Published in final edited form as:

J Cancer Surviv. 2017 December ; 11(6): 822–832. doi:10.1007/s11764-017-0621-4.

Development of a Survivorship Needs Assessment Planning Tool for Head and Neck Cancer Survivors and Their Caregivers: A Preliminary Study

KR Sterba^{1,2}, J Zapka^{1,2}, N LaPelle³, TK Garriss^{2,4}, A Buchanan^{1,2}, M Scallion^{1,2}, and T Day^{2,4}

¹Department of Public Health Sciences, Medical University of South Carolina, Charleston, SC

²Hollings Cancer Center, Medical University of South Carolina, Charleston, SC

³Division of Behavioral Medicine, University of Massachusetts Medical School, Amherst, MA

⁴Department of Otolaryngology-Head and Neck Surgery, Medical University of South Carolina, Charleston, SC

Abstract

Purpose—The purpose of this study was to characterize primary end-of-treatment challenges in head and neck cancer (HNC) to drive the development of a survivorship needs assessment planning (SNAP) tool and evaluate its acceptability and feasibility.

Methods—Using qualitative methods (focus groups, interviews), we identified physical, emotional and social post-treatment challenges from the perspectives of survivors (N=17), caregivers (N=14) and healthcare providers (N=14) and pretested the SNAP tool. After Advisory Board ratings and consensus, the tool was finalized.

Results—Survivors, caregivers and clinicians consistently highlighted the importance of assessing *symptoms and functional abilities* (e.g., dry mouth, speech/swallowing difficulties, weight loss), *health behaviors* (e.g., smoking, alcohol), *emotional concerns* (e.g., depression, isolation, nutritional distress) and *social challenges* (e.g., support, finances). Caregivers were overwhelmed and intensely focused on survivors' nutrition and trach/feeding tube care while clinicians emphasized financial and access concerns. Most participants were enthusiastic about the tool and directed a flexible care plan design due to variability in dyad needs. Over 75% reported high comfort using and navigating questions on a tablet and were in strong agreement that the care plan would help families practically and emotionally. Coordination of survivorship visits with follow-up care was critical to address travel and time barriers. While survivors and clinicians recommended waiting 1–6 months after treatment, caregivers preferred earlier survivorship visits.

Conclusions—Results pinpointed optimal end-of-treatment domains for routine assessment and support the feasibility of implementing a SNAP tool in the clinic.

Corresponding Author: Katherine R. Sterba, PhD, MPH, Medical University of South Carolina, 68 President Street MSC 955, Charleston, SC 29425, 843-876-2419 (telephone), 843-876-2344 (fax); sterba@musc.edu.

Conflict of Interest: The authors declare that they have no conflict of interest.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

Implications for Cancer Survivors—Capitalizing on technology to direct HNC survivorship care is promising.

Keywords

head and neck cancer; survivorship; patient-reported outcomes; dyads

Introduction

Despite growing national attention on survivorship care [1–5], little is known about how to address the significant challenges head and neck cancer (HNC) survivors and their caregivers face at the transition from treatment to the post-treatment period [6]. The post-treatment HNC recovery period can bring severe consequences due to impairments in physical and social functioning (*e.g.*, problems with communication, swallowing, disfigurement) [7–11]. Also, an intense follow-up care regimen with multiple specialists is typically required [12, 13]. There may be other possible challenges such as risky health behaviors [14, 15] and potentially unique post-treatment needs in the growing population of HNC survivors with human papilloma virus (HPV)-positive tumors [16–18]. Furthermore, the informal family caregivers of HNC survivors may have special needs after treatment when they take on unique roles and responsibilities such as wound care and assistance with speech and nutrition [19, 8, 20]. HNC survivorship interventions are therefore needed to assess and address survivor-caregiver needs at the end of treatment.

Technological advances and widespread use of the electronic medical record have increased opportunities for the development of systems for the assessment of patient-reported outcomes in oncology clinics, addressing practical barriers to facilitate systematic assessments as part of standard practice [21–24]. This work has demonstrated promise for improving quality of life and care utilization outcomes in cancer patients [25, 26]. Extending this opportunity to address the specialized needs of HNC survivors and their caregivers [27] has high potential. For example, technology can overcome HNC survivors' speech barriers after treatment with the use of touchscreen tablet-based computers for data collection [22], also providing privacy for collecting data from survivor/caregiver dyads. Given the heterogeneous recovery experiences faced in HNC [9, 11], technology can also automate the targeted identification of high-priority needs, accommodate both survivor and caregiver perspectives and drive timely links to resources.

The overall goal of this study was to develop and pretest a specialized touchscreen tablet-based survivorship needs assessment planning (SNAP) tool whose purpose was to assess HNC survivor and caregiver needs after treatment and generate tailored care plans to prepare dyads for the post-treatment period. To meet this goal, the specific aims of this study were to 1) characterize primary HNC end of treatment challenges from the perspectives of survivors, caregivers and health care providers to drive the content of the SNAP needs assessment tool and map appropriate resources to address needs and 2) evaluate the acceptability and feasibility of the SNAP tool and care plan for future use in the HNC clinic.

Methods

Using a stepped process guided by the *International Society for Quality of Life Research* User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice [28, 29], we used qualitative methods (key informant interviews with HNC survivors and caregivers, and focus groups or individual interviews with multi-disciplinary health care providers) and expert panel ratings and consensus.

Recruitment and Study Procedures

After approval by the Institutional Review Board at the Medical University of South Carolina, HNC survivors with stage I-IVA cancers of the upper aerodigestive tract, who completed treatment (any combination of surgery, chemotherapy and/or radiation) within the past 2 years were identified using clinic rosters. Potential participants were mailed a study letter and called to discuss potential study participation. Interested participants were asked to nominate their primary caregivers (*i.e.*, spouse, family member, friend) to also participate. Multidisciplinary HNC health care providers at the same cancer center and from regional referring practices were contacted by email and phone to discuss participation in a focus group or individual interview. All focus groups and interviews were scheduled at a convenient time for participants. All participants signed informed consents and were provided with a gift card to thank them for participation.

