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## Mental and Physical Health Correlates among Family Caregivers of Patients with Newly-Diagnosed Incurable Cancer: A Hierarchical Linear Regression Analysis

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### Abstract

**Purpose**—Caregiver, relational, and patient factors have been associated with the health of family members and friends providing care to patients with early-stage cancer. Little research has examined whether findings extend to family caregivers of patients with incurable cancer, who experience unique and substantial caregiving burdens. We examined correlates of mental and physical health among caregivers of patients with newly-diagnosed incurable lung or non-colorectal gastrointestinal cancer.

**Methods**—At baseline for a trial of early palliative care, caregivers of participating patients ( $N=275$ ) reported their mental and physical health (Medical Outcome Survey-Short Form-36); patients reported their quality of life (Functional Assessment of Cancer Therapy-General). Analyses used hierarchical linear regression with two-tailed significance tests.

**Results**—Caregivers' mental health was worse than the U.S. national population ( $M=44.31$ ,  $p<.001$ ), yet their physical health was better ( $M=56.20$ ,  $p<.001$ ). Hierarchical regression analyses testing caregiver, relational, and patient factors simultaneously revealed that younger ( $B=0.31$ ,  $p=.001$ ), spousal caregivers ( $B=-8.70$ ,  $p=.003$ ), who cared for patients reporting low emotional well-being ( $B=0.51$ ,  $p=.01$ ) reported worse mental health; older ( $B=-0.17$ ,  $p=.01$ ) caregivers with low educational attainment ( $B=4.36$ ,  $p<.001$ ) who cared for patients reporting low social well-being ( $B=0.35$ ,  $p=.05$ ) reported worse physical health.

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Conflict of interest: The authors declare they have no conflicts of interest.

#### Compliance with Ethical Standards

Research involving human participants and/or animals: The study was approved by the Dana-Farber / Harvard Cancer Center Institutional Review Board. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent: Written informed consent was obtained from all individual participants included in the study.

**Conclusions**—In this large sample of family caregivers of patients with incurable cancer, caregiver demographics, relational factors, and patient-specific factors were all related to caregiver mental health, while caregiver demographics were primarily associated with caregiver physical health. These findings help identify characteristics of family caregivers at highest risk of poor mental and physical health who may benefit from greater supportive care.

### Keywords

incurable cancer; palliative care; informal caregiving; mental health; physical health

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## INTRODUCTION

Roughly 2.8 million Americans serve as informal or family caregivers, providing emotional support and tangible help to loved ones with cancer [1, 2]. This informal care is critical to the health and quality of life (QOL) of patients, especially as cancer care in the U.S. continues to shift from inpatient to outpatient settings with care often provided in the home [3, 4]. However, these caregiving responsibilities also impose significant burdens to caregivers' mental [5–7] and physical health [8–10]. Caregivers of patients with incurable cancer experience the highest care burden [11] and worst long-term QOL [12] relative to caregivers of patients with early-stage cancer. Although prior studies have helped to elucidate factors related to poor mental and physical health for caregivers of patients with early-stage disease, these factors have not been fully evaluated in caregivers of patients with incurable disease.

Patients with incurable lung and gastrointestinal (GI) cancers experience high symptom burden and side effects from treatment, which begins at diagnosis, persists throughout the course of disease, and increases near end-of-life [13]. As patients' cancer progresses and they become more ill, they require more assistance [14], resulting in heightened caregiver burden, and interfering with caregivers' lives, role responsibilities, and social networks [15, 16]. Palliative care services, rooted in the goal of enhancing the entire family's QOL from diagnosis through bereavement [17], are designed to address these caregivers' substantial burdens. Research has demonstrated that these services are most effective when targeted and tailored to those caregivers with the greatest need [18]. Thus, it is important to determine risk factors for poor mental and physical health among caregivers of patients with incurable cancer.

