Experience of Newly Diagnosed Patients With Sarcoma Receiving Chemotherapy

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Purpose/Objectives: To examine symptom distress and quality of life (QOL) in newly diagnosed patients with sarcoma receiving chemotherapy.

Design: Pilot study; descriptive, quantitative.

Setting: Urban community cancer center in the northeastern United States.

Sample: 11 newly diagnosed patients with sarcoma.

Methods: Participants completed the Edmonton Symptom Assessment Scale and the Functional Assessment of Cancer Therapy–General at baseline and on days 1, 15, and 21 of their chemotherapy treatment.

Main Research Variables: Symptom distress and QOL.

Findings: Fatigue was the most prevalent and pervasive symptom. Anxiety, well-being, lack of appetite, drowsiness, and depression were the most commonly reported symptoms during chemotherapy. QOL was negatively affected. The lowest mean score reported was for functional well-being. Outcome profiles for symptom distress increased over time, whereas QOL profiles decreased over time. Exploratory analyses of age, race, sex, and diagnosis group suggested differences that warrant further study.

Conclusions: Overall, increasing symptom distress and reduced QOL over time were reported by patients with sarcoma during chemotherapy. Exploratory analysis by demographic variables and treatment group suggested the need for further research of predictors for symptom distress and QOL.

Implications for Nursing: Clinical and research implications included the need for better understanding about symptom distress and QOL predictors in patients with sarcoma, as well as the evaluation of interventions directed to address this population's specific needs.

Sarcomas constitute a heterogeneous group of rare solid tumors that originate in the connective tissue or bone. Based on the tissue of origin, sarcoma can affect muscle, fat, blood vessels, bones, or other supporting tissues of the body (National Comprehensive Cancer Network [NCCN], 2011b). Soft tissue sarcomas are the most frequent sarcomas (Cormier & Pollock, 2004). In the United States, the incidence of soft tissue sarcomas in 2010 was estimated to be 10,520 cases, with an overall mortality rate of 3,920 cases for adults as well as children (Jemal, Siegel, Xu, & Ward, 2010). The five-year survival rate of soft tissue sarcomas has been estimated at 50%–60% (Pisters, 2002). Sarcoma of the bone is an extremely rare neoplasm, accounting for less than 0.2% of all cancers (Dorfman & Czerniak, 1995; Gurney, Severson, Davis, & Robinson, 1995; Unni, 1996). In the United States, 2,650 new cases and 1,460 related deaths were estimated in 2010 (Jemal et al., 2010).

Primary bone sarcomas often are curable with adequate treatment (NCCN, 2011a). Collectively, sarcomas account for about 1% of all adult malignancies and 15% of pediatric malignancies (Zahm & Fraumeni, 1997). Soft tissue sarcomas may occur at any age but predominate in young adulthood, with soft tissue sarcomas composing 8% of all cancers in people aged 15–29 years (Bleyer, O'Leary, Barr, & Ries, 2006). Primary neoplasms of the bone are uncommon in adolescents and young adults and account for 3% of all neoplasms in this age group (Unni, 1996). The rarity of cases has resulted in a scarcity of sarcoma research, particularly research examining symptom distress and quality of life (QOL) of adult patients diagnosed with sarcoma.

Sarcoma remains a challenging disease to treat. As a result, research has focused mainly on improving survival rates rather than alleviating symptom distress (Hartmann & Patel, 2005; Jebsen et al., 2010; Womer, 1996). Cancer treatment regimens for younger adults typically are more aggressive than those for older adults and may be perceived as causing greater symptom distress (Smith, Redd, Peyser, & Vogl, 1999); however, very little sarcoma research has evaluated symptom distress and QOL in adults. The results of the few available studies conducted with adult sarcoma survivors revealed significant long-term side effects including fatigue, ototoxicity, reduced renal function, and limited physical functioning associated with reduced QOL (Aksnes et al., 2008, 2009; Frances, Morris, Arkader, Nikolic, & Healey, 2007; Servaes, Verhagen, Schreuder, Veth, & Bleijenberg, 2003). In addition, pain in patients with sarcoma has not been the principal

aim of past research; rather, the pain has been examined as a component of QOL assessments.

Advanced cancer pain has been described as moderate to severe in about 40%–50% of patients and as very severe or excruciating in 25%–30% of patients with osteosarcoma (Ripamonti & Dickerson, 2001). Eighty-seven percent of patients with sarcoma experienced phantom pain after undergoing proximal limb amputations; 16% reported that their QOL was worse than before the surgery (Daigeler et al., 2009). Studies exploring multimodality therapies for sarcoma described pain as a significant predictor of QOL (Chang et al., 1989; Sugarbaker, Barofsky, Rosenberg, & Gianola, 1982; Thijssens, Hoekstra-Weebers, Ginkel, & Hoekstra, 2006). Nonetheless, a profound lack of research exists regarding QOL in patient with sarcoma. QOL has been defined as the extent to which the patient's experience reflects his or her expectations of functionality and well-being (Bruley, 1999; Hassan, Cima, & Sloan, 2006). Research findings to date indicate that patients who have unrealistic expectations of functionality and well-being have lower QOL than patients with more practical expectations when the disease worsens or progresses or the patients' condition begins to deteriorate (Hassan et al., 2006). Patients with sarcoma are likely to have higher expectations for their QOL because they tend to be younger than other patients with cancer. Given that sarcoma accounts for 9% of invasive cancers in 15–29 year olds (Bleyer, Montello, Budd, & Saxman, 2005), these patients face severely toxic and demanding chemotherapy treatments (Nielsen et al., 2003). In addition, young patients may require highly invasive surgeries or amputations, which are associated with high symptom distress (Thijssens et al., 2006).

