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Physical and emotional well-being and support in newly diagnosed head and neck cancer patient–caregiver dyads

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Abstract

The purpose of this study was to examine the physical and emotional well-being and social support in newly diagnosed head and neck cancer (HNC) patients and caregivers and identify sociodemographic, clinical, and behavioral risk factors associated with compromised well-being in patients and caregivers. Newly diagnosed HNC patients and their primary caregivers ($N = 72$ dyads) completed questionnaires before treatment assessing physical and mental well-being, depression, cancer worry, and open-ended support questions. Patients reported worse physical well-being than caregivers ($p < 0.05$) but similar levels of mental well-being. Caregivers reported providing emotional and instrumental support most frequently with an emphasis on nutrition and assistance with speech, appearance, and addictions. Both patients and their caregivers reported suboptimal mental well-being and depression. Smoking was associated with compromised well-being in patients, caregivers, and dyads. Compromised well-being in patients and their caregivers was more likely when patients were younger, had worse symptoms, and smoked/consumed alcohol ($p < 0.05$). While patients face more physical strain than caregivers, both equally confront emotional challenges. Results highlight risk factors for compromised well-being in both patients and their caregivers that should be assessed at diagnosis to guide identification of needed dyadic-focused supportive care resources.

Keywords

dyad; emotional well-being; head and neck cancer; physical well-being; social support

Introduction

Head and neck cancers (HNCs) of the oral cavity, larynx, and pharynx, pose a significant public health burden. In the United States in 2016, approximately 61,760 new HNC cases and 13,190 deaths were expected (American Cancer Society, 2016). HNC surgical, chemotherapy, and radiation treatments involve side effects that dramatically influence physical, emotional, and social outcomes (Murphy & Deng, 2015; Rogers et al., 2009; So et al., 2012). In addition to often facing disfigurement, daily functioning can be impacted in

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such critical ways as breathing, communication, and swallowing impairments (Jacobi, van der Molen, Huiskens, van Rossum, & Hilgers, 2010; Murphy & Deng, 2015; Ringash, 2015; So et al., 2012). An emerging body of evidence using varied HNC populations and study designs has begun to characterize the physical and emotional well-being of patients (Chandu, Smith, & Rogers, 2006; Funk, Karnell, & Christensen, 2012; Howren, Christensen, Karnell, & Funk, 2013; Murphy, Ridner, Wells, & Dietrich, 2007; Rogers et al., 2009). In addition to highlighting challenging treatment effects, this research has emphasized unique difficulties some patients face with tobacco and alcohol addictions (Hashibe et al., 2007) and managing complex follow-up care (National Comprehensive Cancer Network, 2016). More research is needed to direct psychosocial HNC intervention development (Howren et al., 2013).

Growing attention has been directed to gaining an understanding of the impact of HNC on family and friends. HNC caregiving may be especially important and include unique responsibilities due to communication losses in patients (Penner, McClement, Lobchuk, & Daeninck, 2012). In a systematic review examining psychological functioning in HNC caregivers, caregivers were shown to experience significant anxiety and were especially susceptible to distress 6 months after treatment (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). Recent studies have examined caregiver adjustment further, finding that caregivers have higher recurrence fears (Hodges & Humphris, 2009), worse illness outlook (Richardson, Morton, & Broadbent, 2015), and more post-traumatic stress disorder (Posluszny et al., 2015) compared to patients. Research has identified some HNC caregivers at risk for poor outcomes, including those caring for patients with more needs (Chen et al., 2009) or worse symptoms during treatment (Badr, Gupta, Sikora, & Posner, 2014). Also, feeling uncomfortable with HNC caregiving is associated with anxiety (Balfe et al., 2016), and communication challenges can have a negative influence on caregivers (Nund et al., 2015).

A limitation in the research to date is that many of the previous studies with HNC dyads were conducted during or after treatment so we lack critical information about dyads' status upon diagnosis, one of the first transitions in cancer care (Blum & Sherman, 2010). Because caregivers' psychological well-being is negatively influenced during treatment (Badr et al., 2014), it is critical to consider early intervention for those in need. Also, most studies have focused on either patients or caregivers rather than jointly considering HNC's impact on both dyad members (Longacre et al., 2012). Specifically, we lack knowledge concerning the prevalence of and risk factors for dyads' compromised well-being. Also, more information is necessary to understand potentially unique aspects of HNC caregiving (Penner et al., 2012) to direct caregiver-focused educational resources and support.

Guided by a quality-of-life framework (Ferrell & Hassey Dow, 1997), the purpose of this study was to characterize physical and emotional well-being and support in newly diagnosed HNC patients and caregivers and identify sociodemographic, clinical, and behavioral risk factors for compromised well-being in patients, caregivers, and dyads.

