Symptom Experiences and Quality of Life of Rural and Urban Older Adult Cancer Survivors

By: Beck, Susan L. PhD, APRN, FAAN; Towsley, Gail L. PhD; Caserta, Michael S. PhD; Lindau, Karen MS; Dudley, William N. PhD

Abstract:
This study examined the symptom experience, health-related quality of life, and functional performance of elderly cancer survivors at 1 and 3 months after the completion of initial treatment. The study used a descriptive, comparative, repeated-measures design. A mixed-methods approach combined completion of survey instruments with qualitative interviews. Of the 52 participants, 22 resided in rural (n = 12) or semirural (n = 10) areas and 30 lived in urban settings. There were 23 women and 29 men ranging in age from 65 to 81 years (mean age, 71.53 years). Survivors experienced a significant number of symptoms (mean, 4.58), which were, on average, moderate in intensity and did not differ based on urban or rural residence. The Medical Outcomes Study SF-12 Physical Component Summary was less than the national norm for elderly individuals or those with a chronic disease. There was minimal improvement 3 months after treatment. Elderly survivors, regardless of whether they were rural or urban, experienced a significant number of unrelieved symptoms, including fatigue, pain, and difficulty sleeping. Eighty-eight percent had other chronic diseases. Comorbidities were associated with greater symptom intensity and less physical health status. Survivorship care for elderly adults should include a comprehensive geriatric assessment and tailored strategies for symptom management.

Article:
It is now estimated that there are nearly 11 million cancer survivors in the United States. The majority (61%) is aged 65 years and older.[1] Epidemiologic data indicate that the burden of cancer falls disproportionately on older Americans.[2,3] There is a 10-fold increase in cancer incident rates for those 65 years and older, a population that is growing exponentially in the United States. As the baby boom generation ages and as people live longer because of advances in cancer detection and treatment, the number of elderly cancer survivors who will experience problems that diminish their quality of life (QOL) will increase.

A series of landmark national reports have addressed the needs of this growing number of cancer survivors.[4-6] These reports have specifically recommended research to establish baseline data regarding the cancer experience in medically underserved populations, including the elderly and those living in rural communities. Such underserved populations may have insufficient access to information, resources, and social support after cancer treatment. The 2005 report "From Cancer Patient to Cancer Survivor: Lost in Transition" noted that during the transition to survivorship, there is sudden loss of contact with the intense support services available during treatment to meet physical and psychosocial needs.[7] However, there is an important gap in our knowledge about the experience of rural and urban elderly cancer patients during this time after cancer treatment.[4] Do their symptoms persist? Do new problems develop? What is the impact of symptoms on their lives? The purpose of this mixed-methods study was to examine the symptom experience, health-related QOL, and functional performance of rural and urban elderly cancer survivors in the first 3 months after the completion

of initial treatment.

The Impact of Cancer on the Symptom Experience and QOL of Older Adults

Cancer survivors may face a range of health-related, financial, social, and psychological problems that persist long after treatment.[5,7,8] These problems are compounded in the elderly by the likelihood of comorbid diseases that develop with advancing age. Population-based data indicate that adults who report a history of cancer have double the likelihood of poor health and disability when compared with those without a cancer history. When coupled with another chronic illness, as often occurs in the elderly, the likelihood of poor health is almost 5 to 10 times what would be expected.[9] Garman and associates [10] reported that the presence of comorbidities is an important correlate of functional status in elderly survivors.

Cancer and the treatment of cancer are associated with considerable morbidity.[8] Persistent physical symptoms, such as pain, fatigue, and insomnia, are often distressing and may diminish QOL.[11] Reiner and Lacasse [12] reviewed 27 studies related to the symptom experience in older adults with cancer. They extended their inclusion criteria to a mean age of 55 years owing to the paucity of research in the gero-oncology population. They concluded that evidence indicated that older adults with cancer frequently experience pain and fatigue and that these symptoms are correlated with insomnia, depression, and losses in functional performance and health status. The role of comorbidities in increasing symptomatology was also supported.

Most of the studies reviewed by Reiner and Lacasse, particularly those in adults older than 65 years, were focused on the treatment trajectory in cancer outpatients. For example, Given and associates [13] found that 18% of aged breast cancer patients (n = 228) had 3 concurrent symptoms-fatigue, pain, and insomnia-and 33% had at least 2 concurrent symptoms. Eight percent of aged prostate cancer patients (n = 249) had all 3 symptoms and 24% had at least 2 symptoms.[13] Patients were more likely to report pain and fatigue if they had 3 or more comorbid conditions; number of comorbidities was also associated with a decrease in physical functioning.

