Published in final edited form as:

J Psychosoc Oncol. 2016 ; 34(4): 336–346. doi:10.1080/07347332.2016.1195901.

Unmet Needs and Relationship Challenges of Head and Neck Cancer Patients and their Spouses

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Abstract

In head and neck cancer (HNC), couple-based interventions may be useful for facilitating treatment completion, patient rehabilitation, and improving both partners' quality of life (QOL). With the goal of identifying targets for future interventions, we conducted a qualitative study to understand patient and spouse unmet needs and relationship challenges during curative radiotherapy for HNC. Semi-structured interviews were conducted with 6 HNC patients (83% male) and 6 spouses (83% female) within 6 months of completing treatment. Interviews were audiotaped and transcribed using Grounded Theory Analysis. Patients and spouses identified several unmet needs including better preparation regarding the severity of physical side effects, a clearer timeline for recovery, and strategies for dealing with their own and each other's emotional reactions. Caregiver unmet needs included balancing competing roles/responsibilities, making time for self-care, and finding effective strategies for encouraging patient self-care. Eighty-three percent of spouses and all patients reported increased conflict during treatment. Other relationship challenges included changes in intimacy and social/leisure activities. Findings suggest that couple-based interventions that emphasize the importance of managing physical and psychological symptoms through the regular practice of self-care routines may be beneficial for both patients and spouses. Likewise, programs that teach spouses ways to effectively motivate and encourage patient self-care may help to minimize conflict and help couples navigate HNC treatment and recovery together as a team.

Keywords

Head and neck cancer; couples; caregiving; spouses; qualitative interviews

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Disclosure Statement: The authors have no conflicts of interest to report.

INTRODUCTION

Head and neck cancers (HNCs) account for 560,000 new cases annually worldwide (Siegel, Ma, Zhaohui, & Jemal, 2014). A recent analysis of Surveillance, Epidemiology, and End Results (SEER) data found that being married reduced HNC patients' risk of dying from cancer by 33% (hazard ratio [HR] = .67) (Aizer et al., 2013). Married HNC patients also have significantly better performance status during treatment than unmarried patients (Konski et al., 2006). One explanation is that HNC treatment results in greater symptom burden (including pain, difficulty eating, talking, and drinking) relative to other cancers and requires substantial caregiving. Patients may thus benefit more from their spouses' active involvement in their care. Patients often undergo intensive radiotherapy (5 days a week for 6 to 7 weeks), either alone or combined with other treatment modalities (National Comprehensive Cancer Network, 2013). Given the intensity of radiation required to successfully treat HNC tumors and the sensitive location that is targeted, patients experience significant side effects (e.g., mucositis, xerostomia) and functional challenges (e.g., dysphagia) that make eating, drinking, talking, and socializing a difficult ordeal (Bjorndal et al., 2000; Epstein, Robertson, Emerton, Phillips, & Stevenson-Moore, 2001). Patients also experience significant decrements in quality of life (QOL) including rapid weight loss, dehydration, and malnutrition as well as social isolation and emotional problems that persist long after they have been definitively treated (Duffy et al., 2006; Epstein et al., 2001; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). Psychoeducational interventions can improve quality of life (QOL) and enhance coping with the aftermath of cancer (Faller et al., 2013); however, few programs have been developed for HNC patients (Semple et al., 2013). In order to guide the development of such programs, a clearer understanding of patients' unmet needs and how they might be better addressed is required.