Methods

Setting, participants, and study design

This study was conducted at a HNC clinic in a regional cancer center in the southeastern United States and recruited participants from February 2010 to January 2013. Following an Institutional Review Board-approved protocol, newly diagnosed HNC patients ≥21 years old presenting with stage I–IV cancer (lip/oral cavity, pharynx, larynx, salivary gland, paranasal sinus, and advanced cutaneous cancers in head and neck region) before treatment initiation were screened for eligibility. Participants were excluded when they did not speak English, had cognitive challenges preventing questionnaire completion, were unable to identify a caregiver or had recurrent disease. Interested participants nominated primary caregivers, the person they reported relying on most for cancer-related support. We screened 183 potential participants and of 158 who met eligibility, 106 (67%) enrolled. Main reasons for declining included lack of interest, being overwhelmed, or nonresponse. Ninety-eight patients nominated caregivers, and surveys were completed by 72 dyads (73% completion rate). All participants signed consent forms, and patients and caregivers completed separate questionnaires by telephone or mail and received a gift card.

Measures

Measure selection was guided by a multidimensional quality of life framework (Ferrell & Hassey Dow, 1997) to examine factors associated with compromised well-being in HNC patients, caregivers, and dyads. We used four brief, validated measures to assess physical well-being (health-related physical well-being) and emotional well-being (health-related mental well-being, depression, and cancer worry). Instead of directly examining social well-being, because available support instruments may not adequately tap HNC-specific support, we used an open-ended question to explore support behaviors. We also selected a set of potential sociodemographic, clinical, and behavioral risk factors for compromised well-being from previous research (So et al., 2012) to examine factors associated with different patterns of well-being in dyads.

Physical well-being

The 12-item Short Form Health Survey (SF-12) (Ware, Kosinski, & Keller, 1996) was used to assess eight quality-of-life domains in dyads. This instrument has been widely used in cancer and has excellent properties (Ware et al., 1996). A physical well-being component score (0–100) was computed; higher scores reflected better well-being (Cronbach's alpha = 0.89 patients, 0.84 caregivers).

Emotional well-being

A mental well-being component score (0–100) was computed using the SF-12; higher scores reflected better well-being. Patient and caregiver depression were measured using the 10-item center for Epidemiologic Studies-Depression Scale (Radloff, 1977). This instrument has demonstrated suitable properties in cancer. Summary scores ranged from 0 to 30 with higher scores representing higher depression (Cronbach's alphas = 0.89 patients, 0.82 caregivers). Cancer worry was assessed in dyads using the five-item Assessment of Survivor

Concerns instrument (Gotay & Pagano, 2007) assessing worry about patients' health and cancer recurrence (Cronbach's alphas = 0.87 patients, 0.85 caregivers).

Support behaviors

To allow an in-depth exploration of HNC support behaviors, we used open-ended questions so participants could respond in their own words. Patients and caregivers were asked to describe the HNC-specific support they received and provided, respectively. Responses were transcribed word for word.

Sociodemographic and relationship variables

Sex, age, race, employment status, and years of education were assessed in dyads. Patients reported relationship type (e.g., spouse, parent, daughter/son, friend, other) and length (years of marriage/relationship).

Clinical variables

Symptoms were measured with the 13-item MD Anderson Symptom Inventory (Cleeland et al., 2000). An average severity score was calculated (from 0 to 10) with higher scores reflecting worse symptoms (Cronbach's alpha = 0.92). Self-reported comorbid conditions were assessed in dyads. Type of cancer and cancer stage were collected from medical records.

Health behaviors

Both patients and caregivers reported lifetime and current (every day, some days, or not at all) cigarette smoking. Former smokers reported when they last smoked and those quitting less than 1 month ago were classified as current/recent smokers. Current alcohol use, frequency, number of drinks, and binge drinking (i.e., ≥5 drinks on one occasion) were also assessed. Drinking status was categorized as none, light (1–4 times monthly, 1–2 drinks per occasion), regular (1–4 times monthly, 3–4 drinks per occasion, or ≥ 2 times weekly, 1–2 drinks per occasion), and heavy (≥2 times weekly, 3–4 drinks per occasion, or any binge drinking).

Data analysis

We used descriptive statistics to characterize patient and caregiver sociodemographic, clinical, and behavioral factors in dyads. We compared well-being (physical and mental well-being, cancer worry, and depression) in patients and caregivers using student *t*-tests. To define typical support behaviors, after transcribing participants' open-ended reports of support received and provided, we used content analysis. Two independent coders (KS and AB) used a codebook reflecting four major types of support (informational, emotional, appraisal, instrumental defined below) (Cohen & Wills, 1985) and allowed additional codes to emerge directly from the data to capture other reported types of support. Themes were examined across patient and caregiver groups and discrepancies in support type codes (e.g., when one coder endorsed general emotional support while the other coded a subtype of emotional support) were resolved with group discussion.

Next, we examined sociodemographic (age, sex, race, education, caregiver type), clinical (comorbid conditions and patient symptoms and cancer site/stage), and behavioral (smoking, drinking) characteristics associated with patient and caregiver well-being (physical well-being, mental well-being, depression, and cancer worry) separately one factor at a time using one-way ANOVAs and Fisher's exact tests for continuous and categorical variables, respectively ($p < 0.05$).

