The Geriatric Cancer Experience at the End of Life: Testing an Adapted Model

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Purpose/Objectives: To test an adapted end-of-life conceptual model of the geriatric cancer experience and provide evidence for the validity and reliability of the model for use in practice and research.

Design: Nonexperimental and cross-sectional using baseline data collected within 24–72 hours of admission to hospice.

Setting: Two hospices in the southeastern United States.

Sample: 403 hospice homecare patients; 56% were men and 97% were Caucasian with a mean age of 77.7 years.

Methods: Confirmatory factor analyses using structural equation modeling with AMOS™ statistical software.

Main Research Variables: Clinical status; physiologic, psychological, and spiritual variables; and quality of life (QOL).

Findings: A three-factor model with QOL as an outcome variable showed that 67% of the variability in QOL is explained by the patient's symptom and spiritual experiences.

Conclusions: As symptoms and associated severity and distress increase, the patient's QOL decreases. As the spiritual experience increases (the expressed need for inspiration, spiritual activities, and religion), QOL also increases.

Implications for Nursing: The model supports caring for the physical and metaphysical dimensions of the patient's life. It also highlights a need for holistic care inclusive of physical, emotional, and spiritual domains.

Aging is a multidimensional process for older adults. A life course approach toward aging enables nurses to see older adults as unique individuals who continue to grow and develop throughout life and to understand that current choices and decisions also are shaped by life experience (Binstock, 2006). Health is critical in aging. If incident rates remain stable, the total number of cancer cases is expected to double by 2050 because of an aging population (Yancik, 2005). Improvements in screening, diagnosis, and treatment have led to greater numbers of cancer survivors. However, most cancer deaths still occur in older adults. The median age of patients with cancer at time of death, across gender and tumor types, ranges from 71–77 years (Yancik). In 2004, the National Institutes of Health (NIH) recommended the development of end-of-life conceptual models to increase scientific rigor and improve evaluation of outcomes in research. Valid conceptual models are needed on which to base healthcare practices and research specific to the complex needs of the older adult with cancer near the end of life. The purpose of the current study was to test an adapted end-of-life conceptual model of the geriatric cancer experience and provide evidence for the validity and reliability of the model for use in practice and research.

Background

Geriatric Cancer Experience

Aging shapes patients' cancer experiences. Older adults with cancer have older organ systems, decreased immune function, and comorbid conditions. They also undergo the pharmacologic interventions associated with those issues. Geriatric syndromes and uncontrolled or poorly managed comorbid conditions affect cancer treatment choices and outcomes (Balducci & Beghe, 2000; Balducci & Extermann, 2000; Rao & Cohen, 2004). Functional status is a strong predictor of morbidity and mortality in older adults with cancer (Hurria, Lachs, Cohen, Muss, & Kornblith, 2006). Psychologically, older adult patients with cancer are at risk for depression, with a prevalence range of 17%–25%. Separating the symptoms associated with cancer from those of depression and making a definitive diagnosis is a challenge to healthcare providers (Hurria et al.; Rao & Cohen).

Spiritually, older adults express a need to practice their faith but often are limited by energy levels or social isolation. Religious beliefs and spiritual practices promote coping for patients with cancer at the end stage of their lives. Patients who use positive religious coping strategies such as forgiveness, direction, helping, seeking support of clergy, surrender, having a benevolent view of religion, and connecting report lower levels of depression, anxiety, and distress (Ano & Vasconcelles, 2005; Chochinov & Cann, 2005; Weaver & Flannelly, 2004). Aging also affects quality of life (QOL) for older adults with cancer. A strong, direct relationship exists between functional status and QOL in the geriatric palliative care population. In older adults enrolled in home-based hospice programs, QOL is dependent on maintaining relationships (Donnelly, Rybicki, & Walsh, 2001; Steele, Mills, Hardin, & Hussey, 2005). Hospice care is delivered in an interdisciplinary setting that seeks to support patients' physiologic, psychological, and spiritual needs to improve QOL at the end of life; conceptual models of the cancer experience in older adults should include all those domains.

Models in End of Life

Further support for the development and testing of conceptual models comes from the National Cancer Institute, which specifically recommended development of conceptual frameworks that have QOL as a primary endpoint and hypothesize the linkages among symptoms, symptom management, and different QOL domains (Buchanan, O'Mara, Kelaghan, & Minasian, 2005). A state-of-the-science review of design issues in end-of-life research noted that many limitations are conceptual in origin (George, 2002). Systematic review of empiric literature related to symptoms in patients with lung cancer found that only 3 of 18 studies explicitly cited a theoretical framework (Cooley, 2000). In an analysis of 130 community clinical oncology program trials, a little more than 50% measured QOL, using 22 different instruments, but QOL was a primary end point in only 5% of the studies analyzed (Buchanan et al.). Taxonomic issues related to the terms *conceptual* or *theoretical* and *framework* or *model* complicate any discussion. A further limitation of current conceptual frameworks is the lack of testing with empiric data, which highlights the need for validated conceptual models in oncology populations.

