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Informational Needs of Head and Neck Cancer Patients

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Abstract

Treatment for head and neck squamous cell carcinoma (HNSCC) can lead to considerable functional impairment. As a result, HNSCC patients experience significant decrements in quality of life, high levels of emotional distress, deteriorations in interpersonal relations, and increased social isolation. Studies suggest that HNSCC patients may have extensive informational and psychosocial needs that are not being adequately addressed. However, few programs have been developed to address the needs of HNSCC patients. Therefore, we conducted a pilot study of HNSCC patients to: 1) characterize patients' informational needs; and 2) describe preferred formats and time points for receiving such information. The majority of participants desired additional information regarding treatment options, managing changes in swallowing and speaking, and staying healthy after treatment. Overall, patients with early-stage disease reported more informational needs compared to patients with advanced disease. Female patients were more likely to desire information about coping with emotional stress and anxiety than male patients. Younger patients (29–49 years) were more interested in receiving information about sexuality after cancer compared to their older (50+) counterparts. Although information was requested throughout the cancer trajectory, most patients preferred to receive such information at diagnosis or within 1–3 months post-treatment. The majority of patients reported having computer and Internet access, and they were most receptive to receiving information delivered via the Internet, from a DVD, or from pamphlets and booklets. The relatively high percentage of patients with computer and Internet access reflects a growing trend in the United States and supports the feasibility of disseminating health information to this patient population via Internet-based programs.

Keywords

Head and neck cancer; informational needs; Treatment side effects; Internet

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Despite advances in diagnostic tools and treatment modalities, treatment for head and neck squamous cell carcinoma (HNSCC) often confers considerable functional impairment. Patients experience difficulty swallowing, dry mouth, nutritional deficits, pain, and declines in social functioning, speech, and sexuality [1]. Physical and psychosocial complaints can occur even after successful therapy [2], and patients may experience significant decrements in quality of life (QOL), poorer interpersonal relations, and increased social isolation [3].

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Studies suggest that psychoeducational interventions and programs can improve quality of life, reduce psychological distress, and enhance coping with cancer in various cancer populations [4, 5]. However, few such programs have been developed for HNSCC patients. This empirical gap is surprising given that studies have noted that HNSCC patients have considerable informational and psychosocial needs that are not being adequately addressed [6]. A primary challenge to meeting these needs is limited access or time to participate in such programs. Patients often find themselves having to manage extensive treatment and rehabilitation appointments and are therefore unable to take advantage of any educational programs or psychosocial services that might be available. Indeed, previous studies have reported low attendance to be a common barrier to delivering programs for HNSCC patients [7, 8], and patients have also reported such services to be inaccessible to them [9].

The challenges that exist are especially troubling in light of empirical data indicating that a lack of information is associated with post-treatment uncertainty and psychological distress [10]. Further, a perception of having obtained adequate information and support is shown to be a predictor of positive rehabilitation outcomes in the 2- to 6-year post-treatment period [11]. Therefore, evaluating new approaches for delivering essential services to HNSCC patients is imperative for enhancing patient care and outcomes.

Advances in technology offer an excellent opportunity to increase knowledge while addressing issues related to access and convenience. Web-based psychoeducational interventions are becoming increasingly common for many health conditions [12–16], and therefore, should be seriously considered for adaptation within the HNSCC context. In preparation for developing appropriate resources for HNSCC patients, we conducted a pilot study to: 1) characterize patients' informational needs; and 2) describe preferred formats and time points for receiving such information. In addition, we explored whether patient characteristics or psychological distress are associated with informational needs and preferences. Based on prior studies [10], it was hypothesized that patients with the most informational needs would report the highest levels of psychological distress.

Methods

Study sample

A cross-sectional sample of HNSCC patients was recruited to assess informational needs and delivery preferences. Participants were 65 HNSCC patients presenting for treatment at a comprehensive cancer center. Participants were predominately male (73.8%) and non-Hispanic white (92.3%) (see Table 1). The mean age of participants was 56.3 years. Fewer than half (43.1%) had early stage disease. Study participants provided written informed consent and then completed a brief questionnaire described below.

Measures

Demographic background—Demographic information, including age, gender, race, and education was obtained via self-report. Information about disease stage was extracted from medical chart review by study research assistants.

Patient distress—The Impact of Events Scale (IES) was used to measure cancer-related distress [17]. This scale includes 15 items rated on a 4-point Likert-type scale. Items were summed to yield a total distress score in which higher scores reflect greater distress. This measure is well-validated and has been extensively used in studies with cancer patients, including head and neck cancer patients [18, 19].

