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**Title:** What contextual factors account for anxiety and depressed mood in hospice family caregivers?

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## Abstract

**Objective:** End-of-life caregiving is associated with poorer mental health compared with other caregiving. The objective of this study was to examine the association between contextual characteristics and appraisal factors on family caregivers' mental health and well-being.

**Methods:** Family hospice caregivers were recruited across four states using a non-probabilistic sampling approach. This study analyzed contextual (demographic, caregiving, economic) and appraisal factors (Medical Outcomes Study Social Support Survey, Zarit Burden Interview) on caregivers' anxiety and depression (Hospital Anxiety and Depression scale, and positive affect and well-being (Positive Affect and Well-being Scale). Hierarchical linear regression models were generated in SPSS version 24.

**Results:** Data from 102 family caregivers were analyzed. On average, participants were 58.93 years of age ( $SD=14.24$ ), mostly female (72.55%), spouses/partners (51.96%), and non-Hispanic White (78.43%). Most (75.49%) described their financial situation as comfortable or more than adequate. Younger age ( $B=-0.11$ , 95% CI= -0.18 to -0.05) and increased caregiving burden ( $B=0.18$ , 95% CI= 0.09 to 0.27) were associated with increased anxiety, while lower perceived financial adequacy ( $B=-1.19$ , 95% CI=-2.07 to -0.32), lower social support ( $B=-0.04$ , 95% CI=-0.06 to -0.01), and increased caregiving burden ( $B=0.15$ , 95% CI=0.08 to 0.22) were associated with worsened depression. Greater social support ( $B=0.10$ , 95% CI=0.05 to 0.14) and lower caregiving burden ( $B=-0.19$ , 95% CI= -0.32 to -0.07) were associated with greater positive affect and well-being.

**Conclusions:** Findings suggest significant impact of contextual factors on mental health and well-being, and support the need for holistic assessment of hospice caregivers' wellbeing and programs and policies providing social services and economic support to caregivers.

**Keywords:** Cancer, caregiver burden, family caregivers, financial stress, hospice care, mental health, social support, oncology

## What contextual factors account for anxiety and depressed mood in hospice family caregivers?

### Background

More than one in five Americans are caregivers.<sup>1</sup> Cancer is one of the top reasons for caregiving and one of the most common diagnoses in end-of-life home hospice services.<sup>2</sup> In home hospice, family members take on a primary care role with support from hospice interdisciplinary care teams, and are often responsible for complex care. Cancer caregiving in the final stage of life is intensive as often cancer patients experience more rapid decline compared to patients with other terminal conditions.<sup>3</sup> Patients may also have substantial emotional and symptom management needs and increasingly rely on their family caregivers for daily care provision, management, coordination, and decision making.<sup>4,5</sup> As such, it is unsurprising that cancer caregivers report high stress at patients' end of life, especially as they transition from primarily serving in a supportive role in outpatient care to primary care responsibility in home hospice.<sup>6</sup>

A body of stress-process theory research has guided understanding of family caregiving across conditions and provided evidence of the association of caregivers' perception of support and burden on their anxiety, depression, and positive affect.<sup>7,8</sup> Fletcher and colleagues' cancer family caregiving model<sup>7</sup> based on stress process theory posits that appraisal of support and caregiving burden predicts mental health, and has been successfully applied to study the stresses of the caregiving experience across the care trajectory.<sup>9</sup> The model identifies cognitive appraisal factors representing perceptions of stressors and resources such as caregiver burden and support, and personal and relational contextual factors that may be fixed (e.g. relationship to patient, gender) or prone to fluctuation (financial situation).<sup>7</sup> These factors contribute to the stress process experienced by caregivers and impact physical, psychological, and emotional health of caregivers.

Previous studies of caregivers of seriously ill patients have established that psychological morbidity such as distress, depression, and anxiety are highly prevalent in this population,<sup>10</sup> and that caregiving burden is positively associated with psychological morbidity.<sup>11</sup> Analyses using the Coping with Cancer cohort study in the US have observed that caregivers for advanced cancer patients are seven times more likely to have a new episode of major depression and three times more likely to have a new diagnosis of generalized anxiety disorder compared to a matched comparison group in the general population.<sup>12</sup> In addition, the cancer caregiving literature suggests that while social and financial support needs increase in the end-of-life caregiving phase,<sup>13</sup> a majority of cancer caregivers report low social and financial support.<sup>14</sup> This is important as emotional support can buffer mental health outcomes associated with advanced cancer caregiving.<sup>15</sup>

Among caregivers of terminally ill cancer patients, younger, spousal caregivers have been found to be at greater risk for poorer mental health outcomes, and female caregivers of advanced cancer patients may be at risk for greater caregiving burden.<sup>16</sup> In addition to being emotionally burdensome, medical expenses for advanced cancer patients can also be financially burdensome—80% of caregivers incur out of pocket caregiving expenses.<sup>17</sup> Additionally, hospice caregivers may be facing the loss of income from employment or the loss of a partner, adding to financial stress.<sup>15</sup> Collectively, these contextual factors can take a toll on mental health—a study of 232 family caregivers in Germany found that caregivers who were female or lower socioeconomic status were three and six times more likely to report moderate to severe depressive symptoms respectively.<sup>18</sup> However, the interplay between contextual characteristics, social support and burden appraisal, and multiple aspects of mental and emotional wellbeing in home hospice, a phase where patients often are heavily dependent on family caregivers, is understudied.

