Published in final edited form as:

J Consult Clin Psychol. 2013 April ; 81(2): 299–317. doi:10.1037/a0029940.

Psychological Factors Associated with Head and Neck Cancer Treatment and Survivorship: Evidence and Opportunities for Behavioral Medicine

M. Bryant Howren, PhD, MPH

VA Iowa City Healthcare System and Department of Psychology, The University of Iowa

Alan J. Christensen, PhD

VA Iowa City Healthcare System and Department of Psychology, The University of Iowa

Lucy Hynds Karnell, PhD

Department of Otolaryngology—Head and Neck Surgery, University of Iowa Hospitals and Clinics

Gerry F. Funk, MD

Department of Otolaryngology—Head and Neck Surgery, University of Iowa Hospitals and Clinics

Abstract

Individuals diagnosed with head and neck cancer (HNC) face not only a potentially life-threatening diagnosis, but must endure treatment that often results in significant, highly visible disfigurement and disruptions of essential functioning, such as deficits or complications in eating, swallowing, breathing, and speech. Each year, approximately 650,000 new cases are diagnosed, making HNC the sixth most common type of cancer in the world. Despite this, however, HNC remains understudied in behavioral medicine. In this article, the authors review available evidence regarding several important psychosocial and behavioral factors associated with HNC diagnosis, treatment, and recovery, as well as various psychosocial interventions conducted in this patient population, before concluding with opportunities for behavioral medicine research and practice.

Keywords

head and neck cancer; cancer survivorship; health psychology; behavioral medicine; health-related quality of life

Individuals diagnosed with head and neck cancer (HNC)—a group of related neoplasms affecting the paranasal sinuses, nasal and oral cavities, pharynx, and larynx—face not only a potentially life-threatening diagnosis, but must endure treatment that often results in significant, highly visible disfigurement and disruptions of essential functioning, such as deficits or complications in eating, swallowing, breathing, and speech. Approximately 650,000 new HNC cases are diagnosed each year, making it the sixth most common type of cancer in the world (Parkin, Bray, Ferlay, & Pisani, 2005) with a five-year survival rate of approximately 60% (Jemal, Thomas, Murray, & Thun, 2002; Ries et al., 2006).¹

The primary etiologic factors are tobacco and/or alcohol as approximately three-fourths of head and neck cancers are attributable to the use of these substances (e.g., Argiris & Eng,

Correspondence concerning this article should be addressed to M. Bryant Howren, Department of Psychology, The University of Iowa, 11 Seashore Hall East, Iowa City, IA 52242. matthew-howren@uiowa.edu..

¹There is considerable variation in survival across primary cancer sites, however. For a site-specific analysis, see Carvalho, Nishimoto, Califano, & Kowalski, (2005).

2003; Freedman, Schatzkin, Leitzmann, Hollenbeck, & Abnet, 2007; Hashibe et al., 2007). Each substance, respectively, is an independent risk factor for the development of HNC, but these behaviors often co-occur (Allison, 2001), resulting in a multiplicative risk of HNC development (Marur & Forastiere, 2008). Estimates indicate that, compared with nonsmokers/drinkers, users of tobacco and alcohol have a fifty-fold (or greater) increased risk of developing HNC (Maier, Dietz, Gewelke, Heller, & Weidauer, 1992). Moreover, continued use of these substances beyond diagnosis complicates treatment, confers greater risk of recurrence or developing a second primary tumor, and ultimately impacts survival (e.g., Day et al., 1994; Do et al., 2003), underscoring the need for immediate cessation. In addition to these major risk factors, increasing evidence also implicates human papillomavirus (HPV) as a causative agent, particularly for oropharyngeal cancers (e.g., Chaturvedi et al., 2011; Chung & Gillison, 2009; Joseph & Pai, 2011).

The typical HNC patient is older, male, and has multiple comorbidities often associated with smoking and drinking behavior (Argiris, Karamouzis, Raben, & Ferris, 2008; Hoffman, Karnell, Funk, Robinson, & Menck, 1998); however, recent trends indicate greater incidence in women and younger populations, likely due to HPV exposure (Curado & Hashibe, 2009; Marur & Forastiere, 2008). Minorities and persons of low socioeconomic status experience differential risk of HNC, tend to present with advanced disease, and have considerably lower survival rates (Molina et al., 2008; Nichols & Bhattacharyya, 2007). Dependent upon the primary cancer site, patients present with symptoms that may include difficulty swallowing, hoarseness, ear pain, enlarged cervical lymph nodes, nasal bleeding or blockage, and/or nonhealing sores or ulcers in the mouth (Marur & Forastiere, 2008).

Treatment for HNC is complex and, often, debilitating. Patients may undergo surgery, radiation therapy, chemotherapy, or some combination thereof (Argiris et al., 2008; Marur & Forastiere, 2008). These treatments are associated with a range of side effects including difficulties with essential functioning such as eating, swallowing, breathing, and speech, as well as loss of taste and smell, decreased sensation, excessive dry mouth, residual pain and swelling, and facial disfigurement (Brockstein & Masters, 2010; List & Bilir, 2004). Moreover, disease and treatment confer marked disability, with nearly half of patients unable to return to work for a substantial period of time beyond treatment cessation (Shone & Yardley, 1991; Taylor et al., 2004). Consequently, HNC survivors often require extensive rehabilitative treatment including speech therapy, swallowing rehabilitation, and dental/maxillofacial rehabilitation, as well as physical and occupational therapies (Ward & Van As-Brooks, 2006). Treatment and recovery also may be complicated by various other factors such as patient delay (Carvalho et al., 2002), the presence of multiple complex chronic conditions (El-Deiry, Futran, McDowell, Weymuller, & Yueh, 2009; Paleri et al., 2010), continued use of tobacco and alcohol, and psychosocial factors including depression, lack of social support, and issues pertaining to body image (see De Boer, McCormick, Pruyn, Ryckman, & Van den Borne, 1999; Llewellyn, McGurk, & Weinman, 2005).

Given the importance one places on the appearance of the head and neck, coupled with the visibility of the disease and treatment sequelae, HNC is arguably the most psychologically traumatic cancer to experience (Koster & Bergsma, 1990; Björklund, Sarvimäki, & Berg, 2010). This has led to an increasing focus in oncology research toward the assessment and consideration of patient-reported outcomes—particularly health-related quality of life (HRQOL)—during all stages of treatment and recovery, in part also because survival has only marginally improved over the past two decades despite diagnostic and treatment advances (Carvalho, Nishimoto, Califano, & Kowalski, 2005; Ries et al., 2005), and to the recognition that patient survival is a wholly insufficient indicator of patient outcome (e.g., Babin, Sigston, Hitier, Dehesdin, Marie, & Choussy, 2008; Morton, 1995; Morton & Izzard, 2003).

HRQOL, which may be defined as the degree to which physical dysfunction, pain, and related distress limit or disrupt one's daily behaviors, social activities, and psychological well-being (Lawton, 2001), is an important patient outcome in its own right because a cancer diagnosis is often associated with decreased life expectancy and treatment rarely affords full recovery. HRQOL scores may be used to evaluate several important (HNC) outcomes, including treatment effectiveness, palliative care benefits, and survival (e.g., Elmqvist, Jordhøy, Bjordal, Kassa, & Jannert, 2009; Karvonen-Gutierrez, Ronis, Fowler, Terrell, Gruber, & Duffy, 2008; Kassa & Loge, 2002; Mehanna & Morton, 2006a; Osthus, Aarstad, Olofsson, & Aarstad, 2011a). In addition to the benefit to clinical science, HRQOL indices provide patients with information which may be used to better understand the impact of disease and treatment on physical and psychological well-being as well as aid decisions regarding different treatment modalities (Mehanna, 2007). The importance of such information cannot be ignored as, in one study, nearly one quarter of HNC patients ranked outcomes other than total cure (e.g., pain, energy, normal functioning, appearance) as their top treatment priority (List et al., 2000).

The nature of HNC and its treatment requires comprehensive HRQOL assessment. As such, both global and condition-specific instruments—for example, the Head and Neck Cancer Inventory (HNCI; Funk, Karnell, Christensen, Moran, & Ricks, 2003) and the HNC module of the European Organization for Research and Treatment of Cancer (EORTC-H&N35; Bjordal et al., 1994)—are necessary in order to delineate domains most strongly linked to psychosocial variables which may serve as targets for clinical intervention (Sherman, Hanna, & Simonton, 2005; Sherman & Simonton, 2010).² Importantly, although summary measures may mask HNC-specific areas in need of attention, they still remain useful (Grignon, Jameson, Karnell, Christensen, & Funk, 2007), allowing for comparisons across patients with diverse presentations, treatment courses, and/or comorbidities.

A considerable body of evidence assessing the trajectory of recovery in HNC survivors indicates that, overall, HRQOL is lowest during treatment and a short time thereafter, before gradually improving and eventually approaching baseline levels approximately twelve months after diagnosis (Funk et al., 2003; Hammerlid, Silander, Hörnrestam, & Sullivan, 2001; Lin et al., 2003; Weymuller, Yueh, Deleviannis, Kuntz, Alsarraf, & Coltrera, 2000). However, there are clear individual differences in this trajectory, as some survivors regain normal function soon after treatment, whereas others remain substantially impaired in various HRQOL domains (e.g., Abendstein et al., 2005; de Graeff, de Leeuw, Ros, Hordijk, Blijham, & Winnubst, 2000a; Hammerlid & Taft, 2001; Ronis, Duffy, Fowler, Khan, & Terrell, 2008), underscoring the need for increased research if behavioral interventions designed to lessen the impact of disease and treatment on recovery are to be implemented in practice.

Below, we review evidence regarding several important psychosocial and behavioral factors associated with HNC diagnosis, treatment, and recovery before concluding with opportunities for behavioral medicine research and practice. Previous reviews have covered some—but not all—of the relevant areas and are limited in other ways, including the level of detail afforded various important behavioral factors and the age of the review (Chandu, Smith, & Rogers, 2006; Frampton, 2001; Ledeboer, Velden, de Boer, Feenstra, & Pruyn, 2005; List & Stracks, 2003; Llewellyn, McGurk, & Weinman, 2005; Morton & Izzard, 2003; Penner, 2009; Sherman, Hanna, & Simonton, 2005). Furthermore, the majority of this research is found in the medical literature and therefore is primarily framed for a medical/oncological audience; health psychologists and behavioral medicine specialists have yet to

²For reviews of global, disease-specific, site-specific, and symptom-specific HRQOL instruments used in HNC research, see Murphy, Ridner, Wells, & Dietrich (2007), Pusic et al. (2007), and Tschiesner, Rogers, Harréus, Berghaus, & Cieza (2008).

fully apply their expertise to the study and treatment of psychosocial issues experienced by HNC patients. These shortcomings, coupled with the considerable growth of this literature over recent years, make the present review a novel and timely addition to the behavioral medicine literature.

For this descriptive review, we conducted searches of the PUBMED and PsychINFO databases for English language studies published between January, 1990 and January, 2012 using the following terms (and combinations thereof): *head and neck cancer* AND *quality of life* AND assessment, measurement, patient-reported outcomes, anxiety, depression, pain, psychological distress, personality, individual differences, alcohol, tobacco, fear of cancer recurrence, illness cognitions, coping, body image, disfigurement, sexual intimacy, caregiver, caregiver support, social support, spousal support, interventions, randomized clinical trials. Additional studies were identified by reviewing the reference sections of retrieved articles and previous systematic reviews. Rather than attempt an exhaustive review of the literature, we identified and selected studies in each area to best illustrate the current state of the literature, which are described in turn.

Psychological Factors in HNC

Psychological Distress

The experience of psychological distress, particularly depression—whether as subclinical depressive symptomatology or clinical depressive disorder—is quite common among cancer patients and may occur throughout the course of illness, often persisting months beyond the conclusion of treatment in cancer survivors (Massie, 2004; Pirl, 2004). The basis for this distress is likely multi-faceted and may be a function of the diagnosis itself, the presence of burdensome disease and treatment sequelae, declines in HRQOL, and/or the possibility of disease progression, recurrence, or death.

Notably, depression in HNC patients has been estimated to be more prevalent than in other types of cancer (Massie, 2004).³ Estimates vary by assessment method (i.e., self-report measures vs. diagnostic interview), but indicate that between approximately fifteen and fifty percent of HNC patients suffer some degree of depression at any given point across the disease trajectory (e.g., Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009; Lydiatt, Moran, & Burke, 2009) and may affect immunocompetence, treatment adherence, self-care behaviors, resocialization, and aspects of HRQOL (DiMatteo, Lepper, & Croghan, 2000; Howren, Christensen, Karnell, & Funk, 2010; Jerant, von Friederichs-Fitzwater, & Moore, 2005; Spiegel & Giese-Davis, 2003). Often, depression and other forms of distress go unreported to, or unrecognized by, HNC clinicians (see Pirl et al., 2007).

Numerous studies have evaluated the impact of depression on various global and HNC-specific HRQOL domains. For example, Howren and colleagues (2010) found that subclinical depressive affect present at diagnosis, before the initiation of treatment, was associated with poorer HRQOL one year later after adjusting for baseline HRQOL values as well as age, gender, marital status, disease site and stage, alcohol and tobacco use, and physical comorbidities. Specifically, those patients scoring 10 or above on the Beck Depression Inventory (BDI; Beck, Rush, Shaw, & Emery, 1979) failed to regain normal functioning by one year postdiagnosis across each of four HNC-specific domains including speech, eating, facial aesthetics, and social disruption as measured by the HNCI (Funk et al., 2003). In contrast, those patients falling below this threshold reached normal functioning, on average, by one year postdiagnosis in three of the four domains listed above. Similarly, in a study assessing depression over time (i.e., at the outset of treatment [baseline], conclusion of

³See Massie (2004) for a comprehensive review of depression rates in patients with cancer.

treatment, and four weeks thereafter) using the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001), Britton et al. (2012) reported that baseline depression was associated with decreased nutritional status over the course of treatment for HNC. In a study of HNC patients with (versus without) persistent posttreatment depressive symptomatology (i.e., patients with consistently elevated BDI scores for six months or more beyond the conclusion of treatment), Karnell and colleagues (2006) reported that patients experiencing persistent depressive affect were more likely to report worse HNC-specific HRQOL outcomes after adjusting for various clinical characteristics. Similar results have been found in other studies measuring depressive symptomatology and/or more general distress in HNC patients (e.g., Bornbaum, Fung, Franklin, Nichols, Yoo, & Doyle, 2011; Chan, Lua, Starmer, Sun, Rosenblatt, & Gourin, 2011; de Leeuw, de Graeff, Ros, Blijham, Hordijk, & Winnubst, 2000a).

