differences in body concerns depending on the type of cancer. Crespi et al. (2010) found statistically significant differences in appearance concerns between BC and NHL survivors, with BCSs having more appearance concerns. However, there were no statistically significant differences in body change concerns. Ongoing assessment of body change, appearance, and relationship concerns are key to determining healthy coping during breast cancer survivorship (Pelusi, 2006).

As the time since treatment increases, the CS may become accustomed to bodily changes and thus express fewer concerns. In addition, as the CS ages, he or she experiences the normal effects of aging and associated adaptations to body image. Studies have shown that the importance of physical appearance decreases with age, and the functional aspects of the body take precedence, in healthy men and women (Mellor, Fuller-Tyskiewicz, McCabe & Ricciardelli, 2010).

Similarly, relationships are likely to be tested in the early and stressful stages of cancer treatment and survivorship, but over the long term, the level of concern may diminish. Supporting this concept, Belizzi and colleagues (2007) examined positive and negative changes after cancer and found that

cancer had the greatest positive change on relationships, in non-Hodgkin's lymphoma survivors, 2 to 5 years post-diagnosis.

Several studies have shown that the presence of a positive partnered relationship is a key component to successful adaptation to all aspects of the cancer experience (Avis, Crawford, & Manuel, 2005; Pistrang & Barker, 1995). Others have shown that there are small negative changes in the partnered relationship, but marital status does not change (Ganz et al., 2002), and the higher the illness severity, the more impact on the relationship (Thornton & Perez, 2006). Most studies are focused on early survivorship; therefore, less is known about the impact of cancer on relationships in long-term CSs. It may be beneficial to measure impact on relationships as an outcome, as with the IOCV2, rather than how it has commonly been studied in the past, as a predictor of adjustment (Thornton & Perez, 2006).

The findings from the present study suggest that as time passes after cancer treatment, there are diminishing body concerns as well as relationship concerns in the CSs that are partnered. The inclusion of a more heterogeneous group of survivors in the present study could have impacted these findings, although subgroups of CSs may be missing. For example, the sample did not include survivors of head and neck cancer that may have had disfiguring surgeries, which are likely to result in a negative impact on body image and relationships, and impact the ability to communicate. In addition,

AYA survivors, who may have more body concerns, comprised a small proportion of the sample.

**Physical symptoms and IOCV2 outcome variables.** Moderate positive correlations were found between the MSAS physical symptom subscale and body concerns, life interferences, worry, negative impact, and employment concerns. This is an expected finding since it is well established that symptoms have a huge impact on quality of life and are likely to be drivers of negative impacts. Common symptoms for CSs include cognitive changes, sexual dysfunction, fatigue, emotional distress, anxiety, and depression (Alfano & Rowland, 2006). Others include neuropathy, pain, sleep problems, and limitations associated with lymphedema (Harrington, Hansen, Moskositz, Todd, & Feuerstein, 2010). All of these symptoms were reported in the present study and contributed to the high-intensity/high-impact profile discussed below.

Crespi et al. (2010) found similar strong to moderate correlations between physical symptoms and PTSD scores, IOCV2 negative impact dimension scores, and intensity of employment concern scores. Spelten, Verbeek & Uiterhoeven et al. (2003) conducted a prospective cohort study and measured return to work at 6, 12, and 18 months post-cancer treatment. They found that fatigue and depression were associated with taking a longer time to return to work, and fatigue levels predicted return to work. In the present study, 64% of the CSs were employed either full time or part time,

with the urban CSs having higher employment rates than the rural CSs. The IOC employment concerns scale is only completed by CSs who had worked within the past 12 months; therefore, in the quantitative strand of the present study, the concerns of CSs who are not working is not known. In addition, alternative sources of income such as self-employment may have been missed. Due to the age of the participants, a high percentage of the non-employed CSs are likely to be retired.

The findings from this study, combined with other studies, provide evidence to support the idea that symptoms are an important influence on the impact of cancer and QOL well into late survivorship, and that they may also impact employment. Symptoms are often disease- and treatment-dependent, and universal measures of QOL may not capture symptoms of interest in a specific situation. Symptoms need to be measured independently of QOL to ensure that they are appropriately recognized and managed. Symptom management guidelines need to be developed for specific cancer types, such as urinary symptoms for prostate CSs, and some could be more generic such as fatigue and depression. Some need to be targeted for specific treatment regimens. Some researchers are advocating for guidelines for return to work for CSs (Verbeek & Spelten, 2006). Improved symptom management in CSs may facilitate less missed work in CSs of working age and could result in a more productive society. Further understanding of the impact of symptoms on employment is needed.

### **Differences between Regions and Locality**

Differences between regions (Alaska and Oregon) and locality (rural and urban), and the interaction effect across the four comparison groups, were reported in Chapter 4. No significant differences were found between region and locality. The analysis of the interaction effect showed that there were significant differences in worry, body concerns, negative impact, and employment concerns although the patterns were not always as hypothesized and results were mixed. For example, the Alaska urban CSs reported a higher negative impact than the Alaska rural group. Yet the Oregon findings on negative impact were just the opposite, with the rural group reporting more negative impact although not statistically significant. Also revealing mixed results, employment concerns were significantly higher for rural CSs from Oregon (supporting hypothesis) and urban CSs from Alaska (not supporting hypothesis).

To the researcher's knowledge, this is the first study to date that has utilized the IOCV2 to compare outcomes between rural and urban CSs, making it necessary to compare the findings with studies that measured slightly different outcomes. In addition, very few studies examining urban and rural survivor populations extend into long-term survivorship. Furthermore, recent studies focusing on rural/urban differences in QOL of cancer survivors are yielding inconsistent results. Some studies are showing poorer outcomes in rural CSs (Burris & Andrykowski, 2010; Lyons & Shelton, 2004; Waldmann

et al., 2007; DiSipio et al, 2010; Weaver et al., 2012); some are showing better outcomes in rural CSs (Schultz & Winstead-Fry, 2001); and some are reporting mixed findings (DiSipio et al., 2010), or no differences (Andrykowski & Burris, 2010).

Burris and Andrykowski (2010), in a preliminary study, examined the disparities in mental health between rural and non-rural survivors of breast, hematologic, and colorectal cancer. They found that rural CSs experienced greater symptoms of anxiety and depression and more emotional problems. These findings were in contrast to the Alaska group showing that urban CSs had more negative impact. However, results from Burris and Andrykowski (2010) were similar to the findings of the positive impact scale in the present study, as those authors found no significant differences in positive mental health outcomes such as benefit finding between the urban and rural CSs. In the present study, there were no statistically significant differences found in the IOC positive impact between the rural and urban CSs.

The rural/urban comparison results in the present study are mixed. The most consistent finding was that the Alaska rural group showed less negative impact than the other groups. The statistically significant differences found in the interaction effect showed that only 3 out of the 9 of the patterns supported the hypothesis that rural CSs have poorer outcomes and may even lend support to the opposite (see Table 18 in Chapter 4). These findings suggest that the differences identified could be due to factors other



than geographical location. It is challenging to sort out the influence of factors unrelated to cancer and/or region and locality on these findings. More research is needed to explain the interaction identified.

**IOCv2 issues.** Areas of concern regarding specificity and overlap with the IOCv2 subscales have previously been discussed. In the present study, a slight overlap was identified between the body change concerns and the memorial symptom scale, as discussed in Chapter 3. There are pros and cons to using one larger instrument versus several smaller, more-specific instruments. A larger instrument such as the IOCv2 provides an opportunity to tap into more domains of survivorship, with fewer items. Utilizing the alternative approach of several specific instruments could prevent overlap; however, it may limit the number of domains studied if there are concerns about increasing participant burden

In addition to examining the higher-order measures of positive and negative impact, it is important to examine each specific construct on the IOCv2, as suggested by Crespi and colleagues (2010). This ensures that the unique aspects of late survivorship and perceptions of impact are captured and further understood.

**Summary of quantitative findings.** In summary, the correlational analysis showed that small, negative correlations were found between age and the variables associated with the negative impact scale, consistent with findings in the literature. Similar correlations were found between time since

treatment and body change concerns and relationship concerns partnered. Symptoms showed a moderate negative correlation with almost all of the negative impact scale variable and employment concerns, consistent with other studies.

No significant differences were found between region and locality. In the interaction effect analysis, significant differences were found in worry, body change concerns, negative impact, and employment concerns. Although results were mixed, similar patterns occurred across these variables, consistently showing the Alaska rural group with the best outcomes, which was contrary to what was hypothesized.

There is growing evidence that positive and negative life changes associated with cancer and survivorship do co-exist (Alfano & Rowland, 2006; Belizzi et al., 2007). Support for this assertion is evidenced by the fact that a number of participants in the present study had concurrently high positive and negative impact scores on the IOC.

The sample in the present study is highly educated and insured, and for the most part they did not have financial concerns. The findings could have been very different in a sample that was more representative of the general survivorship population, with the potential to show higher negative impact.

## **Qualitative Analysis Findings, Themes Revealing Rural/Urban Differences**

### **Diagnosis and Treatment**

**Travel.** Travel burden can be significant for CSs from both urban and rural settings, with a greater impact on the rural CSs. Rural CSs often must travel to urban settings for treatment, and Alaskans frequently travel to the lower 48 states for treatment. Similarly, Lyons (2004) found that rural CSs travel greater distances to appointments. For rural cancer patients, reduced travel to obtain cancer care could be one of the most important outcomes. Elliott and colleagues (2004) measured travel as one of the outcomes in their group-randomized trial, which was conducted in 18 communities in the north-central US. In the communities that received the intervention, which targeted rural providers and their practice environment, the travel for healthcare was significantly reduced in the second year following completion of cancer treatment. In the present study, travel was prominently featured for both rural and urban and was woven throughout in their stories. Travel implications weighed heavily on their treatment decisions; in fact, some CSs advocated receiving treatment closer to their homes. Even in later survivorship, travel for follow-up appointments continues to be a challenge.

Relocation for cancer treatment poses specific challenges for rural and urban survivors alike. Survivors are displaced from support systems and relocation can strain finances, relationships, family life, and responsibilities

(Bettencourt et al., 2007). Rural settings are known for their strong community support, and this is lost during one of the most stressful times for CSs. Davis, Williams, Redman et al. (2003) found that rural BCSs may feel a sense of isolation and displacement when having treatment in urban settings. They may also develop support relationships during treatment in the urban setting, which creates a sense of loss when they return to their rural setting. Ten percent of the CSs in the present study changed their location of residence within one year of completing cancer treatment. It is unknown if the reason was related to cancer diagnosis and treatment, or if it was a change to a rural or urban setting.

Pisu et al. (2010) reviewed the literature for the out-of-pocket costs for BCSs and found that after medical fees, costs associated with transportation were the next largest amount, ranging from \$137 to \$509 per month. Recent economic conditions are likely to make the hardship of these expenses even greater. Several of the rural participants discussed the hardships associated with travel expenses during treatment, and a few described resources from non-profits such as gas cards that were utilized to help offset these expenses.

## **Healthcare**

**Access and care coordination.** The rural CSs in the present study had concerns about access to healthcare and support services, but not enough concerns to relocate their residence permanently. Living in a rural setting is a trade-off for them, and it is how they wish to live their lives. Across

the board they described being extremely happy with rural living. This raises the possibility that the attitude of the CSs may influence their patterns of healthcare access, particularly mental health resources. Andrykowki and Burris (2010) found that rural CSs used fewer mental health services, and personal attitude was the strongest predictor of MH resource use.

Hutson, Dorgan, Phillips, and Behringer (2007) studied cancer disparities in Appalachia through community workgroups. Healthcare challenges were one of the main themes identified, and more specifically navigation and patient-provider trust. The Appalachian population is predominantly uninsured or under-insured, but even when healthcare services were accessed, CSs experienced frustrations with poor communication and care coordination. Even though the populations are very different, and the study based in Appalachia represented more disadvantaged survivors, there were similar concerns with access and care coordination in the present study as well as mistrust of healthcare providers. Lyons (2004) found that low-income rural CSs were less likely to know what services were available to them, in contrast with the rural CSs in the present study, who demonstrated that they were well informed and utilizing resources available to them.

The Alaskan CSs in the present study expressed concerns about care coordination and felt that care coordination was better in other states and Canada. Oregon has more formal survivorship programs in place, and the

interview participants described healthcare that was well coordinated. Prior work has shown that patient navigation is beneficial for cancer patients; however, models for how this care is delivered are still emerging, and there is limited focus on rural populations (Carroll, Humiston, & Meldrum, 2010; Robinson-White, 2010).