Symptom distress and QOL in patients with sarcomas could be comparable to a cohort of patients with cancer receiving aggressive chemotherapy regimens. A large number of studies of patients undergoing stem cell or bone marrow transplantation have reported significant symptom burden including fatigue, anorexia, sleep disturbances, pain, and diminished physical function (Anderson et al., 2007; Epstein et al., 2002; Hann et al., 1997; Schultz-Kindermann, Hennings, Ramm, Zander, & Hasenbring, 2002; Sherman, Simonton, Latif, Spohn, & Tricot, 2004).

Sarcomas are rare in contrast to other malignancies; as a result, adult patients with sarcomas have not been adequately studied and often are under-represented in large-scale studies to elucidate the symptom experiences of those undergoing cancer treatments and responses to interventions. The literature reflects major deficiencies in addressing the needs and concerns of this patient population. Although no known inherent susceptibilities exist based on ethnic or racial dispositions, patients with sarcomas are at high risk for complex physiologic and psychosocial problems associated with the highly aggressive chemotherapy regimens and surgical procedures (including amputations), all of which may have a considerable impact on physical functioning, as well as emotional and social aspects of daily living (Chang et al., 1989; Sugarbaker et al., 1982; Weddington, Segraves, & Simon, 1985).

Unfortunately, the paucity of research to address these concerns has left a significant void in the understanding of the specific challenges related to clinical management of patients with sarcomas and has limited the knowledge of ways in which nursing interventions can be used to improve symptoms and QOL in this population. As a result, the current study aimed to examine symptom distress and QOL in newly diagnosed patients with sarcoma.

Methods

Sample

Newly diagnosed patients with sarcoma receiving chemotherapy at a community cancer center in the northeastern United States were recruited for the quantitative component of this study. After the University of Pennsylvania's institutional review board granted study ap-