Despite evidence of its presence at all stages of the disease trajectory (Hammerlid et al., 1999; Neilson et al., 2010), relatively few studies have primarily aimed to evaluate the association between anxiety and clinical or HRQOL outcomes in this population (e.g., Chen, Yu, Chu, Hung, Tsai, & Liao, 2010; Horney et al., 2011; Nielson et al., 2010). For example, Chen and colleagues (2010) compared 165 HNC inpatients, divided by caseness according to the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), on several outcomes including disease impact, symptom distress, and supportive care needs. The authors found that patients with high levels of anxiety were more likely to report increased disease impact including disease-specific intrusion and avoidance, although the groups did not differ significantly relative to symptom distress and supportive care needs. More commonly, anxiety is considered only when measures such as the HADS are used to capture psychological distress, but depression and anxiety subscale scores are also evaluated as predictors or correlates of HRQOL and/or other clinical and psychosocial outcomes, sometimes as a secondary aim of the study (e.g., Kobayashi, Sugimoto, Matsuda, Matsushima, & Kishimoto, 2008; Kugaya et al., 2000; Llewellyn, McGurk, & Weinman, 2007a).

Body Image/Disfigurement

The effects of disease and treatment often cannot be concealed by HNC patients, making those who suffer from facial disfigurement vulnerable to distress, intimacy issues, social isolation, stigma, and untoward behavior from others (Callahan, 2005; Clarke, 1999; Fingeret, Yuan, Urbauer, Weston, Nipomnick, & Weber, 2011; Lebel, Castonguay, Mackness, Irish, Bezjak, & Devins, 2011). Patients often indicate that disfigurement is a primary treatment concern (e.g., Fingeret et al., 2011; List et al., 2000), which is not surprising given the importance of one's appearance to self-concept. However, few studies have investigated the impact of disfigurement on HRQOL outcomes in HNC. Those studies that have investigated this relationship have not been entirely consistent, perhaps due to the inherent difficulties in assessing disfigurement (see Clarke, 1999; Katz, Irish, Devins, Rodin, & Gullane, 2000) as well as individual differences in perceptions of, and reaction to, disfigurement.

For example, Fingeret and colleagues (2011) surveyed 280 HNC surgical patients at different stages of the disease trajectory (including those less than/greater than one year posttreatment) regarding dissatisfaction with body image and its relation to condition-specific HRQOL. It was reported that over half of patients expressed frequent concern about changes in appearance, one-third would have liked additional resources to help cope with such concerns, and self-reported dissatisfaction with body image predicted worse HRQOL outcomes including emotional, functional, physical, and social well-being. Katz, Irish, Devins, Rodin, and Gullane (2003) similarly reported that disfigurement (assessed via observer ratings) was significantly related to depression in 82 patients approximately two

years removed from treatment. In a study of 51 HNC patients and 44 of their partners, however, Vickery and colleagues (Vickery, Latchford, Hewison, Bellew, & Feber, 2003) did not find an association between observer-rated disfigurement and diminished HRQOL, which is consistent with some other studies on this topic (e.g., Baker, 1992; Rapaport, Kreitler, Chaichik, Algor, & Weissler, 1993).

In part due to these inconsistencies, some have looked for possible moderators of the relationship between disfigurement and HRQOL and/or other indicators of well-being. For example, Hagedoorn and Molleman (2006) investigated the moderating role of social self-efficacy, defined as the extent to which patients believe themselves capable of exerting control over the reactions and openness of others, in 76 HNC patients during a routine clinic visit. Patients were asked to complete measures of social self-efficacy, distress, and social isolation; both patients and physicians completed judgments of facial disfigurement. Regression analyses demonstrated that facial disfigurement was positively associated with psychological distress only when social self-efficacy was low. In addition, the same pattern was observed regarding distress in reaction to others' negative behaviors, as well as social isolation. These results are consistent with work in other patient populations (e.g., Leary, Rapp, Herbst, Exum, & Feldman, 1998), but more research is needed to further specify the importance of social self-efficacy and other possible moderating variables.

Personality/Individual Differences

Fear of Cancer Recurrence—Fear of cancer recurrence (FCR) is not simply a transient affective state manifested upon the conclusion of treatment, but rather is a multidimensional construct capturing the fear or worry (and related, dysfunctional behaviors) associated with the possibility that one may be faced with another cancer diagnosis (Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Simard, Savard, & Ivers, 2010). FCR is present almost universally in cancer survivors (O'Neil, 1975) and studies have shown that FCR can arise even before the initiation of treatment, often remaining stable over a period of several years beyond the conclusion of treatment (e.g., Ghazali, Cadwallader, Lowe, Humphris, Ozakinci, & Rogers, 2012; Koch, Jansen, Brenner, & Arndt, 2012). FCR may be exacerbated by symptoms previously perceived as innocuous (i.e., common physical symptoms such as sore throat or headache; see Lee-Jones, Humphris, Dixon, & Hatcher, 1997) or prior to routine follow-up appointments (Simard & Savard, 2009). FCR has been reported across numerous patient cohorts, including those with breast, colorectal, hematologic, ovarian, prostate, testicular, and head and neck cancers (see Simard, Savard, & Ivers, 2010).

In HNC patients, FCR has been identified as a chief patient concern (Rogers, El-Sheikha, & Lowe, 2009; Rogers, Scott, Lowe, Ozakinci, & Humphris, 2010), affecting from half to more than three-fourths of patients (Campbell, Marbella, & Layde, 2000; Humphris, Rogers, McNally, Lee-Jones, Brown, & Vaughan, 2003). However, few empirical studies have investigated clinical and psychosocial correlates of FCR, including its impact on HRQOL, in this population. In one study, Rogers et al. (2010) attempted to distinguish HNC patients who chose to discuss FCR (among several HNC-related issues) during a routine clinic visit from those who did not on various clinical and demographic characteristics, including gender, stage of disease, treatment modality, and HRQOL. Patients who elected to discuss FCR showed evidence of psychological distress, but did not differ from other patients on any other factors. In another study using Leventhal's (1980) Common Sense Model (CSM; a.k.a. Self-Regulation Model) of illness representations as a theoretical framework to predict the development of FCR, Llewellyn and colleagues (2008) assessed a sample of 82 newly diagnosed HNC patients prior to treatment and then again at six to eight months posttreatment regarding FCR, illness perceptions, coping, and psychological distress. Although unrelated to sociodemographic, disease-, or treatment-related factors, FCR was

associated with components of the CSM framework; however, path analyses demonstrated that the strongest predictors of posttreatment FCR were pretreatment FCR and dispositional optimism. In a prospective study of 189 posttreatment HNC patients, Ghazali and colleagues (2012) investigated predictors of significant, or extreme, FCR. In addition to finding that 35% of patients experienced significant FCR (30% persistently), they reported that younger age and mood/anxiety issues were predictive of significant FCR, yet disease- and treatment-related factors were not (similar to that reported by Llewellyn, Weinman, McGurk, & Humphris, 2008). This latter finding suggests that patients deemed to be at low risk of recurrence based upon clinical factors may experience elevated FCR and require attention. Finally, in a prospective study of 101 HNC patients and their caregivers (representing an understudied group in this context), Hodges and Humphris (2009) also reported that FCR closer to diagnosis predicted subsequent FCR (see Llewellyn et al., 2008). Most notably, using path analyses, these authors found a significant, positive association between patient FCR and caregiver FCR over time. Because recurrence risk is, in fact, higher in HNC compared with other cancers (e.g., Cianfriglia, Di Gregorio, & Manieri, 1999) and such recurrence often is attributable directly to patient behavior (i.e., continued use of tobacco and/or alcohol; Do et al., 2003), the presence of FCR and its impact on treatment and recovery in both patients and caregivers is an important area for further study.

Illness Cognitions—Leventhal's CSM framework (1980) has also been used to study HRQOL outcomes in HNC survivors. The CSM framework is appealing in the context of HNC for several reasons including previous research indicating the importance of patient illness conceptualizations on subsequent distress (e.g., Rabin, Leventhal, & Goodin, 2004) and, more broadly, the body of evidence demonstrating its explanatory power for both coping behaviors and health outcomes across numerous illness populations (see meta-analytic review by Hagger & Orbell, 2003).

Scharloo and colleagues (2005) administered the Illness Perception Questionnaire-Revised (IPQR; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002), a measure developed to capture the various dimensions of the CSM framework, and the general cancer module of the EORTC (Aaronson et al., 1993) in a sample of 68 newly diagnosed HNC patients. After adjusting for age and physical comorbidities, regression analyses demonstrated that better functioning was associated with less belief that the disease was cyclical, attenuated emotional response to disease, and lower internal disease attributions. In another study by the same authors (2010), 177 HNC patients were assessed at diagnosis, twelve, and twenty-four month follow-ups, again using the IPQ-R and general cancer module of the EORTC. Lower internal disease attributions and lower perceived illness consequences at baseline were associated with better functioning measured twenty-four months later; negative perceptions regarding the illness timeline were associated with poorer HRQOL. In contrast, however, Llewellyn, McGurk, and Weinman (2007b) failed to find associations between CSM dimensions and posttreatment HRQOL (as measured by the general cancer module of the EORTC and the SF-12) after adjusting for age, disease stage, and baseline HRQOL. Only with respect to posttreatment depression were significant associations with CSM components reported. Finally, Dempster et al. (2010) found that—after adjustment for age, gender, physical comorbidities, and time since diagnosis—changes in illness perceptions over time were associated with changes in depression and anxiety over time in a sample of 189 HNC survivors assessed at two time-points, twelve months apart. Although the evidence base is small in HNC, collectively these results suggest that patients' illness representations may be targets for intervention; indeed, several such interventions have been conducted in other illness populations (e.g., Petrie, Cameron, Ellis, Buick, & Weinman, 2002).

Personality Traits—Relatively little evidence exists regarding personality influences on HRQOL or other issues associated with HNC. In a pair of studies evaluating the association between the Five Factor Model (Digman, 1990) traits of neuroticism and extraversion and HRQOL in HNC patients at least one year removed from successful treatment, Aarstad and colleagues (2003; 2008) reported that neuroticism was negatively associated with HRQOL as measured by the core cancer and HNC-specific modules of the EORTC; however, a positive association between extraversion and HRQOL was found only in one study (2003).

A few studies have investigated the association of dispositional optimism with health outcomes in HNC patients, yielding mixed results. Using a prospective design, Allison, Guichard, and Gilain (2000) examined the impact of optimism on HRQOL (both before and after treatment) in a sample of French HNC patients. In multivariate regression analyses, dispositional optimism was positively related to several HRQOL domains at both time-points, including the global, role, cognitive, and pain domains of the EORTC core cancer module. In another study using the same patient sample (Allison, Guichard, Fung, & Gilain, 2003), it was found that dispositional optimism predicted one-year survival after adjusting for several clinical and sociodemographic characteristics. In contrast, Yu and colleagues (2001) found no association between optimism measured at the conclusion of treatment and HRQOL four months later in a sample of 211 Chinese HNC patients after adjusting for baseline HRQOL values. Similarly, optimism was unrelated to HRQOL as measured by the SF-12 and SF-36 (Ware & Sherbourne, 1992; Ware, Kosinski, & Keller, 1996) after adjusting for age, gender, and stage of disease in a sample of 86 HNC patients retrospectively identified through a patient registry (Kung et al., 2006). Finally, dispositional optimism has also been shown to be associated with benefit finding in HNC patients (Harrington, McGurk, & Llewellyn, 2008), which is consistent with results from other cancer literatures (e.g., Urcuyo, Boyers, Carver, & Antoni, 2005).

Continued Tobacco & Alcohol Use

Perhaps the most significant problem facing HNC patients and clinicians is the continued use of tobacco and alcohol beyond diagnosis, which negatively affects treatment efficacy, HRQOL, and survival (De Boer et al., 1998; Hall, Groome, & Rothwell, 2000; Mayne, Cartmel, Kirsch, & Goodwin, 2009). For example, continued smoking during and after treatment may worsen the severity of mucositis, a common side effect of chemotherapy and radiotherapy in which the cells lining the inside of the mouth become inflamed, leading to difficulties in eating and swallowing. Mucositis not only causes significant discomfort and compromised functioning, but as severity increases, so do breaks in treatment, patient hospitalizations, and possibly mortality (see Trotti et al., 2003). Similar results in patients who continue to use alcohol after diagnosis have been reported (Miller, Day, & Ravenel, 2006) and, as noted above, these behaviors greatly increase the probability of cancer recurrence and/or the development of a second primary tumor. Estimates indicate that between one-third and one-half (or more) of HNC patients continue to use tobacco and/or alcohol beyond diagnosis and treatment (Danker et al., 2011; Deleyiannis, Thomas, Vaughn, & Davis, 1996; Duffy et al., 2002; Ostroff et al., 1995), perhaps because some patients are unaware that smoking and drinking lead to HNC or believe quitting is futile in light of a life-threatening diagnosis (Fabian, Irish, Brown, Liu, Gullane, 1996; Sharp & Tishelman, 2005). While many patients do manage to quit during treatment, nearly a quarter of those patients relapse within twelve months (Gritz, Schacherer, Koehly, Nielsen, & Abemayor, 1999), highlighting the need to integrate timely, targeted cessation interventions into standard medical care.

At present, relatively little research has evaluated psychological factors associated with continued smoking and/or alcohol use specifically in HNC patients, with much of the work

in this context focusing on tobacco rather than alcohol, in part, because smoking is considered to be the greater of the two risks (Viswanathan & Wilson, 2004). Despite limited evidence, several psychosocial and behavioral factors that may perpetuate continued use (and therefore complicate cessation efforts) and/or decrease HRQOL in HNC patients have been identified including psychological distress, motivation to quit, illness beliefs and attributions, perceived self-efficacy, and patient risk perceptions (e.g., Christensen, Moran, Ehlers, Raichle, Karnell, & Funk, 1999; Duffy, Scheumann, Fowler, Darling-Fisher, & Terrell, 2010; Fabian et al., 1996; Gritz et al., 1993; Gritz et al., 1999; Schnoll, James, et al., 2003).

Very few studies have evaluated the association between distress and the likelihood of cessation following diagnosis and treatment in HNC. For example, Humphris and Rogers (2004) assessed a consecutive sample of 87 HNC patients on four separate occasions over a fifteen month period following treatment. Measures of psychological distress and FCR were administered at each time point. Results indicated that distress, as measured by the HADS, was significantly associated with smoking behavior at fifteen months posttreatment. Although the literature is clearly limited, such results are not surprising given evidence demonstrating that individuals with depression are more likely to smoke as well as use alcohol (e.g., Breslau, Peterson, Schultz, Chilcoat, & Andreski, 1998; Epstein, Induni, & Wilson, 2009; Hasin & Grant, 2002).

