



Support group preferences for patients with head and neck cancer: cross-sectional survey

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Background: To compare and analyse interest in and preferences for a support group for both patients with a diagnosis of head and neck cancer, and their caregivers.

Methods: Cross-sectional design survey distributed from January to May 2019. Responses regarding satisfaction with the level of support provided and preferences for a support group were investigated.

Results: A total of 389 surveys were distributed, 119 were completed and the 103 patient responders were included in the analysis. The majority of respondents (81.5%) were male patients, with a median age of 68 treated with radiotherapy. Fifty-one-point-five-percent indicated that they would like to and 25.2% indicated uncertainty about being involved in a support group. A face-to-face group (69.6%) was the most preferred format followed by an online forum (30.4%). Topics relating to nutrition, new approaches to head and neck cancer treatment, emotional wellbeing and swallowing were the frequently cited topics of interest. Few respondents were aware of other support groups available to them.

Conclusions: While several limitations in the design limit how widely these results can be generalised, this data provides trends as to what type of support could be provided for those recovering from treatment for head and neck cancer.

Keywords: Head and neck cancer; support group; survey

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Introduction

Cancers arising from the head and neck represents the seventh most common cancer site in Australia (1), accounting for over 700,000 (over 5%) new cancer diagnoses worldwide and an estimated 450,000 (4.8%) deaths each year (2). The demographics and prognosis of patients with head and neck cancer are diverse and continually changing. In contrast to tobacco-related mucosal cancer, human papilloma virus (HPV)-related oropharyngeal cancers are

common in younger males (3). HPV associated tumours have a much more favourable prognosis than smoking associated mucosal cancers (4). Several new treatments are emerging, such as immunotherapy, which are prolonging the lives of many patients with head and neck cancer. Improved survival means a larger cohort of patients are living with the long-term effects of the cancer and its treatment on their quality of life (QOL) (5). These patients live with the physical and emotional consequences of

treatment, and have a complex and evolving psychological and physical state that is unlike other cancer diagnoses (6). Education and emotional support are required by many individuals to cope with these challenges.

Cancer support groups have predominantly been implemented and studied in other diagnoses, particularly breast and prostate cancers (7). This is despite the substantial social, vocational, aesthetic, functional and psychosocial effects associated with head and neck cancer diagnosis, treatment and recovery (6). It is challenging to develop a standardized support group format that accounts for the diversity of group purposes, structures and desired outcomes for participants. The goals for support groups vary based on participant cohorts, support group design, outcome measures and study design: to minimise psychosocial issues (8), provide emotional support, education and information (9,10), decrease depression and anxiety (11), share the illness experience and raise public awareness and fundraising (10), advocacy, socialization and affirmation (12); and improve QOL (13,14). Longitudinal evaluation is fraught with challenges inherent in a volitional support group where membership may have a higher turnover rate due to recovery or cancer recurrence. To meet a real, rather than presumed need, support groups in cancer care address several factors: (I) responsiveness to the needs of its members (12); (II) consideration of family, friends and staff (15); (III) a focus on content that is of interest to its members (9), and (IV) consideration of an interface that best suits its community (16,17).

This study investigated the above factors to guide the design of a support group for patients with head and neck cancer and their networks at a tertiary oncology hospital in Sydney, Australia (Chris O'Brien Lifehouse). It was hypothesized that in a survey of both patients and their caregivers, the majority would prefer an in-person support group, with a smaller group interested in an online forum. In a study from the United States of America, Hu *et al.* 2017 found low awareness of available head and neck support groups (10%), we expected similar awareness in our cohort.

We present the following article in accordance with the STROBE reporting checklist (available at <http://dx.doi.org/10.21037/ajo-20-65>) (18).

Methods

This study utilised a cross-sectional survey design. The survey was distributed to patients with a diagnosis of head

and neck cancer and their caregivers between January to May 2019. All patients had been treated with curative intent at Chris O'Brien Lifehouse, Sydney. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Ethics approval was given by Sydney Local Health District Area Health Service, Protocol X18-0089 & LNR/18/RPAH/128 and all patients provided informed consent.

Eligible participants were adults (18 years or older) diagnosed with head and neck cancer in the last 6 years (2013–2019) who had completed treatment. Patient lists were cross-referenced with the NSW death registry. Caregivers were anyone who supported or had a close personal relationship with the patient. The survey questions and supportive topics were written after reviewing existing literature and consulting with an expert panel comprised of a Dietitian, Speech Pathologist, Head and Neck Nurse Specialist, Psych-Oncologist and Head and Neck Surgeon. Surveys were distributed in clinic waiting rooms, online and via post. Those who indicated an interest in participating but had either low literacy skills or were from a culturally or linguistically diverse background were given the option to complete the survey verbally or with an interpreter.