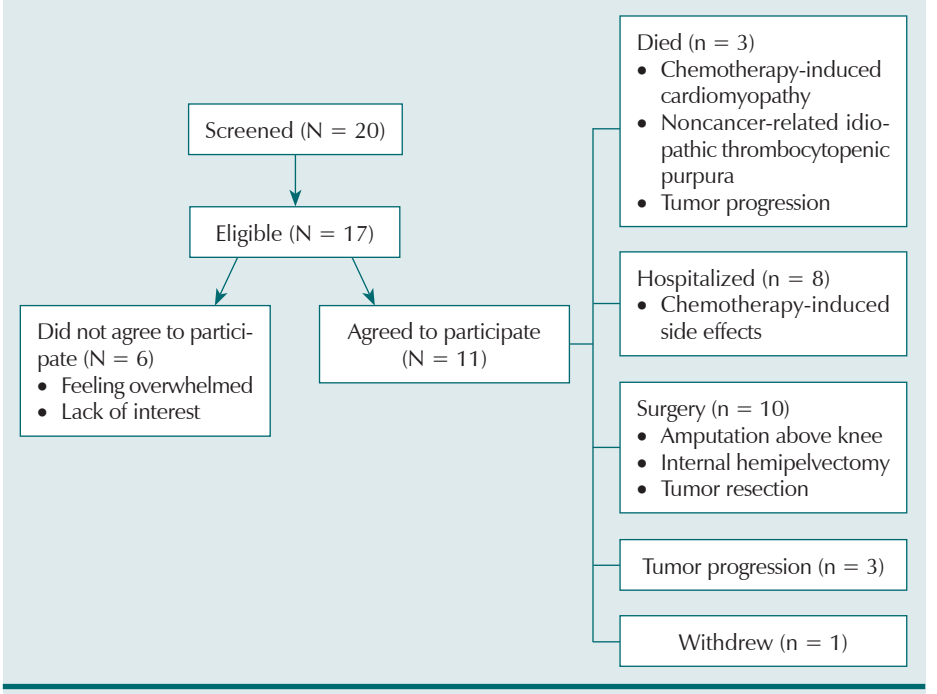

Figure 1. Study Participant Flow Chart

Table 1. Standard Sarcoma Treatment Regimen by Type

Type	Regimen
Soft tissue sarcoma	Doxorubicin is given on days 1–3; ifosfamide and mesna are given on days 1–4 every 21 days for six cycles. Home care with IV fluids are given over four hours; mesna is given four and eight hours after ifosfamide on days 1–4; IV fluids are given over two hours for 2 L on days 5–7; pegfilgrastim is given on day 5; nadir visit occurs on day 9.
Osteosarcoma	Cycle consists of A, B, and C portions every 36 days for a total of six cycles. **Portion A:** Cisplatin and doxorubicin are given on days 1–4; home care with IV fluids occurs on days 2–4; pegfilgrastim is given on day 2; nadir visit occurs on day 9. **Portions B (day 22) and C (day 29):** High-dose methotrexate; home care with IV fluids for 18 hours; blood tests to measure methotrexate levels are taken 24, 48, and 72 hours postadministration of methotrexate; start leucovorin rescue at noon on day 2 and continue until methotrexate level is lower than 0.05 micromolar. Continue IV fluids for three days. Repeat for two cycles before surgery. Following recovery from surgery, proceed with remaining four cycles.

Note. Based on information from National Comprehensive Cancer Network, 2011a, 2011b.

proval, 17 patients who met eligibility requirements were invited to participate in the study. Inclusion criteria were patients aged 18 or older, newly diagnosed with sarcoma, scheduled to start chemotherapy no later than three weeks after the initial visit, and able to understand English. The study was described to patients, and their questions were answered. Of the 17 eligible patients, 11 agreed to participate in the study. Reasons for not participating included feeling overwhelmed and lack of interest (see Figure 1).

Procedure

After the researchers obtained institutional review board approval, they gathered signed consent from all patients. Three trained research assistants conducted the data collection. Patients were divided into two groups based on their sarcoma diagnosis and chemotherapy treatment regimen (see Table 1). Group A consisted of eight patients with soft tissue sarcoma, whereas group B consisted of three patients diagnosed with osteosarcoma. Planned measurement points for group A were every first and 10th day (SD = 3 days) for all treatments until the completion of six cycles of chemotherapy. Planned measurement points for group B were every first, 10th, and 21st day (SD = 3 days) for all treatments until the completion of treatment. Demographic data were collected at baseline, which was defined by date of starting chemotherapy.

Instruments

Outcome measures used in the current study were symptom distress and QOL. Symptom distress was measured on a continuum with the **Edmonton Symptom Assessment Scale (ESAS)**. The ESAS is a valid instrument containing nine items rated on a visual analog scale (Chang, Hwang, & Feuerman, 2000). The ESAS monitors the severity and distress of common cancer symptoms on nine subscales (pain, tired, nausea, depressed, anxious, drowsiness, appetite, well-being, and shortness of breath), all quantified continuously.

QOL was measured with the **Functional Assessment of Cancer Therapy–General (FACT-G)**. The FACT-G is a 27-item assessment tool with a five-point rating scale that measures well-being in physical, social, emotional, and functional dimensions (Cella et al., 1993). A total score is obtained by summing all items; a high score indicates good overall QOL. A major strength of the FACT-G is its minimal variability; therefore, it requires fewer respondents than instruments with large variability (Cheung, Goh, Thumboo, Khoo, & Wee, 2005). All FACT-G measures were quantified on a continuum.

Data Analysis

Demographic and clinical characteristics for all participants were summarized with descriptive statistics. Linear mixed effects models were used to assess changes in outcome from baseline to final assessment and to

Table 2. Demographic Characteristics

Characteristic	n
Gender	
Male	4
Female	7
Ethnicity	
Caucasian	8
African American	3
Type of sarcoma	
Soft tissue	8
Osteosarcoma	3
Karnofsky Performance Status at diagnosis[a]	
80	3
90	7
100	1
Tumor stage	
II	3
III	1
IV	3
Unknown	4

N = 11

[a] Scores of 80, 90, and 100 indicate that the patient can perform normal activity and work with no special care needed.

explore potential predictors of the outcome profile. All models include baseline outcome measure as a covariate. Least-squares means were used to describe outcome in the presence of other significant variables. Covariates considered in the mixed modeling were sex, race (Caucasian versus African American), age (dichotomized at the median age of 48 years), and diagnosis group (A versus B). Levene's test was used to evaluate homogeneity of variance.

Results

Sample Characteristics

Of the 11 patients who consented to participate in the study and completed the baseline questionnaires, three died. Causes of death were chemotherapy-induced cardiomyopathy, noncancer-related causes, and tumor progression after chemotherapy. Eight patients were hospitalized at least once as a result of complications related to cancer treatment. Ten patients underwent surgery, seven had tumor resection after chemotherapy, two had amputations above the knee before chemotherapy, and one had internal hemipelvectomy after chemotherapy. Three patients had tumor progression requiring second-line chemotherapy (reported in cycles 7 and 8). One patient withdrew from the study at the last cycle of chemotherapy (cycle 6) because he "didn't want to talk about it anymore." The mean age of participants was 44.5 years (SD = 13.7 years; range = 20–61). Demographic characteristics of the sample are summarized in Table 2.