Duffy and colleagues (2002; 2007) have conducted studies of the effects of depression and smoking and drinking behavior on HRQOL in HNC. In a sample of 81 HNC patients recruited primarily from a Veterans Affairs (VA) hospital, Duffy et al. (2002) administered smoking, alcohol, and depression measures as well as the SF-36V (Kazis, 1998), a variation of the SF-36 adapted for use in veteran populations, and a condition-specific HRQOL measure. After adjustment for age and disease site and stage, regression analyses indicated that depressive symptomatology and continued smoking behavior were associated with numerous HRQOL domains, but alcohol use was not. Similarly, in a survey of nearly one thousand HNC patients from both university and VA hospitals, Duffy and her co-investigators (2007) reported that depressive symptomatology and smoking were related to global and condition-specific HRQOL, but again, alcohol use was not after adjusting for clinical and demographic characteristics. In a sample of 283 HNC patients, Potash et al. (2010) also found depressive symptomatology, but not alcohol use, to be significantly related to overall HRQOL at one year postdiagnosis in regression analyses; however, subgroup analyses indicated that problem, as opposed to social, drinkers suffered from considerably poorer HRQOL.

A few studies have begun to evaluate the influence of individual difference characteristics on continued use in this population, such as patient beliefs about quitting and patient levels of self-focused attention. For example, Christensen and colleagues (1999) measured perceived behavioral control and illness self-blame in a sample of 55 HNC patients identified as continued users of tobacco and alcohol. It was reported that the interaction between the two variables predicted continued smoking behavior; specifically, patients who attributed the cause of their cancer to previous substance use (i.e., high illness self-blame) were less likely to continue smoking only if they also believed that future, cancer-related health was a function of their own behavior (i.e., high perceived behavioral control). These variables, however, had no influence on continued drinking behavior. In another study by the same group of authors (Raichle, Christensen, Ehlers, Moran, Karnell, & Funk, 2001), individual differences in self-focused attention—operationalized as high public (vs. private) self-consciousness (Fenigstein, Scheier, & Buss, 1975)—were measured in the context of continued smoking after diagnosis of HNC. The authors hypothesized that patients with high public self-consciousness, reflecting a heightened self-awareness of one's appearance to

others, would be more likely to decrease smoking behavior. Using logistic regression analyses ($N = 40$), the authors did indeed find that patients with high public self-consciousness were more likely to decrease this behavior, possibly because such patients were keenly aware that smoking after diagnosis is a socially unacceptable behavior. Schnoll, James, and colleagues (2003) investigated facets of the Cognitive-Social Health Information Processing model (C-SHIP; e.g., Miller & Diefenbach, 1998) including self-efficacy, fatalistic beliefs, and risk perceptions regarding continued smoking by HNC patients. These authors found that low quitting self-efficacy and low perceived risk of recurrence were associated with continued smoking, which aligns with other work in this population (Gritz et al., 1999).

A patient's motivation to quit has also been shown to be important. Gritz and colleagues (1993) conducted a relatively large ($N = 186$), randomized controlled trial of a provider-based smoking cessation intervention which administered a measure based on the Transtheoretical Model (Prochaska & Velicer, 1997) as part of the baseline assessment. Although the intervention effect was not significant, the authors did find that precontemplators were significantly less likely to maintain abstinence over the course of one year as compared to contemplators, much like that found in non-patient samples (Prochaska & Velicer, 1997). It is worth noting that while the evidence reviewed here may help facilitate the development of cessation interventions, some evidence suggests that HNC patients are less likely to enroll in smoking cessation interventions than other cancer populations, meaning there may also be need for the development of motivational interventions to facilitate enrollment (Schnoll et al., 2004).

Social Support

At present, relatively few studies have investigated the extent to which social support (and related interventions) may benefit HNC patients. Although many studies have demonstrated the benefits of social support in numerous cancer populations, particularly breast cancer (e.g., see Falagas, Zarkadoulia, Ioannidou, Peppas, Christodoulou, & Rafailidis, 2007; Helgeson & Cohen, 1996), HNC is unique in that certain HNC-specific domains may require more, less, and/or different supportive care at various points during treatment and recovery. For example, as reviewed above, issues regarding speech/communication and facial disfigurement are often present after treatment. Such issues may precede social isolation and depression, which may impact adherence to self-care or rehabilitation regimens (DiMatteo, Lepper, & Croghan, 2000), as well as influence tobacco and alcohol cessation, which is vitally important in this population.

Collectively, the existing evidence regarding social support in HNC is equivocal. For example, Karnell and colleagues (2007) reported that greater perceived social support measured at one year postdiagnosis was related to more favorable concurrent global and condition-specific HRQOL (as measured by the SF-36 and HNCI, respectively) in a sample of nearly 400 HNC patients. Similarly, Howren et al. (2012) found that perceived social support, measured prior to the initiation of oncological treatment, was associated with several global and HNC-specific HRQOL outcomes one year later after adjusting for several clinical and demographic variables; of note, mean HRQOL differences between those with high (versus low) perceived social support reached a level considered clinically important in several domains. In a sample of 82 ambulatory HNC patients six months removed from treatment, Katz and colleagues (2003) reported that perceived social support was associated with improved adjustment and well-being in female, but not male patients, which is consistent with other studies in the cancer literature (e.g., Manne, Taylor, Dougherty, & Kemeny, 1997). In a study of 104 posttreatment HNC patients, Birkhaug et al. (2002) found no significant association between perceived social support and HRQOL in regression analyses after adjusting for age and gender. One study that evaluated the influences of both

available and received social support on depression in HNC patients (de Leeuw, de Graeff, Ros, Blijham, Hordijk, & Winnubst, 2000b) reported that available support was associated with less depressive symptomatology, but received support was associated with greater depressive symptomatology, which is consistent with extant psychological theory and evidence regarding received, as opposed to perceived, social support (e.g., see Komproe, Rijken, Ross, Winnubst, & Hart, 1997).

The impact of HNC on caregivers has also been studied, albeit to a lesser extent than in other cancer literatures. Collectively, these studies have shown that those caring for patients with HNC experience considerable distress, significant fears of recurrence, are affected by the patient's well-being (and vice versa), and are at increased risk of developing posttraumatic stress disorder, particularly during the six-month window following HNC diagnosis (see Longacre et al., 2012).⁴

For example, Baghi and colleagues (2007) surveyed 78 caregivers of patients with advanced HNC (stage III/IV) at least six months removed from the treatment phase about a range of topics including relationship conflict due to diagnosis, personal needs of the caregiver, and the perceived need for psychological care. Nearly half of caregivers reported needing psychological care as well as a desire to have contact with self-help groups. In a study of 41 patient-caregiver dyads (Verdonck-de Leeuw, Eerenstein, Van der Linden, Kuik, de Bree, & Leemans, 2007), clinical levels of psychological distress (as measured by the HADS) were identified in one-fifth of caregivers and one quarter of patients; interestingly, in half of those cases, the spouse reported clinical levels of distress although the patient did not. As one would expect, these studies suggest that HNC caregivers experience burden comparable to that seen in other cancer populations, yet there remains no interventions specifically aimed at improving HNC caregiver adjustment, despite some previous evidence of efficacy in other cancer caregivers (McMillan et al., 2006). Finally, in a study of 20 HNC patient-caregiver dyads, Offerman, Schroevers, van der Velden, de Boer, and Pruyn (2010) evaluated associations between goal disturbance, goal re-engagement, self-efficacy, and psychological distress. Although goal re-engagement, or the ability to pursue alternative goals when previous goals have become unattainable (due to a cancer diagnosis; Wrosch, Scheier, Miller, Schulz, & Carver, 2003), was significantly related to less distress in patients only, self-efficacy to achieve health outcomes was found to be significantly associated with lower levels of distress (as measured by the HADS) in both patients and caregivers.

Because HNC patients often require extensive posttreatment rehabilitation including speech therapy, physical therapy, and chronic pain management, there may exist opportunities to engage both patients and caregivers by combining brief, psychosocial interventions with such regimens. However, the type and extent of social support interventions in HNC populations requires further study (Semple, Sullivan, Dunwoody, & Kernohan, 2004). A recent study (Singer et al., 2011) reported that HNC patients preferred support services from a social worker and not a psychologist, further suggesting that support cannot be offered indiscriminately to HNC patients during treatment and recovery and highlighting the need for increased development and evaluation of interventions designed to improve psychosocial functioning in patients with HNC.

Coping

The patient's ability to respond to and manage internal and external demands related to HNC has been studied extensively (e.g., Aarstad, Lode, Larsen, Bru, & Aarstad, 2011;

⁴See also meta-analytic review by Hodges, Humphris, & Macfarlane (2005) of psychological distress in cancer patients and their caregivers and recent review by Stenberg, Ruland, & Miaskowski (2010) covering a range of issues experienced by cancer caregivers.

Derks, de Leeuw, Hordijk, & Winnubst, 2005; Dropkin, 2001; Elani & Allison, 2008; Foxwell & Scott, 2011; Johansson, Rydén, & Finizia, 2011; List, Rutherford, Stracks, Haraf, Kies, & Vokes, 2002). Several of these studies have shown, unsurprisingly, that HNC patients adopting avoidant or other negative coping strategies such as drinking or behavioral disengagement tend to experience greater levels of distress and poorer HRQOL (Aarstad et al., 2011; Elani & Allison, 2008; Johansson et al., 2011; List et al., 2002). In a study comparing coping style differences in 78 older and 105 younger HNC patients—which may have implications for the changing patient demographic described above—Derks and colleagues (2005) reported that younger patients were more likely to use active coping strategies before and after treatment while older patients were more likely to rely on avoidant strategies.

Some studies have also begun to investigate coping processes associated with positive changes following HNC diagnosis, namely posttraumatic growth and benefit finding. For example, in a recent study of 103 newly-diagnosed HNC patients conducted by Llewellyn, Horney, and colleagues (2011), it was reported that education, social support, optimism, and active coping strategies were associated with benefit finding. Harrington, McGurk, & Llewellyn (2008) similarly found that optimism and positive reappraisal were related to benefit finding, which meshes with a recent review on this topic (Rajandram, Jenewein, McGrath, & Zwahlen, 2011). Despite these studies, however, posttraumatic growth has been studied considerably less in this population, prompting a call for more research in HNC patients (Rajandram et al., 2011).

Psychological Interventions in HNC

Although there has been some growth in the publication of psychosocial interventions in HNC, there remains a paucity of high quality, theoretically-based, randomized controlled trials examining the efficacy of such interventions, particularly compared to other cancer literatures (see Luckett, Britton, Clover, & Rankin, 2011; Semple et al., 2004). To date, most interventions have focused on issues such as smoking cessation and decreasing psychological distress, have employed varying degrees of methodological rigor, and have implemented a number of different intervention types. Several of these interventions are reviewed below (see Table 1).⁵

Given the urgent nature of tobacco and alcohol cessation in this population, and because cancer patients may be especially receptive to messages regarding health behavior change soon after diagnosis (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005), the development and evaluation of psychosocial interventions aimed at HNC patients who continue to smoke and/or drink is extremely important. In one of the few randomized, theoretically-grounded tests of a psychosocial intervention in the HNC literature, and building on their previous work described above (e.g., Schnoll, James, et al., 2003), Schnoll and colleagues (2005) conducted a study in which the impact of cognitive-behavioral therapy (CBT) for smoking cessation was compared to a health education control arm in a mixed sample of head and neck or lung cancer patients. Those randomized to the intervention arm completed four tailored counseling sessions, three of which were held by phone, targeting psychological factors associated with tobacco cessation including risk perceptions regarding the potential for cancer recurrence, self-efficacy, and distress. Those randomized to the health education (attention control) arm were presented information about the harmful effects of smoking, benefits of cessation, and provided assistance in quitting. Contrary to predictions, Schnoll et al. (2005) failed to demonstrate a significant benefit at one and three month follow-up when

⁵See also Luckett, Britton, Clover, & Rankin (2011) for an in-depth, systematic review of psychological interventions for HNC patients.

compared to general health education, perhaps due to the level of dosing or the active control condition, among other reasons. Although the intervention proved unsuccessful, there was evidence that the level of quit motivation predicted cessation at follow-up, which is consistent with other evidence (e.g., Gritz, et al., 1993). Of note, in a randomized trial comparing a physician-based smoking cessation intervention to usual care in a mixed sample of cancer patients (including those with HNC), Schnoll, Zhang, et al. (2003) also reported that quit motivation was an important predictor of cessation at follow-up.

Duffy et al. (2006) used a randomized design to test the effects of a tailored intervention targeting smoking, alcohol, and depression—all of which are interrelated and may be treated using similar treatment protocols (e.g., CBT)—versus an enhanced usual care control group in a sample of 184 HNC patients who screened positive for (at least) one of these issues. Patients randomized to intervention completed nine to eleven, nurse-led CBT telephone sessions and received pharmacotherapy as necessary. At six month follow-up, there was a significant difference between the intervention and control groups in smoking cessation (i.e., 47% versus 31%, $p < .05$); however, there was no significant difference relative to problem drinking or depression, although both groups demonstrated improvement.

Several interventions have employed various psychoeducational strategies aimed at reducing psychological distress, improving symptom management, and/or generally improving HRQOL. It bears noting that some of these studies were pilot and feasibility endeavors and, therefore, often used non-randomized designs, small samples, and/or had other methodological flaws. For example, Hammerlid, Persson, Sullivan, and Westin (1999) conducted a pair of pilot studies evaluating a psychologist-led, CBT-based group psychotherapy intervention and a provider-based psychoeducational program, respectively, in HNC patients at different points in the disease trajectory. The psychotherapy intervention required newly diagnosed HNC patients to attend several group therapy sessions held at varying intervals throughout treatment (and shortly thereafter), while the briefer, provider-based psychoeducational intervention focused on patients in the rehabilitation phase at least one year removed from diagnosis. Reductions in distress, as measured by the HADS, and improved HRQOL, as measured by the EORTC, were reported for both studies, although significance testing was not conducted. While encouraging, the lengthier group psychotherapy intervention was plagued by attrition, raising questions about its feasibility in HNC patients, particularly during the treatment phase of disease.