Preferences and opinions of the support and education required by participants were collated and assessed through use of a REDCap survey developed for this purpose. REDCap is a secure, web-based application for creating, distributing and analysing research data in health care. The survey questions are outlined in [Appendix 1](#). Results of the surveys were analysed using descriptive statistics. A subsequent analysis was conducted using “The R Project for Statistical Computing 3.6.0” and the lme4 package modelled binomial logistic regressions with various combinations of variables, for example, years post treatment and number of treatments to determine if any variable could predict likelihood that a respondent would express interest in a support group.

Results

The total number of surveys distributed was 389 with 119 respondents (30.6%). There were 103 (86.6%) patients with a diagnosis of head and neck cancer and 16 (13.4%) caregivers. Of the patient cohort, four patients (3.9%) utilised an interpreter for the survey to be completed. Patient demographics, tumour site and treatment are summarised in *Table 1*. *Figure 1* shows little variability between patients' tumour location and their interest in a

Table 1 Sociodemographic and clinical characteristics of participants

Characteristic	No. (%) (N=119 respondents; N=103 patients)
Respondents	
Patient	103 (86.6)
Caregiver	16 (13.4)
Gender (patient)	
Male	84 (81.6)
Female	19 (18.4)
Age (patient)	68 [31–89]
Interpreter required (patient)	
Yes	4 (3.9)
No	99 (96.1)
Site of tumor	
Oropharynx	46 (44.7)
Oral cavity	31 (30.1)
Larynx	6 (5.8)
Parotid	4 (3.9)
Skin	2 (1.9)
Other	14 (13.6)
Treatment modality	
Radiotherapy	93* (90.3)
Surgery	68 (66.0)
Chemotherapy	56 (47.1)
Residence (patient)	
Metropolitan	90 (87.4)
Regional	13 (2.6)
Year of initial diagnosis	
2019	10 (9.7)
2018	22 (21.3)
2017	14 (13.6)
2016	20 (19.4)
2015	14 (13.6)
2014	6 (5.08)
Before 2014	17 (16.5)

*, treatment modality figures amount to >100% due to multimodal treatment regimens.

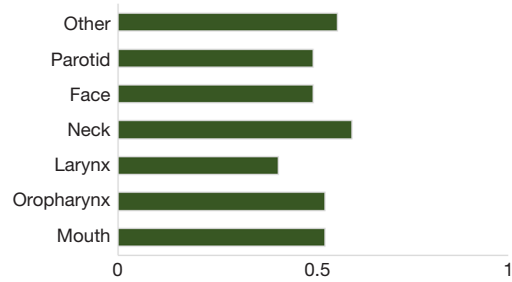


Figure 1 Tumour location and interest in support group.

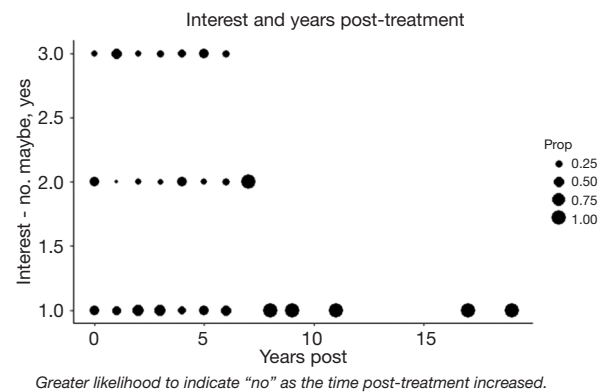


Figure 2 Time post-treatment and interest in support group.

support group. There was no correlation between more treatment modalities and likelihood of indicating “yes”.

Figure 2 was constructed to show the proportion of respondent’s that answered “no”, “maybe” or “yes” given time post treatment. There appear to be no significant relationships between time post treatment and the desire for a support group.

In addition to the above graphical treatment, a number of logistic binomial regression models were run to determine if any variables had predictive power explaining the interest of respondents in a support group—none of these models returned results with significance.

Chart above was constructed to show that there is little variation between patients’ tumour locations and their interest in a support group. Values represent the average likelihood that a patient with a tumour in that location responded either “yes” or “maybe” to the question “do you have interest in a support group?”—note that some patients may fall into more than one category.