Programs that solely target patients fail to consider that problems with the patient (e.g., distress, lack of adherence to self-care recommendations) could be driven by unexamined factors in the spouse (e.g., spouse distress) and vice versa. Spouses' distress rates are comparable to or higher than the distress rates of HNC patients (Hodges, Humphris, & Macfarlane, 2005; Verdonck-de Leeuw et al., 2007), and research has shown that patient physical and psychological symptom burden is highly distressing for spouses (Harding, Higginson, & Donaldson, 2003). Spouses are often tasked with supporting patient adherence to time-consuming, cumbersome, and aversive self-care protocols to control side effects and facilitate rehabilitation with little or no training (McGuire, 2003; Silverman, 2003). In addition to providing emotional support and helping patients cope with a high degree of symptom burden, there is growing recognition that spousal caregivers have their own unique needs and concerns (Girgis & Lambert, 2009). Although they often see themselves as jointly fighting cancer with their loved ones, coping with cancer can be physically, socially, and psychologically challenging for spouses (Osse, Vernooij-Dassen, Schadé, & Grol, 2005). Given that unmet caregiver support needs have been shown to adversely affect both patient and caregiver quality of life in a variety of cancers (Girgis et al., 2013; Hodgkinson et al., 2007), developing a clearer understanding of these needs in the context of HNC may help to facilitate the development of specialized programs to improve both partners' cancer adaptation.

Actively involving spouses in couple-based programs may be important for facilitating both partners' adjustment and improving marital functioning. HNC can be challenging for couples, resulting in modified life plans and physical sequelae that can compromise adaptive communication, sexual intimacy, and marital functioning (Gritz et al., 1999; Low et al., 2009). Although the quality of marital interaction is a strong predictor of adaptation in cancer (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000), researchers have yet to identify the ways in which HNC wears on couples' relationships and the coordination of care. Thus, with the goal of identifying targets for future couple-based interventions, we conducted a qualitative study to identify patient and spouse unmet needs and relationship challenges during radiotherapy for HNC.

METHODS

Recruitment

This study was approved by the Icahn School of Medicine at Mount Sinai institutional review board. Eligible patients had to have completed radiotherapy for HNC within six months of enrollment and have a spouse with whom they lived who served as their primary caregiver. Patients and spouses also had to speak and understand English, and be age 18 or older.

Ten consecutive patients and six spouses were approached during patients' clinic visits. Spouses who were not present were approached by phone. Patients could still participate even if their spouses refused and vice versa. Three patients were ineligible and one declined to participate; all of the spouses we approached were eligible and consented. The final sample comprised six patients and six spouses (5 were married couples).

Procedures

Participants completed a one-page survey that asked about distress levels (NCCN Distress Thermometer) and socio-demographic/medical characteristics, and a 60-minute semi-structured interview. Interview questions were guided by four domains of unmet needs of cancer patients and caregivers that have been previously identified in the literature (Lambert et al., 2012; Sanson-Fisher et al., 2000). Specifically, patients and spouses were asked about their information needs (knowing what to expect, illness and treatment, providing care to the patient), emotional and psychological needs (e.g., fears and concerns, help dealing with their own distress or their partner's), partner impact and daily activities (e.g., impact on lifestyle, schedule, and health, help from others in managing caregiving responsibilities), and relationship needs (i.e., problems communicating with the patient, family, and friends, changes in relationship with the patient, intimacy/sexual needs and concerns). Each participant received a \$50 gift card upon completion.

Data Analysis—Interviews were digitally recorded, transcribed, and validated by the interviewer to ensure accuracy. Guided by Grounded Theory (Strauss & Corbin, 1998), two coders examined the transcripts line-by-line for key words and statements that captured respondents' experiences and codes were developed describing key points. Categories were

constantly compared to examine commonalities, differences, and uniqueness. Coder differences were discussed and resolved through continued comparative analysis of the data.

RESULTS

Sample demographic and medical characteristics are presented in Table 1.

Unmet Information Needs

Five of six patients wanted better preparation regarding the severity of physical symptoms. One man said, “They [the doctors] just explain, ‘Well you might lose a few pounds, you’ll find you can’t eat that much,’ but they didn’t tell me about all the mucus and how my throat would feel...and the pain.” Spouses echoed this sentiment. Participants also expressed the need for a clearer timeline for recovery, “I didn’t quite realize it would end up being [such a long] ordeal.”