Other psychoeducational intervention studies have also utilized relatively brief, provider-based protocols. In a sample of nineteen HNC patients, Katz, Irish, & Devins (2004) tested an intervention (versus usual care control) which included brief, nurse-led, pre- and posttreatment supportive contact in addition to verbal and written psychoeducational information regarding HNC. Despite the small sample, significantly reduced distress and improvements in knowledge and satisfaction with appearance were reported as compared to control. Using a telehealth framework, Head and colleagues (2011) reported about the acceptance and feasibility of an intervention designed to improve HNC symptom management in patients undergoing aggressive treatment. On a daily basis throughout the course of treatment, HNC patients utilized a simple home telehealth device for computerized education and encouragement regarding illness self-management for a variety of symptoms and treatment side effects, with nurse-led consultation as needed. The intervention was found to be both acceptable and feasible, with users reporting high satisfaction, improved ability to self-manage, and an increased sense of security during the treatment phase. The complete trial results have not been reported at this time.

Interventions designed to improve coping strategies in HNC patients have also been conducted. For example, Vilela and colleagues (2006) conducted a quasi-experimental pilot

and feasibility study in which patients participating in a coping skills intervention were compared to a no-contact control arm on several psychosocial outcomes including distress and HRQOL. The intervention consisted of brief, didactic information designed to improve coping with HNC through effective communication, problem-solving, goal setting and social support; psychosocial outcomes were collected at baseline and then again approximately three months later. Within-group comparisons revealed that patients receiving the intervention reported significant improvement in depression and HRQOL from baseline to follow-up, while control participants demonstrated no change. Furthermore, between-groups comparisons suggested that the intervention resulted in improved psychosocial outcomes as compared to control. Semple, Dunwoody, Kernohan, and McCaughan (2009) also conducted a quasi-experimental study of an individually-tailored, CBT-based, problem-focused psychosocial intervention in a sample of 54 posttreatment HNC patients who self-selected into the treatment and usual care control groups, respectively. Specifically, intervention patients (with the help of a therapist) identified up to three problem areas (e.g., appearance, eating/drinking behavior, psychological distress, speech issues) to be addressed over the course of the program. Between two and six in-home sessions—each lasting approximately 90 minutes—were conducted every two weeks and addressed areas of greatest concern through the use of standardized information booklets and skills training. Similar to results reported in Vilela et al. (2006), between-groups, repeated measures ANCOVA demonstrated significantly decreased distress and social impairment as well as better HRQOL in the intervention group.

Collectively, several of these interventions appear promising. However, more rigorous and thorough testing is necessary given the lack of randomized designs and a number of other threats to internal and external validity (see Luckett, Britton, Clover, & Rankin, 2011). Moreover, even the briefest, least burdensome support interventions have reported very low rates of participation in this population (e.g., Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004), making further evaluation key.

Conclusions & Opportunities for Behavioral Medicine

HNC is a debilitating disease with many, often unique, physical and psychological sequelae. The process of treatment and recovery requires a multidisciplinary approach with surgeons, radiation and medical oncologists, dentists, plastic surgeons, and rehabilitation specialists all involved. The evidence reviewed here supports the need for clinical health psychologists and behavioral medicine specialists at all phases of the disease trajectory, from HNC diagnosis through treatment and recovery, a role previously advocated by others (Humphris, 2008).

As such, a number of opportunities exist for behavioral medicine research and practice. First, as evidence for the link between certain types of HNC and human papillomavirus continues to grow, research and practice must recognize the changing patient demographic, which is becoming younger and includes considerably more females (Curado & Hashibe, 2009; Marur & Forastiere, 2008). Moreover, evidence indicates that HPV-positive HNC is often more responsive to treatment and is associated with increased survival as compared to HPV-negative HNC (Marur, D'Souza, Westra, & Forastiere, 2010). This implies the need to distinguish between HNC patients with different disease etiologies (something the literature, at present, does not address) and that current research must either be replicated in HPV-positive HNC populations or that HNC patient populations will require stratification in the future. In addition, because evidence suggests that (risky) sexual contact is the primary means by which individuals with HPV-positive HNC acquire the virus (e.g., Heck et al., 2010; Smith et al., 2004), further development of behavioral interventions targeting at-risk persons is needed, particularly those designed to decrease risky sexual behavior, increase knowledge regarding acquisition of the virus, and/or increase uptake of HPV vaccinations (e.g., Cox, Cox, Sturm, & Zimet, 2010).

The complex nature of continued smoking and drinking behavior in HNC patients is especially well-suited to the expertise of researchers and practitioners in behavioral medicine. At present, more research is needed to better elucidate psychological and behavioral factors that may perpetuate smoking behavior in HNC patients, such as distress, FCR, quit motivation, causal attributions, and risk perceptions. In addition, despite the frequent co-occurrence of continued tobacco and alcohol use in HNC patients, there remains very little research on behavioral factors associated with continued alcohol use in this population (see Pinto & Trunzo, 2005). Such factors must be identified before appropriate interventions may be developed including, perhaps, multifactorial behavioral interventions designed to help patients with tobacco and alcohol cessation as well as other psychosocial issues, such as depression, which are known to influence use of these substances. Given the current state of these literatures, behavioral medicine researchers and practitioners would be wise to consult existing studies and interventions of smoking and alcohol cessation conducted in the general population, as several evidence-based approaches have proven successful and may be amenable to HNC patients (e.g., see Gunzerath, Hewitt, Li, & Warren, 2011; Schnoll & Lerman, 2003).

Currently, there are very few studies of HNC-related posttraumatic stress disorder. In three studies based upon the same longitudinal data set, Kangas and colleagues (2005a, 2005b, 2005c) reported that twenty-two percent of HNC patients met criteria for PTSD six months postdiagnosis. At one-year postdiagnosis, PTSD was present in fourteen percent of patients (Kangas, Henry, & Bryant, 2005b). These figures are consistent with a recent review of the cancer-related PTSD literature indicating that up to one-fifth of cancer patients experience PTSD at some point after a cancer diagnosis (Andrykowski & Kangas, 2010). In addition, a recent study of newly diagnosed HNC patients and their partners (Posluszny et al., 2011) reported that spouses of HNC patients were also at increased risk of developing PTSD. Collectively, these results suggest the need for further studies designed specifically to screen for and treat cancer-related PTSD in the HNC population.

There are also few studies regarding the management of pain on posttreatment adjustment and HRQOL, nor have there been any behavioral intervention studies designed to address this issue in HNC patients. The importance of pain as a patient-reported outcome cannot be overstated as at least half of HNC patients will experience moderate to severe pain and almost all will experience some degree of pain, either at presentation and/or throughout the course of treatment and recovery (Grond, Zech, Diefenbach, Radbruch, & Lehmann, 1996). One study indicated that, besides being cured and living as long as possible, being without pain was a top patient priority (Gill et al., 2011). Posttreatment pain has been linked to a host of deleterious outcomes in HNC patients including discontinued employment after treatment (Buckwalter, Karnell, Smith, Christensen, & Funk, 2007), increased psychological distress and poor long-term HRQOL (Chaplin & Morton, 1999; Funk, Karnell, & Christensen, 2012), and disease recurrence and mortality (Osthus, Aarstad, Olofsson, & Aarstad, 2011b; Scharpf, Karnell, Christensen, & Funk, 2009; Thompson, Pagedar, Karnell, & Funk, 2011). Health psychologists are in key position to assist with patient adjustment to pain at all phases of the disease trajectory through the introduction of various cognitive-behavioral techniques—several of which have proven successful in other cancer populations—designed to help the patient achieve a sense of control over the pain experience (see Breitbart, Park, & Katz, 2010).

Regarding patient-reported outcomes more generally, there is need for more widespread adoption of HRQOL assessment in clinical practice (Mehanna, 2007; Verdonck-de Leeuw, van Nieuwenhuizen, & Leemans, 2012). At present, there exists several, well-validated global and condition-specific measures that are brief and do not substantially increase patient burden, yet the incorporation of such measures in practice has been slow (Donaldson,

2004; Mehanna & Morton, 2006b). Health psychologists offer distinct expertise in the administration and interpretation of these measures, which may confer considerable benefit to both patient and clinician, whether by aiding decisions about treatment choice, improving communication between patient and provider (Velikova et al., 2004), informing patient adjustment to disease and treatment, and capturing issues related to survivorship, among other important outcomes. More recently, there has been increasing recognition that individual patient concerns are also important (as opposed to only those domains captured by standardized HRQOL assessments), resulting in the development of measures such as the Patient Concerns Inventory (Rogers, El-Sheikha, & Lowe, 2009) and Patient Generated Index (Llewellyn, McGurk, & Weinman, 2006). These measures are designed to improve the clinical encounter by delineating specific (often psychosocial) concerns of HNC patients themselves and may be used in conjunction with other standardized HRQOL assessment instruments. Additionally, screening for psychological distress is also important (NCCN, 1999) as even subclinical depression has been shown to impact HRQOL in numerous studies (e.g., Howren et al., 2010; Karnell et al., 2006) and requires attention in this population. Not only has such screening proven to be well-tolerated by HNC patients (Katz, Kopek, Waldron, Devins, & Tomlinson, 2004), but a number of acceptable (and comparable) instruments/methods currently exist (Singer et al., 2008).

The health and well-being of patient caregivers, as well as issues impacting the patient-caregiver dyad, must not go unattended either (Helgeson, 2005). Caregivers of HNC patients may experience significant burden and although this is not unique to the HNC population, as reviewed above, only a few studies have investigated HNC caregiver adjustment, fewer still have evaluated issues specific to the patient-caregiver dyad, and none have tested interventions to improve caregiver adjustment (see Longacre et al., 2012). For example, patient-caregiver dyads may experience issues regarding intimacy/sexuality related to disfigurement or distress; indeed, patient interviews and surveys have indicated that sexual issues are a primary problem in HNC survivors (Hammerlid, Bjordal, et al., 2001; Low et al., 2009; Manne & Badr, 2010). Despite this, however, research remains scant in this area.

Finally, as noted above, there are few high quality intervention trials focusing on HNC patients. Intervention trials are clearly needed, but an impediment to such trials is the relatively small number of patients available for recruitment at any one cancer center (Funk, 2008; Sherman, Hanna, & Simonton, 2005), making collaborative, multi-site studies critical despite the increased complexities and funding challenges specific to conducting such research. While the broader cancer literature may inform interventions designed for HNC-specific issues, it is important that interventional frameworks used in other cancer populations are appropriately tested and adapted for the HNC context given the unique needs of these patients. Moreover, most psychosocial interventions designed for cancer patients focus on those in active treatment or only a few months removed, neglecting long-term survivorship issues (Stanton, 2006). Because disfigurement and certain physical side effects may persist for several months and even years beyond treatment, more attention to long-term HNC survivors is warranted.

In conclusion, HNC remains understudied in the context of behavioral medicine; however, the evidence base is rapidly growing. As such, the role of health psychology and behavioral medicine in HNC is becoming clearer and ever more important. Whether as researchers or clinicians, opportunities for involvement with issues related to HNC prevention, treatment, and adjustment abound.

Acknowledgments

Preparation of this article was supported in part by NIH grant R01 CA106908 through the Office of Cancer Survivorship. This article was also supported in part by an Agency for Healthcare Research and Quality (AHRQ) Centers for Education and Research on Therapeutics cooperative agreement [5U18HSO16094]. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs.

References

- Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: A quality of life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute*. 1993; 85:365–376. [PubMed: 8433390]
- Aarstad AKH, Aarstad HJ, Olofsson J. Personality and choice of coping predict quality of life in head and neck cancer patients during follow-up. *Acta Oncologica*. 2008; 47:879–890. [PubMed: 18568484]
- Aarstad HJ, Aarstad AKH, Birkhaug EJ, Bru E, Olofsson J. Personality and quality of life in HNSCC patients following treatment. *European Journal of Cancer*. 2003; 39:1852–1860. [PubMed: 12932662]
- Aarstad AKH, Lode K, Larsen JP, Bru E, Aarstad HJ. Choice of psychological coping in laryngectomized, head and neck squamous cell carcinoma patients versus multiple sclerosis patients. *European Archives of Otorhinolaryngology*. 2011; 268:907–915. [PubMed: 21085978]
- Abendstein H, Nordgren M, Boysen M, Jannert M, Silander E, Ahlner-Elmqvist M, et al. Quality of life and head and neck cancer: A 5 year prospective study. *The Laryngoscope*. 2005; 115:2183–2192. [PubMed: 16369164]
- Allison PJ. Factors associated with smoking and alcohol consumption following treatment for head and neck cancer. *Oral Oncology*. 2001; 37:513–520. [PubMed: 11435178]
- Allison PJ, Edgar L, Nicolau B, Archer J, Black M, Hier M. Results of a feasibility study for a psycho-educational intervention in head and neck cancer. *Psycho-Oncology*. 2004; 13:482–485. [PubMed: 15227717]
- Allison PJ, Guichard C, Fung K, Gilain L. Dispositional optimism predicts survival status 1 year after diagnosis in head and neck cancer patients. *Journal of Clinical Oncology*. 2003; 21:543–548. [PubMed: 12560447]
- Allison PJ, Guichard C, Gilain L. A prospective investigation of dispositional optimism as a predictor of health-related quality of life in head and neck cancer patients. *Quality of Life Research*. 2000; 9:951–960. [PubMed: 11284214]
- Allison PJ, Nicolau B, Edgar L, Archer J, Black M, Hier M. Teaching head and neck cancer patients coping strategies: Results of a feasibility study. *Oral Oncology*. 2004; 40:538–544. [PubMed: 15006628]
- Andrykowski, MA.; Kangas, M. Posttraumatic stress disorder associated with cancer diagnosis and treatment. In: Holland, JC.; Breitbart, WS.; Jacobsen, PB.; Lederberg, MS.; Loscalzo, MJ.; McCorkle, R., editors. *Psycho-Oncology*. 2nd edition. Oxford University Press; New York: 2010. p. 348-357.
- Argiris A, Eng C. Epidemiology, staging, and screening of head and neck cancer. *Cancer Treatment & Research*. 2003; 114:15–60. [PubMed: 12619537]
- Argiris A, Karamouzis MV, Raben D, Ferris RL. Head and neck cancer. *The Lancet*. 2008; 371:1695–1709.
- Aziz NM. Cancer survivorship research: State of knowledge, challenges, and opportunities. *Acta Oncologica*. 2007; 46:417–432. [PubMed: 17497308]
- Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: Challenge and opportunity. *Seminars in Radiation Oncology*. 2003; 13:248–266. [PubMed: 12903014]
- Babin W, Sigston E, Hitier M, Dehesdin D, Marie JP, Choussy O. Quality of life in head and neck cancer patients: Predictive factors, function and psychosocial outcome. *European Archives of Otorhinolaryngology*. 2008; 265:265–270. [PubMed: 18188577]