Information satisfaction

The majority (82.5%, n=85) of participants who received information at each time interval indicated that they were either satisfied or very satisfied with the information provided. Fourteen (13.6%) were neutral and 4 (3.9%) were unsatisfied or very unsatisfied.

Support group preferences

Fifty-one-point-five percent of respondents (n=53) indicated they would like to be involved in a support group for head and neck cancer, a further 26 (25.2%) were unsure, and 24 (23.3%) declined. Of those who indicated either “yes” or “I’m not sure” (N=79; 76.7%), the majority elected for a regular support group held at their treating hospital (N=55; 69.6%), with 24 (30.4%) preferring an online web-based chat forum. Of those who elected “not sure”, the majority continued to submit their responses and selected multiple

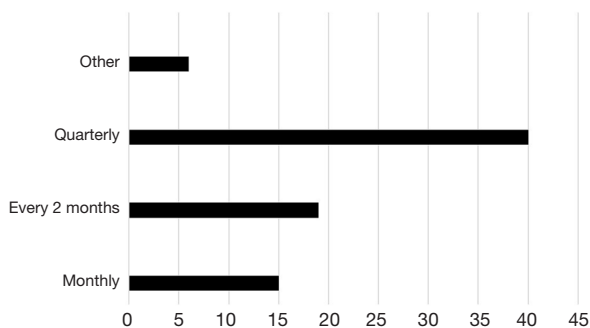


Figure 3 Meeting frequency.

topics of interest.

Participant preferences for frequency and timing of support groups are detailed in Figure 3 with quarterly meetings held on a weekday in the morning being the most preferred.

Figure 4 lists the 15 topics provided; ranked from highest to lowest interest level, the top three subjects were nutrition (53, 67.9%), new approaches and technology relating to head and neck cancer (54, 65.4%), and emotional wellbeing (48, 63.0%). Of those who indicated they were interested or “not sure” if they were interested (N=79) in a support group, the median number of topics selected was 6 (range, 1–15).

Most respondents (93.2%) were unaware of other head and neck support groups available to them. Those who were aware of other support groups were already participating in a NSW laryngectomy group, online international head and neck cancer group, or social media.

Caregiver responses closely mimicked those of the participants with the most common request for education being for emotional wellbeing and nutrition. They too were largely unaware of existing support groups.

Discussion

This study including 103 patients with head and neck cancer demonstrates that many would like to be involved in a dedicated head and neck cancer support group. The higher distribution of males compared to females was representative of what is typically seen in Australia (1). A higher number of oropharyngeal cancers in this cohort is also consistent with the rising incidence of oropharyngeal

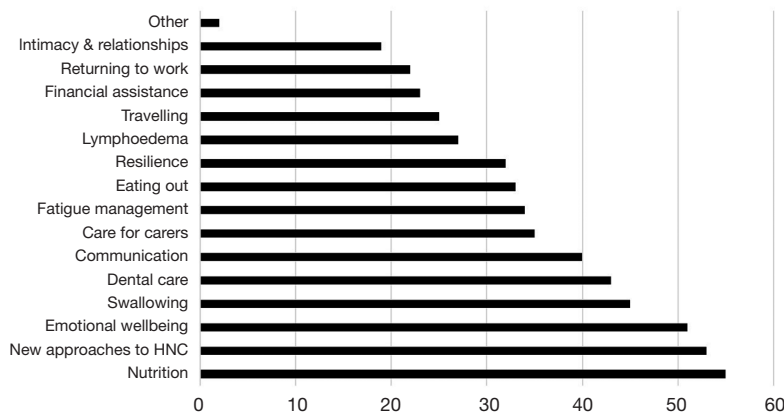


Figure 4 Topics of interest. HNC, head and neck cancer.

cancer (OPC) cancer on account of the HPV (19). While it was hypothesized that respondents with more complex treatments may desire more formal support, this proved not to necessarily be the case. It highlights areas of unfulfilled information and support needs and identifies the support group characteristics desired by head and neck cancer survivors. The breadth of unmet needs discovered likely reflects the diversity of QOL and functional deficits experienced by patients who have undergone head and neck cancer treatment. There were no trends identified as to the patients and caregivers who would be more interested in engaging in a support group.

