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Mental Health, Treatment Preferences, Advance Care Planning, and Location and Quality of Death in Advanced Cancer Patients with Dependent Children

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Abstract

BACKGROUND—Clinicians observe that advanced cancer patients with dependent children agonize over the impact their death will have upon their children. The aim of this study was to determine empirically whether advanced cancer patients with and without dependent children differ in treatment preferences, mental health, and end-of-life (EOL) outcomes.

METHODS—Coping with Cancer is an NCI/NIMH-funded, multi-institutional prospective cohort study of 668 advanced cancer patients. Patients with and without dependent children were compared on rates of psychiatric disorders, advance care planning (ACP), EOL care, quality of last week of life and location of death.

RESULTS—In adjusted analyses, advanced cancer patients with dependent children were more likely to meet Panic Disorder criteria [Adjusted Odds Ratio (AOR)=5.41 95% Confidence Interval (95%CI):2.13-13.69)], feel worried [mean difference in standard deviations (d)=0.09, p=0.006] and prefer aggressive treatment over palliative care [AOR=1.77 (95%CI:1.07-2.93)]. They were less likely to engage in ACP [e.g., Do Not Resuscitate orders [AOR=0.44(95%CI:0.26-0.75)] and had worse quality of life in the last week of life (d=0.15, p=0.007). Among spousal caregivers, those with dependent children were more likely to meet criteria for Major Depressive Disorder [AOR=4.53(95%CI:1.47-14.00)] and Generalized Anxiety Disorder [AOR=3.95(95%CI: 1.29-12.16)].

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CONCLUSIONS—Patients with dependent children are more anxious, less likely to engage in ACP and have worse quality of life in the last week of life. Advanced cancer patients and spousal caregivers with dependent children represent a particularly distressed group warranting further clinical attention, research, and support.

Keywords

cancer; dependent children; psychiatric illness; DNR; hospice; end-of-life; ACP; quality-of-life

Twenty four percent of cancer patients have children under the age of eighteen.¹ Patients with advanced cancer and dependent children must consider the effect their disease and treatment options will have on their roles as parents. Careful consideration of the end-of-life (EOL) offers patients the opportunity to prepare their families, as best they can, for what lies ahead. However, planning for the EOL may be particularly difficult for patients with dependent children because it requires them to confront the possibility of not being present to raise their children.² Patients with dependent children may have an increased willingness to undergo burdensome aggressive treatments in an effort to secure more time with their children.³ A study of breast cancer patients suggested those who lived with and supported dependents were more likely to view smaller gains in length of live from adjuvant chemotherapy as worthwhile despite therapy side effects.^{4,5}

Previous qualitative studies describe how a child's cancer affects their parents and siblings,^{6,7} how parents' cancers impact children,⁸ and the ways that children grieve after losing a parent to cancer.⁹⁻¹³ A thorough review of this literature revealed no empirical studies examining the influence that having dependent children has on advanced cancer patients' mental health, receipt of aggressive care, hospice use, and location and quality of death. The aim of this study was to examine quantitatively the differences in EOL outcomes based upon advanced cancer patients' dependent child status. Using data from a multi-center, longitudinal, prospective study of advanced cancer patients, we examined whether patients' baseline mental health, treatment preferences, and advance care planning differed based on whether or not the patient had dependent children. In the subset of caregivers that were spouses of the patients we examined how the dependent child status of the patient affected the mental health of the caregiver. We also determined whether patients' dependent children status affected the type of care received in the last week of life, as well as the patients' overall quality of life in the last week of life.

We hypothesized that advanced cancer patients with dependent children would be more anxious and less likely to engage in advance care planning initiatives such as Do Not Resuscitate (DNR) orders and living wills. We expected that they would prefer aggressive care to extend life, and be more likely to receive it near death. We hypothesized that they would be less likely to die in an inpatient hospice facility and more likely to die at home due to their wishes for aggressive care and desire to remain home as long as possible with their children. We also predicted that these patients would have worse quality of life in the last week of life due to burdensome efforts to prolong their life as long as possible.

MATERIALS AND METHODS

Data Collection

Data come from the Coping with Cancer (CwC) (National Institutes of Health [NIH] grants MH63892, CA106370) study. CwC is a multi-institutional longitudinal study of advanced cancer patients. Trained interviewers assessed the patients and caregivers at baseline and clinicians and caregivers completed the postmortem evaluations. Detailed descriptions of

this study have been published elsewhere.¹⁴ All study protocol and contact documents were reviewed and approved by the human subjects committee at each participating institution.