- Baghi M, Wagenblast J, Hambek M, Radeloff A, Gsteottner W, Scherzed A, et al. Demands on caring relatives of head and neck cancer patients. *The Laryngoscope*. 2007; 117:712–716. [PubMed: 17415143]
- Baker CA. Factors associated with rehabilitation in head and neck cancer. *Cancer Nursing*. 1992; 15:395–400. [PubMed: 1473082]
- Beck, AT.; Rush, AJ.; Shaw, BF.; Emery, G. *Cognitive therapy of depression*. Guilford Press; New York: 1979.
- Birkhaug EJ, Aarstad HJ, Aarstad AKH, Olofsson J. Relation between mood, social support, and the quality of life in patients with laryngectomies. *European Archives of Otorhinolaryngology*. 2002; 259:197–204. [PubMed: 12064508]
- Bjordal K, Ahlner-Elmqvist M, Hammerlid E, Boysen M, Evensen JF, Björklund A, et al. A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. *Laryngoscope*. 2001; 111:1440–1452. [PubMed: 11568582]
- Bjordal K, Ahlner-Elmqvist M, Tollesson E, Jensen AB, Razavi D, Mahler EJ, et al. Development of a European Organization for Research and Treatment of Cancer (EORTC) questionnaire module to be used in quality of life assessments in head and neck patients. EORTC Quality of Life Study Group. *Acta Oncologica*. 1994; 33:879–885. [PubMed: 7818919]
- Björklund M, Sarvimäki A, Berg A. Living with head and neck cancer: A profile of captivity. *Journal of Nursing & Healthcare of Chronic Illness*. 2010; 2:22–31.
- Bornbaum CC, Fung K, Franklin JH, Nichols A, Yoo J, Doyle PC. A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Supportive Care in Cancer*. 2011 Epub ahead of print.
- Breitbart, WS.; Park, J.; Katz, AM. Pain. In: Holland, JC.; Breitbart, WS.; Jacobsen, PB.; Lederberg, MS.; Loscalzo, MJ.; McCorkle, R., editors. *Psycho-Oncology*. 2nd edition. Oxford University Press; New York: 2010. p. 215-228.
- Breslau N, Peterson EL, Schultz LR, Chilcoat HD, Andreski P. Major depression and stages of smoking: A longitudinal investigation. *Archives of General Psychiatry*. 1998; 55:161–166. [PubMed: 9477930]
- Britton B, Clover K, Bateman L, Odelli C, Wenham K, Zeman A, et al. Baseline depression predicts malnutrition in head and neck cancer patients undergoing radiotherapy. *Supportive Care in Cancer*. 2012; 20:335–342. [PubMed: 21234608]
- Brockstein, B.; Masters, G., editors. *Head and neck cancer*. Kluwer Academic Publishers; Norwell, MA: 2010.
- Buckwalter A,E, Karnell LH, Smith RB, Christensen AJ, Funk GF. Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Archives of Otolaryngology—Head & Neck Surgery*. 2007; 133:464–470. [PubMed: 17520760]
- Callahan C. Facial disfigurement and sense of self in head and neck cancer. *Social Work in Health Care*. 2005; 40:73–87. [PubMed: 15774364]
- Campbell BH, Marbella A, Layde PM. Quality of life and recurrence concerns in survivors of head and neck cancer. *The Laryngoscope*. 2000; 110:895–906. [PubMed: 10852502]
- Carvalho AL, Nishimoto IN, Califano JA, Kowalski LP. Trends in incidence and prognosis for head and neck cancer in the United States: A site-specific analysis of the SEER database. *International Journal of Cancer*. 2005; 114:806–816.
- Carvalho AL, Pintos J, Schlect NF, Oliveria BV, Fava AS, Curado MP, et al. Predictive factors for diagnosis of advanced-stage squamous cell carcinoma of the head and neck. *Archives of Otolaryngology—Head & Neck Surgery*. 2002; 128:313–318. [PubMed: 11886350]
- Chan JYK, Lua LL, Starmer HH, Sun DQ, Rosenblatt ES, Gourin CG. The relationship between depression and initial quality of life and function in head and neck cancer. *The Laryngoscope*. 2011; 121:1212–1218. [PubMed: 21541945]
- Chandu A, Smith ACH, Rogers SN. Health-related quality of life in oral cancer: A review. *Journal of Oral & Maxillofacial Surgery*. 2006; 64:495–502. [PubMed: 16487814]
- Chaplin JM, Morton RP. A prospective, longitudinal study of pain in head and neck cancer patients. *Head & Neck*. 1999; 21:531–537. [PubMed: 10449669]

- Chaturvedi AK, Engels EA, Pfeiffer RM, Hernandez BY, Xiao W, Kim E, et al. Human papillomavirus and rising oropharyngeal cancer incidence in the United States. *Journal of Clinical Oncology*. 2011 Epub ahead of print.
- Chen S, Yu W, Chu T, Hung H, Tsai M, Liao C. Prevalence and correlates of supportive care needs in oral cancer patients with and without anxiety during the diagnostic period. *Cancer Nursing*. 2010; 33:280–289. [PubMed: 20467308]
- Christensen AJ, Moran PJ, Ehlers SL, Raichle K, Karnell L, Funk G. Smoking and drinking behavior in patients with head and neck cancers: Effects of behavioral self-blame and perceived control. *Journal of Behavioral Medicine*. 1999; 22:407–418. [PubMed: 10586379]
- Chung CH, Gillison ML. Human papillomavirus in head and neck cancer: Its role in pathogenesis and clinical implications. *Clinical Cancer Research*. 2009; 15:6758–6762. [PubMed: 19861444]
- Cianfriglia F, Di Gregorio DA, Manieri A. Multiple primary tumors in patients with oral squamous cell carcinoma. *Oral Oncology*. 1999; 35:157–163. [PubMed: 10435150]
- Clarke A. Psychosocial aspects of facial disfigurement: Problems, management, and the role of a lay-led organization. *Psychology, Health, & Medicine*. 1999; 4:127–142.
- Cox DS, Cox AD, Sturm L, Zimet G. Behavioral interventions to increase HPV vaccination acceptability among mothers of young girls. *Health Psychology*. 2010; 29:29–39. [PubMed: 20063933]
- Curado MP, Hashibe M. Recent changes in the epidemiology of head and neck cancer. *Current Opinion in Oncology*. 2009; 21:194–200. [PubMed: 19363341]
- Danker H, Keszte J, Singer S, Thomä J, Täschner R, Brähler E, et al. Alcohol consumption after laryngectomy. *Clinical Otolaryngology*. 2011; 36:336–344. [PubMed: 21682847]
- Day GL, Blot WJ, Shore RE, McLaughlin JK, Austin DF, Greenberg RS, et al. Second cancers following oral and pharyngeal cancers: Role of tobacco and alcohol. *Journal of the National Cancer Institute*. 1994; 86:131–137. [PubMed: 8271296]
- De Boer MF, McCormick LK, Pruyn JFA, Ryckman RM, Van den Borne BW. Physical and psychosocial correlates of head and neck cancer: A review of the literature. *Otolaryngology—Head and Neck Surgery*. 1999; 120:427–436. [PubMed: 10064650]
- De Boer MF, Van den Borne B, Pruyn JFA, Ryckman RM, Volovics L, Knekt PP, et al. Psychosocial and physical correlates of survival and recurrence in patients with head and neck carcinoma: Results of a 6-year longitudinal study. *Cancer*. 1998; 83:2567–2579. [PubMed: 9874465]
- de Graeff A, de Leeuw JRJ, Ros WJG, Hordijk GJ, Blijham GH, Winnubst JAM. Long-term quality of life of patients with head and neck cancer. *The Laryngoscope*. 2000a; 110:98–106. [PubMed: 10646723]
- de Graeff A, de Leeuw JRJ, Ros WJG, Hordijk GJ, Blijham GH, Winnubst JAM. Pretreatment factors predicting quality of life after treatment for head and neck cancer. *Head & Neck*. 2000b; 22:398–407. [PubMed: 10862025]
- de Leeuw JRJ, de Graeff A, Ros WJG, Blijham GH, Hordijk GJ, Winnubst JAM. Prediction of depressive symptomatology after treatment of head and neck cancer: The influence of pre-treatment physical and depressive symptoms, coping, and social support. *Head & Neck*. 2000a; 22:799–807. [PubMed: 11084641]
- de Leeuw JRJ, de Graeff A, Ros WJG, Blijham GH, Hordijk GJ, Winnubst JAM. Negative and positive influences of social support on depression in patients with head and neck cancer: A prospective study. *Psycho-Oncology*. 2000b; 9:20–28. [PubMed: 10668056]
- Deleyiannis FW, Thomas DB, Vaughan TL, Davis S. Alcoholism: Independent predictor of survival in patients with head and neck cancer. *Journal of the National Cancer Institute*. 1996; 88:542–549. [PubMed: 8606383]
- Demark-Wahnefried W, Aziz NM, Rowland JH, Pinto BM. Riding the crest of the teachable moment: Promoting long-term health after the diagnosis of cancer. *Journal of Clinical Oncology*. 2005; 23:5814–5830. [PubMed: 16043830]
- Dempster M, McCorry NK, Brennan E, Donnelly M, Murray LJ, Johnston BT. Do changes in illness perceptions predict changes in psychological distress among oesophageal cancer survivors? *Journal of Health Psychology*. 2010; 16:500–509. [PubMed: 21224333]

- Derks W, de Leeuw JRJ, Hordijk GJ, Winnubst JAM. Differences in coping style and locus of control between older and younger patients with head and neck cancer. *Clinical Otolaryngology*. 2005; 30:186–192. [PubMed: 15839873]
- Digman JM. Personality structure: Emergence of the five-factor model. *Annual Review of Psychology*. 1990; 41:417–440.
- DiMatteo RM, Lepper HD, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine*. 2000; 160:2101–2107. [PubMed: 10904452]
- Do KA, Johnson MM, Doherty DA, Lee JJ, Wu XF, Dong Q, et al. Second primary tumors in patients with upper aerodigestive tract cancers: Joint effects of smoking and alcohol (United States). *Cancer Causes & Control*. 2003; 14:131–138. [PubMed: 12749718]
- Donaldson MS. Taking stock of health-related quality of life measurement in oncology practice in the United States. *JNCI Monographs*. 2004; 33:155–167.
- Dropkin MJ. Anxiety, coping strategies, and coping behaviors in patients undergoing head and neck cancer surgery. *Cancer Nursing*. 2001; 24:143–148. [PubMed: 11318262]
- Duffy SA, Ronis DL, Valenstein M, Fowler KE, Lambert MT, Bishop C, et al. Depressive symptoms, smoking, drinking, and quality of life among head and neck cancer patients. *Psychosomatics*. 2007; 48:142–148. [PubMed: 17329608]
- Duffy SA, Ronis DL, Valenstein M, Lambert MT, Fowler KE, Gregory L, et al. A tailored smoking, alcohol, and depression intervention for head and neck cancer patients. *Cancer Epidemiology Biomarkers & Prevention*. 2006; 15:2203–2208.
- Duffy SA, Terrell JE, Valenstein M, Ronis DL, Copeland LA, Connors M. Effect of smoking, alcohol, and depression on the quality of life of head and neck cancer patients. *General Hospital Psychiatry*. 2002; 24:140–147. [PubMed: 12062138]
- Elani HW, Allison PJ. Coping and psychological distress among head and neck cancer patients. *Supportive Care in Cancer*. 2008; 19:1735–1741. [PubMed: 20872234]
- El-Deiry MW, Futran ND, McDowell JA, Weymuller EA, Yueh B. Influences and predictors of long-term quality of life in head and neck cancer survivors. *Head & Neck*. 2009; 135:380–384.
- Elmqvist MA, Jordhøy MS, Bjordal K, Kaasa S, Jannert M. Health-related quality of life during the last three months of life in patients with advanced cancer. *Supportive Care in Cancer*. 2009; 17:191–198. [PubMed: 18581147]
- Epstein JF, Induni M, Wilson T. Pattern of clinically significant symptoms of depression among heavy users of alcohol and cigarettes. *Preventing Chronic Disease*. 2009; 6:A09. [PubMed: 19080015]
- Fabian MC, Irish JC, Brown DH, Liu TC, Gullane PJ. Tobacco, alcohol, and oral cancer: The patient's perspective. *Journal of Otolaryngology*. 1996; 25:88–93. [PubMed: 8683658]
- Falagas ME, Zarkadoulia EA, Ioannidou EN, Peppas G, Christodoulou C, Rafailidis PI. The effect of psychosocial factors on breast cancer outcome: A systematic review. *Breast Cancer Research*. 2007; 9:R44. [PubMed: 17640330]
- Fenigstein A, Scheier MF, Buss AH. Public and private self-consciousness: Assessment and theory. *Journal of Consulting & Clinical Psychology*. 1975; 43:522–527.
- Fiegenbaum W. A social training program for clients with facial disfigurements: A contribution to the rehabilitation of cancer patients. *International Journal of Rehabilitation Research*. 1981; 4:501–509. [PubMed: 7333763]
- Fingeret MC, Yuan Y, Urbauer D, Weston J, Nipomnick S, Weber R. The nature and extent of body image concerns among surgically treated patients with head and neck cancer. *Psycho-Oncology*. 2011 Epub ahead of print.
- Foxwell KR, Scott SE. Coping together and apart: Exploring how patients and their caregivers manage terminal head and neck cancer. *Journal of Psychosocial Oncology*. 2011; 29:308–326. [PubMed: 21590575]
- Frampton M. Psychological distress in patients with head and neck cancer: Review. *British Journal of Oral & Maxillofacial Surgery*. 2001; 39:1–4.
- Freedman ND, Schatzkin A, Leitzmann MF, Hollenbeck AR, Abnet CC. Alcohol and head and neck cancer risk in a prospective study. *British Journal of Cancer*. 2007; 96:1469–1474. [PubMed: 17387340]