The findings are similar to those reported by Jabour *et al.* (2017) who identified deficits in information provided to patients regarding emotional well-being, psychosexual health and practical aspects such financial assistance (16). Our study provides an outline for others to prioritise and organize their own support group, which addresses the individual care requirements of patients as they evolve over time. The respondents ranged considerably in their time following treatment completion; however, this timing did not affect interest in attending a support group. While those in the early stage of recovery are more likely to be requiring guidance around a complicated rehabilitation process, those who were diagnosed and treated over 5 years ago are more likely to be seeking support to manage the chronic nature of head and neck cancer-related side effects.

The results of this survey will inform a support group delivery model with potential to be replicated in other institutions. The first and third most frequently selected items; nutrition and emotional wellbeing are frequent complications arising from a diagnosis and treatment for head and neck cancer (20,21), affecting patients both physically and emotionally. This is consistent with Rehse and Pukrop (2003) (22) who found that a support group's priority is the provision of emotional support and expressing a shared experience among peers. Problems swallowing, communicating and eating out were areas of unmet need and contribute to the social isolation and difficulties returning to work often experienced by head and neck cancer survivors, a challenge also raised by the respondents of a UK survey (23). These information and support needs reflect patient and their caregiver emphasis on the support of allied health professionals, particularly dietitians, speech pathologists, specialist nurses, social workers and clinical psychologists. It also highlights that support groups combining education with emotional support are most valued by participants (23,24). Preferences

regarding support group delivery mode (face to face or online) are likely to be driven by several factors, dependent on participant computer literacy, geographical location, working status and personality. Many of those who declined interest in a support group specified that information and support received during treatment was sufficient and they no longer required assistance. This is encouraging for the proportion of patients who are successfully rehabilitated.

Although the sample size is small, the disparity between the low proportion of patients aware of support groups (7.8%) and those indicating their interest in one (46.2%) is of concern considering the degree of psychosocial distress and known impact on QOL. This metric may vary by sample population and whether their treating hospital has a support group. Some online resources are available that seek to connect patients and caregivers with support groups in their region (e.g., Beyond Five) (25); however, this is only helpful if such groups are available at location accessible to the individual and appropriately structured to meet the person's needs.

The value and significance of these findings are complex. The question of whether availability of a support group has an impact on the QOL or function of its participants has been met with conflicting results. The majority of studies have found positive correlations between support groups and QOL in cancer care (10,11,13), and specifically in the head and neck cancer population (14). However, Mowry and Wang (2011) (26) and Petruson *et al.* (2003) (27) found no difference in QOL measures between those who did and did not attend the support group; the authors suggest reasons for lack of improved QOL measures may be related to participant's degree of social isolation, patient selection and presence of underlying depressive disorders.

Opportunities provided by new technologies must also be evaluated. The use of telehealth and online support groups (OSG) should be examined in the process of support group planning and implementation. Studies have examined these platforms finding that an online community provided an opportunity for emotional support and stress management (17). There also exists potential for individualised, patient-centred support for clinical and emotional needs; this is of particular value to geographically diverse patients (16).

In our study, interest in a support group was high even though most respondents indicated that they were satisfied with the support and information given before, during and after their treatment. It is surmised that the satisfaction in treatment information is distinct from information required

for living with long term side effects from such treatment. There is also a separate desire to meet others who have lived the same experience. The degree to which information is absorbed can be dependent on the receptibility of the patient and the context of their diagnosis and subsequent treatment; many patients experience a treatment pathway that deviates from their expectations, with considerable associated stress. For this reason, Newell *et al.* (2004) (28) concluded that the content and timing of information provision needs to be individualised. Absorption and application of useful information may be better suited to a post-treatment information and support group.

The results from this study indicate that a support group (face to face and/or online delivery) warrants consideration for those at varying stages of their recovery and with different cancer subsites. Should this be initiated, both Mowry and Wang (2011) (26) and Petruson *et al.* (2003) (27) raise the importance of considering underlying depressive disorders of participants and providing access to the appropriate management and support.

Strengths and limitations

Whether the respondent was a patient or carer, time since diagnosis, location of primary cancer and treatment modality for head and neck cancer diagnosis were examined, however factors such as ethnicity, relationship status, perceived level of support, premorbid mental and physical comorbidities and living arrangements were not ascertained or analysed. The majority of respondents were from metropolitan areas, and as such, our sample may not be representative of the information and support needs of regional residents. This, combined with voluntary participation and literacy requirements for inclusion, may mean the sample is not completely representative of the population of patients with head and neck cancer and their caregivers. Participation and non-response bias cannot be ruled out when applying these results. Specifically, those with low literacy, those who are not proficient in English, minorities and those from non-metropolitan areas may be under-represented, and those who have a particular support need, may be over-represented. While the responses were anonymous, there may have been a tendency for patients to respond in a way they felt was socially desirable and complementary to the service they were treated by, increasing the chance for acquiescence bias. It is also acknowledged that patient preferences may not correlate with improved QOL outcomes.

