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Burden and Well-Being Among a Diverse Sample of Cancer, Congestive Heart Failure and Chronic Obstructive Pulmonary Disease Caregivers

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Abstract

Context—Three important causes of death in the U.S. (cancer, congestive heart failure [CHF], and chronic obstructive pulmonary disease [COPD]) are preceded by long periods of declining health; often, family members provide the majority of care for individuals who are living with serious illnesses and are at risk for impaired well-being.

Objectives—To expand understanding of caregiver burden and psychosocial-spiritual outcomes among understudied groups of caregivers – cancer, CHF, and COPD caregivers – by including differences by disease in a diverse population.

Methods—The current study included 139 caregiver/patient dyads. Independent variables included patient diagnosis and function; and caregiver demographics, and social and coping resources. Cross-sectional analyses examined distributions of these independent variables between diagnoses, and logistic regression examined correlates of caregiver burden, anxiety, depressive symptoms, and spiritual well-being.

Results—There were significant differences in patient functioning and caregiver demographics and socioeconomic status between diagnosis groups, but few differences in caregiver burden or psychosocial-spiritual outcomes by diagnosis. The most robust social resources indicator of caregiver burden was desire for more help from friends and family. Anxious preoccupation coping style was robustly associated with caregiver psychosocial-spiritual outcomes.

Conclusion—Caregiver resources, not patient diagnosis or illness severity, are the primary correlates associated with caregiver burden. Additionally, caregiver burden is not disease-specific

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Disclosures

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to those examined here, but rather a relatively universal experience that may be buffered by social resources and successful coping styles.

Keywords

Cancer caregiving; CHF caregiving; COPD caregiving; caregiver burden; social support; coping

Introduction

Three important causes of death in the United States – cancer, chronic obstructive pulmonary disease (COPD), and congestive heart failure (CHF) – are preceded by long periods of declining health, with family members providing the majority of care for those living with serious illnesses.[1] Over 11 million Americans live with cancer,[2] over 16 million have COPD,[3] and almost five million have CHF.[4] In 2009, approximately 31% of U.S. households reported that at least one person had served as an unpaid caregiver in the previous 12-month period,[5] a number that will likely continue to increase as the population ages. Many family members assume caregiving responsibilities without being fully aware of the burdens associated with this role, including time demands, physical exhaustion, financial costs, mental stress, and even personal health risks.[6] These caregiving demands have been associated with caregiver anger, depression, and anxiety, which often grow over time as the extent of caregiving increases.[7] Caregivers who report high levels of stress are at an increased risk for physical and mental health decrements, including increased mortality.[8-11] The well-being of the caregiver is often the most important factor in keeping a patient out of a hospital or nursing home; therefore, it is vitally important that the needs of informal caregivers are recognized and met.[12] Understanding factors associated with increased burden may help the development of interventions to improve the caregiver and patient experience; reducing caregiver burden has implications for clinical practice, policy-making, and patient-family quality of life.

Effects of caregiving for people with major causes of death in the United States such as heart disease and pulmonary disease have been relatively understudied. [13-18] Most existing research concerning caregiving for chronic illnesses has focused on Alzheimer's disease and other forms of dementia,[19, 20] and more recently, cancer caregiving.[21-23] CHF and COPD differ in clinical presentation and course from cancer and Alzheimer's disease, but little is known regarding whether caregiver outcomes differ between diagnoses.[24, 25] Even the best evidence regarding the impact of caregiving for chronic illnesses is limited by the focus on a limited number of patient diagnoses, small sample size, and inadequate methodology.[26]

There is emerging evidence that illness severity is significantly associated with both patient and caregiver outcomes. One study comparing patients with cancer, CHF, and COPD found that illness severity, rather than diagnosis, was most significantly related to patients' illness experience.[24] Similarly, a study comparing cancer, CHF, and COPD caregivers concluded that the caregiver's report of need for greater help with daily tasks, rather than the patient's functional status or diagnosis, was the most significant predictor of caregiver burden.[27] To our knowledge, this is the only study to report such findings, but it does have some limitations. The sample for this study included few caregivers of minority racial or ethnic status, did not include caregiver characteristics, such as coping style, that have been shown to be associated with caregiver burden, and focused only on caregiver burden as an outcome measure. We were interested, first, in assessing whether these general findings would be consistent in a more diverse sample, and second, what additional caregiver characteristics, both interpersonal and intrapersonal, might be associated with burden and well-being during caregiving.

We are interested in extending on this previous work by addressing the following research questions: 1) Do outcomes vary by diagnosis? 2) Do findings from previous studies hold up in a diverse sample? 3) Do patient factors or caregiver characteristics have a bigger impact on outcomes? By elucidating predictors of poorer caregiver outcomes, clinicians and the interdisciplinary team will be better equipped to develop interventions targeted toward those aspects of caregiver experience most associated with burden and decreased well-being.