- Funk, GF. Health-related quality of life in head and neck cancer survivors. Presented at the Iowa Cancer Summit; Des Moines, IA. Oct 17. 2008
- Funk GF, Karnell LH, Christensen AJ. Long-term health-related quality of life in survivors of head and neck cancer. *Archives of Otolaryngology—Head & Neck Surgery*. 2012 Epub ahead of print.
- Funk GF, Karnell LH, Christensen AJ, Moran PJ, Ricks J. Comprehensive head and neck oncology health status assessment. *Head & Neck*. 2003;561–575. [PubMed: 12808660]
- Funk GF, Karnell LH, Smith RB, Christensen AJ. Clinical significance of health status assessment measures in head and neck cancer. What do quality-of-life scores mean? *Archives of Otolaryngology—Head & Neck Surgery*. 2004; 130:825–829. [PubMed: 15262758]
- Ghazali N, Cadwallader E, Lowe D, Humphris G, Ozakinci G, Rogers SN. Fear of recurrence among head and neck cancer survivors: Longitudinal trends. *Psycho-Oncology*. 2012 Epub ahead of print.
- Gill SS, Frew J, Fry A, Adam J, Paleri V, Dobrowsky W, et al. Priorities for the head and neck cancer patient, their companion and members of the multidisciplinary team and decision regret. *Clinical Oncology*. 2011; 23:518–524. [PubMed: 21550217]
- Grignon LM, Jameson MJ, Karnell LH, Christensen AJ, Funk, Gerry F. General health measures and long-term survival in patients with head and neck cancer. *Archives of Otolaryngology—Head & Neck Surgery*. 2007; 133:471–476. [PubMed: 17520761]
- Gritz ER, Carmack CL, de Moor C, Coscarelli A, Schacherer CW, Meyers EG, Abemayor E. First year after head and neck cancer: Quality of life. *Journal of Clinical Oncology*. 1999; 17:352–360. [PubMed: 10458254]
- Gritz ER, Carr CR, Rapkin D, Abemayor E, Chang LC, Wong W, et al. Predictors of long-term smoking cessation in head and neck cancer patients. *Cancer Epidemiology, Biomarkers, & Prevention*. 1993; 2:261–70.
- Gritz ER, Schacherer C, Koehly L, Nielsen IR, Abemayor E. Smoking withdrawal and relapse in head and neck cancer patients. *Head & Neck*. 1999; 21:420–427. [PubMed: 10402522]
- Grond S, Zech D, Diefenbach C, Radbruch L, Lehmann KA. Assessment of cancer pain: a prospective evaluation of 2266 cancer patients referred to a pain service. *Pain*. 1996; 64:107–114. [PubMed: 8867252]
- Gunzerath L, Hewitt BG, Li TK, Warren KR. Alcohol research: Past, present, and future. *Annals of the New York Academy of Sciences*. 2011; 1216:1–23. [PubMed: 21182533]
- Hagedoorn M, Molleman E. Facial disfigurement in patients with head and neck cancer: The role of social self-efficacy. *Health Psychology*. 2006; 25:643–647. [PubMed: 17014282]
- Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*. 2003; 18:141–184.
- Haisfield-Wolfe ME, McGuire DB, Soeken K, Geiger-Brown J, De Forge BR. Prevalence and correlates of depression among patients with head and neck cancer: A systematic review of implications for research. *Oncology Nursing Forum*. 2009; 36:107–125.
- Hall SF, Groome PA, Rothwell D. The impact of comorbidity on the survival of patients with squamous cell carcinoma of the head and neck. *Head & Neck*. 2000; 22:317–322. [PubMed: 10862012]
- Hammerlid E, Ahlner-Elmqvist M, Bjordal K, Biorklund A, Evensen J, Boysen M, et al. A prospective multicentre study in Sweden and Norway of mental distress and psychiatric morbidity in head and neck cancer patients. *British Journal of Cancer*. 1999; 80:766–774. [PubMed: 10360654]
- Hammerlid E, Bjordal K, Ahlner-Elmqvist M, Boysen M, Evensen JF, Biorklund A, et al. A prospective study of quality of life in head and neck cancer patients. Part I: At diagnosis. *The Laryngoscope*. 2001; 111:669–680. [PubMed: 11359139]
- Hammerlid E, Persson LO, Sullivan M, Westin T. Quality of life effects of psychosocial intervention in patients with head and neck cancer. *Otolaryngology—Head & Neck Surgery*. 1999; 120:507–516. [PubMed: 10187943]
- Hammerlid E, Silander E, Hörnemark L, Sullivan M. Health-related quality of life three years after diagnosis of head and neck cancer—A longitudinal study. *Head & Neck*. 2001; 23:113–125. [PubMed: 11303628]

- Hammerlid E, Taft C. Health-related quality of life in long-term head and neck cancer survivors: A comparison with general population norms. *British Journal of Cancer*. 2001; 84:149–156. [PubMed: 11161369]
- Harrington S, McGurk M, Llewellyn CD. Positive consequences of head and neck cancer: Key correlates of benefit finding. *Journal of Psychosocial Oncology*. 2008; 26:43–62. [PubMed: 19042264]
- Hashibe M, Brennan P, Benhamou S, Castellsague X, Chen C, Curado MP, et al. Alcohol drinking in never users of tobacco, cigarette smoking in never drinkers, and the risk of head and neck cancer: Pooled analysis in the international head and neck cancer epidemiology consortium. *Journal of the National Cancer Institute*. 99:777–789. [PubMed: 17505073]
- Hasin DS, Grant BF. Major depression in 6,050 former drinkers: Association with past alcohol dependence. *Archives of General Psychiatry*. 2002; 59:794–800. [PubMed: 12215078]
- Head BA, Keeney C, Studts JL, Khayat M, Bumpous JM, Pfeifer M. Feasibility and acceptance of a telehealth intervention to promote symptom management during treatment for head and neck cancer. *Journal of Supportive Oncology*. 2011; 9:e1–e11. [PubMed: 21499540]
- Head BA, Studts JL, Bumpous JM, Gregg JL, Wilson L, Keeney C, et al. Development of a telehealth intervention for head and neck cancer patients. *Telemedicine & e-Health*. 2009; 15:44–52. [PubMed: 19199847]
- Heck JE, Berthiller J, Vaccarella S, Winn DM, Smith EM, Shan'gina O, et al. Sexual behaviors and the risk of head and neck cancers: A pooled analysis in the International Head and Neck Cancer Epidemiology (INHANCE) consortium. *International Journal of Epidemiology*. 2010; 39:166–181. [PubMed: 20022926]
- Helgeson VS. Recent advances in psychosocial oncology. *Journal of Consulting & Clinical Psychology*. 2005; 73:268–271. [PubMed: 15796634]
- Helgeson VS, Cohen S. Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*. 1996; 15:135–148. [PubMed: 8681922]
- Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients are their carers. *Psycho-Oncology*. 2009; 18:841–848. [PubMed: 19101920]
- Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine*. 2005; 60:1–12. [PubMed: 15482862]
- Hoffman HT, Karnell LH, Funk GF, Robinson RA, Menck HR. The national cancer data base report on cancer of the head and neck. *Archives of Otolaryngology—Head & Neck Surgery*. 1998; 124:951–962. [PubMed: 9738803]
- Horney DJ, Smith HE, McGurk M, Weinman J, Herold J, Altman K, et al. Associations between quality of life, coping styles, optimism, and anxiety and depression in pretreatment patients with head and neck cancer. *Head & Neck*. 2011; 33:65–71. [PubMed: 20848428]
- Howren MB, Christensen AJ, Karnell LH, Funk GF. Health-related quality of life in head and neck cancer survivors: Impact of pretreatment depressive symptoms. *Health Psychology*. 2010; 29:65–71. [PubMed: 20063937]
- Howren MB, Christensen AJ, Karnell LH, Van Liew JR, Funk GF. The influence of pretreatment social support on health-related quality of life in head and neck cancer survivors: Results from a prospective study. *Head & Neck*. 2012 Epub ahead of print.
- Humphris GM. The missing member of the head and neck multidisciplinary team: The psychologist. Why we need them. *Current Opinion in Otolaryngology & Head and Neck Surgery*. 2008; 16:108–112. [PubMed: 18327028]
- Humphris GM, Ozakinci G. The AFTER intervention: A structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *British Journal of Health Psychology*. 2008; 13:223–230. [PubMed: 18492319]
- Humphris GM, Rogers SN. AFTER and beyond: cancer recurrence fears and a test of an intervention in oral and oropharyngeal patients. To appear in *Social Science & Dentistry*. in press.

- Humphris GM, Rogers S, McNally D, Lee-Jones C, Brown J, Vaughan D. Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients. *International Journal of Oral and Maxillofacial Surgery*. 2003; 32:486–491. [PubMed: 14759106]
- Jemal A, Thomas A, Murray T, Thun M. Cancer statistics, 2002. *CA: A Cancer Journal for Clinicians*. 2002; 52:23–47. [PubMed: 11814064]
- Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Education & Counseling*. 2005; 57:300–307. [PubMed: 15893212]
- Johansson M, Rydén A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer—A longitudinal study. *BMC Cancer*. 2011; 11:283. [PubMed: 21718478]
- Joseph AW, Pai SI. Human papillomavirus and the shifting trends in head and neck cancer. *American Society of Clinical Oncology Educational Book*. 2011:212–216.
- Kangas M, Henry JL, Bryant RA. The relationship between acute stress disorder and posttraumatic stress disorder following cancer. *Journal of Consulting & Clinical Psychology*. 2005a; 73:360–364. [PubMed: 15796646]
- Kangas M, Henry JL, Bryant RA. The course of psychological disorders in the 1st year after cancer diagnosis. *Journal of Consulting & Clinical Psychology*. 2005b; 73:763–768. [PubMed: 16173866]
- Kangas M, Henry JL, Bryant RA. Predictors of posttraumatic stress disorder following cancer. *Health Psychology*. 2005c; 24:579–585. [PubMed: 16287403]
- Karnell LH, Christensen AJ, Rosenthal EL, Magnuson JS, Funk GF. Influence of social support on health-related quality of life outcomes in head and neck cancer. *Head & Neck*. 2007; 29:143–146. [PubMed: 17111431]
- Karnell LH, Funk GF, Christensen AJ, Rosenthal EL, Magnuson SM. Persistent posttreatment depressive symptoms in patients with head and neck cancer. *Head & Neck*. 2006; 28:453–461. [PubMed: 16320360]
- Karvonen-Gutierrez CA, Ronis DL, Fowler KE, Terrell JE, Gruber SB, Duffy SA. Quality of life scores predict survival among patients with head and neck cancer. *Journal of Clinical Oncology*. 2008; 26:2754–2760. [PubMed: 18509185]
- Kassa S, Loge JH. Quality of life assessment in palliative care. *Lancet Oncology*. 2002; 3:175–182. [PubMed: 11902505]
- Katz MR, Irish JC, Devins GM. Development and pilot testing of a psychoeducational intervention for oral cancer patients. *Psycho-Oncology*. 2004; 13:642–653. [PubMed: 15334532]
- Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Reliability and validity of an observer-rated disfigurement scale for head and neck cancer patients. *Head & Neck*. 2000; 22:132–141. [PubMed: 10679900]
- Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender, and social support. *Head & Neck*. 2003; 25:103–112. [PubMed: 12509792]
- Katz MR, Kopek N, Waldron J, Devins GM, Tomlinson G. Screening for depression in head and neck cancer. *Psycho-Oncology*. 2004; 13:269–280. [PubMed: 15054731]
- Kazis, L.; The SF-36V. Center for Health Quality, Outcomes, Economic Research; Bedford, MA: 1998.
- Kobayashi M, Sugimoto T, Matsuda A, Matsushima E, Kishimoto S. Association between self-esteem and depression among patients with head and neck cancer: A pilot study. *Head & Neck*. 2008; 30:1303–1309. [PubMed: 18642296]
- Koch L, Jansen L, Brenner H, Arndt V. Fear of recurrence and disease progression in long-term (5 years) cancer survivors—A systematic review of quantitative studies. *Psycho-Oncology*. 2012 Epub ahead of print.
- Koster M, Bergsma J. Problems and coping behaviours of facial cancer patients. *Social Science & Medicine*. 1990; 30:569. [PubMed: 2408153]

- Komproe IH, Rijken M, Ros WJ, Winnubst JAM, Hart H. Available support and received support: Different effects under stressful circumstances. *Journal of Social & Personal Relationships*. 1997; 14:59–77.
- Kroenke K, Spitzer RL, Williams JBW. The PHQ-9. *Journal of General Internal Medicine*. 2001; 16:606–613. [PubMed: 11556941]
- Kugaya A, Akechi T, Okuyama T, Nakano T, Mikami I, Okamura H, et al. Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer*. 2000; 88:2817–2823. [PubMed: 10870066]
- Kung S, Rummans TA, Colligan RC, Clark MM, Sloan JA, Novotny JA, et al. Association of optimism-pessimism with quality of life in patients with head and neck and thyroid cancers. *Mayo Clinic Proceedings*. 2006; 81:1545–1552. [PubMed: 17165633]
- Lawton, MP. Quality of life and end of life. In: Birren, JE.; Schaie, KW., editors. *Handbook of the psychology of aging*. 5th ed.. Academic Press; San Diego, CA: 2001. p. 593-616.
- Leary MR, Rapp SR, Herbst KC, Exum ML, Feldman SR. Interpersonal concerns and psychological difficulties of psoriasis patients: Effects of disease severity and fear of negative evaluation. *Health Psychology*. 1998; 17:530–536. [PubMed: 9848803]
- Lebel S, Castonguay M, Mackness G, Irish J, Bezjak A, Devins GM. The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-Oncology*. 2011 Epub ahead of print.
- Ledeboer QCP, Velden LA, de Boer MF, Feenstra L, Pruyn JFA. Physical and psychosocial correlates of head and neck cancer: An update of the literature and challenges for the future (1996–2003). *Clinical Otolaryngology*. 2005; 30:303–319. [PubMed: 16209671]
- Lee-Jones C, Humphris G, Dixon R, Hatcher MB. Fear of cancer recurrence—A literature review and proposed cognitive formulation to exacerbation of recurrence fears. *Psycho-Oncology*. 1997; 6:95–105. [PubMed: 9205967]
- Leventhal, H.; Meyer, D.; Nerenz, D. The common sense representation of illness danger. In: Rachman, S., editor. *Medical Psychology*. Pergamon Press; New York: 1980. p. 7-30.
- Lin A, Kim HM, Terrell JE, et al. Quality of life after parotid-sparing IMRT for head and neck cancer: A prospective longitudinal study. *International Journal of Radiation Oncology—Biology, Physics*. 2003; 57:61–70.
- List MA, Bilir SP. Functional outcomes in head and neck cancer. *Seminars in Radiation Oncology*. 2004; 14:178–189. [PubMed: 15095263]
- List MA, Rutherford JL, Stracks J, Haraf D, Kies MS, Vokes EE. An exploration of the pretreatment coping strategies of patients with carcinoma of the head and neck. *Cancer*. 2002; 95:98–104. [PubMed: 12115322]
- List MA, Stracks J, Colangelo L, Butler P, Ganzenko N, Lundy D, et al. How do head and neck cancer patients prioritize treatment outcomes before initiating treatment? *Journal of Clinical Oncology*. 2000; 18:877–884. [PubMed: 10673531]
- Llewellyn CD, Horney DJ, McGurk M, Weinman J, Herold J, Altman K, et al. Assessing the psychological predictors of benefit finding in patients with head and neck cancer. *Psycho-Oncology*. 2011 Epub ahead of print.
- Llewellyn CD, McGurk M, Weinman J. Are psycho-social and behavioural factors related to health related quality of life in patients with head and neck cancer? A systematic review. *Oral Oncology*. 2005; 41:440–454. [PubMed: 15878748]
- Llewellyn CD, McGurk M, Weinman J. Head and neck cancer: To what extent can psychological factors explain differences between health-related quality of life and individual quality of life? *British Journal of Oral & Maxillofacial Surgery*. 2006; 44:351–357. [PubMed: 16105712]
- Llewellyn CD, McGurk M, Weinman J. The relationship between the Patient Generated Index (PGI) and measures of HR-QoL following diagnosis with head and neck cancer: Are illness and treatment perceptions determinants of judgment-based outcomes? *British Journal of Health Psychology*. 2007a; 12:421–437. [PubMed: 17726768]
- Llewellyn CD, McGurk M, Weinman J. Illness and treatment beliefs in head and neck cancer: Is Leventhal's common sense model a useful framework for determining changes in outcomes over time? *Journal of Psychosomatic Research*. 2007b; 63:17–26. [PubMed: 17586334]