Although a growing body of literature has sought to characterize and address the the unique burdens experienced by family caregivers of patients with advanced disease [e.g., 19–21], the majority of health outcomes research involving cancer caregivers has been conducted with caregivers of patients with early stage disease [22]. The stress-appraisal-coping framework [23, 24] applied to the caregiving context [10, 25] posits that factors pertaining to the caregivers' background, to their relationship with the patient, and to the patients' background and disease each independently affect caregivers' psychological and physical health [15]. Cancer caregivers' demographic factors, such as age, gender, socioeconomic status, and concurrent childcare responsibilities have been associated with caregiver health and QOL [26–29]. Relational factors such as being a patient's spouse and spending more

time providing care are also predictive of worse caregiver health and QOL [29–31]. These caregiver-specific and relational factors have been more strongly related to caregivers' own health outcomes than the patients' demographic and disease-related factors [27, 30, 32]; however, patients' self-reported mental and physical QOL have been shown to be interdependent with their caregivers' health [29, 33–35].

Data suggests that family caregivers' self-reported QOL following the patients' cancer diagnosis prospectively predicts caregivers' worse long-term health outcomes [12, 35]. Therefore, understanding the factors related to family caregivers' poor mental and physical health at the patient's diagnosis is critical to identify those most vulnerable for health decline [36]. To address this gap in the literature for caregivers of patients with advanced disease, we examined correlates of mental and physical health of family caregivers for patients with newly diagnosed incurable lung or non-colorectal GI cancer. We hypothesized that caregivers' demographics would be most strongly associated with their own mental and physical health, but that relational and patient-specific factors would also significantly relate to caregivers' health.

## METHODS

### Study Procedures

Data were the baseline measures of a non-blinded, randomized controlled trial of early palliative care integrated with standard oncology care compared with standard oncology care alone ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02349412) Identifier: NCT02349412). From May 2, 2011 to July 20, 2015, patients with newly diagnosed incurable lung or non-colorectal GI cancer were enrolled from the outpatient clinics at Massachusetts General Hospital Cancer Center (Boston, MA). The study was approved by the Dana-Farber / Harvard Cancer Center Institutional Review Board. All who agreed to participate provided written informed consent. Participants completed baseline measures used in the current study by paper or electronically, primarily in-clinic (98%), prior to randomization.

### Participants

**Caregivers**—Caregivers were identified by enrolled patients as a relative or friend who provided the patient help and would likely accompany the patient to clinic visits. Eligible caregivers were: (1) able to read and respond to questions in English or with minimal assistance from family or an interpreter and (2) 18 years of age. Caregivers had up to one month to enroll following the participating patients' consent date. Only one caregiver per patient was permitted to enroll in the study.

**Patients**—Patients were identified through electronic health record review of outpatient thoracic and GI oncology clinics; eligible patients were invited to participate by their oncology clinicians. Patients were eligible to participate if they were within 8 weeks of being informed of a diagnosis of incurable lung (non-small cell, small cell, or mesothelioma) or non-colorectal GI (pancreatic, hepatobiliary, esophageal, gastric) cancer at the participating institution. Patients were required to: (1) have received no prior treatment for metastatic disease; (2) have an Eastern Cooperative Oncology Group (ECOG) status  $\leq 2$ ; (3)

be able to read and respond to questions in English or with minimal assistance from family or an interpreter; and (4) be 18 years of age. Patients were ineligible if they were already engaged in palliative care or if their oncologist believed, based on their clinical judgment, that the patient required an early, immediate referral for outpatient palliative care services or referral for hospice care. As the aim of this sub-study was to identify the mental and physical health correlates for caregivers, patients who participated in the larger study without a caregiver ( $N=75$ ) were excluded from these analyses. Excluded patients did not differ from included patients ( $N=275$ ,  $ps>.23$ ), with the exception that excluded patients were marginally younger than those included ( $p=.06$ ).

## Measures

**Caregiver and relational factors**—Caregivers self-reported their age, gender, employment status, education level, and whether they had dependent children. Caregivers also self-reported whether they were living with the patient and/or married to the patient.

Caregivers self-reported their mental and physical health QOL using the 36-item Medical Outcomes Study Short Form-36 (MOS SF-36 [37]). The mental health component score (MCS) represents a weighted composite of vitality, social functioning, emotional limitations to role requirements, and mental health subscales. The physical health component score (PCS) represents a weighted composite of physical functioning, physical limitations to role requirements, bodily pain, and general health subscales. Both scores have been normalized (U.S. population normalized  $M=50$ ); higher scores reflect better mental and physical health [37].

