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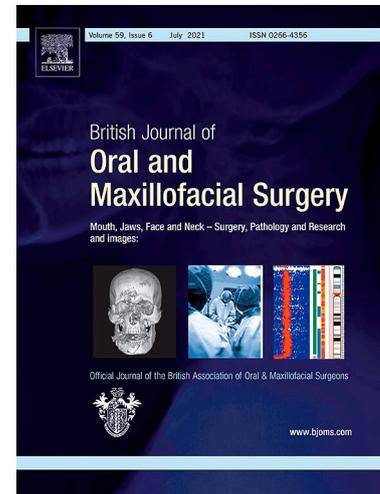
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A survey to ascertain peer support models available in Head and Neck cancer across the United Kingdom

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Keywords: Head and Neck Cancer; Peer Support; Self-help groups; Cancer survivorship; Survey;

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Abstract

In cancers and chronic conditions, peer support (PS) has been shown to improve quality of life (QOL) and provide an important coping mechanism for patients, however there is little evidence for this intervention in Head and Neck cancer (HNC). Peer support allows individuals to come together and share information, encouragement, and experiences. It is delivered in a variety of ways including one-to-one, online, and support groups. There is limited literature regarding the timing, barriers, and types of PS available for individuals with HNC across the United Kingdom (UK). The aim of this project was to survey healthcare professionals with respect to their experience regarding types, timings, and barriers to PS in HNC. The survey was developed based on the literature, feedback and advice from a HNC patient research group and healthcare professionals. It was conducted online and consisted of twelve questions. Eighty-eight individuals responded covering twenty-four of twenty-six cancer alliances across the UK. Three main themes with subthemes were identified: patient barriers (emotional barriers and patient limitations), organisational barriers (administrative problems, limited

time and resources and Covid-19), and staff barriers (lack of departmental support, concerns with PS and matching and timing of support). The survey demonstrated the different types of PS available across the UK and the barriers faced when implementing this support. It highlighted the complexity of being able to satisfactorily deliver appropriate and effective PS in HNC and the challenges involved.

Keywords: Head and Neck Cancer; Peer Support; Self-help groups; Cancer survivorship; Survey

Introduction

Head and neck cancer (HNC) and its treatment is associated with life-changing challenges and side effects. There are many side effects and patient concerns which include dry mouth, pain and difficulty with chewing, speech and swallow, altered body image and fear of recurrence¹. These impact on emotional, physical, and social well-being and can lead to patient's willingness to interact socially². The cancer, treatment burden and outcomes can result in increased anxiety, depression, and reduced quality of life (QOL)^{3,4}. Social support such as PS can improve QOL⁵. Research focusing PS and QOL in breast cancer demonstrates a clear QOL benefit^{6,7}. Peer support in HNC is briefly acknowledged in the National Institute for Health and Care Excellence (NICE) guidelines, although recognised as being important, there is little literature and guidance focusing on HNC PS.

In healthcare PS involves people with the same disease coming together and sharing information, encouragement, and experiences. Peer support can offer social, emotional, practical, and spiritual assistance^{8,9}. Support can be formal or informal. Informal support is the type given by peers when they connect on the ward or waiting room. This support cannot be tracked. Formal support such as support groups can be tracked or monitored. In HNC the literature points to three elements; support groups, one-to-one support, and online support¹⁰. Additional forms include family-to-family support, phone-based support, web- and email-based support, PS via community health workers and mentorship programs¹¹⁻¹³.

There is relatively little literature regarding who initiates and facilitates PS in HNC or healthcare. Peer support is the responsibility of the whole Multidisciplinary Team (MDT). Delivery of PS may be professional-led e.g. nurse-led¹⁴ or patient-led¹⁵. Patient-led support may be facilitated by trained (mentor) or untrained individuals^{12,13}. There is no information regarding the training mentors receive in HNC. Gender and geographical location may be potential barriers affecting PS participation^{16,17}. A review outside of HNC found patients may not engage with PS due to apprehension surrounding connecting with a fellow peer and how they are dealing with their diagnosis or recovery. Healthcare professionals may not recommend PS due to limited availability of support and the difficulty surrounding matching patients¹⁸. It is unknown whether hospitals in the UK match HNC patients (connecting patients with similar characteristics) and the criteria used. The aim of the study was to survey healthcare professionals with respect to their experience regarding types, timing, and barriers to PS in HNC to help inform future development.