The co-occurrence of 3 symptoms (pain, fatigue, and insomnia) has been termed a symptom cluster that appears to be problematic in a subset of cancer patients receiving treatment.[14] The existence of this symptom cluster of pain, fatigue, and sleep disturbance was reported in 3 of the articles reviewed by Reiner and Lacasse.[15-17] Less is known about whether this cluster lingers into survivorship. In one study of breast cancer survivors (not specifically elderly), Bower and associates found that one-third had more severe fatigue than the did the general population and that it was associated with pain, depression, and sleep disturbance.[18] These systemic symptoms can have profound effects on ability to function in usual roles and activities.[19,20] In one of the few studies in rural cancer patients (not elderly or survivors), 344 patients from 2 Northeastern states completed the Functional Assessment of Cancer Therapies-General. As compared with the social, emotional, and physical subscales of the Functional Assessment of Cancer Therapies, functional status, which included items related ability to function and work independently, was scored the lowest and rated most important to QOL.[21]

Early Survivorship in Older Adults

The time period after initial definitive treatment for cancer is a time of transition to survivorship.[7] The daily or weekly support from the healthcare team in the clinic or radiation department is gone and there is often a sense of loss.[22] However, little research has focused on the degree to which elders continue to have unrelieved symptoms and to what extent these symptoms influence their QOL and functional performance. In a series of focus groups conducted by the National Cancer Institute, participants reported that the posttreatment period was a more difficult time than they expected. Up to a year later, many were still coping with the physical adverse effects of treatment and/or the emotional impact of having been diagnosed with cancer.[23] For the elderly, age-related symptoms may be present in addition to problems related to cancer. Elderly survivors may not be able to

access resources as easily or efficiently as other cancer survivors can because of a limited or fixed income and potential limitations in social support.

Challenges Facing Rural Cancer Survivors

Individuals living in a rural area may encounter increased challenges in accessing resources and necessary support services. Rural areas within the Intermountain West of the United States are geographically isolated by mountain ranges and large uninhabited areas. Mountain roads, uncrossable canyons, and inclement winter weather influence travel time, which can be a critical factor in accessing healthcare. Most of the rural and frontier areas in the west are classified as medically underserved.24 Access to care is impeded not only by geography but also by the generally low economic status of rural residents, the scattered population, and the limited numbers of available healthcare providers and healthcare facilities.

There has been little, if any, research focused on cancer survivorship among rural elders. We therefore conducted a descriptive study that compared elderly cancer survivors in rural and urban settings after completion of cancer treatment. The study was guided by Armstrong's 25 Symptoms Experience Model. In this model, the symptom experience includes both symptom occurrence and severity. The model also proposes the co-occurrence of multiple symptoms. We were particularly interested in pain, fatigue, sleep disturbance, and depression. Antecedents that may influence the symptoms experience included demographic and clinical variables as well as residence (urban or rural). Consequences of the symptoms experience included health-related QOL and functional performance.

The primary aims were to:

1. characterize the symptom experience, health-related QOL (physical health status and mental health status), and functional performance in elderly cancer survivors 1 and 3 months after treatment;

2. compare urban and rural elderly cancer survivors, identifying similarities and differences; and

3. examine the relationships between number and type of comorbid conditions and aspects of the symptom experience, QOL, and functional performance.

Methods

The study used a descriptive, comparative, repeated-measures design to compare elderly cancer survivors in rural and urban settings at 1 (time 1) and 3 (time 2) months after completion of cancer treatment. These times were purposefully chosen because the time immediately after treatment is often difficult and little is known about how long problems persist. A mixed-methods approach combined self-completion of psychometrically sound instruments with in-depth qualitative interviews to examine symptoms, functional performance, and aspects of health-related QOL. The study was approved by the University of Utah Institutional Review Board, and written informed consent was obtained from each participant.

Sample and Setting

Eligible individuals had been diagnosed with cancer and had completed initial treatment with a definitive course of chemotherapy, radiation treatment, or concurrent therapy for cure or local control. They were able to read and speak English, were free of communication impairments, showed no overt evidence of psychiatric disorder,

were 65 years or older, and had access to a telephone.

Potential participants were recruited at the Huntsman Cancer Institute medical oncology clinics, the University of Utah Radiation Therapy Department, and a rural hospital. Huntsman Cancer Institute is a National Cancer Institute (NCI)-designated cancer center that reported nearly 45,000 annual outpatient visits in 2007. Nearly half of these patients came from outside of the extended urban area along the Wasatch Mountains; about 20% are from surrounding states. The University of Utah Radiation Therapy Department treats approximately 120 patients at 2 locations per day; annually, about 500 persons older than 65 years receive treatment.

Measures

We sent a booklet of questionnaires to participants to measure demographic and clinical characteristics, symptom experience, health-related QOL, and their functional performance. Demographic variables included age, sex, race, marital status, educational level, annual net income, comorbidities, type of health insurance, and place of residence. Project staff retrieved medical record information regarding the type of cancer (primary site), the current extent of disease, and treatment status. The instruments described below were reformatted into a booklet applying the approach of Dillman,[26] with specific attention to recommended approaches in the elderly. Zip code was used to classify rurality based on a system developed at the University of Washington in which zip codes throughout the United States are coded on a scale of 1 (highly urban) to 10 (frontier).[27]

SIDE EFFECT CHECKLIST

The Side Effect Checklist (SEC) is a measure of side effect severity used in previous research on coping with cancer treatment.[28] Side effects experienced in the past week were rated for severity using a 5-point Likert-type scale of 1 (not at all) to 5 (extremely). A score of 0 is assigned if a particular side effect was not experienced. In cancer patients, SEC summated scores have been correlated with outcome measures such as mood and other QOL domains.[28] This instrument has demonstrated acceptable test-retest reliability ($r = 0.84$) and face and clinical validity.[28]