**Patient factors**—Patients' age, gender, Eastern Cooperative Oncology Group status (ECOG; an objective marker of patient performance status and functioning [38]), and cancer diagnosis (lung or non-colorectal GI) were obtained from medical record review and patients' self-reported demographic questionnaire.

Patients also self-reported their prognostic understanding and treatment goals using items from the Prognosis and Treatment Perceptions Questionnaire (PTPQ [39]). Patients reported their primary treatment goal by responding to "If you had to choose one, what would you say is *your primary goal* of your current cancer treatment?" Patients were classified as reporting that their primary goal was cure versus other (i.e., to lessen suffering, keep hoping, make sure have done everything, extend life, help cancer research, or other). Patients reported their understanding of their health status by responding to "How would you describe your current medical status?" Patients were classified as reporting that their health status was terminal (i.e., "relatively healthy and terminally ill" or "seriously ill and terminally ill") versus not terminal (i.e., "relatively healthy" or "seriously ill and not terminally ill").

Patients self-reported their QOL during the past week using the Functional Assessment of Cancer Therapy-General (FACT-G [40]) questionnaire. The FACT-G has 27 items comprising four separate subscales for physical, social, emotional, and functional well-being, with higher sum scores indicating better QOL.

## Statistical Methods

Measures of central tendency (means and standard deviations or proportions) were used to describe caregiver, relational, and patient factors. Two hierarchical linear regression models were used to test the unique associations of caregiver, relational, and patient factors with caregivers' mental and physical health, respectively. In step 1, unique associations of caregiver factors to caregiver health were tested. Relational factors were added in step 2, testing unique associations of relational factors with caregivers' health beyond effects of caregiver factors. Last, patient factors were added in step 3, testing the unique associations of patient factors with caregivers' health beyond effects of caregiver and relational factors. Analyses were completed using SPSS version 20 (IBM, 2011). Significance testing used  $\alpha$ -level of .05, two-tailed tests.

## RESULTS

### Sample Characteristics

Table 1 summarizes descriptive information for caregiver, relational, and patient factors. The 275 participating caregivers were generally middle-aged (median = 60 years) and primarily female, highly educated, and without dependent children. Caregivers were roughly evenly split between those who were employed versus unemployed. The majority of caregivers lived with the patient and were the patient's spouse.

As also shown in Table 1, two-thirds of patients were rated as ambulatory but restricted in physically strenuous activity (ECOG score of 1). The patient sample was roughly evenly split between those with lung versus GI cancers. Approximately one-third of patients reported their primary treatment goal was to cure their cancer, with less than half of patients self-reporting their health status was terminal. Patients' self-reported domains of QOL were comparable to prior studies of patients with advanced cancer [29, 40].

Caregivers' self-reported mental health was comparable to prior samples of cancer caregivers [11, 29], yet lower than the U.S. population normalized mean ( $t(274)=-7.02$ ,  $p<.001$ ,  $d=0.85$ ). Caregivers' self-reported physical health was somewhat better than prior samples of cancer caregivers [11, 29], and higher than the U.S. population normalized mean ( $t(274)=11.69$ ,  $p<.001$ ,  $d=1.41$ ).

### Factors Associated with Caregivers' Mental and Physical Health

Results from hierarchical linear regression models testing the independent associations between caregiver, relational, and patient factors with caregiver mental and physical health are summarized in Table 2.

**Mental health**—Caregiver factors, tested in step 1, explained 8% of the variance in caregivers' mental health. Caregivers' younger age ( $p=.01$ ) and female gender ( $p=.02$ ) were associated with worse caregiver mental health. Relational factors, tested in step 2, explained an additional 5% of variance in caregivers' mental health beyond effects of caregiver factors. Spousal caregivers ( $p=.003$ ) reported worse mental health beyond effects of caregiver factors and whether they lived with the patient. Patient factors, tested in step 3, explained an

additional 13% of variance in caregivers' mental health beyond effects of caregiver and relational factors. Only patients' worse emotional well-being ( $p=.01$ ) was associated with their caregivers' worse mental health when controlling for all caregiver, relational, and patient factors. Additionally, in this final model including all caregiver, relational, and patient factors, caregiver younger age ( $B=0.31$ ,  $p=.001$ ) and being the patients' spouse ( $B=-8.70$ ,  $p=.003$ ) remained independently related to caregivers' worse mental health, and the final model explained 25% of variance in caregivers' mental health.