The goal of hospice care is to provide holistic services to patients and family members at end of life. Understanding which factors drive outcomes can lead to targeted and tailored services and improved clinical care. This study aims to examine contextual factors associated with mental health and well-being outcomes among a sample of cancer caregivers receiving hospice services. Specifically, we sought to examine the hypothesis that, in addition to social support and burden, contextual factors of age, gender, relationship to patient, and financial adequacy are associated with cancer hospice caregivers' anxiety, depression, and positive affect and well-being.

## **Methods**

This multi-site longitudinal prospective study was approved by the University of Utah Institutional Review Board in February 2016 (IRB#00088662). This paper presents analyses examining cross-sectional survey data from  $N=102$  hospice caregivers of patients with cancer from hospices in four states (Utah, Massachusetts, Florida, and Ohio). Patient census reports were generated weekly, and screened by research staff to identify patients who met eligibility criteria.

### *Eligibility*

Family caregiver participants were identified through patients' records at participating hospice agencies between 2017 and 2020. Kin and non-kin caregivers were eligible to be inclusive of families of choice. Eligible hospice patients were 18 years or older, had a primary diagnosis of cancer, a prognosis of one week or more to live, were being cared for in the home, and had an eligible family caregiver to participate in the study. Eligible caregivers were 18 years or older, and could speak and understand English. Parent caregivers of children with life-limiting cancer were not eligible due to the qualitative differences in caring for a dying child. Eligibility was checked at three stages: screening of hospice records, research staff phone call, and final confirmation at home visit.

### *Screening and recruitment procedures*

Patients' demographic data were logged in a secure, password protected, online database (REDCap) together with family caregiver information. Records for 1,016 hospice patients were screened; of which, 918 patients met initial screening criteria. Up to four calls were attempted to reach the family caregiver to introduce the study and to determine caregiver eligibility ( $n=352$  met patient and caregiver eligibility criteria). Research staff scheduled home visits with caregivers who were interested to learn more about the study ( $n=171$ ). At the home visit, 25 patient-caregiver dyads were deemed ineligible and 44 caregivers declined participation. (see figure 1).

Consent was also obtained from patients if they were physically and/or cognitively able to consent. Caregivers then completed a self-administered baseline survey on an iPad or pen-and-paper surveys which were collated in the REDCap database. A total of 104 caregivers provided consent.

## **Measures**

Measures were selected guided by constructs of the Fletcher Stress Process Model of Family Cancer Caregiving.<sup>7</sup> Measures of context, caregiver appraisal of social support and burden, and mental health and well-being outcomes were completed by caregivers. Pro-rated total scores were computed for participants that completed at least 70% of scale item questions.

### *Contextual Variables*

Caregivers completed self-report sociodemographic questionnaires, including items assessing age, gender, relationship to patient (spouse/partner and non-partner i.e. child, other relative, or friend), and adequacy

of caregivers' financial situation (financial situation is not very good; financial situation is comfortable; financial situation is more than adequate).

Due to the heterogeneity in lengths of prior hospice enrollment among caregivers, length of hospice enrollment was included in the models as a control variable. The median time from hospice admission to completion of surveys was 23.50 days (Interquartile range (IQR): 21 days) from patient admission to hospice. A log transformation was used to address the positive skewness in the variable.

#### *Appraisal Measures*

Social support was assessed by the 4-item Medical Outcomes Study Social Support Survey.<sup>19</sup> The scale is a single factor scale assessing instrumental, information, companionship, and emotional support.<sup>19,20</sup> Responses are scored on a 5-point Likert scale from 0-none of the time to 4-all of the time, summed, and transformed to a scale ranging from 0-100. Higher scores indicate higher social support. The scale demonstrated good internal consistency (Cronbach's  $\alpha=.85$ ).

Caregiving burden was examined with the Zarit Burden Interview Short Form (ZBI-12).<sup>21</sup> The 12-item scale measures the primary and secondary stressors of caregiving demands and demonstrates a two-factor structure measuring direct strain from caregiving and caregiving role strain.<sup>21</sup> Responses are scored on a 5-point Likert scale ranging from "never" to "almost always". Total scores were obtained by summing the responses. Possible scores range from 0-48, with higher scores indicating greater caregiving burden and scores of greater than 16 indicative of severe burden. The ZBI-12 scale demonstrated good internal consistency ( $\alpha=0.89$ ) in the sample.

#### *Mental Health and Well-being Outcome Measures*

Anxiety and Depression were assessed using subscales of the Hospital Anxiety and Depression Scale.<sup>22</sup> The scale was developed for the clinical setting and is widely used to assess for emotional disorders in research.<sup>20</sup> The scale comprises of two factors (Anxiety and Depression) each consisting of 7 items. The 4-point Likert scale responses range from 0-3 with 7 Anxiety items (total score= 0-21) and 7 Depression items (total score= 0-21), with higher scores indicating greater distress. The internal consistency of the two subscales was good (Cronbach's  $\alpha$  Anxiety  $\alpha=.88$ ; Depression  $\alpha=.80$ ).