Methods

Study Procedures and Participants

The data for this study were collected as part of a longitudinal study of patients with late-stage cancer, CHF, or COPD and their caregivers.[28] Patients were selected using clinical criteria associated with an estimated 50% two-year survival. The study recruited patients with Stage IV colon, lung (also Stage IIIb), breast, and prostate cancer; New York Heart Association (NYHA) Class III or IV congestive heart failure (CHF); and chronic obstructive pulmonary disease (COPD) with hypercapnia ($pCO_2 > 46$) who had at least one emergency room visit or hospitalization within the year prior to study enrollment.[28] Eligible patients were identified through hospital databases at Duke University Medical Center and the Durham VA Medical Center, as well as the local tumor registries. Patients were asked to identify the person who spent the most time with them, providing most of the needed day-to-day care, assistance, and support – a caregiver. This paper includes baseline data analyses from 139 patient/caregiver dyads. Additional details regarding the study procedures have been previously published.[28]

Measures

Patient diagnosis included cancer, COPD, and CHF. *Patient illness* factors included functional impairment and disease severity. Activities of daily living (ADLs) was a self-report measure by the patient stating that he or she needed help with five basic self-care tasks: bathing, dressing, feeding, transferring, and toileting.[29] This measure was dichotomized into impaired (need help or cannot do any of the five items) vs. non-impaired based on the low prevalence of impairment in the sample. Instrumental activities of daily living (IADLs) was a self-report measure by the patient stating that he or she needed help with seven more advanced tasks: telephone use, traveling, shopping, preparing meals, doing housework, taking medicine, and handling money.[30] Disease severity was a combination of ordinal-level self-rated health (SRH)[31] and ordinal-level number of days in bed or chair/couch in the past three months. Response categories included: 1) poor/fair SRH and high bed days (at least half); 2) poor/fair SRH and low bed days (fewer than half) or good/excellent SRH and high bed days; and (3) good/excellent SRH and low bed days. This measure of disease severity combined objective (bed days) and subjective (self-rated health) measures to locate patients in their disease trajectory.[24]

As a result of debate in the literature over the relative validity and predictive power of patient health information from patients and caregivers, we measured both patient and caregiver-reported I/ADL status (results available up on request).[32, 33] Caregivers tended to report greater disability in ADLs and IADLs than patients did, but there was an acceptable level of concordance (r=0.6 and 0.8, respectively). Caregiver ratings were more predictive of caregiver burden than patient ratings in some cases, but patterns were inconsistent. Because caregiver burden can influence caregivers' ratings,[34] and because patient and caregiver ratings were similar, we chose to use patient ratings to reduce the chance of identifying reciprocal effects in cross-sectional analyses.

Caregiver relationship to patient was coded as spouse/partner versus other (adult child, friend, sibling, etc.). *Caregiver demographic variables* included age, gender, marital status, and race/ethnicity (nonwhite vs. white; 90% of nonwhite caregivers were African American). *Caregiver socioeconomic resources* included employment status, education level, and financial security. Financial security was a one-item assessment asking, "Without giving exact dollars, how would you describe your household's financial situation right now?" This single-item measure has been shown to have a higher response rate than standard income assessments and uses practical language to assess perceived economic security.[35] Response categories included: 1) you are having difficulty paying the bills, no matter what you do; 2) you have money to pay the bills, but only because you have cut back on things; 3) you have enough money to pay the bills, but little spare money to buy extra special things; 4) after paying the bills, you still have enough money for special things that you want. These responses were dichotomized as difficulty paying bills (1 and 2) vs. no difficulty (3 and 4).

Caregiver social resources included number of people in the caregiver's social network and desire for more help. Number in social network was a self-reported count of relatives and close friends "whom you feel at ease with, can talk to about private matters, or can call on for help." Desire for more help with caregiving was assessed with a single item, "Overall, I wish family and friends would help more with my caregiving responsibilities" Five response categories ranged from "strongly agree" to "strongly disagree." This single item has been validated as an indicator of subjective social support in previous studies.[36]

Caregiver coping resources were assessed using the Mini-Mental Adjustment to Coping Scale (Mini-MAC).[37] The scale taps into five coping styles: 1) helplessness-hopelessness (Cronbach's α=0.86), 2) fighting spirit (Cronbach's α=0.48), 3) anxious preoccupation (Cronbach's α=0.81), 4) cognitive avoidance (Cronbach's α=0.74), and 5) fatalism (Cronbach's α=0.51). Scores for each coping style were measured on a continuous scale, with higher scores indicating greater use of that coping style.

Caregiver burden was assessed with the Caregiver Reaction Assessment (CRA).[38] The 24-item multidimensional instrument measures caregivers' reactions to caring for family members with a variety of chronic illnesses in five areas: 1) caregiver esteem (Cronbach's α=0.83), 2) lack of family support (Cronbach's α=0.79), 3) impact on finances (Cronbach's α=0.75), 4) impact on schedule (Cronbach's α=0.82), and 5) impact on health (Cronbach's α=0.67). Higher scores on each subscale indicated stronger agreement with indicators for that burden dimension. Caregiver esteem was reverse-coded so that higher values indicated lower esteem.