Finally, to characterize patterns of well-being and examine risk factors for compromised well-being in both the patient and caregiver, each dyad was characterized into one category: (1) neither patient nor caregiver had suboptimal scores, (2) only caregiver had suboptimal scores, (3) only patient had suboptimal scores, or (4) both patient and caregiver had suboptimal scores. Suboptimal well-being cut-points were < 50 for physical and mental well-being, 10 for depression, and 3 for cancer worry. Patterns of physical and emotional well-being (whether neither, one or both had suboptimal scores) were tested for associations with patient socio-demographic (age, sex, race, education, caregiver type), clinical (symptoms, stage), and behavioral (smoking, drinking) characteristics one factor at a time using one-way ANOVAs and Fisher's exact tests for continuous and categorical variables, respectively, with the "neither patient/caregiver had suboptimal score" group as reference ($p < 0.05$).

Results

Participant characteristics and physical and emotional well-being

As shown in Table 1 ($N = 72$ dyads), most patients were European American and male and most caregivers were female. Age varied widely and while education levels were similar in patients and caregivers, caregivers were more commonly employed. Approximately half of caregivers were spouses/partners, but other family members and friends were also nominated (11 siblings, 8 children, 6 parents, 2 other relatives, 4 friends).

Clinical characteristics were heterogeneous with oral cavity, oropharynx, and larynx being most common. Most had stage IVA disease (Table 1), and 15 patients had HPV positive tumors. Patients and caregivers both had comorbid conditions but differed in smoking and drinking behaviors. Patients more commonly had a smoking history and were heavier drinkers compared to caregivers.

Average physical and mental well-being, depression, and cancer worry are also presented in Table 1. Across dyads, patients as a group reported significantly worse physical well-being than caregivers. Patients also reported higher depression scores (not significant). Mental well-being and cancer worry were similar in patients and caregivers. When we compared well-being in patients and their caregivers, mental well-being was positively associated (r 0.31, $p = 0.02$) but physical well-being ($r = 0.04$), depression ($r = 0.18$), and cancer worry ($r = 0.21$) were not associated within patients and caregivers.

Support behaviors

Common support themes identified in the content analysis are defined and summarized in Table 2 with illustrative quotes. The most commonly endorsed type of support identified by both patients and caregivers was *emotional* support with frequent emphasis on specific types of emotional support in the forms of spiritual aid and helping patients with appearance concerns and facing addictions.

Caregivers more frequently than patients also emphasized commonly providing critical *instrumental* support including assistance with finances, transportation to appointments, and cooking and other household tasks. Even though patients had not yet started treatment, unique instrumental caregiving tasks were also reported. These included demanding food preparation, feeding tube assistance, and acting as the patient's speech assistant in some cases. While *appraisal* support was less common, when reported it was often in the form of giving and receiving feedback about preparing to face treatment and resulting changes and limitations in abilities. In these cases, patients and caregivers typically focused on hoping to "put the cancer behind us" and "resume a normal life" in the face of expected changes to daily functioning. *Informational* support was least commonly reported but sometimes highlighted caregivers' research online or talking to other caregivers.

Factors associated with patient, caregiver, and dyad well-being

Physical well-being was worse in patients with more severe symptoms ($r = 0.57$, $p < 0.01$) and more comorbid conditions ($r = -0.41$, $p < 0.01$). As shown in Table 3, physical well-being was also worse for African American compared to European American patients and in those who were current/recent smokers. Mental well-being was worse in younger patients ($r = 0.24$, $p = 0.05$) and in those with worse symptoms ($r = -0.28$, $p = 0.03$). Also as shown in Table 3, mental well-being was worse in male patients and in those who were current/recent smokers and drank alcohol more frequently.

Depression was higher in younger patients ($r = 0.34$, $p = 0.003$) and in patients with worse symptoms ($r = 0.71$, $p < 0.001$). Depression was also higher in patients who were current/recent smokers and drank alcohol more frequently (Table 3). Cancer worry was higher in younger patients ($r = -0.45$, $p \leq 0.001$) and in those with worse symptoms ($r = 0.49$, $p < 0.001$). Cancer worry was also higher in patients who were current/recent smokers and in those who drank alcohol more frequently (Table 3).

In caregivers, physical well-being was worse in those with more comorbid conditions ($r = -0.42$, $p < 0.01$). Also, as shown in Table 4, physical well-being was worse in caregivers who were current/recent smokers. Mental well-being, depression, and cancer worry were worse in younger caregivers ($r = 0.35$, $p < 0.01$, $r = -0.36$, $p = 0.002$, and $r = -0.31$, $p = 0.01$, respectively). Cancer worry was also higher in caregivers who were current/recent smokers (Table 4).

As reported in Table 5, patterns of physical and mental well-being, depression, and cancer worry varied in dyads. Physical well-being was most commonly compromised in only the patient (49%). In contrast, poorer mental well-being and depression were more likely experienced by both patient and caregiver in the same dyad, respectively 41% and 37%. Last, cancer worry was variable in dyads with similar numbers of dyads presenting with both the patient and caregiver (25%), the caregiver only (28%), or neither (31%) having high worry.