Adapting the Original Theoretical Framework

When an extensive review of the literature was conducted, no conceptual model specific to the older adult cancer experience at the end of life was found. Emanuel and Emanuel's (1998) Framework of a Good Death includes four components useful for studying older adults at the end of life: (a) fixed characteristics of the patients (clinical status, sociodemographic features); (b) modifiable dimensions of patients' experiences (symptoms, relationships, economics, perceived needs); (c) potential interventions provided to patients, families, friends, healthcare providers, and others; and (d) outcomes. However, the framework, as originally conceptualized, suffers from two limitations: a lack of linear flow of domains across the model and of an easily measurable outcome variable. For that reason, an adaptation of the model was conducted with a focus on the more holistic ethos of end-of-life care. The model was then renamed the Geriatric Cancer Experience in End of Life to distinguish it from the original. The structure of the four components was retained, but the subdomains were modified to include variables supported by the geriatric oncology literature as important to older adults and the direction was made more linear. Clinical status (CS), physiologic (Phy), psychological (Psy), and spiritual (Sp) serve as the fixed and modifiable domains of patients' experiences, and QOL is the outcome variable of interest. Indicator variables for the domains were chosen after an extensive review of the geriatric cancer literature (see Table 1).

This study sought to answer the question: Does the geriatric cancer experience in the end-of-life model accurately represent the self-reported experience of older patients with cancer newly admitted to a hospice home care setting? The authors hypothesized that (a) the geriatric cancer experience in end of life is a five-factor structure composed of clinical status, physiologic, psychological, spiritual, and QOL latent variables; (b) QOL is dependent on other factors proposed in the conceptual model; and (c) a statistically significant pathway links the four factors (clinical status, physiologic, psychological, and spiritual) to QOL in older adults with cancer at the end of life.

Methods

Setting and Sample

The study took place in two nonprofit hospices in the southeastern United States. The sample was from a larger study and consisted of patients with cancer who were receiving hospice home care (5R01 NR008252, S.C. McMillan, principal investigator). Inclusion criteria were being older than age 65 years, having a cancer diagnosis, being able to read and understand English, and being able to pass screening with the Short Portable Mental Status Questionnaire (SPMSQ) (seven or greater) and Palliative Performance Scale (PPS) (40 or greater). The criteria ensured the capacity for informed consent and decreased attrition during the study. Exclusion criteria were confusion, excessive debilitation, comatose or actively dying, and those who lacked a caregiver.

Instruments

The validity and reliability of the instruments was analyzed in a hospice sample prior to the beginning of the study. Correlations supported concurrent validity and reliability was supported by Cronbach alpha.

The Katz **Activities of Daily Living Index (ADLI)**, a widely used geriatric instrument, assesses self-care in bathing, dressing, toileting, transfer, continence, and feeding (Katz, Downs, Cash, & Grotz, 1970). Assessment of the activities results in a seven-point grading from 1 being

Table 1. Domains and Indicator Variables of the Geriatric Cancer Experience in the End-of-Life Model

Domain	Indicator Variable
Clinical status (CS)	Functional status (CS-1, CS-2) Cognitive status (CS-3)
Physiologic (Phy)	Number of symptoms (Phy-1) Severity of symptoms (Phy-2)
Psychological (Psy)	Symptom distress (Psy-1) Depression (Psy-2)
Spiritual (Sp)	Spiritual needs (Sp-1–Sp-5)
Quality of life (QOL)	Psychological and physiologic well-being (QOL-1) Functional well-being (QOL-2) Social and spiritual well-being (QOL-3)

the highest score (independent in all six functions) and 7 being the lowest score (dependent in all six functions). The ADLI was used as a measure of functional status and a measured variable for clinical status (CS-1).

The **Palliative Performance Scale (PPS)** (Anderson, Downing, Hill, Casorso, & Lerch, 1996), modified from the Karnofsky Performance Scale, was developed to measure physical status in palliative patients. The PPS assigns a value of 0–100 to five domains: ambulation, activity and evidence of disease, self-care ability, oral intake, and level of consciousness. The highest possible performance level (normal functioning) is 100 and 0 the lowest (dead). The PPS was used as one of the measures of functional status and was one of the measured variables for clinical status (CS-2).

The SPMSQ is a brief instrument with proven validity in detecting moderate-to-severe cognitive impairment (Lichtenberg, 1999). The total score on the SPMSQ (range 1–10) provided a measured variable for clinical status (CS-3). A higher score denotes better cognitive status. Patients with scores below seven were excluded.

The **Memorial Symptom Assessment Scale (MSAS)** is designed to differentiate among occurrence, severity, and distress from symptoms. Separate five-point Likert-type scales are used for two dimensions: severity of the symptom and the distress it produces. The 25 items are scored by summing the items in each subscale (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, & Kiyasu, 1994). Preliminary assessment of the validity of the score interpretations of the MSAS for use with patients with cancer receiving hospice home care was conducted and included correlation with QOL scores (McMillan & Small, 2002). For the purposes of the current study, three composite variables were created from the information from the MSAS. The first variable (Phy-1) summed the total number of symptoms experienced by the patients, yielding a 0–25 possible score. Zero signifies no symptoms. The second variable (Phy-2) averaged the severity experienced yielding a 0–4 possible score with the higher number signifying greater severity. The third variable averaged the distress experienced yielding a 0–4 possible score, with the higher scores signifying greater distress. The MSAS subscale for distress provided a measured variable for the psychological domain (Psy-1).