Methods

A review of the literature¹⁰ informed the initial outline of the survey. This was discussed at the HaNC Patient and Carer Research Forum¹⁹ and the survey refined. The drafted survey focused on the support available, timing of support, barriers to support, training for peer-supporters and carer specific support. Feedback was sought through interviews with eight colleagues familiar with HNC: speech and language therapists (2), previous MDT chair (1), a lead cancer nurse (1), Clinical Nurse Specialists (2) and patients (2) involved in the HaNC Patient and Carer Research Forum¹⁹. The interview followed the style of a cognitive interview, using verbal probes to look for potential problems with the survey and help understand the respondents interpretation of the survey. The final version of the survey was then uploaded to the Jisc online survey website²⁰. The online survey was tested by those interviewed prior to its distribution.

The target population was healthcare professionals who are familiar or have experience with PS in HNC. The forum directly targeted SLTs registered to the Head and Neck Oncology Clinical Excellence Network for SLTs site. Twitter targeted those following the Liverpool Head and Neck Centre Twitter page. Participants were invited to complete the survey using two platforms: 1) an online Speech and Language Therapists forum and 2) the Liverpool Head and Neck Centre Twitter page. The survey opened on the 19/04/21 for six weeks and two reminders were posted to both sites, one a week after the initial posting and another two weeks later²¹.

The survey responses were collated and analysis was mainly descriptive by questions (numbers and percentages). For the free text responses, qualitative methodology was used to analyse the responses and compare the results where appropriate. Inductive coding was used for the theme analysis. The raw data was interpreted to look for common themes and concepts. The concepts and themes were then drawn together to create a code which was then checked by all the authors and edited. Similar codes were then combined into broader themes and made up the individual subthemes²². This study was approved by Liverpool University Ethics (registration number 8726).

Results

There were 88 responses from 24 of 26 Cancer Alliances across the United Kingdom (UK). As expected the majority of responses were from SLTs, with smaller representation from other professional groups. The most commonly reported types of PS were patient-led and professional-led support groups respectively, seen in Table 1. Six respondents offered other types of PS not covered in the options such as 6 monthly health and wellbeing days and social events, led by professionals with the anticipation that patients would take over. The recommended timing of PS varied depending on the stage of the treatment pathway. The most common time to offer PS was post-treatment (54.5% of respondents choosing always or often). During treatment was less common (53.4% responding rarely or never), illustrated in Table 2. Most units do not offer carers/family members carer specific support

(37.5% responding never or rarely). A fifth of respondents reported that they always or often offered carer specific support. Only 17.0% of peer supporters are offered training. Training may be delivered as informal training, 1:1 training with SLT or CNS, hospital volunteer training or Macmillian support/volunteer training. The ranges of topics covered may include discussion regarding the supporter's role, confidentiality, sensitivity, listening skills, safety, respect, non-judgemental perspective, how to escalate and report concerns or incidents, boundaries and role playing. 18.2% of peer supporters are offered on-going support. The types of support offered include telephone, in-person, email, video or group setting support. 83.0% of units who responded to the survey try to match peers on similar characteristics. The characteristics matched on include surgery/treatment type, age, gender, site and stage and social support, shown in Table 3. The most common characteristic listed was age closely followed by surgery/treatment type and gender.

Theme analysis

Three main themes were identified: patient barriers, organisational barriers and staff barriers.

Illustrative quotes are provided in Table 4.

1. Patient barriers

Respondents noted that PS is reliant on patients taking responsibility for their own care and individuals being confident to participate and volunteer. A concern regarding those who participate with PS is the psychological state of the 'supporter' as this can impact a supportee's experience, additionally it was noted that becoming a peer supporter requires confidence and emotional stability. Other patient factors that may affect engagement with PS, include age, socioeconomic background and geographical proximity to other peers.

2. Organisational barriers

There were difficulties reported regarding coordination of dates and times of meetings and another commented on the difficulties working with charities. The issue of obtaining patient consent were raised. Respondents said PS is limited by availability of staff to facilitate training or support sessions and there were physical space restrictions. Some units reported high patient demand but insufficient capacity. In essence PS is not deemed to be a priority and thus there is a lack of infrastructure. Respondents reported that the Covid-19 pandemic had affected PS with regards to both training and delivery: it had ceased or moved online.

