



Published in final edited form as:

Head Neck. 2016 April ; 38(Suppl 1): E1935–E1946. doi:10.1002/hed.24351.

Survivorship Care Experiences and Information and Support Needs of Oral and Oropharyngeal Cancer Patients

Sharon Manne, Ph.D.^a, Shawna V. Hudson, Ph.D.^a, Soly Baredes, M.D.^b, Antoinette Stroup, Ph.D.^{a,c}, Shannon Myers Virtue, Psy.D.^a, Lisa Paddock, Ph.D, M.P.H.^c, and Evelyne Kalyoussef, M.D.^b

^a Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey

^b Rutgers New Jersey Medical School, Newark, New Jersey

^c Rutgers School of Public Health, Piscataway, New Jersey

Abstract

Background—There is little research documenting the post-treatment experiences and needs of oral/oropharyngeal cancer survivors.

Methods—In this cross-sectional study, 92 patients diagnosed with oral/oropharyngeal cancer diagnosed between 2 and 5 years prior completed a survey about oral cancer information and support needs.

Results—About half retrospectively reported that they did not receive a written treatment summary. The desire for more oral cancer information was common: One-third or more desired more information about long-term effects, recommended follow-up, and symptoms that should prompt contacting a doctor. Support needs were less common: Only a lack of energy was rated as a significant support need. Patients who had a recurrence, did not drink alcohol, and had a greater recurrence fear desired more information. Smokers and more distressed patients reported more support needs.

Conclusions—Survivors reported the desire for more oral cancer information. A desire for assistance was less common.

Keywords

Oral cancer survivors; post-treatment care; information needs; support needs; survivorship care plan

Introduction

An estimated 45,780 new cases of oral and oropharyngeal cancer and 8,650 deaths are expected in the United States in 2015.¹ Less than one-third (31%) of cases are diagnosed at a local stage, for which 5-year survival is 83%.² Treatment entails single modality treatment of surgery or radiation, or a combination of surgery, radiation, and chemotherapy, depending

Conflict of Interest: None

on the disease site. Because of the location of the structures, the disease and its treatment, this disease can cause debilitating and permanent disability. Surgery and radiation can cause a visible disfigurement in facial and neckline appearance and affect vital life functions such as the ability to swallow, taste, speak, and eat.³⁻⁶

The extensive rehabilitation and long-term maintenance needs of this population are complex and involve a diverse set of health care providers including head and neck surgeons, radiation oncologists, medical oncologists, plastic and reconstructive surgeons, nurses, dentists and prosthodontists, physical rehabilitation specialists, speech and swallowing experts, nutritionists, pathologists, and adjunctive services such as addiction services and psychiatry.⁷⁻⁹ Collaboration between the patient and the many providers is key to restoration of swallowing, taste, and speech, and the prevention of further deterioration of physical function. Survivors are expected to understand medical information, adhere to a complicated follow-up care regimen, and coordinate care with providers, and manage comorbid medical conditions. These patients are also at a high risk for disease recurrence. Approximately 20% of patients suffer a recurrence or diagnosis of metastatic disease within the first two years,¹⁰ and thus the follow-up regimen includes regular surveillance. Follow-up care recommendations include an examination every 1 to 3 months in year 1, every 2 to 4 months in year 2, every 4 to 6 months in year 3, and every 6 to 12 months after five years.⁸ Post-treatment baseline imaging of the primary affected area is recommended within three to six months of treatment, as are dental exams, and alcohol and smoking cessation counseling, if indicated.⁸ Because these patients rarely completely recover function, the complex medical needs persist throughout the remainder of the patient's lifetime, and require the commitment of the patient, family, and his/her many health care providers. The limited studies evaluating patient adherence with this demanding post-treatment regimen suggest that adherence may be a challenge, with between 30% and 50% of patients not adhering to recommended follow-up appointments.¹¹⁻¹²

There have been many studies evaluating quality of life in oral/oropharyngeal cancer patients. Studies suggest that patients diagnosed with these cancers have a compromised quality of life compared to the general population (e.g,¹³). Long-term follow up studies suggest these patients continue to score worse on measures of role function (e.g.,¹⁴) and significantly worse than age-matched individuals on disease-specific problems such as swallowing, local pain, and dry mouth 3 years after diagnosis (e.g.,¹⁴) Patients express concerns about appearance, sense of taste, sense of smell, drooling, taking a long time to eat, speech problems, ability to work, intimacy, finances, body image worries, and embarrassment in social settings (e.g.,¹⁵). Adding to this complex picture is the fact that the oral cancer patient population has historically been older, male, and have multiple comorbidities associated with long-term substance use.¹⁶

Due to these issues, negotiating the transition back to “normal” life can be complex and difficult. Oeffinger and McCabe¹⁷ have delineated current practice and proposed general models of survivorship care. At the end of cancer treatment, the “usual practice” is that most cancer survivors are followed by their oncologists, whose focus is on monitoring persistent treatment toxicity and cancer recurrence.¹⁷ Planned or formal transition of the survivor from the oncologist to a primary care physician is infrequent.^{17,18} Patients may have difficulty

with the transition from being “on treatment” to optimum survivor follow-up care.¹⁹ Across cancers, this transition can result in unmet information and support needs. Indeed, research suggests that newly diagnosed oral cancer patients may have a number of unmet information needs.²⁰ Unfortunately, there is little research documenting the unmet information and support needs of oral cancer survivors, both in terms of information and other supportive care needs and post-treatment care experiences. Oskam and colleagues²¹ studied oral cancer survivors’ rehabilitation needs over an 8 to 11 year time period after treatment ended and found that rehabilitation needs decreased after treatment ended, but that quality of life declined significantly. The most frequently-reported medical and rehabilitation needs were dental care and physical therapy.

Unlike oral and oropharyngeal cancers, there is a relatively extensive literature examining unmet needs among survivors of breast, colorectal, gynecological, lung, melanoma, prostate, and childhood cancers (see Harrison et al²² for a review of this topic). These studies have indicated that survivors commonly have medical care needs including: a desire to know what late effects to expect and what the recommended follow-up tests are, a desire for more guidance about diet, a desire to feel that they are managing their cancer with the help of the medical team, and a desire to know that health care services are available when required.²³⁻²⁵ Commonly-reported psychological concerns among survivors include sadness, anxiety, worry about cancer recurrence, spiritual needs (e.g., trying mind/body therapies), help reducing stress, help coping with others’ responses, concerns about the well-being of close family members, and sexual concerns.²⁶⁻³⁰ Commonly-reported physical concerns are pain, lack of energy, not being able to do the things he/she used to do, and being able to work around one's home.^{29,31,32} Less is known about post-treatment care experiences and correlates of information and support needs, although several studies of survivors with other types of cancer have suggested that higher levels of support needs are associated with less education,²³ marital status (mixed results),³³⁻³⁵ time since diagnosis (mixed results),^{23,29} not being in remission,³⁶ age (mixed results),^{30,37} more comorbid medical conditions,³⁸ more physical symptoms,^{29,30,39,40} higher psychological distress,^{23,25,26,40,41} a lower quality of life,^{23,42} and more fear of recurrence.³⁸

This cross-sectional study had two aims. The first aim was to describe the post-treatment care experiences, informational needs, and support needs of oral and oropharyngeal cancer survivors. Treatment care experiences (e.g., receipt of a treatment summary) were described retrospectively. The second aim was to examine background (e.g. age, education, gender, current smoking), medical, and psychosocial correlates of informational and support needs among oral and oropharyngeal cancer survivors. With regard to background factors, we proposed that older and less educated survivors would report more unmet informational and support needs. We proposed that survivors who experienced a cancer recurrence and had more oral-cancer physical symptoms (e.g., trouble swallowing) would report more information and support needs. With regard to psychological factors, we hypothesized that greater informational and support needs would be associated with higher levels of fear of cancer recurrence, a greater negative impact of oral cancer on different aspects of their lives and activities (e.g., social life, appearance), and psychological distress, independent of background and medical factors. The sample consisted of relatively recent survivors (between 2 and 5 years since diagnosis) who were sampled from a state cancer registry.