**Physical health**—Caregiver factors, tested in step 1, explained 15% of the variance in caregivers' physical health. Only caregivers' older age ( $p<.001$ ) and low education ( $p=.002$ ) were associated with worse caregiver physical health. Relational factors, tested in step 2, did not explain additional variance and were unrelated to caregivers' physical health beyond effects of caregiver factors. Patient factors, tested in step 3, did not explain additional variance in caregivers' physical health beyond effects of caregiver and relational factors. However, patients' worse social well-being ( $p=.05$ ) related to their caregivers' worse physical health when controlling for all caregiver, relational, and patient factors. Additionally, in this final model including all caregiver, relational, and patient factors, caregiver older age ( $B=-0.17$ ,  $p=.01$ ) and lower educational attainment ( $B=4.36$ ,  $p<.001$ ) remained independently related to caregivers' worse physical health, and this final model explained 18% of variance in caregivers' physical health.

## DISCUSSION

For this study, we recruited the largest sample of family caregivers of patients recently diagnosed with incurable cancer to date in the United States. The mental health burden among these caregivers was substantial, with the typical caregiver in our study reporting mental health equivalent to the 28<sup>th</sup> percentile of American adults, despite reporting better physical health on average than the general U.S. population. Factors related to the caregivers, their relationship to the patient, and the patient themselves were associated with caregivers' mental health; yet for their physical health, caregiver-specific factors were most relevant. Findings hold important implications for targeting psychosocial interventions, both to address caregivers' needs and utilize available palliative and supportive services most effectively. As worse caregiver mental and physical health at the time of their loved ones' diagnosis prospectively predicts caregivers' own worsening QOL over the following year [35] and following bereavement [41], targeted palliative care interventions provided early following the patients' incurable cancer diagnosis may diminish caregivers' longer-term mental and physical health morbidity risks.

Identifying risk factors for high distress among caregivers immediately following the patients' diagnosis is critical. Previous research suggests that mental health symptoms endorsed by family caregivers early in the patients' cancer trajectory tend not to remit naturally [22, 37]. In keeping with prior literature [26, 28, 30], our finding that younger caregivers reported poor mental health suggests the importance of targeting palliative care services to patients with middle-aged caregivers by providing these caregivers with emotional support. We also demonstrated that spousal caregivers report worse mental health relative to other family caregivers in our analyses that adjusted for confounding factors [26,

43]. Importantly, even while adjusting for other caregiver, relational, and patient factors, caregivers' mental health was found to be related to that of their loved one with cancer. This finding extends evidence of interdependence among patients' and caregivers' mental health, a phenomenon described by the dyadic stress model [44] and previously documented among those with early-stage cancer [33, 34], to those affected by incurable cancer.

Overall, these findings emphasize the importance of mental health assessment and intervention among family caregivers for patients newly diagnosed with incurable cancer. Since each set of factors—caregiver, relational, and patient—helped explain differences among caregivers' mental health, assessment protocols to target caregivers at greatest risk for psychological distress should incorporate information related to the caregiver and the patient. Considering the connection between patients' and caregivers' mental health, dyadic psychosocial interventions addressing both patient and caregiver needs may be most effective in ameliorating psychological distress in these populations [45, 46]. Palliative care, with its focus on the family as the point of intervention, may also be particularly effective in mitigating distress by providing wide-ranging support to both patients and their families [47].

Identifying risk factors related to caregivers' poor physical health at the time of the patient's diagnosis is also critical, as studies show that caregivers' physical health tends to decline over the course of the patient's cancer trajectory [9, 35]. Despite our sample of caregivers reporting relatively high physical health functioning, we found a significant association between older caregiver age and worse physical health in our cohort, consistent with prior literature [48]. Education was also an independent correlate of caregiver physical health, with caregivers receiving a high school education or less reporting worse physical health than those with some college education or greater. Education is a known predictor of health disparities observed in the general population [49] and family caregivers [1]. Higher education may be protective by easing learning of complicated patient care regimens and increasing access to support resources. Level of education may also function as a proxy for socioeconomic status in the current analyses, potentially indicating less financial strain and greater access to health care services.