Guiding Models and Data Collection

We used a broad quality of life framework [30] to develop a semi-structured interview guide to examine post-treatment challenges (physical, emotional, social, and other) and follow-up care experiences and practices from each perspective. Survivors and caregivers were asked to reflect on their post-treatment experiences and describe how they were feeling physically and emotionally at the end of treatment, in the early months after completing treatment and in the year following treatment completion. They were asked about what expectations they had about recovery and about interactions with health care providers (*i.e.*, which providers they saw and how often, how care was coordinated and whether they were given written materials). Lastly, they were asked about interactions with family and friends and what was most helpful or unhelpful during their recovery. Providers were asked to describe the main physical and emotional challenges faced by their patients and their caregivers at the end of treatment and about their typical follow-up care, communication and care coordination practices.

In the final part of the interview, participants completed a mock needs assessment by tablet computer. The needs assessment interface was designed with one question per page, large font and bright colors with 10 example questions concerning symptoms, unmet needs and health behaviors. Participants were instructed to tap the button matching their response for each item and then hit the next button. Participants also reviewed a mock written care plan with a cover page outlining an example HNC survivor's clinical characteristics (care team, diagnosis, and treatment types) followed by three additional sections with messages, referrals and educational materials. After completing this demonstration and care plan review, participants provided feedback on their experiences using the tablet computers and

on the content and format of the needs assessment and care plan. Lastly, participants were asked to describe preferred timing for a survivorship visit.

Key informant interviews and focus groups lasted approximately 45–60 minutes, were digitally recorded and transcribed for analysis. Survivors and caregivers completed a brief questionnaire after the interview to report demographic (age, race, sex, marital status, years of education, health insurance) and clinical (cancer site and stage, treatment type, time since treatment completion, number of doctors seen for follow-up care) characteristics and acceptability (their comfort holding/using the tablet, reading questions, moving from question to question and following instructions on a scale from 1=Not at All Comfortable to 5=Extremely Comfortable). They also reported their agreement (1=Strongly Disagree to 6=Strongly Agree) with whether the information provided in the care plan was helpful emotionally and practically.

Concurrent with interviews and focus groups, we completed individual interviews with Clinical Advisory Board members (N=10; Surgeon, Radiation Oncologist, Medical Oncologist, Nurse Navigator, Maxillofacial Prosthodontist, Smoking Cessation Pharmacist, Social Worker, Oncology Dietitian, Clinical Psychologist, and Speech Pathologist) to determine priority item domains. Board members commonly endorsed use of single items as a screening tool rather than multi-item validated questionnaires to decrease respondent burden [29]. The item selection process was dynamic and after Advisory Board guidance with consideration of local resource availability, items were identified and drafted and Board members completed surveys rating the importance of each potential item (1=Not at All Important to 4=Extremely Important) and an in-person group meeting was held to achieve consensus on SNAP tool content and match each final item to resources.

Data Analysis

Data from transcriptions of digital recordings of interviews with survivor/caregiver dyads and provider focus groups were analyzed using rigorous content analysis methods for systematic theme identification [31–33]. Codebooks were developed by reading and rereading all transcripts, outlining and organizing the key themes addressed by participants as they related to the study purpose. The evolving codebooks and schemata (comparison tables) became templates for the more formal analysis of the transcripts. A template style of analysis [34] was used and two detailed findings comparison tables [35] were constructed as part of the codebooks, with one for survivor/caregiver data and one for provider data. Participant characteristics and acceptability ratings were summarized by role (survivor and caregiver) and Clinical Advisory Board ratings were summarized and ranked.

Results

Participant Characteristics

Thirty-one survivors and caregivers were interviewed. Fourteen interviews were conducted with pairs of survivors and their caregivers (71% spouse/partner) and three additional individual interviews were conducted with survivors alone. Participants had varied clinical and demographic characteristics (Table 1). The majority of survivors were European

American males who nominated female caregivers. Participants' age and education levels varied widely and the majority of survivors had stage IVA cancer, completed at least two treatment types and completed treatment over one year ago. Over half of survivors currently received cancer-related follow-up care from 3 or more specialists.

Twelve health care providers who treated and provided follow-up care for HNC patients participated in a set of three focus groups and 2 providers participated in individual telephone interviews. Participating providers were predominantly female (64%), European American (93%) and had been in practice an average of 7 years (range 0.5–17). A wide variety of specialists were represented including surgeons, radiation oncologists, Ear, Nose and Throat (ENT) specialists, Nurse Practitioners, clinic nurses, maxillofacial and speech/swallowing specialists and others (e.g., dietitian, discharge case manager).

Post-Treatment Physical, Emotional and Social Challenges

Three main HNC post-treatment physical challenge themes were reported by participants including struggling with *symptom management*, *functional abilities and daily activities* and *addictions* (Table 2, Section A). First, survivors, caregivers and health care providers consistently highlighted the prevalent difficulties related to managing appearance concerns as well as dry mouth, speech/swallowing issues and problems with sense of taste and nutritional impairments (e.g., mucus, choking) and their consequences (e.g., severe weight loss). Caregivers also uniquely shared their own caregiving concerns as they assisted survivors with their symptoms and frequently reported worry and a lack of self-efficacy (e.g., to assist with trachea tube management). Providers uniquely emphasized the unpredictable nature of symptoms during HNC recovery. Second, expectations on achieving improved functioning and getting back to former abilities were commonly mentioned, and both survivors and caregivers described desiring a more rapid return to normal and the need to change their expectations over the course of recovery. Third, smoking and alcohol use behaviors represented common physical challenges reported most frequently by caregivers and providers rather than patients, with providers emphasizing difficulties in linking family caregivers to cessation resources.

Four main emotional challenge themes at the end of treatment included *depression and anxiety*, *uncertainty*, *isolation and nutritional distress* (Table 2, Section B). Survivors, caregivers and providers described the emotional consequences of managing symptoms and the worry and uncertainty about recovery timelines, recurrence and dealing with unpredictable symptoms. Providers often expressed the need for more resources to address these emotional challenges in families. Survivors and providers commonly described isolation resulting from coping with recovery challenges and caregivers described their own isolation due to a lack of confidence in their roles as caregivers. A clear distinct theme of *nutritional distress* also emerged from the perspectives of survivors, caregivers and health care providers focusing on the physical and emotional challenges associated with weight loss and feeding tube management.