3. Staff barriers

Some respondents commented on the timing of PS and how patient needs vary during treatment and rehabilitation. Another area of uncertainty was the best time to recommend PS. Respondents commented on the limited pool but large diversity of HNC patients making it hard to find the 'perfect' match. There is also the added difficulty of remembering similar past patients when trying to match.

Another concern is the experience or health status of individuals participating in support and how this may reflect on their peers. If an individual has had a poor experience staff might not keen to promote them as a PS. The final area of concern highlighted was lack of peer training. Respondents commented on the lack of involvement and recommendation of PS by other healthcare professionals and management.

Discussion

The survey is the first of its type and gives an insight into PS currently offered across the UK. The design was enhanced through close collaboration with the HNC patient group and refinement by a

group of healthcare professionals involved with PS. Most of the findings of this survey are based on the SLTs respondents. However, it is possible to infer that the findings represent what is taking place in the individuals department as SLTs have a close working relationship with other members of the MDT team. The participants contributed considerably to the scope of the survey through their use of free text. There was very good national coverage with 24 of the 26 cancer alliances across the UK represented. The study has limitations: the sample denominator is unknown, and respondents cannot be compared to non-respondents. Also, the representativeness of the national position cannot be confirmed.

The majority of units offered PS. Six units currently offer no PS, and some units only offer limited types of PS. Limited availability and type of PS may represent a barrier for patients seeking a support modality which is not available. The types of PS wanted by HNC individuals needs to be further explored. Respondents commented on the timing of PS and how needs change over time. Peer support was most commonly offered post-treatment. Egestad²³ reported on PS during radiotherapy treatment and found patients benefited from support and it helped them cope better with treatment. Kristensen et al.²⁴ found PS following treatment was well received as patients reported feeling afraid of facing another person with the same disease whilst 'on treatment'. Park et al.⁸ reported on unmet needs and PS in cancer patients observing that support needs change depending upon time since diagnosis, stage, and cancer type. This may explain why engagement with support groups decreases as time since treatment increases¹⁶. The survey findings and literature suggest timing of engagement with PS is based on the individual and varies meaning there is not a universal time for PS recommendation, and PS referral should be individualised.

Matching patients was a concern to staff and how they match patients varies between units. There are no current guidelines on how best to match patients and due to the diversity of HNC patients finding a 'perfect' match is very difficult. Online PS expands the patient pool and opportunity for a good match. Online communities have increased due to the Covid-19 pandemic. Criteria for matching requires consideration, it may be that matching needs to be individualised to the patient: some want

someone to relate to regarding challenges, for example treatment and side effects²³ whilst others may want a deeper connection with someone of a similar age, gender, background and personality²⁵.

Peer support appears not to be valued or prioritised by organisations. Consequently, PS tends not to receive the required funding. Management may not be keen to invest in PS due to the cost; two studies looking at cost-effectiveness of PS in diabetes and mental health found that whilst PS was beneficial there was no conclusive evidence to support its cost-effectiveness. However, it was not a costly intervention and may be cost-effective²⁶⁻²⁷. More research is warranted with regards to cost-effectiveness of PS.

Only one tenth of carers were always offered carer specific support. One respondent mentioned that a barrier to support is when the carer wants support, but the patient does not. Another respondent said their unit should focus more on carers as they do not always see them at patient appointments. This emphasises the need for carer specific support to be made available for those who want and should not be dependent on the patient also engaging with support.

Respondents reported that PS is beneficial for those involved. Sometimes staff like to separate patient groups depending on treatment outcome, for example palliative and non-palliative patients as some individuals fear meeting a fellow patient with more advanced cancer²³. It is important to offer as they are more at risk of suffering from depression and anxiety which can lead to a lower QOL²⁸.

Peer support needs greater attention and more needs to be done to raise the importance of PS in HNC. Feedback from respondents demonstrates that it would be helpful to have a framework for PS allowing all patients to have the same access to support resources and care. The barriers and how these can be overcome needs to be explored in more detail. Carers receive little individual support and this is an area that needs to be explored further. More also needs to be done to ascertain the needs and preferences of HNC patients and carers with regards to PS and how best to tailor this support. More in-depth interviewing could be an idea for a future study.