Several characteristics (patient age, sex, symptoms, and smoking and alcohol drinking behaviors) were more common in dyads in which both patients and their caregivers had suboptimal well-being (Table 5a and 5b). As shown in Table 5a, dyads in which both the patient and caregiver or only the patient had poor physical well-being had patients more likely to have worse symptoms ($p = 0.006$ and 0.001, respectively). Also, dyads in which both had poor physical well-being were more likely to have patients who were current/recent smokers ($p = 0.04$).

Also shown in Table 5a, dyads in which both or only the patient had poor mental well-being had patients with worse symptoms ($p = 0.02$ and 0.01, respectively) than those in which neither had suboptimal mental well-being. Also, dyads in which both had poor mental well-being were more likely to have patients who were male ($p = 0.004$), regular or heavy drinkers ($p = 0.007$), and current/recent smokers ($p = 0.047$).

As shown in Table 5b, dyads in which both members were depressed had patients who were more commonly male ($p = 0.02$) and younger ($p = 0.03$) compared to those with neither depressed. Also, dyads in which the patient only or both were depressed had patients who were more likely to smoke ($p = 0.01$ and 0.01, respectively) and have worse symptoms ($p = 0.001$ and $p = 0.006$, respectively). Last, dyads in which only the patient was depressed had patients who were more likely regular or heavy drinkers ($p = 0.049$).

Finally, as shown in Table 5b, dyads in which both had high worry had patients who were more likely to be younger ($p = 0.04$) and dyads in which only the patient had high worry had patients who were more likely to be regular or heavy drinkers ($p = 0.03$) and had worse symptoms ($p = 0.001$).

Discussion

We surveyed newly diagnosed HNC patients and their caregivers to gain a better understanding of their physical and emotional well-being as they faced their cancer diagnosis. In line with growing cancer caregiving research (Given, Given, & Sherwood, 2012; Kent et al., 2016; Northouse, Katapodi, Song, Zhang, & Mood, 2010), we expanded this study to examine the prevalence of compromised well-being in both HNC patients and their caregivers. Dyads had diverse sociodemographic and relationship characteristics and were burdened with considerable health, behavioral, and psychosocial demands. We identified unique and demanding HNC support exchanges between patients and caregivers. Further, we found that in 30–40% of dyads, both the patient and the caregiver had significant depressive symptoms and compromised mental well-being. Last, certain factors (e.g., younger age, worse symptoms, risky health behaviors) were more common in dyads in which both patients and their caregivers had compromised well-being. Findings confirm the importance of addressing both HNC patient and caregiver needs before starting treatment.

Distinct from previous studies in which most HNC caregivers were spouses (Longacre et al., 2012; Sterba, Zapka, Cranos, Laursen & Day, 2016), we found that approximately half of patients turned to other female family members or friends as primary caregivers. In addition to expected patient challenges (comorbid conditions, unemployment/disability), most caregivers also had competing demands including employment and managing their own health conditions. While most patients and caregivers had a smoking history, more patients consumed alcohol than caregivers. These descriptive findings highlight certain dyads that may benefit from focused supportive care resources at diagnosis. For example, female caregivers typically endure more burden in caregiving than males (Navaie-Waliser, Spriggs, & Feldman, 2002). Also, due to potential physical effects from caregiving (Nijboer et al., 1998), caregivers with health problems who engage in risky behaviors may deserve special attention. As smoking and drinking alcohol are two primary risk factors for HNC (Vokes, Weischelbaum, Lippman, & Hong, 1993), these behaviors may pose relationship challenges as seen in prior research examining blame and guilt (Christensen et al., 1999).

In this study, at the group level, patients fared worse than caregivers in physical well-being but both patients and caregivers had similar levels of emotional well-being. Research shows that patient and caregiver emotional reactions to cancer are interrelated (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hodges, Humphris, & Macfarlane, 2005). Importantly, in our study, both patients and caregivers had clinically significant average levels of depression (Radloff, 1977). Previous research comparing adjustment in HNC dyads has shown mixed results but most of these studies were conducted during or after treatment (Longacre et al., 2012). For example, several studies found no differences in adjustment after treatment (Jenewein et al., 2008; Verdonck-de Leeuw et al., 2007; Vickery, Latchford, Hewison, Bellew, & Feber, 2003) but others have found higher levels of distress in patients (Manne & Badr, 2010) or caregivers (Herranz & Gavilan, 1999).

An important goal of this study was to identify risk factors for compromised well-being in patients and in caregivers and move beyond viewing patients and caregivers separately and consider their well-being concurrently. Not surprisingly due to the cancer, we found physical well-being was most commonly compromised in only patients. However, emotional well-being was commonly compromised in both. This finding draws attention to the cancer impacting both dyad members equally and confirms caregivers should not be overlooked. Limited research has been conducted in this area but one study (Verdonck-de Leeuw et al., 2007) found that neither the patient nor the caregiver was distressed in two-thirds of HNC dyads 2 years following treatment. It is likely that adjustment patterns change as dyads move through diagnosis, treatment, and follow-up due to variabilities in symptoms and worries (Badr et al., 2014; Murphy & Deng, 2015).