Improved care coordination was one of the key recommendations in the IOM report, *Lost in Transition* (Hewitt et al., 2006), with the strong recommendation on instituting survivorship care plans (SCPs). Much of the healthcare for long-term CSs is provided by primary care providers, and even more so in rural settings. A model of care shared between primary care providers and oncologists is recommended (Ganz, 2009a).

The majority of the CSs in the present study reported having a summary of their cancer treatment (64%); however, the rates of completion for the summaries for the urban and rural groups were mixed, with rural Alaska CSs having higher rates than urban Alaskan CSs and urban Oregonians having higher rates than rural Oregonian CSs. In the present study, it was unclear if the summaries contained the recommended components of comprehensive SCPs as described by Ganz (2009b). The key elements of the SCP include (a) specific tissue diagnosis and stage, (b) initial treatment plan and dates of treatment, (c) toxicities during treatment, (d) expected short- and long-term effects of treatment, (e) surveillance for recurrence or second cancer, (f) who will take responsibility for survivorship

care, (g) psychosocial and vocational needs, and (h) recommended preventative behaviors/interventions (Ganz, 2009b). SCPs were not a focus during the interviews. More studies are needed to determine if the SCPs are comprehensive and useful for the CSs and their healthcare providers, and if they could improve care coordination. Most studies to date have been focused on rates of completion, not necessarily if they are effective communication tools. In fact, one recent trial found that SCPs did not result in improved outcomes in CSs (Grunfeld et al., 2011).

Programs are emerging that provide patient navigation for cancer patients. A recent systematic review found that navigation services were effective in improving management of BCs (Robinson-White et al., 2010). Most studies are focused on cancer screening practices and acute cancer treatment, and not necessarily on survivorship (Wells et al., 2008). Despite the increase of patient navigator programs, there are currently no standards identifying what services are provided, and there is insufficient evidence that these care models improve patient outcomes (Wells et al., 2008). Some programs include lay trained navigators, while many utilize nurse navigators. Implementing and testing navigation roles and models could improve the negative perceptions about care coordination that were found by the Alaskans in the present study.

## **Getting Through it-Social**

**Community and connecting.** Rural CSs described connections to their communities very positively. Johnson et al. (2011) in a non-cancer-based study in rural Ireland explored health and health needs and found that the rural environment and strong sense of community and dense social networks were identified as key determinants of good mental and physical health. This is similar to other studies that have found these strong networks to be protective. In the present study, the rural CSs described a similar positive sentiment regarding their community and networks.

Lim and Zebrack (2006) found that having a strong support network (formal and informal) enhanced QOL in long-term survivors of leukemia and lymphoma. Relying less on formal social ties such as healthcare professionals was associated with enhanced QOL. The community and networks described by the rural CSs in the present study were more informal and they relied heavily on them. Once treatment was completed, they also became part of the survivorship community, committed to helping others. Rural CSs talked about the importance of their neighbors. In contrast, urban CSs did not talk about their neighbors and may rely more on formal social ties, such as work networks and joining formal organizations. Both urban and rural CSs relied on their church communities extensively, and being active in a religious community has been shown to be beneficial for CSs (Vachon, 2006). Rural CSs in the present study did not report feeling isolated, in



contrast with findings reported by Lyons (2004), who found that low - income rural CSs experienced more isolation.

Studies have tested various types of online support and networking strategies, and video conferencing interventions. The rural CSs in the present study did not discuss this type of connection, even though most of Alaska and Oregon are highly accessible electronically. They preferred one-on-one interactions, mostly informal connections through the community and word of mouth, or an in-person support group. The urban CSs utilized more formal connections through established agencies, such as those that connect CSs with similar diagnoses. Perhaps a younger sample of CSs would have a higher utilization of the digital media.

There is a suggestion in the present study that rural CSs are not experiencing isolation, that they utilize informal networks, and that their unique connection with their small communities may be an asset to the survivorship experience. Community connectedness and support occurs more naturally in rural settings than in urban settings where it is more planned. No studies were found addressing these aspects within the context of cancer survivorship.

### **Cancer and Life Perspectives**

**Identity—public/private journey.** The rural CSs in the present study talked about their identity as cancer survivors more strongly, and they described the pros and cons of having what they described as a “public

journey.”. There was a dichotomy between others knowing and not knowing about their cancer journey. The predominant view of the rural survivors was “everyone knows” and this was considered to be a double-edged sword.

There is a growing body of literature focusing on the cancer survivor identity and the view that it has transitioned from cancer victim to cancer survivor. Deimling and colleagues (2007) asserted that “stories of cancer as an illness now have a place in our culture” (p. 759). Once silenced by the public at large, CSs can now expect “some degree of acceptance and understanding” (Deimling et al., 2007, p. 759). Zebrack (2000) discussed the process of the integration of a new and potential permanent identity as a result of the cancer experience. Belizzi and Blank (2007) studied cancer-related identity in prostate CSs and found that they most commonly identified themselves as “someone who has had prostate cancer” (57%) and 26% identified themselves as survivors (p. 44). Smaller groups viewed themselves as patients or victims. Breaden (1997), utilizing a phenomenological approach, found that “sharing the journey” was an important part of the concept of “living in time” (p. 982). Breaden (1997) described the shared journey as survivors interfacing with their neighbors, communities and through support groups; however, this small study was not focused on rural CSs.

The rural health literature is replete with studies on issues with lack of anonymity of those living in rural settings. Lack of anonymity is a hallmark of

small towns, and this is commonly reported by nurses working in small communities, who have blended roles of healthcare professional, neighbor, and community member (Long & Weinert, 2006). In a rural setting, anonymity, or the wish to maintain privacy, may not be a choice for CSs. Once a rural dweller seeks healthcare, his or her medical issues may be well known by the community and this has been shown to be a deterrent to seeking mental health services (Clay, 2007). No studies were found that focused on the concept of lack of anonymity within the context of rural CSs, or any descriptions of this notion of the tension between the public and private journey associated with the cancer survivorship experience.

**Thinking about death and dying.** In the present study, CSs were very open about discussing their views on death and dying, and several had cared for friends and family who had died. Several CSs shared that they had friends and acquaintances who died while they were fighting cancer. Rural CSs were much more open about death and dying, and one rural CS felt that dying in a rural setting would feel “more normal.” The CSs had thought about death and dying, some extensively, but they did not describe being fearful of it. Similarly, Lyons (2004) reported that low-income rural breast and cervical CSs denied fear of dying.

It wasn't always the spiritual aspects of death and dying that were discussed by CSs in the present study; for some, it was the practical aspects. One rural survivor had planned out the entire process of what she wanted to

occur after she died. Being from a rural/remote community, she had carefully thought out not wishing to have her body transported back to her rural community, if she were to die elsewhere. No literature was found regarding how rural CSs view death and dying.

### **Long-Term Impact**

**Advocacy.** The rural CSs in the present study focused on advocacy more than their urban counterparts. The rural CSs described many examples of advocacy: for themselves, their diagnosis, and survivorship. They also advocated strongly for improved healthcare services in their communities.

Many studies have focused on advocacy and cancer survivorship but not necessarily within the rural/urban context. Clark and Stovall (1996) identified a three--part advocacy continuum. The stages consisted of personal advocacy, community advocacy, and national advocacy. The CSs in the present study participated in personal advocacy through activities such as seeking a second opinion, seeking information (such as online research, and attending survivorship seminars), accessing support resources, asking questions and seeking answers, and fighting for their financial and employment rights. Similarly, Zebrack (2001) identified three types of advocacy efforts: self-advocacy (common in the early stages of cancer diagnosis), advocacy for others, and public advocacy. The rural CSs, in particular, engaged in community advocacy by participating in support

groups, community fundraising, volunteering with survivorship organizations, and speaking publicly about survivorship issues.

Researchers have identified four interrelated skills that are key to engaging in effective advocacy: information-seeking skills, communication skills, problem-solving skills, and negotiation skills (Hoffman & Stovall, 2006; Clark & Stovall, 2004). Information is the key to successful advocacy (Hoffman & Stovall, 2006), and the CSs in the present study demonstrated that they were very informed and became more informed through their advocacy activities.

The cancer support groups that the researcher has worked with have demonstrated similar levels of advocacy. In the researcher's experience with CSs, it starts with awareness, moves into advocacy, and for some develops into activism. The personal and community advocacy demonstrated by the rural CSs in the present study is a very positive aspect of survivorship. The majority of the interview participants in the present study were highly engaged with survivorship, empowered to take action, and served as role models for their families and communities. They would do well with national advocacy efforts and could assist in developing advocacy skills in other survivors.

### **Rural/Urban Health Assumptions**

The rural/urban research within the context of cancer survivorship is sparse; Therefore, it is necessary to examine some of the prevailing views of

rural/urban health from the general and nursing rural theory literature and how they compare with the findings from the present study.

### **General Healthcare Literature—Health and Social Networks**

According to the National Rural Health Association (2007), there are economic factors, cultural and social differences, educational shortcomings, lack of recognition by legislators, and isolation, all contributing to a negative impact on health for rural populations. Some of the factors and effects include (a) only about 10% of physicians practice in rural settings, which creates a disparity since 25% of the general US population is rural; (b) rural residents tend to be poorer; (c) rural residents have higher rates of high blood pressure and smoking; (c) suicide rates in rural men are higher and are rapidly growing in women; and (d) rural populations have poorer outcomes for many health problems such as acute myocardial infarction and trauma. It is well known that access to cancer care and\ resources is less for rural CSs; however, the rural CSs in the present study did not necessarily view themselves as unhealthy. In fact, the rural CSs from Alaska viewed themselves as healthier than the urban CSs from Alaska, and the overall comparisons of self-reported health ratings showed no significant differences. Similar patterns were also shown for ratings of access to healthcare and satisfaction with healthcare. Furthermore, rural CSs from Oregon were more satisfied with their healthcare than their urban counterparts. While not statistically significant, it is still in

contrast to the prevalent rural/urban assumptions about health and healthcare concerning rural dwellers and paints a more positive outlook.

The global health organization Unite for Sight (2013) addresses positive aspects of rural life that contribute to positive health outcomes. They cited the public health literature reporting that “rural areas frequently have strengths including dense social networks, social ties of long duration, shared life experiences, high quality of life, and norms of self-help and reciprocity” (p. 1). The qualitative findings in the present study supported these assumptions about social networks, social ties, and norms of self-help and reciprocity. The highly engaged rural CSs in the present study were extremely active in survivorship programs and community service, and they advocated strongly to improve cancer care services in their communities.

Johnson (2011), studying patients receiving primary care in Ireland, found that the rural environment and sense of community, in combination with strong social networks, were identified as key determinants of good mental and physical health. However, access issues and reluctance to seek help for mental health issues are problems. The strong social networks identified by Johnson and colleagues (2011) is similar to the constructs of connection, community, and networking identified by the rural CSs in the present study. Similarly in Australia, Harvey (2007), conducted a metasynthesis of the literature, which included 1 out of 6 studies focused on rural women with cancer. Harvey found that the social experiences of rural women influence the

way that they view their health and well-being and there was a tension between the rural women's sense of belonging and the experiences of isolation associated with rural living. The highly engaged rural CSs in the present study did not express experiences of isolation; much to the contrary, they described positive views of their community networks.

### **Rural Nursing Theory**

It is important to compare the major themes identified in current rural nursing theory with the themes identified in the present study. Lee and Winters (2006) outlined the key concepts for rural nursing, framed by statements. The first statement reflects how rural dwellers define health with related themes including health beliefs, isolation, and distance. The second statement is in regard to self-reliance, with related themes of outsider, insider, old-timer, newcomer, resources, informal networks, and lay care networks. The third statement relates to lack of anonymity and role diffusion with related themes identified as familiarity and professional isolation. Numerous studies based out of Montana support these themes and were synthesized into concepts. The themes identified in the present study that are consistent with the key concepts outlined by Lee and Winters (2006) include resources (which relates to the theme access to healthcare), informal networks, and lack of anonymity (public/private journey). While insider/outsider was not a theme uncovered in the present study, these dynamics may have contributed to the challenges in recruiting rural participants.



### **Rural/Urban Impact on Cancer Survivorship**

There is very little in the literature addressing rural/urban assumptions within the context of cancer survivorship. There has been a significant focus on comparing cancer mortality rates in rural and urban populations (Wilkensen & Cameron, 2004; Singh et al., 2011). Bettencourt and colleagues (2007) have studied rural breast CSs and argued that cultural and environmental factors interact with rural women's lives and impact their views about having had cancer. Treatment decisions are influenced by whether the breast cancer patient lives in a rural or urban setting. In addition, rural CSs have reported needing more help with physical and daily living needs, and during treatment, rural women felt that taking care of the home and children was more difficult living in a rural setting. These differences were not found in this study, which could have been influenced in part by the fact that it was a mostly middle-aged sample that was not economically disadvantaged.

