Published in final edited form as:

Support Care Cancer. 2017 August ; 25(8): 2437–2444. doi:10.1007/s00520-017-3650-7.

The Self-Care Practices of Family Caregivers of Persons with Poor Prognosis Cancer: Differences by Varying Levels of Caregiver Well-being and Preparedness

J. Nicholas Dionne-Odom, PhD, RN¹, Wendy Demark-Wahnefried, PhD, RD², Richard A. Taylor, DNP, CRNP¹, Gabrielle B. Rocque, MD³, Andres Azuero, PhD¹, Aras Acemgil, MBA⁴, Michelle Y. Martin, PhD⁵, Meka Astin, MPH¹, Deborah Ejem, PhD¹, Elizabeth Kvale, MD⁶, Karen Heaton, PhD¹, Maria Pisu, PhD⁴, Edward E. Partridge, MD³, and Marie A. Bakitas, DNSc, CRNP^{1,6}

¹School of Nursing, University of Alabama at Birmingham (UAB), 1720 2nd Avenue South, Birmingham, AL 35294

²Department of Nutrition Sciences, UAB, 1675 University Blvd., Birmingham, AL 35233

³UAB Comprehensive Cancer Center, 1824 6th Avenue South, Birmingham, AL 35233

⁴Department of Preventive Medicine, UAB, 1720 2nd Avenue South, Birmingham, AL 35294

⁵Department of Preventive Medicine, University of Tennessee Health Science Center, 66 N. Pauline Street, Memphis, TN 38163

⁶Department of Medicine, Division of Geriatrics, Gerontology, and Palliative Care UAB Center for Palliative and Supportive Care, 1720 2nd Avenue South, Birmingham, AL 35294

Abstract

Purpose—Little is known about the impact of family caregiving for adults with poor prognosis cancer on caregivers' own individual self-care practices. We explored differences in caregivers' discrete self-care practices associated with varying levels of caregiver well-being, preparedness, and decision-making self-efficacy.

Methods—Cross-sectional survey within eight community-based southeastern U.S. cancer centers. Family caregivers of Medicare beneficiaries 65 years with pancreatic, lung, brain, ovarian, head & neck, hematologic, or stage IV cancer completed measures of individual self-care practices (health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, stress management, and sleep), well-being (anxiety, depression, and health-related quality of life [HRQoL]), preparedness, and decision-making self-efficacy.

Results—Caregivers ($n=294$) averaged 66 years, were mostly female (72.8%), white (91.2%), Protestant (76.2%), retired (54.4%) and patients' spouse/partner (60.2%). Approximately half

Corresponding author: J. Nicholas Dionne-Odom, PhD, RN, School of Nursing, University of Alabama at Birmingham, 1720 2nd Ave South, 2M019H, Birmingham, AL 35294-1210, dionneod@uab.edu, Fax: 205-975-6194, Office: 205-934-7597.

Conflict of Interest Statement

All authors have declared no relevant conflict of interests. Dr. Dionne-Odom has full control over data for this study and has made it subject to review by *Supportive Care in Cancer*.

were rural-dwellers (46.9%) with incomes <\$50,000 (53.8%). Most provided support 6–7 days/week (71%) for >1 year (68%). Nearly a quarter (23%) reported high depression and 34% reported borderline or high anxiety. Low engagement in all self-care practices was associated with worse caregiver anxiety, depression, and mental HRQoL (all p -values<.05). Caregivers with lower health responsibility, spiritual growth, interpersonal relation, and stress management scores had lower preparedness and decision-making self-efficacy.

Conclusions—A significant proportion of caregivers simultaneously report low engagement in all forms of self-care practices, high depression and anxiety, and low HRQoL mental health scores. Caregiver well-being, preparedness, and decision-making self-efficacy might be optimized through interventions targeted at enhancing health responsibility, stress management, interpersonal relationships, and spiritual growth self-care practices.

Keywords

caregivers; cancer; self-care; well-being

Background

Family caregivers of individuals with poor prognosis cancer provide vital care at home, including symptom, dietary, and medication monitoring and management, emotional and spiritual support, transportation, care coordination and provider communication, and decision-making support [1, 2]. These time consuming tasks (on average of 8 hours a day) [3] may disrupt family caregivers' stress reducing and health preserving self-care practices. Self-care is defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and wellbeing"[4]. Self-care practices include healthy eating, physical activity, adequate rest, balancing solitude and social interaction, stress management, and staying spiritually connected [5].