Caregiver psychosocial-spiritual outcomes included depression, anxiety, and spiritual well-being. We used well-validated measures including 1) the Center for Epidemiological Studies Depression Scale-10 item (CES-D 10)[39, 40] to measure depression (Cronbach's α=0.83); 2) the brief Profile of Mood States (POMS) anxiety subscale[41] to measure anxiety (Cronbach's α=0.88); and 3) the Functional Assessment for Chronic Illness Therapy-Spirituality subscale (FACIT-Sp)[42] to measure spiritual well-being (Cronbach's α=0.83). Higher scores on these continuous scales indicated poor well-being; spiritual well-being was reverse coded so that higher scores indicated poor well-being.

Statistical Analysis

The analytic sample included 139 caregiver/patient dyads with complete information. Nineteen respondents were missing only one item from a multi-item scale (Mini-MAC, CES-D, CRA, and FACIT-Sp). We imputed the mean of the respondent's non-missing responses for that scale in place of the missing item. Descriptive analyses calculated proportions for categorical variables and medians and standard deviations for continuous variables, which were not normally distributed. We calculated separate estimates for the full sample, cancer caregivers, CHF caregivers, and COPD caregivers. Comparisons of medians between diagnostic categories were performed by the Kruskal-Wallis non-parametric analysis of variance test.

Model-based analyses focused on predictors of caregiver burden and psychosocial-spiritual outcomes. Caregiver outcomes were dichotomized to assign a "1" if a caregiver's score was above the sample median (high burden/poor well-being) and a "0" if his or her score was at the median or lower (low burden/good well-being). These dichotomous outcomes were used in bivariate and multivariable logistic regression analyses that estimated the association of patient and caregiver factors with high caregiver burden and poor psychosocial-spiritual well-being. Bivariate analyses were conducted first (results available upon request). Covariates that were significantly associated with caregiver outcomes were used to build multivariable models; covariates that were not significantly associated with caregiver outcomes at the $P<0.01$ level were not examined further (patient ADL impairment, IADL impairment, and disease severity; caregiver age, marital status, gender, work status, perceived support, fighting spirit coping style, and cognitive avoidance coping style). This strategy improved the parsimony of our final multivariable models and improved the ratio of explanatory variables to outcome events.

We used Box-Tidwell transformations to test the linearity of the relationship between continuous variables and the logit of outcome variables. Fatalistic coping style exhibited non-linearity so we categorized it into high (upper quartile), medium, and low (lower quartile) values; all other predictors satisfied the linearity assumption. For all explanatory variables, the variance inflation factor was less than 2.0 and the tolerance level was greater than 0.4; these diagnostics suggest that collinearity among explanatory variables was low and did not lead to unstable model estimates.[43] Because of increased potential for Type I errors when conducting many statistical tests, we report 99% confidence intervals (CI) and note the level of significance with $P<0.01$ or $P<0.001$. We conducted analyses with continuous outcomes to rule out the chance that our findings were a result of the dichotomization cut-point; linear regression results were similar to binary logistic regression results. Overall, general findings were robust to alternate model specifications; thus, for ease of interpretation, we present multivariate, binary models with patient-reported illness factors.

Results

Sample Description

The sample included 139 patient-caregiver dyads: 51 living with cancer, 46 living with CHF, and 42 living with COPD (Table 1). On average, only 23% of patients required ADL assistance and patients needed some help with one to two IADLs. This patient sample is relatively healthy, thus most caregivers are not faced with significant caregiving demands related to ADLs. More than two-thirds of patients reported poor self-rated health and/or high number of bed days in the past three months. The majority of caregivers were the patients' spouse or partner. The caregivers had a median age of 57 years and were predominantly female (81.3%) and married (70.5%). Approximately 70% of the caregivers identified themselves as white/Caucasian. Approximately 50% of the caregivers were currently working (either full- or part-time); 62% had at least some college education; and 25% had difficulty paying their bills. Caregivers reported large social networks (median =13 people) and reported moderate levels of wishing for more help from friends and family. Anxious preoccupation and fatalistic coping styles were most prevalent.

The overall sample was relatively high functioning in terms of psychosocial-spiritual outcomes, with relatively low depressive symptoms, anxiety, and spiritual well-being (reverse coded). Impact on schedule was relatively high, but other burden subscales were relatively moderate (impact on esteem, lack of family support) or low (impact on finances, impact on health).

Differences by Diagnosis

We tested for significant differences in patient illness factors, caregiver characteristics, and caregiver outcomes across cancer, CHF, and COPD diagnoses. Both CHF and COPD patients reported slightly greater IADL impairment than cancer patients. Disease severity also varied by diagnosis, with CHF patients reporting lower disease severity and cancer patients reporting higher disease severity. Most caregivers were women, but there were a greater percentage of male caregivers for cancer than for CHF or COPD. Similarly, most caregivers were white, but there were a greater proportion of nonwhite caregivers for CHF compared to cancer and COPD. There were fewer differences by diagnosis in caregiver resources. Most COPD caregivers were not working, which differed from the pattern for cancer and CHF caregivers. CHF and COPD caregivers reported greater desire for more help from friends and family compared to cancer caregivers. There were no differences by diagnosis in levels of depressive symptoms, anxiety, spiritual well-being, caregiver esteem, or burden associated with finances or personal schedule. Thus, there were significant differences in patient need and caregiver sociodemographic factors and resources between diagnosis groups, but no differences in caregiver burden and psychosocial-spiritual outcomes by diagnosis.