Social challenges centered on three themes including intense *support* needs, the importance of *communication and interactions with health care providers* and *financial concerns* during the recovery period (Table 2, Section C). Survivors, caregivers and health care providers

consistently highlighted the benefits, yet challenges of depending on family for support, and caregivers and providers uniquely commented on caregiver support needs and the benefits caregivers gained from talking to other families and from their faith. Survivors often reported appreciation for caregivers' efforts. Survivors and caregivers described interactions and discussions with health care providers after treatment as focused on what to expect with several highlighting frustration because they were told that "everybody's different". Several survivors and their caregivers described the benefits of working together to try to understand and manage information received from providers. Employment concerns were raised when survivors could not return to work, often due to functional limitations, when insurance did not cover needed supplies or services, and when employed caregivers faced competing demands at home and work. Importantly, support needs were described as dynamic over time.

Cancer Follow-Up Care Experiences

Patterns of follow-up care (type and frequency) varied widely and were complex; participants perceived that every effort was made to coordinate their multiple visits and tests to accommodate scheduling concerns. Provider follow-up care practices and messages varied by specialty. For example, while a specific plan of follow-up appointments and tests was described by surgeons, medical oncologists and radiation oncologists, other specialists such as speech pathologist, dietitian and dental visits often varied by clinical factors such as adherence to exercises, weight loss and prosthesis needs, respectively. Survivors and caregivers reported receipt of some written materials from providers throughout their treatment but none experienced a formal end-of-treatment visit. Reported barriers to follow-up care included coordination of multiple providers, lack of convenient access to local specialists, and transportation and financial concerns. Providers, survivors and caregivers commonly highlighted tests (e.g., a 3-month scan) and improved function (e.g., taste improvement, swallowing gains, shoulder and neck mobility improvement), as important recovery milestones. Honest discussions regarding expectations, even when timelines are uncertain, were desired.

SNAP Tool Pretesting

Overall, participants were enthusiastic about a survivorship program to help facilitate the transition to the post-treatment period. As described by one participant,

"I think that a survivorship visit is wonderful. You don't want cancer to be your identity. It's what you're experiencing, it's what you have, but it's not your life. But when you have 30 days of radiation, every single day, that is your life; then, all of a sudden it's your last day... You've been through the journey and then you leave and you're happy to be gone, but in some ways it's a loss. So having something like this is like 'Okay, I still have the support'."

Participants were generally comfortable using the tablets to complete the needs assessment questions and considered the care plan helpful. Ten survivor/caregiver pairs stated explicitly that they thought a survivorship program would have been a positive support after their intense treatment experience. However, a number of respondents (n=4) voiced concerns that

a program would have to be flexible because every survivor experiences different needs. Participants urged that a program should address both survivor and caregiver concerns.

Needs Assessment Content and Care Plan Format—Participants confirmed the importance of assessing survivor symptoms, unmet needs and health behaviors and also recommended assessing the caregiver's perspectives on survivor's symptom management abilities as well as caregiver's emotional needs after treatment. Survivors, caregivers and clinicians consistently highlighted the importance of assessing a comprehensive set of symptoms in survivors and it was recommended that the needs assessment focus on symptom experiences within the past month (rather than week or day) to capture the full recent experience of HNC survivors. The physical, emotional, and social factor themes highlighted in interviews were confirmed as key primary needs assessment domains. Notably, it was recommended that it is critical to assess both nutritional status and satisfaction with status, and participants highlighted that alignment of survivor and caregiver nutritional goals may be helpful. Participants also emphasized the importance of assessing common fears about recurrence and several also recommended including questions related to physical activity and fitness. When reflecting on care plan design, survivors and caregivers desired both practical tips and support and encouragement regarding symptoms and emotional concerns. Providers shared concerns about patient literacy level and that it was challenging to provide direct referrals to caregivers when they were not their patients.

Acceptability—The majority of participants reported high comfort (i.e., being extremely or very comfortable) holding tablets (94% survivors, 77% caregivers) and using tablets to read (94% survivors, 92% caregivers) and answer (94% survivors, 85% caregivers) questions. The majority also reported high comfort in following instructions for questions (94% survivors, 92% caregivers) and moving from one question to another (94% survivors, 85% caregivers). Also, most were in strong agreement that the information provided in the care plan was helpful emotionally (94% survivors, 92% caregivers) and practically (94% survivors, 92% caregivers). Providers generally reported favorable impressions of the written care plan but highlighted time and clinic space availability as barriers to SNAP visit implementation.

Timing—When asked about preferred timing for a survivorship visit, coordination with routine follow-up for survivorship visits was described as critical to address travel and time concerns. While survivors and clinicians recommended waiting 1–6 months after treatment, caregivers preferred earlier visits. Providers commonly noted that timing should be tailored to the survivor's particular scenario ("when they are ready to take it in").

Resource Identification and Matching

With guidance from interviews and focus groups and consideration of available local resources, Clinical Advisory Board member individual interviews guided the identification of a comprehensive set of priority needs. We relied on two main validated instruments to assess head and neck cancer-specific symptoms [36, 37] and unmet needs [38, 39] and a set of individual investigator-developed items. The list was refined in an iterative fashion by the study team; domains of interest were dropped when deemed overlapping with other items or

when local resources could not be identified (e.g., no formal palliative care program was available at the time, housing resources were limited and not typically needed after treatment, caregiver-focused nutritional support resources were absent). We also removed domains that were considered vague (e.g., worry about health, need for high quality care) as they could vary in meaning and were therefore difficult to match with resources. The remaining list was rated individually by Advisory Board members and finalized after the Board reviewed the group's average ratings and engaged in a consensus discussion to match local resources for care plan content, including messages, educational materials from national sources, and local referrals for each high-priority item (see Table 3 for ranked final domains and the Appendix for survivor and caregiver items). Three additional caregiver items (caregiver burden, concerns about communicating with survivor, and worries about their own health) were added after discussion. Referrals included three programs (Behavioral Medicine, Alcohol Management, Smoking Cessation), and multiple specialist appointments (Dietitian, Social Worker, Speech Pathologist, Chaplain, Maxillofacial Prosthodontist, Financial Counselor, Physical Therapist, Head and Neck Oncology Team).

