

**Health Professionals' Perspectives of Support Needs of Adult Head and Neck Cancer
Survivors and their Families: A Delphi Study**

[accepted in *Supportive Care in Cancer*]

Lauren J Breen^{1*}

Moira O'Connor¹

Samuel Calder¹

Vivian Tai¹

Jade Cartwright^{1,2}

Janet M. Beilby¹

¹School of Psychology and Speech Pathology, Curtin University

²Centre for Neuroscience of Speech, University of Melbourne

*School of Psychology and Speech Pathology, Curtin University, GPO Box U1987, Perth,
Western Australia, 6845.

Lauren.Breen@curtin.edu.au

Tel: +61 8 9266 7943

Fax: +61 8 9266 2464

This research was supported by a grant awarded by the Research and Development
Committee of the School of Psychology and Speech Pathology, Faculty of Health Sciences,
Curtin University.

The authors declare no conflicts of interest.

Abstract

Purpose: The aim was to identify the views of Australian and New Zealand health professionals regarding the support needs of people with head and neck cancer (HNC) and their families and current gaps in service delivery.

Methods: A modified Delphi process assessed support needs of people with HNC following acute medical management. A systematic review of the literature was used to develop items relevant to seven key concepts underpinning the psychological experience of living with HNC. A panel of 105 health professionals was invited to participate in two questionnaire rounds.

Results: Of the potential panellists, 50 (48%) completed Round 1, and of these, 39 (78%) completed Round 2. Following two rounds, there was consensus agreement on the concepts *Uncertainty and waiting*, *Disruption to daily life*, and *Fear of recurrence*. The concepts *The diminished self*, *Making sense of and managing the experience*, *Sharing the burden*, and *Finding a path*, did not achieve consensus. There were no differences in responses according to gender, organization type, or location. Medical professionals had significantly higher agreement for the concept *Uncertainty and waiting* compared to allied health professionals, and professionals with five years' or more experience had significantly higher agreement than those with less experience.

Conclusions: Health professionals agreed that many psychosocial support needs of HNC survivors and families are not being met and that they experience difficulties in meeting these needs. Findings may inform evidence-based treatment programs for HNC survivors and their families to promote psychological resilience and quality of life in this vulnerable population.

Background

Head and neck cancer (HNC) refers to a range of cancers in the lip, mouth, tongue, nasal and sinus cavities, pharynx, and larynx and is associated with tobacco smoking, alcohol consumption, sun exposure, and certain viruses and chemicals [1,2]. Due to the sexual transmission of HPV, the incidence of HNC is increasing and it is affecting younger people [2]. Internationally, there are approximately 680,000 reported cases of HNC each year [3], and HNC is the seventh most common cause of cancer mortality [4]. These cancers are typically aggressive but early detection and treatments are effective [5]. Due to an increase in 5-year survivorship, years lost to disability due to HNC are growing, as are the ongoing economic, social, and psychological effects.

Active intervention usually involves surgery such as partial or full laryngectomy (removal of the larynx), glossectomy (removal of the tongue), maxillectomy and/or mandibulectomy (removal of the upper and lower jaws), and neck dissections, alongside radiation therapy and chemotherapy [6]. Post-active treatment, survivors tend to experience a series of negative physical and functional effects [7], including disfigurement and impairments in voice and speech [8,9], eating [10], and swallowing [11]. Fear of recurrence [12] and reduced quality of life are especially prevalent in survivors of HNC [13-17] and their families [11,18-20].

Health professionals play an essential role in managing people with HNC throughout the active treatment phase, and may provide information to support effective self-management of people with HNC post-active treatment [21,22]. Supportive psychosocial interventions can be effective in reducing depressive symptoms post active treatment [23] and improving health-related quality of life [24,25], and there is a pressing need to extend this support through the development of targeted interventions that address the psychosocial needs of people living with HNC and their families. While there are measures of cancer survivors' unmet needs (e.g., CaSUN [26]), they do not capture the various symptoms and issues experienced by HNC survivors [7], nor are they used in routine practice post-active treatment. As the first step, it is necessary to document these needs from the perspectives of health professionals. The objective of this study was therefore to gain consensus on health professionals' perspectives on the needs of people with HNC and their families and current gaps in service delivery.