Relational and patient factors did not meaningfully explain differences among caregivers' physical health after adjusting for caregiver demographics. That patients' perceived social connection and support uniquely related to caregivers' physical health in the context of all other studied factors is a novel finding that warrants further study, and may help to explain previously documented interdependence among patients' and caregivers' overall QOL. Prior literature has shown that physical morbidity among caregivers at the patient's diagnosis predicts caregivers' declining QOL over the following year [35] as well as interferes with caregivers' ability to provide high-quality care to patients [50]. Collectively, these findings suggest the relevance of health care providers educating caregivers early in the patient's disease course regarding self-care and healthy lifestyle behaviors, particularly older family caregivers and those with lower educational attainment.

A few limitations should be noted that point to future research directions. We used self-report measures of caregivers' mental and physical health, and the MOS SF-36 is not a

diagnostic tool. Future studies should seek to replicate our results using objective markers of mental and physical health through clinical interview, chart review, or psychoneuroimmunological and neuroendocrine markers, when possible. Additionally, the current analyses are cross-sectional, with data collected prior to random assignment to palliative care intervention. Prior literature suggests that early mental and physical health strongly predict later functioning [12, 35], underscoring the relevance of identifying risk factors correlated with poor early health. With its emphasis on the psychological, social, and physical aspects of illness, integrating palliative care into standard oncology practice early may hold promise for improving family caregivers' QOL and health through the patients' end-of-life and into bereavement. Research is ongoing by our group to test these questions.

In conclusion, the current study highlights key findings regarding the differing correlates of mental and physical health among the largest sample to date in the U.S. of family caregivers of patients with newly-diagnosed incurable lung or non-colorectal GI cancer. Caregivers reported good physical health on average, which was primarily associated with factors related to the caregivers themselves. However, caregivers concurrently reported significant impairment to their QOL from poor mental health, which was associated with caregivers' own demographics, their relation to the patient, and patient-specific factors. Findings help to identify caregivers who may benefit most from targeted supportive and palliative care services delivered early in the cancer trajectory. Specifically, younger spousal caregivers caring for patients with poor emotional well-being may benefit from interventions addressing their own and their loved one's psychological distress, while older, less educated caregivers may benefit from health behavior and self-care interventions to address their physical health risks.

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**Table 1**Sample Characteristics of Participants (*N*=275)

	<b>M (SD)</b>	<b>Range</b>	<b>N (%)</b>
<b>Caregiver factors</b>			
Age	57.37 (13.61)	19 – 86	–
Gender (female)	–	–	190 (69.1%)
Employed (working)	–	–	153 (55.6%)
Education (some college or more)	–	–	201 (73.4%)
Children (dependent children)	–	–	55 (20.0%)
<b>Relational factors</b>			
Living with patient (yes)	–	–	208 (78.5%)
Married to patient (yes)	–	–	182 (66.4%)
<b>Patient factors</b>			
Age	65.43 (10.75)	27–88	–
Gender (female)	–	–	122 (44.4%)
<b>ECOG</b>			
0	–	–	74 (26.9%)
1	–	–	174 (63.3%)
2	–	–	27 (9.8%)
Cancer type (lung)	–	–	149 (54.2%)
Self report primary treatment goal is cure	–	–	82 (32.7%)
Self report health status is terminally ill	–	–	128 (46.5%)
<b>FACT-G</b>			
Physical well-being	21.20 (5.69)	0–28	–
Social well-being	24.24 (3.99)	0–28	–
Emotional well-being	16.44 (4.95)	0–24	–
Functional well-being	16.37 (6.29)	0–28	–
<b>Caregiver health</b>			
Mental health (MCS)	44.31 (13.44)	6–70	–
Physical health (PCS)	56.20 (8.80)	23–74	–

*Note.* ECOG= Eastern Cooperative Oncology Group; FACT-G = Functional Assessment of Cancer Therapy-General; MCS= Mental Health Component score; PCS= Physical Health Component score.