- Llewellyn CD, Weinman J, McGurk M, Humphris G. Can we predict which head and neck cancer survivors develop fears of recurrence? *Journal of Psychosomatic Research*. 2008; 65:525–532. [PubMed: 19027440]
- Longacre ML, Ridge JA, Burtneess BA, Galloway TJ, Fang CY. Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncology*. 2012; 48:18–25. [PubMed: 22154127]
- Low C, Fullarton M, Parkinson E, O'Brien K, Jackson SR, Lowe D, et al. Issues of intimacy and sexual dysfunction following major head and neck cancer treatment. *Oral Oncology*. 2009; 45:898–903. [PubMed: 19457705]
- Luckett T, Britton B, Clover K, Rankin NM. Evidence for interventions to improve psychological outcomes in people with head and neck cancer: A systematic review of the literature. *Supportive Care in Cancer*. 2011; 19:871–881. [PubMed: 21369722]
- Lydiatt WM, Moran J, Burke WJ. A review of depression in the head and neck cancer patient. *Clinical Advances in Hematology & Oncology*. 2009; 7:397–403. [PubMed: 19606075]
- Maier H, Dietz A, Gewelke U, Heller WD, Weidauer H. Tobacco and alcohol and the risk of head and neck cancer. *Journal of Clinical Investigation*. 1992; 70:320–327.
- Manne S, Badr H. Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho-Oncology*. 2010; 19:941–954. [PubMed: 19885852]
- Manne SL, Taylor KL, Dougherty J, Kemeny N. Supportive and negative responses in the partner relationship: Their association with psychological adjustment among individuals with cancer. *Journal of Behavioral Medicine*. 1997; 20:101–125. [PubMed: 9144035]
- Marur S, Forastiere AA. Head and neck cancer: Changing epidemiology, diagnosis, and treatment. *Mayo Clinic Proceedings*. 2008; 83:489–501. [PubMed: 18380996]
- Marur S, D'Souza G, Westra WH, Forastiere AA. HPV-associated head and neck cancer: A virus-related cancer epidemic. *Lancet Oncology*. 2010; 11:781–789. [PubMed: 20451455]
- Massie MJ. Prevalence of depression in patients with cancer. *Journal of the National Cancer Institute Monographs*. 2004; 32:57–71. [PubMed: 15263042]
- Mayne ST, Cartmel B, Kirsch V, Goodwin WJ. Alcohol and tobacco use prediagnosis and postdiagnosis, and survival in a cohort of patients with early stage cancers of the oral cavity, pharynx, and larynx. *Cancer Epidemiology, Biomarkers & Prevention*. 2009; 18:3368–3374.
- McMillan SC, Small BJ, Weitzner M, Schonwetter R, Tittle M, Moody L, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer. *Cancer*. 2006; 106:214–222. [PubMed: 16329131]
- Mehanna HM. What has quality of life research done for the head and neck cancer patient? *Oncology News*. 2007; 1:17–19.
- Mehanna HM, Morton RP. Does quality of life predict long-term survival in patients with head and neck cancer? *Archives of Otolaryngology—Head & Neck Surgery*. 2006a; 132:27–31. [PubMed: 16415425]
- Mehanna HM, Morton RP. Why are head and neck cancer clinicians not measuring quality of life? *Journal of Laryngology & Otology*. 2006b; 120:861–864. [PubMed: 16707035]
- Miller PM, Day TA, Ravenel MC. Clinical implications of continued alcohol consumption after diagnosis of upper aerodigestive tract cancer. *Alcohol & Alcoholism*. 2006; 41:140–142. [PubMed: 16308354]
- Miller, SM.; Diefenbach, MA. C-SHIP: A cognitive-social health information processing approach to cancer. In: Krantz, D., editor. *Perspectives in Behavioral Medicine*. Lawrence Erlbaum Associates, Inc.; Mahwah, NJ: 1998. p. 219-244.
- Molina MA, Cheung MC, Perez EA, Byrne MM, Francheschi D, et al. African American and poor patients have a dramatically worse prognosis for head and neck cancer: An examination of 20,915 patients. *Cancer*. 2008; 113:2797–2806. [PubMed: 18839393]
- Morton RP. Evolution of quality of life assessment in head and neck cancer. *Journal of Laryngology and Otology*. 1995; 109:1029–1035. [PubMed: 8551114]
- Morton RP, Izzard ME. Quality-of-life outcomes in head and neck cancer patients. *World Journal of Surgery*. 2003; 27:884–889. [PubMed: 14509523]

- Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. The revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health*. 2002; 17:1–16.
- Murphy BA, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer: A review of the current state of the science. *Critical Reviews in Oncology/Hematology*. 2007; 62:251–267. [PubMed: 17408963]
- National Comprehensive Cancer Network (NCCN). NCCN practice guidelines for the management of psychosocial distress. *Oncology*. 1999; 13:113–147. [PubMed: 10370925]
- Neilson KA, Pollard AC, Boonzaier AM, Corry J, Castle DJ, Mead KR, et al. Psychologic distress (depression and anxiety) in people with head and neck cancers. *Medical Journal of Australia*. 2010; 193:S48–S51. [PubMed: 21542446]
- Nichols AC, Bhattacharyya N. Racial differences in stage and survival in head and neck squamous cell carcinoma. *The Laryngoscope*. 2007; 117:770–775. [PubMed: 17473666]
- Offerman MPJ, Schroevers MJ, van der Velden LA, de Boer MF, Pruyn JFA. Goal processes and self-efficacy related to psychological distress in head & neck cancer patients and their partners. *European Journal of Oncology Nursing*. 2010; 14:231–237. [PubMed: 20185368]
- O'Neil MP. Psychological aspects of cancer recovery. *Cancer (Supplement)*. 1975:271–273.
- Osthus AA, Aarstad AKH, Olofsson J, Aarstad HJ. Health-related quality of life scores in long-term head and neck cancer survivors predict subsequent survival: A prospective cohort study. *Clinical Otolaryngology*. 2011a; 36:361–368. [PubMed: 21624101]
- Osthus AA, Aarstad AKH, Olofsson J, Aarstad HJ. Head and neck specific health related quality of life scores predict subsequent survival in successfully treated head and neck cancer patients: A prospective cohort study. *Oral Oncology*. 2011b; 47:974–979. [PubMed: 21856209]
- Ostroff JS, Jacobsen PB, Moadel AB, Spiro RH, Shah JP, Strong EW, et al. Prevalence and predictors of continued tobacco use after treatment of patients with head and neck cancer. *Cancer*. 1995; 75:569–576. [PubMed: 7812925]
- Ostroff JS, Ross S, Steinglass P, Ronis-Tobin V, Singh B. Interest in and barriers to participation in multiple family groups among head and neck cancer survivors and their primary family caregivers. *Family Process*. 2004; 43:195–208. [PubMed: 15603503]
- Paleri V, Wight RG, Silver CE, Haigentz M, Takes RP, Bradley PJ, et al. Comorbidity in head and neck cancer: A critical appraisal and recommendations for practice. *Oral Oncology*. 2010; 46:712–719. [PubMed: 20850371]
- Parkin DM, Bray F, Ferlay J, Pisani P. Global cancer statistics: 2002. *CA: A Cancer Journal for Clinicians*. 2005; 55:74–108. [PubMed: 15761078]
- Penner JL. Psychosocial care of patients with head and neck cancer. *Seminars in Oncology Nursing*. 2009; 25:231–241. [PubMed: 19635402]
- Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine*. 2002; 64:580–586. [PubMed: 12140347]
- Petruson KM, Silander EM, Hammerlid EB. Effects of psychosocial intervention on quality of life in patients with head and neck cancer. *Head & Neck*. 2003; 25:576–584. [PubMed: 12808661]
- Pinto BM, Trunzo JJ. Health behaviors during and after a cancer diagnosis. *Cancer*. 2005; 104(Supplement):2614–2623. [PubMed: 16247806]
- Pirl WF. Evidence report on the occurrence, assessment, and treatment of depression in cancer patients. *Journal of the National Cancer Institute Monographs*. 2004; 32:32–39. [PubMed: 15263039]
- Pirl WF, Muriel A, Hwang V, Kornblith A, Greer J, Donelan K, et al. Screening for psychosocial distress: A national survey of oncologists. *Journal of Supportive Oncology*. 2007; 5:499–504. [PubMed: 18240673]
- Posluszny DM, Dew MA, Johnson JT, Argiris AE, Ferris RL, Gibson MK, et al. Posttraumatic stress disorder (PTSD) symptoms in newly diagnosed head and neck cancer patients and their partners. *Annals of Behavioral Medicine*. 2011; 41(Supplement):s59.
- Potash AE, Karnell LH, Christensen AJ, Vander Weg MW, Funk GF. Continued alcohol use in patients with head and neck cancer. *Head & Neck*. 2010; 32:905–912. [PubMed: 19918984]

- Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. *American Journal of Health Promotion*. 1997; 12:38–48. [PubMed: 10170434]
- Pusic A, Liu JC, Chen CM, Cano S, Davidge K, Klassen A, et al. A systematic review of patient-reported outcome measures in head and neck cancer surgery. *Otolaryngology—Head & Neck Surgery*. 2007; 136:525–535. [PubMed: 17418246]
- Rabin C, Leventhal H, Goodin S. Conceptualization of disease timeline predicts posttreatment distress in breast cancer patients. *Health Psychology*. 2004; 23:407–412. [PubMed: 15264977]
- Rajandram RK, Jenewein J, McGrath CPJ, Zwahlen RA. Posttraumatic growth: A novel concept in oral cavity cancer care? *Oral Oncology*. 2010; 46:791–794. [PubMed: 20850373]
- Rajandram RK, Jenewein J, McGrath CPJ, Zwahlen RA. Coping processes relevant to posttraumatic growth: An evidence-based review. *Supportive Care in Cancer*. 2011; 19:583–589. [PubMed: 21298449]
- Raichle KA, Christensen AJ, Ehlers S, Moran PJ, Karnell L, Funk G. Public and private self-consciousness and smoking behavior in head and neck cancer patients. *Annals of Behavioral Medicine*. 2001; 23:120–124. [PubMed: 11394553]
- Rapaport Y, Kreitler S, Chaichik S, Algor R, Weissler K. Psychosocial problems in head and neck cancer patients and their change with time since diagnosis. *Annals of Oncology*. 1993; 4:69–73. [PubMed: 8435366]
- Ries, LAG.; Melbert, D.; Krapcho, M.; Mariotto, A.; Miller, BA.; Feuer, EJ., et al. SEER Cancer Statistics Review, 19751–2004. National Cancer Institute; Bethesda, MD: 2006.
- Rogers SN, El-Sheikha J, Lowe D. The development of a patient concerns inventory (PCI) to help reveal patient concerns in the head and neck clinic. *Oral Oncology*. 2009; 45:555–561. [PubMed: 19028135]
- Rogers SN, Scott B, Lowe D, Ozakinci G, Humphris GM. Fear of recurrence following head and neck cancer in the outpatient clinic. *European Archives of Otorhinolaryngology*. 2010; 267:1943–1949. [PubMed: 20582704]
- Ronis DL, Duffy SA, Fowler KE, Khan MJ, Terrell JE. Changes in quality of life over 1 year in patients with head and neck cancer. *Archives of Otolaryngology—Head & Neck Surgery*. 2008; 134:241–248. [PubMed: 18347247]
- Scharpf J, Karnell LH, Christensen AJ, Funk GF. The role of pain in head and neck cancer recurrence and survivorship. *Archives of Otolaryngology—Head & Neck Surgery*. 2009; 135:789–794. [PubMed: 19687400]
- Scharloo M, de Jong RJB, Langeveld TPM, van Velzen-Verkaik E, den Akker MMD, Kaptein AA. Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head & Neck*. 2005; 27:857–863. [PubMed: 16114002]
- Scharloo M, de Jong RJB, Langeveld TPM, van Velzen-Verkaik E, den Akker MMD, Kaptein AA. Illness cognitions in head and neck squamous cell carcinoma: Predicting quality of life outcome. *Supportive Care in Cancer*. 2010; 18:1137–1145. [PubMed: 19718524]
- Schnoll RA, James C, Malstrom M, Rothman RL, Wang H, Babb J, et al. Longitudinal predictors of continued tobacco use among patients diagnosed with cancer. *Annals of Behavioral Medicine*. 2003; 25:214–221. [PubMed: 12763716]
- Schnoll, RA.; Lerman, C. Smoking behavior and smoking cessation among head and neck cancer patients. In: Ensley, JF.; Gutkind, JS.; Jacobs, JR.; Lippman, SM., editors. *Head and neck cancer: Emerging perspectives*. Academic Press; San Diego, CA: 2003. p. 185-200.
- Schnoll RA, Rothman RL, Lerman C, Miller SM, Newman H, Movsas B, et al. Comparing cancer patients who enroll in a smoking cessation program at a comprehensive cancer center with those who decline enrollment. *Head & Neck*. 2004; 26:278–286. [PubMed: 14999804]
- Schnoll RA, Rothman RL, Wielt DB, Lerman C, Pedri H, Wang H, et al. A randomized pilot study of cognitive-behavioral therapy versus basic health education for smoking cessation among cancer patients. *Annals of Behavioral Medicine*. 2005; 30:1–11. [PubMed: 16097900]
- Schnoll RA, Zhang B, Rue M, Krook JE, Spears WT, Marcus AC, et al. Brief physician-initiated quit-smoking strategies for clinical oncology settings: A trial coordinated by the eastern cooperative oncology group. *Journal of Clinical Oncology*. 2003; 21:355–365. [PubMed: 12525530]