Unmet Emotional and Psychological Needs

Patients talked about the stress of radiotherapy. “I was surprised at how emotional I got,” said one man. Spouses talked of their distress in witnessing the patient’s suffering. “I just felt so helpless because I’ve never really seen my husband so sick.” Five of six spouses also reported difficulty dealing with patients’ emotional reactions – particularly anger and mood swings. “He was extremely difficult to deal with,” said one woman. “He was very unreasonable, short-tempered, and he would become very angry at times. It was almost uncontrollable and I didn’t know how to deal with it.” Another said, “I understood he was sick, but he could get very irritable and snap at me....It’s been frustrating.” To cope, some spouses tried positive affirmations or to diffuse the situation. “Trying to keep his spirits up was my focus,” said one woman. “And if he wavered, I would remind him that it’s temporary and things would get better.” Other spouses were hurt or frustrated by patients’ behavior and responded by giving them “their space” or “putting up” with their mood swings to avoid conflicts.

Overall, participants were aware of the existence of support groups but cited barriers including time, competing priorities, and distance. A patient said, “They suggested some groups but we were so busy with doctors’ appointments and visits every day at the hospital. You come home tired after all that running around.” Highlighting the lack of access, a spouse said, “I told my husband when he was very depressed to go to a support group but they were all [far away] in the city, so we couldn’t attend.”

Partner Impact and Daily Activities

Spouses assumed much of the responsibility for patient care. “She would get on top of everything more than me,” said one man. Spouses also monitored patients’ health status and liaised with the medical team. “I literally had to be his voice because he could not talk to tell the doctors how he was.” Four of six spouses struggled with balancing their caregiving role with other responsibilities. They felt guilty if they thought about taking a break or doing something enjoyable for themselves while the patient was struggling with side-effects. As a consequence, many neglected their own health. “I just took my vitamins and kept going

because I had to,” said one woman. Spouses acknowledged skipping or rescheduling routine appointments because “they could wait.” One woman said, “How could I leave him alone and go to the doctor to complain about my own illness?” Another said she felt like her health condition “wasn’t as severe as having cancer.”

Five of six spouses mentioned at least one positive aspect of caregiving. Some talked about their sense of accomplishment that they were part of their partners’ recovery, “The reward for me was just seeing her get back on track and knowing that I was big part of that.” Others talked introspectively, “I learned I had more patience and am a lot stronger than I thought.” In lieu of mentioning a positive aspect of caregiving for herself, the sixth spouse focused on the positive outcome for her husband, “The only rewarding thing is that he’s still alive and the tumor is gone.”

Relationship Needs

Communication often decreased during treatment because the patient felt poorly, “He was always sleeping or tired or in pain so we weren’t communicating much and it felt like we were leading separate lives.” Patients and spouses also shielded their partners from cancer-related concerns. A patient said, “Sometimes, if it’s not a positive thought, you don’t want to share it; you want to keep quiet about it.” Other patients did not want or know how to initiate cancer discussions, “There were times I didn’t say anything because I didn’t want to burden her. Then, she would say, ‘Tell me what’s wrong,’ and I would wind up telling her.” While spouses said they wished their partners were more forthcoming, patients were aware their spouses held back and were grateful for it. One explained, “He helped me out a lot because he did his crying but it wasn’t around me. Around me he was always so strong.” However, the act of holding back and putting up a strong front was stressful for spouses, “I was stressed all the time because I felt like I had to be strong for him. I couldn’t break down. I just couldn’t.”

Patients and spouses reported that non-sexual expressions of physical intimacy (e.g., kissing, hugging, touching) had decreased markedly since treatment and that sexual relations ceased. Body image was one factor affecting intimacy. One man said, “I’m still having a hard time with sexual relations because of the feeding tube.” Physical side effects (e.g., mucus, dry mouth, bad breath) were also cited as barriers, in addition to a lack of “sex drive”. Spouses mourned the loss of sexual intimacy and closeness to their partners, while patients were more pragmatic, “With all that’s on me right now, the sex is just not there yet.”

Patients and spouses also reported changes in their social and leisure routines. A patient said, “I looked so messed up... I just didn’t want to stand out, so [we went] from work to the hospital to home [and back].” Describing her experience, a spouse remarked, “We tried to go out and do a few things, but he couldn’t. It was disappointing but I understood it, and I tried to let him know that it wasn’t a problem for me.” Other spouses grieved their shared time as a couple, “Before all this happened we used to go out to movie theaters, out to eat. Now we can’t do those things together...and [it will probably be that way] for the rest of our lives.”