BRIEF PAIN INVENTORY-SHORT FORM

Pain intensity, pain relief, and interference with function were measured with the Brief Pain Inventory-Short Form (BPI-SF), a self-report tool widely used to measure pain.[29] The BPI-SF is short, easy to complete, and has been administered in paper-pencil formats. The first part of the BPI-SF consists of 4 items that ask the patient to rate pain intensity: worst pain in last week, least pain in last week, average pain in the last week and pain now. Each item is rated on a scale from 0 (no pain) to 10 (the worst I can imagine). One item rates the degree of pain relief from 0% to 100%. The third part measures the degree to which pain interferes with physical and psychosocial function in 7 common areas: general activity, mood, walking, working, relations with others, sleeping, and enjoyment of life. Each item is measured on scale of 0 (does not interfere) to 10 (completely interferes). The 7 items are summed to yield an interference score. Internal consistency for the intensity scale was reported at .87 and for the interference scale at .91 to .94.[30]

GENERAL FATIGUE SCALE

The General Fatigue Scale is a 7-item scale that measures the amount of fatigue today and on most days, the highest level of fatigue in the last 48 hours, and the highest level of fatigue in the last week. It also measures fatigue severity and distress overall as well as interference with usual function. The General Fatigue Scale has a Cronbach [alpha] reliability coefficient of .92, stability coefficient of 0.79, completion rate of 96%, significant

sensitivity to change (t = 3.77, P < .001), and a factor analysis explaining 68% of the variance in fatigue.31

PITTSBURGH SLEEP QUALITY INDEX

Sleep was measured using the Pittsburgh Sleep Quality Index (PSQI), a self-rated questionnaire that measures sleep quality and disturbances over a 1-week period.32,33 There are 19 items that yield 7 component scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The sum of scores for the components yields a global score, which has been demonstrated to discriminate good and poor sleepers. The instrument has demonstrated good internal consistency (Cronbach [alpha] = .83), stability (test-retest reliability = 0.85, P < .001), and discriminant validity. There is evidence to support the use of the PSQI in cancer patients.33

GERIATRIC DEPRESSION SCALE-SHORT FORM

The Geriatric Depression Scale-Short Form (GDS-SF) is a 15-item tool composed of dichotomous items that assess level of depression in elderly populations.34 The GDS-SF is useful because of the dichotomous questions that are easy for elderly persons to answer, because it eliminates physical symptoms that can be confounding variables in aging populations, and because it can detect clinical depression. A GDS-SF score of greater than 5 indicates the need for a more thorough evaluation, and a score greater than 10 is indicative of moderate to severe depression. The GDS-SF demonstrates a specificity of 0.90, test-retest reliability 34 of 0.94, and internal consistency reliability 34 (Cronbach [alpha]) of .74.

HEALTH-RELATED QOL

The 12-item short form of the Medical Outcomes Study Health Survey (MOS SF-12) was used to measure 2 aspects of health-related QOL: physical and mental. The MOS SF-12 was derived from items in the highly reliable and valid Medical Outcomes Study 36-Item Short Form Health Survey (MOS SF-36).35 The MOS SF-12 achieved multiple R^2 values of 0.91 and 0.92 in prediction of the MOS SF-36 Physical Component Summary (PCS) and the MOS SF-36 Mental Component Summary (MCS) scores, respectively. Two-week test-retest correlations were 0.89 and 0.76 for the MOS SF-12 PCS and the MOS SF-12 MCS subscales, respectively.35

FUNCTIONAL PERFORMANCE INVENTORY

The Functional Performance Inventory (FPI) was used to measure functional status. The FPI consists of 65 items and 6 subscales: body care, household maintenance, physical exercise, recreation, spiritual activities, and social activities. Participants respond to each activity on a scale from 1 (activity performed easily with no difficulty) to 4 (activity no longer performed for health reasons). A "not applicable" option is available for those who choose not to perform an activity for reasons other than health. Items are reverse coded so that a low score indicates low functioning. Participants do not receive a score for activities they do not perform (for reasons other than health). Subscales and total scores are computed. The FPI has been tested in individuals with chronic obstructive pulmonary disease. There is evidence of internal consistency reliability (Cronbach [alpha] = .96) and validity.36

TELEPHONE INTERVIEW

Interviews allowed participants to tell their story of the symptom experience and how it affected their life. Two project staff members conducted the interviews using a semistructured interview guide that addressed specific symptoms, physical and emotional, as well as the impact of the symptoms. The interviewers asked about

problems encountered since completing treatment, how distressing they were, and how they have been managed. The interviewers probed for greater detail as needed. At the second interview, the participant was asked about any changes that had occurred since time 1.

Procedure

We identified potential study participants completing treatment by screening the medical records of all identified eligible individuals. After consultation with the treating physician and/or primary nurse, the project staff member approached eligible individuals and provided them with a brochure that briefly introduced the study. If they were interested in participating, the staff obtained informed consent and scheduled a time with the participant to complete the time 1 telephone interview, 1 month after completion of treatment. We then mailed a survey containing the selected self-administered questionnaires to the participant 1 week before the interview. A $20 gift certificate was provided once the survey was returned and the interview was complete. Two months after (time 2), these procedures were repeated, thus yielding comparative data at 1 and 3 months posttreatment.

Analysis

All questionnaire data were entered using double data entry and then imported into Statistical Package for the Social Sciences software (v. 12) for cleaning and analysis. Analyses are primarily descriptive, using summary statistics. Because the sample size in each group was small, comparisons between rural and urban survivors were conducted using either $[chi]^2$ tests of association or Mann-Whitney U tests for independent groups. Nominal data were collapsed as appropriate to meet assumptions for $[chi]^2$ tests. Paired t tests were used to evaluate change over time. With complete matched data on 47 participants, we estimated that there was 0.80 power to detect a moderate effect ($>=0.50$) at a $P < .01$ level of significance (2-tailed). We recognized the need to be cautious in the interpretation of the findings owing to the multiple tests and small sample.