The majority of the rural/urban differences revealed in the quantitative comparisons did not support the rural/urban differences as hypothesized (in fact, they support the opposite), and the differences identified in the qualitative findings were subtle. Approximately half of the constructs revealing urban/rural differences indicated a more positive outlook for rural CSs, indicating that the findings in the present study are challenging the prevailing assumptions that rural CSs have poorer outcomes than their urban counterparts.

### **Survivorship Frameworks**

A summary and comparison of several cancer survivorship frameworks with the framework resulting from the present study is presented in Appendix K. The table in the appendix shows the progression of the frameworks and reveals how the thinking and portrayal of cancer survivorship has progressed since the mid-1980s. While several of the frameworks portray survivorship as temporal in nature, very few explore the details of late survivorship. The well-accepted framework developed by Ferrell and colleagues (1992, 1995) provided the framework for the design of the present study. The components of QOL as outlined by Ferrell et al. (1992, 1995) were apparent in the “getting through it” theme identified in the present study. However, the components identified by Ferrell did not carry through as a comprehensive framework into the progression of later survivorship, and they do not portray the temporal nature of survivorship. New constructs emerged that were unique to the process of moving forward through later survivorship such as reconciling, cancer perspectives/life perspectives, survivorship identity, and long-term impact. The framework from the present study is the first known framework to recognize the varying levels of intensity and impact extend into late survivorship (ranging from minimal to extensive).

In summary, there is currently no known framework that illustrates the concepts of long-term survivorship in a temporal pattern. Most frameworks focus on the acute treatment phases and early survivorship phases. The

framework from the present study provides a jumping-off point for longitudinal studies to further define the trajectory of long-term survivorship. There is an opportunity to include geographical differences and cultural aspects into a comprehensive framework.

### **Profiles of Intensity and Impact**

The profiles of intensity presented in Chapter 4 emerged from the qualitative data and were then compared with profiles analyzed from the quantitative outcomes variables. This provided for a narrative case exemplar, as well as a statistical summary for each profile identified (see Tables 22 through 24). The three profiles identified were (a) less intense treatment experience/none or minimal prolonged impact, (b) intense treatment experience/minimal prolonged impact, and (c) intense treatment experience/extensive prolonged impact. The following discussion focuses on the patterns across the profiles and how they relate to the quantitative findings in the present study.

One major question from these data is why profile #1 has a lower positive and higher negative impact score on the IOC than the other groups. At a glance, one might expect profile #1 to have the best outcomes. However, many of the items on the IOCV2 are existential in nature, and CSs in profile #2 have had to work through intense experiences and adjustments that cause them to reconcile many things such as the meaning of life, how they want to

live their lives, and their choices, priorities, and relationships. Given these aspects, these patterns in the profiles are not surprising.

These data provide evidence that symptoms are a major player in the long-term cancer survivorship experience. The mean symptom score was highest for the high-intensity profile group and lowest for the lower-intensity/impact group. This is consistent with the relationships that were previously discussed above between symptoms and the IOC negative impact scale variables. This is also consistent with the findings of Harrington et al. (2010), who conducted a systematic review of studies focusing on late effects and/or long-term symptoms associated with long-term survivorship. In that review, the authors found that survivors of four major types of cancer (breast, prostate, gynecological, and rectal/colon cancers) experienced symptoms more than 10 years into survivorship. However, the researchers did not focus on the impact of the symptoms for the CSs.

Time since treatment does not seem to be a factor, as this is similar across groups. Number of co-morbidities could be a factor, as profile #1 experienced more than #2. This could also explain some of the IOC impact findings discussed earlier. There were a few more rural CSs included in profile #3, and as expected, all of the CSs that had experienced cancer more than once were included in #3. These identified profiles provide preliminary evidence that the IOCV2 instrument is tapping into the overall impact of the survivorship experience appropriately. The IOCV2 could be a useful tool, when

combined with symptom and QOL measures, to predict CSs who are at risk for challenges and decreased QOL extending into later stages of survivorship, and it could be tested in future research. It is important to note that the qualitative sample size from which these profiles emerged was small (n=19) and limited generalizability can be inferred.

### **Implications**

The findings in the present study provide evidence to challenge the prevailing assumptions that rural CSs are faring worse than their urban counterparts with regard to physical, psychological, social, and spiritual well-being, and they raise several important questions. The findings support access to healthcare as an important factor, but this was not viewed negatively by rural CSs. From the interview data, the importance of community and connectedness emerged as key differences between the urban and rural CSs, with the rural CSs describing a stronger sense of community.

The mixed findings in this study and the results of previous studies suggest that other factors may be at play in accounting for the rural/urban differences, such as gender, ethnicity, education, socioeconomic status, support systems, type of cancer, co-morbidities, and personality characteristics. Important questions still need to be answered such as the possibility that the differences could be related to characteristics that are inherent in rural dwellers such as resilience and independence. In addition, it

raises the possibility that the positive impacts of the rural community networks and connectedness are a protective factor for rural CSs.

There are implications for current and developing programs focusing on cancer survivorship. The constructs associated with later survivorship such as reconciliation, cancer/life perspective, survivor identity, and long-term impact need to be considered within the context of the support that CSs need to ensure safe passage through the journey of survivorship. The findings suggest that instruments to assess how CSs are faring with regard to QOL and the impact of cancer, such as the IOCV2 and a symptom measure, are potentially useful in assessing CSs at all stages of survivorship. The present study provides a preliminary framework that extends into later survivorship. The intensity and impact profiles provide a preliminary tool for describing the level of intensity and impact of the overall experience.

Symptoms emerged as a constant theme throughout the study, and they are a key driver of the survivorship experience. The correlations indicated that an association between the symptom severity and the negative impact dimensions on the IOCV2 as well as employment concerns. While differences in symptoms were not identified from the qualitative data, they were still prevalent throughout the narratives of both the urban and rural CSs. Furthermore, the symptom scores provided support for the profiles of intensity and impact, with the higher physical symptom scores being exhibited by profile #3 (highest intensity/impact). The findings support the continued use of

symptom measures even into the later stages of survivorship. More longitudinal studies are needed to determine the timing that physical and psychological problems appear across the cancer survivorship trajectory. Clinical providers need to remain vigilant about assessing for symptoms and their impact (physical and psychosocial), even into late survivorship. It is vital to explore options to better predict, prevent, and, when necessary, manage the symptoms. This will in turn improve function and decrease distress for CSs.

Worry emerged as a theme across both strands of the study, and it is worthy of continued attention in long-term survivors. Further research is needed to determine how worry, uncertainty, and fear of recurrence influence the profiles of intensity identified, and if the level of worry could be a predictor of positive or negative outcomes in physical and mental health. One question identified for future research is if there are more negative aspects associated with longer-term survivorship than positive. Lastly, there is an opportunity to improve care coordination and expand formal survivorship programs in Alaska.

### **Study Limitations**

The cross-sectional design did not capture changes in survivorship over time. Perceptions identified at the time of the study may be different from those experienced earlier in the survivorship trajectory. A convenience sample of volunteers resulted in hearing from a highly engaged group of CSs. In addition, the sample is highly representative of the very educated CS, with good access to healthcare and other resources, and is not representative of the general

population. The heterogeneous nature of the sample with regard to cancer diagnosis makes site-specific recommendations a challenge. Recruitment challenges with rural CSs may have been due to insider/outsider dynamics (Long & Weinert, 2006).

Methodological limitations include the following: (a) the IOCV2 was not coupled with a generic QOL measure; (b) there were no comparisons between the CSs and the general population; therefore, it cannot be confirmed that the findings are unique to CSs; (c) cancer acuity was not measured in detail; (d) quantitative data were collected by self-report and self-administered (not during an interview); therefore, the participants may not have been answering within the context of their cancer survivorship experience; (e) medical diagnosis and treatment profiles were not confirmed; (f) nonverbal cues were lost in the phone interview data collection process; and (g) qualitative descriptive methods provided a less theoretical interpretation of the interview data.

There are limitations to how employment was measured in the study. Choices did not provide the participants an opportunity to disclose if they were self-employed or had other income sources; therefore, less traditional sources of income may not have been captured.

### **Additions to the Body of Knowledge**

This study provided rural urban comparisons across multiple states and includes CSs in some of the most remote locations of the US. The sample



includes CSs who are under-represented in the current body of research including rural dwellers, Alaska Natives/American Indians, men, and survivors of a variety of cancer diagnoses. It is one of the few studies to explore the potential positive aspects of rural living, within the context of cancer survivorship, and identified rural/urban differences not reported previously in the literature. The study provides evidence for the effectiveness of the IOC instrument in detecting differences in a diverse population, especially with regard to the constructs associated with negative impact.

The study provides the first framework, to the researcher's knowledge, that extends into long-term survivorship, with a depiction that is temporal. The study provides evidence to support exploring the risks associated with, prediction of, and the impact of the higher-intensity/impact profile, especially in rural survivors, who may go undetected. CSs in profile #2 experienced a high-intensity treatment experience yet positive outcomes during survivorship and provide a learning opportunity for those at risk for negative outcomes. Overall, this study has demonstrated that mixed methods is a valuable approach to studying cancer survivorship.

### **Recommendations for Future studies**

The use of community based participatory research methodologies is an effective strategy to engage rural survivor populations. The CSs in this study demonstrated a high level of engagement with survivorship, and this combined with the CPPR approach could lead to successful engagement of

CSs with future research, especially in their communities. They are an untapped resource in survivorship research, showing potential for leadership roles through their advocacy efforts. Other studies have had success utilizing local community leaders to serve as liaisons between researchers and the community (Hutson et al., 2007).

Because survivorship is a temporal phenomenon, longitudinal studies extending into long-term survivorship are needed and will develop a well-understood and meaningful model for long-term survivorship. Measuring outcomes at distinct time points along the survivorship trajectory offers several advantages, which include the ability to (a) identify changes over time, sequences of events, and patterns, both at the individual and group level; (b) further identify short- and long-term phenomenon associated with survivorship; and, (c) assist in predicting who is at risk for negative sequelae. Such studies are currently being conducted by the ACS (Smith et al., 2006), although they do not include an impact of cancer measure.

In future studies, there is an opportunity to combine the IOCV2 with measures of quality of life and functional status, and more studies are needed utilizing the IOCV2 to compare rural and urban survivor populations. Specific concepts unique to the rural CSs need to be explored more in depth, such as the concept of public/private journey; the notion of community and connectedness, which may be protective; and the high level of focus on advocacy. While the theme of reconciling did not include any rural/urban

differences, this theme has not been well described in the survivorship literature and appears to be a vital part of the process that leads to developing the long-term survivor identity, thus warranting further study.

Further study is needed on the intensity and impact profiles with a larger sample size. This has the potential to improve clinicians' and researchers' ability to predict survivors at risk for negative impact long term, as well as to identify survivors who are doing well. More survivorship programs and support services are needed in Alaska, such as formal navigation programs. In future studies, it will be important to ask if having had cancer was a reason for relocation of residence, and to more fully explore the reasons for living in a rural or urban setting within the context of cancer survivorship. Efforts to recruit less engaged CSs in research are also needed.

### **Summary**

This study challenges prevalent assumptions about rural-dwelling cancer survivors and their risk for negative outcomes. Findings provide insight into the differences and similarities between rural and urban cancer survivors. Among the rural/urban comparison groups, the Alaska rural group stands out with the least negative impact from having experienced cancer. From the qualitative findings, a preliminary framework of survivorship emerged, which extends into later stages of survivorship. Unique themes, not previously described, as rural/urban differences were discovered and a profile of rural survivorship emerged. Rural CSs were found to not experience isolation,

viewed their access to healthcare positively, relied on informal community networks, often experienced a very public cancer journey, thought more about death and dying, and were more engaged in personal and community advocacy. The common thread across these themes was community. Access to healthcare may not be the driver of the survivorship experience. Symptoms have a strong impact. There is an opportunity to influence healthcare providers and developing programs serving this growing population with complex issues, building on the strengths of both rural and urban living, and the engagement of the cancer survivor community.

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## Appendix A

### Glossary of Terms

#### Borough

The state of Alaska is divided into boroughs. Boroughs function similarly to counties in the lower 48 states; however, not all of the state is designated as an organized borough. These regions are referred to as unorganized boroughs. These generally cover very remote areas of the state. The urban areas are organized into consolidated city boroughs (Wikipedia, 2012).