Material and Methods

Participants and Procedures

Patients were eligible for this study if they were diagnosed with oral or oropharyngeal cancer in 2011 and currently free of cancer. Participants completed a written survey that took an average of 59 minutes to complete (range = 20 minutes to 5 hours). Prior to initiation, the Institutional Review Board of the Rutgers Robert Wood Johnson Medical School approved this study, and written informed consent was received from all participants. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Participants were recruited from the New Jersey State Cancer Registry (NJSCR). The NJSCR confirmed the patient's eligibility and contacted the patients' physician to ensure that there were no contraindications for participation (e.g., patient deceased, mentally incapable of consenting or completing a written survey). After physician contact, patients were sent an introductory packet by the NJSCR. The NJSCR packet contained an informed consent, survey, a stamped envelope, and a letter asking interested participants to complete the survey and return it. For a small subset of patients, the NJSCR packet contained only a written consent form permitting the Rutgers Cancer Institute of New Jersey (RCINJ) staff to contact them regarding the study. In this scenario, participants who returned the consent were then contacted by the RCINJ staff, and, if interested, an informed consent, survey, and stamped envelope was provided. Study staff contacted participants weekly by telephone if they did not return the survey. Patients were considered passive refusers as they did not return a survey after repeated call attempts during daytime hours, nights, and weekends over a three week period after the letter (or survey) was sent.

Of the 214 patients approached, 17 were not eligible (for various reasons), 105 refused, and 92 patients completed an informed consent and survey. The acceptance rate among eligible patients was 46.2%. Most participants were passive refusers (i.e., they did not respond to contacts and did not send in a survey). Comparisons between refusers and participants on the available background (age category, gender, white vs non-white race) and medical (cancer site, stage) information indicated there were no significant differences between participants and refusers.

Measures

Background information—The survey contained information about age, marital status, gender, education, ethnicity/race, health insurance coverage, and income.

Substance use—Current substance use measured alcohol consumption by assessing how many days a week or month the person had at least one drink of alcohol (days per week, days in past 30 days, or no drinks in past 30 days) as well as cigarette smoking use (*every day, some days, not at all*). For the current study, a dichotomous variable was used (*yes/no*) to indicate current smoking status and current use of alcohol (any).

Medical information—Date of diagnosis, type of cancer, cancer stage, recurrence history, treatment history (surgery, chemotherapy, radiation), and a confirmation that the patient was currently free of disease were collected from patients. Diagnosis date was confirmed by the NJSCR. The type and stage of disease were provided by the NJSCR, along with the hospital where the patient was treated. The 35-item EORTC QLQ H&N35⁴³ was used to assess common side effects of oral cancer and its treatment including swallowing, dry mouth, taste, smell, social eating, and pain. Items were rated from 1 = *not at all*, to 4 = *very much*. For purposes of this study, an average of the 35 items was used. Higher scores indicate more symptoms. Internal consistency, as measured by Cronbach's alpha, was .96.

Follow-up care experiences—Survey items from the National Cancer Institute Follow-up Care Use Among Survivors (FOCUS) survey were used to assess the follow-up care experiences.⁴⁴ The FOCUS has been used in prior research.^{45,46} Follow-up care history assessed: whether the patient saw a physician for follow-up care in the past two years, the reasons for those appointments, and where the care was received (general medicine clinic, specialty clinic). Several questions assessed what follow-up information was provided: “Has a doctor or health care professional ever discussed with you what late or long term side effects of cancer treatment you may experience over time?” (No, Yes, Discussed somewhat, Yes, Discussed in detail) and, “At the completion of treatment, did you receive a written summary from your doctor that mentioned details of the treatment you had received and provided other important details regarding your cancer care?” (*No, Yes, Not sure*). Follow-up treatment experiences were also assessed, which included what treatment care was received, participants' satisfaction with care, who the primary cancer care was obtained from, participants' preferences for who should provide follow-up cancer care, and participants' views of ideal follow-up care.

Impact of cancer—A 17-item instrument was developed for this study to assess the positive and negative impact of oral cancer on participants' lives. Items included, “Your work life or career,” “Your body image and confidence in your appearance,” “Your participation in social activities,” “Your exercise activities,” and “Your ability to enjoy life”. Response choices were: 0 = “*does not apply*,” 1 = “*very negative impact*”, 2 = “*somewhat negative impact*”, 3 = “*no impact*,” to 5 = “*very positive impact*.” Participants were asked to consider the time since they were first diagnosed with oral cancer to the present when providing ratings. Higher scores indicate a more positive impact of cancer. Internal consistency, as calculated by Cronbach's alpha, was .91.

Fear of recurrence—The first four items of the Concerns about Recurrence Scale were adapted for this study.⁴⁷ These items assess global fears about disease recurrence and assess the amount of time spent thinking about recurrence, how upsetting the possibility of a recurrence is, how often the person worries about recurrence, and fear of recurrence. Items were rated on a 6-point Likert scale (e.g., 1 = *I don't think about it at all*, to 6 = *I think about it all the time*). An average item score was used in the analysis, with higher scores indicating greater fear of recurrence. Internal consistency, as calculated by Cronbach's alpha, was .94.

Cancer-Specific Distress—The Impact of Events Scale-Revised⁴⁸ is a 22-item scale that assesses cancer-related distress. The scale has intrusive symptoms (dreams), avoidant symptoms (try not to think about it), and hyper-arousal symptoms (e.g., felt watchful or on-guard). Items were rated on a five point scale (0 = *Not at all*, 1 = *a little*, 3 = *quite a bit*, and 5 = *extremely*). Participants rated their responses to their oral cancer diagnosis and treatment. Feelings within the past week were assessed. A total score was used in the analysis. Internal consistency, as calculated by Cronbach's alpha, was .97.

Oral Cancer-Related Information Needs—An 11-item scale was adapted from the Information about Health Related Topics section of the FOCUS survey.⁴⁴ Four items from the FOCUS survey included: information about health related topics, managing anxiety about recurrence, and late and long terms side effects from oral cancer treatment. The remaining 7 items were composed for this study which contained health-related topics about which oral cancer survivors might need more information. Items were created based on a review of the literature on the side effects of oral cancer and included desiring more information about what follow-up tests were needed, what symptoms should prompt a call to a doctor, what late and long-term side effects to expect, and how to manage anxiety and maintain good oral health. Participants were asked whether they would like more information about each topic “at this time”. Responses were rated *yes* or *no*. A total score was used in the analysis. Internal consistency, as calculated by Cronbach's alpha, was .90. Items are shown in Table 2.