Eligibility criteria included: 1) diagnosis of advanced cancer (presence of distant metastases, disease refractory to first-line chemotherapy, and clinician estimate of life expectancy of less than six months); 2) diagnosis at a participating site; 3) age \geq 20 years; 4) identified unpaid, informal caregiver; 5) clinic staff and interviewer assessment that the patient had adequate stamina to complete the interview. Patient-caregiver dyads in which either the patient or caregiver met criteria for dementia or delirium (by neuro-behavioral cognitive status exam), or did not speak either English or Spanish, were excluded. Potentially eligible patients were identified by clinicians at each site. Trained research staff approached each identified patient to offer participation in the study by telephone call or hospital visit. Once the patient's written informed consent was obtained, medical records and clinicians were consulted to confirm eligibility.

Of the 958 patients who were approached for participation and confirmed to be eligible, 289 (30%) declined participation. The most common reasons for non-participation included “not interested” (120), “caregiver refuses” (37), and “too upset” (20). Compared with participants, non-participants reported more distress on a 5-point Likert scale whose extremes ranged from 1 “minimal/nonexistent” to 5 “distracted” (mean score of 2.72 vs. 2.34, $p < 0.0001$). A higher percentage of participants were of Hispanic ethnicity (12.5% vs. 5.6%, $p = 0.002$). Non-participants did not differ significantly from participants in gender, age or education.

Each enrolled patient participated in a baseline interview. Interviews were conducted in English or Spanish and took approximately 45 minutes to complete. Patients and caregivers received \$25 as compensation for completing the interview. Information on care received in the last week of life was obtained in the post mortem assessment.

During the baseline interview patients were asked with whom they live. The response options were 1=spouse, 2=dependent child, 3=independent child, 4=dependent adult, 5=other relative, 6=friend, paid employee, parent or other. Patients who responded “2” were categorized as having a dependent child. Patients that did not indicate that they live with dependent children were defined as patients without dependent children.

The McGill Quality of Life questionnaire^{15,16,17}, a validated assessment of global, physical, psychological, emotional and existential well-being for patients at all stages of illness, was used to assess patients' feelings of “worry,” “sadness,” and “terror”¹⁸. Each item was scored on a scale of 0 to 10, with 10 signifying extremely “worried, sad or terrified”.

The Structured Clinical Interview for the DSM-IV (SCID) Axis I Modules¹⁹ was used to diagnose current Major Depressive Disorder (MDD), Current Depression (Endicott Criteria), Generalized Anxiety Disorder (GAD), Post-Traumatic Stress Disorder (PTSD) and Panic Disorder (PD). The SCID is widely used and has proven reliability and validity.²⁰

Patients' peacefulness was assessed with the NIA/Fetzer Multidimensional Measure of Religiosity/Spirituality for Use in Health Research.²¹ Patients who reported experiencing feeling “deep inner peace or harmony,” “many times a day,” “everyday,” or “most days” were coded as “peaceful.” Those reporting “some days,” “once in a while,” or “never or almost never” were considered not peaceful. Steinhauser et al²² showed that a one-item assessment of peacefulness was strongly correlated with emotional and spiritual well-being, faith and purpose subscales, and had broad applicability across different definitions of spirituality.

Terminal illness acknowledgement was determined by asking patients to describe their current health status as either “relatively healthy,” “seriously ill but not terminally ill,” “relatively healthy and terminally ill,” or “seriously and terminally ill.” Those patients indicating their current health status as “terminally ill” were considered to exhibit terminal illness acknowledgement. This measure has been used in several studies of terminally ill patients, and found to be associated with higher rates of completion of DNR orders and use of hospice services.^{18,23-25}

Patients were asked the following EOL questions on care wishes and life expectancy: “Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?” and “Have the doctors talked with you about how much time you have left to live?”^{23,34}

Patients were also asked specific questions regarding individual treatment preferences at the EOL: e.g., “Would you want to be kept alive if it required you being on a breathing machine for: 1 year, 6 months, 3 months, 1 month, 2 weeks, 1 week, 1 day?” and “If you had an infection that would let you die painlessly, would you want the doctors to give you antibiotics to keep you alive: 1 year, 6 months, etc.?” Patients reporting preference for ventilator or feeding tube for any period of time were counted as having preference for a ventilator or feeding tube. Those wanting antibiotics or chemotherapy if it kept them alive respectively for two weeks or less or one week or less were counted as having preference for antibiotics or chemotherapy.

Patients were also asked, “If you could choose, would you prefer: 1) a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or 2) on a plan of care that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?”

Patients were asked the following questions regarding completed advance care planning initiatives: “Have you completed a Do Not Resuscitate (DNR) order?” and “Do you have a signed, living will, or health care proxy, durable power of attorney for health care, all or none?”²⁶

Location of death, hospice use, care received during the last week of life and the quality of the patient's last week of life and death were documented by clinicians and caregivers in the postmortem assessment.²⁶ The respondent rated “the overall quality of the patient's death/last week of life” on a scale of 0 to 10, with 0 being “worst possible” and 10 being “best possible”.

