

Hosp Palliat Nurs. Author manuscript; available in PMC 2012 September 1.

Published in final edited form as:

J Hosp Palliat Nurs. 2011 September; 13(5): 288–297. doi:10.1097/NJH.0b013e31821adb2d.

Predictors of Quality of Life in Elderly Hospice Patients with Cancer

Christopher M. Garrison, MSN, ARNP, University of South Florida, College of Nursing

Janine Overcash, PhD, ARNP, and University of South Florida, College of Nursing

Susan C. McMillan, PhD, ARNP, FAAN University of South Florida, College of Nursing

Abstract

Purpose—While quality of life is the focus of care in hospices, limited research has been conducted on the quality of life of cancer patients in hospice home care. The purpose of this study was to explore the predictors of quality of life of older adults who are receiving hospice care in their homes.

Methods—A secondary analysis of data from a larger study was conducted using linear regression and including the following predictor variables: age, functional status, number of symptoms endorsed, overall symptom distress, pain intensity, and depressive symptoms. The outcome variable was quality of life.

Results—The sample consisted of 533 adults with an average age of 78.1 years (SD=7.4). A regression model that included symptom distress, number of symptoms, depression, and functional status accounted for 46% of the variance in quality of life. Pain, age, and caregiver depression did not contribute to predicting quality of life and therefore were not included in the final model.

Conclusions and Implications—Because both physical symptoms and depression are predictors of quality of life, a continued focus is needed on these factors by those providing care to older adults with cancer near the end of life.

Introduction

Approximately 83% of the people cared for by the hospices in the U.S. are over the age of 65 years, and almost 40% of these are diagnosed with some form of cancer¹ which is considered to be a disease of aging ². The focus of hospice care is improving the quality of life (QOL) of patients and families¹. Patients diagnosed with cancer who are nearing the end of life face more QOL declines as compared to those in hospice care who are not diagnosed with cancer³. Because so many hospice and palliative care patients are older adults who are diagnosed with cancer, it is important to identify some of the issues that can affect their QOL. The purpose of this study was to explore the predictors of quality of life of older adults who are receiving hospice care in their homes.

Background

Differences in Older Adults

Older patients differ from younger adults in several important respects. First, many older people live with chronic disease. The average person over the age of 75 lives with three chronic conditions and takes 4.5 prescription medications⁴. Second, patients living with chronic disease benefit from a focus on maintaining function since their condition cannot be cured⁵. Third, the elderly respond to pharmaceuticals differently than younger adults. They have atypical clinical responses and metabolize medications more slowly. The older adult is much more prone to polypharmacy, putting them at risk for interactions between multiple drugs prescribed for a variety of conditions⁶. In addition, prior studies have shown that older adults with advanced cancer report less symptom intensity than younger patients⁷.

Quality of Life

QOL is a complex construct that considers issues of physical, social, functional, spiritual, and emotional well-being, ^{7–10} and may be defined as "those aspects that make life worth living"¹¹(p. 282). As distressing symptoms increase, QOL decreases in older cancer patients at end of life ¹². Cancer patients who are receiving chemotherapy experience problems with symptom control which also have an impact on QOL ¹³. Factors such as psychological symptom distress, pain, and anxiety are associated with decreased QOL in hospice patients ^{14,15}. Problems associated with caregiver availability, depression, functional status, and age are also aspects to consider when measuring QOL.

It is important to evaluate QOL at each patient contact. Asking the patient to express QOL concerns is important because many caregivers inaccurately report distressing symptoms ^{16,17}. When assessing QOL by patient interview, better QOL is often reported at end-of-life than might have been expected ¹⁸.

Depression in Palliative Care

One dimension of QOL is emotional health. People who suffer from depression tend to experience other problems such as pain and fatigue¹⁹ which can lead to lower reported QOL. Approximately 45% of people in palliative care suffer from depression²⁰. Depression is associated with symptom distress in older cancer patients, and the total number of distressing symptoms is increased in patients who suffer from moderate clinical depression²¹. Depression not only affects the patient, but it also affects the family members and caregivers²²; thus, attention should be directed to support the family members and caregivers to manage problems such as depression²³.

Functional Status in Palliative Care

Functional Status is defined as the ability to perform basic activities that are important to maintain independence such as eating, dressing, bathing, continence, and walking²⁴. Other activities that are vital to independence are more refined activities such as the ability to cook, clean, drive, manage money, and other everyday tasks²⁵. Functional status is an important element of patient assessment in that scores predict survival in hospice patients²⁶. Depression and functional status have been shown to be related, and improvement in emotional or functional status will improve QOL²⁷.

Pain

Pain is a central component of hospice care and one of the most common problems addressed by palliative care teams²⁸. QOL, fatigue, nausea, and sleep problems are all improved when cancer pain is managed²⁹. Pain is often part of a symptom cluster in that it is

generally accompanied by feelings of reduced energy, poor nutritional intake³⁰, and sleep problems³¹. By controlling pain, other problems may also resolve that affect QOL of the patient and caregiver. Interestingly, patients with cognitive impairment report more intense pain as compared to people who are receiving hospice care and are not cognitively impaired³².

Hospice care has traditionally focused on pain assessment and management. Patients in hospice care who have been admitted with severe pain reported reduced pain as they received ongoing care³³. One study showed that approximately 70% of patients underwent a pain assessment upon admission to hospice care³⁴. Pain is also assessed by observing issues such as global health improvement, satisfaction with treatment, and physical and emotional functioning³⁵.

Age

Because cancer is a disease of aging², it is important to consider age in a QOL model. Many older people and even those aged 90 years and over, receive both curative and palliative cancer treatment with 41% receiving surgical interventions, 9% receiving chemotherapy, and 12% receiving radiation therapy³⁶. Despite the number of older adults who are diagnosed and treated with cancer, many older people are not offered hospice services. People aged 85 years and over are least likely to receive hospice care when compared to younger people³⁷.