Multivariate Analyses

Multivariate analyses estimated the relative contribution of patient diagnosis, caregiver race, and caregiver socioeconomic, social and coping resources to caregiver burden (Table 2) and psychosocial-spiritual outcomes (Table 3). As noted in the statistical analysis section, only variables that demonstrated a significant bivariate association with caregiver outcomes were included in multivariable models. Although diagnosis was associated with spiritual well-being in bivariate analyses, diagnosis was not significantly associated with any burden or psychosocial-spiritual outcomes in multivariable models. Similarly, caregiver race was associated with impact on finances and lack of family support in bivariate analyses, but was not associated with caregiver outcomes in multivariable models. Caregiver socioeconomic resources – ability to pay bills – were only associated with burden related to finances.

The most robust social resource indicator of caregiver burden was desire for more help from friends and family; greater agreement with this statement was associated with significantly higher odds of health burden (odds ratio [OR]=1.58, 99% CI=1.00, 2.49) and lack of family support (OR=1.95, 99% CI=1.19, 3.19). Desire for more help was also associated with impact on schedule and depressive symptoms, but at the $P<0.05$ level.

Caregiver coping resources also only associated with one burden outcome: greater use of helpless-hopeless coping style was associated with increased odds of burden related to caregiving esteem (OR=1.22, 99% CI=1.01, 1.49). Also, low fatalism was associated with increased odds of poor spiritual well-being (OR=7.38, 99% CI=1.54, 35.42). The most robust finding was that those caregivers with an anxious preoccupation coping style had significantly higher odds of all three poor well-being outcomes: depressive symptoms (OR=1.26, 99% CI=1.06, 1.51), anxiety (OR=1.38, 99% CI=1.14, 1.68), and poor spiritual well-being (OR=1.28, 99% CI=1.05, 1.55).

Discussion

This study examined a sample of caregivers of seriously-ill patients with cancer, CHF and COPD. Three key findings enhance our understanding of variability in caregiver outcomes. First, diagnosis was not significantly associated with caregiver burden or psychosocial-spiritual outcomes in multivariate models. Second, a desire for more help from friends and family was the most robust social resources indicator of caregiver burden. Third, anxious preoccupation coping style was significantly associated with caregiver psychosocial-spiritual well-being. All of this suggests that caregiver burden is not disease-specific in the context of the conditions studied here, but rather a relatively universal experience that may be buffered by social resources and successful coping styles. Caregiver resources, not patient diagnosis or illness severity, may be the primary factors associated with facets of caregiver burden and well-being.

Participants in this study reported similar levels of caregiver burden to those in other caregiving populations,[44] but few differences between diagnosis groups. We did find significant differences in patient need and caregiver sociodemographic factors between diagnosis groups, but no differences in psychosocial-spiritual outcomes. This study corroborates the existing literature[27] and advances the field by building on and extending the previous findings in several key ways. First, our sample was racially and socioeconomically diverse. Second, this study augmented previous research by assessing multiple domains of caregiver burden as well as a variety of additional caregiver psychosocial-spiritual outcomes. Third, this study moves beyond assessment of the impact of social resources on caregiver outcomes to test the influence of psychological coping styles. The inclusion of these additional measures extends the literature and highlights which characteristics have isolated effects and which demonstrate robust patterns across caregiver outcomes.

We found that the most robust social resources indicator of caregiver outcomes was desire for more help from friends and family; greater agreement with this statement was associated with significantly higher odds of facets of burden. This finding is particularly interesting given that the size of the network reported in our caregiving population was relatively large, yet the number of individuals does not appear to be translating into more help. In addition, this finding is consistent with the social support literature indicating that perceived quality of social support is more important than size of the social network in improving caregiver outcomes.[45] Future research should assess where the additional help that caregivers need should come from if it is not derived from the size of the social network. The well-being of the caregiver is often the most important factor in keeping a patient out of a hospital or nursing home; therefore, it is vitally important for both the patient and the caregiver to recognize and meet the needs of informal caregivers.[12]

The finding regarding need for additional help from family and friends is similar to the finding reported in previous research that the caregiver's report of need for greater help with daily tasks was the strongest predictor of caregiver burden.[27] Our study corroborated that finding in a more diverse sample. Whereas the wording of the questions is slightly different, the results are strikingly similar. Taken together, these findings suggest that there may be clinical relevance to using a simple question assessing a caregiver's need for additional help with caregiving tasks as a preliminary screening tool for burden. This single-item assessment would be used in a similar way as the question "Are you depressed?" that has demonstrated clinical validity.[46] If such a simple screening question was found to be clinically valid, it could be used to refer for more in-depth assessment and treatment, if indicated, or to refer caregivers to available community resources.