While patient self-care behaviors have been a topic of considerable research interest, to our knowledge, there has been very little research examining caregiver self-care practices, particularly in the cancer context. Specifically, it is unknown to what degree cancer caregivers' engagement in self-care practices impacts their own well-being and their ability to perform in the caregiving role. Theories of self-care, including Pender's Health Promotion Model [6] and Riegel's Middle-Range Theory of Self-Care of Chronic Illness [7], suggest that engagement in self-care behaviors leads to better health, functional ability, and quality of life. In the setting of cancer caregiving, individuals may be so engrossed in caregiving tasks that they neglect their self-care and increase their risk of worse health and quality of life. As has been suggested by some, worse caregiver well-being and functional ability might then further impact the quality of care delivered to patients [8, 9]. Hence, our group aimed to describe the specific self-care practices of family caregivers of individuals with advanced cancers and to determine their association with caregiver well-being and caregiving preparedness.

Methods

We conducted a cross-sectional mail survey study of family caregivers of older adults with cancer affiliated with eight medical centers in three states (Alabama, Florida, Tennessee) from March 2015–July 2015. The institutional review boards of all participating medical centers approved this study. Participants' consent was implied through voluntary completion of the survey.

Participants

Family caregivers were identified via care recipients who were participating in a Center for Medicare and Medicaid Services (CMS) Health Care Innovation Challenge-funded demonstration project called Patient Care Connect (PCC). PCC, described in detail elsewhere [10], was a large-scale lay navigation program for community-dwelling Medicare beneficiaries 65 years with a cancer diagnosis living in the southeastern U.S.. Family caregivers were identified by a subset of PCC patients who had “poor prognosis” cancers, defined within the CMS project as documented diagnosis of cancers with known high morbidity, mortality, distress, and healthcare utilization rates (regardless of stage) that included pancreatic, lung, brain, ovarian, head and neck, hematologic, in addition to any and all stage IV cancers. These patients were asked in a mailed letter to identify an eligible caregiver, defined as a “friend or family member who helps the most with your medical care, who is not paid for their support, and who may or may not live in the same home with you.”

Procedures

The mailed survey was conducted using a modified Dillman-tailored design approach [11]. A pre-notice letter was sent to patients to inform them that in the next few days, they would receive a survey to be completed by their primary family caregiver (as defined above). Five days later, a paper survey and cover letter were mailed. A postcard was sent one week later that expressed thanks to individuals if their caregivers had returned a survey and if not, to prompt them to please do so. Three weeks after the postcard, a replacement survey was sent to the patient if no caregiver survey had been received. Caregivers who completed a survey were sent a thank-you letter and a \$10 check. A REDCap database was used for tracking and storing survey data, which was double-key entered by study coordinators.

Survey Measures

Self-reported caregiver demographic data included: age, gender, race, marital status, total household income, religious affiliation, employment status, rural/suburban/urban residence, relationship to care recipient, number of months as a caregiver, number of days per week and hours per day providing care, and care recipient age, gender, diagnosis, and perceived health from “Excellent” to “Poor”.

Self-care practices

Health promoting lifestyle profile II (HPLP-II)—Self-care practices were measured using the 52-item HPLP-II. Six subscales represent engagement in six different self-care practices: health responsibility (e.g., reporting symptoms and health concerns to healthcare professionals); physical activity (e.g., following an exercise program, taking part in leisure-

time physical activities); nutrition (e.g., limiting sugar intake, reading food labels), spiritual growth (e.g., working towards long-term goals, believing that life has purpose, connecting with a force greater than myself); interpersonal relations (e.g., getting support from caring people, showing concern, love, and warmth to others), and stress management (e.g., taking time to relax, using stress control methods, pacing myself). Response categories are “Never=1,” “Sometimes=2,” “Often=3,” or “Routinely=4”; higher scores indicate more frequent engagement in the self-care practice [12]. In this study, Cronbach’s alpha reliability was .95 for the total scale and ranged from .78 to .89 for the six subscales.