A 10-item version of the **Center for Epidemiological Studies–Depression (CES-D)** short form has been developed to balance ease of administration and psychometric concerns. Items are scored as present or absent, rather than rated for frequency as with the full CES-D, yielding a 0 (no depressive symptoms) to 10 (10 depressive symptoms) score. Irwin et al. (1999) assessed psychometric characteristics of the CES-D short form. Results showed that Cronbach alpha was 0.92 for the short form and test-retest reliability was 0.83. Correlation of the short form and full CES-D was 0.88. The CES-D provided a measured variable for psychological domain (Psy-2).

The **Spiritual Needs Inventory Scale** assesses the extent to which patients have spiritual needs and whether those needs are met (Hermann, 2001). The 17-item questionnaire has two main parts. First patients are asked to rate the items in response to the stem: "In order to live my life fully, I need to:" The stem is followed by items such as "sing/listen to inspirational music" and "talk with someone about spiritual issues." The subject responds to each item on a scale from 1 (never) to 5 (always). Scores in the section may range from 17–85, with a higher score representing a greater spiritual need. The respondents also indicate which of these needs remains unmet by marking yes or no. Validity was assessed by Hermann (2006) using factor analysis that confirmed the inclusion of all items. Reliability was assessed using Cronbach alpha (0.85). The measured variables for spiritual needs were the five subscales from the study: outlook, inspiration, spiritual activities, religion, and community (Sp-1, Sp-2, Sp-3, Sp-4, and Sp-5).

The **Hospice QOL Index-14 (HQLI-14)** is a shortened version of the previously used and validated 28-item Hospice QOL Index (McMillan & Weitzner, 2000). Each item is scored on a 0–10 scale (10 being the most favorable response) and item scores are added to obtain a total scale score. Total scores can range from 0 (worst QOL) to 140 (best QOL). Construct validity of the short form was evaluated by correlation with the original HQLI. The correlation between total scale scores was very strong at $r = 0.94$ ($p < 0.001$). Reliability of the scores from the short form was estimated with Cronbach alpha (0.77) for the shortened scale. Psychometric analysis shows a three-factor structure: psychological and physiologic, functional, and social and spiritual well-being. The subscales of the instrument provide the measured variables for QOL (QOL-1, QOL-2, and QOL-3).

Standard demographic data, age, race, gender, education, religion, marital status, relationship to caregiver, home setting, most recent job, and diagnosis, were collected from the patients and the patients' records. Psychometric analyses of the instruments with the current sample are available from the first author.

Procedures

The proposal was approved by the institutional review board of the University of South Florida and administrators of the two hospices involved. Informed consent and data collection by trained research assistants were obtained on admission to the study. The research design was nonexperimental and cross sectional using baseline data collected within 24–72 hours of admission to hospice. All data were de-identified prior to analysis and entered into a SPSS® (v.15.0) database.

Data Analyses

Analytic strategy made use of the AMOS™ graphic interface testing the psychometric soundness of a first order confirmatory factor model (measurement model), which allowed for the testing of hypotheses and confirmed whether indicator variables adequately measure the latent variables (Byrne, 2001). After the measurement model was found to be operating adequately, the full structural equation model was tested for validity using the strategies recommended for testing a causal structure (Byrne). Fit indices help to determine the goodness of fit between the hypothesized model and the sample data. Although many fit indices are available, Byrne's recommendations were followed. Absolute fit indices test how far apart the covariance matrices of the hypothesized model and sample data were, whereas incremental fit indices tested the hypothesized model against an independent model. For absolute fit indices, a nonsignificant x^2 and a root mean square error of approximation (RMSEA) of 0.05 or less was accepted and confidence intervals reported. For a Type III incremental fit index, a comparative fit index (CFI) of 0.95 or less was accepted (Byrne; Hu & Bentler, 1998). Areas of misfit were identified using the residual matrix. Modification indices produced by AMOS were then examined.

Results

Setting and Sample

Samples from the two hospice sites were assessed for meaningful differences using x^2, t tests, and bivariate correlations, and aggregated when none were found. The original sample included 428 subjects. Ninety-four percent had completed data, leaving 403 subjects to include in the analysis. Analysis of the deleted subjects showed no specific patterns of missing data. Table 2 shows the demographic characteristics of the sample. The average subject was likely to be a man, Caucasian, self-identified as Christian, aged 78 years, living with a spousal caregiver in a suburban setting, and diagnosed with lung or pancreatic cancer. Instruments and mean scores are shown in Table 3.