Symptom Distress and Quality of Life Profiles

Fatigue as measured by the ESAS tired subscale was the most prevalent symptom reported in most cycles (see Table 3). Anxiety, well-being, appetite, drowsiness, and depression were among the most commonly reported symptoms experienced by patients at various times during their chemotherapy treatment. Mean fatigue scores increased from 4.85 at baseline to 6.33 at cycle 6. Patients who required second-line chemotherapy represented in cycle 7 (3 patients) and cycle 8 (1 patient) experienced even higher levels of fatigue, with mean scores of 7.17 at cycle 7 and 8 and at cycle 8. Table 4 provides the ranking for all symptoms as measured by the ESAS at baseline (cycle 1), midtreatment (cycle 3), and end of treatment (cycle 6). Mean scores for tiredness, nausea, depression, anxiety, drowsiness, well-being (i.e., overall physical and mental comfort), and shortness of breath increased from cycle 1 to cycle 6 (see Figure 2). Mean total ESAS scores increased from 32.3 at cycle 1 to 38.5 at cycle 6. Table 5 shows a dramatic increase in depression, anxiety, and fatigue reported by patients who received additional chemotherapy. Higher scores on the ESAS were indicative of increased symptom distress.

Lower scores on the FACT-G were indicative of diminished QOL. Table 6 demonstrates that total mean FACT-G scores decreased from 68.49 at cycle 1 to 58.75 at cycle 6 and 36 at cycle 8. Among the four dimensions measured by the FACT-G, functional well-being emerged as the lowest mean score at each chemotherapy cycle except at cycle 8. Physical dimension reported the lowest mean score (2.5) at cycle 8, followed by functional dimension (4.5); however, the authors note that by cycle 8, the representative sample reflects responses from only one patient.

Table 3. Prevalence of Top Symptoms Reported on the Edmonton Symptom Assessment Scale

Variable	$\bar{X}$	SD	Min	Max
Cycle 1 (N = 11)				
Poor well-being	4.98	2.26	1.5	8
Tired	4.85	2.8	1	9
Drowsiness	4.08	2.76	0	9
Total	32.3	15.66	10.5	56
Cycle 2 (N = 10)				
Tired	6.08	2.16	2.5	9
Poor well-being	5.2	2.19	2	9
Poor appetite	4.8	2.2	1.5	9
Total	36.78	16.49	8.5	70
Cycle 3 (N = 10)				
Tired	5.73	2.97	1	10
Poor appetite	4.67	2.24	1	8.5
Poor well-being	4.43	2.62	0	8
Total	34.03	16.4	3	68
Cycle 4 (N = 11)				
Tired	5.33	2.41	1	9
Poor well-being	4.06	1.94	1	7
Anxious	3.89	3.56	0	10
Total	30.23	15.88	5	61
Cycle 5 (N = 10)				
Tired	6.33	2.31	1.5	9
Drowsiness	5.18	2.42	0	9
Poor well-being	4.73	2.51	1	8
Total	37.3	16.91	5.5	61
Cycle 6 (N = 6)				
Tired	6.33	2.14	4	9
Poor well-being	5.17	1.72	2	7
Drowsiness	4.75	2.48	2	8.5
Anxious	4.75	3.24	1	9.5
Total	38.5	14.46	15	55
Cycle 7 (N = 3)				
Tired	7.17	0.76	6.5	8
Anxious	6.33	3.06	3	9
Depressed	5.5	2.78	3	8.5
Total	39.83	10.75	29	50.5
Cycle 8 (N = 1)				
Poor appetite	9.5	–	9.5	9.5
Tired	8	–	8	8
Depressed	8	–	8	8
Total	66	–	66	66

Max—maximum; Min—minimum

Table 4. Symptom Distress on the Edmonton Symptom Assessment Scale in Cycles 1, 3, and 6

	Cycle 1 (N = 11)		Cycle 3 (N = 10)		Cycle 6 (N = 6)	
Symptom	Rank	$\bar{X}$	Rank	$\bar{X}$	Rank	$\bar{X}$
Poor well-being	1	4.98	3	4.43	2	5.17
Tired	2	4.85	1	5.73	1	6.33
Drowsiness	3	4.08	4	4.42	3	4.75
Poor appetite	4	4.03	2	4.67	7	3.25
Anxious	5	3.85	5	3.17	3	4.75
Pain	6	3.77	7	3.07	6	3.5
Depressed	7	3.03	6	3.17	4	4
Nausea	8	1.89	8	2.37	8	3.08
Shortness of breath	9	1.82	9	2.23	5	3.67

Exploratory Analysis of Outcome Predictors

Symptom distress and QOL profiles over time were explored for differences according to treatment group and demographic variables representing age, race, and sex. Tables 7 and 8 summarize the mixed-model results in terms of parameter estimates associated with changes over time for the various subgroups of interest.

With the exception of pain, symptom distress in older patients showed an increasing trend over time, whereas symptom distress in younger patients did not show increases (tired, depressed, and anxious subscales) or decreased (appetite subscale) over time. Pain increased over time among younger patients and in women. Fatigue increased over time in Caucasians and patients with osteosarcoma but not in African Americans and patients with soft tissue sarcoma.

QOL diminished over time among older patients but not among younger patients. Total FACT-G scores diminished over time among Caucasians, women, and patients with soft tissue sarcoma. FACT-G physical well-being scores decreased over time in patients with osteosarcoma.

Symptom distress differed over time among age groups. Older participants generally demonstrated increases in symptom distress over time, whereas scores among younger participants remained stable. Total ESAS score in patients older than 48 years increased over time ($p = 0.001$), but the trend did not occur in younger patients. The following ESAS symptom scores increased over time among patients older than 48 years: fatigue ($p = 0.002$), depression ($p = 0.003$), anxiety ($p = 0.005$), and appetite ($p = 0.022$). Pain was the only symptom that demonstrated increased scores over time in patients younger than 48 years ($p = 0.03$). Therefore, the data suggest older participants may have demonstrated diminished QOL compared to younger participants. Total FACT-G score in patients older than 48 years decreased over time ($p = 0.002$), with both physical well-being ($p = 0.001$) and functional well-being ($p = 0.021$) scores decreasing over time compared to the physical and functional well-being scores of younger patients.

Race also was associated with important findings that suggest areas in need of future research. Caucasian scores for fatigue on the ESAS demonstrated increasing profiles over time ($p = 0.014$), whereas scores among African Americans did not. Total FACT-G ($p = 0.011$) as well as physical well-being ($p = 0.011$) scores decreased over time in Caucasians but not in African Americans. ESAS pain scores increased over time in women ($p = 0.002$) but not in men. Similarly, total FACT-G scores decreased over time in women ($p = 0.014$), whereas men did not demonstrate changes over time.

Diagnosis and treatment also were associated with important findings in need of further study. Patients with osteosarcoma reported increased fatigue ($p = 0.0012$) and drowsiness ($p = 0.016$), with corresponding decreases in physical well-being over time ($p = 0.014$).

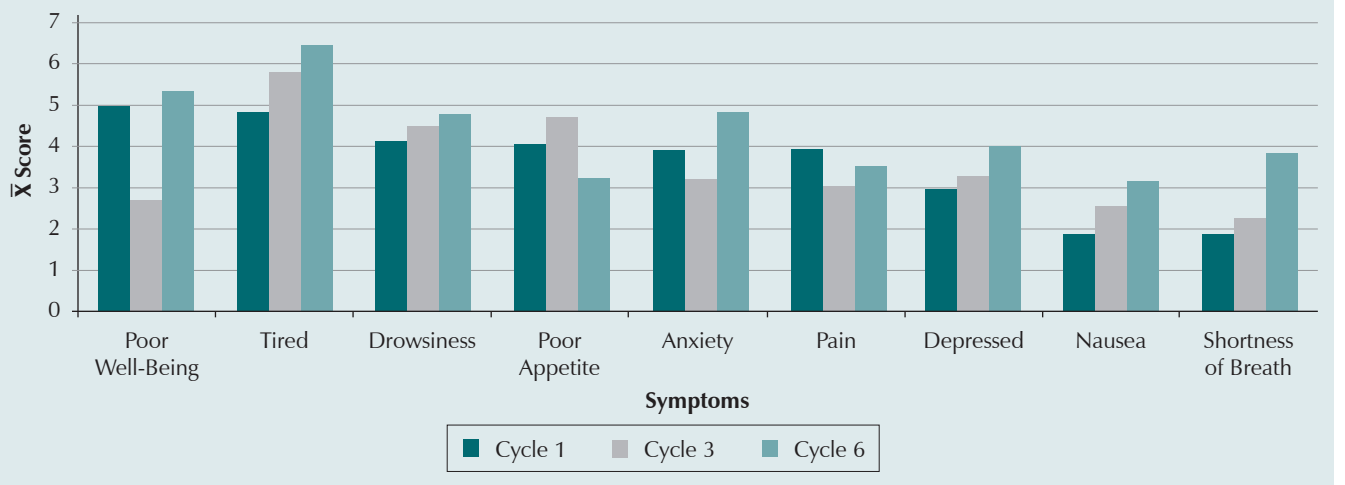

Figure 2. Mean Symptom Distress Scores in Patients With Sarcoma During Chemotherapy Cycles 1, 3, and 6

Table 5. Symptom Distress on the Edmonton Symptom Assessment Scale in Patients Who Received Second-Line Chemotherapy

	Cycle 7 (N = 3)		Cycle 8 (N = 1)	
Symptom	Rank	$\bar{X}$	Rank	$\bar{X}$
Tired	1	7.17	2	8
Anxious	2	6.33	5	6.5
Depressed	3	5.5	2	8
Poor appetite	4	5	1	9.5
Poor well-being	4	5	3	7.5
Pain	5	4.33	4	7
Drowsiness	6	4	2	8
Shortness of breath	7	1.33	2	8
Nausea	8	1.17	6	3.5

In summary, outcome profiles over time for symptom distress and QOL suggested potential differences according to age group, race, sex, and diagnosis group. Among older patients, symptoms tended to increase over time, whereas QOL tended to diminish over time. Pain was the exception among symptoms, with pain increasing over time in younger patients. Caucasian patients experienced increased fatigue and decreased total FACT-G and physical well-being scores, whereas women experienced increased levels of pain and diminished overall QOL over time. Patients with osteosarcoma demonstrated increased fatigue and drowsiness scores over time, as well as decreased physical well-being QOL scores; patients with soft tissue sarcoma experienced diminished overall QOL scores over time.

Discussion

The current study provided a comprehensive assessment of nine symptoms during the course of chemotherapy for treatment of sarcoma. Fatigue was the most prevalent and pervasive symptom at baseline and throughout the treatment. This finding is similar to other studies in sarcoma populations; Servaes et al. (2003) reported severe fatigue in 28% of patients with bone and soft tissue tumors (malignant and benign), even long after they had finished treatment ($\bar{X}$ = 3.3 years). The authors found that patients who had finished treatment recently or who had more than one surgery experienced higher levels of fatigue. In addition, another comparative study reported that bone cancer survivors had significantly higher fatigue scores than the general population (Aksnes, Hall, Jebsen, Fossa, & Dahl, 2007).

In addition, the current study's fatigue finding was similar to reports in other cancer populations undergoing aggressive chemotherapy. For example, fatigue was one of the most frequently reported symptoms in patients undergoing autologous bone marrow transplantation (Wettergren, Langius, Bjorkholm, & Bjorvell, 1997) and patients immediately after hematopoietic cell transplantation (Epstein et al., 2002), as well as in long-term survivors of stem cell transplantation (Gielissen et al., 2007; Hann et al., 1997; Hjermstad et al., 2004).

The current study found that all symptom mean scores increased significantly over time except for pain and lack of appetite. Although the mean score for lack of appetite did not change significantly over time, it was consistently reported among the three top symptoms. The finding is congruent with previous work reporting frequent loss of appetite in patients with cancer receiving high doses of chemotherapy during stem cell transplantation (Anderson et al., 2007; Epstein et al., 2002). In addition, mean symptom intensities were mild at baseline, increased gradually during the treatment at each cycle, and peaked at the last cycle of chemotherapy. The pattern of symptom change over time was demonstrated by seven of the nine symptoms assessed in the study. Anxiety, decreased well-being, lack of appetite, drowsiness, and depression were the most commonly reported symptoms throughout the course of treatment.

The current study's findings indicated that QOL scores in patients with sarcoma decreased significantly over time, with the lowest scores reported on functional well-being during most chemotherapy cycles. Similarly, a number of studies of patient with sarcoma reported reduced QOL; however, most of the studies measured patient outcomes after undergoing surgical procedures (e.g., amputation, limb salvage procedures, hemipelvectomies) rather than after chemotherapy treatments (Beck et al., 2008; Daigeler et al., 2009; Eiser, Darlington, Stride, & Grimer, 2001; Refaat, Gunnoe, Hornicek, & Mankin, 2002; Thijssens et al., 2006). According to the FACT-G, functional well-being includes the ability to work, enjoy life, accept illness, sleep well, and be content with QOL. A study of patients with extremity soft tissue sarcoma reported that restriction in participation in life roles because of functional impairment had the most significant impact on QOL (Schreiber et al., 2006). Other studies found diminished QOL in bone cancer survivors compared to the general population (Eiser et al., 2001); however, the lowest scores were on physical function rather than functional status when compared to other cancer populations (Aksnes et al., 2007; Maunsell, Pogany, Barrera, Shaw, & Speechley, 2006).

The current study's QOL findings were similar to those reported in other cancer populations receiving chemotherapy. For example, reduced QOL and functional status were found in patients with various malignancies (e.g., breast, lung, and colorectal cancers; non-Hodgkin lymphoma) after three cycles of chemotherapy (Dodd, Miaskowski, & Paul, 2001). Decreased QOL affecting physical, social, emotional, and cognitive functions was reported in patients after receiving high-dose chemotherapy and allogeneic hematopoietic cell transplantation (Epstein et al., 2002). In addition, mean scores on functional well-

being and QOL decreased over time during bone marrow transplantation (McQuellon et al., 1998).

The findings suggest that symptom distress and QOL may differ according to age, race, gender, and diagnosis. For example, symptom distress and QOL over time were worse for older patients compared to younger participants. Mor, Allen, and Malin (1994) reported a similar finding that older patients have lower functional QOL than younger patients; in the same study, they found that older patients experienced fewer psychosocial problems than the younger group. However, the current study found that pain was the only symptom that had higher scores over time in the younger population. Given that the anxiety and depression scores of younger patients did not demonstrate change over time, the increased pain scores could be explained, at least in part, by patients' perception of pain and its impact in their daily activities. Evidence exists that patients who perceived pain as interfering with their activities and enjoyment of life had significantly higher pain scores than those who did not perceive pain as an interference (Zimmerman, Story, Gaston-Johansson, & Rowles, 1996).

Table 6. Measures of Well-Being on the Functional Assessment of Cancer Therapy–General

Variable	Rank	$\bar{X}$	SD	Min	Max
Cycle 1 (N = 11)					
Functional	1	14.65	4.67	6	21.5
Emotional	2	15.8	4.34	9	22
Physical	3	17.64	5.24	9	26
Social	4	20.4	5.01	11.5	27
Total	–	68.49	16.48	36.5	88
Cycle 2 (N = 10)					
Functional	1	11.68	5.73	2	20
Emotional	2	14.73	4.8	8	21
Physical	3	15.15	6.3	3	22
Social	4	17.59	5.24	7	22.52
Total	–	59.15	18.03	20	84.02
Cycle 3 (N = 10)					
Functional	1	12.31	6.77	2.5	23
Physical	2	15.6	7.27	4	27
Emotional	3	15.77	5.26	5.5	21.33
Social	4	18.3	5.61	5.5	25
Total	–	61.98	19.49	17.5	87.52
Cycle 4 (N = 11)					
Functional	1	15.82	7.37	6	27
Physical	2	15.65	7.73	5	28
Emotional	3	16.32	5.09	5.5	23
Social	4	20.04	5.73	6.5	25
Total	–	67.83	20.95	19.5	92
Cycle 5 (N = 10)					
Functional	1	11.48	7.8	2	24
Emotional	2	14.83	5.43	6	24
Physical	3	14.87	8.14	3	26.5
Social	4	19.01	6.07	7	26
Total	–	60.19	22.47	24	93
Cycle 6 (N = 6)					
Functional	1	13.17	6.52	2	20
Physical	2	13.75	5.96	4	20
Emotional	3	14.58	4.57	9	20
Social	4	17.25	8.07	4	27
Total	–	58.75	17.51	32	81
Cycle 7 (N = 3)					
Functional	1	7.83	4.25	3.5	12
Emotional	2	13.83	1.44	13	15.5
Physical	3	14.5	3.28	11	17.5
Social	4	16.17	10.21	4.5	23.5
Total	–	52.33	14.36	36	63
Cycle 8 (N = 1)					
Physical	1	2.5	–	2.5	2.5
Functional	2	4.5	–	4.5	4.5
Emotional	3	6	–	6	6
Social	4	23	–	23	23
Total	–	36	–	36	36

Max—maximum; Min—minimum

Race and gender may be predictors of symptom distress and QOL in patients with sarcoma. Caucasians experienced more fatigue and overall decreased QOL than African Americans, particularly in the physical well-being dimension. However, the results must be interpreted cautiously given that the study sample of African Americans and Caucasians was small. In addition, women reported increasing pain scores and decreased QOL over time. Similarly, Maunsell et al. (2006) found that female survivors of childhood cancers had poorer outcomes than male survivors. When comparing gender-associated differences in QOL after allogeneic bone marrow transplantation, Heinonen et al., 2001) reported that women experienced worse QOL, emotional well-being, fatigue, and sleep disturbance than men.

Diagnosis as well as treatment may be predictors for symptom distress and QOL in patients with sarcoma. Although patients in both groups reported diminished QOL, patients with bone cancer experienced worse physical well-being, fatigue, and drowsiness than patients with soft tissue sarcoma. The current study showed a difference between the two groups despite the small sample size in the osteosarcoma group. Similarly, Maunsell et al. (2006) found that a diagnosis of bone cancer and the addition of three treatment modalities (chemotherapy, surgery, and radiation therapy) were associated with poor QOL compared to diagnoses of other childhood cancers, including soft tissue sarcoma. In sum, the cohort of patient with sarcoma in the current study underwent a combination of modality treatments including first- and second-line chemotherapy regimens and surgical procedures, which affected patients' QOL.

Limitations

The study findings should be interpreted cautiously. Sample size was a significant limitation. Given the rarity of soft tissue and bone sarcomas, studying a large

Table 7. Mixed-Model Results for Predictors of Symptom Distress and Quality of Life by Age and Ethnicity

	Age (Years)						Ethnicity					
	Younger Than 48			Older Than 48			Caucasian			African American		
Scale	Est	SE	p	Est	SE	p	Est	SE	p	Est	SE	p
ESAS												
Tired	0.022	0.138	0.869	0.48	0.15	0.002	0.285	0.114	0.014	–0.031	0.25	0.901
Pain	0.29	0.13	0.03	0.17	0.15	0.237	–	–	–	–	–	–
Depressed	–0.014	0.118	0.903	0.4	0.13	0.003	–	–	–	–	–	–
Anxious	0.05	0.095	0.607	0.299	0.104	0.005	–	–	–	–	–	–
Appetite	–0.37	0.146	0.013	0.371	0.16	0.022	–	–	–	–	–	–
Total	–0.6	0.67	0.367	2.64	0.73	0.001	–	–	–	–	–	–
FACT-G												
Physical well-being	0.003	0.35	0.993	–1.3	0.379	0.001	–0.739	0.287	0.011	0.098	0.635	0.878
Functional well-being	–0.27	0.266	0.313	–0.67	0.287	0.021	–	–	–	–	–	–
Total	–0.49	0.659	0.46	–2.286	0.703	0.002	–1.383	0.536	0.011	–1.136	1.175	0.336

ESAS—Edmonton Symptom Assessment Scale; Est—estimate; FACT-G—Functional Assessment of Cancer Therapy–General; SE—standard error
Note. Parameter estimates represent "cycle x variable" interaction term or estimates of change over time for the subgroup of interest.

cohort of patients is difficult. The rigorous nature of treatment for sarcoma also precluded some patients from being willing to participate in any additional activities, including collection of research data about their disease. Patient burden should be considered carefully when identifying research tools and study design in this population. In addition, missed or delayed cycles of chemotherapy are common in rigorous regimens such as those used to treat sarcomas and resulted in incomplete data collection. Significant findings associated with outcome profiles over time by demographic or treatment variables should be regarded as preliminary given the sample size of the study. Therefore, statistically significant study findings should be interpreted with caution and warrant further study.

Conclusions

The study findings provided new information about the experience of newly diagnosed patients with sarcoma undergoing chemotherapy. Specifically, patients reported increasing symptom distress and reduced QOL over the duration of the treatment. Fatigue was the most prevalent symptom, and QOL related to functional well-being received the lowest score over time during the treatment course.

Implications for Nursing

The authors found that conducting research in a clinical setting was challenging. The setting was a community cancer center and hospital rather than an academic

Table 8. Mixed-Model Results for Predictors of Symptom Distress and Quality of Life by Gender and Group

	Gender						Group					
	Male			Female			A (Soft Tissue Sarcoma)			B (Osteosarcoma)		
Scale	Est	SE	p	Est	SE	p	Est	SE	p	Est	SE	p
ESAS												
Tired	–	–	–	–	–	–	0.11	0.112	0.33	0.769	0.235	0.002
Pain	–0.208	0.209	0.324	0.347	0.11	0.002	–	–	–	–	–	–
Drowsy	–	–	–	–	–	–	0.022	0.127	0.865	0.651	0.267	0.016
FACT-G												
Physical well-being	–	–	–	–	–	–	–0.419	0.288	0.148	–1.533	0.609	0.014
Total	–1.146	1.048	0.277	–1.381	0.553	0.014	–1.15	0.54	0.035	–2.138	1.131	0.062

ESAS—Edmonton Symptom Assessment Scale; Est—estimate; FACT-G—Functional Assessment of Cancer Therapy–General; SE—standard error
Note. Parameter estimates represent "cycle x variable" interaction term or estimates of change over time for the subgroup of interest.

setting. The lack of an infrastructure for conducting this type of research was a barrier addressed by partnering with researchers from an affiliated university school of nursing. Practical considerations, including adding the tasks of consenting patients, data collection, and analysis to the clinical roles and responsibilities of the team, underscored the difficulty of conducting a research study without additional funding. This type of nursing research is crucial to understanding the experience of patients undergoing chemotherapy; therefore, support is needed through partnering and funding.

The study findings have clinical as well as research implications. Given that little is known about the symptom burden and QOL of patients with sarcoma during chemotherapy, the current study provided valuable information about symptom trajectory, frequently reported symptoms, and impact on QOL dimensions that patients experienced during their treatment. Oncology nurses could use the findings to provide more effective patient care by strategically directing nursing interventions to the specific needs of patient with sarcoma. For example, nurses could assess for potential age and gender differences (e.g., decreased functional status in older patients, increased psychosocial distress in younger patients and women) and implement requisite clinical interventions. Awareness of the potential for fatigue, lack of appetite, and other symptoms should help nurses incorporate proactive symptom management. If nurses are cognizant that functional well-being may be adversely affected by sarcoma treatment, referrals to physical and occupational therapy may be indicated. Proactive work with members of an interdisciplinary team including nutritionists, physical therapists, and psychologists could help to abate the effects of chemotherapy in this population and provide opportune measures to avoid significant decline in QOL.

The current pilot study provided preliminary data on distress levels and QOL in patients with sarcoma during chemotherapy treatment. Additional research is needed to confirm the current study's findings with a larger sample and to increase understanding of symptoms and QOL predictors. In addition, future research must include the evaluation of interventions directed to address the physical, emotional, social, and functional dimensions of this vulnerable population. Some studies have reported the effectiveness of psychosocial and rehabilitation interventions for patients with sarcoma (Parsons & Davis, 2004; Payne, Lundberg, Brennan, & Holland, 1997; Spears, 2008). However, more studies are needed to carefully measure patient outcomes linked to clinical interventions directed to symptom control and the multidimensionality of QOL in this patient cohort.

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