#### Cancer survivorship

Theoretical definitions: “from the time of diagnosis and for the balance of life” (NCCS, 2012, p. 1). In addition, “cancer survivorship is a dynamic, multifaceted and individualized experience and process that includes changes in physical, psychological, social, and spiritual well-being” (McNulty, 2007. p 1).

Operational definition for this study: Adult cancer survivors who have completed primary treatment and who are without evidence of cancer.

#### Cancer illness trajectory

The cancer illness trajectory is best described by the NIC in their Cancer Care Continuum (see Chapter 2, page 41). The phases are outlined as prevention, detection, diagnosis, treatment, and survivorship. This study focuses on survivorship.

#### Chemotherapy

The treatment of disease by means of chemicals that have a specific toxic effect on the disease-producing microorganisms, or that selectively destroy cancer tissue (anticancer therapy) (Hewitt, Greenfield, & Stovall, 2006).

#### Co-morbidity

The co-occurrence of two disorders or syndromes (not symptoms) in the same patient. The presence of co-morbidities can affect treatment options, survival, and risk of late effects (Hewett et al., 2006).

### Frontier

Frontier is defined as “a population density of less than 6 per square mile and driving time to a hospital of either 60 minutes or severe geographic and/or seasonal climatic conditions” (Buehler et al., 2006, p. 130).

### Indian Health Service/tribal beneficiary

Alaska Natives and American Indians residing in Alaska are eligible to receive healthcare in the tribal healthcare system. The tribal healthcare system is managed by regional health corporations around the state and receives some funding from the Indian Health Service. The healthcare services that are provided to AI/ANs in Anchorage, managed by the Alaska Native Tribal Health Consortium and the South Central Foundation, are the most sophisticated and extensive of all regions in Indian Country in the lower 48 states.

### Late effects

Side effects of cancer treatment that appear months or years after treatment has ended. Late effects include physical and mental problems and second cancers (Hewitt et al., 2006).

### Long-term effects

“Any side effects or complication of treatment for which a cancer patient must compensate; also known as persistent effects, they begin during treatment and continue beyond the end of treatment. Late effects, in contrast, appear months to years after the completion of treatment” (Hewitt et al., 2006, p. 69).

### Long-term survivorship

Cancer survivors are generally considered long term when it has been at least 5 years since their cancer diagnosis. In studies, they are often grouped at 5 to 10 years post-diagnosis or end of treatment (Zebrack, 2007).

### Participant bias

Those who participate in research may be more optimistic than others who choose not to participate (Foley et al., 2006).

### Primary treatment

The therapeutic interventions provided with the intention to cure cancers. In clinical situations in which the treatment of recurrent disease is curative, the therapeutic approaches may be viewed as “primary treatment,” which if successful is followed by a phase of post-treatment survivorship (Hewitt et al., 2006).

### Quality of life

The overall enjoyment of life and the aspects of an individual’s sense of well-being and ability to carry out the various activities of life (Hewitt et al., 2006). In this study, the Quality of Life Model Applied to Cancer Survivors outlines the major domains of quality of life relevant to cancer survivorship, which are physical well-being and symptoms, psychological well-being, social well-being, and spiritual well-being (Ferrell et al., 1995).

### Recurrence

Cancer that has returned after a period of time during which the cancer could not be detected. It may come back to the same place or to another place in the body (Hewitt et al., 2006).

### Rural

Rural communities have a population of less than 1,000 people with less than 400 people per square kilometer (Leipert, 2006).

### Rural/remote/isolated

Rural remote communities are 80-400 km or 1-4 hours transport in good weather from a major regional hospital. Rural isolated communities are more than 400 kilometers or 4 hours transport in good weather from a major regional hospital (Leipert, 2006).

### Rural definitions for this study

Because of the stark differences in geography, and type of transportation used in the two states, a rural definition unique to each state was utilized in this study.

*Alaska.* In this study, participants from the major cities in Alaska were considered urban. These cities are Anchorage, Fairbanks, Juneau, and parts of the Matanuska Valley. Rural communities may be on the road system in Alaska or may be reached by boat or plane access only, within 1-4 hours.

Remote and isolated communities will be greater than 4 hours from a major regional hospital.

*Oregon.* Rural is defined as a geographic area that is at least 30 miles by road from an urban community (Crandall & Weber, 2005).

### Strand

A phase of a mixed methods study in which a quantitative or qualitative approach is used in data collection or analysis procedures. Phases/strands may be concurrent or sequential (Tashakkori & Teddlie, 2003).

### Subsistence

State and federal laws define subsistence as the “customary and traditional uses of” wild resources for food, clothing, fuel, transportation, construction, arts, crafts, sharing and customary trade. Subsistence uses are central to many of the Alaska Native People. Subsistence fishing and hunting are important sources of employment and nutrition in most rural communities in Alaska (State of Alaska, 2010).

### Surveillance, Epidemiology and End Results (SEER) Program

A program of the National Cancer Institute that collects and publishes cancer incidence and survival data from 14 population-based cancer registries and three supplemental registries covering approximately 26% of the US population.

### Survivor bias

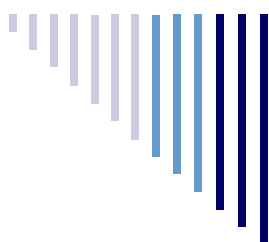
In survivorship research, we are only hearing from those who are living survivors and not from those who have died (Garman et al., 2003).

### Urban

Alaska: the larger cities on the road system with ready access to healthcare, as well as Juneau, which is the state capitol and not accessible by road.

Oregon: Urban areas are defined by the census bureau and the Oregon Office of Rural Health. They generally include the cities in the Willamette Valley area, and a few smaller urban communities in the central and southern parts of the state, which include the Bend and Medford areas.

## Appendix B Participant Flyer and Lay Handout/Protocol



OREGON  
HEALTH & SCIENCE  
UNIVERSITY

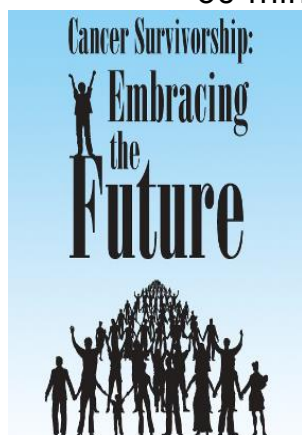
### School of Nursing Participants Needed for Cancer Survivorship Research

The goal of this study is to find out how cancer impacts adults living in rural and urban settings in Alaska and Oregon. The study will look at experiences of adults who have survived cancer, and compare these experiences between the adults living in the rural and urban settings. The study will find out how people are feeling physically, mentally, spiritually, and how they are relating with others. It will look at positive as well as negative experiences.

You are eligible for this study if you:

- were diagnosed with cancer when you were age 18 or older
- have experienced any type of cancer (except for some types of skin cancer)
- are currently cancer free and not receiving active treatment (some types of ongoing medications, such as Tamoxifen are okay)

As a participant in this study, you will be asked to: complete three forms related to the impact of cancer, symptom experiences, and some brief demographic information. You may also be asked to participate in an interview. Your participation would involve 30 minutes to complete the forms, which can be mailed to your home or completed on line. If you participate in an interview, this will take approximately 45 to 60 minutes, and can be in person or over the phone.



For more information about this study, or to volunteer for this study, please contact: *Julie McNulty, RN*, at 907-729-2937 or 907-230-5996 or toll-free at 877-678-5996 Email: [mcnultyj@ohsu.edu](mailto:mcnultyj@ohsu.edu)

This study has been reviewed by, and received ethics clearance through, the Research Integrity Office of Oregon Health & Science University  
IRB # IRB00005399

## Lay Language Handout/Protocol Summary

Principal Investigator: **Lillian Nail** IRB# IRB00005399

Study/Protocol **Cancer Survivorship in Rural & Urban Adults: A Descriptive & Mixed Methods Study**

1. Briefly describe the purpose of this protocol.

The goal of this study is to find out how cancer impacts adults living in rural and urban settings in Alaska and Oregon. The study will look at experiences of adults who have survived cancer, who are now cancer free, and compare these experiences between the adults living in the rural and urban settings. The study will find out how people are feeling physically, mentally, spiritually, and how they are relating with others. It will look at their positive as well as negative experiences.

2. Briefly summarize how participants are recruited.

Volunteer participants will be recruited from the community (newspaper ads, radio ads, flyers in community settings, flyers in clinics and health centers, referral from cancer support groups, etc) in rural and urban settings.

3. Briefly describe the procedures subjects will undergo.

There are 2 phases to this study.

Phase 1: Study participants will be asked to complete 3 forms. This will take approximately 30 minutes. At a later time, they may be asked to participate in an interview with the researcher, based on their scores in phase I.

Phase 2: Some participants will be asked to participate in an interview. They will be asked about their experiences with cancer, and to explain further about some of their answers on the forms. This will take approximately 45 to 60 minutes.

4. If applicable, briefly describe survey/interview instruments used.

The forms and a brief description of each:

- a. Participant data form: this form will ask questions about age, marital status, type of cancer treatment, where they live, and if they are feeling healthy.
  - b. Impact of cancer survey: This form has 50 questions and will ask about how people are feeling about their cancer and experiences with cancer. It will ask about positive and negative experiences and how they are feeling about them. It asks if they have a job and if they are married or living with someone.
  - c. Symptom survey: This form asks about 32 symptoms (things like pain, feeling sad, feeling tired, etc), if they are experiencing them, and how much the symptoms bother them.
5. If this is a clinical trial using an experimental drug and/or device, or an approved drug and/or device used for an unapproved purpose, briefly describe the drug and/or device.

This does not apply to this study

6. Briefly describe how the data will be analyzed to address the purpose of the protocol.

The scores on the forms will be tallied and grouped by people living in the two settings. Using statistical software, each type of data will be compared to see if there are differences in people living in the different locations. It will also be determined if the length of time since the person has had cancer is related to how they are feeling and if they are having symptoms or not feeling well.

The scores on the forms will also show who is doing well and who is struggling with their cancer survivorship experience. People who are doing well, and people who are struggling will be asked to participate in a talk with the researcher. People will be asked what is going well and what is not going well. The talks will be tape recorded and then typed word for word. This information will help to further understand their experiences and help to clarify their answers on the forms.



### Appendix C-Pre-enrollment Screening Questionnaire

Date of Screening: \_\_\_\_\_ Screener Initials \_\_\_\_\_

**Qualified: No Yes**

Cancer Survivorship in Rural & Urban Adults: A Descriptive & Mixed Methods Study

#### Pre-enrollment Screening Questions: CANCER SURVIVOR

##### Contact Information

Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Best Time to Call: \_\_\_\_\_

Email Address: \_\_\_\_\_

Preferred Method of Communication: Phone Email (circle one)

Mailing Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Date of 1<sup>st</sup> contact \_\_\_\_\_ result \_\_\_\_\_

2<sup>nd</sup> \_\_\_\_\_ result \_\_\_\_\_

3<sup>rd</sup> \_\_\_\_\_ result \_\_\_\_\_ 4<sup>th</sup> \_\_\_\_\_ result \_\_\_\_\_

5<sup>th</sup> \_\_\_\_\_ result \_\_\_\_\_ 6<sup>th</sup> \_\_\_\_\_ result \_\_\_\_\_

Date of Birth: \_\_\_\_\_

##### Screening Script

Thank you for your interest in this research study. Before giving you more details about this study, I need to mention that this is a research study on cancer survivorship. For this study I need to ask you a few questions to see if you are eligible to participate. By answering these questions you are consenting to provide this information to determine your eligibility for this study. If you think you qualify for this study, we will tell you more about the study to see if you want to participate.

- Have you been diagnosed with cancer in the past (any type of cancer except for non-melanoma (skin cancer))
  - Yes    No    (circle one)
  - *Must be yes*
- What type or site? \_\_\_\_\_
  - *(Can be any type except for non-melanoma skin cancer)*
- Have you completed your active cancer treatment?
  - Yes    No    (circle one)
  - *Must be yes*
- Are you currently undergoing radiation therapy or chemotherapy for cancer?
  - Yes    No    (Circle one)
  - *(must be no)*
- How long ago did you complete your active cancer treatment?  
 \_\_\_\_\_ *(must be greater than 8 weeks)*
- What was your age when you were diagnosed with cancer?  
 \_\_\_\_\_ *(must be  $\geq 18$  years of age)*

**IS PARTICIPANT ELIGIBLE?**    Yes    No    (Circle one)

**IF YES:** It sounds like you might be eligible to participate in this study.

Would you like to hear more about it?

If yes, refer to *lay language proposal summary*.

If no, reason \_\_\_\_\_

**IF NO:** I'm sorry, you are not eligible to participate in this particular study, but thank you very much for taking the time to talk to us.