Positive caregiving outcomes are understudied in the caregiving literature, however, they are an important aspect of cancer caregiving.<sup>7</sup> To provide a more holistic characterization of mental health outcomes, positive affect and wellbeing was assessed in addition to anxiety and depression. Positive Affect was assessed using the 9-item version of the Neuro-QOL Positive Affect and Well-being Scale.<sup>23</sup> The scale measures overall outlook and feeling of purpose in life (e.g. , "I have a sense of balance in my life", and "my life has purpose") on a 5-point Likert scale ranging from 1 to 5, with higher scores indicating greater emotional and psychological well-being. Total scores were standardized and transformed to T scores (0-100).<sup>28</sup> The internal consistency of the scale in this sample was excellent (Cronbach's  $\alpha=0.937$ ).

#### *Statistical Methods*

All analyses were conducted in IBM SPSS version 24. Descriptive statistics were computed for sample demographics as well as to assess outcome variable normality distribution assumptions. Hierarchical linear regression models were conducted to assess unique associations of caregiving burden and support on three outcome measures: anxiety, depression, and positive affect and well-being. The variables were informed *a priori* by the Fletcher Caregiving Stress Model. Specifically, we were interested in examining the contribution of participant demographic and caregiving characteristics in addition to social support and caregiving burden. We incorporated these second set of variables in a second step to allows us to

assess if as a whole, participants' contextual factors improved the explained variance of the model. The conceptual approach to model building is more in line with hierarchical regression rather than exploratory stepwise regression. Furthermore, hierarchical regression modeling was preferred over stepwise regression to avoid model overfitting and inflated estimates,<sup>24</sup> which artificially inflate significant results. Exploratory analyses were conducted with social support and burden as interaction terms using mean centered scores.

## Results

A total of  $N=102$  caregivers provided baseline survey data for the study. Demographic data is presented in Table 1. Caregivers' mean age was 58.83 ( $SD=14.24$ ), and a majority of caregivers were female ( $n=74$ , 73%) and married ( $n=71$ , 70%). Half of the participants were spouses of the patient ( $n=53$ , 52%) and  $n=39$  (38%) were adult children. The majority of caregivers were non-Hispanic White ( $n=80$ , 80%) and had higher than a high school education ( $n=85$ , 84%). Over three quarters ( $n=80$ , 78%) perceived their financial situation as comfortable or more than adequate.

Participants' reported a mean score of 63.88/100 ( $SD=25.48$ ) for social support (min-max: 0-100,  $n=95$ ), 16.68/48 ( $SD=9.24$ ) for caregiving burden (min-max: 0-39,  $n=94$ ), 7.61/21 ( $SD=4.27$ ) for anxiety (min-max: 0-18,  $n=100$ ), 5.95/21 ( $SD=3.45$ ) for depression (min-max: 0-15,  $n=98$ ), and 45.89/100 ( $SD=5.80$ ) for positive affect and well-being scores (min-max: 26.3-54.4,  $n=90$ ). Mean scores by subgroups of gender, spousal relationship, financial adequacy, and Pearson's correlations between social support and burden and outcome measures are presented in Table 2. Association of these measures with the outcomes were tested statistically when incorporated in the regression models and controlling for other contextual factors.

### Regression Models

Table 3 shows the results from the hierarchical linear regression models for the influence of social support and caregiving burden while controlling for contextual variables. In Model 1, social support and caregiving burden entered together explained 30.6% of the variance in anxiety, 35.0% of the variance in depression, and 40% of the variance in positive affect and wellbeing, as determined by  $R^2$  values. In Model 1, caregiving burden was a significant predictor for all mental health outcomes with increased caregiving burden associated with poorer outcomes, while social support was a significant predictor for positive affect and wellbeing and depression. In Model 2, caregiving burden remained a significant predictor for poorer mental health outcomes, and social support remained significant for positive affect and wellbeing and depression. The addition of context variables in Model 2 significantly improved the overall model fit for anxiety and depression but not positive affect and wellbeing, as indicated by significant  $F$  change, and the models suggest that contextual characteristics explain between 1.67% to 9.90% of the variance indicated by the change in  $R^2$  values.

*Anxiety.* In Model 1, caregiving burden was found to be positively associated with anxiety ( $B=0.24$ , 95% CI=0.15 to 0.33,  $p<0.001$ ). In Model 2, controlling for contextual factors, caregiving burden among hospice caregivers continued to be positively associated with anxiety ( $B=0.18$ , 95% CI=0.09 to 0.27,  $p<0.001$ ) and older age was negatively associated with anxiety ( $B=-0.11$ , 95% CI= -0.18 to -0.05,  $p<0.001$ ). No other contextual variables were significantly associated with anxiety.