This study examined the association between caregiver coping style and outcomes, and our findings suggest areas in which treatment may be helpful. Anxious preoccupation coping style was significantly associated with caregiver well-being, including depressive symptoms, anxiety, and spiritual well-being. This coping style, when applied to caregivers, is characterized by high anxiety that is often focused on seeking more information about the patient's illness.[37] Unfortunately, such information seeking may not alleviate the anxiety, and this coping style has been identified as maladaptive and associated with negative psychosocial outcomes.[37, 47, 48] There is an extensive body of literature documenting increased risk for physical and mental health decrements, including increased mortality, in caregivers who report high levels of stress.[8-11] Identifying caregivers who exhibit this anxious coping style and targeting them for support and interventions focusing on emotional state and coping, rather than simply informational needs, could lead to a significant improvement in caregiver well-being.

This study has several limitations. First, analyses are cross-sectional so there is no way to assess the direction of relationship between predictors and outcomes. Although steps were taken to reduce reverse causation (for example, using patient-reported functional status and disease severity measures), it is possible that caregiver burden and poor psychosocial-spiritual well-being influence caregivers' ratings of variables like social support. Longitudinal analyses would not only clarify relationships but also inform understanding of outcomes across the caregiving career. Second, the sample was drawn from one region in the southern U.S. and included mostly white and African-American participants. Thus, findings may not be generalizable. Third, the current study lacks measures of caregiver health status, which may influence caregiver outcomes. Fourth, the large number of statistical tests increases the chance of falsely identifying significant associations. Several parameters were only significant at the $P<0.05$ level; however, our most important predictors of burden and well-being – need more help and anxious preoccupation coping style – stand up to more stringent tests at the $P<0.01$ and $P<0.001$ levels. Finally, the patients studied here are relatively healthy, with 77% of patients requiring no ADL assistance and an average of two IADL impairments. Similarly, the caregivers in the study report relatively high psychosocial-spiritual well-being with small variation. Patterns and outcomes may differ for caregivers who face more significant caregiving demands.

Our findings indicate that caregiver resources, not patient diagnosis or illness severity, are the primary predictors of facets of caregiver burden and other caregiver outcomes. Additionally, caregiver burden is not disease-specific, but rather a relatively universal experience among cancer, CHF, and COPD caregivers that may be buffered by social resources and successful coping styles. Thus, instead of focusing on disease category and other patient characteristics, future research and interventions should address caregiver resources, particularly the presence of a strong and effective social network and the use of healthy and adaptive coping styles.

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References

1. Wilkinson AM, Lynn J. Caregiving for advanced chronic illness patients. Tech Reg Anesth Pain Manag. 2005; 9:122–132.
2. The American Cancer Society. [Accessed January 8, 2010] Cancer prevalence: how many people have cancer?. 2010. Available from http://www.cancer.org/docroot/cri/content/cri_2_6x_cancer_prevalence_how_many_people_have_cancer.asp
3. National Lung Health Education Program. [Accessed January 8, 2010] 2010. Available from http://www.nlhep.org/faqs.html
4. National Heart, Lung and Blood Institute. [Accessed January 8, 2010] Congestive heart failure in the United States: a new epidemic. 2010. Available from http://library.thinkquest.org/27533/facts.html
5. National Alliance for Caregiving in Collaboration with AARP. [Accessed January 25, 2011] Caregiving in the U.S. 2009. 2009. Available from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf
6. Rabow M, Hauser J, Adams J. Supporting family caregivers at the end of life: "They don't know what they don't know. JAMA. 2004; 291:483–491. [PubMed: 14747506]
7. Zarit, SH. Assessment of family caregivers: a research perspective; A Report from a National Consensus Development Conference Caregiver Assessment: principles, guidelines, and strategies for change; San Francisco: National Center on Caregiving at Family Caregiver Alliance. 2006; p. 12-36.Available from www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf
8. Roth DL, Perkins M, Wadley VG, Temple E, Haley WE. Family caregiving and emotional strain: associations with psychological health in a national sample of community-dwelling middle-aged and older adults. Qual Life Res. 2009; 18:679–688. [PubMed: 19421895]
9. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. JAMA. 1999; 282(23):2215–2219. [PubMed: 10605972]
10. Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. J Gerontol B Psychol Sci Soc Sci. 2007; 62:P126–P137. [PubMed: 17379673]
11. Vitaliano PV, Scanlan JM, Zhang J. Is caregiving hazardous to one's physical health? A meta-analysis. Psychol Bull. 2003; 129:946–972. [PubMed: 14599289]
12. Family Caregiver Alliance. [Accessed June 15, 2010] Caregiving. Available from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2313
13. Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. Eur J Heart Fail. 2005; 7:592–603. [PubMed: 15921800]
14. Gure TR, Kabeto MU, Blaum CS, Langa KM. Degree of disability and patterns of caregiving among older Americans with congestive heart failure. J Gen Intern Med. 2008; 23(1):70–76. [PubMed: 18030537]
15. Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. J Am Geriatr Soc. 2000; 48:S101–S109. [PubMed: 10809463]
16. Lynn J. Serving patients who may die soon and their families: the role of hospice and other services. JAMA. 2000; 285:925–932. [PubMed: 11180736]
17. Caress A, Luker KA, Chalmers KI, Salmon MP. A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. J Clin Nurs. 2009; 18(4):479–491. [PubMed: 19191997]
18. Pinto RP, Holanda MA, Medeiros MMC, Mota RMS, Pereira EDB. Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease. Respir Med. 2007; 101:2402–2408. [PubMed: 17624751]
19. Haley, WE.; Bailey, S. Research on family caregiving in Alzheimer's disease: implications for practice and policy. In: Vellas, B.; Fitten, JL., editors. Research and practice in Alzheimer's disease. Vol. 2. Serdi Publishers; Paris: 1999. p. 321-332.

20. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. Gerontologist. 1995; 35:771–791. [PubMed: 8557205]
21. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology. 2010; 19:1013–1025. [PubMed: 20014159]
22. Hanratty B, Holland P, Jacoby A, Whitenhead M. Financial stress and strain associated with terminal cancer-a review of the evidence. Palliat Med. 2007; 21:595–607. [PubMed: 17942498]
23. Weitzner M, Haley WE, Chen H. The family caregiver of the older cancer patient. Hematol Oncol Clin North Am. 2000; 14:269–281. [PubMed: 10680082]
24. Steinhauser KE, Arnold RM, Olson MK, et al. Comparing three life-limiting diseases: does diagnosis matter, or is sick, sick? J Pain Symptom Manage. Sep; 2011 42(3):331–341. [PubMed: 21276704]
25. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003; 289(18):2387–2392. [PubMed: 12746362]
26. Stajduhar K, Funk L, Toye C, et al. Part 1: Home-based family care-giving at the end of life: a comprehensive review. Palliat Med. 2010; 24(6):573–593. [PubMed: 20562171]
27. Garlo K, O'Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. J Am Geriatr Soc. 2010; 58:2315–2322. [PubMed: 21087225]
28. Steinhauser K, Clipp E, Hays J, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. Palliat Med. 2006; 20:745–754. [PubMed: 17148529]
29. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged: the index of ADL, a standardized measure of bilogical and psychosocial function. JAMA. 1963; 185(2): 914–919. [PubMed: 14044222]
30. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969; 9:179–186. [PubMed: 5349366]
31. Mossey JM, Shapiro E. Self-rated health: a predictor of mortality among the elderly. Am J Public Heath. 1982; 72(8):800–808.
32. Gardner DS, Kramer BJ. End-of-life concerns and care preferences: congruence among terminally ill elders and their family caregivers. Omega. 2009; 60(3):273–297. [PubMed: 20361726]
33. Dumont S, Turgeon J, Allard P, et al. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. J Palliat Med. 2006; 9(4):912–921. [PubMed: 16910806]
34. Brazil K, Bédard M, Willison K, Hode M. Caregiving and its impact on families of the terminally ill. Aging Ment Health. 2003; 7(5):376–382. [PubMed: 12959807]
35. Moore M, Zhu C, Clipp E. Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. J Gerontol B Psychol Sci Soc Sci. 2001; 56(4):S219–228. [PubMed: 11445614]
36. Clipp E, George L. Caregiver needs and patterns of social support. J Gerontol. 1990; 45:S102–111. [PubMed: 2335732]
37. Watson M, Law M, dos Santos M, et al. The Mini-MAC: further development of the Mental Adjustment to Coping scale. J Psychosoc Oncol. 1994; 12:33–46.
38. Given CW, Given B, Stommel M, et al. The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Res Nurs Health. 1992; 15:271–283. [PubMed: 1386680]
39. Andersen E, Malmgren J, Carter W, Patrick D. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). Am J Prev Med. 1994; 10:77–84. [PubMed: 8037935]
40. Radloff L. The CES-D Scale: a self-report depressional scale for research in the general population. Appl Psychol Meas. 1977; 1:385–401.
41. Cella D, Jacobsen P, Orav E, et al. A brief POMS measure of distress for cancer patients. J Chronic Dis. 1987; 40(10):939–942. [PubMed: 3611291]
42. Brady M, Peterman A, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. Psychooncology. 1999; 8:417–428. [PubMed: 10559801]

43. Allison, PD. Logistic regression using the SAS system: Theory and application. SAS Institute, Inc.; Cary, NC: 1999.

44. Grov EK, Fossa SD, Tonnessen A, Dahl AA. The Caregiver Reaction Assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. Psychooncology. 2006; 15:517–527. [PubMed: 16189843]

45. Roth DL, Mittleman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spousal caregivers of person with Alzheimer's disease. Psychol Aging. 2005; 20(4):634–644. [PubMed: 16420138]

46. Skoogh J, Ylitalo N, Larsson Omeróv P, et al. A no means no'--measuring depression using a single-item question versus Hospital Anxiety and Depression Scale (HADS-D). Ann Oncol. 2010; 21(9):1905–1909. [PubMed: 20231301]

47. Grassi L, Buda P, Cavana L, et al. Styles of coping with cancer: the Italian version of the Mini-Mental Adjustment to Cancer (Mini-MAC) scale. Psychooncology. 2005; 14(2):115–124. [PubMed: 15386782]