Methods

This study was approved by the Curtin University Human Research Ethics Committee (Approval Number PSYCH SP 2014-82). A two-round modified-Delphi method was used to

assess health professionals' perspectives on the psychosocial support needs of people with HNC and their families following acute management of disease, defined as three months to three years post active treatment. The design facilitated the collection of data through an iterative process where the successive stage is dependent on the results from previous rounds of inquiry [27].

Questionnaire Development

A systematic review and meta-synthesis of 29 qualitative studies of psychological experiences of living with HNC revealed six core concepts for the questionnaire – uncertainty and waiting, disruption to daily life, the diminished self, making sense of the experience, sharing the burden, and finding a path [21]. Fear of recurrence was added, due to the emerging research identifying it as a major issue for HNC survivors [12] (Table 1). These concepts were used to design *Likert* statements on a 5-point scale ranging from 'strongly disagree' to 'strongly agree'. Panellists were asked to rate each item using the scale according to whether the items reflected their professional experiences. The draft 82-item questionnaire was piloted with 11 health professionals (Cronbach's alpha = .73). Nine open-ended questions were included to evaluate coherence, clarity, and feasibility. Item-total correlations indicating item redundancy, combined with the feedback, led to a revised questionnaire comprising 55 items and 4 open-ended questions for administration with the expert panel.

Panel Recruitment

Professionals were eligible for recruitment to the panel if they met the following *a priori* inclusion criteria: (a) a professional qualification, (b) professional experience in the management of people with HNC, and (c) located in Australia or New Zealand.

Panellists were purposively selected to optimise data validity [28]. Eligible health practitioners were identified through contacting relevant medical and allied health professional groups, researchers' contacts in HNC management, and 'snowballing', whereby existing panellists suggested potential panellists. These strategies yielded a total of 105 potential panellists for the questionnaire.

Questionnaire Administration

Each potential panellist received an email that included an individual link to the questionnaire hosted on *Qualtrics* and were invited to complete the Round 1 questionnaire within 14 days. A reminder email was sent five days before the deadline. Those who did not complete Round 1 were ineligible for the following round.

Questionnaire Revision and Administration

The Round 2 questionnaire was revised and modified according to the Round 1 analysis (see conventions described in Watkins et al [29]). Concepts were removed if they achieved consensus, defined as a minimum of 70% of panellists agreeing/strongly agreeing on each item [30]. Items with fewer than 60% of panellists agreeing/strongly agreeing were rejected or modified based on the feedback. If multiple items relating to the same concept did not achieve consensus, the entire concept was readministered. Three items (2,3,5) were not re-administered due to low agreement rates, indicating consensus with disagreement with the items. Some items were expanded after Round 1 according to feedback and administered in Round 2. Panellists were provided with feedback representative of comments, and group% agreement and median rating for each item, to encourage reflection on Round 1 responses, which afforded a robust basis for construct validity of findings [31]. An email reminder was sent five days before the questionnaire closed. Panellists who completed both rounds were eligible to win one of five \$20 gift vouchers.

Statistical Analysis

Relevant items were recoded to reflect scaling in the same direction across items. Descriptive statistics (frequency, median, and interquartile deviation) were reported for each statement. Kendall's tau-b was used to calculate test-retest reliability of responses to the 40 items answered by panellists across both rounds. Wilcoxon signed-rank tests were used to compare agreement between statements for all items administered both rounds. Mann-Whitney *U* tests were used to compare panellists based on age (median split), experience (>/< five years' experience working with people with HNC; >/< five years since tertiary graduation), gender (male/female), service provision (MDT/non-MDT), profession (medical and nursing/allied health), organisation type (public hospital/private hospital) and organisation location (metro/rural). All statistical analyses were conducted using *IBM SPSS Version 22.0*.

Results

Of the 105 identified potential panellists, 60 (57%) responded to Round 1, yielding 50 completed questionnaires (83% completion rate). Of the 50 potential Round 2 panellists, 41 (82%) responded, yielding 39 completed questionnaires (95% completion rate). Following Round 1, 70% belonged to a multidisciplinary team (MDT) and 88% of panellists had more than five years' experience working with people with HNC (Table 2).

Internal Consistency Reliability

There was moderate to strong internal consistency for the first five concepts across both rounds (Table 3). The remaining concepts had inadequate alpha values.