Caregiver well-being

Hospital anxiety and depression scale (HADS)—Symptoms of anxiety and depression over the past week were measured using the 14-item HADS [13] which includes seven items each for anxiety and depression. Subscale scores range from 0 to 21; scores of 0–7 indicate normal mood, 8–10 indicate borderline cases, and 11–21 indicate abnormal (poor) mood. Cronbach’s alphas for this study were .84 for anxiety and depression subscales.

Short form 12 health survey questionnaire version 2 (SF12v2)—Health-related quality of life (HRQoL) over the past 4 weeks was measured using the 12-item SF12v2 [14]. Physical and mental health subscale scores are converted using an algorithm that standardizes the scores to a T-scale with a mean of 50 (based on the U.S. general population) and standard deviation of 10; higher scores represent higher HRQoL. Cronbach’s alpha in the general U.S. population is .88 for physical and .82 for mental HRQoL.

Caregiver preparedness

Preparedness for caregiving scale—This is an 8-item scale [15] that measures multiple domains of caregiving such as providing physical care, emotional support, and setting up in-home support services. Mean score totals range from 0 to 4; higher scores indicate better preparedness. Cronbach’s alpha for this study was .91.

Family decision-making self-efficacy scale (FDMSES)—Caregiver decision-making ability was measured using the 13-item FDMSES [16], which asks caregivers if they could help sick loved ones make decisions on a 5-point scale ranging from “Cannot do at all=0” to “Certain I can do=5.” Items include decisions about resuscitation, care at the end of life, continuing to fight the disease, food and fluids, making decisions consistent with beliefs, and family burden. Scores range from 13–65; higher scores indicate higher confidence in being able to help with the patient’s decision-making. Cronbach’s alpha for this study was .96.

Statistical Analysis

Participant demographic characteristics were tabulated as counts and percentages. Descriptive statistics including overall mean, median, and range were calculated for self-care practice and caregiver well-being and performance scores. Differences in individual self-care practices were calculated using Kruskal-Wallis test by level of well-being (i.e. anxiety, depression, physical and mental health) and caregiver performance (i.e. competence, preparedness, and decision-making self-efficacy). Anxiety and depression scores were

divided into tertiles (high, borderline, and low). For exploratory purposes, physical and mental health scores, caregiver competence, and caregiver preparedness were grouped into quartiles (high, middle (second and third quartiles), and low. For decision-making self-efficacy, the distribution was left-skewed, hence, values were grouped into high (top 3 quartiles) and low (first quartile). To correct for multiple testing, we adjusted all p-values using a False Discovery Rate (FDR) [17]. The FDR measures study error defined as the expected fraction of erroneous findings among all ‘statistically significant’ findings. The overall percentage of missing data in the analytical dataset was under 3%. Prior to analysis, the missing data were imputed using a Random Forest approach [18].

Results

Two-hundred and ninety-four of 695 potential participants returned surveys for an overall response rate of 42.3%. Nonresponder analyses revealed significant differences in patients’ race and marital status. Fewer caregivers of Black or African-Americans ($p<.01$) and unmarried care recipients ($p<.01$) responded to the survey. There were no significant differences in age, gender, and cancer type.

Caregivers had a mean (SD) age of 65.5 (12.7) years, were mostly female ($n=214$ [72.8%]), white ($n=268$ [91.2%]), married or living with a partner ($n=243$ [82.6%]), Protestant ($n=224$ [76.2%]), retired ($n=160$ [54.4%]), rural-dwelling ($n=130$ [46.9%]), and spouses or partners of the patient ($n=177$ [60.2%]). Caregivers came from a range of total household incomes, with 29.3% ($n=86$) having incomes $<\$30,000$, 24.5% ($n=72$) having $\$30,000$ – $49,999$, and 36.4% ($n=107$) having $\$50,000$ – $100,000$. Mean length of caregiving was 33.5 months. Most provided support 6–7 days/week ($n=209$ [71%]) and 32% ($n=96$) provided care >5 hours/day. Care recipients had a mean age (SD) of 75.3 (6.6) years and were mostly male ($n=160$ [54.4%]) with lung ($n=114$ [38.8%]), head and neck ($n=62$ [21.1%]), and leukemia and non-Hodgkin lymphoma ($n=30$ [10.2%]) cancer diagnoses. Forty-three percent ($n=127$) of caregivers reported that the care recipient’s health was poor or fair (Table 1).