Table 2. Demographic Characteristics

Characteristic	$\bar{X}$	SD
Age (years)	77.7	12.5
Years of school	12.5	33.2
Characteristic	**n**	**%**
Gender		
Male	226	56
Female	177	44
Relationship to patient		
Spouse	258	64
Parent	77	19
Child	8	2
Other	60	15
Marital status		
Married	266	66
Widowed	89	22
Divorced	32	8
Other	16	4
Ethnicity		
Caucasian	392	97
African American	4	1
Hispanic	4	1
Other	3	< 1
Religion		
Christian	346	86
Jewish	8	2
Other	1	< 1
None	48	12
Cancer diagnosis		
Lung	149	37
Pancreas	45	11
Colon	28	7
Prostate	28	7
Liver	16	4
Other	137	34
Most recent job		
Professional	85	21
Manager or administrator	48	12
Service	48	12
Other	222	55
Home setting		
Urban	4	1
Suburban	326	81
Rural	73	18

N = 403

Note. Because of rounding, not all percentages total 100.

Assessment of the Measurement Model

Data were assessed for assumptions of normality, linearity, and independence (see Table 4). The greatest Mahalanobis' distance (a measurement of multivariate outliers) was 45.19, with a gradual increase in the distance but no extreme values. A correlation matrix of indicator variables was constructed (see Table 5)

Table 3. Sample Scores on Instruments

Instrument	$\bar{X}$	SD	Range
Katz Activities of Daily Living Index	2.45	2.18	1–7
Palliative Performance Scale	56.34	10.79	40–100
Short Portable Mental Status Questionnaire	9.12	0.99	7–10
Memorial Symptom Assessment Scale			
• Occurrence	9.66	4.32	0–25
• Severity	2.07	0.55	0–4
• Distress	1.96	0.85	0–4
Center for Epidemiological Studies–Depression	2.95	2.2	0–10
Spiritual Needs Inventory Scale	53.16	14.02	17–85
• Number unmet	1.15	1.72	0–17
Hospice Quality-of-Life Index-14	102.28	17.39	0–140

and analyzed. Bivariate correlations showed significant relationships between all indicator variables that had been grouped together *a priori*, reflecting the latent construct. The three QOL indicators were significantly correlated to the other constructs, supporting the hypothesis that it was a dependent variable. However, some correlations, although significant at both the 0.05 and 0.01 levels, were still weak-to-moderate in magnitude. Further analysis showed significant strong relationships between the Psy-1 and Psy-2 and Phy-1 and Phy-2 variables. The design of the study guaranteed the independence of the subjects. The five factor measurement model was then reproduced in AMOS with the graphic interface (see Figure 1). Convergence was achieved and a x^2 of 307.36 (degree of freedom = 80, $p < 0.001$), CFI of 0.93, and RMSEA of 0.08 resulted. The levels did not meet *a priori* determined levels for fit indices. The analysis became exploratory. AMOS produces a modification index (MI). The largest MI was for a covariance of the error terms for Sp-1 and Sp-5. Inspection of the standardized residual matrix shows misfit occurring in Psy-2, QOL-3, Sp-1, Sp-5, and CS-1 and CS-3. The decision was made to remove the problematic indicators and, because of the strong correlations in the bivariate correlation matrix, to collapse the psychological and physiologic factors into one factor that was then named the symptom experience. This necessitated removing the latent variable clinical status from the model, leaving a three-factor measurement model. Analysis was then rerun. The new model resulted in an acceptable x^2 of 18.324 (df = 17, $p = 0.37$), a CFI of 0.99, and a RMSEA of 0.01 (90% confidence interval [CI] = 0–0.048).

Assessment of the Full Structural Model

The structural adaptation of the three-factor model with QOL as an endogenous variable was entered into AMOS. For parsimony's sake, no covariance was hypothesized between the symptom experience and the spiritual experience because there had been no significant covariance in the measurement model. Analysis of the model generated a x^2 of 19.803 (df = 18, $p = 0.344$), a CFI of 0.99, and a RMSEA of 0.016 (90% CI 0.–0.048).

This three-factor structural model with QOL as an outcome variable shows that 67% of the variability in QOL is explained by patients' symptom experiences, particularly (a) the number of symptoms, the severity and distress that they caused, and the person's spiritual experience and (b) the need for inspiration, spiritual activities, and religion (see Figure 2).

As the number of symptoms and their severity and distress increase, patients' QOL decreases. However, as patients' spiritual experiences increase, their QOL also increases. The R^2 between measured and latent variables remains the same as in the measurement model and range from 0.5–0.95. All regression pathways between the latent and measured variables are statistically significant and pathways from the symptom experience and spiritual experience to QOL are significant at alpha 0.05. The difference between the measurement (CMIN = 18.324, df = 19) and structural (CMIN = 19.803, df = 18) models was $x^2 = -1.479$ (df = 1), which is not unexpected because the structural model is an adaptation of the measurement model. Garson (n.d.) recommended that if the x^2 shows no significant difference, the more parsimonious of the two models should be accepted. The structural model is the most parsimonious.