Statistical Methods

Descriptive statistics were used to characterize the demographics of the study sample. Comparative tests were conducted to determine if patients with dependent children differed significantly from those patients without dependent children on the analyzed variables. T-tests were used for continuous variables, Cochran-Mantel-Haenszel Statistics were used for categorical variables and chi square statistics were used for binary variables. Multiple regression models adjusted for significant confounding influences. Every sociodemographic (e.g., age, gender) and physical health variable was investigated as a potential confounder in each analysis. The source of the post mortem assessment (clinician or caregiver) was examined as a confounder for the quality of the patient's last week of life/death. Variables were placed into the multiple regression model and those significantly ($p < 0.05$) associated with the examined outcome were considered confounders and retained. Dependent child status and possible confounders were independent variables in the final multiple regression models. Logistic regression models estimated the prevalence of mental disorders,

peacefulness, EOL discussions, terminal illness acknowledgement, treatment preferences, advance care planning, aggressive care and location of death based on the respondents' dependent child status. Linear regression models estimated the McGill quality of life measures “worried”, “sad” and “terrified”, and the “overall quality of the patient's death/last week of life” from the postmortem assessment. Data were analyzed with the SAS System for Windows v. 9.1 (SAS Institute, Inc., Cary, NC).

RESULTS

The characteristics of the 668 patients and 343 spousal caregivers who enrolled and completed the evaluation as well as a comparison of those patients with and without dependent children and their spousal caregivers are displayed in Tables 1a and 1b. There were no significant differences between patients with and without dependent children in survival time from baseline or in whom (caregivers or clinicians) completed their post mortem assessments.

In comparison to those patients without dependent children, in adjusted analyses controlling for all confounding sociodemographic and physical variables, patients with dependent children were significantly more worried [mean difference in standard deviations (d)=0.09, p=0.006], were more likely to meet criteria for a SCID diagnosis of Panic Disorder [AOR=5.41 (95%CI:2.13-13.69)] and were half as likely to be peaceful [AOR=0.53 (95%CI:0.32-0.87)]. Among the spousal caregivers, in adjusted analyses, those caregivers married to patients with dependent children were more likely to meet criteria for Major Depressive Disorder [AOR=4.53(95%CI:1.47-14.00)] and Generalized Anxiety Disorder [AOR=3.95(95%CI:1.29-12.16)].

Patients with dependent children did not significantly differ from patients without dependent children in terminal illness acknowledgement or in discussions with their physician regarding EOL wishes or life expectancy. Twenty-eight percent and 36% of patients with and without dependent children acknowledged being terminally ill. Thirty-one percent of both patients with and without dependent children had discussion of EOL wishes with their physicians and 36% and 38% of patients with and without dependent children had prognostic communication discussions with their physician.

In adjusted analyses, patients with dependent children were more likely than those patients without dependent children to prefer a course of treatment that focused on extending life as much as possible rather than a course of treatment that focused on relieving pain and discomfort as much as possible [AOR=1.77(95%CI:1.07-2.93)]. They were less likely to have advance care planning initiatives in place at baseline [DNR: AOR=0.44(95%CI: 0.26-0.75); living will: AOR=0.49(95%CI:0.28-0.87); and durable power of attorney and/or health care proxy: AOR=0.21(95%CI:0.10-0.43)].

Patients with dependent children did not significantly differ from those patients without dependent children in EOL care received in the last week of life. The majority of all patients died at home (54% of both patients with and without dependent children). Most patients dying at home received outpatient hospice services (89% of both patients with and without dependent children). The next most common location of death for these patient groups was the hospital, with 38% of patients with dependent children and 29% of patients without dependent children. According to postmortem ratings by their clinicians and caregivers, in adjusted analyses, those patients with dependent children had worse quality of life during the last week of life (d=-0.12, p=0.04).

DISCUSSION

Results of this study indicate that in comparison to advanced cancer patients without dependent children advanced cancer patients with dependent children have significantly more anxiety, are less at peace, have more preference for a course of treatment focused on extending life rather than relieving pain and discomfort, are less inclined to engage in certain types of advance care planning and experience worse quality of life in the last week of life. These results suggest that patients with dependent children and their families may need enhanced psychosocial support. Patients' families could use support in adapting to the patients' illness while patients could benefit from guidance in how to discuss their illness with their children. The lack of difference between these patient groups in EOL discussions with their physician indicate that physicians are not shying away from EOL conversations with their patients whom have dependent children.