Selection of Predictors

The selection of predictor variables was based on prior findings on QOL in hospice patients with cancer. Decline in functional status, increased number of symptoms, symptom distress, pain, depression, and social support have all been associated with QOL in hospice patients with cancer^{11,19}.

Summary

Care of the older hospice patient with cancer is a complex orchestration of assessment and intervention. Understanding how to identify and manage problems that impact QOL will aid in the care of patients and families.

Research Question

This study was designed to answer the following question: What are the predictors of quality of life in older adults with advanced cancer in home hospice care?

Methods

Design

This is a secondary analysis of data from a larger NIH-funded clinical trial of systematic assessment of cancer patients in home hospice care (5R01 NR008252). Although it was a longitudinal study, only baseline data were used for this analysis and only patients over 65 years of age were included.

Setting

This multisite study was conducted at two large hospices in the area surrounding a large, public university. Both are private, not-for-profit hospices that serve more than one county and do not compete with one another. A unique feature of this study is the research coalition formed by a group of five hospices and the university. The hospices involved in this project

are two of the five hospices that are involved in the *Center for Hospice*, *Palliative Care and End of Life Studies* at the affiliated university.

Sample

The original study sample consisted of patients and caregivers who were receiving hospice home care from one of the two involved hospices. Baseline data were available for 709 patients; 533 of these were 65 years or older and were included in this secondary analysis. Some caregiver data also were included in the analysis because of the effect the caregiver's status could have on the patient.

Instruments

Palliative Performance Scale

The purpose of the Palliative Performance Scale (PPS) is to assess the physical condition and functional status of persons receiving palliative care³⁸. The PPS is scored from 0–100% at 10% increments. Data collectors interviewed patients to determine PPS scores. Validity and reliability of the instrument were evaluated³⁸. Reliability was evaluated in our earlier work. Inter-rater reliability between two raters was very strong (r=.95)¹⁹.

Short Portable Mental Status Questionnaire

The 10-item Short Portable Mental Status Questionnaire (SPMSQ) was used as a screening instrument for cognitive impairment in both patients and caregivers. While the SPMSQ is a brief instrument that may lack sensitivity to mild cognitive impairment, it has demonstrated validity in detecting moderate-to-severe cognitive impairment^{39,40}.

Memorial Symptom Assessment Scale

Symptom distress has been defined as how bothered patients were by symptoms^{41,42}. Earlier investigators have emphasized the need to differentiate symptom distress from symptom intensity and frequency^{41–44}. The Memorial Symptom Assessment Scale (MSAS) was designed to differentiate between intensity and distress from symptoms. The original MSAS has 33 items reflecting symptoms commonly associated with cancer. Separate five-point (0–4) Likert-type scales measure these dimensions: (1) severity of the symptom; and (2) the distress it produces. The items are scored by summing the items in each subscale (i.e., physical, psychological). The higher the score, the more severe or distressing the cluster of symptoms is for the patient⁴⁵. Validity and reliability data have been strong when the tool was used with persons receiving active cancer therapy.

For this project, a revised MSAS was used that had been previously developed and used with hospice patients with cancer to increase appropriateness of items and to decrease the burden on very ill patients. A group of hospice experts including researchers reviewed the items and removed those that seemed least likely to be problematic for hospice patients; for example, alopecia is a side effect seen with chemotherapy but seldom in palliative care. In addition, a constipation item was added because it had been omitted from earlier versions. A total of 25 items was included in the revised version of the MSAS. Items are rated from 0 to 4 for severity and from 0 to 4 for distress, resulting in subscale scores for intensity and distress that range from 0–100 for each. Global distress scores for this study reflect the summed distress scores for all items^{46,47}.

Hospice Quality of Life Index-14

The Hospice Quality of Life Index-14 (HQLI-14) was used as a general assessment of patient QOL. It is a shortened version of the previously used and validated Hospice Quality

of Life Index¹¹. The HQLI includes three aspects of overall QOL: psychophysiological well-being; functional well-being; and social/spiritual well-being¹¹. The last item on the scale asks about intensity of pain at its worst, but is not added into the total score. Evidence of validity for the original was provided by the ability of the HQLI to differentiate between hospice patients and apparently healthy controls using both discriminate analysis (p=.00) and comparison of means (p=.00). The finding that HQLI scores correlated at the expected level (r=.26; p=.00) with functional status scores provides further evidence of validity. Finally, factor analysis confirmed the factor structure of the HQLI. Reliability of the HQLI was provided by generation of coefficient alphas for both total scale scores and subscale scores. Subscale alphas all were .84 and the total scale alpha was high for both cancer (r=. 88) and AIDS (r=.93) patients⁴⁸.

The shortened version (HQLI-14) is designed for repeated clinical use with hospice patients. Each item is scored on a 0 to 10 scale with 10 being the most favorable response; item scores are added to obtain a total scale score ranging from 0 (worst QOL) to 140 (best QOL).

As part of the parent NIH-funded trial, construct validity of the short form was evaluated by correlation with the original HQLI. The correlation between total scale scores was very strong (r=.94; r=.000). Correlations between the original subscales and the shortened subscales were as follows: psychophysiological well-being (r=.90, r=.000), functional well-being (r=.96, p=.000), and social/spiritual well-being (r=.89, p=.000). These strong correlations provide excellent evidence of the validity of the shortened HQLI. Reliability of the short form was estimated using Cronbach's alpha. Alpha for the total tool was strong (r=.77). For the subscales, the alphas were as follows: psychophysiological (r=.68), functional (r=.72), and social/spiritual (r=.82). It is to be expected that shorter scales with fewer items have lower alpha coefficients. Thus, these results are acceptable.