Table 2 shows overall descriptive statistics for self-care practice and caregiver well-being and performance scores. Of the individual self-care practices, caregivers had the highest mean scores for spiritual growth and interpersonal relations and the lowest mean scores for physical activity. On average, caregivers fell into normal mood ranges for anxiety and depression scores.

Association between Self-Care Practices and Caregiver Well-Being

Table 3 shows associations between caregivers’ self-care practices and levels of anxiety (normal, borderline, high), depression (high, middle, low quartiles) and physical and mental health (high, middle, low quartiles) scores. Nearly a quarter of respondents reported high depression scores ($n=68$ [23%]) and 34% ($n=99$) reported borderline or high anxiety scores. All self-care practices were statistically significantly worse (all p-values $.01$) for participants with higher anxiety and depression scores and for participants with the lowest quartile of mental health scores. These findings remained significant even after adjusting for multiple testing.

Associations between Self-Care Practices and Level of Caregiving Performance

Table 3 also shows associations between caregivers' self-care practice scores and levels of caregiving performance scores (i.e. caregiver competence, preparedness, and decision-making self-efficacy). Lower self-care practice scores for health responsibility, physical activity, spiritual growth, interpersonal relations, and stress management were associated with lower caregiver preparedness (all p values $< .05$). Lower spiritual growth and stress-management self-care practice scores were associated with the lowest 25% of participants for all three performance measures. Lower health responsibility and stress management scores were associated with lower caregiver preparedness and decision-making self-efficacy (all p -values $< .01$). Again, these findings remained robust after applying False Discovery Rates.

Discussion

This is the first study to comprehensively examine the self-care practices of caregivers of adults with poor prognosis cancers. Results from surveys of 294 advanced cancer patients' family caregivers demonstrated that low scores in *every* self-care practice were associated with worse caregiver well-being (i.e. anxiety, depression, and mental HRQoL scores). Furthermore, caregivers who engaged in fewer health responsibility, spiritual growth, interpersonal relation, and stress management self-care practices were associated with poorer performance in caregiving activities (i.e., competence, preparedness, and decision-making efficacy).

There were strong associations between low engagement in *all* self-care practices and worse caregiver anxiety, depression, and mental HRQoL scores. These findings suggest that these caregivers were either unable or reluctant to engage in activities to maintain their health. Adding to this concern of such poor caregiver self-care was the additional finding that approximately 1-in-4 reported clinically high depression and low mental health scores and 1-in-3 reported borderline or high anxiety scores. These rates of poor caregiver mental health are consistent with other studies [19–22] and further underscore the risk that advanced cancer caregiving can have on mental well-being.

Lack of engagement in self-care practices may be partly due to caregivers not having enough time to do so; indeed, 7-out-of-10 caregivers were caring for their care recipient 6–7 days per week and 1-out-of-3 provided care for >5 hours per day. Caregivers may also be neglecting their self-care needs out of a sense of duty to be dedicated to providing support. A qualitative study by Furlong and colleagues [23] of dementia caregivers found that caregivers felt unworthy of self-care and their self-care needs were not seen as important by those they cared for. Future work might explore this possible tension between balancing the needs of the care recipient with the self-care of these caregivers. Researchers should consider developing interventions that help caregivers balance the support they give to care recipients with their own self-care needs, perhaps by leveraging respite and paid care.

Poorer spiritual growth and interpersonal relations self-care practices were associated with lower scores for all three caregiver performance measures (competence, preparedness, and decision-making self-efficacy). Caregivers endorsing poor spiritual growth practices may

have difficulty assigning a higher meaning, value and sense of purpose to their caregiving role [24, 25]. This may in turn decrease motivation to become more knowledgeable and proficient in caregiving tasks. It is also possible that individuals who perform caregiving tasks less than optimally take longer to complete tasks, thus taking time away from spiritually-enriching activities and practices. Individuals with low caregiving performance scores also endorsed fewer practices that fostered interpersonal relationships that were close, meaningful, and allowed them to share thoughts and feelings. Researchers might consider developing behavioral activation programs that facilitate spiritual growth and interpersonal relations while at the same time offering education, training, and external assistance to increase caregiving performance.