Five of six spouses and all the patients reported increases in spousal conflict during treatment. In all cases, the focus was patient lack of adherence to self-care

recommendations. One spouse said, “I pretty much had to keep pushing and reminding him, making sure food and water was available at all times because he didn’t want to do any of it. Then he would snap at me and say ‘You already said that’. I would just fire back, ‘Why are you yelling at me? I am just trying to help you’.” Another spouse knew that her constant reminding was a source of irritation, but felt it was necessary, “If I didn’t do what I was doing it would have been a different outcome -- more missed appointments, more not taking medication...I wouldn’t accept that, so we had to bump heads.” One spouse tried positive reinforcement, “I didn’t push because I cannot imagine what he was going through. When he was able to at least take a spoon and swallow, I would say, ‘I’m so proud of you.’ That’s how I tried to keep him motivated.” Different strategies that spouses used to encourage self-care are in Table 2. Overall, the struggle over self-care was difficult for spouses, “It made me frustrated because I wanted the best for her and when she didn’t see it, I felt neglected and unappreciated.”

Despite the challenges, patients and spouses noted positive aspects of going through the treatment process together. For example, one spouse said, “We are closer now. I see it in his eyes now when he looks at me. He appreciates me more and my taking care of him.” Another said, “It’s just another obstacle in life that you go through together and it makes you feel stronger. [This experience] can either make you stronger or it can destroy a family. And if we could go through this, it’s almost like there’s nothing else that we can’t handle.”

DISCUSSION

This study sought to understand patients’ and spouses’ unmet needs and relationship challenges during radiotherapy for HNC. Patients and spouses identified unmet needs such as better preparation regarding the severity of side effects, a clearer timeline for recovery, and strategies for dealing with emotional reactions, both their own and those of their partner. Of note, spouse average distress at the time of recruitment, which was after treatment was completed, was 5.6 out of 10, which was higher than patient distress ($\bar{X} = 3$ out of 10) and exceeds the NCCN cut-off of 5 indicating significant distress (National Comprehensive Cancer Network (NCCN), 2005). One possibility is that the daily challenges of caregiving coupled with watching their partners suffer lead to feelings of helplessness which exacerbated spouses’ distress (Soothill et al., 2001). Another possibility is that spouses had difficulty coping with patient anger and mood swings. Future couple-based interventions may thus benefit from including a coping skills training component for managing individual-level distress as well as a communication component to teach spouses how to diffuse/respond more effectively to patient anger and negative mood.

With all of their new caregiving responsibilities, many spouses missed their own doctor appointments and neglected their own health. This is consistent with research showing that caregivers often experience negative health consequences after assuming this role (Beesley, Price, & Webb, 2011; Rohleder, Marin, Ma, & Miller, 2009) and suggests that healthcare professionals should educate spouses about ways to maintain their own health while providing care for their partners.

All the patients in this study were treated by the same physician/nurse team and were given educational hand-outs explaining self-care protocols. The radiation oncologist met with them weekly to review symptoms and the nurse saw them daily. Despite this, patients and spouses reported difficulty adhering to self-care protocols and spouses engaged in social control tactics to encourage patient self-care. Social control is a term that comes from the social/health psychology literature that refers to attempts to influence behavior to support adherence (Lewis, Gladstone, Schmal, & Darbes, 2006). In a recent observational study, spouses' positive social control (e.g., reminding, offering to help, positive reinforcement) was associated with greater HNC patient positive mood and self-efficacy for symptom management (Badr, Yeung, Lewis, Milbury, & Redd, 2015). Programs that teach spouses to engage in more positive social control and to minimize negative social control may help to ease spousal tension over self-care. More research is also needed to determine how to facilitate better communication between patients, spouses, and the healthcare team to encourage patient adherence to self-care protocols.