Brief Pain Inventory

The purpose of the Brief Pain Inventory (BPI) is to assess pain in cancer and non-cancer patients by using a self-administered questionnaire that measures pain at its worst, its least, average, and current level^{49,50}. Only present pain intensity was used in this analysis. The instrument can be self administered if the patient is able to do so or completed by the interviewer with the patient answering the questions. The majority of the instrument is scored on a 0–10 numeric rating scale for level of pain.

Center for Epidemiological Studies - Depression Short Form

The Center for Epidemiological Studies – Depression (CES-D) scale⁵¹ is a widely used scale that has proven useful both as a screening instrument to detect individuals at risk for depression and to measure the symptoms of depression. The CES-D is widely used in research on depression, has been translated into multiple languages, and has impressive reliability, validity, sensitivity, and specificity⁵².

A shorter version of the CES-D (sometimes referred to as the "Boston short form") has been validated for use in clinical settings and large-scale survey research projects. The CES-D SF has been developed to balance ease of administration and psychometric concerns. Items are scored as either present or absent, rather than rated for frequency as with the full CES-D. Results of reliability testing showed strong internal consistency reliability (Cronbach's alpha =.92) for this short form, and very good test-retest reliability (r=.83; p=.00). Correlation of the short form and full CES-D was .88, suggesting that the short form is highly correlated with the lengthier and more widely validated full version⁵³.

Procedures

Approvals

The study was approved by each of the two involved hospices and the Institutional Review Board of the University. Interdisciplinary teams in each of the hospices were identified that provided homecare.

Patients and caregiver dyads from these teams were approached by the Research Assistants (RAs), consisting of an RN and a social worker team in each hospice. The RA teams contacted caregivers to arrange visits during which the study was explained, consent of both patient and caregiver obtained, and the mental status of the patient and caregiver assessed with the SPMSQ. Patients who did not pass screening were dropped from the study. About 2% of caregivers in the study failed this screening; they also were dropped from the study and the hospice was notified. Baseline data were collected from dyads if both met eligibility criteria.

Data Analysis

Data was analyzed using SPSSR version 18 statistical software (IBM, Somers, NY). Bivariate correlations were computed for the potential predictor variables and the outcome variable of interest. Caregiver depression was not significantly correlated with patient QOL (r=-.055, p=.233), so it was not entered into the initial model. All other hypothesized predictors were significantly correlated with QOL (see table 1). Stepwise linear regression was used to further examine the relationship between the predictor variables and QOL. We made no a priori assumptions about which predictors would contribute to the model so the stepwise method was chosen with backward entry of predictors.

Results

Sample

The sample of 533 hospice patients with cancer had a mean age of 78.1 years (SD=7.4) and were primarily married (Table 2). The majority of caregivers (63%) were spouses. The most common type of cancer, by far, was lung (36.2%) followed by pancreas (9.4%) and colon (7.3%). The vast majority of the sample (97%) was white.

Descriptive Results

Means and standard deviations for the measures included in the study were calculated (Table 3). Functional performance measured by the PPS was low at 56.5 (SD=10.8). Patient and caregiver depression means were similar at 2.8. An average of 9.6 symptoms was endorsed by patients; however, their global distress score was low at 19.9 (SD=13.6). Present pain ratings from the BPI for the first site of pain mentioned was also low at 1.6 (SD=2.4). With a possible range of 0–140, QOL scores were relatively high at 103 (SD=17.2).

Regression

Bivariate correlations were calculated among the study variables. Significant relationships were found between QOL scores and functional status, patient depression, number of symptoms, symptom distress, and pain intensity (Table 1).

The following predictors were entered in the initial model: pain scale score, patient age, global symptom distress as measured by the MSAS, number of symptoms, patient depression scale score as measured by the CES-D, and functional status as measured by the PPS. The initial regression model accounted for 46% of the variance in QOL score, F(6,

489) = 70.323, p = .00. In this model neither pain intensity score (t= -1.903, p = .058) nor age (t = 1.669, p = .096) had significant partial effects in the model, so a second regression model was run without these predictors. The final model using global distress, number of symptoms, patient depression score, and functional status accounted for 46% of the variance in QOL scores, F(4, 492) = 103.092, p = .00. The full regression is detailed in Table 4.

Assessment of the Model

The model was assessed to ensure that all assumptions for linear regression were met. All predictor variables were quantitative and continuous. The Durbin-Watson statistic was 1.897 confirming independence of error. The data were assessed for multicollinearity. None of the predictors correlated above the level of .90. The variance inflation factor (VIF) was run as a collinearity diagnostic. VIF for predictors ranged from 1.019 to 3.134 and tolerance statistics ranged from .319 to .981 indicating that excessive collinearity was not a significant problem. Casewise diagnostics were performed to assess for the influence of outliers on the model. Only one case of 497 had a standardized residual more than three standard deviations from the mean and 19 of 497 cases or 3.8% of cases had standardized residuals more than two standard deviations from the mean. Standardized residuals were plotted against standardized predicting values. The plot supports the assumptions of homogeneity of variances and linearity. A normally distributed histogram and linear P-P plot support that residuals are normally distributed.

Discussion

Sample

The sample size was dictated by the original clinical trial and provided a sizable sample for conducting this analysis with only patients over 65 years. The fact that most were married is an artifact of the study; patients could only be in the study if they had family caregivers. Thus, single and widowed patients were more likely to be excluded. The very low representation of minorities in the sample is a limitation of the study; available patients were included, and relatively few minority patients are receiving services from these two hospices. Both hospices strive to reach underserved minorities, but accepting the hospice benefit from Medicare is voluntary, and minority patients may not choose it. The fact that the most common cancer seen in the sample was lung is consistent with mortality statistics in this country. Lung cancer is a very common cancer and is the one most likely to cause death⁵⁴.