Discussion

Evidence is increasing concerning the benefits of incorporating automated patient-reported outcome assessment systems into clinical practice with effective programs to train clinicians to use these systems [40, 41, 25]. HNC survivors and their caregivers face unique recovery challenges and caregiving tasks [9, 11, 8, 20, 19] and based on the complexity and variability in their experiences [13], may especially benefit from completing a comprehensive needs assessment and receiving a tailored care plan after treatment. In this study, we developed and pretested a tablet-based survivorship needs assessment planning tool. Our qualitative work guided the development of the SNAP tool by confirming optimal end-of-treatment domains [42–44] for routine assessment after HNC treatment and finding that survivors, caregivers and head and neck oncology providers considered the tool useful and feasible. These results are promising as previous research has demonstrated it is feasible to collect patient-reported outcomes in diverse HNC patients [45, 46].

From the perspectives of survivors, caregivers and health care providers and consistent with the literature [43, 9, 11, 44], high-priority end of treatment needs assessment domains included a comprehensive set of HNC-specific symptoms, emotional and social concerns and health behaviors. Importantly, it was recommended that the most critical recovery items (e.g., symptom management abilities, teamwork in dyads (survivors and caregivers abilities to work together), survivor nutritional status) be assessed from both the survivor and caregiver view. While national guidelines direct survivorship visits to be held at end of treatment [47], our findings highlighted that HNC survivors may not be ready for this visit until they have completed their initial recovery period. However, because caregivers preferred earlier intervention, it is possible that a dynamic delivery approach for HNC dyadic survivorship care (e.g., addressing some high-priority caregiver needs at the end of treatment and holding a clinic visit for both survivors and caregivers later in the recovery period) may be ideal so both survivor and caregiver needs can be met in a timely fashion [48–50].

Overall, SNAP was viewed favorably by survivors, caregivers and health care providers and few challenges were experienced with the technology. Time and space barriers highlighted by providers clearly point to the need for training of providers to understand the benefits of building systems into routine practice to improve patient outcomes. Our results also guided the content and format of a tailored HNC care plan. In addition to clinical information (care team, diagnosis, treatment and follow-up care plan), three resource sections (messages, referrals and educational resources) were rated favorably by participants and directed the need for both practical tips and support and encouragement regarding symptom management and emotional concerns in HNC care plans. Survivors and caregivers also recommended framing messages to clarify recovery timelines when possible. Providers highlighted the importance of considering needed referrals in caregivers, particularly for problems with smoking and drinking.

Building on prior HNC mHealth intervention studies [51–54], this research highlights the promise of technology to streamline identification and management of high-priority survivorship concerns [44, 9] in dyads. Research continues to highlight that the burden of patient-reported outcome assessment can be alleviated when built into clinic systems as part of standard care [55]. Education may be needed to improve oncology provider openness to these systems [40].

Strengths and Limitations

This study used rigorous qualitative methods to develop and pre-test the SNAP tool and relied on the input of key stakeholder groups and an expert Clinical Advisory Board to drive development of a system that will be acceptable and feasible to assess and address HNC dyads' needs after treatment. However, our sample size was limited and recruitment took place in a single cancer center so further research is needed to see if findings apply beyond this group. Also, the majority of survivors in this study received surgery in addition to radiation and/or chemotherapy and it is important to consider whether survivors receiving other treatment types (e.g., radiation only) may have unique needs. It is critical to take the next steps to extend the study of this tool to consider the generalizability of these findings to other cancer center settings and with survivors with diverse clinical characteristics and treatment types.

Conclusion

A flexible approach to HNC survivorship programs is needed with tailoring to match the dynamic needs of HNC survivors and their caregivers. It is critical to assess and address both survivor and caregiver needs, but caregivers may need resources earlier than survivors. Next steps will require testing the SNAP tool in real-time in the HNC clinic, and future studies are needed to examine a comprehensive set of survivor and caregiver outcomes including unmet needs, quality-of-life and adherence to follow-up care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This research was funded by a National Cancer Institute (R21CA173271) with database support from the South Carolina Clinical and Translational Research Institute (NIH UL1TR000062) and technology development by the Technology Applications Center for Healthful Lifestyles at the Medical University of South Carolina. Katherine Sterba's work on this manuscript was also supported by a Mentored Research Scholar Grant in Applied and Clinical Research (MRS-G-12-221-01-CPPB) from the American Cancer Society.