Fewer health responsibility and stress management self-care practices were associated with lower scores for caregiver preparedness and decision-making self-efficacy. As speculated above, persons poorly prepared for caregiving may take longer to perform tasks thereby taking time away from their health responsibility and stress management practices. Alternatively, individuals not feeling prepared for caregiving might reflect their own limited knowledge of how to maintain health in general, as evidenced by their lack of managing their own health. A review by Bevan and Pecchioni [26] aiming to understand the link between family caregiver health literacy and patient health outcomes suggested that caregivers lacking adequate health literacy themselves was associated with uneasiness in supporting patients. Future work might include aims to understand why some caregivers engage in these health responsibility and stress management practices while others do not.

This study has several limitations. Our response rate of 42.3% is lower than the 60% benchmark purported by Dillman [11]. However, our response rate is significantly higher than other surveys of caregiver populations, which have had response rates of 20–30% [27–29]. Because care recipients in this study were all 65 years and from the Southeast U.S. (Alabama, Tennessee, and Florida), caution is warranted in generalizing results to younger adults and those living in other areas of the U.S.. This was a cross-sectional study, hence, causality cannot be implied. However the goals of this study, while exploratory, were necessary to identify specific self-care behaviors and high-risk subgroups that if intervened upon may incur better caregiver well-being, performance, and patient outcomes. Future analyses based on these exploratory results will include modeling to examine the effect of covariates on key outcomes. Finally, results may be biased by differential survey response rates by Blacks/African-Americans and unmarried individuals. Future research should target these groups.

The proportion of patients with cancer who depend upon the assistance of unpaid family caregivers is rising exponentially. By 2020, the number of individuals with cancer is expected to swell by 31% from 13 million to over 18 million [30, 31]. Given the magnitude of support provided by family caregivers, national organizations including the National Cancer Institute [32] and the Institute of Medicine [9] have stressed the imperative to develop programs to support family caregiving. Our findings point towards novel new directions to potentially answer these calls that shift away from a disease- and burden-focused paradigm to one that is focused on health and wellness. Caregivers who take the time to care for themselves may be better able to tolerate the stresses that accompany

supporting someone with serious, life-limiting illness. Understanding self-care practices and how to enhance them in caregivers might lead to interventions that enhance caregivers' own health and resultantly their capacity to provide high-quality care to patients.

Acknowledgments

This study was funded by a University of Alabama at Birmingham, Center for Palliative and Supportive Care PREP Grant (PI: Dionne-Odom) and was conducted under the auspices of a Centers for Medicare and Medicaid Services Health Care Innovation Challenge demonstration project (PI: Partridge). Dr. Dionne-Odom is supported by the NIH/NINR (1K99NR015903), the National Cancer Institute (2R25CA047888-24), the National Palliative Care Research Center, and the American Cancer Society (RSG PCSM – 124668). Dr. Demark-Wahnefried receives support from the NIH/NCI UAB Cancer Center Core Grant (5 P30 CA13148). Dr. Rocque is funded by a Frommeyer Fellowship in Investigative Medicine. Dr. Bakitas is funded by the NIH/NINR (R01NR013665) and the American Cancer Society (RSG PCSM-124668).