Agreement, Test-retest Reliability, and Response Stability

Following Round 1, consensus was achieved for 26 (47.27%) items, and consensus was achieved for another 20 (45.45%) items following Round 2. Kendall's tau-b for 20/41 items indicated positive correlations between responses between rounds and Wilcoxon signed-rank tests indicated stability of agreement between 37/41 items administered both rounds (Table 4).

Comparisons According to Panellist Characteristics

There were no significant differences in responses between panellists according to gender, service provision, organisation type, or location. Agreement in panellists with 5 years or more experience (*Mean Rank*=21.71, *n*=33) was significantly higher than those with less than five years' experience (*Mean Rank*=10.58, *n*=6) for the concept *Making sense of and managing the experience*, $U=42.5$, $z=-2.217$, $p=.027$). For the concept *Uncertainty and waiting*, medical health professionals (*Mean Rank*=24.43, *n*=20) had significantly higher agreement (*Mean Rank*=15.34, *n*=19) than those in allied health professions ($U=101.50$, $z=-.2.543$, $p=.011$).

Open-ended Responses

In Round 1, 48 panellists responded to the open-ended items. Of these, 96% disagreed that items were irrelevant to understanding the needs of people with HNC and their families and 96% disagreed that statements were difficult to understand. Most (85%) agreed the questionnaire captured their beliefs regarding the psychosocial needs of people with HNC and their families. Sixteen (33%) included comments for consideration in developing the Round 2 questionnaire. Common responses included the importance of MDT management of HNC; private patients' disadvantage due to increased financial costs and reduced access to MDT support; disadvantage of rural patients due to distance from treatment and reduced access to MDT support; access to psychosocial support needs for patients and families should be individualized but that patients experience difficulty initiating the support; and that a large number of HNC patients are single, socially-isolated, middle-aged men who smoke and drink excessively, and may be reluctant to communicate their emotional and psychosocial needs.

Round 2 panellists commented that people with HNC would be best supported through MDT management that explicitly targeted psychosocial issues associated with the illness for the survivor and their family. Suggestions included integrating social workers or clinical psychologists into standard allied health management. Additional comments related to specific areas of difficulty related to impairment, such as swallowing difficulties and physical disfigurement, as well as patient access to medical treatment.

Conclusions

This study is the first systematic investigation of Australian and New Zealand health professionals' perspectives of the psychosocial support needs of people with HNC and their families. Following Round 1, there was consensus for 26 (47%) of the 55 items and for the core concepts *Uncertainty and waiting*, *Disruption to daily life*, and *Fear of recurrence*. These concepts are well-documented in the literature [12,21,32,33] and might be more observable through management of people with HNC in both active treatment and rehabilitation phases. Following Round 2, consensus was achieved for 20 (45%) of the 44 items but not for the remaining concepts (*The diminished self*, *Making sense of and managing the experience*, *Sharing the burden*, and *Finding a path*). The median rating for these was neither agree nor disagree and this may be due to the highly subjective nature of these concepts. The latter two of these concepts, alongside *Fear of recurrence*, had inadequate internal consistency reliability coefficients; these concepts may relate more directly to psychological experiences that do not elicit a shared understanding or priority among health professionals.

There were no significant differences in responses according to service provision, organisation type or location, despite these issues featuring in the open-ended responses, meaning that the panellists had similar views on psychosocial support needs generally. Panellists with more experience were more likely to agree with the concept *Making sense of and managing the experience*. This may be because professionals with more experience may have seen the struggles of people with HNC face in managing their illness; however, this concept did not achieve consensus among panellists. Medical professionals had significantly higher agreement concerning the concept *Uncertainty and waiting* than those in allied health professions and may be because much of their role is in active treatment, whereas allied health professionals are more likely to have greater involvement in post-treatment rehabilitation. However, panellists agreed that access to medical treatment was adequate, but only for patients in metropolitan areas. While the effectiveness of telehealth for the delivery of behavioural intervention is well-established [34], the functional communication needs of people with HNC may not be met easily via telehealth models. HNC survivors with greater functional oral impairments show reduced adherence across a range of intervention delivery models [35]. However, the increasing numbers of younger, and therefore more technologically adept, HNC survivors might be more willing to use and adhere to telehealth interventions [36,37].