All interviews were transcribed; reviewed by the interviewer for errors and addition of notes related to tone, emphasis, or emotional expression; and organized using N-Vivo software (v. 2.0). The initial coding was based on the specific questions from the interview guide. Specific nodes (N-Vivo term for codes) relevant to this report include those related to specific symptoms (fatigue, depression, pain, and insomnia) and the "distress" associated with each symptom and how it interfered with usual life activities. Qualitative data are used as exemplars to complement the quantitative findings in this report.

Results

Sample Characteristics

There were 62 individuals recruited to the study; 7 (11.3%) later withdrew and 3 provided incomplete data at time 1 and were excluded. Of the 52 participants, 22 resided in rural (n = 12) or semirural areas (n = 10) and 30 lived in urban settings. They came from 5 states: Utah, Wyoming, Idaho, Nevada, and Montana; 75% were from Utah. Table 1 summarizes the demographic characteristics and Table 2 indicates the types of cancer and the types of treatment that participants had received. There were 23 women and 29 men, ranging in age from 65 to 81 years (mean, 71.54 years); 26.9% were 75 years or older. Of the participants, 98% were white and the majority had some college education or a degree (67.3%) and were married (61.1%). The majority (63.5%) was retired, but 21% continued to work full- or part-time. In terms of financial situation, 37.3% reported "problems making ends meet." Seven survivors were receiving Medicaid. The most common types of cancer were breast (27%) and prostate (29%). The remaining participants had a variety of primary sites. Most participants (80.8%) had completed radiation therapy, either alone or in combination with chemotherapy. Per the eligibility criteria, all patients had local or regional disease. As expected with elderly individuals, 88.5% had other chronic

diseases. Almost 25% had 3 or more. Of these, the most prevalent were arthritis (38.5%), diabetes (25%), and hypertension (23.1%).

Characteristic	Urban (n = 30)		Rural (n = 22)		Total (n = 52)	
	No.	%	No.	%	No.	%
Gender[a]						
Female	16	53.3	7	27.3	23	44.2
Male	14	46.7	15	72.7	29	55.8
Race/ethnicity						
Non-Hispanic white	29	96.7	22	100	51	98.1
Hispanic white	1	3.3	0	0	1	1.9
Marital status						
Single	1	3.3	0	0	1	1.9
Separated or divorced	6	20.0	4	18.2	10	19.2
Widowed	5	16.7	4	18.2	9	17.3
Married	18	60.0	14	63.6	32	61.5
Education						
Less than high school	2	6.7	1	4.5	3	5.8
High school	5	16.7	9	40.9	14	26.9
Some college/technical	17	56.6	9	40.9	26	50.0
Associate degree plus	6	20.0	3	13.6	9	17.3
Income per year						
<$20,000	7	23.3	11	50.0	18	34.6
$20,000–$40,000	12	40.0	4	18.2	16	30.8
>$40,000	11	36.7	7	31.8	18	34.6
Age						
Mean		71.37		71.77		71.54
SD		5.0		4.90		4.92
Range		66–81		65–81		65–81

[a]$P = .059.$

Table 1 Demographic Characteristics of the Study Sample (n = 52)

	No.	%
Type of cancer		
Prostate	15	28.8
Breast	14	26.9
Head and neck	4	7.7
Colorectal	4	7.7
Uterine/cervical/ovarian	3	5.7
Lymphoma	6	11.5
Other	6	11.5
Type of treatment		
Radiation therapy	38	73.1
Chemotherapy	10	19.2
Both	4	7.7
Comorbidities		
Arthritis	20	38.5
Diabetes	13	25.0
Hypertension	12	23.1
Heart disease	11	21.2
Lung disease	5	9.6
Neuromuscular disease	4	7.7

Table 2 Clinical Characteristics of Older Adult Cancer Survivors (n = 52)

Symptom Experience

In the first month after treatment for cancer, elderly survivors experienced a number of physical symptoms that are common adverse effects of cancer treatment. Occurrence was coded as positive if the survivor reported at least a mild level (>=2 on a scale of 1-5) of a symptom (see Table 3). Physical symptoms reported by at least 30% of participants included urinary frequency (57.7%), cough (38.5%), pain (38.5%), and shortness of breath (34.6%). There were a variety of "write-in" other symptoms including leg cramps, dry mouth, and numbness. The mean scores are summarized in Table 3. There were negligible and nonsignificant changes in the occurrence or severity at 3 months. Especially at the first month posttreatment, treatment-related problems such as diarrhea were common. One man receiving radiation therapy for prostate cancer explained, "I have been plagued with occasional diarrhea, which I think is probably still some influence of the procedure and the radiation still having some influence on my body function with regard to my elimination."