48. Ho SM, Fung WK, Chan CL, Watson M, Tsui YK. Psychometric properties of the Chinese version of the Mini-Mental Adjustment to Cancer (MINI-MAC) scale. Psychooncology. 2003; 12(6):547–556. [PubMed: 12923795]

Table 1

Variable Distributions for Full Sample and by Diagnosis

	Total (*n*=139)	**Cancer (*n*=51)**	**CHF (*n*=46)**	**COPD (*n*=42)**
Patient Illness				
ADL Impaired	23.02%	11.76%	34.78%	23.81%
Patient IADLs (7-21)[c]	9 (3.00)[b]	7 (2.12)	10 (2.99)	10.50 (3.25)
Patient Disease Severity				
Low	28.78%[a]	17.65%	41.30%	28.57%
Moderate	41.01%[a]	39.22%	41.30%	42.86%
High	30.22%[a]	43.14%	17.39%	28.57%
Caregiver-Patient Relationship				
Spouse/Partner	56.83%	64.71%	54.35%	50.00%
Other (Child, Friend, Sibling)	43.17%	35.29%	45.65%	50.00%
Caregiver Demographics				
Age in years (22-100)	57 (14.88)	54 (14.21)	57.5 (17.10)	59.50 (13.12)
Gender				
Female	81.29%[a]	66.67%	95.65%	83.33%
Male	18.71%[a]	33.33%	4.35%	16.67%
Marital Status				
Single	29.50%	29.41%	30.43%	28.57%
Married/Living as Married	70.50%	70.59%	69.57%	71.43%
Race/Ethnicity				
White/Caucasian	69.78%[a]	80.39%	50.00%	78.57%
Nonwhite	30.22%[a]	19.61%	50.00%	21.43%
Caregiver Socioeconomic Resources				
Employment Status				
Working	48.92%[a]	62.75%	52.17%	28.57%
Not Working	51.08%[a]	37.25%	47.83%	71.43%
Education				
High School/GED or Less	38.13%	23.53%	47.83%	45.24%
Some College or More	61.87%	76.47%	52.17%	54.76%
Financial Security				
Difficulty Paying Bills	25.90%	19.61%	32.61%	73.81%
Able to Pay Bills	74.10%	80.39%	67.39%	26.19%
Caregiver Social Resources				
# in Social Network	13 (6.29)	13 (6.37)	14 (6.07)	13 (6.58)
Desire for More Help (1-5)	2 (1.19)[a]	2 (1.25)	3 (1.09)	3 (1.12)
Caregiver Coping Resources (Mini-MAC)				

	Total (*n*=139)	**Cancer (*n*=51)**	**CHF (*n*=46)**	**COPD (*n*=42)**
Helpless-Hopeless (8-32)	15 (3.54)[a]	14 (3.48)	15 (3.43)	14 (3.42)
Fighting Spirit (8-32)	11 (1.94)[a]	12 (1.90)	11 (2.09)	11 (1.55)
Fatalism (5-20)	17 (1.82)	17 (1.92)	17 (1.75)	18 (1.74)
Anxious Preoccupation (8-32)	20 (4.05)	20 (4.09)	20 (4.27)	19 (3.68)
Cognitive Avoidance (4-16)	9 (2.15)	9 (2.29)	10 (2.12)	9 (2.02)
Caregiver Outcomes				
CES-D Depression (0-26)	6 (5.87)	6 (5.66)	6.5 (5.40)	6.5 (6.67)
POMS Anxiety (0-20)	5 (4.58)	5 (4.25)	7 (4.86)	5 (4.74)
Facit-SP Spiritual Well-being (0-48)	11 (7.79)	12 (7.59)	12 (8.33)	9 (7.26)
CRA Caregiver Burden				
Impact on Esteem (7-35)	12 (4.12)	12 (4.66)	14 (3.63)	13 (3.95)
Lack of Family Support (5-25)	11 (3.85)	10 (3.85)	12 (3.96)	11.5 (3.48)
Impact on Finances (3-15)	6 (2.84)	6 (3.10)	7 (2.70)	7 (2.58)
Impact on Schedule (5-25)	15 (4.54)	13 (4.34)	15 (5.00)	16 (4.10)
Impact on Health (4-20)	8 (2.75)	8 (2.61)	10 (2.51)	8.5 (2.92)

Note: All results are reported as median (standard deviation) for continuous variables and percentage for categorical variables.

[a] $P<0.01$. indicate significant differences by diagnosis based on Kruskal Wallis tests.

[b] $P<.001$. indicate significant differences by diagnosis based on Kruskal Wallis tests.

[c] Possible value ranges are listed in the first column for continuous variables.