*Depression.* In Model 1, caregiving burden and social support were both associated with depression. Greater caregiving burden ( $B=0.18$ , 95% CI=0.11 to 0.25,  $p<0.001$ ) was significantly associated with increased depression, while higher social support was associated with lower depression ( $B=-0.04$ , 95% CI=-0.06 to -0.01,  $p=0.003$ ). In Model 2, both caregiving burden ( $B=0.15$ , 95% CI=0.08 to 0.22,  $p<0.001$ ) and social support ( $B=-0.04$ , 95% CI=-0.06 to -0.01,  $p=0.006$ ) continued to contribute to depression,

while higher perceived financial adequacy was negatively associated with depression ( $B=-1.19$ , 95% CI=-2.07 to -0.32,  $p=0.008$ ). No other contextual variables were significantly associated with depression.

*Positive affect.* In Model 1, caregiving burden was negatively associated with positive affect ( $B=-0.22$ , 95% CI=-0.34 to -0.10,  $p=0.001$ ), while social support was positively associated ( $B=0.11$ , 95% CI= 0.07 to 0.15,  $p<0.001$ ). Addition of contextual characteristics in Model 2 did not improve model fit ( $p=.223$ ), although age approached significance ( $B=0.08$ , 95% CI= -0.01 to 0.16,  $p=0.066$ ). Associations between caregiving burden ( $B=-0.19$ , 95% CI=-0.32 to -0.07,  $p=0.003$ ) and social support ( $B=0.10$ , 95% CI=0.05 to 0.14,  $p<0.001$ ) remained significant.

### **Exploratory analyses for interactions**

In exploratory analyses, interaction variables were added to evaluate the change in  $R^2$ . Interaction variables were not significant nor did they improve model fit for anxiety and depression; however, the interaction between support and burden improved the variance explained in the model for positive affect and wellbeing ( $\Delta R^2 = 0.042$ ), indicating for individuals with higher burden greater social support was associated with greater increases in positive affect and wellbeing ( $B=0.0054$ , 95% CI= 0.0010 to 0.0099,  $p=0.017$ ; Table 3).

### **Discussion**

#### *Main findings/results of the study*

Findings from this study highlight the appraisal and contextual factors associated with hospice family caregivers' anxiety, depression, and positive affect and well-being, and contributes to the small body of literature examining the financial implications of caregiving. As end-of-life care is both complex and intensive, hospice caregivers are a population of caregivers that are at risk for greater caregiving burden and mental health outcomes than the general population.<sup>25</sup> Hospice caregivers' appraisals or perceptions may indicate adjustment to the effects of chronic caregiving stress,<sup>26</sup> however, little is known about how other factors like caregivers' financial context affect multiple aspects of mental health for caregiving at the end of life. Understanding the influence of these contextual factors is important as the mental health of caregivers may have downstream implications for bereavement adjustment.<sup>27</sup>

This finding is consistent with meta-analyses of caregiving studies supporting that psychological health is poorer in caregiving populations.<sup>28</sup> In the current study, cancer hospice family caregiver participants reported higher caregiving burden, anxiety and depression, and lower social support than compared with average scores of other palliative care and caregiving populations,<sup>19,29</sup> which supports the great need for psychosocial support during this period of caregiving.

Consistent with the model proposed by Fletcher and colleagues,<sup>7</sup> our findings confirm that social support and caregiving burden significantly contribute to various aspects of caregivers' mental health. Social support, including from both informal and formal sources, is a source of tangible and emotional support for cancer caregivers, and helps buffer against negative effects of caregiving such as stress and depression.<sup>30</sup> In nationally representative studies for stroke caregivers, caregivers with greater caregiving strain were found to be at greatest risk for poorer psychosocial and emotional health.<sup>31</sup> In this study, we observed that while burden contributed to all measures of mental health, caregivers' perception of social support was not associated with anxiety, emphasizing the multi-faceted nature of stressors and psychological wellbeing.

#### *What this study adds*

Our findings suggest that younger adult hospice caregivers may be at greatest risk for anxiety. There is surprisingly little research on cancer caregivers who are young adults; however, earlier studies suggest that young adult caregivers on average, provide care equivalent to a part-time job and almost three quarters report difficulty finding formal caregiving supports for care recipients.<sup>32</sup> In addition, young adult caregivers are disproportionately female, single, lower income, and unemployed,<sup>33</sup> factors which could contribute to greater caregiver stress. Future research should examine how caregiving stress affects mental health outcomes for caregivers across the lifespan.

A situational stressor that is particularly difficult for caregivers is financial concerns,<sup>15</sup> which was associated with depression in our findings. Financial strain and its relationship to quality of life is well documented among hospice,<sup>15</sup> Alzheimer's disease,<sup>34</sup> as well as cancer spousal caregivers earlier in the care trajectory.<sup>35</sup> Financial strain is an area that requires further research at the end of life as the end of life is a period associated with a substantial proportion of all medical spending.<sup>36</sup> Financial burden may be higher for caregivers in high intensity caregiving situations.<sup>35</sup> Despite bearing employment and financial consequences related to caregiving,<sup>34</sup> cancer caregivers may be reluctant to discuss these concerns openly with health care providers, employers, or their social networks.<sup>37</sup> They may also not receive adequate support with financial screening, paid leave, adjusted work schedules, or monetary contributions from family and friends. Financial well-being requires an integrated approach including the health care system and policy efforts at the community, state, and national levels. In recognition of these financial implications, many developed countries such as the United Kingdom, Australia, and Canada have well established policies to provide financial support to caregivers.<sup>4,38</sup> The United States lags behind in terms of policies that provide economic relief to caregivers, but there is growing interest in expanding paid leave, addressing flexible employment, and providing tax benefits for caregivers. Due to the differences in economic factors across healthcare systems, more studies in the US are needed to provide greater insight into the financial stressors affecting caregivers.