Hierarchical Linear Regression Results of Caregiver, Relational, and Patient Factors with Caregivers' Mental and Physical Health

Table 2

	Mental Health (MCS)				Physical Health (PCS)			
	Unstandardized		Std		Unstandardized		Std	
	<i>B</i>	[95% CI]	$\beta$	<i>p</i>	<i>B</i>	[95% CI]	$\beta$	<i>p</i>
Caregiver factors	$R^2=.08, F=4.09 [5, 239], p<.001$				$R^2=.15, F=8.46 [5, 239], p<.001$			
Age	<b>0.22</b>	<b>[0.07, 0.38]</b>	<b>.22</b>	<b>.01</b>	<b>-0.16</b>	<b>[-0.26, -0.06]</b>	<b>-.25</b>	<b>.001</b>
Gender	-	[-8.00, -4.28]	-.15	.02	0.27	[-2.03, 2.57]	.01	.82
Employed	1.54	[-2.31, 5.39]	.06	.43	2.50	[0.13, 4.88]	.14	.04
Education	1.84	[-1.99, 5.68]	.06	.34	<b>3.68</b>	<b>[1.31, 6.04]</b>	<b>.19</b>	<b>.002</b>
Children	-	[-6.05, 1.31]	-.04	.59	-	[-3.21, 2.65]	-.01	.85
Relational factors	$R^2=.05, F=6.29 [2, 237], p=.003$				$R^2=.004, F=0.44 [2, 237], p=.61$			
Living with patient	2.29	[-3.54, 8.11]	.07	.44	-0.71	[-4.40, 2.97]	-.02	.70
Married to patient	-	<b>[-13.78, 8.35]</b>	<b>-.29</b>	<b>.003</b>	1.63	[-1.80, 5.07]	.09	.35
Patient factors	$R^2=.13, F=3.58 [11, 226], p<.001$				$R^2=.03, F=0.73 [11, 226], p=.61$			
Age	0.11	[-0.08, 0.29]	.08	.27	-0.06	[-0.19, 0.07]	-.07	.36
Gender	0.67	[-3.69, 5.04]	.03	.76	0.09	[-2.63, 3.22]	.01	.95
ECOG	1.33	[-1.59, 4.25]	.06	.37	0.29	[-1.26, 3.62]	.02	.77
Cancer type	-	[-3.89, 2.82]	-.02	.75	-	[-2.38, 2.13]	-.004	.95
Self-report primary treatment goal is cure	-	[-6.18, 1.06]	-.09	.17	1.19	[-1.60, 2.33]	.06	.34

	Mental Health (MCS)				Physical Health (PCS)			
	Unstandardized		Std	p	Unstandardized		Std	p
	B	[95% CI]	$\beta$		B	[95% CI]	$\beta$	
Self-report health status is terminally ill	-.34	[-6.84, 0.15]	-.12	.06	1.27	[-1.12, 3.56]	.07	.29
Physical well-being	0.07	[-0.30, 0.43]	.03	.73	0.12	[-0.15, 0.35]	.08	.35
Social well-being	0.31	[-0.20, 0.82]	.08	.23	<b>0.35</b>	[-0.003, <b>0.68</b> ]	<b>.14</b>	<b>.05</b>
Emotional well-being	<b>0.51</b>	<b>[0.15, 0.88]</b>	<b>.19</b>	<b>.01</b>	-0.03	[-0.25, 0.27]	-.02	.82
Functional well-being	0.21	[-0.15, 0.56]	.10	.25	-	[-0.40, 0.08]	-.13	.14

Note. N = 275. Final models testing all 3 blocks simultaneously accounted for 25% variance in MCS and 18% variance in PCS. Bold font indicates factors that remained significantly related to the health outcome in the final model controlling for all caregiver, relational, and patient factors; Std= Standardized; MCS= Mental Health Component score; PCS= Physical Health Component score; Gender= 0 male, 1 female; Employed= 0 not employed, 1 employed; Education= 0 high school or less, 1 college or more; Children= 0 no dependent children, 1 dependent children; Living with patient= 0 not living with patient, 1 living with patient; Married to patient= 0 not married to patient, 1 married to patient; ECOG= Eastern Cooperative Oncology Group; Cancer type= 0 lung, 1 GI; Self-report primary goal of treatment= 0 other, 1 cure; Self-report health status= 0 not terminal, 1 terminal.