Table 2

Caregiver Burden Outcomes: Odds Ratios and 99% Confidence Intervals

	Impact on Schedule[c]	**Impact on Caregiver Esteem**	**Impact on Finances**	**Impact on Health**	**Lack of Family Support**
Patient Diagnosis (cancer ref.)					
CHF	1.67 (0.44, 6.32)	2.20 (0.60, 8.09)	1.48 (0.37, 5.96)	2.03 (0.52, 7.89)	1.35 (0.33, 5.52)
COPD	2.51 (0.71, 8.85)	2.41 (0.68, 8.50)	2.84 (0.76, 10.62)	2.05 (0.56, 7.51)	1.71 (0.45, 6.52)
Caregiver Demographics					
Nonwhite (White/Caucasian ref.)	0.61 (0.18, 2.07)	0.99 (0.29, 3.38)	1.22 (0.34, 4.34)	0.84 (0.23, 3.05)	2.36 (0.64, 8.74)
Caregiver Socioeconomic Resources					
Some College or More (HS or less ref.)	0.72 (0.25, 2.12)	1.09 (0.36, 3.24)	0.38 (0.12, 1.20)	0.84 (0.27, 2.58)	1.06 (0.33, 3.42)
Difficulty Paying Bills (no difficulty ref.)	1.02 (0.32, 3.21)	1.08 (0.33, 3.53)	4.35 (1.20, 15.82)[a]	0.57 (0.16, 2.00)	1.36 (0.39, 4.71)
Caregiver Social Resources					
# in Social Network	0.95 (0.88, 1.04)	1.03 (0.95, 1.12)	0.95 (0.87, 1.04)	0.96 (0.88, 1.04)	0.93 (0.85, 1.01)
Desire For More Help	1.41 (0.92, 2.16)	1.07 (0.69, 1.65)	1.33 (0.84, 2.10)	1.58 (1.00, 2.49)[a]	1.95 (1.19, 3.19)[b]
Caregiver Coping Resources					
Helpless-Hopeless	0.92 (0.77, 1.10)	1.22 (1.01, 1.49)[a]	0.96 (0.79, 1.16)	1.10 (0.90, 1.33)	1.03 (0.84, 1.26)
Anxious Preoccupation	1.13 (0.97, 1.32)	0.92 (0.79, 1.07)	0.99 (0.84, 1.16)	1.16 (0.98, 1.38)	1.12 (0.95, 1.32)
High Fatalism (moderate ref.)	0.75 (0.23, 2.50)	0.43 (0.12, 1.50)	0.39 (0.10, 1.51)	2.46 (0.66, 9.16)	0.76 (0.20, 2.98)
Low Fatalism (moderate ref.)	0.43 (0.11, 1.66)	1.56 (0.41, 5.84)	0.56 (0.14, 2.31)	1.52 (0.40, 5.82)	1.13 (0.29, 4.36)
Pseudo R-Squared	0.1406	0.1633	0.2329	0.2171	0.254
C Statistic	0.711	0.731	0.783	0.782	0.806

n=139.

[a] $P<0.01$.

[b] $P<0.001$.

[c] All outcomes are binary; logistic regression models predict likelihood of high burden (above median).

Table 3

Caregiver Well-Being Outcomes: Odds Ratios and 99% Confidence Intervals

	Depressive Symptoms[c]	**Anxiety**	**Spiritual Well-Being**
Patient Diagnosis (cancer ref.)			
CHF	1.22 (0.30, 5.06)	2.05 (0.49, 8.69)	0.72 (0.16, 3.23)
COPD	1.37 (0.36, 5.17)	1.46 (0.39, 5.49)	0.24 (0.05, 1.09)
Caregiver Demographics			
Nonwhite (White/Caucasian ref.)	0.66 (0.17, 2.51)	0.75 (0.20, 2.83)	0.55 (0.13, 2.23)
Caregiver Socioeconomic Resources			
Some College or More (HS or less ref.)	1.06 (0.33, 3.40)	1.93 (0.59, 6.27)	1.28 (0.34, 4.74)
Difficulty Paying Bills (no difficulty ref.)	0.79 (0.23, 2.77)	0.60 (0.17, 2.14)	1.54 (0.42, 5.61)
Caregiver Social Resources			
# in Social Network	0.89 (0.81, 0.98)	0.99 (0.91, 1.09)	0.94 (0.85, 1.04)
Desire For More Help	1.48 (0.92, 2.39)	1.22 (0.77, 1.94)	1.27 (0.76, 2.12)
Caregiver Coping Resources			
Helpless-Hopeless	0.99 (0.81, 1.21)	0.98 (0.80, 1.20)	1.09 (0.88, 1.36)
Anxious Preoccupation	1.26 (1.06, 1.51)[b]	1.38 (1.14, 1.68)[b]	1.28 (1.05, 1.55)[a]
High Fatalism (moderate ref.)	1.78 (0.46, 6.81)	2.04 (0.52, 8.01)	0.72 (0.17, 3.05)
Low Fatalism (moderate ref.)	1.22 (0.31, 4.79)	0.95 (0.23, 3.84)	7.38 (1.54, 35.42)[a]
Pseudo R-Squared	0.2499	0.2508	0.3523
C Statistic	0.798	0.802	0.848

n=139.

[a] $P<0.01$.

[b] $P<0.001$.

[c] All outcomes are binary; logistic regression models predict likelihood of poor well-being (above median).