While positive affect and wellbeing are less studied mental health outcomes in the cancer caregiving literature, caregiving research with among patients with neurodegenerative disorders have found that the optimism may be protective against the development of caregiver distress.<sup>39</sup> Our findings that social support and caregiving burden contribute the most to caregivers' perceptions of positive affect and wellbeing. In particular, social support may be most beneficial to the positive affect and wellbeing of the caregivers experiencing greater burden; this finding highlights the importance of continued intervention to improve informal and formal social networks of support in home hospice caregivers.

Although prior caregiving studies have found that emotional support is associated with reduced caregiver distress,<sup>16</sup> we found that social support was not protective for anxiety after controlling for burden and contextual factors in this sample. This null finding could be due to the complex nature of social support. A previous examination of social support in this sample has found that over a third of participants reported members of their social networks who contribute to both social support and stress.<sup>40</sup> These findings highlight the complex nature of mental health and wellbeing, and emphasize the need for providers to conduct in-depth and comprehensive evaluations of hospice caregivers' mental health that encompasses these multiple aspects.

Contrary to earlier studies with caregivers of terminally ill and hospice patients,<sup>16</sup> we did not find significant associations female or spousal caregivers for any of the mental health outcomes. It is possible these may be due to cohort effects of changing gender role expectations related to caregiving over time, or the smaller sample size that limit the ability to detect positive findings. The trend toward significance for age and positive affect and wellbeing in this sample suggests the need for future research examining the relationship between age and mental health among hospice caregivers with a larger sample. Future longitudinal analyses are also warranted, as cancer caregivers' anxiety and depression during caregiving are associated with poorer psychological wellbeing during bereavement.<sup>11</sup>

### *Study limitations*

This study examines hospice cancer caregivers across four U.S. states, which is a strength of the study as hospice caregivers are an understudied population in the caregiving literature. However, while the larger study is longitudinal, the findings presented in this study are cross-sectional which limits understanding of the directionality of relationships. An additional limitation is that the study did not control for the potentially-confounding influence of caregivers' preexisting psychological diagnoses, which was not collected in the larger study. The non-probabilistic sampling approach and the challenges in recruiting hospice caregivers may introduce selection bias. Recruitment for hospice studies is challenging and response rates of less than 50% are common.<sup>55</sup> Caregiver participants in the study were also mostly White which limits generalizability to diverse caregivers. Nationwide, racial and ethnic distributions of the hospice patient population are 82% White, 8.2% Black or African American, 6.7% Hispanic/Latino, and 3.1% other races.<sup>2</sup> While the current sample is under-representative of Black hospice caregivers, the diversity represented in the sample nevertheless is reflective of the general hospice caregiver population.<sup>2</sup>

### *Clinical implications*

Our research indicates context has important direct impacts on well-being outcomes. Greater attention needs to be focused on targeting and tailoring inclusive programs and research to support caregivers, especially those who are younger and less financially secure-- over and above assessing for social support and caregiving burden. Findings also highlight the importance of social support for high burden caregivers. Additionally, findings support the need for additional research, programs, and policies targeted at addressing the economic implications of caregiving.

### **Declarations of conflicts of interest**

The authors declare that there are no conflicts of interest.

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### **Author Contributions**

DT contributed to the analysis and interpretation of the data, drafted the article, approved the final version, and accepts full responsibility for the work. EI contributed to the analysis and interpretation of the data, revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work, MR contributed to the conceptualization and design of the work, interpretation of the data, drafted and revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work. KGC contributed to the conceptualization and design of the work, revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work. MJ contributed to the acquisition of the data, drafted and revised it critically

for intellectual content, approved the final version and accepts full responsibility for the work. MCTH contributed to the interpretation of the data, revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work. KM contributed to the conceptualization and design of the work, revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work. ACB contributed to the conceptualization and design of the work, revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work. LE contributed to the conceptualization and design of the work, interpretation of the data, drafted and revised it critically for intellectual content, approved the final version, and accepts full responsibility for the work.