Descriptive Results

Functional performance (PPS) scores were low with a mean in the 50's. This is to be expected in a group of hospice patients. However, this score has a restricted range because patients with scores lower than 40 were systematically excluded from the original study. Thus, results may be biased in some unknown ways by exclusion of lower-functioning elders.

Both patients and caregivers reported approximately three depressive symptoms out of the list of 10. This score is not as revealing as the numbers who endorsed four or more symptoms. In this sample, 23.5% of patients and 22.5% of caregivers reported scores higher than 4. A score of 4 has been correlated with clinical depression in earlier studies⁵². Thus, depression and depressive symptoms is an issue that deserves the hospice team's attention.

Patients had multiple symptoms, with the average patient reporting almost 10 symptoms. This supports earlier studies ^{12,19,21} and points to the need for hospice staff to focus on multiple symptoms simultaneously, as a way to help support overall QOL. Both global

symptom distress and present pain intensity were low and QOL scores were high. This is consistent with earlier studies of older cancer patients who typically report less symptom intensity and better overall QOL⁵⁵. It is not clear why older patients have lower symptom intensity. It may be that there is a diminution of sensation so that physical symptoms actually do not cause as much discomfort. It also could be that older cancer patients have different expectations and life experiences so that they take symptoms in stride more than younger patients might. Further study into this area seems warranted.

Regression

The significant correlations found between QOL and other patient variables (functional status, depressive symptoms, number of symptoms, global symptoms distress, and pain intensity) support findings of earlier studies^{14,15}. However, when these predictors were entered into the model, pain intensity and age were not found to have significant partial effects and were removed.

There is potential overlap between the predictors and the outcome of QOL that may explain some of predictive power of the model; however, prior research has shown that QOL is a multi-faceted concept that can be influenced by a combination of factors and the complex interplay between physical, psychosocial, and functional variables¹¹. For example, depression may impact how an individual experiences their physical symptoms and functional decline. It is likely that QOL is a construct that is composed of more than the sum of its parts. It therefore appropriate to evaluate predictors using a regression model, rather than by simple correlations, to better capture the interplay between the various factors underlying QOL.

The purpose of this secondary analysis was to explore what factors predict QOL in older adult hospice patients with cancer. Several interesting findings emerged from this analysis. In this sample, caregiver depression scores, pain intensity, and age did not predict patient QOL. The mean pain intensity score was relatively low at 1.6 on a 0–10 scale indicating that pain was relatively well-controlled. It is possible that being in hospice care resulted in improved pain management, although these data were collected within 24–72 hours of hospice admission. The findings that symptom distress, number of symptoms, and functional status impacted QOL are consistent with prior findings in the literature ^{12,19, 21}. It is not clear what impact this restriction of range might have had on these regression results. Number of symptoms and symptom distress both contributed separately to QOL. In addition, patient depression scores uniquely contributed to predicted QOL as much as symptom distress and the number of symptoms.

Clinical Implications

Findings of this study have implications for hospice professionals in terms of patient assessment and care planning. Completing a thorough symptom assessment, including assessing for a wide range of possible symptoms, will be important to plan individualized care that maximizes QOL. In addition, a focus on the level of distress caused by symptoms also seems warranted. Current practice focuses on symptom intensity; however, because symptom distress was shown to be a separate predictor of QOL, it deserves attention by the health care team. It also will be important for the hospice team to address psychosocial as well as physical concerns.

Functional decline has been associated with lower QOL in community dwelling older adults⁵⁶. Evaluating function in elderly hospice patients with cancer is complicated by the interplay between existing chronic conditions and the terminal diagnosis. In addition, functional decline in an older adult may be a manifestation of a readily treatable condition

such as a urinary tract infection or an adverse drug reaction rather than progression of their malignancy. The hospice team should incorporate functional assessment into routine evaluation of older adult clients. When evaluating symptoms, in addition to assessing the intensity and distress caused by the symptom, the impact on function needs to be considered.

Depression is prevalent in seriously ill older adults, is often unrecognized or under-treated, and results in significant declines in QOL^{57, 58}. Depression in older adults can present atypically and older adults may be more likely to deny psychiatric symptoms⁷. The hospice team should incorporate assessment for depression into on-going patient evaluation. It is recommended that assessment for depression in older adults be done with a screening instrument that has been validated for use with this population such as the CES-D or the Geriatric Depression Scale (GDS) ^{59, 60}. On-going assessment for depression resulted in improved QOL among hospice patients with cancer ⁶¹.

Recommendations for clinicians from this study for the care of older adults with cancer in home hospice include the following:

- When assessing symptoms, assess not only for the presence and intensity of symptoms, but also for the degree of distress that the symptom is causing the patient.
- Assess for the impact of symptoms on the patient's functional abilities.
- When a patient experiences functional decline look for correctable problems such as infections or adverse drug reactions.
- Incorporate depression screening, using a validated tool, into on-going patient assessment.

Limitations and Implications for Future Research

There are several limitations of this analysis. First, we were limited to the variables assessed in the original trial. There may be other important predictors of QOL in older adults that were not included in this analysis. Future research should attempt to identify other predictors. Findings from a cross-sectional study need to be interpreted cautiously because of the inability to control for confounding variables. Causation cannot be established due to the use of a non-experimental design. The sample was limited to hospice patients from a single region in one state and was overwhelmingly white. It would be helpful to be able to replicate these findings in a multi-site study with a more diverse sample. The findings from this study could be used to identify targets for a controlled trial of interventions to promote QOL in older adult cancer patients in hospice.

Conclusions

Study results suggest that symptom distress, number of symptoms experienced, depression, and functional status are predictors of quality of life in older patients with cancer receiving hospice home care. Hospice interdisciplinary teams should focus on the symptom experience, including number of symptoms and the distress they cause, as well as management of depression. Further research with this vulnerable population is needed.

Acknowledgments

The support of the National Institute for Nursing Research (5R01 NR008252) at the National Institutes of Health is gratefully acknowledged.