Even though patients and spouses go through the HNC experience together, they have their own needs and role demands that may sometimes make it difficult to effectively communicate. Given that adaptive communication is associated with both partners' adjustment to cancer (Manne & Badr, 2008), programs are needed that acknowledge the individual needs of patients and spouses as well as their shared needs or concerns and challenges as a couple. One such challenge is coping with changes social/leisure activities. Given that spending time together is an important component of relationship satisfaction (Johnson, Zabriskie, & Hill, 2006), research is needed to determine whether/how changes in this domain wears on couples over time and how they adapt.

Sexual well-being is an important aspect of patients' psychological rehabilitation (Herranz & Gavilán, 1999), but very little information or support regarding intimacy is available to HNC couples. Addressing this is important given the rapid rise of HPV+ oropharyngeal cancers, which will soon become the predominant type of HNC (Chaturvedi et al., 2011). HPV+ oropharyngeal patients tend to be younger and have a better long-term prognosis than those with HPV-negative tumors (Licitra et al., 2006) making resumption of sexual relations an important QOL concern. Moreover, the fact that their disease was caused by a sexually transmitted virus may have unique implications for the patient, their partner, and their relationship. This, coupled with the dental/oral problems and body image concerns mentioned suggests the need for programs that tackle these issues as part of the couple's adjustment to the "new normal" after cancer.

This study has limitations. First, most patients were male and most spouses were female. Although approximately 70% of HNC patients are male (Siegel et al., 2014), our findings may not generalize to female patients and their male spouses or same-sex couples. Second, we asked participants to recall their experiences during treatment. Caregiver emotional states at the time of the interview and the patient's current level of symptom burden may have influenced their descriptions (recall bias). Third, our sample was small (N=12), but qualitative research guidelines regarding the minimum sample size required were followed (Guest, Bunce, & Johnson, 2006). There was also strong agreement between participants regarding their unmet needs as indicated by the number who expressed similar unmet needs

and concerns. Thus, while the sample size was small, the fact that similar issues were reiterated time and again by participants suggested thematic saturation, and we deemed it unnecessary to recruit a larger sample. Finally, the reliability and validity of the themes identified from the qualitative interviews should be investigated in a future quantitative study.

In conclusion, couples coping with HNC deal with numerous challenges including physical symptom burden, demanding caregiving responsibilities, and changes in communication and intimacy. These couples may benefit from programs that emphasize the importance of physical and psychological symptom management through the regular practice of stress management and self-care routines. Programs that also provide communication skills training to teach spouses how to effectively motivate patients to engage in self-care may help to minimize spousal conflict over symptom management and help couples navigate treatment and recovery together as a team.

Acknowledgments

This study was supported by a grant from the National Cancer Institute R21CA178478.

References

- Aizer AA, Chen M-H, McCarthy EP, Mendu ML, Koo S, Wilhite TJ, et al. Marital Status and Survival in Patients With Cancer. *Journal of Clinical Oncology*. 2013; 31(31):3869–3876. [PubMed: 24062405]
- Badr H, Yeung C, Lewis MA, Milbury K, Redd WH. An observational study of social control, mood, and self-efficacy in couples during treatment for head and neck cancer. *Psychology & Health*. 2015; 30(7):783–802. [PubMed: 25471820]
- Beesley V, Price M, Webb P. Loss of lifestyle: health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Supportive Care in Cancer*. 2011; 19(12):1949–1956. [PubMed: 21125296]
- Bjorndal K, De Graeff A, Fayers P, Hammerlid E, van Pottelsberghe C, Curran D, et al. A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35) in head and neck patients. *European Journal of Cancer*. 2000; 36(14):1796–1807. [PubMed: 10974628]
- 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; 29(32):4294–4301. [PubMed: 21969503]
- 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, and Prevention*. 2006; 15(11):2203–2208.
- Epstein J, Robertson M, Emerton S, Phillips N, Stevenson-Moore P. Quality of life and oral function in patients treated with radiation therapy for head and neck cancer. *Head & Neck*. 2001; 23(5):389–398. [PubMed: 11295813]
- Faller H, Schuler M, Richard M, Heckl U, Weis J, Küffner R. Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis. *Journal of Clinical Oncology*. 2013 JCO. 2011.2040. 8922.
- Giese-Davis J, Hermanson K, Koopman C, Weibel D, Spiegel D. Quality of couples' relationship and adjustment to metastatic breast cancer. *Journal of Family Psychology*. 2000; 14:251–266. [PubMed: 10870293]
- Girgis, A.; Lambert, S. Caregivers of cancer survivors: the state of the field; Paper presented at the Cancer Forum; 2009.