References

1. AARP with the United Hospital Fund. Home Alone: Family Caregivers Providing Complex Chronic Care. AARP Public Policy Institute; Washington DC: 2012.
2. Bee P, Barnes P, Luker K. 6pA systematic review of informal caregivers' need in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing*. 2008; 18:1379–1393.
3. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer*. 2009; 115(18 Suppl):4362–73. [PubMed: 19731345]
4. Hartweg, D. Dorothea Orem: Self-Care Deficit Theory. Newbury Park, CA: Sage Publications; 1991.
5. McDonald PE, Fink SV, Wykle ML. 6pSelf-reported health-promoting behaviors of black and white caregivers. *West J Nurs Res*. 1999; 21(4):538–48. [PubMed: 11512169]
6. Pender, N., Murdaugh, C., Parsons, M. Health Promotion in Nursing Practice. 5. Upper Saddle River, NJ: Pearson Prentice Hall; 2006.
7. Riegel B, Jaarsma T, Strömberg A. 6pA middle-range theory of self-care of chronic illness. *ANS Adv Nurs Sci*. 2012; 35(3):194–204. [PubMed: 22739426]
8. Park SM, et al. 6pImpact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. *Support Care Cancer*. 2010; 18(6): 699–706. [PubMed: 19484480]
9. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: 2014.
10. Rocque GB, et al. The Patient Care Connect Program: Transforming Health Care Through Lay Navigation. *J Oncol Pract*. 2016
11. Dillman, D., Smyth, J., Christian, L. Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method. 3. Hoboken, NJ: John Wiley & Sons, Inc; 2009.
12. Walker SN, Sechrist KR, Pender NJ. 6pThe Health-Promoting Lifestyle Profile: development and psychometric characteristics. *Nurs Res*. 1987; 36(2):76–81. [PubMed: 3644262]
13. Bjelland I, et al. 6pThe validity of the Hospital Anxiety and Depression Scale: An updated literature review. *Journal of Psychosomatic Research*. 2002; 52(2):69–77. [PubMed: 11832252]
14. Cheak-Zamora NC, Wyrwich KW, McBride TD. 6pReliability and validity of the SF-12v2 in the medical expenditure panel survey. *Qual Life Res*. 2009; 18(6):727–35. [PubMed: 19424821]
15. Archbold PG, et al. 6pMutuality and preparedness as predictors of caregiver role strain. *Res Nurs Health*. 1990; 13(6):375–84. [PubMed: 2270302]
16. Nolan MT, et al. 6pDevelopment and validation of the Family Decision-Making Self-Efficacy Scale. *Palliat Support Care*. 2009; 7(3):315–21. [PubMed: 19788773]
17. Glickman ME, Rao SR, Schultz MR. 6pFalse discovery rate control is a recommended alternative to Bonferroni-type adjustments in health studies. *J Clin Epidemiol*. 2014; 67(8):850–7. [PubMed: 24831050]

18. Stekhoven DJ, Bühlmann P. 6pMissForest--non-parametric missing value imputation for mixed-type data. *Bioinformatics*. 2012; 28(1):112–8. [PubMed: 22039212]
19. Nipp RD, et al. Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Ann Oncol*. 2016
20. Zavagli V, et al. 6pAssociations between caregiving worries and psychophysical well-being. An investigation on home-cared cancer patients family caregivers. *Support Care Cancer*. 2016; 24 (2): 857–63. [PubMed: 26201751]
21. Fasse L, et al. 6pDescribing and understanding depression in spouses of cancer patients in palliative phase. *Psychooncology*. 2015; 24(9):1131–7. [PubMed: 25707938]
22. Nielsen MK, et al. 6pPsychological distress, health, and socio-economic factors in caregivers of terminally ill patients: a nationwide population-based cohort study. *Support Care Cancer*. 2016; 24 (7):3057–67. [PubMed: 26887588]
23. Furlong KE, Wuest J. 6pSelf-care behaviors of spouses caring for significant others with Alzheimer's disease: the emergence of self-care worthiness as a salient condition. *Qual Health Res*. 2008; 18(12):1662–72. [PubMed: 19008361]
24. Kim Y, Carver CS, Cannady RS. 6pCaregiving Motivation Predicts Long-Term Spirituality and Quality of Life of the Caregivers. *Ann Behav Med*. 2015; 49(4):500–9. [PubMed: 25637107]
25. Ferrell BR, Baird P. 6pDeriving meaning and faith in caregiving. *Semin Oncol Nurs*. 2012; 28 (4): 256–61. [PubMed: 23107183]
26. Bevan JL, Pecchioni LL. 6pUnderstanding the impact of family caregiver cancer literacy on patient health outcomes. *Patient Educ Couns*. 2008; 71(3):356–64. [PubMed: 18372142]
27. Edelman LS, et al. 6pSurvey methods and response rates among rural community dwelling older adults. *Nurs Res*. 2013; 62(4):286–91. [PubMed: 23817286]
28. Sadler E, et al. 6pFactors affecting family satisfaction with inpatient end-of-life care. *PLoS One*. 2014; 9(11):e110860. [PubMed: 25401710]
29. Stone P, et al. 6pCancer-related fatigue--a difference of opinion? Results of a multicentre survey of healthcare professionals, patients and caregivers. *Eur J Cancer Care (Engl)*. 2003; 12(1):20–7. [PubMed: 12641553]
30. Miller KD, et al. 6pCancer treatment and survivorship statistics, 2016. *CA Cancer J Clin*. 2016; 66 (4):271–89. [PubMed: 27253694]
31. Mariotto AB, et al. 6pProjections of the cost of cancer care in the United States: 2010–2020. *J Natl Cancer Inst*. 2011; 103(2):117–28. [PubMed: 21228314]
32. Kent EE, et al. 6pCaring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*. 2016; 122(13):1987–95. [PubMed: 26991807]