References

1. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. *Cancer Epidem Biomar*. 2011; 20(10):1996–2005. DOI: 10.1158/1055-9965.EPI-11-0729
2. Hudson SV, Chubak J, Coups EJ, Blake-Gumbs L, Jacobsen PB, Neugut AI, et al. Identifying key questions to advance research and practice in cancer survivorship follow-up care: a report from the ASPO Survivorship Interest Group. *Cancer Epidem Biomar*. 2009; 18(7):2152–4. DOI: 10.1158/1055-9965.EPI-18-7-ASPO01
3. Hewitt, ME., Greenfield, S., Stovall, E. From cancer patient to cancer survivor: lost in translation. Washington DC: The National Academies Press; 2006.
4. Grunfeld E, Earle CC. The interface between primary and oncology specialty care: treatment through survivorship. *J Natl Cancer I*. 2010; 2010(40):25–30. DOI: 10.1093/jncimonographs/lgq002
5. Bhatia S, Robison LL. Cancer survivorship research: opportunities and future needs for expanding the research base. *Cancer Epidem Biomar*. 2008; 17(7):1551–7. DOI: 10.1158/1055-9965.EPI-08-0490
6. Miller MC, Shuman AG. American Head and Neck Society's Committee on Survivorship. Survivorship in Head and Neck Cancer: A Primer. *JAMA Otolaryngol Head Neck Surg*. 2016; 142(10):1002–8. DOI: 10.1001/jamaoto.2016.1615 [PubMed: 27414519]
7. De Boer MF, McCormick LK, Pruyn JF, Ryckman RM, van den Borne BW. Physical and psychosocial correlates of head and neck cancer: a review of the literature. *Otolaryngol Head Neck Surg*. 1999; 120(3):427–36. doi:S0194599899000789 [pii]. [PubMed: 10064650]
8. Longacre ML, Ridge JA, Burtneiss BA, Galloway TJ, Fang CY. Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncol*. 2012; 48(1):18–25. DOI: 10.1016/j.oraloncology.2011.11.012 [PubMed: 22154127]
9. Murphy BA, Deng J. Advances in supportive care for late effects of head and neck cancer. *J Clin Oncol*. 2015; 33(29):3314–21. DOI: 10.1200/JCO.2015.61.3836 [PubMed: 26351334]
10. 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. *Crit Rev Oncol Hematol*. 2007; 62(3):251–67. [doi]. DOI: 10.1016/j.critrevonc.2006.07.005 [PubMed: 17408963]
11. Ringash J. Survivorship and quality of life in head and neck cancer. *J Clin Oncol*. 2015; 33(29):3322–7. DOI: 10.1200/JCO.2015.61.4115 [PubMed: 26351336]
12. Klabunde CN, Ambs A, Keating NL, He Y, Doucette WR, Tisnado D, et al. The role of primary care physicians in cancer care. *J Gen Intern Med*. 2009; 24(9):1029–36. DOI: 10.1007/s11606-009-1058-x [PubMed: 19597893]
13. National Comprehensive Cancer Network practice guidelines in oncology: head and neck cancers V.1.2016. [Accessed 2 January 2016] 2016. http://www.nccn.org/professionals/physician_gls/PDF/head-and-neck.pdf
14. Blot WJ, McLaughlin JK, Winn DM, Austin DF, Greenberg RS, Preston-Martin S, et al. Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res*. 1988; 48(11):3282–7. [PubMed: 3365707]
15. 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. *JNCI-J Natl Cancer I*. 2007; 99(10):777–89. DOI: 10.1093/jnci/djk179
16. Chaturvedi AK, Engels EA, Anderson WF, Gillison ML. Incidence trends for human papillomavirus-related and -unrelated oral squamous cell carcinomas in the United States. *J Clin Oncol*. 2008; 26(4):612–9. DOI: 10.1200/JCO.2007.14.1713 [PubMed: 18235120]

17. Nygard M, Aagnes B, Bray F, Moller B, Mork J. Population-based evidence of increased survival in human papillomavirus-related head and neck cancer. *Eur J Cancer*. 2012; 48(9):1341–6. DOI: 10.1016/j.ejca.2012.03.014 [PubMed: 22516210]
18. Ragin CC, Taioli E. Survival of squamous cell carcinoma of the head and neck in relation to human papillomavirus infection: review and meta-analysis. *Int J Cancer*. 2007; 121(8):1813–20. DOI: 10.1002/ijc.22851 [PubMed: 17546592]
19. Sterba KR, Zapka J, Cranos C, Laursen A, Day T. Quality-of-life in head and neck cancer patient-caregiver dyads: A systematic review. *Cancer Nurs*. 2016; 39(3):238–50. DOI: 10.1097/NCC.0000000000000281 [PubMed: 26121180]
20. Penner JL, McClement S, Lobchuk M, Daeninck P. Family members' experiences caring for patients with advanced head and neck cancer receiving tube feeding: a descriptive phenomenological study. *J Pain Symptom Manage*. 2012; 44(4):563–71. DOI: 10.1016/j.jpainsymman.2011.10.016 [PubMed: 22699088]
21. Abernethy AP, Ahmad A, Zafar SY, Wheeler JL, Reese JB, Lyerly HK. Electronic patient-reported data capture as a foundation of rapid learning cancer care. *Med Care*. 2010; 48(6 Suppl):S32–8. DOI: 10.1097/MLR.0b013e3181db53a4 [PubMed: 20473201]
22. Abernethy AP, Herndon JE 2nd, Wheeler JL, Patwardhan M, Shaw H, Lyerly HK, et al. Improving health care efficiency and quality using tablet personal computers to collect research-quality, patient-reported data. *Health Serv Res*. 2008; 43(6):1975–91. DOI: 10.1111/j.1475-6773.2008.00887.x [PubMed: 18761678]
23. Sharma P, Dunn RL, Wei JT, Montie JE, Gilbert SM. Evaluation of point-of-care PRO assessment in clinic settings: integration, parallel-forms reliability, and patient acceptability of electronic QOL measures during clinic visits. *Qual Life Res*. 2016; 25(3):575–83. DOI: 10.1007/s11136-015-1113-5 [PubMed: 26373852]
24. Donaldson MS. Taking PROs and patient-centered care seriously: incremental and disruptive ideas for incorporating PROs in oncology practice. *Qual Life Res*. 2008; 17(10):1323–30. DOI: 10.1007/s11136-008-9414-6 [PubMed: 18991021]
25. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol*. 2016; 34(6):557–65. DOI: 10.1200/JCO.2015.63.0830 [PubMed: 26644527]
26. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol*. 2014; 32(14):1480–501. DOI: 10.1200/JCO.2013.53.5948 [PubMed: 24711559]
27. Chen SC, Tsai MC, Liu CL, Yu WP, Liao CT, Chang JT. Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nurs*. 2009; 32(6):473–81. DOI: 10.1097/NCC.0b013e3181b14e94 [PubMed: 19816161]
28. International Society for Quality of Life Research. [Accessed 26 September 2016] (prepared by Aaronson N ET, Greenhalgh J, Halyard M, Hess R, Miller D, Reeve B, Santana M, Snyder C). User's guide to implementing patient-reported outcomes assessment in clinical practice version 2. 2015. <http://www.isoqol.org/research-publications/isoqol-publications>
29. Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Halyard MY, et al. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res*. 2012; 21(8):1305–14. DOI: 10.1007/s11136-011-0054-x [PubMed: 22048932]
30. Ferrell BR, Hassey Dow K. Quality of life among long-term cancer survivors. *Oncology*. 1997; 11(4):565–8. [PubMed: 9130276]
31. Fonteyn ME, Vettese M, Lancaster DR, Bauer-Wu S. Developing a codebook to guide content analysis of expressive writing transcripts. *Appl Nurs Res*. 2008; 21(3):165–8. DOI: 10.1016/j.apnr.2006.08.005 [PubMed: 18684411]
32. Krueger, R. Analyzing and reporting focus group results. In: Morgan, DLKR., King, JA., editors. *The focus group kit*. Thousand Oaks, CA: Sage; 1998.