Informational needs and delivery preferences—To characterize informational needs, participants were provided with a list of ten topics and instructed to indicate whether having additional information on each topic would be helpful to them. Topics were broadly designed to relate to medical needs (e.g., information about head and neck cancer and its treatment options), physical needs (e.g., changes in swallowing), practical needs (e.g., strategies to improve speech after treatment), emotional needs (e.g., managing emotional distress and anxiety), and social needs (e.g., managing social situations). In addition, participants were provided with an open-ended item to add any other topics about which they would like to receive more information.

Participants were asked to indicate at which time points during their cancer treatment they would like to receive such information. Participants were allowed to indicate multiple time points, ranging from cancer diagnosis (pre-treatment), during cancer treatment, shortly after completing treatment (1–3 months post-treatment) or longer (more than 3 months post-treatment). Finally, to assess preferred mode of information delivery, participants were provided with a variety of options including one-on-one (face-to-face) meetings with a health educator or healthcare professional; group meetings with other head and neck cancer patients led by a health educator or healthcare professional; receiving pamphlets or booklets that patients could view at home; receiving DVDs that patients can view on their home TV or computer; or receiving an Internet-based program that patients can log onto from the computer. Participants were allowed to select more than one mode of delivery. Participants also reported whether they had a computer in the home and whether they had access to the Internet.

Statistical Analyses

Descriptive statistics were used to characterize participants' informational preferences and choices. Chi-square analyses or one-way analyses of variance[1] (ANOVAs) were used to evaluate potential associations between demographic variables, psychological distress, and preferences regarding informational needs, delivery time point, and delivery format.

Results

Informational Needs

The majority of participants (83.1%) reported desiring additional information on at least one topic, and over one-third of participants reported having informational needs on 5 or more topics. The majority (49/65 patients or 75.4%) expressed interest in receiving information about how to stay healthy after treatment (see Table 2). Over half of the sample expressed interest in receiving information about head and neck cancer and its treatment options (53.8%) and about changes in swallowing and speaking following treatment (52.3%). Approximately 46% desired learning strategies for making eating and speaking easier, and over 32% indicated an interest in obtaining information on coping with emotional stress and anxiety. Relatively fewer participants were interested in receiving information regarding communication with family members, coping with changes in appearance, managing social situations, or intimacy and sexuality after cancer. Four participants completed the open-ended item and requested information specifically on: future pregnancies after cancer and radiation treatment; nutrition; post-surgical care; and the availability of support programs in other geographic regions and locations.

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[1] One-way analysis of variance is a statistical test that is used to compare whether the means of two or more groups differ from each other. This technique can be used only with continuous variables. For categorical variables, or non-numerical data, chi-square analyses were used to compare the frequency of observed responses across groups.

The total number of informational needs did not differ by patient gender, age, or education level. However, a greater proportion of patients with early-stage disease (50%) had 5 or more informational needs compared to patients with advanced disease (19.4%), $\chi^2(1)=6.67$, $p=0.01$. With respect to specific needs, patients with early-stage disease were more likely to desire information on coping with emotional stress and anxiety (46.4%) compared to patients with advanced disease (19.4%), $\chi^2(1)=5.34$, $p < 0.03$ (see Table 2). Further, a greater proportion of patients with early-stage disease wanted information on how to highlight the positive aspects of one's cancer experience (42.9%) and strategies for improving communication with family members (35.7%) compared to patients with advanced disease, both χ^2s>4.13, *p*s < 0.05.

Other demographic variables were also associated with informational needs. Specifically, female patients were more likely to want information on coping with stress and anxiety (62.5%) compared to male patients (20.8%), $\chi^2(1)=9.70$, $p=0.002$. Similarly, female patients (56.3%) were also more interested in highlighting the positive aspects of one's cancer experience relative to male patients (20.8%), $\chi^2(1)=7.21$, $p<0.01$. With respect to age, the youngest subgroup of patients (29–49 years) expressed interest in receiving information about intimacy and sexuality after cancer (31.3%) compared to patients who were 50–64 years of age (11.8%) or older (0%), $\chi^2(2)=6.35$, $p<0.05$.

Finally, having more informational needs was associated with greater distress. Specifically, those patients who reported 5 or more informational needs had significantly higher levels of distress (M=25.4, SD=15.8) compared to patients with fewer informational needs (M=15.5, SD=12.6), $F(1,61) = 7.11$, $p < 0.01$.

Delivery Preferences: Time Point and Format

Over 84% of participants reported owning a computer, and 90% reported that they had regular access to the Internet. All of the female patients reported owning a computer, whereas 79.2% of male patients did so, $\chi^2(1)=3.95$, $p<0.05$. Although Internet access did not significantly differ by gender, it did vary by age. Younger patients (29–49 years) all reported having Internet access, as well as 93.9% of 50–64 year old patients, but only 71.4% of older patients (65+ years) reported Internet access, $\chi^2(2)=8.04$, $p<0.02$.