This is the first empirical study to demonstrate that advanced cancer patients with dependent children are more anxious than advanced cancer patients without dependent children. The significantly higher rates of Panic Disorder, lower rates of peacefulness and higher McGill "worried" scores indicate that patients with dependent children suffer more from feelings of anxiety, as well as from at least one form of anxiety disorder. Cognitive behavioral and pharmacologic therapies have proven effective for the treatment of anxiety in cancer patients.²⁷⁻²⁹ Nevertheless, it may be difficult to alleviate anxiety completely with psychotherapy and medication.

Our results suggest a need for further research to enhance understanding of the specific worries cancer patients have regarding their children, as well as the development of interventions to address these concerns. Potential interventions might be in the realm of psychosocial support for the children, strategies to enhance the parenting competencies of the surviving parent, and assurance that the patient will not be forgotten by his/her children.

Although this study did not reveal any significant differences in the healthcare patients with dependent children received during the last week of life, these patients may have received more aggressive care than patients without dependent children in periods not assessed in CWC (e.g. ICU stays prior to the patient's final week). The lower rates of completion of living wills, DNR orders, and durable power of attorney for health care and/or health care proxies show that advanced cancer patients with dependent children plan differently for their approaching death than advanced cancer patients without dependent children and indicate difficulty among patients with dependent children with some forms of EOL planning. Our data suggest that patients with dependent children experience more distress at the EOL and have poorer quality of life in the last week of life.

The mean time from baseline assessment to death was 192 days (6.19 months); respectively, 65% and 84% of the patients died within six months of the baseline interview or one year of the baseline interview. The Medicare eligibility criteria for hospice care are that the terminally ill patient has a prognosis of six months or less if the disease runs its normal course. This, together with the inclusion criteria that required the patient have advanced cancer indicates that the majority of the sampled patients were within a proximity to death when planning for advanced cancer treatment would be appropriate.

Our findings must be interpreted within the context of a study design that included baseline interviews, a review of patients' medical records, and follow-up interviews with caregivers, but not multiple assessments of patients or detailed information about their dependent children. A longitudinal study with frequent assessments would provide further insights into how these patients' understanding of their disease, treatment preferences, decisions, and outcomes (including toxicities) unfold over time. It would also allow an analysis of how

these decisions alter bereavement outcomes for their families. Future research should explore the factors influencing patients' care preferences and decisions, including differences in oncologist treatment of patients with and without dependent children and whether familial pressures from partners/spouses or extended family members explain some of the differences in mental health and advance care planning between these patient groups and caregiver groups. It is both a strength and limitation that the definition of dependent children is left up to patient interpretation. Additional information on the children, such as age and gender, and number of children would provide a greater breadth of understanding of how different parenting roles of mothers and fathers and age of the children affect the EOL experience for these patients and caregivers. Given the rarity of some outcomes such as rates of psychiatric illness, we may be underpowered to demonstrate significant findings in these outcomes. In this way our results provide a conservative estimate of these associations and larger samples may yield more significant adverse outcomes associated with advanced cancer patients with dependent children. Due to the lack of national statistics on family members of cancer patients, it is difficult to assess the generalizability of the sample of patients with dependent children. However, it is strength of the study that patients are drawn from various sites throughout the country.

This is the first empirical examination of the differences in the EOL experience for advanced cancer patients with and without dependent children. These preliminary findings highlight the need for additional research in this population to determine the nature of these patients' unmet needs and barriers to better quality of life at the EOL. Data are needed to inform interventions designed to reduce the exceptional emotional and physical suffering and strain experienced by dying cancer patients who are leaving behind dependent children. Research is needed to improve our understanding of the factors contributing to parental anxieties and barriers to better quality of deaths that may not only benefit the cancer patient, but also the children and spouses whom survive them.

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REFERENCES

1. National Health Interview Survey 1992, National Cancer Institute, Division of Cancer Control and Population Sciences, Office of Cancer Survivorship.
2. Rauch PK, Muriel AC. The importance of parenting concerns among patients with cancer. *Critical Reviews in Oncology/Hematology*. 2004; 49:37–42. [PubMed: 14734153]
3. Yellen SB, Cella DF. Someone to live for: social well-being, parenthood status, and decision-making in oncology. *Journal of Clinical Oncology*. 1995; 5:1255–1264. [PubMed: 7738630]
4. Duric V, Stockler M. Patients' preferences for adjuvant chemotherapy in early breast cancer: a review of what makes it worthwhile? *Lancet Oncology*. 2001; 2:691–697. [PubMed: 11902540]
5. Duric VM, Stockler MR, Heritier S, et al. Patients' preferences for adjuvant chemotherapy in early breast cancer: what makes AC and CMF worthwhile now? *Annals of Oncology*. 2005; 16:1786–1794. [PubMed: 16126738]
6. Easson, WM. *The dying child*. Knopf; Springfield: 1981.
7. Sahler, OJZ. *The child and death*. St Louis; The C.V. Mosby Company: 1978.
8. Harpham, WS. *When a parent has cancer. A guide to caring for your children*. Harper Collins; New York: 1997.
9. Klass, D.; Silverman, PR.; Nickman, SL. *Continuing bonds*. Taylor and Francis; Washington, DC: 1996.