**Data Availability Statement**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

**Table 1. Demographic Characteristics of Family Caregivers (N = 102)**

<b>Personal Characteristics (Sociodemographics)</b>	Mean (SD)	Range
<b>Age (n=98); missing (n=4)</b>	58.93 (14.24)	27-87
	Median	IQR
Prior Length of Hospice Enrollment (days)	23.50	21
Overall Length of Stay in Hospice <sup>a</sup> (days)	53	67
	<i>n</i>	(%)
<b>Gender</b>		
Female	74	72.55
<b>Race/Ethnicity<sup>b</sup></b>		
Non-Hispanic White	80	78.43
Hispanic/Latino	12	11.76
Black or African American	4	3.92
Other or multiple races (Non-Hispanic/Latino)	4	3.92
Missing	2	1.96
<b>Marital Status</b>		
Married/Committed Relationship	79	77.45
<b>Highest Education</b>		
High School or Equivalent or Less	17	16.67
Some College or Vocational School	36	35.29
College Graduate	25	24.51
Some Graduate or Professional School	7	6.86
Graduate or Professional Degree	17	16.67
<b>Employment</b>		
No	47	46.53
Part Time	38	37.62
Full Time	16	15.84
Missing	1	0.98
<b>Perceived Adequacy of Financial Situation</b>		
Not very good	22	21.57
Comfortable	54	52.94
More than adequate	23	22.55
Missing	3	2.94
<b>Religion</b>		
Has a Religious Affiliation	67	65.69

**Relational Characteristics (Caregiving context)**

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**Relationship to Patient**

Spouse/Partner	53	51.96
Sibling	4	3.92
Child	39	38.24
Friend/Other	6	5.88

**Choice in Caregiving**

Yes	52	50.98
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<sup>a</sup>Overall length of stay in hospice was computed from first billed hospice visit to patients' date of death or last billed hospice visit. This variable not included in regression models

<sup>b</sup>“Hispanic/Latino” ethnicity included White and non White races. “Other races” included American Indian, Alaska Native (1) and Asian/Eastern Indian (2).

**Table 2. Means and Standard Deviations of Outcome Measures by Subgroup (N=100)**

Subgroups <sup>a</sup>	Anxiety (N=100) <sup>b,c</sup>	Depression (N=98) <sup>b,c</sup>	Positive Affect and Well-being (N=90) <sup>b,c</sup>
	M (SD) <sup>c</sup>	M (SD) <sup>c</sup>	M (SD) <sup>c</sup>
<b>Gender, n</b>			
Female (66)	7.70 (4.14)	5.85 (3.38)	46.02 (6.16)
Male (24)	7.39 (4.66)	6.21 (3.68)	45.53 (4.80)
<b>Race, n</b>			
White Non-Hispanic/Latino (71)	7.59 (4.44)	5.95 (3.57)	45.81 (5.63)
Hispanic/Latino (12)	8.29 (4.18)	6.40 (3.23)	44.89 (7.62)
Other and multi races (7)	6.88 (3.09)	5.88 (2.85)	48.73 (5.30)
<b>Marital Status, n</b>			
Spouse (48)	7.16 (4.08)	5.90 (3.58)	44.89 (5.98)
Non-spouse, (42)	8.11 (4.45)	6.00 (3.34)	47.04 (5.44)
<b>Age groups, n</b>			
18-39 (10)	11.64 (4.11)	7.44 (2.89)	45.36 (3.35)
40-64 (40)	8.19 (3.91)	6.92 (3.31)	44.81 (6.57)
65 and older (36)	6.01 (3.91)	4.71 (3.20)	46.96 (5.05)
<b>Adequacy of Financial Situation, n</b>			
Not very good (15)	8.36 (3.93)	7.31 (3.53)	44.37 (5.83)
Comfortable (50)	8.31 (3.88)	6.37 (3.05)	45.26 (5.40)
More than adequate (22)	5.64 (4.97)	4.09 (3.54)	47.78 (6.37)
<b>Correlations</b>			
<b>Caregiving Burden</b> , <sup>b,c,d</sup>	0.575***	0.585***	-0.481***
<b>Perceived Social Support</b> <sup>b,c,d</sup>	-0.298**	-0.426***	0.554***

<sup>a</sup>Counts presented in subgroups represent participants who completed all measures

<sup>b</sup>Perceived Social Support: Medical Outcomes Survey-Social Support Scale; Caregiving Burden: Zarit Burden Inventory; Anxiety: Hospital Anxiety and Depression Scale-Anxiety subscale; Depression: Hospital Anxiety and Depression Scale-Depression subscale; Positive Affect and Well-being: Positive Affect and Well-being scale.

<sup>c</sup>M (SD) were computed with total scores of participants who completed all items and pro-rated scores of completed items for participants who completed more than 70% of the items.

<sup>d</sup>\*\*significance at the 0.01 level, \*\*\*significance at the <0.001 level.

**Table 3. Hierarchical Linear Regression Models for Anxiety, Depression, and Positive Affect and Well-being (N=85)**

Independent Variables	Anxiety <sup>a,b</sup>		Depression <sup>a,b</sup>		Positive Affect and Well-being <sup>a,b</sup>	
	(B, 95% CI)	$\Delta R^2$ , sig.	(B, 95% CI)	$\Delta R^2$ , sig.	(B, 95% CI)	$\Delta R^2$ , sig.
<b>Model 1</b>		<b>.31, p&lt;.001</b>		<b>.35, p&lt;.001</b>		<b>.40, p&lt;.001</b>
Perceived Social Support <sup>a</sup>	-0.03 [-0.06, 0.00]		<b>-0.04 [-0.06, -0.01]</b>		<b>0.11 [0.07, 0.15]</b>	
Caregiving Burden <sup>a</sup>	<b>0.24 [0.15, 0.33]</b>		<b>0.18 [0.11, 0.25]</b>		<b>-0.22 [-0.34, -0.10]</b>	
<b>Model 2</b>		<b>.13, p=.005</b>		<b>.09, p=.030</b>		<b>.05, p=.223</b>
Perceived Social Support	-0.03 [-0.06, 0.01]		<b>-0.04 [-0.06, -0.01]</b>		<b>0.10 [0.05, 0.14]</b>	
Caregiving Burden	<b>0.18 [0.09, 0.27]</b>		<b>0.15 [0.08, 0.22]</b>		<b>-0.19 [-0.32, -0.07]</b>	
Time on hospice until baseline survey <sup>c</sup>	0.19 [-2.10, 2.48]		-0.59 [-2.41, 1.23]		-1.24 [-4.40, 1.91]	
Age (years)	<b>-0.11 [-0.18, -0.05]</b>		-0.04 [-0.09 to 0.01]		0.08 [-0.01, 0.16]	
Spouse/partner caregiver	0.70 [-0.98, 2.39]		0.39 [-0.95, 1.73]		-2.15 [-4.45, 0.14]	
Female gender	-0.05 [-1.71, 1.61]		0.29 [-1.02 to 1.61]		-0.27 [-2.49, 1.96]	
Adequacy of Financial Situation	-0.61 [-1.72, 0.49]		<b>-1.19 [-2.07, -0.32]</b>		0.95 [-0.57, 2.46]	
<b>Model 3</b>		.00, p=.541		.00, p=.90		<b>0.04, p=0.02</b>
Perceived Social Support	-0.03 [-0.06 to 0.01]		<b>-0.04 [-0.06, -0.01]</b>		<b>0.10 [0.06, 0.14]</b>	
Caregiving Burden	<b>0.18 [0.09, 0.27]</b>		<b>0.15 [0.08, 0.22]</b>		<b>-0.22 [-0.35, -0.10]</b>	
Time on hospice until baseline survey <sup>c</sup>	0.11 [-2.22, 2.43]		-0.61 [-2.45, 1.24]		-1.86 [-4.95, 1.23]	
Age (years)	<b>-0.11 [-0.18, -0.05]</b>		-0.04 [-0.09, 0.01]		0.07 [-0.01, 0.16]	
Spouse/partner caregiver	0.75 [-0.95, 2.45]		0.40 [-0.96, 1.75]		-1.78 [-4.03, 0.46]	
Female gender	-0.12 [-1.80, 1.56]		0.28 [-1.06, 1.62]		-0.50 [-2.66, 1.66]	
Adequacy of Financial Situation	-0.65 [-1.76, 0.46]		<b>-1.20 [-2.08, -0.31]</b>		0.89 [-0.58, 2.35]	
Support*Burden <sup>d</sup>	0.0010 [-0.0022, 0.0041]		0.0002 [-0.0023, 0.0026]		<b>0.0054 [0.0010, 0.0099]</b>	

<sup>a</sup>Perceived Social Support: Medical Outcomes Survey-Social Support Scale; Caregiving Burden: Zarit Burden Inventory; Anxiety: Hospital Anxiety and Depression Scale-Anxiety subscale; Depression: Hospital Anxiety and Depression Scale-Depression subscale; Positive Affect and Well-being: Positive Affect and Well-being scale.

<sup>b</sup>Bolded values indicate significance at the  $p < 0.05$  level

<sup>c</sup>Log transformed using log10 transformation

<sup>d</sup>Interactions were computed using mean-centered scores

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## References

1. National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. National Alliance for Caregiving and the AARP; 2020.
2. National Hospice and Palliative Care Organization. *2020 Edition. Hospice Facts and Figures*. Alexandria, VA: National Hospice and Palliative Care Organization; August 2020.
3. Harris P, Wong E, Farrington S, et al. Patterns of functional decline in hospice: What can individuals and their families expect? *J Am Geriatr Soc*. 2013; **61**(3): 413-417.
4. Ornstein KA, Kelley AS, Bollens-Lund E, Wolff JL. A national profile of end-of-life caregiving in the United States. *Health Affairs*. 2017; **36**(7): 1184-1192.
5. Stajduhar KI, Funk L, Toye C, Grande G, Aoun S, Todd CJ. Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliat Med*. 2010; **24**(6): 573-593.
6. Duggleby W, Tycholiz J, Holtlander L, et al. A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliat Med*. 2017; **31**(7): 602-616.
7. Fletcher BS, Miaskowski C, Given B, Schumacher K. The cancer family caregiving experience: An updated and expanded conceptual model. *Eur J Oncol Nurs*. 2012; **16**(4): 387-398.
8. Pearlman LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*. 1990; **30**(5): 583-594.
9. Ketcher D, Trettevik R, Vadaparampil ST, Heyman RE, Ellington L, Reblin M. Caring for a spouse with advanced cancer: Similarities and differences for male and female caregivers. *J Behav Med*. 2020; **43**(5): 817-828.
10. Areia NP, Fonseca G, Major S, Relvas AP. Psychological morbidity in family caregivers of people living with terminal cancer: Prevalence and predictors. *Palliat Support Care*. 2019; **17**(3): 286-293.
11. Kapari M, Addington-Hall J, Hotopf M. Risk factors for common mental disorder in caregiving and bereavement. *J Pain Sympt Manage*. 2010; **40**(6): 844-856.
12. Trevino KM, Prigerson HG, Maciejewski PK. Advanced cancer caregiving as a risk for major depressive episodes and generalized anxiety disorder. *Psycho-oncology*. 2018; **27**(1): 243-249.
13. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. Paper presented at: Seminars in oncology nursing, 2012.
14. Girgis A, Lambert S, Johnson C, Waller A, Currow D. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: A review. *J Oncol Pract*. 2013; **9**(4): 197-202.
15. Oliver DP, Demiris G, Washington KT, Clark C, Thomas-Jones D. Challenges and strategies for hospice caregivers: A qualitative analysis. *Gerontologist*. 2016; **57**(4): 648-656.
16. Shaffer KM, Jacobs JM, Nipp RD, et al. Mental and physical health correlates among family caregivers of patients with newly-diagnosed incurable cancer: A hierarchical linear regression analysis. *Support Care Cancer*. 2017; **25**(3): 965-971.
17. Skufca L Rainville, C. *Caregiving Out-of-Pocket Costs Study 2021*. Washington, DC: AARP Research; June 2021.
18. Oechsle K, Ullrich A, Marx G, et al. Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care. *BMC Palliat Care*. 2019; **18**(1): 1-14.
19. Gjesfjeld CD, Greeno CG, Kim KH. A confirmatory factor analysis of an abbreviated social support instrument: The MOS-SSS. *Res Social Work Pract*. 2007; **18**(3): 231-237.
20. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res*. 2002; **52**(2): 69-77.
21. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a New short version and screening version. *Gerontologist*. 2001; **41**(5): 652-657.

22. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica*. 1983; **67**(6): 361-370.
23. Salsman JM, Victorson D, Choi SW, et al. Development and validation of the positive affect and well-being scale for the neurology quality of life (Neuro-QOL) measurement system. *Qual Life Res*. 2013; **22**(9): 2569-2580.
24. Smith G. Step away from stepwise. *Journal of Big Data*. 2018; **5**(1): 1-12.
25. Kim Y, Shaffer KM, Carver CS, Cannady RS. Quality of life of family caregivers 8 years after a relative's cancer diagnosis: Follow-up of the National Quality of Life Survey for caregivers. *Psycho-oncology*. 2016; **25**(3): 266-274.
26. Hwang IC, Kim YS, Lee YJ, et al. Factors associated with caregivers' resilience in a terminal cancer care setting. *Am J Hosp Palliat Care*. 2018; **35**(4): 677-683.
27. Caserta M, Utz R, Lund D, Supiano K, Donaldson G. Cancer caregivers' preparedness for loss and bereavement outcomes: Do preloss caregiver attributes matter? *Omega*. 2019; **80**(2): 224-244.
28. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychol Aging*. 2003; **18**(2): 250-267.
29. Grov EK, Dahl AA, Moum T, Fosså SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol*. 2005; **16**(7): 1185-1191.
30. Gouin J-P, da Estrela C, Desmarais K, Barker ET. The impact of formal and informal support on health in the context of caregiving stress. *Fam Relat*. 2016; **65**(1): 191-206.
31. Roth DL, Perkins M, Wadley VG, Temple EM, Haley WE. Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Qual Life Res*. 2009; **18**(6): 679-688.
32. Levine C, Hunt GG, Halper D, Hart AY, Lautz J, Gould DA. Young adult caregivers: A first look at an unstudied population. *Am J Public Health*. 2005; **95**(11): 2071-2075.
33. Haugland BSM, Hysing M, Sivertsen B. The Burden of Care: A national survey on the prevalence, demographic characteristics and health problems among young adult carers attending higher education in Norway. *Front Psychol*. 2020; 10:2859.
34. Miller VJ, Killian MO, Fields N. Caregiver identity theory and predictors of burden and depression: Findings from the REACH II study. *Aging Ment Health*. 2020; **24**(2): 212-220.
35. Jeong A, Shin D, Park JH, Park K. Attributes of caregivers' quality of life: A perspective comparison between spousal and non-spousal caregivers of older patients with cancer. *J Geriatr Oncol*. 2020; **11**(1): 82-87.
36. Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. *Health Serv Res*. 2010; **45**(2): 565-576.
37. Xu J, Ellington L, Heyman RE, Vadaparampil ST, Reblin M. Money matters: An analysis of advanced cancer couples' communication about financial concerns. *Support Care Cancer*. 2020; **28**(5): 2239-2246.
38. Gardiner C, Taylor B, Robinson J, Gott M. Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study. *Palliat Med*. 2019; **33**(9): 1189-1211.
39. Díaz A, Ponsoda JM, Beleña A. Optimism as a key to improving mental health in family caregivers of people living with Alzheimer's disease. *Aging Mental Health*. 2020; **24**(10): 1662-1670.
40. Guo J-W, Reblin M, Tay DL, Ellington L, Beck AC, Cloyes KG. Patterns of stress and support in social support networks of in-home hospice cancer family caregivers. *J Social Personal Relat*. 2021; doi: 10.1177/02654075211024743.