Participants reported varying preferences for when and how they desired to receive additional information, but almost 25% wanted to receive information at more than one time point in their cancer experience. Approximately 39% wanted to receive informational programs at diagnosis, 31% desired such programs during treatment, and 34% preferred this information during the 1- to 3-month period following treatment. Few participants (14%) wanted to receive such information more than 3 months post-treatment.

Younger patients (29–49 years) were more likely to desire receiving additional programs at diagnosis (62.5%) compared to their older counterparts (32.4% of patients aged 50–64, and 21.4% of patients aged 65+), $\chi^2(2)=6.19$, $p<0.05$. A greater proportion of patients with early-stage disease (46.4%) was interested in receiving programs during the 1- to 3-month period following treatment compared to patients with advanced disease (22.2%), $\chi^2(1)=4.19$, $p<0.05$. No other factors were associated with patients' preferred time point for receiving such programs.

With respect to delivery format, 9 participants (13.8%) selected none of the provided options. Of the remaining 56 participants, most were interested in receiving information delivered in a format that could be viewed at the patients' convenience (i.e., pamphlets or booklets, DVD, or Internet program). Specifically, 43.1% was interested in information delivered via the Internet, 40.0% from a DVD, and 36.9% from pamphlets or booklets.

Participants were least interested in attending one-on-one meetings (15.4%) or group meetings (21.5%) with a health professional.

As above, demographic variables were associated with preferred mode of delivery. Specifically, a greater proportion of women were receptive to one-on-one meetings (31.3%) compared to men (10.4%), $\chi^2(1)=3.95$, $p<0.05$, and women were significantly more interested in receiving an Internet-based program (68.8%) compared to men (35.4%), $\chi^2(1)=5.42$, $p<0.02$. Higher educational attainment was also associated with greater preference for an Internet-based program, with 66.7% of participants with post-graduate education preferring an Internet-based program compared to 44.1% of college-educated participants, 53.1% of those with some college or trade school education, and 24.0% of high school educated participants, $\chi^2(3)=7.73$, $p=0.052$. Age was not significantly associated with any program preferences, including Internet-based programs, $\chi^2(2)=4.00$, $p>0.13$. Neither patient preferences for specific time point nor modes of delivery were significantly associated with patient distress.

Discussion

These findings begin to inform our understanding of HNSCC patients' informational needs and their preferred modes of delivery. Collectively, the majority of patients were interested in receiving more information about treatment and its side effects as well as how to stay healthy after treatment. In addition, patients were receptive to receiving information at multiple time points throughout the cancer trajectory, but most notably at diagnosis and around the time of treatment. Younger patients were more likely to desire receiving information at diagnosis compared to older patients. Indeed, other studies have noted younger age to be a significant predictor of seeking additional information when making treatment decisions [20]. Similarly, younger gynecologic and breast cancer survivors were more likely than their older counterparts to desire receiving additional information in general, particularly pertaining to emotional and social needs [21–23].

Although male and female patients did not differ on the total number of informational needs they reported, women were more likely to desire information about coping with emotional needs and stress compared to men. This is consistent with the observation that men are less likely to participate in psychosocial programs than women [24]; however, a previous study of male cancer patients receiving active treatment noted that nearly half of the surveyed patients desired information and support even though few men actually took part in any education or counseling services [25]. The patients in that study expressed interest in attending informational programs in which they could learn about various topics including nutrition, stress management, and sexual functioning [25]. Therefore, it is likely that the manner in which such programs are presented or marketed to patients influences the acceptability and uptake of such programs among specific subgroups, such as men.

Although none of the demographic factors was associated with number of informational needs, patients with early-stage disease were more likely to report having 5 or more informational needs. Further, we confirmed prior findings that having more informational needs was associated with greater distress [10, 26]. Therefore, future studies may be developed to evaluate whether addressing HNSCC patients' informational needs will be beneficial in terms of reducing patient distress and enhancing psychosocial functioning.

With respect to preferred modes of delivery, our findings indicate that a greater percentage of patients preferred receiving information in a format that is available or accessible from home (i.e., Internet, DVD, or pamphlets/booklets), rather than in individual or group formats held in-person at a hospital or healthcare setting. This is consistent with previous research showing poor compliance with programs that entail in-person attendance at hospital-based programs [27]. Poor attendance may be attributed, in part, to the challenge of scheduling programs around appointments with physicians, nurses, and rehabilitation specialists. Patient fatigue and burden may also make it difficult to retain any information delivered in hospital-based programs that occur after healthcare appointments (i.e. information overload). As a result, informational programs that require in-person attendance or multiple interactions may be a significant barrier to participation among HNSCC patients [27–29].