10. Krementz, J. How it feels when a parent dies. Knopf; New York: 1981.
11. Le Shan, E.; Giovanolopoulos, P. Learning to say good-bye: when a child's parent dies. NY Macmillan; New York: 1976.
12. Worden, JW. Children and grief. The Guilford Press; New York: 1996.
13. Silverman, PR. Never too young to know: death in children's lives. Oxford University Press; New York: 2000.
14. Kadan-Lottick N, Vanderwerker L, Block S, et al. Psychiatric disorders and mental health service use in patients with advanced cancer. *Cancer*. 2005;2872–2881. [PubMed: 16284994]
15. Cohen SR, Mount BM, Bruera E, et al. Validity of the McGill quality of life questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliative Medicine*. 1997; 11:3–20. [PubMed: 9068681]
16. Ray A, Block S, Friedlander R, et al. Peaceful awareness in advanced cancer patients. *Journal of Palliative Medicine*. 2006; 9(6):1359–68. [PubMed: 17187544]
17. Cohen SR, Mount BM, Strobel MG, et al. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliative Medicine*. 1995; 9:207–219. [PubMed: 7582177]
18. Maciejewski PK, Zhang B, Block SD, et al. An Empirical Examination of the Stage Theory of Grief. *JAMA*. 2007; 297(9):716–723. [PubMed: 17312291]
19. First, MB.; Spitzer, RL.; Gibbon, M.; Williams, JBW. Biometrics Research Department. New York State Psychiatric Institute; New York: 1995. Structured clinical interview for the DSM-IV axis I disorders - patient edition (SCID-I/P, version 2.0).
20. Williams JBW, Gibbon M, First MB, et al. The structured clinical interview for DSM-III-R (SCID): II. multitest-retest reliability. *Archives of General Psychiatry*. 1992; 49:630–636. [PubMed: 1637253]
21. NIA/Fetzer Multidimensional Measure of Religiousness/Spirituality for Use in Health Research: A Report of the Fetzer/National Institute on Aging Working Group. 1999. http://www.fetzer.org/PDF/total_fetzer_book.pdf
22. Steinhäuser KE, Voils CI, Clipp EC, et al. “Are you at peace?” one item to probe spiritual concerns at the end of life. *Arch Intern Med*. 2006; 166:101–105. [PubMed: 16401817]
23. Wright AA, Ray A, Zhang B. Medical care and emotional distress associated with advanced cancer patients' end-of-life discussions with their physicians'. *JAMA*. (resubmitted).
24. Zhang B, Wright A, Nilsson M, et al. Medical Costs in the last week of life: Associations with Patient Reports of EOL Discussion. *Arch Intern Med*. (accepted).
25. Prigerson HG. Socialization to dying: social determinants of death acknowledgment and treatment among terminally ill geriatric patients. *J Health Soc Behav*. 1992; 33:378–395. [PubMed: 1464721]
26. Mack JW, Nilsson M, Balboni T, et al. Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE): Validation of a Scale to Assess Acceptance and Struggle With Terminal Illness. *Cancer*. 2008; 112(12):2509–17. [PubMed: 18429006]
27. Sheard T, Maguire P. The effect of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *Br J Cancer*. 1999; 11:1770. [PubMed: 10468295]
28. Devine EC, Westlake SK. The effects of psychoeducational care provided to adults with cancer: meta-analysis of 166 studies. *Oncol Nurs Forum*. 1995; 22:1369. [PubMed: 8539178]
29. Meyer TS, Mark MM. Effects of psychological interventions with adult cancer patients: a meta-analysis of randomized experiences. *Health Psychol*. 1995:14.
30. Rothman, KJ.; Greenland, S. *Modern Epidemiology*. Lippincott-Raven Publishers; Philadelphia: 1998.