Although the specific aims to fit and confirm the model of the geriatric cancer experience in end of life were met,

Table 4. Descriptive Statistics for the Indicator Variables

Variable	$\bar{X}$	SD	Range	Skewness	Kurtosis[a]
CS-1	2.45	2.2	0–8	1.35	0.48
CS-2	5.33	1.1	1–8	–0.75	1.32
CS-3	1.87	0.99	1–4	0.84	–0.46
QOL-1	42.47	9.3	18–60	–0.26	–0.54
QOL-2	23.84	8.3	5–40	–0.02	–0.69
QOL-3	36.16	4.5	19–40	–1.34	1.38
Phy-1	9.75	4.1	1–25	0.43	0.08
Phy-2	20.62	11	1–66	0.7	0.48
Psy-1	19.85	13	0–74	0.92	1.11
Psy-2	2.9	2.17	0–9	0.58	–0.49
Sp-1	18.71	4.1	5–25	–0.51	–0.13
Sp-2	9.85	4.7	1–20	0.5	–0.64
Sp-3	6.59	3.7	2–15	0.78	–0.53
Sp-4	6.27	2.9	0–10	–0.19	–1.35
Sp-5	11.64	2.5	3–15	–0.65	0.29

[a] Mardia's coefficient = 8.11 and critical ratio = 3.6

CS—clinical status; Phy—physiologic; Psy—psychological; QOL—quality of life; Sp—spiritual

Table 5. Correlations of the Indicator Variables

Variable	Sp-1	Sp-2	Sp-3	Sp-4	Sp-5	Psy-1	Psy-2	Phy-1	Phy-2	QOL-1	QOL-2	QOL-3	CS-1	CS-2	CS-3
Sp-1	1	–	–	–	–	–	–	–	–	–	–	–	–	–	–
Sp-2	0.42**	1	–	–	–	–	–	–	–	–	–	–	–	–	–
Sp-3	0.35**	0.8**	1	–	–	–	–	–	–	–	–	–	–	–	–
Sp-4	0.38**	0.7**	0.61**	1	–	–	–	–	–	–	–	–	–	–	–
Sp-5	0.59**	0.42**	0.33**	0.3**	1	–	–	–	–	–	–	–	–	–	–
Psy-1	0.004	0.07	0.091	0.023	0.085	1	–	–	–	–	–	–	–	–	–
Psy-2	–0.16**	–0.049	–0.026	–0.098*	–0.069	0.47**	1	–	–	–	–	–	–	–	–
Phy-1	0.005	0.07	0.095	0.02	0.062	0.862**	0.4**	1	–	–	–	–	–	–	–
Phy-2	–0.011	0.048	0.053	–0.006	0.072	0.93**	0.44**	0.88**	1	–	–	–	–	–	–
QOL-1	0.078	0.053	0.029	0.033	–0.024	–0.55**	–0.42**	–0.53**	–0.55**	1	–	–	–	–	–
QOL-2	0.17**	0.14**	0.119*	0.107*	0.089	–0.53**	–0.44**	–0.47**	–0.53**	0.5**	1	–	–	–	–
QOL-3	0.31**	0.26**	0.2**	0.26**	0.22**	–0.221**	–0.25**	–0.23**	–0.21**	0.31**	0.29**	1	–	–	–
CS-1	0.04	–0.041	–0.079	0.005	0.13**	0.006	0.012	–0.03	0.035	0.02	–0.123*	–0.012	1	–	–
CS-2	–0.074	–0.1*	–0.053	–0.077	–0.049	0.049	0.094	0.023	0.061	–0.056	–0.23**	–0.123*	0.43**	1	–
CS-3	–0.027	–0.05	–0.09	–0.053	–0.035	–0.14**	–0.082	–0.16**	–0.116*	0.074	0.017	0.048	0.17**	0.22**	1

* p = 0.05 (two-tailed), ** p = 0.01 (two-tailed)

CS—clinical status; Phy—physiologic; Psy—psychological; QOL—quality of life; Sp—spiritual

the fit indices were not accepted on the five-factor model. During an exploratory phase of model specification, the geriatric cancer experience in end of life was found to be a three-factor structure composed of the symptom experience, spiritual experience, and QOL.