In line with previous research at both the individual and dyad level, we observed that those with poor well-being tended to be younger, facing more symptoms, and reported more smoking and drinking. These results are consistent with previous research demonstrating that younger individuals experience more distress throughout the cancer experience (Wada et al., 2015) and that smoking places individuals at risk for compromised health (Duffy et al., 2007; Llewellyn, McGurk, & Weinman, 2005). Results are also in line with research showing that cancer-related symptoms play a major role in well-being; one study observed that HNC patient but not caregiver distress was worse when patients had poorer functioning (Verdonck-de Leeuw et al., 2007). In contrast, another study (Patterson, Rapley, Carding, Wilson, & McColl, 2013) found caregivers had worse quality of life when patients had dysphagia or a feeding tube. These mixed findings may suggest relationships between clinical factors and caregivers' well-being vary over time as patients' needs increase (Chen et al., 2014; Chen et al., 2009; Verdonck-de Leeuw et al., 2007). Broadly, results characterize certain dyads as higher risk and also highlight that smoking, drinking alcohol, and worse symptoms were also more prevalent when only the patient had suboptimal well-being. However, cancer stage was not associated with patterns of well-being and this may be because patients had not yet started treatment when the consequences of these clinical factors may accelerate.

The importance of social support in cancer has been extensively studied and HNC patients report high support needs (Chen et al., 2009). In responses to open-ended questions about support, participants highlighted emotional and instrumental support as most commonly provided around diagnosis. They also highlighted the unique and frequent support tasks of food preparation and feeding tube assistance (Penner et al., 2012) before starting treatment. Other specialized caregiving tasks included assisting patients with speech, appearance concerns, and facing addictions. These unique and time-consuming caregiving responsibilities were described as distressing, consistent with prior research showing increased burden for HNC caregivers when patients have more needs (Chen et al., 2009). HNC caregiver interventions are limited (Howren et al., 2013) and future emphasis should be placed on addressing caregivers' needs as they undertake new care responsibilities. Interestingly, caregiver type was not associated with well-being patterns, highlighting potential equal HNC impact on caregivers at this time.

Strengths, limitations, and future directions

This study employed a cross-sectional design, had a modest sample size, and was conducted at one cancer center so our results are limited, yet provide an in-depth look at HNC dyads around diagnosis. Enrollment being dependent upon consenting two people can limit accrual and this represents a challenge in dyadic studies as it is possible that those who declined had increased challenges (Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004). We excluded those unable to nominate caregivers and this group deserves future study. Given our modest sample size, it is important to examine risk factors for compromised well-being in HNC dyads in future, larger-scale, longitudinal studies. Also, when considering factors associated with well-being patterns, we only studied patient factors for this initial study given our modest sample size and future studies should consider caregivers' characteristics (e.g., smoking) and consider a dyadic data analysis approach (Kenny, Kashy, & Cook, 2006), if appropriate to the research questions under study. Generally, seeking to limit participant burden, we selected a brief set of validated instruments to explore emotional and physical well-being. Despite these study limitations, study strengths included the use of validated instruments along with open-ended support questions and our focus on the diagnosis time period to provide a preliminary examination of well-being in HNC dyads.

Future directions include the need to consider the long-term dynamic interplay of adjustment in HNC dyads. Because distress causes may differ in patients and caregivers (Badr et al., 2014), it is important to appropriately match resources to address causal factors for compromised well-being. This work should also identify effective educational intervention targets to address smoking cessation, alcohol management, symptoms, and emotional needs in dyads as promising previous work has shown positive effects from treating comorbid smoking, drinking, and depression in HNC (Duffy et al., 2006). Educational interventions are also critically needed to prepare HNC caregivers for the unique caregiving tasks they encounter.

Conclusion

Findings from this research help provide a better understanding about the challenges faced by HNC patients and their primary caregivers before treatment. Also, results highlight factors that may place both dyad members at higher risk for compromised well-being and resulting potential targets for education and support. Because HNC caregivers prefer to receive informational support directly from health care providers (Longacre, Galloway, Parvanta, & Fang, 2015), results from this study highlight that oncology clinicians could target higher-risk HNC dyads (e.g., those facing more severe symptoms) who may especially benefit from screening and supportive resources before treatment. This research fits with recent national efforts by the American Association of Retired Persons (http://aarp.org) to pass state legislation requiring the systematic identification, documentation, and training of caregivers in the hospital setting [Caregiver Advise, Record, and Enable Act; (Coleman, 2016)]. In building better systems for addressing HNC caregiver needs, dyads with compromised well-being at diagnosis should be targeted for proactive provision of educational resources and referrals.

This study characterized a high burden of physical, emotional, and social challenges in a diverse group of HNC patients and their caregivers and suggests that while patients endure more physical burden at diagnosis, no such distinction is present between patients and caregivers in emotional well-being. Also, in approximately one-third of dyads, both patients and their caregivers had high levels of depression and in over 40% of dyads, both had suboptimal mental well-being. Potential risk factors for compromised well-being in both patients and their caregivers included younger age, more severe symptoms, and a smoking/drinking history, and patients with these risk factors and their caregivers may have additional resource needs when facing treatment.