TABLE 1a

Characteristics of the Study Population of Patients with Advanced Cancer

Attribute	Total Sample N (%)	Patients with Dependent Children	Patients without Dependent Children	Comparative Test (t or X ²) p value
No. of cases	668	135(20)	533 (80)	
Women no. (%)	316(47)	73 (54)	243 (46)	0.08
Race/ethnicity, N (%)				0.007^a
White, non- Hispanic	478 (72)	86 (64)	392 (74)	
Black, non-Hispanic	94 (14)	74 (14)	20(15)	
Hispanic	81 (12)	22(16)	59(11)	
Asian	13(2)	7(5)	6(1)	
Other	2(0)	0(0)	2(0)	
Age at evaluation (yrs)				<0.0001
Mean (SD)	58.8 (12.7)	48.1 (10.7)	61.5(11.7)	
Median (range)	59 (22-93)	47 (24-88)	62 (22-93)	
Education				0.71
Mean (SD)	12.93(4.00)	12.81 (4.38)	12.96(3.90)	
Median (range)	12(0-24)	12(0-23)	13(0-24)	
Marriage ^b				
Yes no. (%)	416(66)	98 (76)	318(63)	0.007
No no. (%)	216(34)	31 (24)	185(37)	
Income ^b N (%)				
<\$31,000	184(42)	37(41)	147 (42)	0.85
≥\$31,000	254 (58)	53 (59)	201 (58)	
Treatment center ^b , N (%)				0.009^a
Yale Cancer Center	160(25)	31 (25)	129(25)	
VA	23(4)	1(1)	22(4)	
MSKCC	61 (10)	14(11)	47(9)	
Simmons	42(7)	12(10)	30(6)	
Parkland	181 (29)	43 (34)	138(27)	
DFCI	40(6)	10(8)	30(6)	
NHOH	117(19)	11 (9)	106(21)	
Other	10(2)	4(3)	6(1)	
Cancer Site ^b , N (%)				0.02^a
Lung	152(24)	20(15)	132(26)	
Colon	80(13)	17(13)	63(12)	
Pancreatic	56(9)	10(8)	46(9)	

Attribute	Total Sample N (%)	Patients with Dependent Children	Patients without Dependent Children	Comparative Test (t or X ²) p value
Breast Cancer	55(9)	21 (16)	34(7)	
Other	299 (47)	63 (48)	236 (46)	
Insurance Status ^b , N (%)				0.24
Insured	465(71)	90 (67)	375 (72)	
Uninsured	192(29)	45 (33)	147 (28)	
Religion: N (%)				0.14 ^a
Catholic	282 (42)	49 (36)	233 (44)	
Protestant	128(19)	30 (22)	98(18)	
Baptist	68(10)	14(10)	54(10)	
Jewish	33(5)	2(2)	31(6)	
Other	124(19)	30 (22)	94(18)	
None	33(5)	10(7)	23(4)	
Physical Health: Mean (SD)				
Charlson Comorbidity	8.14(2.16)	6.86 (2.25)	8.47 (2.62)	<0.0001
Karnofsky	69(17)	72(17)	68(17)	0.02
Mcgill Symptom Burden	12.16(6.37)	12.19(6.83)	12.15(6.26)	0.95

Note: Bolded p-values represent significant differences between patients with and without dependent children.

^a Cochran-Mantel-Haenszel Statistics

^b Missing Responses (No.): Marriage (36), Income (230), Treatment Center (34), Cancer Site (26), Zubrod (21), Insurance Status (11),

TABLE 1b

Characteristics of the Study Population of Spousal Caregivers of Patients with Advanced Cancer

Attribute	Total Sample N (%)	Patients with Dependent Children	Patients without Dependent Children	Comparative Test (t or X ²) p value
No. of cases	343	79 (23)	264 (77)	
Women no. (%)	222 (65)	43 (54)	179(68)	0.03
Men no. (%)	121 (35)	36 (46)	85 (32)	
Race/ethnicity ^b , N (%)				0.002
White, non- Hispanic	268 (79)	53 (67)	215(82)	
Black, non-Hispanic	31(9)	10(13)	21(8)	
Hispanic	28(8)	10(13)	18(7)	
Asian	9(3)	6(8)	3(1)	
Other	5(1)	0(0)	5(2)	
Age at evaluation (yrs)				<0.0001
Mean (SD)	58.16 (28.55)	45.9(9.1)	61.8(31.3)	
Median (range)	57 (24-86)	46 (24-72)	60 (24-86)	
Education				0.36
Mean (SD)	13.59(3.44)	13.66(3.70)	13.57(3.38)	
Median (range)	13(0-23)	14(3-21)	13(0-23)	
Income ^b N (%)				0.54
<\$31,000	79(31)	23 (34)	56 (30)	
≥\$31,000	177(69)	45 (66)	132(70)	
Treatment center ^b , N (%)				0.006
Yale Cancer Center	87 (26)	21 (28)	66 (26)	
VA	17(5)	0(0)	17(7)	
MSKCC	37(11)	9(12)	28(11)	
Simmons	24(7)	10(13)	14(6)	
Parkland	60(18)	19(25)	41 (16)	
DFCI	31(9)	7(9)	24(9)	
NHOH	67 (20)	7(9)	60 (24)	
Other	7(2)	3(4)	4(2)	
Cancer Site ^b , N (%)				0.01
Lung	74 (22)	11(14)	63 (25)	
Colon	38(11)	10(13)	28(11)	
Pancreatic	34(10)	7(9)	27(11)	
Breast Cancer	22(7)	11(14)	11 (4)	
Other	158(50)	39 (50)	122(49)	
Insurance Status ^b , N (%)				0.34