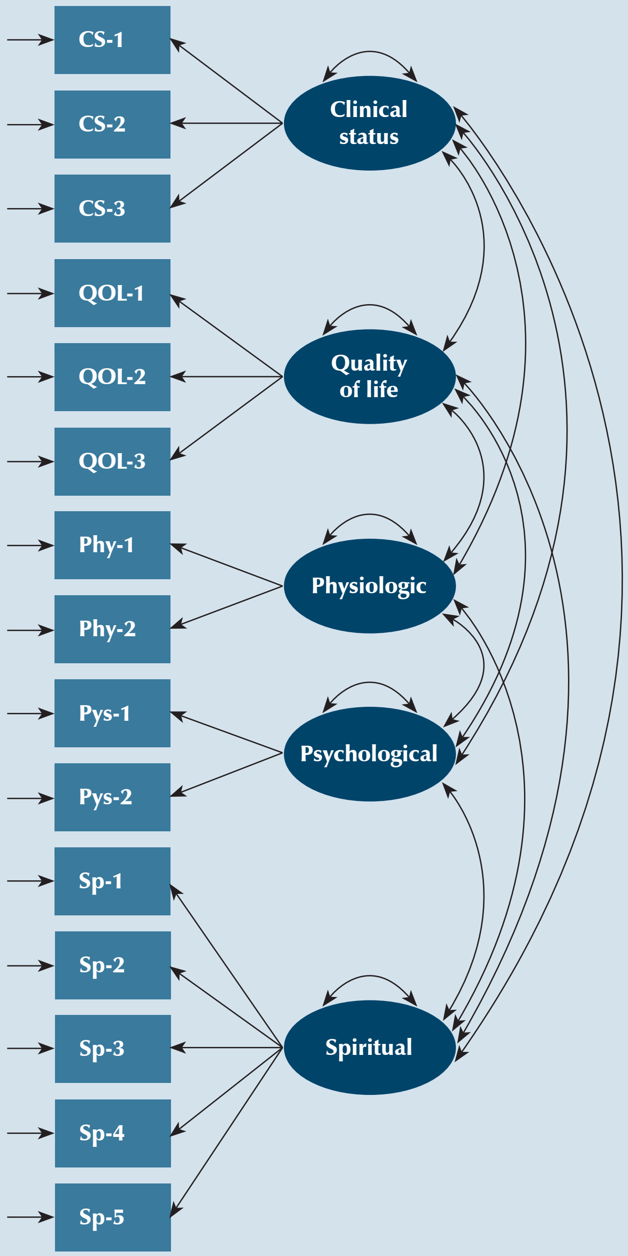
Discussion

Sample

Although the sample may not reflect every older adult who dies of cancer in the United States, it compares demographically with national data sets of hospice patients (NHPCO, 2008). The sample reported an average of more than nine symptoms, 2.07 symptom severity score (range 0–4), and 1.96 symptom distress score (range 0–4). The results are reflective of samples in the literature. Mean numbers of symptoms in previous research in geriatric populations with metastatic cancer have been reported to range from 3–11, with severity and distress levels in the first and second quartile of the scale (Klinkenberg, Willems, van der Wal, & Deeg, 2004; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, & Coyle, 1994). An overall QOL index of 102.28 (range = 0–140) reported by the sample was comparable with other studies, occurring in the 50th–75th percentile on the scale (Brown et al., 2006; Donnelly et al., 2001; McMillan & Weitzner, 2000). An average of one unmet spiritual need was found, with 71% of the sample reporting no or one unmet spiritual needs (range 0–10 out of a possible 0–17). The finding also is reflective of previous studies (Hermann, 2001; Murray, Kendall, Boyd, Worth, & Benton, 2004; Taylor, 2003).

Key Findings

Establishing the fit of the measurement model and confirming the structural model: Emanuel, Alpert, Baldwin, and Emanuel (2000) used exploratory factor analysis in a follow-up study to assess the construct validity and stability over time of their framework, and reported the model was valid and stable. They found that eight factors accounted for 46% of the variability in the patients' responses. Three of the factors identified are comparable with the current study: psychological distress, spirituality and religiosity, sense of purpose; however, odds ratios and correlations are the only statistics reported by Emanuel et al., making comparison with the current study problematic. No other testing of the framework using structural equation modeling (SEM) was found. No studies were found that measured QOL as an outcome variable with SEM in the oncology or end-of-life literature. Nuamah, Cooley, Fawcett, and McCorkle (1999) tested a Roy Adaptation Model-based theory of health-related QOL (HRQOL) in newly diagnosed patients with cancer. Only two latent variables (severity and HRQOL) were hypothesized, with six measured exogenous variables. Although