In examining consensus at the item level, there was 100% consensus for items concerning worries about the future, functional impairments affecting self-confidence, and the need for effective coping strategies and clinical psychology services for people with HNC. There was very high consensus (98%) regarding physical appearance and psychosocial wellbeing of people with HNC and the need for psychosocial support for family members of people with HNC. The notion that family members, too, would benefit from access to psychosocial support, has been documented previously [18,33,38]. The most salient psychosocial concerns centred on fear of recurrence, worry, diminished confidence, and the need for psychosocial support and effective coping strategies. These issues reflect the wider oncology literature where fear and anxiety [39-41] and confidence [42] are reported directly by patients. These psychosocial concerns may be supported through behavioural interventions to assist people with HNC and their families cope with, and adapt to, life after HNC [21,38] but are currently untested in this population.

There was consensus amongst panellists regarding people with HNC feeling overwhelmed by information; this reflects existing literature [20-22] although there are other studies showing that people with HNC express strong needs for more information [43]. However, there was a lack of consensus regarding health professionals' ability to provide information. Health professionals may be ill-equipped to provide information for a variety of reasons, including busy schedules, full caseloads, and difficulty communicating information [44]. The health professionals agreed that they are fundamental in providing psychosocial support to people with HNC but experience difficulties providing such support; this discord is also reflected in oncology generally [45]. Additionally, health professionals might not have access to the information that is tailored to the specific needs of this population, particularly those considered 'at-risk' due to social isolation.

Study Limitations

The design used a somewhat arbitrary, although common, definition of consensus, and precluded the investigation of differences between panellists and non-responders to the study. While we aimed to develop a holistic picture of health professionals' perspectives of support needs of adult head and neck cancer survivors and their families, the discipline of medical oncology, which plays an increasing role in providing chemotherapy treatment for HNC [6], was not represented in the sample. It is, however, noteworthy that the majority of panellists were experienced practitioners working within current models of best practice. An additional strength is the 82% response rate between rounds, which is considered high [38].

Clinical Implications

The results may inform the development of interventions to address the clinical gaps and holistic rehabilitation needs of adults living with HNC, following acute management of the disease, using the concepts and items that achieved consensus as an evidence-base on which to address priority areas. There is a need to investigate the support needs and service gaps from the perspectives of people with HNC and their families so that interventions targeting these identified needs may be developed and tested. Such interventions are especially important in addressing the well-documented functional impairments [7-12] and reductions in quality of life for HNC survivors and their families [13-20]. In developing these clinical interventions, health professionals would likely benefit from assistance to recognise and respond to emotional cues and psychosocial needs for this population [45]. The results may inform the development of interventions to address the clinical gaps and holistic rehabilitation needs of adults living with HNC, following acute management of the disease, using the concepts and items that achieved consensus as an evidence-base on which to address priority areas. Given the increasing incidence of HNC, especially among younger adults [2], the two patient groups (i.e., the ‘typical’ older group versus the younger HPV positive group) that present with HNC might be have different service requirements that may need to be taken into consideration in future service development.

Ethical approval: 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.