Attribute	Total Sample N (%)	Patients with Dependent Children	Patients without Dependent Children	Comparative Test (t or χ^2) p value
Insured	271 (81)	61 (77)	210(82)	
Uninsured	64(19)	18(23)	46(18)	
Religion: N (%)				0.33
Catholic	147 (43)	29 (37)	118(45)	
Protestant	67 (20)	16(21)	51 (19)	
Baptist	29(8)	3(4)	21(8)	
Jewish	23(7)	17(22)	20(8)	
Other	51 (15)	5(6)	34 (14)	
None	25(7)	8(10)	20(8)	
Patient Physical Health: Mean (SD)				
Charlson Comorbidity	7.95 (2.63)	6.61 (2.33)	8.37 (2.58)	<0.0001
Karnofsky	70(17)	74(16)	69(17)	0.04
Mcgill Symptom Burden	11.84(5.98)	11.40(6.85)	11.98(5.70)	0.49

Note: Bolded p-values represent significant differences between patients with and without dependent children.

^a Cochran-Mantel-Haenszel Statistics

^b Missing Responses (No.): Race (2), Income (87), Treatment Center (13), Cancer Site (10), Insurance Status (7)

Table 2a

Baseline Characteristics Associated with Advanced Cancer Patient Having Versus Not Having Dependent Children

Measure	Unadjusted Analyses		Adjusted Analyses	
	d ^a or O.R. (95% CI)	p-value	d ^a or O.R. (95% CI)	p-value
McGill Quality of Life Measures				
Worried ^c	0.10	0.01	0.09	0.006
Sad ^d	0.03	0.37	0.06	0.14
Terrified ^e	0.08	0.03	0.03	0.43
Mental Health				
Current Major Depressive Disorder ^{b,f}	1.68 (0.86-3.28)	0.13	1.92 (0.94-3.93)	0.07
Current Depression (Endicott criteria) ^{b,g}	1.88(0.93-3.82)	0.08	1.73(0.81-3.70)	0.16
Current Generalized Anxiety Disorder ^{b,h}	2.15(0.72-6.42)	0.17	2.09(0.68-6.41)	0.20
Current Panic Disorder ^{b,i}	4.94(2.05-11.92)	0.0004	5.41 (2.13-13.69)	0.0004
Current PTSD ^{b,j}	1.98(0.74-5.33)	0.17	1.05 (0.34-3.26)	0.94
Peaceful ^k	0.67 (0.44-1.02)	0.06	0.54 (0.33-0.86)	0.01
Terminal Illness Acknowledgement ^l	0.67 (0.42-1.04)	0.08	0.71 (0.42-1.19)	0.20
EOL Discussions				
Discussion of EOL Care Wishes ^m	0.95(0.49-1.82)	0.87	0.98(0.59-1.61)	0.92
Discussion of Life Expectancy ⁿ	1.01 (0.65-1.57)	0.96	1.09 (0.54-2.20)	0.81
Treatment Preferences				
Preference for chemotherapy ^o	0.86(0.58-1.29)	0.47	0.82(0.52-1.27)	0.37
Preference for antibiotics ^p	1.64(1.08-2.49)	0.02	1.49 (0.92-2.42)	0.11
Preference for feeding tube ^q	1.62(1.05-2.48)	0.03	0.85(0.44-1.65)	0.64
Preference for respirator ^r	1.17(0.74-1.84)	0.50	0.75(0.45-1.24)	0.26
Preference for any type of advanced treatment ^s	1.63(1.00-2.67)	0.05	0.94(0.54-1.63)	0.83
Extend Life Versus Relieve Pain ^t	2.05(1.33-3.16)	0.001	1.77(1.07-2.93)	0.03
Advance Care Planning				
DNR ^u	0.48 (0.30-0.75)	0.002	0.44 (0.26-0.75)	0.003
Living will ^v	0.39 (0.26-0.61)	<0.0001	0.49 (0.28-0.87)	0.01
Health Care Proxy and/or Durable Power of Attorney ^w	0.46 (0.30-0.70)	0.0003	0.21 (0.10-0.43)	<0.0001

Note: Bolded rows represent significant differences between patients with and without dependent children.