References

 National Hospice and Palliative Care Organization (NHPCO). NHPCO Facts and Figures: Hospice Care in America: 2009. Alexandria, VA: NHPCO; 2009.

- Altekruse, SF.; Kosary, CL.; Krapcho, M., et al. [Accessed December 19, 2010] SEER Cancer Statistics Review, 1975–2007. 2010. Available at http://seer.cancer.gov/csr/1975_2007/index.html
- 3. Downey L, Engelberg RA. Quality-of-life trajectories at the end of life: assessments over time by patients with and without cancer. J Am Geriatr Soc. 2010; 58:472–479. [PubMed: 20398115]
- 4. Kovner CT, Mezey M, Harrington C. Who cares for older adults? Workforce implications of an aging society. Health Aff. 2002; 21:78–89.
- Quinn ME, Berding C, Daniels E, Gerlach, et al. Shifting Paradigms: Teaching Gerontological Nursing from a New Perspective. J Gerontol Nurs. 2004; 30:21–27. [PubMed: 14753055]
- Scott-Tilley D, Marshall-Gray P, Valadez A, Green A. Integrating long-term care concepts into baccalaureate nursing education: The road to quality geriatric health care. J Nurs Educ. 2005; 44:286–290. [PubMed: 16021808]
- 7. Thompson GN, Chochinov HM. Reducing the potential for suffering in older adults with advanced cancer. Palliat Support Care. 2010; 8:83–93. [PubMed: 20163764]
- 8. Cella DF, Tulsky DS, Gray G, et al. The functional assessment of cancer therapy scale: development and validation of the general measure. J Clin Oncol. 1993; 11:570–579. [PubMed: 8445433]
- 9. Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. Quality of life in breast cancer. Part II: Psychological and spiritual well-being. Cancer Nurs. 1998; 21:1–9. [PubMed: 9494225]
- 10. Overcash JA. Using narrative research to understand the quality of life of older women with breast cancer. Oncol Nurs Forum. 2004; 31:1153–1159. [PubMed: 15547638]
- 11. McMillan S, Weitzner M. Quality of life in cancer patients: A revised hospice index. Cancer Pract. 1998; 6:282–288. [PubMed: 9767348]
- 12. Buck HG, Overcash J, McMillan SC. The geriatric cancer experience at the end of life: testing an adapted model. Oncol Nurs Forum. 2009; 36:664–673. [PubMed: 19887354]
- 13. Schonwetter RS, Roscoe LA, Nwosu M, Zilka B, Kim S. Quality of life and symptom control in hospice patients with cancer receiving chemotherapy. J Palliat Med. 2006; 9:638–645. [PubMed: 16752969]
- 14. Kutner JS, Bryant LL, Beaty BL, Fairclough DL. Time course and characteristics of symptom distress and quality of life at the end of life. J Pain Symptom Manage. 2007; 34:227–236. [PubMed: 17572055]
- 15. Siegert RJ, Gao W, Walkey FH, Higginson IJ. Psychological well-being and quality of care: a factor-analytic examination of the palliative care outcome scale. J Pain Symptom Manage. 2010; 40:67–74. [PubMed: 20471782]
- 16. Kurtz ME, Kurtz JC, Given CC, Given B. Concordance of cancer patient and caregiver symptom reports. Cancer Pract. 1996; 4:185–190. [PubMed: 8900759]
- 17. McMillan SC, Moody LE. Hospice patient and caregiver congruence in reporting patients' symptom intensity. Cancer Nurs. 2003; 26:113–118. [PubMed: 12660560]
- 18. Diehr P, Lafferty WE, Patrick DL, Downey L, Devlin SM, Standish LJ. Quality of life at the end of life. Health Qual Life Outcomes. 2007; 5:51. [PubMed: 17683554]
- 19. McMillan SC, Small BJ. Symptom distress and quality of life in patients with cancer newly admitted to hospice home care. Oncol Nurs Forum. 2002; 29:1421–1428. [PubMed: 12432413]
- O'Connor M, White K, Kristjanson LJ, Cousins K, Wilkes L. The prevalence of anxiety and depression in palliative care patients with cancer in Western Australia and New South Wales. Med J Aust. 2010; 193:S44–47. [PubMed: 21542445]
- 21. McMillan SC, Rivera H. The relationship between depression symptoms and symptom distress in patients with cancer newly admitted to hospice home care. J Hosp Palliat Nurs. 2009; 11:41–44.
- 22. Hernandez AM, Bigatti SM. Depression among older Mexican American caregivers. Cultur Divers Ethnic Minor Psychol. 2010; 16:50–58. [PubMed: 20099964]

23. Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. J Gerontol B Psychol Sci Soc Sci. 2009; 64:788–798. [PubMed: 19318470]