Finally, can you tell me:

- How did you hear about this study?

\_\_\_\_\_

I would like to reiterate that this call was only in regard to a research study on cancer survivorship, if you have any future appointments for care at *(the name of the agency where they receive care)*, please keep these as this study is not connected in any way with your care for cancer or for any other medical conditions

**Appendix D-Demographic Data****Demographic Data-Participant Data**

Current Age: \_\_\_\_\_ Gender: ☐ F ☐ M

Education: highest grade completed: \_\_\_\_\_

Marital Status: ☐ Married ☐ Never Married ☐ Divorced,  
widowed or separated  
☐ Not married/in a committed relationship

Employment Status -Check One:

☐ Employed full time ☐ Employed part time

☐ Not employed outside the home

Type of health insurance: \_\_\_\_\_

Current address:

\_\_\_\_\_  
\_\_\_\_\_

How long have you resided at this address? \_\_\_\_\_

Please list the towns/states you have lived in since you were  
diagnosed with cancer and for how long (if more than 3, indicate where  
you lived the longest)

Town/state:

How long:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Ethnicity:

☐ Hispanic or Latino ☐ Non Hispanic or Latino ☐ Unknown

Race:

☐ White      ☐ Black or African American

☐ Native Hawaiian/Other Pacific Islander      ☐ Alaska Native

☐ American Indian    ☐ Other

☐ More than one race

Age at time of cancer diagnosis: \_\_\_\_\_

Date at time of cancer diagnosis: \_\_\_\_\_

Type of Cancer (or site): \_\_\_\_\_

Past Cancer treatment: (check all that apply and indicate the year that you had each treatment)

☐ Chemotherapy, year \_\_\_\_\_      ☐ Radiation, year \_\_\_\_\_      ☐

Surgery, year \_\_\_\_\_

When did you complete your primary cancer treatment? (month/year)

\_\_\_\_\_

Current cancer treatment: \_\_\_\_\_

Date of last visit to healthcare provider: \_\_\_\_\_

Type of healthcare provider you regularly see: (check all that apply)

☐ Primary care/family doctor      ☐ Nurse practitioner      ☐ Physician's Assistant

☐ Oncologist      ☐ Other specialist: \_\_\_\_\_

Do you have a summary of your cancer treatment available to you that a healthcare provider could use to see exactly what treatment you had?

☐ Yes      ☐ No

Have you had cancer more than once? ☐ Yes      ☐ No

If yes, how many times? \_\_\_\_\_

Previous type/site of cancer? \_\_\_\_\_

Do you receive any traditional healing, holistic therapies or any type of complementary and alternative medicine treatments?

☐ Yes

☐ No

If yes, what type are you receiving:

---

How would you rate your satisfaction with the healthcare that you are receiving:

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

How would you rate the access that you have to healthcare:

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

In general, would you say that your health is:

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

Did your doctor or healthcare provider ever tell you that you had any medical conditions such as high blood pressure, heart disease, stroke, asthma, arthritis, liver disease, diabetes, depression, etc.). Please list all that you are aware of.

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Has having cancer had an impact on your ability to maintain your normal Activities of daily living?

☐ Yes

☐ No

If yes please describe:

---



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May we contact you to clarify any answers that you have provided?

☐ Yes

☐ No

Would you be interested in participating in a follow up interview with the researcher about your cancer survivorship experiences? This will take approximately 60 minutes. If yes, please include your current phone number and/or e-mail.

Phone number:    Home: \_\_\_\_\_  
                            Cell: \_\_\_\_\_  
                            Work: \_\_\_\_\_

E-mail: \_\_\_\_\_

Best time to contact you: \_\_\_\_\_

Thank you for providing this information, you have now completed the demographic data section.

## Appendix E-Impact of Cancer Instrument

### Impact of Cancer Version 2 (IOCv2)

Instructions: Given your life as it is now, how do you feel about having had cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. Having had cancer makes me feel unsure about my future.....	1	2	3	4	5
2. I worry about my future.....	1	2	3	4	5
3. I feel like time in my life is running out.....	1	2	3	4	5
4. I do not take my body for granted since the cancer..... ...	1	2	3	4	5
5. Having had cancer has made me more concerned about my health.....	1	2	3	4	5
6. I am more aware of physical problems or changes in my body since having had cancer	1	2	3	4	5
7. I worry about my health.....	1	2	3	4	5
8. I worry about the cancer coming back or about getting another cancer.....	1	2	3	4	5
9. New symptoms make me worry about the cancer coming back.....	1	2	3	4	5
10. Having had cancer makes me feel uncertain about my health.....	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11. I am concerned that my energy has not returned to what it was before I had cancer...	1	2	3	4	5
12. I am bothered that my body cannot do what it could before having had cancer.....	1	2	3	4	5
13. I worry about how my body looks.....	1	2	3	4	5
14. I feel disfigured.....	1	2	3	4	5
15. I sometimes wear clothing to cover up parts of my body I do not want others to see.....	1	2	3	4	5
16. Having had cancer has made me take better care of myself (my health).....	1	2	3	4	5
17. I consider myself to be a cancer survivor.....	1	2	3	4	5
18. I feel a sense of pride or accomplishment from having survived cancer.....	1	2	3	4	5
19. I learned something about myself because of having had cancer.....	1	2	3	4	5
20. I feel that I am a role model to other people with cancer.....	1	2	3	4	5
21. Having had cancer has made me feel old.....	1	2	3	4	5
22. I feel guilty today for not having been available to my family when I had cancer.....	1	2	3	4	5
23. Having had cancer turned into a reason to	1	2	3	4	5



	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
make changes in my life.....					
24. Because of cancer I have become better about expressing what I want.....	1	2	3	4	5
25. Because of cancer I have more confidence in myself..... ....	1	2	3	4	5
26. Having had cancer has given me direction in life..... ....	1	2	3	4	5
27. I feel like cancer runs my life.....	1	2	3	4	5
28. Because of having had cancer I feel that I have more control of my life.....	1	2	3	4	5
29. I feel a special bond with people with cancer..	1	2	3	4	5
30. Because I had cancer I am more understanding of what other people may feel when they are seriously ill.....	1	2	3	4	5
31. Having had cancer has made me more willing to help others.....	1	2	3	4	5
32. I feel that I should give something back to others because I survived cancer.....	1	2	3	4	5
33. Having had cancer has made me feel alone...	1	2	3	4	5
34. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me.....	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
35. Uncertainty about my future affects my decisions to make plans.....	1	2	3	4	5
36. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family).....	1	2	3	4	5
37. On-going cancer-related or treatment-related symptoms interfere with my life.....	1	2	3	4	5

38. Are you currently married, living together as married, or in a significant relationship?

\_\_\_ 1 Yes → Please skip to question 42 on the next page

\_\_\_ 2 No



Please answer questions 39-41 only if you are *not* currently married, living together as married, or in a significant relationship.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
39. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship.....	1	2	3	4	5
40. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer.....	1	2	3	4	5
41. I worry about not having a spouse, partner, boyfriend or girlfriend.....	1	2	3	4	5

Please skip to question 46 on the next page

Answer questions 42-45 only if you are currently married, living together as married, or in a significant relationship. Otherwise, please skip to question 46.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
42. I am open and willing to discuss my cancer with my spouse/partner.....	1	2	3	4	5
43. My spouse/partner is open and willing to discuss my cancer with me.....	1	2	3	4	5
44. Uncertainty about my health has created problems in my relationship with my spouse/partner..... ....	1	2	3	4	5
45. I worry about my spouse/partner leaving me if I were to become ill again.....	1	2	3	4	5

46. Are you fully retired from paid employment?

\_\_\_ 1 Yes → Thank you, you have now completed the IOCv2 questionnaire.

\_\_\_ 2 No



47. Were you employed and earning income at some time during the last 12 months?

\_\_\_ 0 No → Thank you, you have now completed the IOCv2 questionnaire.

\_\_\_ 1 Yes



Please answer questions 48-50 only if you were employed and earning income at some time during the last 12 months.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
48. I am concerned about not being able to work if I were to become ill again.....	1	2	3	4	5
49. Concerns about losing health insurance keep me in the job I have now.....	1	2	3	4	5
50. I worry about being forced to retire or quit work before I am ready.....	1	2	3	4	5

Thank you, you have now completed the IOCv2 questionnaire.

## Appendix F

### Comparison of Psychometric Properties of Measures-Cancer Survivorship Quality of Life

<b>Instrument and Concept</b>	<b>Author and Citation</b>	<b>Description</b>	<b>Reliability Estimates</b>	<b>Validity Estimates</b>	<b>Utility and Applicability</b>
<p>Quality of Life-Cancer Survivors (QOL-CS)</p> <p>Quality of life in long-term cancer survivors, includes survivors less than 5 years post-diagnosis.</p>	Ferrell, B., et al. (1995).	<p>41 items representing the 4 domains of QOL: psychological well-being (18 items), physical well-being (8 items), social well-being (8 items), and spiritual well-being (7 items).</p> <p>Previous pilot testing was conducted with in-depth qualitative interviews to determine additional content.</p>	<p><u>Test-retest</u>-In a sample of 70, subjects completed the tool at 2 different intervals, 2 weeks apart. Overall reliability was <math>r = 0.89</math>. For the subscales, it was psychological well-being (<math>r = 0.88</math>), physical well-being (<math>r = 0.88</math>), social well-being (<math>r = 0.81</math>), and spiritual well-being (<math>r = 0.90</math>).</p> <p><u>Internal consistency</u>-Cronbach's alpha of the entire instrument (<math>r = 0.93</math>). Subscale alpha scores were <math>r = 0.71</math> for spiritual well-being, <math>r = 0.77</math></p>	<p><u>Content validity</u>-utilized a panel of QOL researchers and nurses with oncology expertise (results not reported).</p> <p><u>Stepwise multiple regression</u> was conducted to determine factors most predictive of overall QOL in cancer survivors. 17 variables were found to be statistically significant, accounting for 91% of the variance in overall QOL. Variables accounting for the greatest</p>	<p>Strengths-41 items is reasonable and not too burdensome for participants. Strong psychometrics (close in length to the IOC v2).</p> <p>Limitations-mostly breast cancer survivors. Needs to be tested in a broader group of cancer survivors. Including ethnic minorities and underserved groups.</p>

			<p>for physical well-being, <math>r = 0.81</math> for social well-being, and <math>r = .0.89</math> for psychological well-being.</p>	<p>percentage were control, aches/pain, uncertainty, satisfaction, future, appearance, and fatigue.</p> <p><u>Pearson's correlations</u> conducted to estimate the relationships between the subscales of the QOL-CS and the subscales of the established Functional Assessment of Cancer Therapy-General (FACT-G). Moderate to strong correlations were found between associated scales: QOL-CS physical to FACT-G physical (<math>r = 0.74</math>), QOL-CS</p>	<p>Doesn't seem to be widely utilized. Only 6 citations were listed in the Health and Psychosocial Instruments (HAPI) data base, and 5 out of the 6 were studies done by the same group of authors from the University of Southern California.</p> <p>Focuses on items that are specific to off-treatment survivors, but are not necessarily distinct from commonly used generic QOL and health status measures</p>
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				<p>psychological to FACT-G emotional (<math>r = 0.65</math>) QOL-CS social to FACT-G social (<math>r = 0.44</math>). The overall QOL-CS correlation with the FACT-G was 0.78.</p> <p>Factor analysis and construct validity discriminating known groups of cancer survivors was mentioned but not described.</p>	<p>such as the SF-36, or instruments commonly used in patient receiving active treatment (Zebrack et al., 2006)</p>
<p>The Impact of Cancer (IOC) Instrument</p> <p>Designed to measure unique aspects of long-term survivorship (5 years or more post-survivorship) not measured by existing</p>	<p>Zebrack et al. (2006).</p>	<p>Testing was conducted on an 81-item self-report instrument with 6 subscales: employment, life outlook, body and health, feelings about cancer, meaning of cancer, and social activities and relationship. Items are worded to indicated</p>	<p><u>Internal consistency</u> of subscales ranged from 0.67 to 0.89</p>	<p><u>Content validity</u>-expert panel utilizing a process as described previously (detailed results not provided).</p> <p><u>Construct validity</u>-factor analysis was conducted resulting in a reorganization of</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>-includes input from cancer survivors. Attempts to be specific to LTS. Measures distinct and relevant constructs for LTS.</li> <li>-taps into aspects of LTS</li> </ul>