^a = mean differences expressed in standard deviations of baseline data^b = Determined by a Structured Clinical Interview for the DSM (SCID) diagnosis; Confounders^c = gender, symptom burden and Simmons

d = NHOH, health insurance, gender, symptom burden and Parkland

e = White Race, age, symptom burden, Catholic, Parkland and gender

f = symptom burden and DFCI

g = symptom burden and marriage

h = symptom burden and age

i = gender and symptom burden

j = age and symptom burden

k = White Race, No Religion and Simmons

l = Yale, Black Race, Hispanic Race, symptom burden and breast cancer

m = Yale and Karnofsky

n = Simmons

o = Charlson Index of Comorbidity and DFCI

p = White Race, Age, Catholic and DFCI

q = age, income, health insurance and Simmons

r = age

s = age, Hispanic Race and symptom burden

t = White Race, age, Yale, Parkland and DFCI

u = White Race, Yale and Karnofsky

v = White Race, age, education, Black Race and NHOH

w = White Race, education, marriage, income, Yale, lung cancer, Black Race, Simmons, NHOH

Table 2b

Baseline Caregiver Characteristics Associated with Advanced Cancer Patient Having Versus Not Having Dependent Children

Measure	Unadjusted Analyses		Adjusted Analyses	
	O.R. (95% CI)	p-value	O.R. (95% CI)	p-value
Mental Health				
Current Major Depressive Disorder ^{a,b}	3.64(1.23-10.76)	0.02	4.53(1.47-14.00)	0.01
Current Generalized Anxiety Disorder ^{a,c}	3.71 (1.34-10.28)	0.01	3.95(1.29-12.16)	0.02
Current Panic Disorder ^{a,d}	4.30(1.40-13.24)	0.01	3.32(1.00-11.06)	0.05
Current PTSD ^{a,e}	5.42(1.49-19.79)	0.01	2.32(0.48-11.25)	0.30

Note: Bolded rows represent significant differences between patients with and without dependent children.

^a = Determined by a Structured Clinical Interview for the DSM (SCID) diagnosis; Confounders

^b = gender and DFCI

^c = Yale and patient health insurance

^d = age, Yale, DFCI and Charlson Index of Comorbidity

^e = Yale and Catholic

Table 3

End Of Life Characteristics Associated with Advanced Cancer Patient Having Versus Not Having Dependent Children

Measure	Unadjusted Analyses		Adjusted Analyses	
	d ^a or O.R. (95% CI)	p-value	d ^a or O.R. (95% CI)	p-value
EOL Care				
Outpatient Hospice ^b	0.92(0.53-1.59)	0.76	0.96(0.52-1.76)	0.89
ICU ^c	1.56 (0.66-3.68)	0.31	1.43(0.60-3.41)	0.43
Ventilator ^d	1.05(0.38-2.90)	0.93	0.82 (0.29-2.35)	0.72
Resuscitation ^e	0.69(0.15-3.13)	0.63	0.49(0.10-2.32)	0.36
Feeding Tube	0.94 (0.34-2.58)	0.90	0.94 (0.34-2.58)	0.90
Chemotherapy	0.91 (0.30-2.78)	0.87	0.91 (0.30-2.78)	0.87
Any Aggressive ^f	1.03(0.53-2.03)	0.93	1.06(0.53-2.09)	0.88
Location of death				
Inpatient Hospice ^g	0.10(0.01-0.70)	0.02	0.09(0.01-0.66)	0.02
Home ^h	1.02(0.60-1.74)	0.94	1.10(0.61-2.00)	0.75
ICU ^c	1.94(0.81-4.67)	0.14	1.18(0.45-3.12)	0.74
Hospital (Non ICU) ⁱ	1.24 (0.68-2.28)	0.49	1.61 (0.85-3.04)	0.14
Hospital Total (ICU and Non ICU) ^j	1.52 (0.88-2.64)	0.14	1.29 (0.68-2.45)	0.44
Quality of Death/ Last Week of Life ^k	-0.14	0.01	-0.12	0.04

Note: Bolded rows represent significant differences between patients with and without dependent children.

^a = mean differences expressed in standard deviations of baseline data; Confounders

^b = Yale and Karnofsky

^c = Black Race and age

^d = White Race and age

^e = White Race and Simmons

^f = Simmons

^g = Yale

^h = Yale and Black Race

ⁱ = age and symptom burden

^j = age, symptom burden and Parkland

^k = symptom burden and post mortem assessor

Table 4

Location of Patient Death

Location	Patients with Dependent Children (N=68)	Patient without Dependent Children (N=280)
	% (N)	% (N)
Hospital (ICU)	12% (8)	6% (18)
Hospital (Other)	26% (18)	23% (63)
Hospital Total	38% (26)	29% (81)
Nursing Home/ Long Term Care Facility	6% (4)	3% (9)
Patient's Home	47% (32)	49% (138)
Surrogate's Home	3% (2)	3% (9)
Other Home	4% (3)	1% (4)
Home Total	54% (37)	54% (151)
Inpatient Hospice	1% (1)	14% (38)
Other	0% (0)	0% (1)