- 24. Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. Gerontologist. 1970; 10:20–30. [PubMed: 5420677]
- 25. Lawton M, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969; 9:179–186. [PubMed: 5349366]
- 26. Weng LC, Huang HL, Wilkie DJ, Hoenig, et al. Predicting survival with the Palliative Performance Scale in a minority-serving hospice and palliative care program. J Pain Symptom Manage. 2009; 37:642–648. [PubMed: 18823751]
- 27. Helvik AS, Engedal K, Selbaek G. The quality of life and factors associated with it in the medically hospitalised elderly. Aging Ment Health. 2010; 14:861–869. [PubMed: 20737319]
- 28. Dhillon N, Kopetz S, Pei BL, Fabbro ED, Zhang T, Bruera E. Clinical findings of a palliative care consultation team at a comprehensive cancer center. J Palliat Med. 2008; 11:191–197. [PubMed: 18333733]
- 29. Park KU. Assessment of change of quality of life in terminally ill patients under cancer pain management using the EORTC Core Quality of Life Questionnaire (QLQ-C30) in a Korean sample. Oncology. 2008; 74 (Suppl 1):7–12. [PubMed: 18758191]
- 30. Tsai JS, Wu CH, Chiu TY, Chen CY. Significance of symptom clustering in palliative care of advanced cancer patients. J Pain Symptom Manage. 2010; 39:655–662. [PubMed: 20226623]
- 31. Given BA, Given CW, Sikorskii A, Hadar N. Symptom clusters and physical function for patients receiving chemotherapy. Semin Oncol Nurs. 2007; 23:121–126. [PubMed: 17512439]
- 32. Allen RS, Haley WE, Small BJ, McMillan SC. Pain reports by older hospice cancer patients and family caregivers: the role of cognitive functioning. Gerontologist. 2002; 42:507–514. [PubMed: 12145378]
- 33. Payne S, Froggatt K, O'Shea E, et al. Improving palliative and end-of-life care for older people in Ireland: a new model and framework for institutional care. J Palliat Care. 2009; 25:218–226. [PubMed: 19824284]
- 34. Herr K, Titler M, Fine P, et al. Assessing and treating pain in hospices: current state of evidence-based practices. J Pain Symptom Manage. 2010; 39:803–819. [PubMed: 20471542]
- 35. Miaskowski C. Outcome measures to evaluate the effectiveness of pain management in older adults with cancer. Oncol Nurs Forum. 2010; 37 (Suppl):27–32. [PubMed: 20797940]
- 36. Extermann M, Crane EJ, Boulware D. Cancer in nonagenarians: profile, treatments and outcomes. Crit Rev Oncol Hematol. 2010; 75:160–164. [PubMed: 20656211]
- 37. Abarshi E, Echteld MA, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. The oldest old and GP end-of-life care in the Dutch community: a nationwide study. Age Ageing. 2010; 39:716–722. [PubMed: 20817932]
- 38. Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): A new tool. J Palliat Care. 1996; 12:5–11. [PubMed: 8857241]
- MacNeil, SE.; Lichtenberg, PA. Screening instruments and brief batteries for assessment of dementia. In: Lichtenberg, PA., editor. Handbook of assessment in clinical gerontology. New York: John Wiley; 1999. p. 417-441.
- 40. Zarit, S.; Zarit, J. Mental disorders in older adults: Fundamentals of assessment and treatment. New York: Guilford Press; 1998.
- 41. Chiou CP. Development and psychometric assessment of the Physical Symptom Distress Scale. J Pain Symptom Manage. 1998; 16:87–95. [PubMed: 9737099]
- 42. Rhodes VA, McDaniel RW, Matthews CA. Hospice patients' and nurses' perceptions of self-care deficits based on symptom experience. Cancer Nurs. 1998; 21:312–19. [PubMed: 9775481]
- 43. McClement S, Woodgate R, Degner L. Symptom distress in adult patients with cancer. Cancer Nurs. 1997; 20:236–43. [PubMed: 9265809]
- 44. Tishelman C, Degner L. Measuring symptom distress in patients with lung cancer. Cancer Nurs. 2000; 23:83–90.

45. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer. 1994; 30A:1326–1336. [PubMed: 7999421]

- 46. McMillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. Cancer. 2006; 106:214–222. [PubMed: 16329131]
- 47. McMillan SC, Small BJ. Using the COPE intervention for family caregivers to improve patients' symptoms: A clinical trial. Oncol Nurs Forum. 2007; 34:313–321. [PubMed: 17573295]
- 48. McMillan SC, Mahon M. Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index. Qual Life Res. 1994; 3:437–447. [PubMed: 7866362]
- 49. Daut RL, Cleeland CS, Flaner RC. Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. Pain. 1983; 17:197–210. [PubMed: 6646795]
- McCormack JP, Li R, Zarowny D. Inadequate treatment of pain in ambulatory patients. Clin J Pain. 1993; 9:279–283. [PubMed: 8118093]
- 51. Radloff LS. The CES-D scale: A self report depression scale for research in the general population. Appl Psychol Meas. 1977; 1:385–401.
- 52. Lewinsohn PM, Seeley JR, Roberts RE, Allen NB. Center for Epidemiological Studies-Depression Scale (CES-D) as a screening instrument for depression among community-residing older adults. Psychol Aging. 1997; 12:277–287. [PubMed: 9189988]
- Irwin M, Artin KH, Oxman MN. Screening for depression in the older adult: Criterion validity of the 10-item Center for Epidemiological Studies Depression Scale. Arch Intern Med. 1999; 159:1701–1704. [PubMed: 10448771]
- 54. American Cancer Society. Cancer Facts and Figures 2010. Atlanta, GA: American Cancer Society; 2010.
- 55. McMillan SC. The relationship between age and intensity of cancer-related symptoms. Oncol Nurs Forum. 1989; 16:237–241. [PubMed: 2928272]
- 56. White SM, Wojcicki TR, McAuley E. Physical activity and quality of life in community dwelling older adults. Health Qual Life Outcomes. 2009:7. [PubMed: 19193211]
- 57. Amelia EJ. Geriatrics and palliative care: Collaboration for quality of life until death. J Hosp Palliat Nurs. 2003; 5:40–48.
- 58. Bishop TF, Morrison RS. Geriatric palliative care-part I: Pain and symptom management. Cl Geriatr. 2007; 15:25–32.
- Gellis ZD. Assessment of a brief CES-D measure for depression in homebound medically ill older adults. J Gerontol Soc Work. 2010; 53:289–303. [PubMed: 20461617]
- 60. Kurlowicz, L.; Greenberg, SA. [Accessed February 26, 2011] The Geriatric Depression Scale (GDS). 2007. Available at http://consultgerirn.org/uploads/File/trythis/try_this_4.pdf
- 61. McMillan SC, Small BJ, Haley WE. Improving hospice outcomes through systematic assessment: A clinical trial. Cancer Nursing. (In Press).