instruments.		<p>level of agreement (strongly agree, agree, neutral., disagree, strongly disagree).</p> <p>Factor analysis resulted in 10 new and specific subscales: health awareness, body changes, health worries, positive and negative self-evaluation, positive and negative life outlook, social life interferences, relationships, and meaning of cancer. Initial steps included qualitative interviews with 47 long-term cancer survivors (LTS). 145 codes were organized into a framework of QOL. An expert panel of researchers, clinicians, and cancer survivors provided</p>		<p>items and numerous factor loadings were included in the report.</p> <p><u>Concurrent validity</u>- estimated by comparing the IOC subscales with subscales from 2 other QOL scales, the MOS SF-36, and the City of Hope QOL-SC (previously described)</p> <p><u>Discriminant validity</u>-compared IOC variables with several other populations based health outcomes studies.</p>	<p>that other instruments do not.</p> <p>Limitations:</p> <ul style="list-style-type: none"> <li>-qualitative coding only conducted by one researcher.</li> <li>-still need evaluation of responsiveness to change over time and test-retest reliability.</li> <li>-study lacked power enough for a confirmatory factor analysis; further work is needed on confirming the factor structure.</li> <li>-minimal data to support estimates of reliability, lacking measures of overall internal</li> </ul>
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		feedback on 325 potential items with a resultant 125 items. After further piloting, resulted in the 81-item instrument.			consistency. -does not measure impact on exercise or diet behaviors. -limited items focusing on symptoms. -may not be as relevant to early survivorship.
IOC version 2 (IOCv2)  Concepts similar to the original version of the IOC. Reduced from 81 items to 41 to 44.	Crespi et al. (2008).	Conducted exploratory factor analysis. Shorter version of the above IOC. -2 higher order subscales with 4 subscales within each scale. -screens for relationship and employment status so that the questions are only relevant to that status.  New subscales: Positive Impact Scale -altruism empathy -health awareness	High <u>internal consistency</u> (Cronbach's alpha = 0.76-0.89).	Good <u>concurrent validity</u> when compared to the Center for Epidemiologic Studies Depression Scale (CES-D) and the Breast Cancer Prevention Trial Symptom Checklist (BCPT).  Good <u>construct validity</u> when compared with demographic, medical, and treatment characteristics.	-shorter and more practical than the longer IOC. -loses a few constructs/items from the IOC including: -some existential aspects -perceptions of other health problems -examples related to certain items (i.e., specific symptoms, aspects of



		<p>-meaning of cancer -positive self-evaluation</p> <p>Negative Impact Scale:</p> <p>-appearance concerns -body change concerns -life interferences -worry</p> <p>-employment concerns -relationship concerns (partnered) -relationship concerns (not partnered)</p>			<p>uncertainty to make plans) -life reflection -feelings about doctors -feeling angry and guilty -feeling abandoned after treatment -concern about children getting cancer -concerns about infertility -openness of partner -worry about partner leaving</p> <p>Strengths:</p> <p>-only 10-15 min. to complete instrument -demonstrated as a reliable and valid measure of the impact of cancer on QOL</p> <p>Limitation:</p>
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					-only psychometric testing done in BCSs
<p>The Brief Cancer Impact Assessment (BCIA)</p> <p>16 items, much shorter than the original IOC</p>	Alfano et al. (2005).	<p>Factor analysis- Promax oblique rotation. Data was collected at 3 time periods, at baseline (on the avg of 6.1 months following dx), a 2<sup>nd</sup> interview 24.4 months later &amp; a 3<sup>rd</sup> assessment (QOL survey) on avg 34.5 months after the baseline.</p> <p>Measures:</p> <ul style="list-style-type: none"> <li>-BCIA</li> <li>-Life Orientation Test-revised (LOT-R) to measure dispositional optimism</li> <li>-Perceived Stress Scale (PSS)</li> <li>-Fear of Recurrence (FOR) questionnaire</li> <li>-Post Traumatic Growth Inventory</li> </ul>	<p><u>Internal consistency</u> coefficients were generally high across the scales. Cronbach's alpha estimates by scale were care giving/finances, 0.77; exercise/diet, 0.63; social/emotional, 0.75, and religiosity, 0.81</p>	<p><u>Construct validity:</u> FA revealed 4 factors measuring the IOC on care giving &amp; finances, exercise &amp; diet behaviors, social &amp; emotional functioning &amp; religiosity.</p> <p>There was no unique effect of time since dx (2-5 years) on any of the BCIA scale scores.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>-large &amp; ethnically diverse sample</li> <li>-the opportunity to relate BCIA scales to relevant psychosocial &amp; health-related QOL instruments</li> <li>-added items related to health behaviors</li> </ul> <p>Limitations:</p> <ul style="list-style-type: none"> <li>-the limited # of instruments to use for construct validation</li> <li>-relied on retrospective reports of the perceived IOC</li> <li>-the BCIA does</li> </ul>

		<ul style="list-style-type: none"> <li>-Health-related QOL-SF-36</li> <li>-demographic variables</li> <li>-stage of BC and rx (based on SEER data)</li> </ul>			not capture all of the domains of the IOC
The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-CORE 30 (EORTC QLQ-C30).	Victorson et al. (2007).	Measures physical, role emotional and social functioning, along with disease specific symptoms, financial impact, and global QOL. In addition to the CORE questionnaire, researchers may also administer modules related to tumor site, treatment approach, or a QOL domain	Aaronson et al. (1993) reported acceptable to good <u>reliability coefficients</u> for individual scales (Cronbach's alpha = 0.65 – 0.92)	7 scales predict differences in patient clinical status	Has been used in numerous studies with CSs including breast, Hodgkin lymphoma, colorectal., prostate, and lung.
The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-CORE 30 (EORTC QLQ-C30).	Aaronson et al. (1993).	<ul style="list-style-type: none"> <li>-30 items, composed of multi-item scales and single items that reflect the multidimensionality of the QOL construct.</li> <li>-5 functional scales (physical, role, cognitive, emotional, and social)</li> </ul>	<ul style="list-style-type: none"> <li>-<u>reliability coefficients</u> for the multi-item scales ranged from .54 to .86 at T1 and .89 at T2.</li> <li>-With one exception, <u>reliability estimates</u> were similar across the 3 cultural</li> </ul>	-item-scale correlations exceed the .40 criteria for item- <u>convergent validity</u> for 7 of the 9 hypothesized scales at both measurement points. The mean	Strengths: <ul style="list-style-type: none"> <li>-exhibited satisfactory to excellent psychometric properties</li> <li>-tests of validity based on comparisons between patient</li> </ul>

		<p>-3 symptom scales (fatigue, pain, nausea &amp; vomiting)</p> <p>-global health and QOL scale</p> <p>-various single items related to symptoms &amp; perceived financial impact of the disease and treatment</p> <p>-2<sup>nd</sup> generation instrument, takes approximately 12 min. to complete</p> <p>-this study in patients with lung cancer, measured at 2 timeframes (just following diagnosis and prior to treatment, and once during treatment)</p> <p>-sample size was 305 from 13 different countries</p>	<p>subgroups; differences could be explained by the different approaches to cancer treatment in the countries which showed differences.</p>	<p>item-scale correlations across all 9 scales were .53 for T1 and .59 for T2. Low # of scaling errors provides strong support for the hypothesized scale structure</p> <p>-all <u>inter-scale correlations</u> were statistically significant (<math>p &lt; .01</math>), reflecting the conceptual non-orthogonality of the scales and the effect of a large sample size. The strongest correlations were between the physical functioning, role functioning and fatigue scales (ranging from .54 to .63)</p> <p>-Substantial correlations were</p>	<p>subgroups known to differ in clinical status yielded generally consistent results</p> <p>- measured cross cultural validity (often lacking in measures)</p> <p>-used widely in international clinical trials</p> <p>Limitations:</p> <p>-not specific to survivorship, very acute cancer rx oriented</p> <p>-less successful in discriminating between patients with different stages of disease</p> <p>-homogenous sample, restricted to</p>
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				<p>noted between the fatigue, emotional and social functioning scales (<math>&gt; .40</math>)</p> <p>-weak correlations were noted between the emotional functioning scale and the physical and role functioning scales</p> <p>-the global QOL scale correlated substantially with most of the other scales</p> <p>-in general., the <u>inter-scale correlations</u> were moderate, indicating that although related, they are assessing distinct components of the QOL construct</p> <p>-<u>clinical validity</u>-known groups comparisons:</p>	<p>lung cancer patients</p> <p>-sample size limitations required the use of rather coarse cultural categories</p> <p>-free standing nature of the study prevented obtaining more objective data on changes in clinical status over time</p> <p>-future versions will need to test alternative role functioning items that encompass a broader range of activities and that allow for a wider range of responses</p> <p>-needs to be compared with other cancer</p>
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				<p>Patients with a better performance status reported significantly higher levels of physical, role, and cognitive functioning, a significantly higher overall QOL and significantly lower symptoms levels for all 7 symptoms (sx's) when compared with patients with changes from a poorer performance status.</p> <p>-clinical validity-  <u>responsiveness to change</u>: using the total patient sample, repeated measures ANOVA failed to detect any statistically significant changes from T1 to T2 in scores on the functional</p>	QOL instruments
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				<p>scales or on 6 of the 7 sx scales. This could be explained by the heterogeneity of the sample in terms of change in health status over time</p> <p>-when analyzing subgroups, statistically significant between group differences over time for 5 of the scales: physical functioning (<math>p &lt; .001</math>), role functioning (<math>p &lt; .001</math>), fatigue (<math>p &lt; .01</math>), nausea and vomiting (<math>p &lt; .05</math>), and global QOL (<math>p &lt; .01</math>)</p>	
The European Organization for Research and Treatment of Cancer Quality of Life	Groenvold et al. (1997).	<p>Same instrument as above</p> <p>In this study, with a sample size of 95 patients with breast</p>		<p>Overall agreement between patients and observers, median overall agreement was 0.85</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>-overall agreement was high</li> <li>-combined qualitative and</li> </ul>

<p>Questionnaire-CORE 30 (EORTC QLQ-C30).</p>		<p>and ovarian cancer, agreement between the patients and the researcher's ratings was measured. (patients and healthcare professionals do not necessarily share the same form of reference)</p> <p>The purpose was to determine whether patients interpret the questionnaire in the same way as the researchers who analyze and report the results, and if not, how these interpretations differ.</p> <ul style="list-style-type: none"> <li>-utilized individual item analysis</li> <li>-qualitative interviews were utilized to discuss ratings and any misunderstandings</li> </ul>		<p>-according to kappa values, there was "almost perfect agreement" for 18 items, and "substantial agreement" for 9 items, and 3 items in the "moderate agreement" range; no items had kappas below this level</p>	<p>quantitative methods</p> <p>Limitations:</p> <ul style="list-style-type: none"> <li>-incomplete conclusions could have been made during the analysis of the data</li> <li>-agreement could have been overestimated</li> <li>-selective reporting could influence results</li> </ul>
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## Appendix G-Memorial Symptom Assessment Scale Short Form

### Memorial Symptom Assessment Scale-Short Form [MSAS-SF]

Citation: Chang VT; Hwang, SS; Feruerman M; Kasimis BS; Thaler HT. The Memorial Symptom Assessment Scale Short Form (MSAS-SF). Cancer 2000;89:1162-71.

Instructions: Below is a list of symptoms. If you had the symptom DURING THE PAST WEEK, PLEASE CHECK Yes. If you did have the symptom, please check the box that tells us how much the symptom DISTRESSED or BOTHERED you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	If YES: How much did it DISTRESS or BOTHER you?					
	Yes ✓	Not at all[0]	A little bit[1]	Some-what[2]	Quite a bit[3]	Very much[4]
Difficulty Concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling Drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

## Appendix H-Interview Guide

### Interview Guide

Cancer Survivorship in Rural and Urban Adults: A Descriptive and Mixed Methods Study

Phase II of the study consists of in-depth participant interviews.

Note-This guide ensures that the ideas important to the study are discussed by the participant. The interviews will begin with broad questions and become more specific. The topics will emerge and are guided by the participant's response to the questions. This guide is an example of what might be asked. In addition, probing questions such as "can you tell me a little bit more about that", or "can you give me a specific example", or "can you tell me a story about that" may be used. Probing questions elicit the richness and depth of data desired in order to fully explore the phenomenon of cancer survivorship. Additional probing questions are also listed below.

### Guide:

I am interested in your experiences as a cancer survivor. I would like to ask you questions about your experiences, your feelings and your symptoms. I would like to start with some general questions. I would also like to ask you about some of the answers that you gave on your questionnaires to try to explore more in-depth your experiences and how you are feeling.

#### 1. What it is like to have experienced cancer?

Probes:

- how has cancer changed your life?
- what are some of the positive experiences or aspects?
- describe some of the challenging experiences or aspects?