References

1. Maehara Y (2010) Alcohol drinking, cigarette smoking, and the development of squamous cell carcinoma of the esophagus. *Int J Clin Oncol* 15;125-125.
2. Westra W (2009) The changing face of head and neck cancer in the 21st century: the impact of HPV on the epidemiology and pathology of oral cancer. *Head Neck Pathol* 3;78-81.
3. Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F (2015) Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer* 136;e359-e386.
4. Mehanna H, Paleri V, West CM, Nutting C (2010) Head and neck cancer—Part 1: Epidemiology, presentation, and prevention. *BMJ* 341;663-666.
5. Gourin CG, Podolsky RH (2006) Racial disparities in patients with head and neck squamous cell carcinoma. *Laryngoscope* 116;1093-1106.
6. Choong N, Vokes E (2008) Expanding role of the medical oncologist in the management of head and neck cancer. *CA: a cancer journal for clinicians* 58(1);32-53.
7. So WKW, Chan RJ, Chan DNS, Hughes BGM, Chair SY, Choi KC, Chan CWH (2012) Quality-of-life among head and neck cancer survivors at one year after treatment: a systematic review. *Eur J Cancer* 48;2391-2408.
8. Jacobi I, van der Molen L, Huiskens H, Van Rossum MA, Hilgers FJ (2010) Voice and speech outcomes of chemoradiation for advanced head and neck cancer: a systematic review. *Eur ArchOto-Rhino-Laryngol* 267;1495-1505.
9. Robertson SM, Yeo JC, Dunnet C, Young D, MacKenzie K (2012) Voice, swallowing, and quality of life after total laryngectomy—results of the west of Scotland laryngectomy audit. *Head & Neck* 34;59-65.
10. Ehrsson YT, Langius-Eklöf A, Laurell G (2012) Nutritional surveillance and weight loss in head and neck cancer patients. *Support Care Cancer* 20;757-765.
11. Raber-Durlacher JE, Brennan MT, Verdonck-de Leeuw IM, Gibson RJ, Eilers JG, et al. (2012) Swallowing dysfunction in cancer patients. *Support Care Cancer* 20;433-443.
12. Van Liew JR, Christensen AJ, Howren MB, Hynds Karnell L, Funk GF (2014) Fear of recurrence impacts health-related quality of life and continued tobacco use in head and neck cancer survivors. *Health Psychol* 33;373-381.
13. Bornbaum CC, Fung K, Franklin JH, Nichols A, Yoo J, Doyle PC (2012) A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Support Care Cancer* 20;2157-2165.
14. Keereweer S, Kerrebijn JD, Al-Mamgani A, Sewnaik A, de Jong RJB, van Meerten E (2012) Chemoradiation for advanced hypopharyngeal carcinoma: a retrospective study on efficacy, morbidity and quality of life. *Eur Arch Oto-Rhino-Laryngol* 269;939-946.
15. Nagy J, Braunitzer G, Antal M, Berkovits C, Novák P, Nagy K (2014) Quality of life in head and neck cancer patients after tumor therapy and subsequent rehabilitation: an exploratory study. *Quality of Life Research* 23;135-143.
16. Vickery LE, Latchford G, Hewison J, Bellew M, Feber, T (2003) The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck* 25;289-296.
17. Wissinger E, Griebisch I, Lungershausen J, Byrnes M, Travers K, Pashos CL (2014) The humanistic burden of head and neck cancer: a systematic literature review. *PharmacoEconomics* 32;1213-1229.
18. Bond SM, Hawkins MDK, Murphy BA (2014) Caregiver-reported neuropsychiatric symptoms in patients undergoing treatment for head and neck cancer: a pilot study. *Cancer Nurs* 37;227-235.

19. Drabe N, Zwahlen D, Büchi S, Moergeli H, Zwahlen RA, Jenewein J (2008) Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. *Psycho-Oncol* 17;199-204.
20. Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans CR (2007) Distress in spouses and patients after treatment for head and neck cancer. *The Laryngoscope* 117;238-241.
21. Lange H, France E, Williams B, Humphris G, Wells M (2013) The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psycho-Oncol* 22;2648-2663.
22. Parker V, Bellamy D, Rossiter R, Graham V, Britton B, Bennett L, Giles M (2014) The experiences of head and neck cancer patients requiring major surgery. *Cancer Nurs* 37;263-270.
23. Van der Meulen IC, May AM, de Leeuw JRJ, Koole R, Oosterom M, Hordijk GJ, Ros WJG (2014) Long-term effect of a nurse-led psychosocial intervention on health-related quality of life in patients with head and neck cancer: a randomised controlled trial. *Bri J Cancer* 110;593-601.
24. Semple CJ, Dunwoody L, Sullivan K, Kernohan WG (2006) Patients with head and neck cancer prefer individualized cognitive behavioural therapy. *Eur J Cancer Care* 15;220-227.
25. Vakharia KT, Ali MJ, Wang SJ (2007) Quality-of-life impact of participation in a head and neck cancer support group. *Otolaryngology--Head and Neck Surgery* 136;405-410.
26. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, Wain G (2007) The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncol* 16;796-804.
27. Hsu CC, Sandford BA (2007) Minimizing non-response in the Delphi process: How to respond to non-response. *Practical Assessment, Research & Evaluation* 12;62-78.
28. Hasson F, Keeney S, McKenna H (2000) Research guidelines for the Delphi survey technique. *J Advanced Nurs* 32;1008-1015.
29. Watkins RE, Elliott EJ, Halliday J, O'Leary CM, D'Antoine H, Russell E et al (2013) A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Pediatrics* 13(1);1.
30. Keeney S, Hasson F, McKenna H (2011) *The Delphi Technique in Nursing and Health*. Wiley-Blackwell.
31. Okoli C, Pawlowski SD (2004) The Delphi method as a research tool: An example, design considerations and applications. *Information and Management* 42;15-29.
32. Ghazali N, Cadwallader E, Lowe D, Humphris G, Ozakinci G, Rogers SN (2013) Fear of recurrence among head and neck cancer survivors: longitudinal trends. *Psycho-Oncol* 22;807-813.
33. Hodges LJ, Humphris GM (2009) Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncol* 18;841-848.
34. Wootten R (2012) Twenty years of telemedicine in chronic disease management: an evidence synthesis. *Journal of Telemedicine and Telecare* 18;211-220.
35. Wall LR, Ward EC, Cartmill B, Hill AJ, Porceddu, SV (2016) Adherence to a prophylactic swallowing therapy program during (chemo) radiotherapy: Impact of service-delivery model and patient factors. *Dysphagia*, advance online publication.
36. Cartmill B, Wall LR, Ward EC, Hill AJ, Porceddu SV (2016) Computer literacy and health locus of control as determinants for readiness and acceptability of telepractice in a head and neck cancer population. *Int J Telerehabilitation* 8;49-60.