33. LaPelle N. Simplifying qualitative data analysis using general purpose software tools. *Field Methods*. 2004; 16(1)
34. Crabtree, BF., Miller, WL. *Doing qualitative research in primary care: Multiple strategies*. 2. Newbury Park, CA: Sage Publications; 1999.
35. Miles, MB., Huberman, AM. *Qualitative data analysis*. 2. Thousand Oaks, CA: Sage Publications; 1994.
36. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, Engstrom MC. Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. *Cancer*. 2000; 89(7): 1634–46. DOI: 10.1002/1097-0142(20001001)89:7<1634::AID-CNCR29>3.0.CO;2-V [PubMed: 11013380]
37. Rosenthal DI, Mendoza TR, Chambers MS, Burkett VS, Garden AS, Hessel AC, et al. The M. D. Anderson symptom inventory-head and neck module, a patient-reported outcome instrument, accurately predicts the severity of radiation-induced mucositis. *Int J Radiat Oncol Biol Phys*. 2008; 72(5):1355–61. [PubMed: 18501527]
38. Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G. Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psychooncology*. 2007; 16(9):805–13. [PubMed: 17177180]
39. Hodgkinson K, Butow P, Hunt GE, et al. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psychooncology*. 2007; 16:796–804. 2007. [PubMed: 17177268]
40. Santana MJ, Haverman L, Absolom K, Takeuchi E, Feeny D, Grootenhuis M, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Qual Life Res*. 2015; 24(7):1707–18. DOI: 10.1007/s11136-014-0903-5 [PubMed: 25589231]
41. Basch E. Patient-reported outcomes - Harnessing patients' voices to improve clinical care. *N Engl J Med*. 2017; 376(2):105–8. DOI: 10.1056/NEJMp1611252 [PubMed: 28076708]
42. So WK, Chan RJ, Chan DN, Hughes BG, Chair SY, Choi KC, et al. Quality-of-life among head and neck cancer survivors at one year after treatment--a systematic review. *Eur J Cancer*. 2012; 48(15):2391–408. DOI: 10.1016/j.ejca.2012.04.005 [PubMed: 22579456]
43. Chera BS, Eisbruch A, Murphy BA, Ridge JA, Gavin P, Reeve BB, et al. Recommended patient-reported core set of symptoms to measure in head and neck cancer treatment trials. *JNCI-J Natl Cancer I*. 2014; 106(7)doi: 10.1093/jnci/dju127
44. Ringash J, Bernstein LJ, Cella D, Logemann J, Movsas B, Murphy B, et al. Outcomes toolbox for head and neck cancer research. *Head Neck*. 2015; 37(3):425–39. DOI: 10.1002/hed.23561 [PubMed: 24318166]
45. Pollom EL, Wang E, Bui TT, Ognibene G, von Eyben R, Divi V, et al. A prospective study of electronic quality of life assessment using tablet devices during and after treatment of head and neck cancers. *Oral Oncol*. 2015; 51(12):1132–7. DOI: 10.1016/j.oraloncology.2015.10.003 [PubMed: 26475062]
46. de Bree R, Verdonck-de Leeuw IM, Keizer AL, Houffelaar A, Leemans CR. Touch screen computer-assisted health-related quality of life and distress data collection in head and neck cancer patients. *Clin Otolaryngol*. 2008; 33(2):138–42. DOI: 10.1111/j.1749-4486.2008.01676.x [PubMed: 18429869]
47. American College of Surgeons. [Accessed 2 January 2017] Cancer program standards 2016: Ensuring patient-centered care. 2016. <https://www.facs.org/quality-programs/cancer/coc/standards>
48. Badr H, Krebs P. A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology*. 2013; 22(8):1688–704. DOI: 10.1002/pon.3200 [PubMed: 23045191]
49. Badr H, Smith CB, Goldstein NE, Gomez JE, Redd WH. Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer*. 2015; 121(1):150–8. DOI: 10.1002/cncr.29009 [PubMed: 25209975]
50. 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. *Psychol Health*. 2015; 30(7):783–802. DOI: 10.1080/08870446.2014.994633 [PubMed: 25471820]

51. Head BA, Keeney C, Studts JL, Khayat M, Bumpous J, Pfeifer M. Feasibility and acceptance of a telehealth intervention to promote symptom management during treatment for head and neck cancer. *J Support Oncol*. 2011; 9(1):e1–e11. DOI: 10.1016/j.suponc.2010.12.006 [PubMed: 21499540]
52. 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. *Telemed J E Health*. 2009; 15(1):44–52. DOI: 10.1089/tmj.2008.0061 [PubMed: 19199847]
53. van den Brink JL, Moorman PW, de Boer MF, Pruyn JF, Verwoerd CD, van Bommel JH. Involving the patient: a prospective study on use, appreciation and effectiveness of an information system in head and neck cancer care. *Int J Med Inform*. 2005; 74(10):839–49. DOI: 10.1016/j.ijmedinf.2005.03.021 [PubMed: 16043392]
54. van den Brink JL, Moorman PW, de Boer MF, Hop WC, Pruyn JF, Verwoerd CD, 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. *J Am Med Inform*. 2007; 14(2):198–205. DOI: 10.1197/jamia.M2199
55. Schougaard LM, Larsen LP, Jessen A, Sidenius P, Dorflinger L, de Thurah A, et al. AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases. *Qual Life*. 2016; 25(3):525–34. DOI: 10.1007/s11136-015-1207-0