#### 2. Tell me what it is like to be a cancer survivor?

Probes:

- what were your experiences like when you first completed your treatment?
- how have your experiences changed as you have progressed through survivorship?
- are your experiences what you expected?

#### 3. How has the experience of having survived cancer affected you?

Probes: Relationships,  
Leisure activities/work

Beliefs, spirituality  
Physical activities; daily life; how you spend your time?  
Psychological impact?

4. How has this experience of going through cancer treatment changed your life?

Probes:

- what helps you with your experiences as a survivor?
- what has made things easier for you as a survivor?

5. What has not been helpful?

Probe:

- what has made things more challenging for you as a survivor?

6. How do you think living in a rural (or urban) area has impacted your experience as a survivor?

Probes:

- do you think your experiences would be different if you lived in a (rural or urban) setting?
- how do you think it would be different?

7. Can you tell me more about (a specific response on the Impact of Cancer Instrument)

8. Can you tell me more about (a specific response on the Memorial Symptom Assessment Scale)

Probe:

- is there a particular symptom that is bothersome?
- how does it affect you?

9. Is there anything else about being a cancer survivor that you would like me to know?

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

## **Appendix I-Informed Consent**

### OREGON HEALTH & SCIENCE UNIVERSITY Consent & Authorization Form

TITLE: Cancer Survivorship in Rural and Urban Adults: A Descriptive and Mixed Methods Research Study.

PRINCIPAL  
INVESTIGATOR

Lillian Nail, RN, PhD, FAAN (503) 494-5618

CO-INVESTIGATORS:

Julie McNulty, RN, MS, Doctoral Student,  
(907) 729-2937 or  
907-230-5996,  
Rebecca Block, MSW, PhD, (503) 494-6047  
Brandon Hayes-Lattin, MD, (503)-494-1318  
Frances Lee-Lin, PhD, RN (503) 494-3725

SPONSOR: None, Unfunded doctoral research study

This form contains important information about the study in which you are being invited to participate. Please read the form carefully, ask questions of the investigators or others who are obtaining your consent to participate in the study, and take time to think about your participation. You may want to discuss the study with your family or friends before agreeing to be in the study.

What is the purpose of this study?

The goal of this study is to find out how cancer affects adults living in rural and urban settings in Alaska and Oregon. The study will look at experiences of adults who have survived cancer, and compare these experiences between the adults living in the rural and urban settings, in the same region and between the two regions. The study will find out how people are feeling physically, mentally, spiritually and how they are relating with others. It will look at their positive as well as negative experiences.

What is required to participate in this study?

To be included in this study, you must meet the following criteria:

1. You are an adult, at least 18 years old, who has had any type of cancer (except for certain types of skin cancer), and have completed active cancer treatment.
2. It must be at least 8 weeks since you have completed active cancer treatment

3. If you are taking hormones or long term treatment (such as Tamoxifen) you can still be in this study
4. You are now cancer free
5. You were at least 18 years old when you were diagnosed with cancer
6. Be able to read and write English

#### What can I expect as a study participant?

Phase I: We will ask you to complete a form specific to the impact of cancer, and a form about your symptom experience. There will also be a form asking you about your health history, current health status, employment, age, marital status, etc. The forms will either be on paper or on the internet. If you have high or low scores on these forms, you may be selected for an interview with the researcher, which is phase II of the study.

Phase II: We may call you on the telephone to clarify your answers. After the forms are reviewed, which may take several weeks, we may invite you to participate in an interview with the researcher. The interview will take place either in person or over the phone, will be scheduled at your convenience, and will include more detailed questions about your cancer survivorship experiences. It will take approximately 45 minutes to one hour.

If you have any questions regarding this study, now or in the future, please contact Lillian Nail at (503) 494-5618 or Julie McNulty at (907)-729-2937

#### What effect will this study have on my care?

Being in this study will not affect any healthcare that you may be receiving.

#### How will my privacy be protected?

We will protect your privacy in the following ways:

1. Your name or other protected information will not be used. Instead, we will identify you by a numerical code, only known by the researcher.
2. Only Julie McNulty will be able to access your information and know the numerical code.

The specific health information we will collect from you will be limited to your responses on the forms. Health data such as cancer treatment history, symptom experience and any other illnesses that you currently have will be collected. The purposes of our use and disclosure of this health information that you provide are described in the Purpose section of this Consent & Authorization Form.

The persons who are authorized to use and/or disclose the health information that you provide are all of the investigators who are listed on page one of this Research Consent Form and the OHSU Institutional Review Board.

The investigator will permit study-related monitoring, audits, and inspections by the IRB, government regulatory bodies, and university compliance and quality assurance groups of all study-related documents.

This authorization will expire and we will no longer keep protected health information that we collect from you in this study when the study is completed. It is expected to be completed by June 2012.

What are the possible risks of participating in this study?

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality. In addition, the experience of having had cancer may be difficult to remember and discuss. While it is unlikely, participating in this study may cause you to become upset. If this should occur, and you feel that you need assistance, you will be given a referral to a mental health practitioner or support group.

What are the possible benefits of participating in the study?

You may or may not personally benefit from being in this study. However, by serving as a participant, you may help us learn how to help cancer survivors in the future. If you participate in phase II of the study and provide an interview, you will receive a gift card.

Will it cost anything to participate?

The only cost to you for participating in this study is your time.

What if I am harmed or injured in this study?

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Julie McNulty at 907-729-2937.

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

What are my rights as a participant?

1. If you have any questions regarding your rights as a research participant, you may contact the OHSU Research Integrity Office at (503) 494-7887.
2. You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.
3. You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your healthcare or your relationship with your healthcare provider.
4. The information about you that is used or disclosed in this study may be re-disclosed and no longer protected under federal law. However, federal or state law may restrict re-disclosure of HIV/AIDS information, mental health information, genetic information and drug/alcohol diagnosis, treatment, or referral information. OHSU tries to protect against re-disclosure without your permission by being very careful in releasing your information.
5. If the researchers publish the results of this research, they will do so in a way that does not identify you unless you allow this in writing.
6. You may be removed from the study if:
  - The investigator stops the study.
  - Your cancer health status changes.
7. To participate in this study, you must read and sign this consent and authorization form. If you withdraw your authorization for us to use and disclose your information as described above, you will be withdrawn from the study.
8. We will give you a copy of this signed form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

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Participant Signature

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Date

Investigator obtaining consent:

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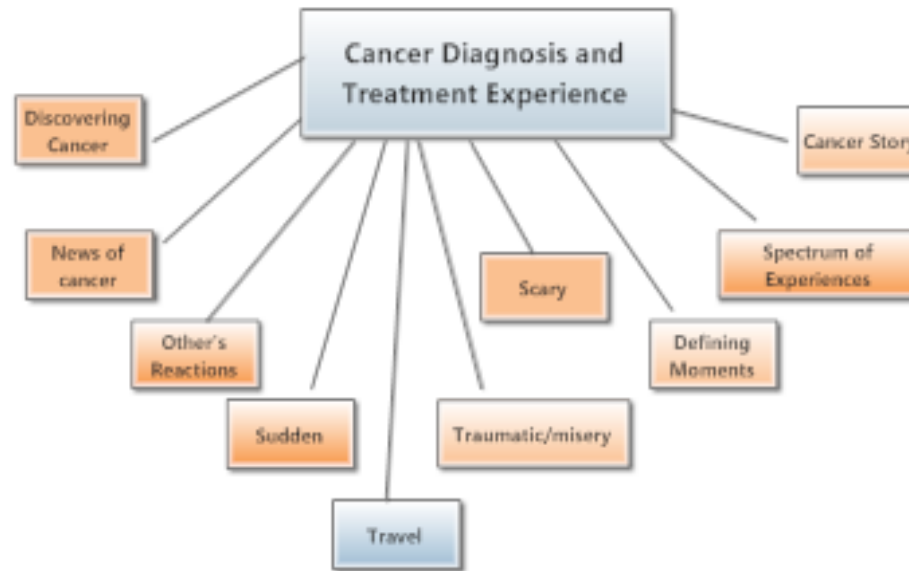
Print

Signature

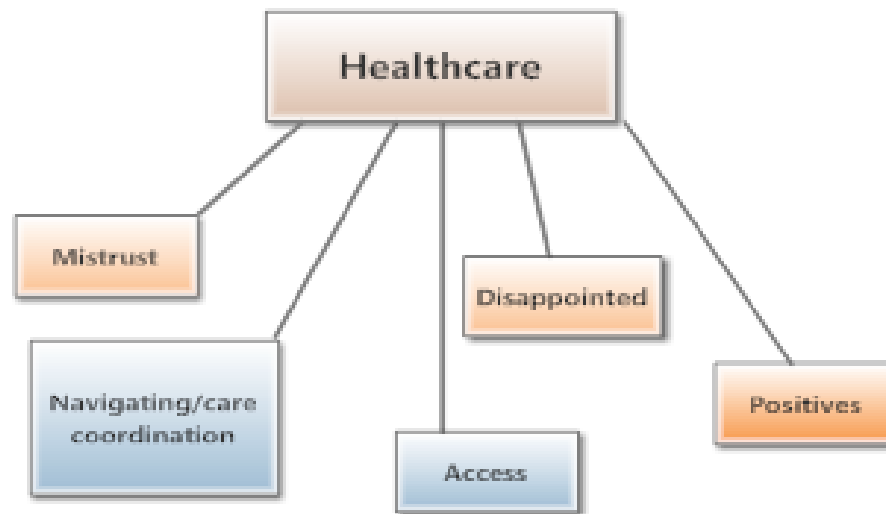
Date



## Appendix J- Mind Maps-Qualitative Findings

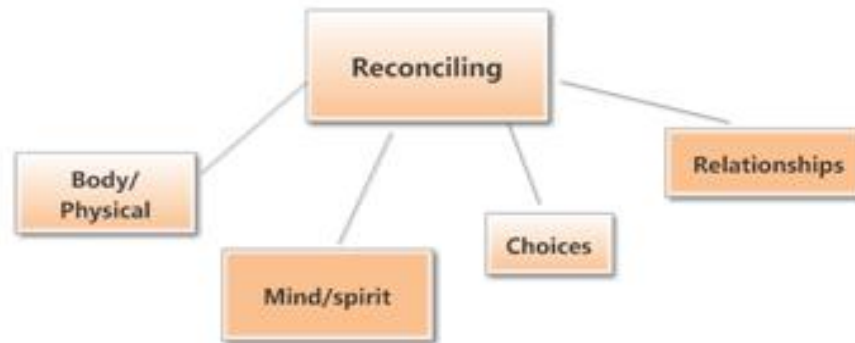


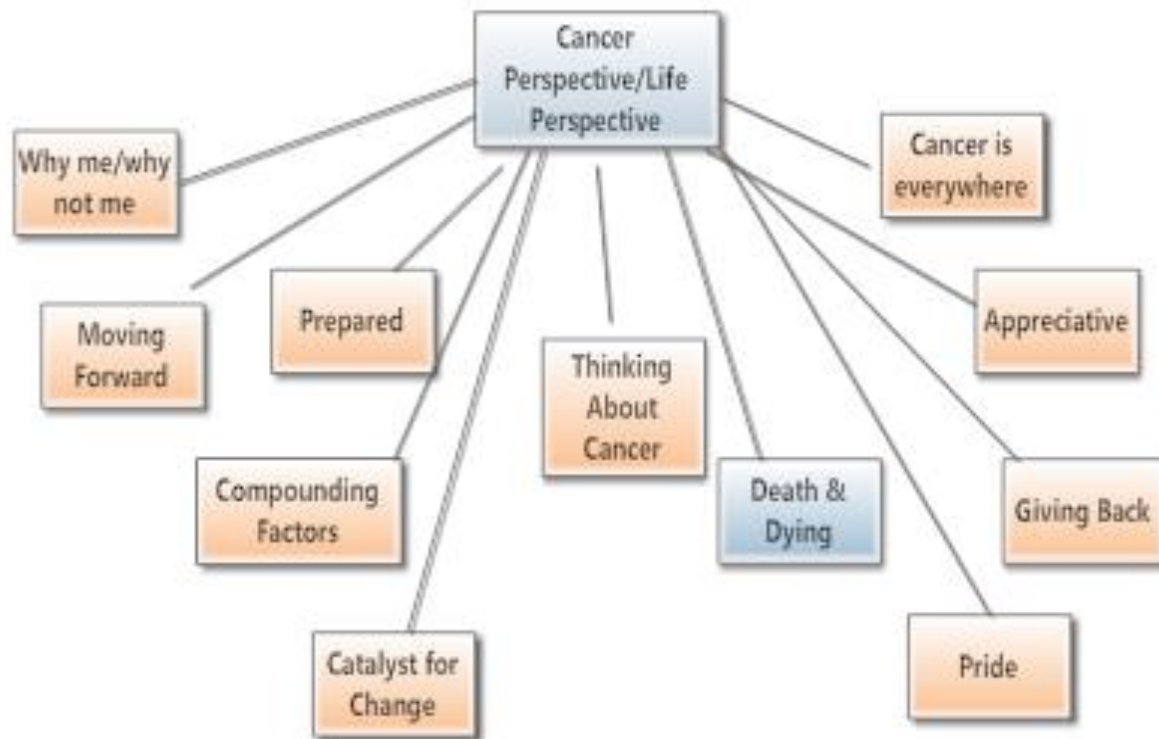
Blue shading indicates where rural/urban differences are present