Table 1

Garrison et al.

Correlations Among Study Variables

PPS PPS r 096 081 046 103 032 036 .174 p .027 .061 .293 .019 .469 .408 .000 P. CES-D . .076 .421 .451 .185 .045 .501 .408 .000 r .	PPS	Patient CES-D	Caregiver CES-D	Number of Symptoms	Global Distress	Pain Intensity	Age	HQLI
ES-D 096 081 046 103 032 032 032 033 032	PPS							
ES-D 523 601 523 619 449 440 440 481 <td></td> <td>960'-</td> <td>081</td> <td>046</td> <td>103</td> <td>032</td> <td>036</td> <td>.174</td>		960'-	081	046	103	032	036	.174
ES-D 530 521 518 530 531 1096 076 421 451 .185 -045 1037 . 082 000 000 .000 .301 1525 . . .042 .046 .056 .006 .007 .204 1041 056 .036 .008 .008 .008 .009 .009 .006 .	р	.027	.061	.293	.019	.469	.408	000
ES-D C976 421 451 451 .185 046 .002 .002 .000 .000 .001 .301 .525 .082 .000 .000 .001 .301 .081	и	525	530	521	518	530	531	499
-096 - 076 - 421 - 451 - 451 - 185 - 0.04 525 - 082 - 000 - 000 - 000 - 301 EE-D - 681 - 076 - 076 - 076 - 076 - 081 - 076 - 076 - 076 - 076 - 076 - 081 - 082 - 076 - 076 - 076 - 076 - 081 - 082 - 076 - 076 - 076 - 076 - 082 - 082 - 082 - 076 - 076 - 076 - 083 - 084 - 084 - 082 - 082 - 082 - 083 - 084 - 084 - 082 - 082 - 082 - 084 - 084 - 084 - 082 - 082 - 082 - 084 - 084 - 084 - 084 - 084 - 084 - 085 - 084 - 084 - 084 - 084 - 084 - 084 - 085 - 084 - 084 - 084 - 08	Pt. CES-D							
523 .082 .000 .000 .000 .301 EE-D .523 .517 .514 .525 .526 EE-D .081 .524 .525 .526 .526 .526 .081 .082 .284 .412 .821 .523 .213 .046 .421 .024 .412 .821 .521 .521 .522 .046 .421 .026 .204 .020 .021 .522 .213 .222 .037 .046 .204 .020 .020 .000		1	970.	.421	.451	.185	045	507
EB-D 515 517 514 525 526			.082	000.	000.	000.	.301	.000
E.B.D CEAD 056 .036 .056 .056 .056 .056 .056 .056 .056 .056 .056 .056 .056 .057 .051 .051 .051 .051 .051 .051 .052 .213 .213 .052 .213 .213 .213 .213 .214 .252			525	517	514	525	526	500
-081 .076 056 056 054 054 054 054 054 054 054 054 054 054 054 053 013 053 013 013 013 013 014 015	CG CES-D							
.061 .082 .204 .412 .882 .213 .304 .525 .521 .531 .532 .046 .421 .056 .204 .226 .226 .293 .000 .204 .204 .000 .000 .513 .451 .036 .226 .226 .000 .019 .000 .412 .000 .000 .000 .000 .183 .006 .252 .238 .179 .017 .469 .000 .852 .000 .000 .000 .000 .304 .204 .204 .213 .114 .114 .114 .408 .000 .252 .200 .000 .114 .114 .31 .213 .214 .214 .214 .114 .114 .408 .321 .232 .114 .114 .114 .114 .114 .408 .321 .322 .323		.076	1	.056	.036	008	054	055
530 525 521 518 518 518 518 518 518 518 518 518 518 519 520 <td></td> <td>.082</td> <td></td> <td>.204</td> <td>.412</td> <td>.852</td> <td>.213</td> <td>.223</td>		.082		.204	.412	.852	.213	.223
-046 .421 .056 - .820 .252 - .206 .293 .000 .204 .000 .000 .000 .204 .000 .103 .451 .036 .820 - .238 .1.79 .103 .000 .412 .000 . .000 .000 .183 .186 .252 .238 .179 .017 .469 .000 .852 .000 .000 .017 .104 .036 .046 .052 .238 .179 .107 .107 .408 .000 .252 .206 .000 .017 .104 .036 .046 .056 .056 .179 .104 .408 .301 .213 .210 .408 .301 .213 .408 .301 .302		525		521	518	531	532	499
-046 -421 .056 . 820 . 250 . 206 .293 .000 . 201 . 600 . 600 . 600 .103 . 451 . 626 . 626 . 626 .103 . 451 . 636 . 626 . 626 .103 . 451 . 600 . 600 . 600 . 600 .134 . 600 . 600 . 600 . 600 . 600 . 600 . 600 . 600 . 600 . 600 . 600 . 794 . 600 . 600 . 600 . 600 . 600 . 825 . 626 . 626 . 610 . 610 . 610 . 836 . 600 . 600 . 600 . 610 . 610 . 836 . 825 . 626 . 610 . 610 . 610 . 831 . 826 . 827 . 828 . 610 . 610 . 848 . 840 . 600 . 600 . 610 . 610 . 848 . 840	# Symptoms							
231 500 204 .000 .000 .000 .000 .001 .001 .223 .223 .002 -1403 .002 .003 .003 .003 .003 .000 .000 518 .185 .008 .252 .238 .179 .017 469 .000 .852 .000 .000 .017 .104 530 .248 .048 .250 .218 .118 .1104 .1104 408 .024 .026 .020 .000 .000 .1104 .1104 408 .301 .213 .200 .200 .1104 .1104 .1104 408 .301 .213 .000 .000 .017 .1104 .1104 408 .301 .312 .232 .313 .000 .017 .1104 531 .325 .332 .332 .312 .313 .313 .314 .314 .314 .314 .314 .314 .314 .314 .314 .314 .314 .314		.421	.056	•	.820	.252	206	596
521 517 521 519 521 522 518		000.	.204		000.	000.	000	000
sss sss -103 .820 238 179 .019 .000 .412 .000 .000 .032 .183 .213 .213 .210 .032 .185 .000 .000 .000 .001 .469 .000 .852 .000 .000 .017 .530 .231 .210 .210 .210 .210 .036 .045 .054 .104 .104 .104 .104 .408 .301 .213 .000 .017 .104 104 .408 .301 .213 .000 .017 104 .408 .301 .213 .000 .017 .31 .32 .32 .31		517	521		519	521	522	500
.103 .451 .036 .820 - .238 - .179 .019 .412 .000 .000 .000 .000 .518 .194 .032 .185 .008 .252 .000 .000 .104 .469 .036 .231 .210 .213 .117 .213 .036 .045 .056 .179 .1104 .408 .301 .213 .408 .301 .213 .408 .301 .213	Distress							
.019 .000 .412 .000 .000 .000 .000 .000 .000 .000 .000 .000 .000 .000 .010 .469 .000 .852 .000 .000 .017 .017 .530 .035 .031 .226 .179 .104 .232 .036 .036 .037 .104 .104 .104 .232 .408 .301 .213 .000 .017 .104 104 .408 .301 .322 .332 .312 .313 104 104 .408 .301 .302 .313 .302 .313 104 104 .408 .301 .302 .313 .314 104		.451	.036	.820	1	.238	179	765
518 514 518 519 519 519 519 519 519 519 519 519 519 519 510 <td></td> <td>000</td> <td>.412</td> <td>000.</td> <td></td> <td>000.</td> <td>000</td> <td>.000</td>		000	.412	000.		000.	000	.000
-032 .185 008 .252 .238 104 .469 .000 .852 .000 .007 .017 530 525 531 521 518 .177 .036 054 206 179 104 - .408 .301 .213 .000 .017 - .531 .525 .519 .532 .317		514	518	519		518	519	498
032 .185 008 .252 .238 104 .469 .000 .852 .000 .000 .017 .530 .231 .218 .218 .213 .232 036 045 054 104 104 104 104 .408 .301 .213 .000 .017 104 .531 .532 .532 .532 .532	Pain							
.469 .000 .852 .000 .000 .017 530 531 521 518 532 036 045 054 206 179 104 - 408 .301 .213 .000 .007 .017 - 531 522 519 532 .532 .		.185	008	.252	.238	•	104	250
530 525 531 521 518 532 036 045 054 206 179 104 - 4.08 .301 .213 .000 .007 .017 531 526 532 519 532		000	.852	000.	000.		.017	000
036 045 054 206 179 104 - .408 .301 .213 .000 .007 .017 .531 .526 .532 .519 .532		525	531	521	518		532	499
036 045 054 206 179 104 - .408 .301 .213 .000 .007 .017 .531 .526 .532 .519 .552	Age							
.408 .301 .213 .000 .000 .017 531 526 532 519 532		045	054	206	179	104	•	.165
531 526 532 522 519 532		.301	.213	000.	000.	.017		000.
		526	532	522	519	532		500