Support Needs—An shortened version of the Supportive Care Needs Survey³⁶ was used. This 25-item survey assessed needs across five domains: physical, psychological, health care systems and information, patient care and support, and sexuality domains. Nine items were excluded from the original Supportive Care Needs Survey to shorten the instrument. Items were selected to minimize overlap with other items on the scale (i.e., “feelings of sadness” was deleted due to the overlap with “feeling down or depressed”; “changes in sexual feelings” was deleted due to overlap with “changes in your sexual relationship”). . . Participants were asked to indicate the extent to which they needed help (1 = *Did not need help*, 5 = *High need*) in the past month. The measure has four domains: Physical/daily living, psychological, patient care and support, sexuality, and health system and information needs. Support needs in each domain were averaged and a total score was calculated across domains. Internal consistency for the total score, as calculated by Cronbach's alpha on the entire scale was .97.

Statistical analysis plan: Data were analyzed utilizing Statistical Packages for Social Sciences (SPSS). To address the first aim, we calculated descriptive statistics for the on the post-treatment care experiences were reported, and oral cancer-related informational and support needs. To address the second aim, analyses were conducted in two steps. In the first step, correlations (for continuous variables) or t-tests (for dichotomous variables) were calculated for the demographic, medical, and psychological variables included in the predictive model. The demographic variables included age, gender (dichotomous), ethnicity (white or not white; dichotomous), marital status (married vs. not, dichotomous), household income, education, smoking status (dichotomous), and current alcohol intake (dichotomous).

Medical variables included stage of disease, whether the cancer recurred or not (dichotomous), time since original diagnosis, and the number of oral cancer symptoms. Psychological variables included impact of cancer, fear of recurrence, and cancer-related distress. In the second step, a stepwise regression was conducted entering significant correlates from each category, in three steps. That is, the background, medical, and psychosocial variables were entered in three separate steps. The dependent variable, support needs, was comprised of an average item score across all of the domains assessed, and the information needs scale was an average across all items, as well. Note that the analyses of support needs in the separate domains were the same as those for the total score. For simplicity, only the total score results are presented for the support needs scale.

Results

Descriptive information on the sample

Descriptive information about the sample is in Table 1. The majority of participants were white (88%), more than two thirds were male, the average age was 62 years, and more than half of the sample completed some college or a lower level of education. Two-thirds of the sample was married, and the vast majority of participants carried medical insurance (98%). A third of the sample worked full-time and a third were retired. About 15% of participants were current smokers and about 60% currently drank alcohol.

The most common tumor sites were the base of the tongue (47%) and tonsils (31.5%). Over half were diagnosed with stage 4 disease (53.3%), and a portion of the sample (7.6%) experienced a recurrence of the cancer since the original diagnosis. Average time since the original diagnosis was approximately three years (range = 2 years to 5 years). All participants with the exception of one had completed medical treatment. The most common treatments given at the time of the original diagnosis and recurrence were surgery, radiation and chemotherapy combined (33.6%), followed by radiation and chemotherapy combined (31.4%). The most commonly-experienced oral cancer side effects were dry mouth, sticky saliva, and dental problems (see Table 5). There was missing data on hospital site the participant was treated at for 38% of the sample. Among the participants for whom treatment site information was in the SEER records, participants received treatment or evaluation at 35 different hospitals. Thirty-five percent received treatment/assessment at a comprehensive cancer center.

Comparisons were made with the SEER statistics for the United States for cases diagnosed in 2007 to 2012². The ethnicity, gender, and stage composition of the sample was very similar to the population of persons diagnosed with oral and oropharyngeal cancers. However, the present sample was comprised of a higher percentage of patients with tongue cancer (30%) and tonsil cancer (18%) and a lower percentage of oropharyngeal cancers (18%) than the US population.

Post-treatment Care Experiences

Table 2 provides a summary of the key post-treatment care experiences. Most participants reported that they were informed by their treating physician that there was a need for follow-

up medical care after treatment ended. Of the participants who reported that they were informed of the need for follow-up care, the primary reason they were told they needed this care was to check for signs of disease recurrence. Participants also reported that checking for signs of disease recurrence as the most important reason for obtaining follow-up care. The vast majority of participants reported that they had been seen by a cancer specialist for follow-up care since their original oral cancer diagnosis. Additional health care providers that participants reported they received follow-up care from were: a dentist a primary care physician, an ear, nose, and throat specialist a speech pathologist a cardiologist (8.7%), and a physical therapist.

Most participants considered the cancer specialist as their primary health care provider for cancer-related follow-up care. The most commonly-nominated provider identified among those not nominating the oncologist were an ear, nose, and throat specialist and a primary care physician. About half of participants reported that a health care professional had discussed in detail the possible late or long-term side effects of oral cancer treatment they might experience over time, 29.7% of patients reported that a health care provider discussed possible effects in a somewhat detailed manner, and 22% reported possible late and long-term side effects were not discussed with any health care professional. Satisfaction with follow-up cancer care was extremely high, with 89.8% of participants reporting the quality was *very good or excellent*.

In terms of post-treatment care plans, approximately half of the participants reported that they did not receive a written summary of the cancer treatments they received and details about recommended post-treatment cancer care. More than half of the sample reported they would have liked to have a summary provided.

Oral Cancer-related Information and support needs

Oral cancer-related information needs are summarized in Table 3. The most commonly-reported topics that patients desired more information about regarded the late and long-term side effects to expect, recommended oral cancer-related follow-up tests, suspicious symptoms that should prompt contacting a doctor, and how to maintain good oral health. Managing changes in marital or dating life and dealing with social life problems were the least-endorsed information needs, with 21% or fewer participants stating that they desired more information about marital/dating or social life.

Support needs are summarized in Table 4. Support needs that were rated “moderate” or “high” need for help were in the pain and daily living and health system domains: lack of energy (25%), being informed of test results in a timely manner (24.2%), being adequately informed about the benefits and side effects of treatments before choosing them (23.4%), and having a health care provider to talk to about his/her condition, treatment, and follow-up (24.2%). In contrast, support needs that were reported as issues the participant did not need help with in the past month by the majority of the sample were: having more choice about which cancer specialist the patient sees (90%), feelings about death and dying (82.6%), and being treated in a clinic that was as physically pleasant as possible (81%).