- Sample CJ, Dunwoody L, Kernohan WG, McCaughan E. Development and evaluation of a problem-focused for patients with head and neck cancer. *Supportive Care in Cancer*. 2009; 17:379–388. [PubMed: 18626666]
- Sample CJ, Sullivan K, Dunwoody L, Kernohan WG. Psychosocial interventions for patients with head and neck cancer: Past, present, and future. *Cancer Nursing*. 2004; 27:434–441. [PubMed: 15632782]
- Sharp L, Tishelman C. Smoking cessation for patients with head and neck cancer: A qualitative study of patients' and nurses' experiences in a nurse-led intervention. *Cancer Nursing*. 2005; 28:226–235. [PubMed: 15915068]
- Sherman, AC.; Hanna, E.; Simonton, S. Quality of life outcomes in head and neck cancer. In: Adelstein, DJ., editor. *Current clinical oncology: Squamous cell head and neck cancer*. Humana Press Inc.; Totowa, NJ: 2005. p. 305–321.
- Sherman AC, Simonton S. Advances in quality of life research among head and neck cancer patients. *Current Oncology Reports*. 2010; 12:208–215. [PubMed: 20425081]
- Shone G, Yardley M. An AUDIT into the incidence of handicap after unilateral radical neck dissection. *Journal of Laryngology & Otology*. 1991; 105:760–762. [PubMed: 1833491]
- Simard S, Savard J. Fear of Cancer Recurrence Inventory: Development and initial validation of a multidimensional measure of fear of cancer recurrence. *Supportive Care in Cancer*. 2009; 17:241–251. [PubMed: 18414902]
- Simard S, Savard J, Ivers H. Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. *Journal of Cancer Survivorship*. 2010; 4:361–371. [PubMed: 20617394]
- Singer S, Danker H, Dietz A, Homemann B, Kosciely S, Oeken J, et al. Screening for mental disorders in laryngeal cancer patients: A comparison of 6 methods. *Psycho-Oncology*. 2008; 17:280–286. [PubMed: 17614095]
- Singer S, Krauss O, Keszte J, Siegl G, Papsdorf K, Severi E, et al. Predictors of emotional distress in patients with head and neck cancer. *Head & Neck*. 2011 Epub ahead of print.
- Siston AK, List MA, Schleser R, Vokes E. Sexual functioning and head and neck cancer. *Journal of Psychosocial Oncology*. 1997; 15:107–122.
- Smith EM, Ritchie JM, Summersgill KF, Klussmann JP, Lee JH, Wang D, et al. Age, sexual behavior, and human papillomavirus infection in oral cavity and oropharyngeal cancers. *International Journal of Cancer*. 2004; 108:766–772.
- Stanton AL. Psychosocial concerns and interventions for cancer survivors. *Journal of Clinical Oncology*. 2006; 24:5132–5137. [PubMed: 17093275]
- Steinglass P, Ostroff JS, Steinglass AS. Multiple family groups for adult cancer survivors and their families: A 1-day workshop model. *Family Process*. 2011; 50:393–409. [PubMed: 21884077]
- Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*. 2010; 19:1013–1025. [PubMed: 20014159]
- Taylor JC, Terrell JE, Ronis DL, Fowler KE, Bishop C, Lambert MT, et al. Disability in patients with head and neck cancer. *Archives of Otolaryngology—Head & Neck Surgery*. 2004; 130:764–769.
- Thompson TL, Pagedar NA, Karnell LH, Funk GF. Factors associated with mortality in 2-year survivors of head and neck cancer. *Archives of Otolaryngology—Head & Neck Surgery*. 2011; 137:100–1105.
- Trotti A, Bellm LA, Epstein JB, Frame D, Fuchs HJ, Gwede CK, et al. Mucositis incidence, severity and associated outcomes in patients with head and neck cancer receiving radiotherapy with or without chemotherapy: A systematic literature review. *Radiotherapy & Oncology*. 2003; 66:253–262. [PubMed: 12742264]
- Tschiesner U, Rogers SN, Harrs U, Berghaus A, Cieza A. Content comparison of quality of life questionnaires used in head and neck cancer based on the international classification of functioning, disability, and health: A systematic review. *European Archives of Otorhinolaryngology*. 2008; 265:627–637. [PubMed: 18392633]
- Urcuyo KR, Boyers AE, Carver CS, Antoni MH. Finding benefit in breast cancer: Relations with personality, coping, and current well-being. *Psychology & Health*. 2008; 20:175–192.

- Vakharia KT, Ali MJ, Wang SJ. Quality of life impact of participation in a head and neck cancer support group. *Otolaryngology—Head & Neck Surgery*. 2007; 136:405–410. [PubMed: 17321868]
- van den Brink JL, Moorman PW, de Boer MF, Hop WCJ, Pruyn JFA, Verwoerd CDA, et al. Impact on quality of life of a telemedicine system supporting head and neck cancer patients: A controlled trial during the postoperative period at home. *Journal of the American Medical Informatics Association*. 2007; 14:198–205. [PubMed: 17213498]
- Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology*. 2004; 22:714–724. [PubMed: 14966096]
- Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans R. Distress in spouses and patients after treatment for head and neck cancer. *The Laryngoscope*. 2007; 117:238–241. [PubMed: 17277616]
- Verdonck-de Leeuw IM, van Nieuwenhuizen A, Leemans CR. The value of quality-of-life questionnaires in head and neck cancer. *Current Opinion in Otolaryngology & Head and Neck Surgery*. 2012; 20:142–147. [PubMed: 22249168]
- Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck*. 2003; 25:289–296. [PubMed: 12658733]
- Vilela LD, Nicolau B, Mahmud S, Edgar L, Hier M, Black M, et al. Comparison of psychosocial outcomes in head and neck cancer patients receiving a coping strategies intervention and control subjects receiving no intervention. *Journal of Otolaryngology*. 2006; 35:88–96. [PubMed: 16527026]
- Viswanathan H, Wilson JA. Alcohol—The neglected risk factor in head and neck cancer. *Clinical Otolaryngology & Allied Sciences*. 2004; 29:295–300. [PubMed: 15270811]
- Ward, EC.; Van As-Brooks, CJ., editors. *Head and neck cancer: Treatment, rehabilitation, and outcomes*. Plural Publishing, Inc.; San Diego, CA:
- Ware J, Kosinski M, Keller SD. A 12-item Short-Form Health Survey: Construction of scales and preliminary test of reliability and validity. *Medical Care*. 1996; 34:220–233. [PubMed: 8628042]
- Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). *Medical Care*. 1992; 30:473–483. [PubMed: 1593914]
- Watt-Watson J, Graydon J. Impact of surgery on head and neck cancer patients and their caregivers. *The Nursing Clinics of North America*. 1995; 30:659–671. [PubMed: 7501534]
- Weymuller EA Jr. Yueh B, Deleviannis FW, Kuntz AL, Alsarraf R, Coltrera MD. Quality of life in head and neck cancer. *The Laryngoscope*. 2000; 110:4–7. [PubMed: 10718406]
- Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: Goal disengagement, goal reengagement, and subjective well-being. *Personality & Social Psychology Bulletin*. 2003; 29:1494–1508. [PubMed: 15018681]
- Yu CL, Fielding R, Chan CL, Sham JS. Chinese nasopharyngeal carcinoma patients treated with radiotherapy: Association between satisfaction with information provided and quality of life. *Cancer*. 2001; 92:2126–2135. [PubMed: 11596029]
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*. 1983; 67:361–370.

Table 1

Summary of psychological interventions for patients with HNC

Reference	Design (Allocation)	Sample	Intervention/Delivery	Outcomes (Measure)	Results
Allison, Edgar, et al., 2004 Allison, Nicolau, et al., 2004 Vilela et al., 2006	Pre/post with control group (matched-group allocation)	101 posttreatment outpatients, Stages I–IV	PE+SM, Nurse-led (I/G)	HRQOL (EORTC QLQ-C30) Anxiety/Depression (HADS)	Intervention group showed significant improvement in HRQOL (global, PF, SF) and depression from baseline to f/u; significant between-group differences found only in global HRQOL
Duffy et al., 2006	RCT w/enhanced usual care control arm	184 postdiagnosis outpatients who screened positive for smoking, alcohol and/or depression, Stages I–IV	CBT, Nurse-led (I)	Depression (GDS-SF) Smoking Status Alcohol Intake (AUDIT)	Alcohol and depression rates improved, but no significant between-group differences; significant between-group differences in 6-month smoking cessation reported
Fiegenbaum, 1981	Pre/post with control group (matched-group allocation)	17 posttreatment outpatients with facial disfigurement	CST, Behavioral Therapist-led (G)	Social Anxiety Self-insecurity	Intervention group showed significant improvement in insecurity; significant between-group differences in anxiety reported
Hammerlid et al., 1999	(a) Pre/post with control group (non-randomized allocation) (b) Pre/post without control group (N/A)	(a) 47 active treatment outpatients, Stages I–IV (b) 14 posttreatment rehabilitation outpatients (and partners), Stages I–IV	(a) CBT+SM, Psychologist-led (G) (b) SET+PE, Provider-led (I/G)	(a,b) HRQOL (EORTC QLQ-C30), Anxiety/Depression (HADS)	(a) At 1 year f/u, intervention group improved 10 points on several HRQOL domains including CF, EF, SF, pain, and appetite loss; number of intervention patients scoring > 7 on either the HADS-Anxiety or HADS-Depression subscales reduced from 75% to 13% (b) No significant change from before to 4 weeks after rehabilitation on EORTC-QLQ-C30; number of patients scoring > 7 on either the HADS-Anxiety or HADS-Depression subscales reduced from 29% to 14%
Head, Studts, et al., 2009 Head, Keeney, et al., 2011	RCT w/standard of care control arm	80 active treatment outpatients, Stages I–IV	PE, Telehealth-based (I)	HRQOL (FACT-H&N) Physical & Emotional Symptom Distress (MSAS)	Acceptance/feasibility established; trial results not yet reported
Humphris & Ozakinci, 2008 Humphris & Rogers, in press	RCT w/ usual care control arm	87 posttreatment outpatients	CBT+SM, Nurse-led (I/G)	FCR (WOC), Anxious Preoccupation (MAC), Anxiety/Depression (HADS)	Significant between-group change score differences in FCR and anxious preoccupation with cancer, but not general anxiety and depression, were found between 7- and 11-month f/u; differences did not remain significant at 15-month f/u
Katz et al., 2004	RCT w/usual care control arm	19 surgical inpatients, Stages I–IV	PE, Nurse-led (I)	HRQOL (EORTC QLQ-C30), Anxiety (STAI)	Significant between-group differences in anxiety; other

Reference	Design (Allocation)	Sample	Intervention/Delivery	Outcomes (Measure)	Results
Petruson et al., 2003	Pre/post with control group (matched-group allocation)	144 active treatment outpatients, Stages I-IV	PE+SG, Nurse-led (I)	Depression (CES-D), Self-Efficacy (SICPA)	between-group differences non-significant
Schnoll et al., 2005	RCT w/general health education control arm	109 pre-, active, and posttreatment head and neck or lung cancer patients, Stages I-IV (29.4% HNC)	CBT, Health Educator-led (I)	HRQOL (EORTC QLQ-C30), Anxiety/Depression (HADS)	Significant change in global HRQOL favoring control group; no significant between-group differences found in possible/probable depression cases
Seiple et al., 2009	Pre/post with control group (self-selected)	54 posttreatment outpatients, Stages I-IV	CBT+PE+CST, Nurse-led (in-home; I)	HRQOL (UWQOLv4), Anxiety/Depression (HADS)	No significant difference in 30-day point prevalence abstinence between CBT and GHE groups at 1-month (44.9% vs. 47.3%, respectively) or 3-month (43.2% vs. 39.2%, respectively) f/u
Steinglass et al., 2011	N/A, pilot & feasibility of adapted MFG protocol only (N/A)	15 posttreatment outpatients + family caregivers	PE+MFG (G)	N/A	Significant between-group differences in HADS anxiety/depression and UWQOLv4 composite and transitional scores
van den Brink et al., 2007	Pre/post with control group (non-randomized allocation)	163 posttreatment outpatients	PE+SG, Telehealth-based (I/G)	HRQOL (Rationally-derived scales assessing physical, cognitive, and emotional domains)	Acceptance/feasibility of single day, MFG protocol established
Vakharia et al., 2007	Post only with control group (self-selected)	47 posttreatment outpatients	SG, Provider-led (G)	HRQOL (HNQOL)	Significant between-group improvements in 5 of 22 HRQOL domains at 6 weeks post-baseline (general physical complaints, eating/swallowing, physical self-efficacy, fear related to condition-specific issues, anxiety); only for physical self-efficacy did between-group difference remain significant at 12 weeks post-baseline
					Significant between-group differences in eating, emotion, pain, global bother, and treatment response

Note.

AUDIT = Alcohol Use Disorder Identification Test; CBT = cognitive behavioral therapy; CES-D = Center for Epidemiological Studies Depression Scale; CF = cognitive functioning; CST = communication skills training; EF = emotional functioning; EORTC QLQ-C30 = European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire—Core; FACT-H&N = Functional Assessment of Cancer Therapy—Head and Neck Scale; FCR = fear of cancer recurrence; f/u = follow-up; G = group-based; GDS-SF = Geriatric Depression Scale—Short Form; GHE = General Health Education; HADS = Hospital Anxiety and Depression Scale; HNC = head and neck cancer; HNQOL = Head and Neck Quality of Life Instrument; HRQOL = health-related quality of life; I = individual-based; MAC = Mental Adjustment to Cancer Scale; MFG = multiple family group; MSAS = Memorial Symptom Assessment Scale; PE = psychoeducation; PF = physical functioning; RCT = randomized controlled trial; SET = supportive expressive therapy; SF = social functioning; SG = support group; SICPA = Stanford Inventory of Cancer Patient Adjustment; SM = stress management; STAI = State-Trait Anxiety Inventory; UWQOLv4 = University of Washington Quality of Life Questionnaire (Version 4); WOC = Worry of Cancer Scale.