- Girgis A, Lambert SD, McElduff P, Bonevski B, Lecathelinais C, Boyes A, et al. Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-Oncology*. 2013; 22(7):1557–1564. [PubMed: 22941765]
- Gritz ER, Carmack CL, de Moor CA, Coscarelli A, Schacherer CW, Meyers EG, et al. The first year after head and neck cancer: Quality of life. *Journal of Clinical Oncology*. 1999; 17(1):352–360. [PubMed: 10458254]
- Guest G, Bunce A, Johnson L. How many interviews are enough? *Field methods*. 2006; 18(1):59–82.
- Harding R, Higginson IJ, Donaldson N. The relationship between patient characteristics and carer psychological status in home palliative cancer care. *Supportive Care in Cancer*. 2003; 11(10):638–643. [PubMed: 12905058]
- Herranz J, Gavilán J. Psychosocial adjustment after laryngeal cancer surgery. *Annals of Otolaryngology, Rhinology and Laryngology*. 1999; 108(10):990–997.
- Hodges L, Humphris G, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science and Medicine*. 2005; 60:1–12. [PubMed: 15482862]
- Hodgkinson K, Butow P, Hunt G, Wyse R, Hobbs K, Wain G. Life after cancer: couples' and partners' psychological adjustment and supportive care needs. *Supportive Care in Cancer*. 2007; 15(4):405–415. [PubMed: 17043776]
- Johnson HA, Zabriskie RB, Hill B. The contribution of couple leisure involvement, leisure time, and leisure satisfaction to marital satisfaction. *Marriage & family review*. 2006; 40(1):69–91.
- Konski AA, Pajak TF, Movsas B, Coyne J, Harris J, Gwede C, et al. Disadvantage of men living alone participating in Radiation Therapy Oncology Group head and neck trials. *Journal of Clinical Oncology*. 2006; 24(25):4177–4183. [PubMed: 16943534]
- Lambert SD, Harrison JD, Smith E, Bonevski B, Carey M, Laws C, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ supportive & palliative care*. 2012; 2(3):224–230.
- Lewis MA, Gladstone E, Schmal S, Darbes LA. Health-related social control and relationship interdependence among gay couples. *Health Education Research*. 2006; 21(4):488–500. [PubMed: 16459342]
- Licitra L, Perrone F, Bossi P, Suardi S, Mariani L, Artusi R, et al. High-risk human papillomavirus affects prognosis in patients with surgically treated oropharyngeal squamous cell carcinoma. *J Clin Oncol*. 2006; 24(36):5630–5636. [PubMed: 17179101]
- 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(10):898–903. [PubMed: 19457705]
- Manne S, Badr H. Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer*. 2008; 112(11 Suppl):2541–2555. [PubMed: 18428202]
- McGuire D. Barriers and strategies in implementation of oral care standards for cancer patients. *Supportive Care in Cancer*. 2003; 11(7):435–441. [PubMed: 12692708]
- National Comprehensive Cancer Network. NCCN clinical practice guidelines in oncology: Head and neck cancers version 2.2013. 2013 Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/head-and-neck.pdf.
- National Comprehensive Cancer Network (NCCN). Distress: Treatment guidelines for patients. 2005 Retrieved from http://www.nccn.org/patients/patient_gls/_english/_distress/contents.asp#.
- Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP. The problems experienced by patients with cancer and their needs for palliative care. *Supportive Care in Cancer*. 2005; 13(9):722–732. [PubMed: 15702349]
- Rohleder N, Marin TJ, Ma R, Miller GE. Biologic cost of caring for a cancer patient: dysregulation of pro-and anti-inflammatory signaling pathways. *Journal of Clinical Oncology*. 2009; 27(18):2909–2915. [PubMed: 19433690]
- Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer*. 2000; 88(1):226–237. [PubMed: 10618627]