Table 1

Participant Characteristics

Characteristic		Survivor N=17	Caregiver N=14
Age (mean, range)		59 (33–75)	61 (29–83)
Sex (% male)		59	43
Race (% European American)		94	93
Education			
	% High School/GED (General Educational Development test)	29	36
	% Some College	41	21
	% College Graduate	29	43
Employment Status			
	% Employed	25	35.7
	% Retired	44	57.6
	% Unemployed/Receiving Disability	38	14.2
Insurance			
	% Private/HMO	53	
	% Medicare	29	--
	% Medicaid	12	
	% Self-pay/No insurance	18	
Cancer Stage			
	% I-III	41	--
	% IVA	59	
Cancer Site			
	% Lip/Oral Cavity	29	--
	% Oropharynx	18	
	% Larynx	29	
	% Other	24	
Time Since Treatment Completion			
	% 12 months	41	--
	% 13–24 months	59	
Treatment Type			
	% Surgery	82	
	% Chemotherapy	59	--
	% Radiation	82	
Number of Doctors Seen for Cancer Follow-up Care			
	% None	6	
	% One	6	
	% Two	29	--
	% Three	35	
	% Four	18	
	% Five or more	6	

Table 2

Primary Post-Treatment Challenges and Exemplary Quotes in Head and Neck Cancer Survivors, Caregivers and Health Care Providers

Theme	Summary	Survivor Comments	Caregiver Comments	Provider Comments
A. Physical Challenges				
Symptom Management	Coping with the management of appearance changes, dry mouth, speech/swallowing, sense of taste, mucus and other related nutritional intake concerns.	<ul style="list-style-type: none"> <i>I worry about ever being able to speak again.</i> Having surgery last was stressful because I saw others who had it first and were horribly disfigured. I was worried... <i>My teeth began chipping/abscessing/bleeding from being radiated.</i> 	<ul style="list-style-type: none"> It is very scary dealing with a trach... <i>It was tough when she could not speak; she used sign language that was hard to understand at first.</i> <i>More resources [needed] for the caregiver... especially focusing on the patient's physical side effects.</i> 	<ul style="list-style-type: none"> Patients/caregivers don't have skills to take care of trachs. (Nurse Practitioner) Patients want some guidance and resources for all of the major symptoms. (Medical Oncologist)
Functional Abilities and Daily Activities	Perspectives on recovery challenges and goals to achieve improved functional status and former abilities.	<ul style="list-style-type: none"> <i>I hoped I'd be normal and could get right back to work, but I don't think there is ever going to be a normal.</i> <i>Everything in my life has changed. I have to relearn to talk, to eat, wake up 2-3 times/night to moisturize with artificial saliva. I can't go anywhere without advance planning.</i> <i>I've struggled all year to gain some weight back; still can't taste/eat a lot of foods.</i> 	<ul style="list-style-type: none"> <i>I wanted to return to where we had left off, to normal life.</i> 	<ul style="list-style-type: none"> Understanding they won't be back to normal for a full year. (Surgeon) We will recommend physical therapy, but the patient doesn't always get referred. (Medical Oncologist) Caregivers typically have concerns about the patient choking. (Maxillofacial Prosthodontist) Patients will sometimes use the feeding tube as a crutch to avoid dealing with swallowing issues. (Dietitian)
Addictions	Smoking and alcohol use behaviors and	<ul style="list-style-type: none"> <i>...A lot of trouble trying to quit smoking...</i> 	<ul style="list-style-type: none"> <i>Addressing drinking [after]</i> 	<ul style="list-style-type: none"> Those with alcoholism ... little support

Theme	Summary	Survivor Comments	Caregiver Comments	Provider Comments
	cessation challenges during the post-treatment period.	<p><i>I know Chantix is a prescription but it is not covered by insurance.</i></p> <ul style="list-style-type: none"> <i>The only alcohol I can drink without discomfort is wine and the dentist says I have to stop that too, and also electronic cigarettes.</i> <i>Self-medication with alcohol to intensify the effect of the pain meds helped; also helped with emotional pain until it started burning my mouth.</i> 	<i>treatment] would be important.</i>	<p>for them once out of the hospital; frustrates caregivers. (Nurse Practitioner)</p> <ul style="list-style-type: none"> Will have a conversation about whether smoking is affecting them (e.g. mucus production, poor wound healing) ... Will [discuss] that drinking liquor may cause irritation. (Speech Pathologist) How to address needs of caregiver who is not our patient but who... may need support to stop smoking? (Nurse Practitioner)
B. Emotional Challenges				
Depression and Anxiety	Feelings of sadness, distress and other cancer-related mood concerns.	<ul style="list-style-type: none"> <i>When I finally realized I was going to live, it was an adjustment because I was prepared to die.</i> <i>I got really sick after finishing chemo ... so felt bad even though I wanted to feel good. It was crazy emotionally.</i> <i>Although I had a real good attitude when starting treatment, I was in bad shape at the end; didn't care much about living.</i> 	<ul style="list-style-type: none"> <i>I need to have patience and understand it is a marathon, not a sprint; and that [the patient] will have mood swings.</i> <i>I was anxious when he attempted to talk as this increased the swelling.</i> 	<ul style="list-style-type: none"> Depression is not addressed very well; many do not address it. (Ear, Nose and Throat Referring Provider) Caregiver anxiety about cancer diagnosis and possibility of recurrence, trach care and fear of doing harm; dressing changes; treating wounds. (Nurse Practitioner)
Uncertainty	Lacking clarity about cancer-related recovery issues and life after treatment.	<ul style="list-style-type: none"> <i>Feeling down about having teeth removed and having a feeding tube; not knowing what the results</i> 	<ul style="list-style-type: none"> <i>I was very fearful that the treatment would not cure her.</i> <i>Right after surgery the biggest</i> 	<ul style="list-style-type: none"> I try to emphasize that better days are coming... encouraging and positive expectations. (Ear, Nose and