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Table 1

Participant characteristics and bivariate analyses comparing sociodemographic, behavioral, and psychosocial factors in patient and caregiver groups.

Participant characteristic	Patient (*N* = 72) Mean, range		Caregiver (*N* = 72) Mean, range	
Age	**60.6, 32–89**		**58.1, 29–87**	
	n	**%**	***n***	**%**
Sex				
Male	53	74	17	24
Female	19	26	55	76
Race				
European American	60	83	60	83
African American	10	14	10	14
Other	2	2	2	2
Education				
<12 years	15	21	6	8
High school/GED	13	18	18	25
Some college	19	27	21	29
≥College graduate	24	34	27	38
Employment status				
Employed	27	38	42	58
Unemployed/disability	24	33	9	12
Retired	21	29	21	29
Relationship type[a]				
Partner			41	57
Other family/friend			31	43
Smoking status				
Never smoker	18	25	33	46
Former smoker	17	24	20	28
Current/recent smoker	37	51	18	25
Drinking status				
Never	17	24	22	31

Participant characteristic	**Patient ($N = 72$) Mean, range**		**Caregiver ($N = 72$) Mean, range**		
Age	**60.6, 32–89**		**58.1, 29–87**		
	n	**%**	***n***	**%**	
Light	18	26	26	37	
Regular	17	24	13	19	
Heavy	18	26	9	13	
Primary tumor site					
Oral cavity	23	32			
Oropharynx	18	25			
Hypopharynx/larynx	10	14			
Other	21	29			
Cancer stage					
I, II, III	28	39			
IVA-C	44	61			
	Mean		Mean		*p* value[b]
Comorbid conditions	2.0		1.1		
Symptom severity (range 0–10)	2.8				
Physical well-being (range 0–100)	40.5		50.6		<.0001
Mental well-being (range 0–100)	43.1		45.5		0.25
Depression (range 0–30)	11.9		10.1		0.11
Cancer worry (range 1–4)	2.8		3.1		0.08

[a] Average length: 38 years (range: 2–73);

[b] student's *t* test.

Table 2

Patient and caregiver-defined head and neck cancer support behaviors.

Type	Definition	Patient illustrative quotes	Caregiver illustrative quotes
		Emotional support	
General	General nurturing support providing empathy, concern and care concerning cancer	*She has been wonderful, very encouraging…tries to keep my mind off my cancer and problems. When I get down about things she is always there to pick me up.* (Male, Age 54, Oropharynx Cancer)	*I lift him up, try to be there for him no matter what. We take one day at a time. When he has emotional breakdowns I tell him, 'I'm okay. You're gonna be okay'*. (Female, Age 62, Wife of Oral Cavity Cancer Patient)
Spiritual	Emotional support emphasizing faith as a way to cope with emotions	*She helps me a lot and tells me to pray, go to church, and read the Bible.* (Male, Age 32, Oral Cavity Cancer)	*We have a very strong belief in God that helps heal her.* (Female, Age 58, Sister-in-law of Oral Cavity cancer patient)
Addictions	Emotional support focused on facing tobacco and alcohol addictions	*She scolds me for smoking.* (Male, Age 53, Larynx Cancer)	*I love my brother but he is an alcoholic so we are not as close as we could be.* (Male, Age 55, Brother of Lip Cancer Patient)
Appearance	Emotional support focused on disfigurement	*He has shut down…he has trouble looking at me.* (Female, Age 45, Tongue Cancer)	*Most of the support is emotional regarding how he is looking… looking forward to the final surgery to repair his face.* (Female, Age 81, Wife of Salivary Gland Cancer Patient)
		Instrumental support	
General	Caregiving tasks focused on practical aspects of care	*She lays out medications and makes sure I take them. She prepares my food and does everything.* (Male, Age 60, Salivary Gland Cancer)	*Currently, I manage his medication, schedule, and accompany him to doctor visits, do banking, and bill pay, grocery shop and provide evening meals.* (Female, Age 57, Daughter of Salivary Gland Cancer Patient)
Nutrition	Managing patient nutrition to prevent weight loss, including cooking and feeding tube management	*She goes out of her way nutrition wise, helps to supplement my diet.* (Male, Age 43, Tongue Cancer)	*We've had to adjust diet to support foods that can be consumed…we've had to experiment to see what she can expand to. It's a slow process.* (Male, Age 60, Husband of Oropharynx Cancer Patient)
Speech/communication	Communicating with health care providers and assisting with speech challenges	*She communicates to doctors for me.* (Male, Age 81, Salivary Gland Cancer)	*Talking is a struggle for him.* (Female, Age 56, Wife of Larynx Cancer Patient)
		Appraisal support	
General	Feedback and affirmation provided to encourage and reassure the patient	*She helps talk me through decisions and decide what to do.* (Male, Age 62, Larynx Cancer)	*We talk twice as much, making sure everything is OK… keeping him in a good state of mind, praying together. He is angry… I am trying to remind him that he has control over the course of his cancer.* (Female, Age 53, Mother of Oral Cavity Cancer Patient)
New normal	Specific feedback and reassurance thinking forward to life after treatment	*We talk several times a week and she lets me talk about things like my emotions and my concerns about dealing with every day and trying to figure out … life after having cancer.* (Female, Age 40, Unknown Primary Cancer)	*I want to help him resume a normal life.* (Female, Age 56, Wife of Larynx Cancer Patient)
		Informational support	
General	Cancer-related advice and information seeking to support patient	*Writes down information and instructions from doctors. She has looked up information on oral cancer on internet. Talked with other people who*	*I have helped a lot through computer research and looking up various wordings concerning the diagnosis. I also encourage him and tell him he has to make the decision–it's his body and I just*