- Semple C, Parahoo K, Norman A, McCaughan E, Humphris G, Mills M. Psychosocial interventions for patients with head and neck cancer. Cochrane database of systematic reviews (Online). 2013; 7:CD009441.
- Siegel R, Ma J, Zhaohui Z, Jemal A. Cancer statistics, 2014. CA: A Cancer Journal for Clinicians. 2014; 64(1):9–29. [PubMed: 24399786]
- Silverman, S. Oral Cancer. 5th. Vol. 1. Hamilton, Ontario: B.C. Decker; 2003.
- Soothill K, Morris S, Harman J, Francis B, Thomas C, McIlmurray MB. Informal carers of cancer patients: what are their unmet psychosocial needs? Health & social care in the community. 2001; 9(6):464–475. [PubMed: 11846826]
- Strauss, A.; Corbin, J. Basics of qualitative research: Techniques and procedures for developing grounded theory. 2nd. Thousand Oaks, CA: Sage; 1998.
- Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans CR. Distress in spouses and patients after treatment for head and neck cancer. Laryngoscope. 2007; 117(2):238–241. [PubMed: 17277616]
- Zabora J, Brintzenhofeszc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psycho-Oncology. 2001; 10:19–28. [PubMed: 11180574]

Table1

Sample characteristics

	Patients (N=6)	Spouses (N=6)
Gender (%)		
Male	5 (83)	1 (17)
Female	1 (17)	5 (83)
Age in years	$\bar{X}=55.3$, SD=5.9 (Range=51 to 67)	$\bar{X}=50.8$, SD=9.3 (Range=38 to 63)
Race/Ethnicity (%)		
White (non-Hispanic)	3 (50)	1 (17)
White (Hispanic)	--	2 (33)
Black (non-Hispanic)	3 (50)	2 (33)
Asian	--	1 (17)
Married (%)	4 (66)	5 (83)
Length of marriage/relationship in years	$\bar{X}=20.0$, SD=8.9 (Range=12 to 30)	$\bar{X}=21.2$, SD=7.4 (Range=13 to 30)
Type of HNC (%)		
Oropharyngeal	3 (50)	
Other HNCs	3 (50)	
Stage of cancer (%)		
1	2 (33)	
4	4 (67)	
Treatment received (%)		
Radiotherapy (RT) only	1 (17)	
Surgery followed by RT	2 (33)	
Concurrent chemotherapy and radiotherapy (CRT)	2 (33)	
Surgery followed by CRT	1 (17)	
Length of time since completion of radiotherapy	$\bar{X}=2.1$ months, SD=1.80 (Range=.16 to 5.19 months)	
NCCN distress at time of recruitment	$\bar{X}=3.0$, SD=2.8 (Range=0 to 7)	$\bar{X}=5.6$, SD=3.1 (Range=0 to 9)

Table 2

Strategies used by spouses to encourage patient adherence to self-care recommendations

Strategy	Quotes
Monitoring	<p>"I would keep checking back to look to see if he finished the food or the water."</p> <p>"I would monitor how many calories he ate each day...how much protein...I wrote it all down."</p>
Reminding	"He would be like, 'Oh I'm in a lot of pain,'" but I'd just remind him and say, 'Remember, you have to. Here, let's do it.'"
Asking	"He would ask me, 'Did you use the mouth wash? Are you still using it?' Even if he wasn't around me, he would call me and ask, 'Did you do this, did you do that?'"
Encouraging	"He was saying, 'I can't do it.' So I said 'Of course you can do it.'"
Putting things in perspective	<p>"If he did waiver at all, I would tell him it's temporary and remind him to do the physical work necessary [so it would be temporary].</p> <p>I would just tell him, 'Even if it doesn't taste good, you just have to do it.'"</p>
Ensuring easy access to tools/products to facilitate adherence	<p>"I kept stuff by the side of his bed, I kept Ensure and plenty of water -- electrolyzed water, and a little juice, and I would say, 'If you can drink this one, take one sip. Relax. Take another sip.'"</p> <p>"I would make up the baking soda rinses for him and put them in the bathroom for him to use."</p>