Table 1

Family caregiver (n=294) characteristics

Characteristic	No.	%
Age, Mean (SD)	65.5	(12.7)
Female gender	214	72.8
Race		
White	268	91.2
Black	23	7.8
Asian	1	0.3
American Indian or Native Alaskan	2	0.7
Marital Status		
Married or living with partner	243	82.6
Divorced or separated	21	7.1
Single	20	6.8
Widowed	10	3.4
Socioeconomic Status (Total Household Income)		
<\$30,000	86	29.3
\$30,000–\$49,999	72	24.5
\$50,000–\$100,000	107	36.4
>\$100,000	29	9.9
Religion		
Protestant	224	76.2
Catholic	25	8.5
No religious affiliation	19	6.5
Other	26	8.8
Employment Status		
Employed full or part time	67	22.8
Retired	160	54.4
Unemployed	27	9.2
Other	40	13.6
Residence type		
Urban	36	12.2
Suburban	120	40.8
Rural	130	46.9
Relationship to patient (This person is my...)		
Spouse/partner	177	60.2
Parent	47	16.0
Child	31	10.5

Characteristic	No.	%
Other family member	16	5.4
Sibling	9	3.1
Friend	9	3.1
<hr/>		
Months as a caregiver, Mean (SD)	33.5	(40.3)
<hr/>		
Days/week providing care		
1 day	32	11
2–3 days	28	10
4–5 days	25	9
6–7 days	209	71
<hr/>		
Hours/day providing care		
1 hr	61	21
1–2 hrs.	64	22
3–4 hrs.	73	25
5–8 hrs	42	14
>8 hrs.	54	18
<hr/>		
Care recipient age, Mean (SD)	75.3	(6.6)
<hr/>		
Care recipient female gender	134	45.6
<hr/>		
Care recipient cancer diagnosis		
Lung	114	38.8
Head and neck	62	21.1
Leukemia/Non-Hodgkin lymphoma	30	10.2
Ovarian	28	9.5
Other	60	20.4
<hr/>		
My care recipient's health is...		
Poor or fair	127	43
Good	116	40
Very good or excellent	51	17

Table 2

Descriptive statistics for self-care practice and caregiver well-being and performance scores (n=294)

Measure	Score Range	Mean (SD)	Median	Range
Self-Care Practices				
Physical activity *	1–4	2.0 (.73)	1.9	1–4
Health responsibility *	1–4	2.4 (.57)	2.3	1–4
Stress management *	1–4	2.5 (.56)	2.4	1.1–4
Nutrition *	1–4	2.5 (.58)	2.6	1.1–4
Spiritual growth *	1–4	2.8 (.57)	2.8	1.2–4
Interpersonal relations *	1–4	2.8 (.50)	2.9	1.2–4
Caregiver Well-Being				
Anxiety (higher scores=worse anxiety)	0–21	6.3 (4.0)	6.0	0–21
Depression (higher scores=more depressed)	0–21	6.6 (4.4)	6.0	0–21
Physical Health (higher scores=better health)	0–100	39.0 (5.1)	39.2	19.9–51.5
Mental Health (higher scores=better health)	0–100	50.9 (11.8)	52.8	12.8–72
Caregiver Performance				
Preparedness (higher scores=more prepared)	0–4	2.8 (.73)	2.9	.63–4.0
Decision-making self-efficacy (higher scores=higher efficacy)	13–65	58.5 (9.6)	62.0	13.0–65.0

* Higher scores=self-care practice engaged in more frequently

Table 3

Association between self-care practices and well-being and caregiving performance, Mean (SD)