Alternative options for delivering programs, which do not require in-person attendance and could be accessed at the patient's convenience, would greatly reduce or eliminate such barriers and make these programs more appealing and acceptable to patients. Of particular note is the finding that HNSCC patients are receptive to Internet-based programs. Further, a high percentage of patients in the present study reported having a computer and Internet access (84% and 90%, respectively), which reflects an overall growing trend of increasing Internet access and use in the United States [30]. In fact, reported computer and Internet use in the present study is higher than that reported in an earlier study of HNSCC patients in which 48% of participants had never used a computer [31].

This finding also complements other recent data suggesting that Internet-based programs are growing in acceptability among cancer patients [21, 32], although many of these studies were conducted among female cancer patients. Indeed, in the present study, women were more interested in receiving an Internet-based program and were slightly more likely to own a computer compared to men. Higher educational level was also associated with preference for an Internet-based program, although it was not associated with a greater likelihood of owning a computer or access to the Internet. However, older patients (those 65 years or older) were less likely than younger patients to have Internet access. Despite age-related differences in access to the Internet, older age was not associated with less preference for an Internet-based program. Therefore, if access issues can be effectively addressed, patient acceptability of Internet-based programs may actually be relatively high across all age groups. But until such access issues are resolved, a combination of approaches for information delivery may be essential for disseminating important health information across all patient subgroups.

The present study has several limitations. First, the sample size is modest and based on convenience sampling. As a result, we were not able to investigate, in detail, informational needs and preferences within specific patient subgroups. Second, this was a cross-sectional assessment of patients at one point in time, but informational needs and preferences may change over time and across the cancer trajectory. Third, the patient population was racially/ethnically homogeneous and may not be representative of HNSCC patients in general. A broader sampling of HNSCC patients across multiple institutions may yield greater differences in socioeconomic status and racial/ethnic diversity. However, the findings from the present study begin to inform our understanding of the informational needs and preferences of HNSCC patients. More importantly, these data demonstrate a growing awareness of and receptivity to Internet-based programs and health technology in this patient population.

In conclusion, few programs have been developed for HNSCC patients despite empirical data demonstrating that patients have considerable informational needs that are not being adequately addressed [6]. Findings from our study suggest that patients are interested in treatment-related information, treatment side effects, and how to maintain their health after treatment. In addition, our findings indicate patient preferences for content that is viewable at home, including Internet programming. Given advances in information technology, receptivity to information delivered via Internet-based or multimedia DVD programs unlocks new opportunities for health promotion programs to be developed for this patient population with high informational needs and few available resources.

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Table 1

Participant Characteristics

Variable	
Age[a]	M = 56.33 years (SD=11.4;Range=29–85)
29–49 years	24.6%
50–64 years	52.3%
65+ years	21.5%
Gender[a]	73.8% male
Race/Ethnicity[a]	
Caucasian	92.3%
African American/Black	3.1%
Hispanic	1.5%
Asian	1.5%
Education[a]	
High school	38.5%
Some college/Vocational school	23.1%
College degree	13.8%
Post-graduate degree	23.1%
Disease stage[a]	
Early-stage	43.1%
Advanced	55.4%
Psychological distress	M = 18.85 (SD = 13.88; Range=0–50)
Information delivery format preferences*	
Internet-based program @ home	43.1%
DVD that can be viewed @ home	40.0%
Pamphlets/booklets @ home	36.9%
Group meeting led by health prof	21.5%
One-on-one meeting with health prof	15.4%

[a] Percentages do not add to 100% due to missing data from one participant.

* Patients could select more than one option.

Table 2

Types of Information Requested by All Patients and by Disease Stage

Topic	**% of Patients**	**Early-stage**	**Advanced**	χ^2
1. How to stay healthy after treatment	75.4%	78.6%	72.2%	0.34
2. Information about treatment and side effects	53.8%	50.0%	55.6%	0.20
3. Information about changes in swallowing and speaking	52.3%	53.6%	50.0%	0.08
4. Strategies to improve eating and speaking issues	46.2%	50.0%	41.7%	0.44
5. Tips for coping with emotional stress and anxiety	32.3%	46.4%	19.4%	**5.34** *
6. How to highlight positive things in one's cancer experience	30.8%	42.9%	19.4%	**4.14** *
7. How to improve communications with family members	20.0%	35.7%	8.3%	**7.30** **
8. How to cope with changes in appearance	18.5%	21.4%	16.7%	0.23
9. How to manage social situations and social interactions	15.4%	17.9%	13.9%	0.19
10. Close relationships, intimacy, and sexuality	13.8%	21.4%	8.3%	2.24

Note:

[*] $p < 0.05$

[**] $p < 0.01$.