Type	Definition	Patient illustrative quotes	Caregiver illustrative quotes
		have had cancer… (Male, Age 88, Oral Cavity Cancer)	*put the information out there.* (Female, Age 49, Wife of Oropharynx Cancer Patient)

Table 3

Factors associated with patient well-being.

	Physical well-being (n = 63)		Mental well-being (n = 63)		Depression (n = 72)		Cancer worry (n = 71)	
	Mean	p^a	**Mean**	p^a	**Mean**	p^a	**Mean**	p^a
All	40.5		43.1		11.9		2.8	
Gender								
Male	40.1	0.65	41.2	**0.049**	12.5	0.35	2.9	0.83
Female	41.7		48.6		10.5		2.8	
Race								
White	42.4	**<0.001**	43.7	0.20	11.9	0.98	2.8	0.44
Black	27.5		39.2		12.0		3.0	
Education								
<12 years	34.1	0.11	38.8	0.53	12.0	0.70	2.7	0.25
HS/GED	38.7		44.6		12.1		3.2	
Some college	40.9		45.0		10.3		2.6	
≥College graduate	44.7		44.1		13.0		2.9	
Relationship type								
Partner	42.5	0.13	45.1	0.13	11.0	0.23	2.7	0.06
Other	37.8		40.5		13.2		3.0	
Smoking status								
Never	48.1	**<0.001**	45.7	**0.02**	9.9	**<0.001**	2.2	**<0.001**
Former	44.9		49.2		7.1		2.6	
Current/recent	35.0		39.2		15.2		3.2	
Alcohol drinking status								
Never	39.2	0.16	48.5	**0.01**	10.5	**0.03**	2.6	**0.02**
Light	44.1		48.5		8.6		2.5	
Regular	42.4		37.2		13.3		3.1	
Heavy	34.9		39.1		15.6		3.3	
Primary tumor site								
Oral cavity	38.0	0.60	40.6	0.11	13.7	0.56	3.0	0.7
Oropharynx	43.6		41.0		11.8		2.8	

	Physical well-being (n = 63)		**Mental well-being (n = 63)**		**Depression (n = 72)**		**Cancer worry (n = 71)**	
	Mean	**p^a**	**Mean**	**p^a**	**Mean**	**p^a**	**Mean**	**p^a**
Hypopharynx/larynx	42.0		53.0		10.4		2.7	
Other	40.1		44.0		10.9		2.7	
Cancer stage								
≤III	41.1	0.77	44.9	0.39	11.3	0.54	2.7	0.16
IVA–C	40.1		42.1		12.4		2.9	

[a] *t*-test or ANOVA,

[b] rank-sum test or Kruskal–Wallis test.

Note. Bold values represent significant findings ($p < .05$).

Table 4

Factors associated with caregiver well-being.

	Physical well-being (*n* = 67)		Mental well-being (*n* = 67)		Depression (*n* = 71)		Cancer worry (*n* = 72)	
	Mean	P^a	**Mean**	P^a	**Mean**	P^a	**Mean**	P^a
All	50.6		45.5		10.1		3.07	
Gender								
Male	49.5	0.63	49.8	0.07	7.8	0.05	2.82	0.14
Female	50.9		44.2		10.8		3.15	
Race								
White	50.8	0.42	45.7	0.76	9.7	0.87	3.09	0.23
Black	46.8		46.9		10.1		2.82	
Education								
<12 years	45.9	0.58	44.2	0.86	10.2	0.81	3.1	0.78
HS/GED	49.9		47.7		8.9		3.2	
Some college	49.6		44.9		10.9		3.1	
≥College graduate	52.6		44.9		10.3		3.0	
Relationship type								
Partner	51.7	0.34	45.6	0.99	10.6	0.48	3.0	0.35
Other	49.0		45.5		9.5		3.2	
Smoking status								
Never	52.8	**0.002**	45.0	0.55	9.8	0.77	3.0	**0.03**
Former	54.5		48.1		9.4		2.9	
Current/recent	43.4		44.1		10.7		3.4	
Alcohol drinking status								
Never	46.7	0.10	44.5	0.63	10.6	0.42	3.2	0.61
Light	51.4		44.5		10.8		3.0	
Regular	54.0		48.5		8.8		2.9	
Heavy	55.8		48.8		7.3		3.3	
Patient primary tumor site								
Oral cavity	50.8	0.57	48.1	0.46	9.3	0.68	2.9	0.31
Oropharynx	53.3		42.3		11.6		3.0	