	PPS	Patient CES-D	Caregiver CES-D	Caregiver CES-D Number of Symptoms	Global Distress	Pain Intensity	Age	ногі
	.174	507	055	969.–	765	250	.165	'
b	000.	000.	.223	000.	000.	000.	000.	
и	499	500	499	200	498	499	500	

Table 2

Frequency and Percent of Patients by Demographic Variables

Variable	Frequency	Percent
Gender		
Male	307	57.6
Female	226	42.4
Ethnicity		
White	517	97.0
Black	8	1.5
Hispanic	5	$\overline{\lor}$
Other	3	$\overline{}$
Marital Status		
Married	342	64.2
Widowed	126	23.6
Divorced	42	7.9
Never married	18	3.4
Separated	4	$\overline{\lor}$
Missing data	1	abla
Relationship to Caregiver		
Spouse	334	63
Parent	111	21
Significant other	23	4.3
Sibling	15	3.0
Adult Child	10	2.0
Friend/other	39	7.0
Missing data	1	abla
Type of Cancer		
Lung	193	36.2
Pancreas	50	9.4
Colon	39	7.3
Prostate	36	8.9
Gynecological	26	5.0

Variable	Frequency Percent	Percent
GU/Bladder or kidney	26	5.0
Breast	25	4.7
Liver	21	3.9
Stomach or esophagus	21	3.9
Lymphoma	18	3.0
Sarcoma/bone	12	2.0
Other solid tumors	09	11.0
Leukemias/Myelodysplastic Syndrome	10	2.0
Multiple Myeloma	9	1.1

Table 3

Means and Standard Deviations for Predictor and Outcome Variables

Variable	N	Mean	Standard Deviation	Range
Palliative Performance Scale score	531	56.6	10.8	30–100
Patient CES-D (Depression) Scale score	526	2.8	2.2	0–9
Caregiver CES-D Scale score	532	2.8	2.1	0-10
Number of symptoms endorsed	522	9.6	4.2	0-23
MSAS Global Distress Score	519	19.9	13.6	0-131
Present Pain Rating from BPI	532	1.6	2.4	0-10
Hospice Quality of Life Index score	500	103.4	17.2	59-140

Regression Model

Table 4

Ľ

Predictor	В	SE of B Beta	Beta	t	d
Constant	116.389	3.469		33.288	000.
# of Symptoms	-1.147	.240	276	-4.774	000
Depression	-2.094	.298	264	-7.025	000.
Global Distress	305	.074	238	-4.047	000.
Function	.175	.053	.110	3.271	.001

 $R^2 = .456$