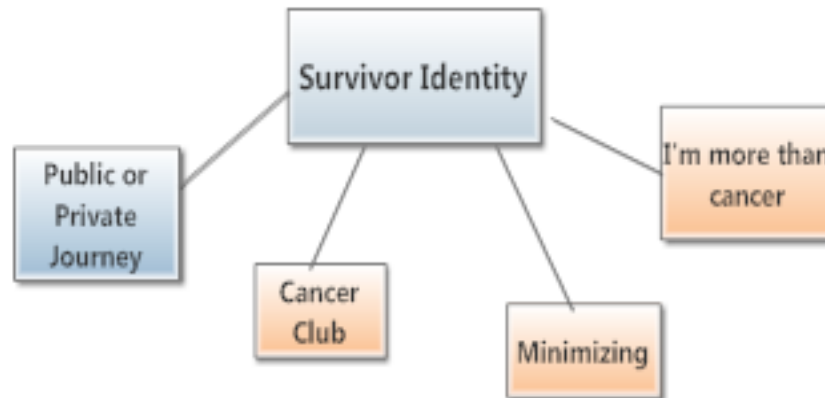


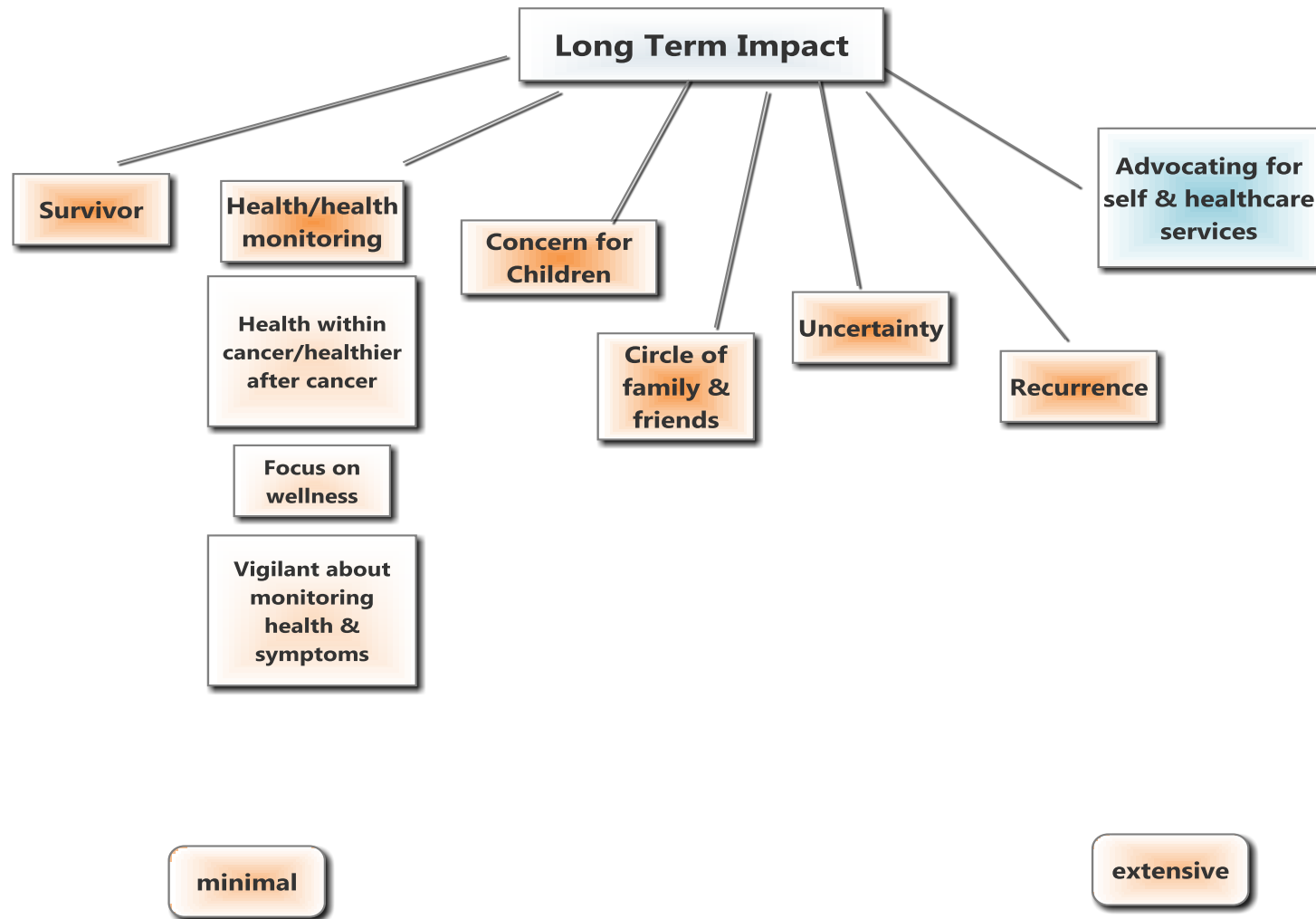
Blue shading indicates category where rural/urban differences are present











## Appendix K

### Comparison of Cancer Survivorship Frameworks And Trajectories With The Current Study

Author	Description/key components	Influence on survivorship	Strengths & Limitations	Comparison with this study
Mullan, 1985,	<p>Essay written by a physician who is a cancer survivor. Describes 3 “seasons of survival,” each stage having its own unique concerns</p> <p><u>Acute:</u> begins with the cancer diagnosis and the focus is diagnostic and treatment efforts. Associated with fear and anxiety.</p> <p><u>Extended:</u> basic treatment has terminated, patient goes into remission. This stage is associated with watchful waiting and is dominated by a fear of recurrence. Associated with diminished strength and significant physical challenges.</p> <p><u>Permanent:</u> associated with a cure; however, the experience and its effects remain with the survivor.</p>	<p>-highly influential and heavily cited.</p> <p>-very influential in framing the early work of survivorship research and advocacy.</p> <p>-provided some of the foundational work for the National Coalition of Cancer Survivorship (NCCS).</p>	<p>Strengths: describes the temporal nature of survivorship and accurately depicts the essence of the post-treatment and long-term survivorship stages.</p> <p>Limitations: breaking down survivorship into stages; may lose sight of survivorship as a whole process.</p>	<p>-both temporal in nature</p> <p>-Mullan’s acute phase is similar to “diagnosis and treatment,” “getting through it, and “healthcare.”</p> <p>-Mullan’s extended and permanent phases correspond with the post-treatment phases described in this study.</p>



Welch-McCafferey et al., 1989	<p>Framed survivorship by trajectories:</p> <ul style="list-style-type: none"> <li>-living free of cancer for many years.</li> <li>-live long cancer-free but die rapidly of late recurrence.</li> <li>-live cancer-free (first cancer) but develop a subsequent primary cancer.</li> <li>-live with intermittent periods of active cancer.</li> <li>-live with persistent cancer.</li> <li>-live after expected death.</li> </ul>		<p>Strengths: describes a range of survivorship trajectories.</p> <p>Limitations: can be viewed as fragmented, only considers medical aspects, no description of psychosocial issues associated with each trajectory.</p>	<p>Trajectories identified by Welch-McCafferey et al. were:</p> <ul style="list-style-type: none"> <li>-living free of cancer for many years.</li> <li>-live cancer-free, but develop a subsequent primary cancer (in this study, CSs were cancer-free at the time of the study but may have had a 2<sup>nd</sup> cancer or recurrence at an earlier time).</li> </ul>
Hassey-Dow, 1990	<p>Expands on the work of Mullan and provides implications for nursing.</p> <p>Asserts that the meaning of surviving is less on the temporal aspects and more a focus on truth and the meaning of one's life.</p>	-Brings a nursing perspective to the survivorship literature	<p>Strength: first to focus on nursing implications.</p> <p>Weakness: methods not well described.</p>	<p>Several themes are similar; "getting through it" (same), "working through" (reconciling), "cancer doesn't define me" (I'm more than cancer), building on past experiences.</p>

Ferrell et al., 1992, 1995	<p>Conceptual framework based on a QOL model applied to CSs.</p> <p>Identifies 4 domains of QOL (physical, psychological, social and spiritual well-being). -domains are multidimensional and inter-related.</p>	<p>-Has informed many studies and was featured in the IOM report, <i>Lost in Transition</i>.</p> <p>-is the most tested FW.</p> <p>-has been used to design educational programs focused on survivorship.</p> <p>-has been used to develop instruments specific to survivorship.</p> <p>-there is general agreement on the major domains as conceptualized in the FW.</p>	<p>Strengths: concepts resonate with the descriptions of survivorship in the literature; spiritual aspects are well-developed.</p> <p>Limitations: does not capture survivorship as a process over time; does not address cultural aspects, but the spiritual aspects are comprehensive.</p>	<p>This FW heavily influenced the current study -provided the FW for the study design and literature review organization.</p> <p>-the early developmental work of the IOC was based on the QOL work done by Ferrell et al.</p> <p>-the FW guided the interview questions for qualitative strand of the study.</p> <p>The 4 domains were captured in the “getting through it” theme, but they did not extend into the post-survivorship themes that were more temporal in nature, and extending into long-term survivorship.</p>
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Bushkin, 1993,	<p>A nurse who is a survivor frames survivorship with the metaphor of being a traveler, which exemplifies the process of survivorship.</p> <p>Describes a journey from “insurmountable odds” to “endless possibilities,” with numerous “signposts” of survivorship.</p>	<p>-given as a lecture at the national ONS conference by the author’s husband after she died.</p> <p>-influential on nursing’s emphasis on cancer survivorship.</p>	<p>Strengths-written in language that survivors and non-survivors can easily identify with, lays the groundwork for conceptual development</p> <p>Limitations: mainly focuses on the acute treatment phases.</p>	<p>-both describe survivorship as a process with temporal aspects</p> <p>-Some similar concepts including “lightening bolt” (sudden), “ladders” (mentors), “control” (same)</p>
Farmer, 2002	<p>Concept analysis, identified themes and attributes of cancer survivorship.</p> <ul style="list-style-type: none"> <li>-complex</li> <li>-individualized</li> <li>-process</li> <li>-unique</li> <li>-relational</li> <li>-dynamic</li> </ul>	<p>-only comprehensive and systematic concept analysis found in the literature.</p> <p>-describes the evolution of the definitions of cancer survivorship over time.</p>	<p>Strengths: one of the few to recognize that the survivorship literature does not adequately address survivorship from an ethnic and cultural perspective.</p> <p>Weaknesses: only addresses breast cancer in African American women in the implications.</p>	<p>-survivorship as a process was evident in the qualitative findings of the current study.</p>
Feuerstein, 2006	<p>Offers an example of a stage-based framework, combining his perspective as a survivor, perspectives from the</p>	<p>-offers a strategy to organize research and thinking about survivorship.</p>	<p>Strengths: depicts survivorship over time, is multidimensional, and</p>	<p>-overlap between diagnosis and treatment concepts.</p>

	literature, and clinical stages of diagnosis, treatment, acute, sub-acute, chronic and end stage, which are influenced by medical, sociocultural, individual, and environmental factors.	reflects the complexity of the phenomenon. Recognizes geographical issues and aspects of medical care (access, quality, and cost).	-both are multidimensional. -similar constructs identified include symptoms, access to healthcare, social support, coping, positive health behaviors.
		Limitations: does not incorporate cultural influences.	-both approaches bring into play the medical, personal, social, and geographical perspectives.
NCI, Cancer Control Continuum, 2007	Defines the continuum as prevention, detection, diagnosis, treatment, and survivorship.	Strengths: survivorship is a stage along the continuum.  Limitations: does not portray the essence of survivorship.	Explores the constructs associated with long-term survivorship more fully.