In conclusion the most common type of PS currently offered across the UK is professional-led support groups. The survey found three broad barriers to PS: patient barriers, staff barriers and organisational barriers. It highlighted the complexity of being able to satisfactorily deliver appropriate and effective PS in HNC and the challenges involved.

Acknowledgement

We acknowledge the HNC patient research group and the healthcare professionals who helped with the development of the survey and all those who completed the survey.

Conflict of Interest

We have no conflicts of interest.

Ethics Statement / Confirmation of Patient's Permission

The data was collected for service evaluation and was approved by Liverpool University Ethics (registration number 8726). Patient permission not applicable

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Table 1: Types of peer support offered

	Peer support healthcare professional is aware of	Peer support offered in unit
Professional-led support groups	63 (71.6%)	51 (58%)
Patient-led support groups	73 (83%)	41 (46.6%)
Untrained one-to-one support	46 (52.3%)	40 (45.5%)
Telephone-based peer support	36 (40.9%)	26 (29.5%)
Web- and email-based support	60 (68.2%)	25 (28.4%)
Trained one-to-one support	35 (39.8%)	24 (27.3%)
Mobile phone-based support	27 (30.7%)	18 (20.5%)
Not aware of any peer support/ No peer support offered	5 (5.7%)	10 (11.4%)
Family-to-family support	11 (12.5%)	6 (6.8%)
Other	0 (0%)	6 (6.8%)

Multi answer- percentage of respondents who selected each answer option (e.g., 100% would represent that this option was chosen by all respondents)

Table 2: Timing and frequency of peer support

	Before Treatment	During Treatment	After Treatment
Always	21 (24.9%)	5 (5.7%)	20 (22.7%)
Often	19 (21.6%)	12 (13.6%)	28 (31.8%)
Sometimes	25 (28.4%)	22 (25%)	20 (22.7%)
Rarely	11 (12.5%)	28 (31.8%)	12 (13.6%)
Never	10 (11.4%)	19 (21.6%)	7 (8%)
Unsure	2 (2.3%)	2 (2.3%)	1 (1.1%)

Table 3: Characteristics used to match patients.

Characteristics used to match	Number of respondents
Age	57
Surgery/treatment type	49
Gender	48
Cancer site, stage and prognosis	32
Social support and socio-economic status	15
Employment status and background	15
Other*	9
Personality	8
Race, religion and culture	7
Interests	7

* Others include patient concerns, method of communication, local in area to each other, side effects and comorbidities.

Table 4: Themes and subthemes related to perceived barriers to peer support

Patient barriers
<i>Emotional Barriers</i>
<ul style="list-style-type: none"> • “[It is an] Emotional burden for [a] patient taking on another patient's 'story'”
<i>Patient limitations</i>
<ul style="list-style-type: none"> • “Younger patients tend not to come to support groups once well as have work and family commitments so tends to be retired and often more middle class patients who link in. Those from lower classes often know someone who has had H&N ca so form their own informal support networks rather than engage with the formal ones.”
Organisational barriers
<i>Administrative problems</i>
<ul style="list-style-type: none"> • “Gaining permission from patients in advance as to whether they would be happy to support patients in the future”
<i>Limited time and resources</i>
<ul style="list-style-type: none"> • “Lack of broad range/availability of peer support and focuses more on laryngectomy patients”
<i>Covid-19</i>
<ul style="list-style-type: none"> • “COVID has been a bit restrictive as sometimes internet connection is unstable or user problems”.
Staff barriers
<i>Lack of departmental support</i>
<ul style="list-style-type: none"> • “Perceived by management as an added benefit rather than part of therapy”
<i>Concerns with peer support and matching</i>
<ul style="list-style-type: none"> • “The pool of young professional patients who are available for peer support has been quite small” • “We don't routinely recommend support group to patient who are palliative to protect the main group, referring those patients to day hospice instead of they would benefit from peer support however some of the support group have ended up with recurrence and been palliative so the group [h]as needed more support at these times”
<i>Timing of support</i>
<ul style="list-style-type: none"> • “Often at diagnosis patients overwhelmed with information we need to gauge the best time to suggest peer support”

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