WELL-BEING		n (%)	Health responsibility	p (FDR)	Physical activity	p (FDR)	Nutrition	p (FDR)	Spiritual growth	p (FDR)	Inter-personal relations	p (FDR)	Stress management	p (FDR)
Anxiety														
Normal		194 (66)	2.4 (.58)		2.1 (.75)		2.6 (.58)		3.0 (.53)		3.0 (.49)		2.6 (.56)	
Borderline		55 (19)	2.4 (.50)	<.01 (.07)	1.7 (.58)	<.001 (.01)	2.5 (.53)	<.001 (.01)	2.6 (.50)	<.001 (.01)	2.7 (.46)	<.001 (.01)	2.3 (.48)	<.001 (.01)
High		44 (15)	2.1 (.51)		1.7 (.67)		2.2 (.56)		2.3 (.48)		2.5 (.39)		2.1 (.38)	
Depression														
Normal		172 (59)	2.5 (.54)		2.2 (.74)		2.7 (.55)		3.1 (.44)		3.0 (.43)		2.7 (.51)	
Borderline		54 (18)	2.2 (.46)	<.001 (.01)	1.7 (.52)	<.001 (.01)	2.4 (.47)	<.001 (.01)	2.6 (.45)	<.001 (.01)	2.6 (.40)	<.001 (.01)	2.3 (.46)	<.001 (.01)
High		68 (23)	2.1 (.63)		1.6 (.63)		2.3 (.62)		2.3 (.57)		2.5 (.47)		2.1 (.48)	
Physical Health														
Highest 25%		73 (25)	2.3 (.59)		2.0 (.70)		2.5 (.54)		2.8 (.54)		2.8 (.49)		2.4 (.53)	
Middle 50%		148 (50)	2.4 (.54)	.29 (1.0)	2.1 (.76)	.08 (.49)	2.6 (.59)	.07 (.44)	2.9 (.56)	.17 (.96)	2.9 (.47)	.03 (.21)	2.5 (.56)	.09 (.53)
Lowest 25%		73 (25)	2.3 (.60)		1.8 (.69)		2.5 (.59)		2.7 (.62)		2.8 (.55)		2.4 (.57)	
Mental Health														
Highest 25%		73 (25)	2.5 (.59)		2.3 (.71)		2.7 (.62)		3.1 (.50)		3.0 (.51)		2.7 (.54)	
Middle 50%		148 (50)	2.4 (.56)	.01 (.07)	2.1 (.75)	<.001 (.01)	2.6 (.52)	<.001 (.01)	2.9 (.51)	<.001 (.01)	2.9 (.47)	<.001 (.01)	2.6 (.52)	<.001 (.01)
Lowest 25%		73 (25)	2.2 (.53)		1.5 (.49)		2.2 (.55)		2.4 (.50)		2.6 (.45)		2.1 (.45)	
CAREGIVER PERFORMANCE														
Caregiver preparedness														
Highest 25%		74 (25)	2.6 (.62)		2.2 (.76)		2.6 (.61)		3.1 (.57)		3.0 (.50)		2.7 (.62)	
Middle 50%		143 (48.6)	2.3 (.53)	<.001 (.01)	1.9 (.67)	.04 (.27)	2.6 (.57)	.48 (1.0)	2.8 (.53)	<.001 (.01)	2.8 (.48)	<.001 (.01)	2.5 (.53)	<.001 (.01)
Lowest 25%		77 (26)	2.3 (.53)		2.0 (.77)		2.5 (.58)		2.6 (.55)		2.7 (.48)		2.3 (.48)	
Decision-making self-efficacy														
Highest 75%		219 (75)	2.4 (.58)	<.01 (.07)	2.0 (.75)	.34 (1.0)	2.5 (.58)	.44 (1.0)	2.9 (.54)	<.001 (.01)	2.9 (.47)	<.001 (.01)	2.5 (.57)	<.01 (.07)
Lowest 25%		75 (26)	2.2 (.52)		1.9 (.66)		2.5 (.57)		2.5 (.57)		2.6 (.51)		2.3 (.49)	

FDR: False Discovery Rate, FDR<.10 considered significant

Notes: p-values from independent samples Kruskal Wallis Test

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript