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Relationship Between Physical and Psychological Status of Cancer Patients and Caregivers

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Abstract

The purpose of this study was to describe the relationship between patient physical and emotional status and caregiver mood state for patients with advanced cancer. Data were collected from 299 cancer patients and their caregivers from a cancer center. We used a longitudinal design and collected data through interviews. The relationships between patient and caregiver emotional states over time were moderate and statistically significant at all three points in time (p values = .012-.0001). Patient physical and emotional status predicted caregiver mood state at all points in time (β s = -.22 to -.25) and caregiver mood state at baseline predicted patient emotional status at 3 months (β = -.16, p = .013). Relationships between patient emotional status and caregiver mood state were moderately strong. Addressing the emotional needs of both patients and caregivers has the potential to yield improved emotional outcomes for both over time.

Keywords

oncology; patient/caregiver dyads; HRQoL

According to the American Cancer Society, it was projected that there would be ~1.6 million new cancer cases and ~590,000 cancer deaths in the United States in 2015 (American Cancer Society, 2015). Modern therapies have transformed some types of cancers from terminal diseases to chronic illnesses, but many cancers are life-limiting, and a terminal phase is an inevitable part of the disease trajectory. Given the improvement in survival periods and a shift in emphasis to outpatient care, family members of patients with advanced cancer have assumed an increasingly vital role as caregivers (Son et al., 2012).

Distress in Advanced Cancer Patients and Their Caregivers

The physical and psychological impact of serving as a caregiver to a patient with advanced cancer has been well documented (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Hoskins, 1995; Pitceathly & Maguire, 2003; Thomas, Morris, & Harman, 2012) with reports of high levels of caregiver distress, stress, and worsening physical and mental health (Ell,

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Declaration of Conflicting Interests

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Nishimoto, Mantell, & Hamovitch, 1988; Hodges, Humphris, & MacFarlane, 2005; Shahi et al., 2014). Similar findings have been reported for patients as well (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Litzelman & Yabroff, 2015; Segrin & Badger, 2014). While meta-analytic reviews have indicated that patient and caregiver distress are related (Hagedoorn et al., 2008) and some studies have shown that they are related over time (Kurtz, Kurtz, Given, & Given, 1995), very few studies have incorporated both physical and psychological status for patient and caregiver into their analyses. Recent work (Litzelman & Yabroff, 2015) has examined relationships between cancer survivors and their spouses' distress, depression, and health-related quality of life (HRQoL) over time. Their work, which included a large sample and longitudinal data, showed that depressed mood and poor HRQoL in spouses related to increased risk of depressed mood in cancer survivors. These findings have been reported in other cancer populations (Segrin & Badger, 2014) but these studies, like the work of Litzelman and Yabroff (2015), focused solely on spousal caregivers and cancer survivors and did not include non-spouse caregivers nor cancer patients in all phases of treatment and care. Thus, there is a need to examine the relationship between patient and caregiver physical and psychological outcomes in a sample that includes non-spouse caregivers as well as spousal caregivers. In addition, it is important to examine the nature of these relationships over a period of time that encompasses diagnosis, treatment, and post-treatment—doing so will add to our understanding of the phenomenon and will increase our ability to develop policies and strategies to enhance not only patient psychological outcomes but also caregiver outcomes over time.

Purpose

While examination of dyadic psychosocial interventions for cancer patients and their spousal caregivers has been tested (Badr, Carmack, & Diefenbach, 2015; Li & Loke, 2014; Manne, 1994; Regan et al., 2012), little work has examined interventions that have been tested for spousal as well as non-spousal caregivers. Therefore, the goal of this project was to describe the relationship between patient physical and psychological HRQoL and caregiver psychological state over a 9-month period of time to explore whether patient-caregiver relationships (for spousal as well as non-spousal caregivers) were significant and consistent over time. In addition, little research has examined the nature of these relationships over a period of time that encompasses diagnosis, treatment, and post-treatment.

Method

Design

The larger study, from which our data were obtained, was a quasi-experimental, two-group, clinical trial whose aim was to examine the efficacy of an interdisciplinary Cancer Support Team (CST) on quality of care indicators (hospice use) and HRQoL in a population with advanced cancer. Caregivers of patients with advanced cancer were also enrolled in the study, and the impact of the CST on psychological and physical outcomes of these caregivers was examined as well.

Sample and Setting

Adult patients with newly diagnosed Stage III or IV lung, gastrointestinal (GI), or gynecologic (GYN) cancer, regardless of life expectancy and admitted to the outpatient clinic of a Comprehensive Cancer Center, were screened for eligibility. In addition to age (>18 years) and cancer type, eligibility criteria included Eastern Cooperative Oncology Group (ECOG; Zuckin et al., 2013) performance status ≤ 3 , capacity to provide informed consent, and intention to receive treatment at the Cancer Center. Patients with Stage II B pancreatic cancer were also considered eligible because of similar poor prognosis.

Caregivers were defined as the primary caregivers responsible for providing physical and/or psychological support as identified by the patient. Patients and caregivers enrolled during the first 10 months of the study comprised the control group; those enrolled afterward comprised the intervention group and received the intervention as part of routine care. The study was approved by the study site's institutional review board and registered on [ClinicalTrials.gov](https://clinicaltrials.gov) (Number Clinical Trial identifier [NCT] 00684801).

Procedures and Measures

Measures related to physical and psychological outcomes were obtained at baseline (within 3 weeks of diagnosis of advanced cancer), and then 3 and 9 months afterward. Prior reports from the primary study indicated that there were no statistically significant differences between patient groups on any of the specific indicators of quality of care (Daly, Douglas, Gunzler, & Lipson, 2013), nor were there any significant differences between caregiver groups on any indicators of psychological well-being (Daly et al., 2013). Therefore, experimental and control groups were combined for the present analysis.

Following informed consent, the research assistant interviewed the patient and caregiver to obtain demographic and clinical information as well as psychological and physical data. Telephone or in-clinic interviews were conducted again at 3 and 9 months later. Demographic data were obtained through in-person interviews, and clinical data were obtained from medical record review. HRQoL for patients was measured with the Functional Assessment of Cancer Therapy–General (FACT-G) with the emotional and physical subscales reflecting patient emotional and physical HRQoL (Cella et al., 1993). Total and subscale scores for the FACT-G are scored, so that higher scores indicate better health (physical or emotional). The Profile of Mood States–Short Form (POMS-SF) total score was used to reflect overall mood disturbance—a psychological construct that included the measurement of anger, tension, depression, confusion, fatigue, and vigor. Higher scores of the POMS-SF indicate greater amounts of the attribute (e.g., anger, depression) with higher total scores indicating poor emotional mood state (Baker, Denniston, Zabora, Polland, & Dudley, 2002). Reliability and validity of both measures have been well established with cancer populations (Baker et al., 2002; Cella et al., 1993). Cronbach's alpha was .68 for the FACT-G and .88 for the POMS-SF in the present study.

Analysis

Pearson's correlation analysis was conducted to examine the bivariate associations between patient emotional HRQoL (FACT-G, Emotional subscale) and caregiver mood state (POMS-

SF). Both variables met the assumptions of the Pearson correlation. Repeated measures of analysis of variance (RMANOVA) was used to examine whether there were differences in outcome variables over time and variables met the assumption of RMANOVA. Multiple linear regression analysis was used to examine the relationship between patient emotional and physical HRQoL (FACT-G, Physical subscale) and caregiver mood state at baseline, 3 months, and 9 months. In addition, multiple linear regression was used to examine whether any predictor variables (patient physical HRQoL, patient emotional HRQoL, caregiver mood state at prior time point) were related to the criterion variable (caregiver mood state) at 3 months and 9 months. Finally, multiple linear regression was used to examine the relationships between patient physical HRQoL and caregiver mood state upon patient emotional HRQoL as well as to examine whether predictor variables (patient physical HRQoL, caregiver mood state, patient emotional HRQoL at prior time point) were related to the criterion variable (patient emotional HRQoL) at 3 months and 9 months. There were no multicollinearity or independence of observation concerns. For all analyses, a non-directional p value $<.05$ was considered to be statistically significant, and SPSS (version 22) was used for analyses.

Results

Sample Characteristics

As shown in Figure 1, 382 caregiver–patient dyads were enrolled and consented to participate in the study. After attrition, data from 299 dyads were analyzed in this study. As shown in Table 1, the average age of caregivers was 56.9 years with a majority being female and Caucasian. Almost one third of the caregivers were non-spousal caregivers, and more than half were employed. In general, at study baseline, caregivers ranked their physical health status in the adequate-good range and identified their greatest source of burden to be the disruption of their schedule. More than half of the patients had Stage IV cancer with an ECOG performance score of 0 or 1; more than one third of the patients died during the study period.

Patient HRQoL and Caregiver Mood State Over Time

Patient emotional and physical HRQoL and caregiver mood state were assessed at baseline (within 3 weeks of diagnosis of advanced cancer), 3 months (during treatment), and 9 months (post-treatment) later. Using RMANOVA, we examined whether there were differences over time for patient emotional and physical HRQoL as well as caregiver mood state. There were no statistically significant differences over time for patient FACT-G (Emotional; $p = .16$), FACT-G (Physical; $p = .89$), or caregiver POMS ($p = .48$). Next, we examined whether there were differences over time by gender but found no statistically significant differences for FACT-G (Emotional; $p = .55$) or POMS ($p = .29$).

Relationships Between Patient Emotional HRQoL and Caregiver Mood State

As seen in Figure 2, bivariate correlations between patient emotional HRQoL and caregiver mood state were examined over time. At all three time points, the relationships were statistically significant and moderate in size. Given the scoring of the tools for these variables, an inverse relationship indicated that as patient emotional HRQoL worsened (low

FACT-G, Emotional), so did the caregiver's overall mood disturbance (high POMS). The lower limits of the 95% confidence intervals (CIs) around each r value ranged from -0.298 to -0.507 , indicating that in the population, an effect size ranging from moderate to large could be possible.

Relationships Between Demographic Variables and Emotional Status

Using multiple regression, we examined the impact of demographic variables shown in prior research related to patient emotional HRQoL and caregiver mood state. We included patient age and gender as predictor variables and patient emotional HRQoL at baseline as the criterion variable. None of the predictor variables had a significant relationship with the criterion variable. Next, we examined the impact of caregiver predictor variables (age, gender, and relationship to patient) on the criterion variable of caregiver mood state at baseline. We did find a statistically significant relationship between caregiver gender ($p = .004$) and age ($p = .004$) with caregiver mood state. For both gender and age, the variables had small-medium relationships with caregiver mood state. As caregiver age increased, mood improved and men had better mood states than women. These variables were included as covariates in the overall analyses when caregiver mood state was the criterion variable.

Next, using multiple regression, we examined the impact of patient physical and emotional HRQoL on caregiver mood state at baseline, 3 months, and 9 months. Caregiver gender and age were included in all models as covariates. For baseline analysis, after including the covariates (caregiver gender and age), we added patient emotional and physical HRQoL to the model with caregiver mood state as the criterion variable. The R^2_{adj} was .12, with a significant change in F seen with the addition of patient emotional and physical HRQoL variables ($p = .0001$). For 3-month analyses, after entering the covariates, we included baseline patient emotional and physical HRQoL as well as baseline caregiver mood state. All variables were non-significant.

Next, we added 3-month patient emotional and physical HRQoL variables to the model. This model had an R^2_{adj} of .19, with a significant change in F found with the addition of the 3-month patient emotional and physical HRQoL variables ($p = .0001$). This analytic approach was used for examining predictors of caregiver mood state at 9 months. The same pattern of non-significance was observed when 3-month patient emotional and physical HRQoL variables were predictor variables and caregiver mood state at 9 months was the criterion variable. In this analysis, the R^2_{adj} was .16, with a significant change in F associated with the addition of 9-month patient emotional and physical HRQoL variables ($p = .0001$). This relationship did not hold when examining the predictive value of caregiver mood at 3 months upon patient emotional HRQoL at 9 months.

As shown in Figure 3, neither patient emotional nor physical HRQoL at one point predicted caregiver mood at the next time point. However, when examining standardized coefficients at each time point, patient physical HRQoL had a significant relationship with caregiver mood state at all three time points and patient emotional HRQoL had a significant relationship with caregiver mood state at 3 months and 9 months. Low levels of patient physical well-being were associated with higher caregiver mood disturbance. The strength of the relationship was moderate (β s = $-.23$ to $-.25$) and consistent at all points in time.

Caregiver Mood and Patient Physical HRQoL as Predictors of Patient Emotional HRQoL

Next, we wanted to examine the impact of caregiver mood state and patient physical HRQoL in predicting patient emotional HRQoL. We followed the same analytic approach as outlined above. No covariates were included in these analyses. As shown in Figure 4, patient physical HRQoL had a significant and strong relationship with patient emotional HRQoL at all three time points with β s ranging from .35 to .49 ($p = .0001$). As patient physical HRQoL improved, so did patient emotional HRQoL. When examining the predictive nature of baseline variables upon patient emotional HRQoL at 3 months, we found that baseline caregiver mood made a significant unique contribution to predicting patient emotional HRQoL at 3 months ($p = .013$). In addition, caregiver mood had a significant relationship with patient emotional HRQoL ($p = .006$); as caregiver mood worsened, so did patient emotional HRQoL. When examining the predictive nature of 3-month variables upon patient emotional HRQoL at 9 months, we found no significant predictors. We did find that caregiver mood had a significant relationship with emotional HRQoL ($p = .04$); as caregiver mood worsened, so did patient emotional HRQoL. The R^2_{adj} at baseline was .17 ($p = .0001$), at 3 months it was .34 ($p = .0001$), and at 9 months it was .21 ($p = .0001$).

Discussion

Our findings support prior work (Kamen et al., 2015; Kurtz et al., 1995; Northouse, Mood, Templin, Mellon, & George, 2000) that demonstrate a moderate relationship between patient and caregiver emotional states. In addition, when examining the impact of caregiver mood on patient emotional HRQoL and vice versa (when patient physical HRQoL was included in the model), we found that the magnitude of the relationship between patient emotional HRQoL and caregiver mood state remained the same at all points in time.

We also found that caregiver mood state scores in our sample were lower (more positive affective state) than those reported in an outpatient cancer caregiver sample (Siston et al., 2001; $M = 23.8$) and yet similar to those reported in an outpatient cancer caregiver registry ($M = 11.7$; Daly, Douglas, Lipson, & Foley, 2009). However, patient emotional HRQoL scores were similar to norms reported for general population ($M = 19.9$; Webster, Cella, & Yost, 2003) as well as other cancer populations ($M = 18.1$; Brucker, Yost, Cashy, Webster, & Cella, 2005). Our sample represented caregivers who had lower than average mood disturbance scores and patients who had relatively average emotional HRQoL scores. Thus, in another sample more representative of others' work (Brucker et al., 2005; Siston et al., 2001; with cancer caregiver scores worse than those reported for our sample), it is possible that the nature of the relationship between caregiver and patient emotional scores would be even greater than that reported here.

Unlike prior work, we did not find a significant relationship between caregiver relationship to patient (spouse vs. other) and caregiver mood state at any point in time. While we did find that caregiver gender was significantly related to caregiver mood state (females experiencing more negative mood state than males), it did not alter the strength or direction of the relationship between patient and caregiver emotional state when included in the model.

Finally, we found that the nature of the patient–caregiver relationship between emotional HRQoL and caregiver mood state did not vary much across different phases of the patients' illness. At baseline (within weeks of diagnosis), the relationship was weakest—yet moderate in size and statistically significant. By 3 months (during treatment phase) the nature of the relationship was larger in size with the relationship remaining large at 9 months. This finding is in contrast to reports by others (Hodges et al., 2005; Northouse et al., 2000) who have reported various findings—all of which indicate a change in the relationship between patient and caregiver emotional states at different points in the illness trajectory.

Although some research has examined the relationship between caregiver and patient emotional status (e.g., distress), little work has been done to date examining the changes in the nature of these relationships over time. Our major finding that there is a moderately strong and significant relationship between patient emotional HRQoL and caregiver mood state that holds over time supports the need for interventions that address both patient and caregiver emotional states throughout the trajectory of care. While the nature of the patient–caregiver relationship was weakest at baseline (diagnosis), it was moderate, nonetheless. In addition, caregiver mood at baseline was a significant predictor of patient emotional HRQoL at 3 months. These findings have significance for clinical practice in addition to guiding research in this area. One clinical application that relates to our findings is the recommendation that caregiver mood be assessed at baseline. Using a clinically applicable measure such as the Distress Thermometer (Donovan, Grassi, McGinty, & Jacobsen, 2014), we may be able to identify those caregivers who are at risk for negative mood states. As a result, these caregivers might benefit from additional support, referral, or intervention early in the cancer care process which could moderate their mood state and minimize the negative impact upon not only their own mood over time but also the patients' emotional HRQoL months later. Given our findings of the strong relationship between patient physical and emotional HRQoL, identifying and supporting caregivers with poor mood states at baseline will benefit not only the caregivers but patients as well. Future research should focus upon the testing of an intervention that addresses the emotional needs of patients and caregivers throughout the various phases of their illness—such an intervention has the potential to yield the greatest results for patients as well as their caregivers. While some interventions have been shown to enhance either patient or caregiver psychological outcomes (Archer, Buxton, & Sheffield, 2015; DuBenske et al., 2014; Northouse, Williams, Given, & McCorkle, 2012), testing of single interventions that can improve outcomes for both has been identified as a need that has not yet been well tested (Badr et al., 2015; Gentles, Lokker, & McKibbin, 2010).

Our investigation makes two contributions to the evidence base for how to provide expert care for advance cancer patients and their caregivers throughout their trajectory of care. First, this study adds to the evidence of moderately strong and significant relationships between patient emotional HRQoL and caregiver mood state (Hodges et al., 2005; Kurtz et al., 1995; Northouse et al., 2000; Shahi et al., 2014). Our work adds to that evidence the finding that the nature of the relationship holds over a 9-month time period. This supports the need for interventions that address both patient and caregiver emotional status. Second, the predictive nature of baseline caregiver mood state to 3-month patient emotional HRQoL supports the need to add additional focus to caregivers early in the disease treatment process.

Assessing caregiver mood state early can contribute to the patient's emotional HRQoL as well as the caregiver's mood going forward. We recognize that the predictive nature may, in fact, be the opposite—that patient emotional HRQoL predicts caregiver mood state. Thus, adequate attention to patient emotional status early in the disease trajectory may also serve to reduce psychological morbidity of the caregiver over time. Again, this supports our earlier recommendation that interventions that can focus on enhancing caregiver mood as well as patient emotional HRQoL will benefit both members of this dyad directly and indirectly and potentially yield greater benefits than has been seen with the more traditional patient-focused interventions.

There are limitations to the present study. First, we reported a 30% refusal rate in the original study, and it may be the case that patients or caregivers who refused participation and inclusion of data were those who were most distressed and who might have had significantly different caregiver depression or patient spirituality scores than those who chose to participate in the study. While a 30% refusal rate does not risk threats of internal or external validity (Babbie, 1993), generalizability is limited to patients who are like those who agreed to participate. Second, by limiting ourselves to specific cancer types (lung, GI, GYN) we realize that we have excluded some clinical subgroups. As a result, our findings cannot be generalized to all patients with advanced cancer as the nature of relationships between and among variables might be different for those patients.

In summary, our work has demonstrated that the role of patient physical HRQoL upon both patient and caregiver mood state was consistent and moderate to strong. If we are to develop strategies that will maximize the emotional health of patients and caregivers, we need to also continue to attend to the physical components of the patient's care. Issues related to pain and symptom management, while shown to contribute to improvement in patient emotional HRQoL, can now be seen as contributing to caregiver mood state as well. We must continue to strive to deliver the best physical and emotional care to these patients and their caregivers to enhance outcomes for both.

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Figure 1.
Caregiver subject flow diagram.

Figure 2.

Relationship between patient emotional HRQoL and caregiver mood state over time ($N=299$).

Note. The r value and 95% confidence interval around r . HRQoL = health-related quality of life.

Figure 3.
Predictors of caregiver mood state over time ($N = 299$).
Note. HRQoL = health-related quality of life.

Figure 4.
Predictors of patient emotional HRQoL over time ($N = 299$).
Note. HRQoL = health-related quality of life.

Table 1.Patient and Caregiver Descriptive Variables ($N=299$).

Variable	Patient		Caregiver	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age (years)	63.50	11.10	56.90	12.90
Charlson comorbidity	0.70	1.10	—	—
Physical health status	—	—	3.86	0.90
FACT-G ^a (emotional HRQoL)				
Baseline	18.83	4.40	—	—
3 months	19.43	3.80	—	—
9 months	19.09	4.10	—	—
FACT-G ^a (physical HRQoL)				
Baseline	22.55	4.40	—	—
3 months	22.69	4.40	—	—
9 months	22.79	4.80	—	—
POMS—Total mood disturbance ^b				
Baseline	—	—	12.36	17.70
3 months	—	—	12.20	19.30
9 months	—	—	10.61	20.30
	<i>n</i>	%	<i>n</i>	%
Female gender	171	57.20	200	66.90
Caucasian race	256	85.60	255	85.30
Married	213	71.20	237	79.30
Household income—<50K/year (yes)	138	49.50	98	34.60
Employed	—	—	169	58.50
Relationship to patient				
Spouse	—	—	194	67.10
Child	—	—	62	21.50
Other	—	—	33	11.40
Cancer type GI/colorectal	131	43.80	—	—
Lung	103	34.40	—	—
GYN	65	21.70	—	—
Cancer stage				
III	122	41.20	—	—
IV	174	58.80	—	—
ECOG status				
0	101	34.20	—	—
1	159	53.90	—	—
2	23	7.80	—	—
3	12	4.10	—	—

Variable	Patient		Caregiver	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Prior cancer: Yes	57	19.10	—	—
Clinical trial: Yes	43	14.90	—	—
Mortality: Yes	106	36.30	—	—

Note. FACT-G = Functional Assessment of Cancer Therapy–General; HRQoL = health-related quality of life; POMS = Profile of Mood States; GI = gastrointestinal; GYN = gynecologic; ECOG = Eastern Cooperative Oncology Group.

^a. Higher scores indicate better physical or emotional status.

^b. Higher scores indicate worse mood state.