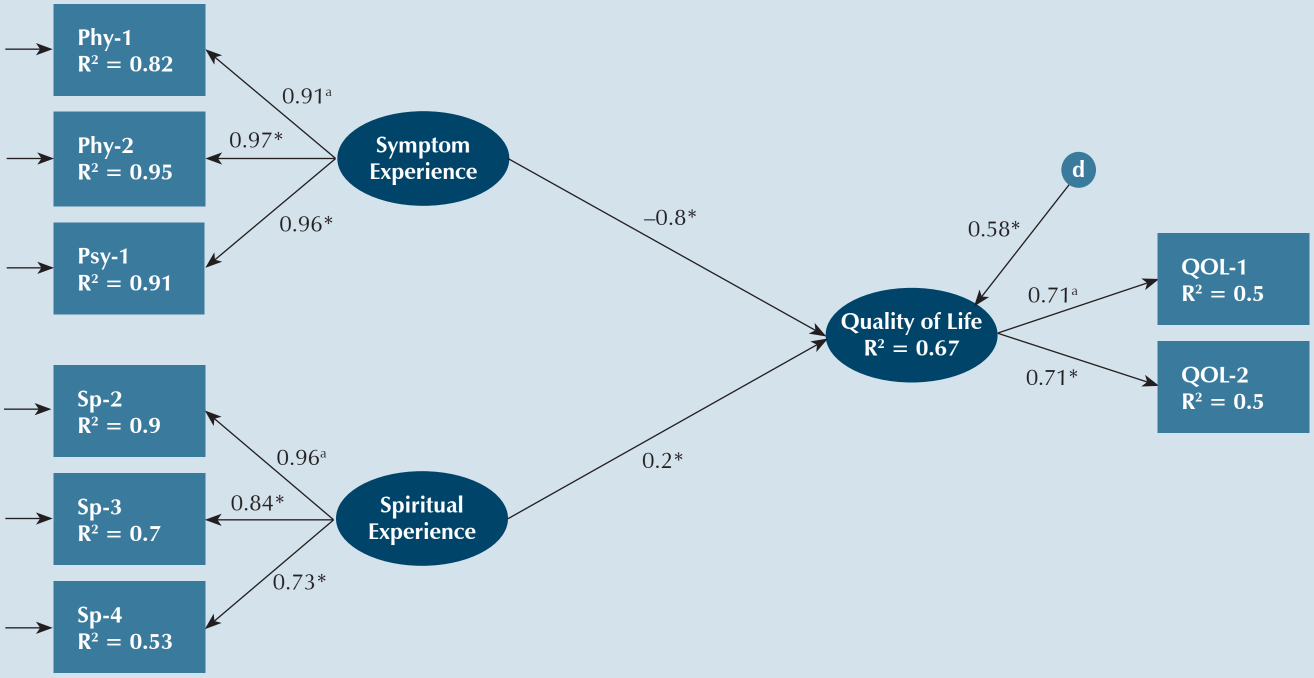
CS—clinical status; Phy—physiologic; Psy—psychological; QOL—quality of life; Sp—spiritual

Figure 1. The Geriatric Cancer Experience in the End-of-Life Measurement Model

hypothesis testing was conducted and fit indices of the models were reported, symptom distress, functional status, and depression were conceptualized as the measured indicators of HRQOL—a HRQOL scale was not used. For the current study, symptom distress (Psy-1), functional status (CS-2), and depression (Psy-2) served as predictors and not outcome variables. Also, no squared multiple correlations were reported in the Nuamah et al. study between the indicators and latent variables, nor between the predictors and outcome variables, making it impossible to compare and contrast the two studies. Hofer et al. (2005) tested a conceptual model of HRQOL based on Wilson and Cleary's (1995) theoretical model of HRQOL in patients with early-stage heart disease using SEM. The study reported that 49% of the variability in HRQOL was predicted by a very nonparsimonious model. However, the fit indices accepted were not as rigorous as in the current project. For example, a x^2 of 513.28, df of 188, CFI of 0.92, and a RMSEA of 0.06 were accepted. If less rigorous fit indices had been accepted for the current study, no model modification would have been needed, and the five-factor model would have been retained. The design of Hofer et al.'s model also made comparison with the current study problematic. For example, the model theorized that physical functioning would mediate symptom status. The geriatric cancer experience in end of life does not. Nuamah et al. and Hofer et al. noted the paucity of research with which to compare samples, methods, and findings.

Symptom experience: In the geriatric cancer experience in the end-of-life model the symptom experience latent variable encapsulates the number of symptoms patients are experiencing, the severity level of those symptoms, and the distress levels patients report. The most frequently reported symptoms (more than 50%) were lack of energy (86%), dry mouth (71%), pain (68%), lack of appetite (61%), shortness of breath (58%), and feeling drowsy (57%). The mean severity level per symptom reported was 2.07 (possible 0–4), and mean distress level per symptom was 1.96 (possible 0–4). This also is reflective of previous research with the MSAS in comparable populations (Kris & Dodd, 2004; Tranmer et al., 2003). The contribution that the current study makes to the understanding of the geriatric end-of-life experience is the very strong negative effect of the symptom experience on QOL. QOL is becoming an outcome variable of importance and this study supports the contention that uncontrolled symptoms and the distress they cause degrade QOL at the end of life.

Spiritual experience: The measurement of religious or spiritual needs may be more meaningful than religiosity or religious coping at the end of life (Sulmasy, 2002). The premise is supported by a study conducted among patients with advanced cancer that showed unmet needs inversely predicted QOL (Hwang, et al., 2004). The instrument used in the current study, the Spiritual Needs Inventory, was developed to measure the spiritual needs of patients near the end of life. Significant measurement issues were related to univariate non-normality, communality, and error-term covariance with the subscales in the study. The five indicator structure of the Spiritual Needs Inventory was retained until the decision was made to exclude all indicators with large non-normality, low communality, and error covariance. Those spiritual need indicators retained factored onto the inspiration (to talk about spiritual matters, sing or listen to inspirational music, be with people who share my beliefs, and read a religious text), spiritual



* $p = 0.05$

[a] Pathway fixed to one in unstandardized model

CS—clinical status; d—disturbance term; Phy—physiologic; Psy—psychological; QOL—quality of life; R^2—squared multiple correlation; Sp—spiritual

Figure 2. The Geriatric Cancer Experience in End-of-Life Model

activities (use inspirational materials, use phrases from a religious text, and read inspirational materials), and religion (pray and go to religious services) factors. The contribution that the study makes to the understanding of the geriatric end-of-life experience is the moderate, positive effect of personal spiritual practices on QOL. People who express a greater dependence on spiritual behaviors experience an increase in QOL.