Symptom	Time 1 (n = 52)			Time 2 (n = 47)		
	Occurrence Rate (With at Least a Mild[a] Score)		Severity[b]	Occurrence Rate (With at Least a Mild[a] Score)		Severity[b]
	No.	%	Mean (SD)	No.	%	Mean (SD)
Urinary frequency	30	57.7	3.16 (0.93)	26	55.3	3.15 (0.73)
Cough	20	38.5	2.83 (1.15)	19	40.4	3.05 (0.95)
Pain	20	38.5	3.00 (0.89)	25	53.2	2.96 (0.74)
Shortness of breath	18	34.6	2.60 (0.94)	15	31.9	2.64 (0.81)
Decreased appetite	15	28.8	2.67 (0.98)	8	17.0	2.50 (0.76)
Constipation	14	26.9	2.93 (0.92)	11	23.4	2.73 (0.65)
Rectal irritation	14	26.9	2.86 (1.03)	7	14.9	2.38 (0.92)
Hot flashes	12	23.1	3.15 (1.07)	13	26.6	2.90 (0.76)
Diarrhea	13	25.0	2.64 (0.54)	8	17.0	2.78 (1.09)
Swelling	9	17.3	2.56 (0.73)	11	23.4	2.64 (0.81)
Red/ peeling skin	9	17.3	2.50 (1.08)	2	4.2	1.50 (0.71)
Sore mouth	8	15.4	2.50 (0.54)	4	8.5	2.50 (0.58)
Nausea	7	13.5	2.57 (0.54)	7	14.9	2.86 (.90)
Urinary burning	7	13.5	2.67 (0.65)	8	17.0	2.50 (0.76)
Vomiting	3	5.8	2.67 (0.58)	2	4.2	3.0 (1.41)
Other	19	36.5	3.37 (0.83)	17	14.9	3.53 (0.71)

[a]Includes all patients who scored a 2 or more on a scale of 1 (not at all) to 5 (extremely), indicating at least a mild level of symptom severity.
[b]Includes all patients who indicated yes to symptom occurrence.

Table 3 Occurrence Rate and Severity of Physical Symptoms Reported on the Side Effect Checklist for the Past Week

Reports from the SEC indicated that survivors experienced from 1 to 13 symptoms, with an average of 4.58 at time 1 and 3.91 at time 2 (P = .06). Specific tools were used to measure more common and distressing symptoms including pain, fatigue, depression, and sleep disturbance. Findings are summarized in Tables 4 and 5; qualitative data helped to contextualize these reports.

Symptom	Urban, %		Rural, %		Total, %	
	1 mo (n = 30)	3 mo (n = 27)	1 mo (n = 22)	3 mo (n = 18)	1 mo (n = 52)	3 mo (n = 45)
Individual symptoms						
Moderate to severe fatigue[a]	63.3	51.9	72.7	61.1	67.3	55.6
Moderate to severe pain[a]	20.0	23.3	18.2	27.3	19.2	25
Poor sleep quality[b]	51.7	48.1	31.8	33.3	44.0	42.2
Moderate to severe depression[c]	3.3	7.4	9.1	11.1	3.8	6.4
Symptom pairs						
Fatigue and pain	20	25.9	18.2	33.3	19.2	28.9
Fatigue and poor sleep	48.3	25.9	23.8	27.8	38.0	26.7
Fatigue and depression	3.3	3.7	4.5	11.1	3.8	6.4
Symptom cluster[d]						
Fatigue and pain and poor sleep	17.2	11.1	9.5	11.1	14.0	11.1

[a]Mean score of 4 or greater (on a scale of 0–10) on the General Fatigue Scale or Brief Pain Inventory Short Form Intensity Subscale.
[b]Mean score of 8 or greater (on a scale of 1–21) on the Pittsburgh Sleep Quality Index global sleep score.
[c]Mean score of greater than 10 (on a scale of 0–15) on the Geriatric Depression Scale Short Form.
[d]All 4 symptoms not included because of low prevalence of depression.

Table 4 Comparison of Moderate to Severe Symptoms Between Urban and Rural Participants

Variable[a]	Time 1 Mean (SD)	Time 2 Mean (SD)	P Value of Paired t Test (Time 1–2)
No. of symptoms from the Side Effect Checklist	4.58 (2.82)	3.91 (2.23)	.06
Severity of symptoms from the Side Effect Checklist[b]	0.77 (0.58)	0.66 (0.42)	.14
GDS-SF	3.24 (3.11)	3.18 (3.43)	.87
GFS total	4.77 (2.06)	4.53 (2.30)	.40
GFS intensity subscale	5.07 (2.11)	4.79 (2.41)	.36
GFS distress (item 6)	3.29 (2.53)	3.40 (2.62)	.77
GFS impact on daily activities	4.78 (2.51)	4.36 (2.64)	.21
BPI-SF intensity (n = 19 patients with pain)	4.17 (1.56)	3.63 (1.50)	.19
BPI-SF interference with function	4.11 (1.94)	4.09 (2.22)	.97
PSQI-global sleep score	7.33 (3.37)	7.33 (3.49)	1.0
Sleep quality	0.93 (0.67)	0.86 (0.60)	.32
Sleep latency	1.08 (1.11)	1.26 (1.11)	.21
Sleep duration	0.93 (0.90)	0.84 (0.83)	.42
Sleep efficiency	0.90 (1.02)	1.05 (1.05)	.44
Sleep disturbances	1.30 (0.55)	1.39 (0.58)	.35
Use of sleeping medications	1.18 (1.345)	0.91 (1.33)	.10
Daytime dysfunction	0.98 (0.60)	0.93 (0.67)	.62

Abbreviations: BPI-SF, Brief Pain Inventory-Short Form; GDS-SF, Geriatric Depression Scale-Short Form; GFS, General Fatigue Scale; PSQI, Pittsburgh Sleep Quality Index.
[a]GDS-SF ranges from 1 (low) to 15 (high); GFS ranges from 1 (low) to 10 (high); BPI-SF ranges from 0 (low) to 10 (high); PSQI (PSQI) global score ranges from 1 (good) to 21 (poor); and component scores range from 0 (good) to 3 (poor).
[b]Mean severity including all responses; no symptom occurrence recoded as 0 intensity.

Table 5 Comparison of Symptoms 1 and 3 Months Posttreatment (n = 47)

Fatigue was the most common symptom and was moderate to severe in intensity for 67.3% at time 1 and 55.6% at time 2. Fatigue distress was also moderate (3.37) on average, and the degree to which fatigue interfered with usual activities ranged from 1 to 9 (mean, 4.75). Fatigue persisted well after the completion of treatment. As one person explained, "Well, in general, I've been feeling…I'm tired all the time." The impact of fatigue was quite different depending on lifestyle and typical daily activities. For example, one rural man explained, "There's a lot of times you know when you go out to feed the cows. I mean you'd like to complete the job and come back in. Well, sometimes, I have to leave it midstream and take my little rest and go out and complete it."

The need to stop and rest, even lie down, was often reported. Many different types of activities were affected by the fatigue. As one person explained, "I have to lay [sic] down and so I don't get as much done or don't get to do as many things as I would have done." Although there was no significant improvement in fatigue at time 2, 55.6% had an improved score and many reported that fatigue had improved. For example, "I'm getting my strength back little by little, and some days, it feels like its all back. But I feel 100% better than I did even 6 weeks ago." Others seemed to have a more persistent problem. One explained, "I still have fatigue. Some days I feel really good and other days I feel terrible."

For those who reported that they had pain (n = 23, or 44.2%, at time 1), 43.5% reported a BPI-SF intensity level that was moderate or severe. This represented 18.2% of the total sample. Mean pain intensity scores on a 0 to 10 scale were moderate, 4.17 at time 1 and 3.63 at time 2. Interference scores were also moderate on average. Many patients described pain that was sharp or shooting and brief and intermittent in nature. One reported, "It's mostly momentary. A minute or something like that and then it goes away or mostly away." Some patients related pain to cancer or treatment. For example, "…the ear and the area that they've treated, the nerves are still trying to grow back or something. And they, from time to time, they let me know that they're around-rather sharply as a matter of fact." Others indicated that pain was not necessarily related to cancer but to some comorbid condition. One man explained, "My hands hurt all the time. It's just arthritis I think, but they hurt all the time. And if I do any walking, my feet and my legs hurt."

Many patients also had difficulty sleeping; 58% had time 1 PSQI global scores of greater than 5-a cutoff that would classify participants as poor sleepers.32 According to the cutoff of 8 as recommended by Carpenter and

Andrykowski 37 for cancer patients, this number would decrease to 44% at time 1 and 42% at time 2. The highest component score was sleep disturbances (mean of 1.30 on a scale of 0-3) Only 46% at time 1 and 42% at time 2 had a sleep efficiency score greater than the recommended amount of 85%. About one-third reported trouble falling asleep within 30 minutes 2 or more times per week and 27.5% were using a sleeping medication 3 or more times per week. As one person described, "I never can sleep through the full night. But I wake up about, oh, maybe about 1:00 and I come out here in my chair and just sit and I go back to sleep and wake up about 4:30 or 5:00."

The majority (90.4%) of survivors were not depressed; only 2 survivors (3.8%) at time 1 and 3 survivors (6.4%) at time 2 scored greater than 10, indicating moderate to severe depression as measured by the GDS-SF. Another 3 survivors (5.7%) scored greater than 5 on the GDS-SF at time 1, indicating a mild level of depression; this increased to 4 survivors (8.5%) at time 2. The positive coping strategies used by these participants have been previously described.38

Although the patterns varied somewhat by symptom, there were no significant differences in symptoms between rural and urban survivors. Most symptoms persisted over time.

We also examined the occurrence of symptom clusters by calculating the number of patients who experienced moderate to severe levels of pain, fatigue, poor sleep quality, and/or depression (see Table 4). The combination of fatigue and poor sleep was most common, experienced by 38% of patients at time 1 and 26% of patients at time 2. Only 14% experienced the cluster of pain, fatigue, and poor sleep at time 1, decreasing to 11.1% at time 2. The very low prevalence of depression resulted in only 1 patient having all 4 symptoms. We did not specifically probe for information about the experience of multiple symptoms in the interviews, and data from the 7 patients with this cluster were not informative in this regard.

Health-Related QOL

Functional performance was assessed by the FPI; the total and subscale scores at each time are reported in Table 6. It is important to note that there are several items that are often not applicable because they are gender-specific or not appropriate to all individuals. This phenomenon is managed by including only applicable items in the subscale means. Overall, participants retained a high level of functioning and the data were skewed to reflect this. This high level of functioning was particularly true in self-care activities entitled "body care," which included toileting, bathing, and others. The greatest impact (lowest score due to reverse coding) was noted in the area of physical exercise (mean [SD], 1.93 [0.99] on a scale of 0 to 3). Activities that were most affected (at least 10 participants reporting much difficulty or unable to do) were those that required both strength and energy, including cleaning bathrooms or washing floors; mowing the lawn or shoveling snow; performing physical activities such as walking and climbing stairs; engaging in activities like swimming, golfing, jogging, and others; and engaging in sexual activity.

Variable	Time 1 Mean (SD)	Time 2 Mean (SD)	P Value of Paired t Test (Time 1–2)
MOS SF-12 physical component score	37.06 (12.85)	39.16 (12.13)	.11
MOS SF-12 mental component score	54.00 (10.18)	52.99 (11.66)	.38
FPI total	2.48 (0.49)	2.59 (0.38)	.12
FPI body care	2.88 (0.25)	2.90 (0.21)	.53
FPI household maintenance	2.51 (0.65)	2.61 (0.50)	.21
FP physical exercise	1.93 (0.99)	2.11 (0.89)	.19
FPI recreation	2.53 (0.60)	2.70 (0.42)	.03[a]
FPI spiritual activities	2.81 (0.48)	2.83 (0.26)	.79
FPI social activities	2.24 (0.66)	2.35 (0.51)	.19

Abbreviations: FPI, Functional Performance Inventory; MOS SF-12, 12-item Medical Outcomes Study Short Form.
Range from 0 (low) to 3 (high); a lower score indicates worse health status.

Table 6 Mean, SD, and P value of Difference of Health-Related Quality-of-Life Measures at 1 and 3 Months Posttreatment

Physical functioning as measured by the mean MOS SF-12 PCS scale was 37.06 (SD, 12.85) and was less than the national norm for elderly individuals (43.33) (age 65-74 years) and closer to the norm for those 75 years or older (37.79). The mean PCS was also less than norms for those with chronic illness (44.92) and cancer (45.12).39 This difference between normed samples was even more marked in the rural areas, where the PCS at time 1 was 35.09 (SD, 11.08). The mean MOS SF-12 MCS was 54.00 at time 1 and 52.99 at time 2; both of these are higher than the national norms and consistent with the low scores on the GDS-SF.

Correlations between symptom variables and aspects of health-related QOL at time 1 are displayed in Table 7. As expected, the strongest relationships (P < .001) are between depression and mental health status and between fatigue and physical health status (in both cases, r = -0.71). Nonsignificant and weak correlations were found between the MCS and pain intensity and between the MCS and number of comorbidities. The remaining correlations were low to moderate in strength.

Symptoms	MOS SF-12 Physical	MOS SF-12 Mental	FPI Total
No. of symptoms	−0.375[a]	−0.517[a]	−0.343[b]
No. of comorbidities	−0.356[a]	−0.234	−0.384[a]
Side Effect Checklist mean severity	−0.495[a]	−0.496[a]	−0.552[a]
Geriatric Depression Scale total	−0.313[b]	−0.710[a]	−0.505[a]
Brief Pain Intensity mean (n = 23)	−0.533[a]	−0.157	−0.536[a]
Global Pittsburgh Sleep Quality Index score	−0.297[b]	−0.492[a]	−0.312[b]
General Fatigue Scale mean	−0.711[a]	−0.346[b]	−0.498[a]

Abbreviations: FPI, Functional Performance Inventory; MOS SF-12, 12-item Medical Outcomes Study Short Form.
[a]Correlation is significant at <.01 level (2-tailed).
[b]Correlation is significant at <.05 level (2-tailed).

Table 7 Correlations Between Symptoms and Aspects of Health-Related Quality of Life at Time 1

Influence of Comorbidities

Those who had lung disease (9.8%) had significantly worse physical health (P < .05) and more difficulty exercising (P < .001), whereas those with arthritis (39.2%) had worse fatigue (P < .05) but not significantly worse pain. Those with diabetes, neuromuscular disease, and chronic fatigue syndrome had significantly higher scores on the GDS-SF; these mean scores were still within the range of mild (score of 5-10) versus moderate-severe (score of >10) depression. The total number of comorbidities was significantly correlated with fatigue (r = 0.31), depression (r = 0.43), and global sleep quality (r = 0.38), as well as the PCS of the MOS SF-12 (r = -0.35) and the FPI (r = -0.38).

Discussion

Knowledge about the symptom experience and QOL in elderly cancer survivors, especially those who live in rural areas, provides a better understanding of elderly cancer survivors' experience and needs. This descriptive study was designed to describe the symptom experience and QOL (functional performance, physical health status, and mental health status) in elderly (>=65 years) cancer survivors 1 and 3 months after treatment. Not surprisingly, only 27% were 75 years or older as the number of survivors per age cohort decreases with age. The sample of 52 older adults included 22 (42.3%) who resided in rural areas. This percentage somewhat overrepresented the proportion of cancer survivors from rural areas but allowed for comparisons. One of the challenges in research with rural patient populations is that the numbers are sparse and distributed over wide geographic areas. Given that many elderly are on a fixed income, more than two-thirds of the sample had an income of less than $40,000 per year. Half of the rural participants had an income less that $20,000. The sample represented both sexes and common types of malignancies but was racially and ethnically homogeneous. The generalizability of the findings to other racial and ethnic groups is limited.

The primary aim of this study was to characterize the symptom experience, QOL (physical and mental health status), and functional performance of elderly cancer survivors 1 and 3 months after treatment. The study used mixed methods, and the sequencing of the data collection, quantitative before qualitative, may have influenced the results.

The results indicate that numerous symptoms are present and unrelieved during the transition into cancer survivorship. As in other studies,12,15 patients usually experienced more than 1 symptom and had as many as 13 at time 1 and 10 at time 2. The systemic symptoms that are commonly associated with cancer treatment were present in this sample, including fatigue, insomnia, and pain. Similar to findings of Given and associates,13 who reported that from 8% (prostate) to 18% (breast) of patients had fatigue, pain, and insomnia, 14% experienced this cluster at time 1. This pattern persisted at time 2 for most of these patients. Likewise, 38% (compared with 33% in the Given et al 13 sample) had 2 concurrent symptoms. The prevalence of depression was lower than in other studies 40-43 and more similar to point prevalence in healthy community samples. It is possible that depressed patients declined to participate. Specific localized adverse effects of treatment also were problematic for some patients. It is not surprising that some symptoms may linger 1 month after treatment; however, there was minimal improvement at the 3-month time. Longitudinal research is needed to document whether problems become chronic or if there is a normal recovery trajectory. Deimling and associates 44 reported that 40% of older long-term (>5 years) survivors reported at least 1 symptom, with pain being most prevalent. A subgroup of patients with chronic, unrelieved symptoms may be particularly vulnerable and should be targeted for more intensive symptom management interventions.

The overall physical health status of these older cancer survivors was lower than that of similar populations of elders or individuals with chronic disease. Mental health status was not a major problem for most of these patients. In our qualitative analysis of the findings, we identified that these patients "learned to live with it" and used a variety of positive coping skills.38 As symptom severity increased, all aspects of physical health status and functional performance declined. Fatigue was strongly correlated with physical health status; and depression, with mental health status. These results validate findings of others in elder patients undergoing cancer treatment or with advanced illness.12,17 The lack of a significant correlation between pain intensity and mental health status was surprising, but the number who reported pain was small.

In a recent review of published research on QOL in patients across cancer diagnosis, Bloom and associates 45 concluded that QOL is generally good to excellent for long-term survivors. However, QOL varies according to treatment received and by age for all groups, with older persons generally reporting better QOL. Research in long-term survivors indicates that age-related factors may be more important than cancer-related factors in

predicting functional problems.46 The trajectory of QOL also varies by type of cancer. It remains important to identify which cancer survivors are at greatest risk over time for experiencing chronic problems and to target these patients for intervention. Those with multiple comorbid conditions and those who experience multiple symptoms, especially the debilitating cluster of pain, fatigue, and insomnia, may be helped by targeted and tailored interventions.

The second aim was to compare urban and rural elderly cancer survivors, identifying similarities and differences. There were no clear patterns of difference in the occurrence of symptoms and no statistically significant differences in the symptom experience. Patients from rural areas experience equivalent numbers and severity of debilitating symptoms. As indicated in a report on the Rural Cancer Patient Care Project, rural patients have a need for knowledge related to cancer and management of associated symptoms.47 Although nonparametric tests were used, the small sample size may limit the power to detect differences. The scores of rural survivors were lower than national norms in physical health status, indicating that the impact of cancer treatment may be greater in these patients. This is comparable to the findings by Schultz and Winstead-Fry.21 Further research should evaluate this trend in larger samples.

The third aim examined the influence of comorbid conditions on the symptom experience. There was a very high rate of comorbid conditions, consistent with large national studies.48 One in 4 patients had 3 or more comorbid conditions, which adds to the complexity of symptom management.12,13 Number of comorbidities was associated with severity of symptoms (fatigue, poor sleep quality, and depression) and functional performance.10 Older patients with multiple comorbid conditions may require a more intensive level of care management. It should be noted that arthritis was both very common and associated with greater fatigue. This finding has not been reported elsewhere in the cancer survivor literature.

This mixed-methods study allowed us to explore whether rural residency makes a difference in the experience of elder survivors and whether there is a difference in the month immediately after treatment as compared with 3 months after treatment. Findings indicate that symptom burden is considerable and persistent for elderly cancer survivors regardless of residency. Future intervention research should be designed to reach rural as well as urban residents. In addition, interventions focused at the time of transition into survivorship are critical. Early cancer survivors continue to experience distressing symptoms. Those with comorbid conditions and the symptom cluster of pain, fatigue, and sleep disturbance may be more at risk.

Implications

National and state goals to reduce cancer morbidity and mortality will not be achieved without implementing effective interventions aimed at rural populations. The National Action Plan for Cancer Survivors calls for "minimizing preventable pain, disability, and psychosocial distress for those living with, through, and beyond cancer as well as assisting cancer survivors in accessing family, peer, community support, and other resources they need to cope with their disease."6 The need for these actions in elderly patients and those in rural areas is supported by the findings of this study. In addition, the number and severity of symptoms and comorbid conditions confirms the need for a comprehensive geriatric assessment with consistent follow-up.49 Future research should focus on understanding the mechanisms for ongoing symptoms as well as testing and implementing interventions and community-based resources for this underserved population.50 Specific recommendations include developing programs to ensure that all survivors completing treatment receive adequate information and ongoing assessment. Targeted educational campaigns should inform survivors about community resources that might be of help, including patient financial advocates and organizations that might provide tangible support. There is a need to systematically educate survivors about self-care strategies tailored to manage their specific symptoms after treatment and to provide follow-up support for the use of effective

coping strategies during the transition to early survivorship.

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