Relative strengths were the inclusion of both patients and caregivers, those from culturally and linguistically diverse backgrounds and a combination of patients from metropolitan and regional areas.

Future studies

Future studies could assess whether head and neck cancer support groups are most effective at particular time points along the cancer journey (diagnosis, treatment or recovery). Comparing the needs of the patient versus caregiver, genders, age and tumour sites may also yield more targeted results. As the trajectory of diagnosis, treatment and recovery in head and neck cancer varies greatly, it may also be valuable to determine if support groups should be separated into cancer sites, aetiology or treatment modalities. A separate information and support group for those requiring palliative care may also be warranted. Pre-existing mental health conditions, anxiety and support networks should also be assessed when planning the degree of professional involvement, eligibility criteria and duration of the group.

To our knowledge this is the first study that examines the unmet information and support needs of patients who have completed treatment for head and neck cancer to inform the development and implementation of a tailored support group. The objective of the study was to establish support group interest in a cohort of patients from our facility, providing literary support to oncology care clinicians considering similar projects. The results highlight the importance of consultation with prospective participants prior to commencing a support group to ensure a real rather than a presumed need is met.

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Footnote

Reporting Checklist: The authors have completed the STROBE reporting checklist. Available at <http://dx.doi.org/10.21037/ajo-20-65>

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Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <http://dx.doi.org/10.21037/ajo-20-65>). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Ethics approval was given by Sydney Local Health District Area Health Service, Protocol X18-0089 & LNR/18/RPAH/128 and all patients provided informed consent.

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Please select from below, which best describes you:

- Person diagnosed or treated for head and neck cancer
- Person caring or supporting someone with head and neck cancer
- Other

How recently did you have your diagnosis?

What sort of cancer were you diagnosed with?

- mouth
- oropharynx (base of tongue or tonsil)
- larynx or glottis
- neck
- face
- parotid
- other

What sort of treatment did you receive?

- radiotherapy
- chemotherapy
- surgery
- immunotherapy
- combination

Did you receive information and support before your treatment?

- Yes
- No

How satisfied were you with the information and support you received before your treatment?

- Very satisfied
- Satisfied
- Neutral
- Unsatisfied
- Very unsatisfied

Did you receive information and support during your treatment?

- Yes
- No

How satisfied were you with the information and support you received during your treatment?

- Very satisfied
- Satisfied
- Neutral
- Unsatisfied
- Very unsatisfied

Did you receive information and support after your treatment?

- Yes
- No

How satisfied were you with the information and support you received after your treatment?

- Very satisfied
- Satisfied
- Neutral
- Unsatisfied
- Very unsatisfied

Please add any comments you may have about the information you received during your, or your loved one's, cancer treatment.

(Please note any additional information or support you would have liked to receive.)

Would you be interested in accessing an education and support group run through Chris O'Brien Lifehouse?

- Yes
- No
- I'm not sure

If you were interested in additional education and support, what format would you prefer?

- Online web based chat forum
- A regular group meeting held at Chris O'Brien Lifehouse
- Other

If other, please describe what sort of support or information group you would like to be involved with.

If you were to attend a Head and Neck Cancer Education and Support group, how frequently would you like to meet?

- Monthly
- Every two months
- Quarterly
- Other

If you were to attend a Head and Neck Cancer Education and Support Group, which would be suitable for you?

- Weekday
- Weekend

If you were to attend a Head and Neck Cancer Education and Support group, what time would best suit you?

- Morning
- Afternoon
- Evening

If you were to attend a Head and Neck Cancer Education and Support Group, what information would you like covered?

- Care for carers
- Communication
- Dental care
- Eating out
- Emotional wellbeing
- Fatigue management
- Financial assistance
- Intimacy & relationships
- Lymphoedema (swelling)
- New approaches & technology relating to head and neck cancer
- Nutrition
- Resilience
- Returning to work
- Swallowing
- Travelling
- Other

If you have any further topic ideas, please detail them here.

Please suggest any other support that would be of benefit to you

Are you aware of any other head and neck cancer education and support groups that are available to you?

- Yes
- No