Theme	Summary	Survivor Comments	Caregiver Comments	Provider Comments
		<ul style="list-style-type: none"> <i>of treatment would be.</i> <i>Everybody's different so doctors really can't tell us what to expect.</i> <i>Doctors told me I should start feeling better but it might take 6 months to a year and that my immune system would leave me more susceptible to colds and that I was malnourished.</i> <i>I am fearful that it will return. I would not want to ever go through treatment again.</i> 	<ul style="list-style-type: none"> <i>challenge was knowing I was doing everything correctly.</i> <i>Would have liked more instruction/ information at discharge on what to expect and how to care for the feeding tube and trach.</i> 	Throat Referring Provider)
Isolation After Cancer	Feeling alone, confused or without aid after cancer treatment.	<ul style="list-style-type: none"> <i>I felt alone and had no one to talk to with the same experience, but also was glad it was over.</i> <i>I can only eat smoothies and soup since most of my tongue is gone. Since I have trouble speaking, some people think I am mentally handicapped now and it is demeaning.</i> <i>I was almost a recluse at first due to physical looks, lack of energy.</i> 	<ul style="list-style-type: none"> <i>Overwhelmed - isolated, no one to talk to about how to deal with mucus.</i> 	<ul style="list-style-type: none"> Patients need help getting to the next phase – sometimes they get stuck. (Radiation Oncologist)
Nutritional Distress	Worries and concerns specific to survivor nutritional status.	<ul style="list-style-type: none"> <i>I didn't get feeding tube soon enough so crashed from malnourishment and dehydration.</i> <i>I've struggled all year to gain some weight back; still can't taste/eat a lot of foods.</i> 	<ul style="list-style-type: none"> <i>If [patient] had gotten the feeding tube and requested a port instead of refusing, things would have been much better.</i> 	<ul style="list-style-type: none"> Some caregivers feel guilty about eating in front of the patient. (Speech Therapist) Sometimes I have to get creative to find nutrition supplements for patients.

Theme	Summary	Survivor Comments	Caregiver Comments	Provider Comments
				(Social Worker) <ul style="list-style-type: none"> Patients have a lot of fear and misconceptions about feeding tubes. (Dietitian)
C. Social Challenges				
Support Needs	Existing or lacking types and sources of assistance when coping with cancer recovery.	<ul style="list-style-type: none"> <i>When people saw that I was starting to get better, it felt like they deserted me – stopped coming over, calling.</i> <i>It was so hard to depend on other people to take care of me and my children and to see my husband struggling.</i> <i>My spouse and children provided unbelievable care.</i> 	<ul style="list-style-type: none"> <i>I was overwhelmed trying to manage our kids and my job and fearful that I might lose my wife.</i> <i>I was feeling OK; had a good support system...my faith.</i> 	<ul style="list-style-type: none"> Caregivers are burned out and exhausted. (Nurse Practitioner) Patient usually accompanied by caregivers to all appointments. If disease free at 2 years, then they often come by themselves. (Radiation Oncologist) Sometimes caregivers have goals that the patient may not necessarily have. (Speech Therapist)
Communication and Interactions with Providers	Relationships and communication with oncology health care providers.	<ul style="list-style-type: none"> I had discussions but was preoccupied and can't remember – too much information at one time! <i>Docs told me what symptoms to watch out for that could signify recurrence.</i> <i>They told me there would be checkups and to watch for white patches on my tongue.</i> <i>They painted a factual/accurate picture, not a rosy one.</i> 	<ul style="list-style-type: none"> <i>All the techs, residents and administrative staff were very upbeat and that really helps families.</i> 	<ul style="list-style-type: none"> <i>Often traditional therapists [back home] are unfamiliar with how to work with head and neck cancer patients. (Speech Therapist).</i> We discuss any new symptoms – signs and symptoms of recurrence. (Nurse Practitioner)
Finances/Access/ Employment	Reflections on primary financial concerns,	<ul style="list-style-type: none"> <i>I started back to work part-time after the feeding tube</i> 	<ul style="list-style-type: none"> <i>Insurance did not cover obturator expense.</i> 	<ul style="list-style-type: none"> Resources for unfunded people are lacking and

Theme	Summary	Survivor Comments	Caregiver Comments	Provider Comments
	including access to needed services and impact of recovery on employment, after treatment.	<ul style="list-style-type: none"> <i>was removed; but it was hard not being able to do what I could do before.</i> <i>Work required ability to communicate a lot and I could only whisper... had to accept a different position at lower pay.</i> 	<ul style="list-style-type: none"> <i>Important to include information regarding coordination of benefits, getting records transferred.</i> <i>Insurance only covered certain procedures.</i> 	<ul style="list-style-type: none"> changes are anticipated due to national health care changes. (Social Worker) Low literacy level makes written instructions useless for patient and/or caregiver. (Nurse Practitioner)

Table 3

Clinical Advisory Board Ratings

	Item Category Type					
	<i>Symptoms</i>		<i>Emotional & Social Concerns</i>		<i>Health Behaviors</i>	
Ranked Importance Level^a	1	Pain	1	Teamwork in dyads (D)	1	Tobacco (D)
	2	Swallowing/chewing	2	Follow-up care adherence self-efficacy (D)	2	Nutritional intake
	3	Mouth sores		Information seeking self-efficacy (D)	3	Alcohol use (D)
	4	Choking/coughing			4	Nutritional status satisfaction (D)
	5	Shortness of breath	3	Cancer/treatment information (D)		
		Symptom distress (D)		Fear of recurrence (D)	5	Weight change
		Symptom management abilities (D)		Financial concerns	6	Information about healthy diet (D)
		Voice/speech	4	Adjusting to life changes		Physical activity (D)
	6	Dry mouth	5	Appearance		
		Vomiting		Employment		
	7	Taste		Isolation (D)		
		Sadness		Peer support (D)		
		Symptom impact on relationships	6	Reducing stress (D)		
	8	Mucus	7	Sexuality & intimacy		
	9	Numbness/tingling	8	Spiritual assistance (D)		
	10	Distress (D)	9	Complementary & alternative medicine		
	11	Nausea				
	12	Opening mouth				
		Symptom impact on mood				
	13	Disturbed sleep				
		Range of motion				
	14	Appetite				
		Teeth/gum problems				
	15	Fatigue				
		Memory				
	16	Constipation				
	17	Drowsiness				
	18	Skin pain				

^aUsing an iterative process, a final item pool was ranked at a consensus meeting by our head and neck cancer Clinical Advisory Board (N=10).

^bD = assessed in dyads (both survivors and caregivers)