37. Lea J, Lockwood G, Ringash J (2005) Survey of computer use for health topics by patients with head and neck cancer. *Head and Neck* 27;8-14.
38. Becker S, Kirchberger I, Cieza A, Berghaus A, Harréus U, Reichel O, Tschiesner U (2010) Content validation of the comprehensive ICF core set of head and neck cancer (HNC): the perspective of psychologists. *Psycho-Oncol* 19;594-605.
39. O'Connor M, Tanner P, Watts K, Miller L, Musiello T (Accepted April, 2016) Introducing routine screening for distress in a gynaecological cancer setting: a mixed methods study. *Clin J Oncol Nurs*.
40. Watts K, Good L, McKiernan S, Miller L, O'Connor M, Kane R, Kruger D, Adams, B, Musiello T (2016) Undressing distress among cancer patients living in urban, regional and remote locations in Western Australia. *Support Care Cancer* 24;1963-1973.
41. Lebel S, Gozde-Ozakinci, Humphris G, Thewes B, Prins J, Dinkel A, Butow P (2016) Current state and future prospects of research on fear of cancer recurrence. *Psycho-Oncol*. doi:10.1002/pon.4103
42. Wagland R, Fenton D, Tarrant R, Howard-Jones G, Richardson A (2015) Rebuilding self-confidence after cancer: a feasibility study of life-coaching. *Support Care Cancer* 23;651-659.
43. So WKW, Choi KC, Chen JMT, Chan CWH, Chair SY, Fung OWM, Wan RWM, Mak SSS, Ling WM, Ng WT, Yu BWL (2014) Quality of life in head and neck cancer survivors at one year after treatment: the mediating role of unmet supportive care needs. *Support Care Cancer* 22;2917-26.
44. Chung H-O, Oczkowski SJW, Hanvey L, Mbuagbaw L, You JJ (2016) Educational interventions to train healthcare professionals in end-of-life communication: A systematic review and meta-analysis. *BMC Medical Education* 16;131.
45. Butow P, Brown R, Cogar S, Tattersall M, Dunn S (2002) Oncologists' reactions to cancer patients' verbal cues. *Psycho-Oncol* 11;47-58.

Table 1. Core concepts (adapted from Lange et al.²⁰, p.2655)

Concept	Description
Uncertainty and waiting	Being in limbo; uncertainty of living with the disease and of the future.
Disruption to daily life	Disruption to the person's physical, emotional and social functioning.
The diminished self	Temporary or longer-lasting functional, social, and existential losses survivors experience.
Making sense of and managing the experience	Survivors' efforts to make sense of cancer and their expectations about a likely outcome.
Sharing the burden	Importance of a supportive relationship with health professionals in maintaining survivors' self-worth; impact on, and needs of, family members.
Finding a path	Nature of life beyond cancer; perception of the future being diminished or changed.
Fear of recurrence	Fear associated with the possibility that the cancer will return or progress.