	Physical well-being (n = 67)		**Mental well-being (n = 67)**		**Depression (n = 71)**		**Cancer worry (n = 72)**	
	Mean	**p^a**	**Mean**	**p^a**	**Mean**	**p^a**	**Mean**	**p^a**
Hypopharynx/larynx	47.8		44.8		9.3		3.4	
Other	49.1		46.2		10.1		3.2	
Patient cancer stage								
≤III	48.1	0.12	44.8	0.68	10.0	0.92	3.1	0.63
IVA–C	52.4		46.0		10.2		3.0	

[a] *t*-test or ANOVA,

[b] rank-sum test or Kruskal–Wallis test.

Note. Bold values represent significant findings ($p < .05$).

Table 5

Dyad well-being and associations with sociodemographic, clinical, and behavioral factors.

a. Physical and mental well-being.

	Physical well-being status in dyads					Mental well-being status in dyads				
Patient characteristic	**Neither < 50 $^{(Ref)}$ 9 (15%)**	**Caregiver Only < 50 7 (12%)**	**Patient only < 50 29 (49%)**	**Both < 50 14 (24%)**	**Overall *p*-value^{a}**	**Neither < 50 $^{(Ref)}$13 (22%)**	**Caregiver only < 50 8 (14%)**	**Patient < 50 14 (24%)**	**Both 24 (41%)**	**Overall *p*-value^{a}**
Patient age (mean)^{a}	56.6	63.8	61.7	59.9	0.60	62.2	66.3	63.0	56.8	0.14
Patient sex (% male)	89	57	79	79	0.54	46	88	79	92	0.02
Patient race (% African American)	0	0	14	29	0.20	8	0	14	21	0.52
Patient education (% ≤high school)	11	0	21	62	0.25	15	0	15	33	0.23
Caregiver type (% partnered)	78	71	55	50	0.52	69	75	43	58	0.44
Cancer stage (% stage IV)	56	57	76	36	0.08	69	38	64	62	0.53
Patient symptom severity (mean)	1.1	0.9	3.5**	3.2**	<0.001	1.6	2.2	3.5**	3.1*	0.04
Patient smoking status (% current/recent)	22	29	62	71*	0.052	31	38	64	67*	0.12
Patient drinking status (% regular/heavy)	44	33	55	64	0.61	23	43	57	71**	0.04

b. Depression and cancer worry.

	Depression status in dyads					Cancer worry status in dyads				
Patient characteristic	**Neither ≥ 10 $^{(Ref)}$ 22 (24%)**	**Caregiver Only ≥ 10 11(15%)**	**Patient only ≥ 10 17 (24%)**	**Both ≥ 10 21 (37%)**	**Overall *p*-value^{a}**	**Neither ≥ 3 $^{(Ref)}$ 22 (31%)**	**Caregiver only ≥ 3 20 (28%)**	**Patient only ≥ 3 11 (15%)**	**Both ≥ 3 18 (25%)**	**Overall *p*-value^{a}**
Patient age (mean)	64.1	64.5	57.5	56.6	0.07	64.3	62.0	57.8	56.5	0.15
Patient sex (% male)	55	73	76	90	0.06	68	80	64	83	0.55
Patient race (% African American)	18	9	12	14	0.79	14	5	36	11	0.15
Patient education (% high school)	23	9	13	33	0.40	32	16	18	17	0.63
Caregiver type (% partnered)	64	73	35	57	0.20	64	65	55	39	0.36
Cancer stage (% stage IV)	64	45	71	62	0.62	64	40	64	78	0.29
Patient symptom severity (mean)	1.8	1.5	4.2	3.4	<0.001	2.1	2.2	4.5	3.3	0.003

b. Depression and cancer worry.

Patient characteristic	Depression status in dyads					Cancer worry status in dyads				
	Neither ≥ 10 (Ref) 22 (24%)	Caregiver Only ≥ 10 11(15%)	Patient only ≥ 10 17 (24%)	Both ≥ 10 21 (37%)	Overall *p*-value[a]	Neither ≥ 3 (Ref) 22 (31%)	Caregiver only ≥ 3 20 (28%)	Patient only ≥ 3 11 (15%)	Both ≥ 3 18 (25%)	Overall *p*-value[a]
Patient smoking status (% current/recent)	27	27	76	71	0.007	32	50	73	67	0.14
Patient drinking status (% regular/heavy)	33	45	71	55	0.15	33	37	82	67	0.02

Dyad groups significantly different from the reference group *(Ref)* are noted with

[*] $p < 0.05$ and

[**] p 0.01. Reference group is dyads in which neither the patient nor caregiver had suboptimal well-being.

[a] ANOVA and Fisher's exact tests were used for continuous and categorical variables, respectively.