Concerns about recurrence, cancer-specific distress, and impact of cancer

Descriptive information is in Table 5. Concerns about cancer recurrence were relatively low ($M = 2.5$, $SD = 1.4$, 6 is the highest rating). Single item means ranged between 2.3 to 2.7. An examination of frequency ratings indicated that approximately 9% of participants reported a great deal of time spent worrying about recurrence (e.g., a rating of 5 or 6, 6 = “*I think about it all the time*”). The most highly-rated item was the degree of upset when considering the possibility of recurrence, with approximately 20% of participants reporting that it would make them very or extremely upset (rating of 5 or 6; 6 = *It makes me extremely upset*). In terms of cancer-specific distress ($M = 12.5$, $SD = 18.0$), there are limited data on mixed gender populations of cancer survivors (two to five years post-treatment) using the IES-R. The IES-R item mean of .57 ($SD = .82$) is significantly lower than means reported in a study of mixed gender rectal cancer survivors ($M = 1.22$; $SD = .40$; $t(168) = 7.2$, $p < .05$).⁴⁹

The overall impact of oral cancer on life domains was somewhat negative, with the mean score for the scale of 2.1 (2 = *Somewhat negative impact*) ($SD = .89$). The areas of life most negatively impacted were patients’ diet—what the patient can and cannot eat (49.5%), finances (38%), body image and confidence in one’s appearance (36%), exercise activities (33%), and the ability to enjoy life (31%).

Predictors of Information and Support Needs

Bivariate associations between background variables and total information needs suggested that age, gender, marital status, education level, income, health insurance status, and current smoking status were not significantly associated with information needs. However, non-white participants ($t(88) = 3.1$, $p < .01$) and participants who did not currently drink alcohol ($t(88) = 3.0$, $p = .004$) reported significantly more total information needs. Associations between medical variables and information needs indicated that participants who were diagnosed with later stage disease ($F(4,82) = 4.5$, $p < .01$), participants who had experienced a cancer recurrence ($t(88) = 3.4$, $p = .001$), and participants who reported a greater number of oral cancer symptoms ($r = .46$, $p < .001$) reported significantly higher information needs. Time since diagnosis was not significantly associated with information needs. Associations between psychosocial variables with information needs suggested that greater cancer-specific distress ($r = .47$, $p < .001$) and higher fears of recurrence ($r = .51$, $p < .001$) were significantly associated with greater information needs, but impact of cancer was not significantly associated with information needs. The final regression predicting information needs included ethnicity (white/non-white) and alcohol use in the first step, stage (1 to 3 vs 4), cancer recurrence, and oral cancer symptoms in the second step, followed by cancer-specific distress and fear of recurrence in the third step. Results are shown in the top panel of Table 6. Higher informational needs were significantly associated with not drinking alcohol, having a recurrence, and higher fear of recurrence. The group of variables accounted for 45.3% of the variance in information needs.

Associations between background variables and support needs suggested that age, gender, education level, marital status (married or not), ethnicity, health insurance status, and current alcohol use were not significantly associated with total support needs. However, participants

with a lower income ($r = -.23, p < .05$) and who currently smoked ($t(89) = -5.4, p < .01$) reported significantly more support needs. Associations between medical variables and support needs indicated that participants who were survivors for a longer time period ($r = .22, p < .05$) and had a greater number of oral cancer symptoms ($r = .76, p < .001$) reported significantly greater support needs. Stage of disease and cancer recurrence were not significantly associated with total support needs. Associations between psychosocial variables with total support needs suggested that greater cancer-specific distress ($r = .85, p < .001$) and higher fears of recurrence ($r = .44, p < .001$) were significantly associated with greater total support needs but impact of cancer was not associated with total support needs. The final regression predicting total support needs included income and smoking status in the first step, time since diagnosis and oral cancer symptoms in the second step, followed by cancer-specific distress and fear of recurrence in the third step. Results are shown in the bottom panel of Table 6. Higher total support needs were associated with being a smoker and greater cancer-specific distress. The group of variables accounting for 79% of the variance in support needs.

Discussion

Although survivors of oral and oropharyngeal cancers typically experience significant long-term side effects from the cancer itself and its treatment,⁵⁰ little is known about survivors' post-treatment care experiences and their long-term information and support needs. This study sought to characterize survivorship care experiences of a population of patients in the state of New Jersey, evaluate information and support needs, and describe background, medical, and psychological correlates of these needs.

In our study, oral cancer survivors maintained their post-treatment care provision with the treating oncologist, rather than move into the primary care setting for their follow-up care. Indeed, like other studies of cancer survivors,⁵¹⁻⁵³ patients considered their cancer specialist as their primary physician for cancer-related follow-up care rather than a primary care doctor. This finding may be due to the fact that the vast majority of participants experienced more than one treatment side effect such as dry mouth, sticky saliva, and dental problems which require specialized follow-up care. This may also be due to the frequent post-treatment surveillance that is recommended and difficult or impossible for a primary care provider to perform (e.g., scoping).

Satisfaction with follow-up cancer care provided by the oncologist was extremely high in our sample. Despite the current satisfaction with oncology follow-up care, preparation at the end of treatment was not ideal. Slightly more than half of our study participants retrospectively reported that they did not receive a written summary of the cancer treatments they received and details about recommended post-treatment cancer care. The percentage of patients reporting that they did not receive a written treatment summary is similar to other studies which examined patients with head and neck cancers as well as patients diagnosed with other types of malignancies.^{44,54,55}

Furthermore, the majority of the patients who retrospectively reported that they did not receive a written summary (or were unsure if they received one) stated that they would have

liked to receive one. Almost a quarter of participants reported that a health care professional had not discussed possible late and long-term side effects. These findings are consistent with prior research with survivors of other types of cancer³⁸ and suggest that oral cancer survivors may want more detailed information about their treatment, surveillance protocols, and other follow-up recommendations. Information needs were consistent with the fact that these survivors had not been provided with written information about recommended follow-up care. Survivors reported the desire for more information about what late and long-term side effects to expect, oral cancer-related follow-up tests recommended, the suspicious symptoms that should prompt contacting a doctor, and how to maintain good oral health. Each of these topics is a recommended component of the survivorship care plan^{19,56} which is now a requirement for participating hospitals by the American College of Surgeons' Commission on Cancer.⁵⁷ Support needs reported in this study were similar to previous studies of newly diagnosed oral cancer patients²⁰ and studies of support needs of oral cancer survivors.³² These studies have found that health system needs including obtaining test results in a timely manner being adequately informed about the benefits and side effects of treatments before choosing them, and having a health care provider with whom the patient can talk to about all aspects of his/her condition, treatment, and follow-up along with physical needs (lack of energy) and daily living needs are the most prevalent needs.²⁰ Overall, health system and daily living support needs were rated higher than psychosocial needs. These results are also consistent with studies of patients who are newly diagnosed with other types of cancer^{58,59} and survivors of other types of cancer.²⁴ Our study differs from other studies of newly diagnosed oral cancer patients,²⁰ studies of patients recently diagnosed with other types of cancer,^{60,61} and reviews of support needs of cancer survivors⁵⁸ in that psychosocial concerns (e.g., anxiety, depression, and fear of death and dying) were not rated as significant support needs in our study. Unlike prior studies (e.g., Zabora et al⁶²) the majority of our sample did not worry about disease progression or recurrence or report high levels of cancer-related distress. Low levels of worry about cancer progression and distress would lead to low levels of psychological support needs. It is interesting to note that, when evaluating the pattern of results across information and support needs, information needs were much more prevalent than support needs. A third or more of the sample desired more information about oral-cancer specific topics, whereas only one domain, a lack of energy, was rated as a moderate or high level support need.