Limitations

Alternate models: In studies with highly correlated exogenous variables and cross-sectional data, the likelihood of alternative models increases. A review of 53 published covariance structural models found that 90% could yield a plausible alternative model and 50% of the studies yielded more than 16 equivalent models (MacCallum, Wegener, Uchino, & Fabrigar, 1993). The validity of the conclusions drawn by the investigators can be called into question when alternative models exist and are not given careful consideration. MacCallum et al. noted that areas of substantive interest may have alternative explanations of the same data, and the investigator does better to confront and evaluate the alternative models than ignore them. When goodness of fit indices cannot distinguish among models, interpretability of parameter estimates and meaningfulness of the model become the criteria. The nonsignificant x^2 change between the measurement and structural model in the study suggests that they are alternative models.

Secondary analysis: The current study suffered from restrictive limitations. The aim of the larger study, from which data were obtained, was to determine whether using standardized assessment tools for hospice patients improved outcomes. Functional and cognitive status were used as screens for admission to the study, and psychometric problems related to restriction of range were present. Conceptual problems also existed with using just functional and cognitive status as indicators of patients' overall clinical status. The addition of number of comorbidities, number of recent hospitalizations, nutritional status, and number of falls also would strengthen the analysis (Balducci, 2003; Hurria et al., 2006; Rao & Cohen, 2004). The original adaptation of Emanuel and Emanuel's (1998) framework divided the physiologic and psychologic domains, whereas the data in the current study showed that they were reflective of a higher level latent variable, here called symptom experience. Although secondary analysis has known limitations, in a time when funding is becoming very competitive, the use of large data sets for additional analysis is recommended to provide further knowledge beyond the original aims of the studies.

Model modification: The overall purpose of covariance structure analysis, as in SEM, is to answer the question as to whether the model being tested fits the data well and whether the fit is affected if the model is simplified or made more complex (MacCallum, Roznowski, & Necowitz, 1992). The study made use of a common method referred to as model development or model generating. In the method, an initial model is specified, tested, and modified until better fit indices are obtained. A limitation of the method is that the model may fit the sample data so much that it no longer fits the population data (Garson, 2009; Raykov & Marcoulides, 2006). Because of the underlying mathematical structure, data-driven strategies risk capitalization on chance problems. For that reason, further confirmatory testing with unique samples is recommended.

Conclusion

The significance of the current study is twofold. First, the model will provide a validated framework for the development of healthcare processes for geriatric end-of-life care. Older adults continue to grow and develop throughout their lives. The end of life is a developmental stage that calls for models of care that address these needs. Integration of life experiences and acceptance of self facilitate a peaceful end of life (Erickson, 1963, Levinson et al., 1986). This developmental understanding has been lacking in the oncology literature. The current study also provides evidence for the importance of symptom assessment and spiritual assessment, the development of plans of care inclusive of symptom control and spiritual care, and the implementation and evaluation of those plans using QOL as an indicator for the utility of the care provided. Although both the symptom experience and spiritual experience independently contributed to QOL in the study, the magnitude of the effect of the symptom experience was far greater than that of the spiritual experience, supporting the argument for adequate symptom management in the allocation of limited resources and testing of new symptom management interventions before spiritual care practices.

Second, in the research setting, testing of the three-factor model provides evidence for its validity as a conceptual model to guide end-of-life research for older adults. Although the study made use of a hospice population, the literature shows that the domains also are important earlier in the disease trajectory. The model should be tested in future studies with patients with cancer in disease stages I–III. Furthermore, the model should be tested in older adults who chose not to use palliative or hospice care. Additional testing in younger oncology or nonhospice populations may provide evidence that the model, although developed for the older hospice population, may have broader applications. The model is hypothesized to strengthen future studies by providing a useful guide for understanding the relationships among symptoms (frequency, severity, and distress), spiritual needs (the need for inspiration and religion), and QOL in the experience of older adults with cancer. It will also be useful to guide the selection of variables and hypotheses, once again strengthening the science.

Because hospice care is delivered in an interdisciplinary setting where significant role blending occurs, the model provides a conceptualization of the human experience that can be used by multiple disciplines. Patients, caregivers, physicians, nurses, social workers, volunteers, and chaplains can benefit from understanding the interplay of the symptom experience, the spiritual experience, and QOL. The model supports the need for caring for the physical and metaphysical dimensions of patients' live. It also highlights a need for holistic care inclusive of the physical, emotional, and spiritual domains.

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