The second goal of our study was to delineate the patient factors that were associated with information and support needs. Not surprisingly, our results suggest that two types of patients—those who had experienced a recurrence of their cancer and symptoms and those who have a greater fear of cancer recurrence—desired more oral cancer information. These findings are consistent with previous studies of survivors of other types of cancers showing that patients who are more worried about disease recurrence are more likely to actively seek information.³⁸ In addition, health behavior theory suggests that persons who worry about risk are more likely to seek out information.⁶³ In addition, we found that oral cancer survivors who did not currently drink alcohol had significantly higher information needs. One possible explanation for this finding is that oral cancer survivors who still drink alcohol after an oral cancer diagnosis may be less interested in maintaining or improving their health. A post-hoc examination of other differences between survivors who currently drank

alcohol and did not drink alcohol suggested that survivors who still drank had higher income levels than those who did not, which may account for the finding (although income was not significantly associated with information needs). There were no other differences (age, ethnicity, education, cancer type, oral cancer symptoms, fear of recurrence, cancer-related distress, or impact of cancer) that might explain the finding. Future research may need to ascertain why survivors who continue to drink after treatment have fewer information needs as well as the underlying risk factors that are associated with income or socioeconomic status.

A different set of factors was associated with support needs. After controlling for other background and medical factors, we found that current smokers and patients reporting greater cancer-specific distress reported higher support needs. Overall, there was a very strong association between support needs and greater cancer-specific distress ($r = .85$) and more oral cancer symptoms ($r = .75$). These strong associations were seen across all four key support needs domains, and were not exclusively present in the associations with psychological support needs. Although prior research has indicated an association between both global psychological distress and cancer-specific distress and unmet support needs,^{25,30,64} the extremely strong association between cancer-specific distress and support needs after controlling for relevant background and medical variables suggests that intrusive thoughts and feelings and experiential avoidance and experiencing more side effects from oral cancer treatment may motivate survivors to desire more support. Current smokers also indicated higher support needs, and these differences were noted across all support need domains with the exception of sexual issues. One possible explanation for this finding is that patients who continue to smoke reported more oral cancer side effects as well as higher levels of cancer-related distress. Thus, the higher level of support needs across all domains may be explained by smokers' higher levels of medical side effects and psychological distress.

This study has a number of limitations. First, as this is a cross-sectional study, we were not able to control for the fact that support needs may change over time²¹ and are unable to draw causal inferences between needs and psychological distress. Second, the sample was primarily white, carried medical insurance, and a relatively large proportion were diagnosed with stage 4 cancer, which may have biased the sample. Third, the participation rate was not high, and the results may be biased towards an unknown characteristic of those who participated versus those who did not. Fourth, we did not assess whether the patient's oral cancer was HPV-related or not, and we did not assess medical comorbidities. Patients with non-HPV-related cancers and patients with more medical comorbidities have been shown to have higher information and support needs.^{9,38} Fifth, the sample was comprised of patients with more tongue and tonsil cancers and fewer oropharyngeal cancers than the US population and thus may not be representative of the population of these cancers. Sixth, the treatment data (e.g., receipt of a care plan, surgery, chemotherapy, and radiation therapy) were self-reported. Because participants were diagnosed between two and five years prior, it is possible that recollection of treatment facts may be compromised by the passage of time. A final limitation is that the measure of alcohol use was global in that participants who drank on only one day in the past month were classified as using alcohol. A finer-grained

analysis of alcohol consumption would yield more information about the role of alcohol consumption on information and support needs.

This study suggests that, following the completion of oral cancer treatment, most patients reported that they would like to receive a survivorship care plan, information regarding late and long-term side effects, and information about active surveillance for suspicious lesions. Our sample of survivors did not report elevated worry about cancer recurrence and distress. Oral/oropharyngeal cancer survivors who do not drink alcohol, who continue smoking, experience a cancer recurrence, report more fear of recurrence, and experience cancer-related distress report more needs for either information or health care support. These survivor populations may benefit from targeted follow-up services.

Acknowledgments

Funding: This work was supported by a Cancer Prevention and Control pilot grant awarded to Sharon L. Manne by the Cancer Center Support Grant P30 CA 072720. The New Jersey State Cancer Registry, receives support from the Surveillance, Epidemiology, and End Results Program of the National Cancer Institute, under contract HHSN 261201300021I, the National Program of Cancer Registries, Centers for Disease Control and Prevention, under cooperative agreement 5U58/DP003931, the State of New Jersey and the Rutgers Cancer Institute of New Jersey.

We would like to acknowledge Jaime Betancourt, Sara Frederick, Tina Gajda, Natalia Herman and Travis Logan, and the staff at the New Jersey State Cancer Registry.

References

1. American Cancer Society. [March 24th, 2015] Cancer Facts & Figures, 2015. <http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2015/index>.
2. Howlader, N.; Noone, AM.; Krapcho, M., et al. [March 24th, 2015] SEER Cancer Statistics Review, 1975-2011. http://seer.cancer.gov/csr/1975_2011/.
3. List, MA.; Stracks, J. Quality of life and late toxicities in head and neck cancer.. In: Brockstein, B.; Masters, G., editors. Head and Neck Cancer. Kluwer Academic Publishers; Dordrecht: 2003. p. 331-352.
4. Eades M, Chasen M, Bhargava R. Rehabilitation: long-term physical and functional changes following treatment. *Semin Oncol Nurs*. 2009; 25:222–230. [PubMed: 19635401]
5. Kiss NK, Krishnasamy M, Loeliger J, Granados A, Dutu G, Corry J. A dietitian-led clinic for patients receiving (chemo)radiotherapy for head and neck cancer. *Support Care Cancer*. 2012; 20:2111–2120. [PubMed: 22086406]
6. Rieger JM, Zalmanowitz JG, Wolfaardt JF. Functional outcomes after organ preservation treatment in head and neck cancer: a critical review of the literature. *Int J Oral Maxillofac Surg*. 2006; 35:581–587. [PubMed: 16697144]
7. Dingman C, Hegedus PD, Likes C, McDowell P, McCarthy E, Zwilling C. A coordinated, multidisciplinary approach to caring for the patient with head and neck cancer. *J Supp Oncol*. 2008; 6:125–131.
8. Pfister, DG.; Ang, KK.; Brizel, DM., et al. [March 24th, 2015] National Cancer Comprehensive Network.. Head and Neck Cancer (Version 2.2013). <http://www.oralcancerfoundation.org/treatment/pdf/head-and-neck.pdf>.
9. Tippet DC, Webster KT. Rehabilitation needs of patients with oropharyngeal cancer. *Otolaryngol Clin North Am*. 2012; 45:863–878. [PubMed: 22793857]
10. Kissun D, Magennis P, Lowe D, Brown JS, Vaughan ED, Rogers SN. Timing and presentation of recurrent oral and oropharyngeal squamous cell carcinoma and awareness in the outpatient clinic. *Br J Oral Maxillofac Surg*. 2006; 44:371–376. [PubMed: 16624459]

11. Deutschmann MW, Skyes KJ, Harbison J, Cabrera-Muffly C, Shnyder Y. The impact of compliance in posttreatment surveillance in head and neck squamous cell carcinoma. *JAMA Otolaryngol Head Neck Surg.* 2015; 141:519–525. [PubMed: 25950859]
12. Toljanic JA, Heshmati RH, Bedard JF. Dental follow-up compliance in a population of irradiated head and neck cancer patients. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod.* 2002; 93:35–38. [PubMed: 11805775]
13. Funk GF, Karnell LH, Dawson CJ, et al. Baseline and post-treatment assessment of the general health status of head and neck cancer patients compared with United States population norms. *Head Neck.* 1997; 19:675–683. [PubMed: 9406746]
14. Hammerlid E, Taft C. Health-related quality of life in long-term head and neck cancer survivors: a comparison with general population norms. *Br J Cancer.* 2001; 84:149–156. [PubMed: 11161369]
15. Semple CJ, Dunwoody L, George Kernohan W, McCaughan E, Sullivan K. Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. *J Adv Nurs.* 2008; 63:85–93. [PubMed: 18598253]
16. Argiris A, Karamouzis MV, Raben D, Ferris RL. Head and neck cancer. *Lancet.* 2008; 371:1695–1709. [PubMed: 18486742]
17. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol.* 2006; 24:5117–5124. [PubMed: 17093273]
18. Hewitt, ME.; Ganz, PA. [March 24th, 2015] From cancer patient to cancer survivor: lost in translation.. An American Society of Clinical Oncology and Institute of Medicine Symposium. http://www.nap.edu/openbook.php?record_id=11613&page=R1.
19. Institute of Medicine of the National Academies. [March 24th, 2015] Cancer Survivorship Care Planning. <https://www.iom.edu/~media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheetcareplanning.pdf>
20. Chen SC, Lai YH, Liao CT, Chang JT, Lin CC. Unmet information needs and preferences in newly diagnosed and surgically treated oral cavity cancer patients. *Oral Oncol.* 2009; 45:946–952. [PubMed: 19631574]
21. Oskam IM, Verdonck-de Leeuw IM, Aaronson NK, et al. Prospective evaluation of health-related quality of life in long-term oral and oropharyngeal cancer survivors and the perceived need for supportive care. *Oral Oncol.* 2013; 49:443–438. [PubMed: 23318122]
22. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer.* 2009; 17:1117–1128. [PubMed: 19319577]
23. Park BW, Hwang SY. Unmet needs and their relationship with quality of life among women with recurrent breast cancer. *J Breast Cancer.* 2012; 15:454–61. [PubMed: 23346176]
24. Salz T, Baxi SS, Blinder VS, et al. Colorectal cancer survivors' needs and preferences for survivorship information. *J Oncol Pract.* 2014; 10:e277–e282. [PubMed: 24893610]
25. Urbaniec OA, Collins K, Denson LA, Whitford HS. Gynecological cancer survivors: assessment of psychological distress and unmet supportive care needs. *J Psychosoc Oncol.* 2011; 29:534–51. [PubMed: 21882933]
26. Chambers SK, Girgis A, Occhipinti S, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *Eur J Cancer Care.* 2012; 21:213–223.
27. Erci B, Karabulut N. Appraising the self-assessed support needs of Turkish women with breast cancer. *Eur J Cancer Care.* 2007; 16:137–143.
28. Geller BM, Vacek PM, Flynn BS, Lord K, Cranmer D. What are cancer survivors' needs and how well are they being met? *J Fam Practice.* 2014; 63:E7–E16.
29. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. Predictors of change in unmet supportive care needs in cancer. *Psychooncology.* 2010; 19:508–16. [PubMed: 19598292]
30. Rowlands IJ, Janda M, McKinnon L, Webb PM, Beesley VL, Australian National Endometrial Cancer Study Group. Prevalence, predictors, and correlates of supportive care needs among women 3-5 years after a diagnosis of endometrial cancer. *Support Care Cancer.* 2015; 23:1205–1214. [PubMed: 25304121]

31. Holm LV, Hansen DG, Johansen C, et al. Participation in cancer rehabilitation and unmet needs: a population-based cohort study. *Support Care Cancer*. 2012; 20:2913–2924. [PubMed: 22415608]
32. Morrison V, Henderson BJ, Zinovieff FA, et al. Common, important, and unmet needs of cancer outpatients. *Eur J Oncol Nurs*. 2012; 16:115–23. [PubMed: 21555246]
33. Newell S, Sanson-Fisher RW, Girgis A, Ackland S. The physical and psychosocial experience of patients attending an outpatient medical oncology department: a cross-sectional study. *Eur J Cancer Care*. 1999; 8:73–82.
34. Ream E, Quennell A, Fincham L, et al. Supportive care needs of men living with prostate cancer in England: a survey. *Br J Cancer*. 2008; 98:1903–1909. [PubMed: 18506142]
35. Yoon J, Malin JL, Tisnado DM, et al. Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Res Treat*. 2008; 108:69–77. [PubMed: 17638071]
36. Boyes A, Girgis A, Lecathelinais C. Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *J Eval Clin Prac*. 2009; 15:602–606.
37. Jorgensen ML, Young JM, Harrison JD, Solomon MJ. Unmet supportive care needs in colorectal cancer: differences by age. *Support Care Cancer*. 2012; 20:1275–81. [PubMed: 21691847]
38. O'Malley DM, Hudson SV, Ohman-Strickland PA, et al. Follow-up care education and information: identifying cancer survivors in need of more guidance [published online December 20 2014]. *J Cancer Edu*. 2014
39. Akechi T, Okuyama T, Endo C, et al. Patient's perceived need and psychological distress and/or quality of life in ambulatory breast cancer patients in Japan. *Psychooncology*. 2011; 20:497–505. [PubMed: 20878850]
40. Au A, Lam WW, Kwong A, et al. Validation of the Chinese version of the short-form Supportive Care Needs Survey Questionnaire (SCNS-SF34-C). *Psychooncology*. 2011; 20:1292–1300. [PubMed: 22114044]
41. Fiszer C, Dolbeault S, Sultan S, Bredart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology*. 2014; 23:361–74. [PubMed: 24677334]
42. Lam WW, Au AH, Wong JH, et al. Unmet supportive care needs: a cross-cultural comparison between Hong Kong Chinese and German Caucasian women with breast cancer. *Breast Cancer Res Treat*. 2011; 130:531–541. [PubMed: 21617919]
43. Bjordal K, de Graeff A, Fayers PM, et al. A 12 country field study of the EORTC QLQC30 and the Head and Neck Cancer Specific Module (EORTC QLQ-H&N35) in Head and Neck Patients. EORTC Quality of Life Group. *Eur J Cancer*. 2000; 36:1796–1807. [PubMed: 10974628]
44. National Cancer Institute. [March 24th, 2015] Follow-up Care Use among Survivors (FOCUS) Survey. <http://cancercontrol.cancer.gov/ocs/resources/focus.html>.
45. Bellizzi KM, Aziz NM, Rowland JH, et al. Double Jeopardy? Age, Race, and HRQOL in older adults with cancer. *J Cancer Epidemiol*. 2012; 2012:478642. [PubMed: 22888348]
46. Kent EE, Arora NK, Rowland JH, et al. Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Educ Couns*. 2012; 89:345–352. [PubMed: 23021856]
47. Vickberg SM. The Concerns About Recurrence Scale (CARS): a systematic measure of women's fears about the possibility of breast cancer recurrence. *Ann Behav Med*. 2003; 25:16–24. [PubMed: 12581932]
48. Weiss, DS.; Marmar, CR. The Impact of Event Scale-Revised.. In: Wilson, JP.; Keane, TM., editors. *Assessing Psychological Trauma and PTSD: A Practitioner's Handbook*. Guilford Press; New York: 1997. p. 399-411.
49. Ristvedt SL, Trinkaus KM. Trait anxiety as an independent predictor of poor health-related quality of life and post-traumatic stress symptoms in rectal cancer. *Br J Health Psychology*. 2009; 14:705–715.
50. So WK, Choi KC, Chen JM, et al. Quality of life in head and neck cancer survivors at 1 year after treatment: the mediating role of unmet supportive care needs. *Support Care Cancer*. 2012; 22:2917–2926. [PubMed: 24839941]

51. Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. *J Clin Oncol*. 2009; 27:2489–2495. [PubMed: 19332716]
52. Hudson SV, Miller SM, Hemler J, et al. Adult cancer survivors discuss follow-up in primary care: ‘not what I want, but maybe what I need’. *Ann Fam Med*. 2012; 10:418–27. [PubMed: 22966105]
53. Mao JJ, Bowman MA, Stricker CT, et al. Delivery of survivorship care by primary care physicians: the perspective of breast cancer patients. *J Clin Oncol*. 2009; 27:933–938. [PubMed: 19139437]
54. Forsythe LP, Parry C, Alfano CM, et al. Use of survivorship care plans in the United States: associations with survivorship care. *J Natl Cancer Inst*. 2013; 105:1579–1587. [PubMed: 24096621]
55. Merport A, Lemon SC, Nyambose J, Prout MN. The use of cancer treatment summaries and care plans among Massachusetts physicians. *Support Care Cancer*. 2012; 20:1579–1583. [PubMed: 22526150]
56. Mayer EL, Gropper AB, Neville BA, et al. Breast cancer survivors’ perceptions of survivorship care options. *J Clin Oncol*. 2012; 30:158–163. [PubMed: 22162585]
57. American College of Surgeons. [March 24th, 2015] Cancer Program Standards 2012: Ensuring Patient-Centered Care. <https://www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012.ashx>.
58. Puts MT, Papoutsis A, Springall E, Tourangeau AE. A systematic review of unmet needs of newly diagnosed older cancer patients receiving treatment. *Support Care Cancer*. 2012; 20:1377–1394. [PubMed: 22476399]
59. Minstrell M, Winzenberg T, Rankin N, Hughes C, Walker J. Supportive care of rural women with breast cancer in Tasmania, Australia: changing needs over time. *Psychooncology*. 2008; 17:58–65. [PubMed: 17410518]
60. Macvean ML, White VM, Pratt S, Grogan S, Sanson-Fisher R. Reducing the unmet needs of patients with colorectal cancer: a feasibility study of The Pathfinder Volunteer Program. *Support Care Cancer*. 2007; 15:293–299. [PubMed: 16947039]
61. Siedentopf F, Marten-Mittag B, Utz-Billing I, Schoenegg W, Kantenich H, Dinkel A. Experiences with a specific screening instrument to identify psychosocial support needs in breast cancer patients. *Eur J Obstet Gynecol Reprod Biol*. 2010; 148:166–171. [PubMed: 19944516]
62. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001; 10:19–28. [PubMed: 11180574]
63. Miller E. Helping cancer survivors. *Am J Nurs*. 2007; 107:13. author reply. [PubMed: 17667370]
64. Ugalde A, Aranda S, Krishnasamy M, Ball D, Schofield P. Unmet needs and distress in people with inoperable lung cancer at the commencement of treatment. *Support Care Cancer*. 2012; 20:419–423. [PubMed: 22038481]

Table 1

Socio-demographic and clinical characteristics of respondents (N=92)

Characteristics	No. of patients	%	Mean (SD)	Range
Gender				
Male	68	73.9		
Female	24	26.1		
Age			62.1(8.9)	33.4-79.0
Household Income			\$60,000-74,000	< \$20,000->120,000
Ethnicity				
Caucasian/White	81	88.0		
African American /Black	4	4.35		
Hispanic/Latino	4	4.35		
Asian/Pacific Islander	1	1.10		
American Indian	1	1.09		
Missing data	1	1.09		
Education Level				
Less than High School	8	8.7		
High School	19	20.6		
Some college/trade school	30	32.6		
College graduate or higher	17	18.4		
Marital Status				
Married	61	66.3		
Not married	30	32.6		
Missing data	1	1.1		
Employment Status				
Employed	43	46.7		
Homemaker/Caregiver	11	11.9		
Retired	6	6.5		
Not employed	3	3.2		
Medical Insurance (yes)	89	93.7		
Self-reported primary cancer				
Tongue	43	46.7		
Floor of mouth	6	6.5		
Gum/other area in mouth	8	8.7		
Tonsil	29	31.5		
Oropharynx	6	6.5		
Self-reported surgery (yes)	61	66.3		
Self-reported location of surgery				
Neck	33	54.1		
Tongue	21	34.4		
Jaw	8	13.1		
Tonsil	9	14.8		

Characteristics	No. of patients	%	Mean (SD)	Range
Floor of mouth/cheek	7	11.5		
Throat	9	14.8		
Nodal dissection	8	13.1		
Self-reported chemotherapy (yes)	60	65.2		
Self-reported radiation (yes)	77	83.7		
Self-reported cancer recurrence (yes)	7	7.6		
Self-reported month since diagnosis			41.3 (6.4)	23.1-70.0
Disease stage				
1	12	13.0		
2	8	8.7		
3	14	15.2		
4	49	53.3		
Unknown	9	9.8		

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2

Post-Treatment Oral Cancer Care Experiences

Variable	No. of patients (%)
Was informed by physician about the need for follow-up care	88 (95.7)
Was a reason provided for follow-up care *	
Did not discuss a reason	8 (9.1)
Yes, discussed somewhat	17 (19.3)
Yes, discussed in detail	62 (70.4)
Missing data	1 (1.1)
Reason for follow-up care provided *	
Check for recurrence	79 (98.3)
Additional treatment	1 (1.2)
Determine if have health problems as a result of cancer treatment	1 (1.2)
To receive tests or exams for non-cancer diseases such as heart disease, hypertension, or diabetes	1 (1.2)
Patient-reported most important reason for follow-up care *	
Check for recurrence	67 (76.1)
Additional treatment for cancer if needed	4 (4.5)
Determine if have health problems as a result of cancer treatment	3 (3.4)
Treatment for any symptoms or side effects of treatment	1 (1.1)
Routine physical exam	2 (2.3)
Screening for other types of cancer	1 (1.1)
Missing data	11 (12.5)
Physician/HCP discussed late and long-term side effects of oral cancer treatment	
No, did not discuss	20 (21.7)
Yes, discussed somewhat	27 (29.3)
Yes, discussed in detail	44 (47.8)
Missing data	1 (1.1)
Written treatment summary about cancer care provided	
Yes	32 (34.8)
No	48 (52.2)
Unsure	10 (10.9)
If you received a summary, summary can be located *	
Yes	15 (16.3)
No	4 (4.3)
Unsure	13 (14.1)
Would have liked to receive a written treatment summary	
Yes	46 (17.4)
No	16 (50.0)
Unsure	9 (14.1)
Has seen a HCP for oral cancer-related follow-up care since diagnosis	86 (93.5)
Type of HCP was seen for follow-up care (more than one choice)	

Variable	No. of patients (%)
Cancer specialist	70 (65.4)
PCP	18 (16.8)
Dentist	1 (.9)
Plastic surgeon	1 (.9)
Cardiologist	1 (.9)
Ear, Nose, and Throat Specialist	16 (14.8)
Has a HCP considered the primary provider of follow-up care	83 (90.2)
HCP that is considered primary provider of follow-up care	
Cancer specialist	62 (74.6)
PCP	7 (8.4)
Ear, Nose, and Throat Specialist	11 (13.2)
Dentist	2 (2.4)
Oral cancer-related follow-up care provided was helpful	
Always	35 (40.6)
Usually	10 (11.6)
Sometimes	6 (7.0)
Never	2 (2.3)
Missing data	33 (38.4)
Quality of oral cancer-related follow-up care	
Excellent	57 (62)
Very Good	23 (25)
Good	8 (8.7)
Fair	0 (0)
Poor	1 (1.1)
Missing	3 (3.3)

Note: HCP = Health care provider

* Denominator reflects the number of persons who answered yes to the relevant item

Table 3

Descriptive information regarding oral cancer-related information needs

Information Needs	No. of patients	%
What late and long-term side effects of oral cancer treatment to expect	53	58.9
Oral cancer follow-up tests that you should have	52	58.4
Oral cancer symptoms that should prompt you to call your doctor	52	57.7
Maintaining good nutrition and diet given issues with eating	37	41.1
Improving your speech or swallowing issues	31	34.4
Getting or maintaining health, life or disability insurance after cancer	30	33.3
Maintaining good oral health	30	33.3
Managing anxiety about recurrence of your cancer	28	31.5
Dealing with changes in my facial appearance due to surgery/radiation	22	24.4
Dealing with social life such as eating public	18	20.2
Dealing with the effects of oral cancer on your marital or dating life	17	18.9

Note: The percentage refers to the percentage of patients endorsing “yes” and Ns varied between 89 and 90.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 4

Descriptive information regarding support needs

Support Needs	Percent of Sample Moderate or High Need
<i>Physical and Daily living</i>	
Pain	12.1
Lack of energy	25.0
Feeling unwell	13.1
Work around home	12.1
Not being able to do things	20.9
<i>Psychological</i>	
Anxiety	17.6
Feeling down or depressed	13.4
Fear of cancer spreading	18.5
Uncertainty about future	13.2
Keeping a positive outlook	12.0
Feelings about death and dying	10.8
<i>Health Systems and Information</i>	
Being given written information about care	13.2
Being given information about aspects of managing your illness and side effects at home	13.2
Being adequately informed about the benefits and side effects of treatment before you choose to have them	23.4
Being informed about your test results as soon as feasible	24.2
Having access to professional counseling should you need it	15.4
Being given explanations for tests that you would like explained	15.4
Being informed about things you can do to help yourself	19.8
Being treated in a health care clinic that is physically pleasant	14.6
Having a HCP with whom you can talk to about all aspects of your condition, treatment and follow up	23.1
<i>Patient Care and Support</i>	
More choice about which cancer specialist to see	4.4
Reassurance by HCP that feelings are normal	12.1
HCP attending promptly to physical needs	9.9
HCP to acknowledge and show sensitivity	13.2
<i>Sexuality</i>	
Changes in your sexual relationship	18.0

Note: HCP = Health care provider

Table 5

Descriptive information on oral cancer symptoms, fear of cancer recurrence, cancer-related distress

Variable	Mean (SD)	No. of patients (%)	Range
Oral cancer symptoms			
Average pain item score	1.66 (.6)		1-4
Pain	1.60 (.7)		1-4
Swallowing	1.62 (.7)		1-4
Senses	1.78 (.8)		1-4
Speech	1.50 (.7)		1-4
Social Eating	1.70 (1.0)		1-4
Social Contact	1.34 (.6)		1-4
Sexuality	1.60 (1.0)		1-4
Teeth	2.13 (1.3)		1-4
Opening mouth	1.83 (1.1)		1-4
Dry mouth	2.70 (1.1)		1-4
Sticky saliva	2.40 (1.2)		1-4
Coughing	1.27 (.65)		1-4
Take pain killers		30 (32.6)	1-2
Take nutritional supplement		37 (40.2)	1-2
Use feeding tube		4 (4.3)	1-2
Lost weight		14 (15.2)	1-2
Gained weight		20 (21.7)	1-2
Impact of Cancer	34.67 (15.9)		0-85
Fear of recurrence	2.50 (1.4)		1-6
Cancer-specific distress	12.47 (18.0)		0-86

Note: For the impact of cancer and fear of recurrence scales, the mean item rating was calculated.

Table 6

Stepwise regression of the associations between background, medical, and psychological variables and oral cancer-related information and support needs

Dependent variable: Oral cancer-related information															
	Model 1			Model 2			Model 3								
Variables	B	SE	β	F	R ² Change	B	SE	β	F	R ² Change					
Constant	.14	.17				-.16	.18				-.27	.18			
Block 1															
<i>Background</i>				4.7	.11										
Ethnicity ^a	.30	.14	.29			.24	.10	.16			.01			.08	
Alcohol use	-.14	.07	-.23			-.13	.06	-.22			-.18			-.25	
Block 2															
<i>Medical</i>									6.3	.18					
Cancer stage						.21	.06	.08			-.05	.11		.08	
Medical recurrence						.11	.16	.21			.19	.15		.23	
Oral cancer symptoms						-.08	.07	.36			.15	.07		.25	
Block 3															
<i>Psychological</i>													6.6	.09	
Cancer-specific distress											-.00	.00		-.02	
Fear of recurrence											-.08	.03		.38	
Dependent variable: Support needs															
	Model 1			Model 2			Model 3								
Variables	B	SE	β	F	R ² Change	B	SE	β	F	R ² Change					
Constant	1.64	.17				.14	.44				1.25	.36			
Block 1															
<i>Background</i>				18.49	.34										

Dependent variable: Support needs

Variables	Model 1				Model 2				Model 3							
	B	SE	β	F	R ² Change	B	SE	β	F	R ² Change	B	SE	β	F	R ² Change	
Income	-.06	.03	-.21			-.02	.02	-.06			-.00	.02	-.01			
Smoking	1.04	.21	.50			.56	.18	-.27			.46	.13	.22			
Block 2																
<i>Medical</i>																
Time since diagnosis									24.74	.25						
Oral cancer symptoms						.00	.01	.06			-.01	.00	-.06			
Block 3																
<i>Psychological</i>																
Cancer-specific distress						-.01	.03	.73						43.43	.21	
Fear of recurrence						-.01	.00	-.03								

Note:

^aWhite vs non-white ethnicity. For cancer recurrence | = no, 2 = yes. Bolded figures indicate statistically significant beta coefficients.