Table 2. Summary of panellist characteristics–round 1 (N=50)

Characteristic	N(%)
Gender	
Male	9(17)
Female	41(82)
Organisation location	
Australia (metro)	42(84)
Australia (regional/rural/remote)	5(10)
New Zealand/Aoteroa (metro)	2(4)
New Zealand/Aoteroa (regional/rural/remote)	1(2)
Organisation type	
Public hospital	37(74)
Private hospital	6(12)
Community clinic	1(2)
Non-profit organisation	3(6)
Other (employed across types)	3(6)
Discipline	
Dental specialty	2(4)
Dietetics	3(6)
Head & neck surgeon	9(18)
Nursing	10(20)
Psychology	1(2)
Radiation oncology	5(10)
Social work	1(2)
Speech pathology	16(32)
Other (physiotherapy, health promotion, cancer care coordination)	3(6)
>5 years since graduation	44(88)
>5 years working with people with HNC	39(78)
Member of multidisciplinary team	35(70)
	M(SD)
Age(years)	38.25(9.45)

Table 3. Internal consistency reliability

Concept	Round 1	Round 2
Overarching statements	.716	.605
Uncertainty and waiting	.694	.596
Disruption to daily life	.590	.590
Diminished self	.683	.683
Making sense of and managing the experience	.750	.523
Sharing the burden	.254	.363
Finding a path	.332	.530
Fear of recurrence	.028	.370

Table 4. Agreement with statements on psychosocial support needs of people with head and neck cancer and their families

Statement	Round 1		Round 2		Kendall's tau-b	Wilcoxon Z
	N	%Agree (median; IQD)	N	%Agree (median; IQD)		
Section 1:Overarching Statements						
1.Access to medical treatment for people with HNC is adequate	50	54(4;2)	39	18(2;1)	.192	-3.605***
a) Access to medical treatment for people with head and neck cancer living in metropolitan areas is adequate			39	72 (4;1)		
b) Access to medical treatment through private services for people with HNC is adequate			39	34(3;2)		
c) Access to medical treatment through public services for people with HNC is adequate			39	59(4;2)		
2.Access to psychosocial support for people with HNC is adequate	50	22(2;1)				
3.Access to psychosocial support for family members of people with HNC is adequate	50	16(2;1)				
4.Health professionals experience difficulties in supporting psychosocial needs of people with HNC [†]	50	74 (4;3)				
5.People with HNC feel their cancer is regarded as being less important than other cancers [†]	50	22(3;1)	39	32(4;2)	.363**	-.557
6.High levels of distress are common for people with HNC [†]	50	94 (5;1)				
7.High levels of distress are common for family members of people with HNC [†]	49	90 (4;1)				
Section 2:Uncertainty and Waiting						
8.There is uncertainty and waiting associated with a HNC diagnosis [†]	49	82 (4;1)				
9.People with HNC worry about their future [†]	48	100 (5;1)				
10.People with HNC worry about their physical appearance [†]	48	98 (4;1)				
11.People with HNC experience negative psychological reactions/distress due to their ongoing treatment and side-effects [†]	49	92 (5;1)				
a) People with HNC benefit from access to clinical psychology services integrated into active treatment and rehabilitation			38	100 (4;1)		

Section 3: Disruption to Daily Life						
12. Disruption to daily life due to HNC affects the psychosocial wellbeing of people with HNC [†]	50	98 (5;1)				
13. Living with pain disrupts daily life for people with HNC [†]	50	96 (5;1)				
Section 4: The Diminished Self						
14. People with HNC experience a loss of identity [†]	50	68(4;1)	39	80 (4;:50)	.457**	-.824
15. People with HNC experience difficulties with intimacy [†]	50	62(4;1)	39	77 (4;:50)	.278	-.595
16. Functional impairments associated with HNC affect the self-confidence of people with HNC [†]	50	96 (4;1)	39	100 (5;1)	.214	-.943
17. Changes in physical appearance lead to social withdrawal of people with HNC [†]	50	86 (4;1)	38	92 (4;:50)	.350*	-.243
18. Changes in physical appearance lead to a negative body image for people with HNC [†]	50	84 (4;1)	39	92 (4;:50)	.224	-.655
19. Feeling 'diminished' is related to poorer survival outcomes for people with HNC [†]	50	40(3;1)	39	46(3;1)	.212	-.502
20. People with HNC experience diminished social support [†]	49	55(4;1)	39	62(4;1)	.174	-.925
Section 5: Making Sense of and Managing the Experience						
21. People with HNC have difficulty making sense of their experience of HNC [†]	50	54(4;1)	38	63(4;1)	.440**	-.209
22. Family members of people with HNC have difficulty making sense of their family member's experience of HNC [†]	50	60(4;1)	38	82 (4;0)	.393**	-1.043
23. People with HNC feel guilty about their illness [†]	50	22(3;:50)	37	22(3;1)	.248	-.303
24. People with HNC feel shameful about their illness [†]	50	30(3;1)	39	29(3;1)	.328**	.000
25. People with HNC experience regret about their illness [†]	49	59(4;1)	39	69(4;:50)	.252	-.218
26. People with HNC are less likely to seek help for psychosocial difficulties compared to physical difficulties	49	63(4;1)	39	85 (4;1)	.335*	-.758
27. People with HNC re-evaluate their life priorities [†]	50	72 (4;:50)	39	90 (4;0)	.130	-1.342
28. People with HNC receive adequate information from health professionals to manage their cancer	49	41(3;2)	39	33(3;2)	.444**	-.463
29. People with HNC feel overwhelmed by information provided by health professionals [†]	50	76 (4;:50)	39	92 (4;0)	.365	-1.217
30. People with HNC feel health professionals do not communicate	48	17(3;1)	39	21(3;1)	.150	-.876

sensitively [†]						
31. Health professionals are responsive to the needs of people with HNC	49	75 (4;.50)	39	97 (4;0)	.255	-2.310*
Section 6: Sharing the Burden						
32. Supportive networks help people with HNC cope with their cancer	50	84 (4;0)	39	92 (4;.50)	.152	-1.327
33. Families are the main source of emotional support for people with HNC	50	80 (4;0)	39	90 (4;0)	.346*	.000
34. Families are the main source of practical support for people with HNC	50	88 (3;0)	38	89 (4;0)	.180	-.447
35. Other people with HNC are the main source of emotional support for people with HNC	49	20(3;1)	39	8(2;3)	.329*	-2.276*
36. Other people with HNC are the main source of information for people with HNC	50	22(3;1)	39	13(3;1)	.239	-1.574
37. The internet/social networking are useful avenues of information for people with HNC	48	46(3;1)	39	35(3;1)	.326*	-1.091
38. The internet/social networking are useful avenues of information for families of people with HNC	47	51(3;1)	39	39(3;1)	.374*	-1.031
39. The internet/social networking are useful avenues of social support for families of people with HNC	50	40(3;1)	39	34(3;1)	.344*	-.393
40. People with HNC rely on health professionals for psychosocial support	49	71 (4;1)	36	89 (4;0)	.294	-1.995*
41. Family members of people with HNC rely on health professionals for psychosocial support	50	72 (4;1)	39	90 (4;0)	.044	-1.895
42. People with HNC are reluctant to disclose feelings of distress to health professionals [†]	49	53(4;2)	38	55(4;1)	.449**	-.179
43. People with HNC feel abandoned when active medical treatment ends [†]	50	52(4;1)	39	48(3;1)	.590***	-.447
44. Family members of people with HNC would benefit from access to psychosocial support after active medical treatment	50	98 (4;1)	39	97 (4;.50)	.609***	-1.667
Section 7: Finding a Path						
45. People with HNC focus on the future to help manage uncertainty	50	36(3;1)	39	26(3;1)	-.002	-1.372
46. People with HNC accept they might not return to normal	50	58(4;1.50)	39	64(4;1)	.317*	-1.055
47. People with HNC find positives from the experience of HNC	50	28(3;1.50)	38	13(3;1)	.540***	-1.212
48. Effective coping strategies are essential to wellbeing for people with	50	100 (4;1)	39	97 (4;1)	.429**	-.905

HNC						
49. Adopting a positive mindset/attitude improves wellbeing for people with HNC	50	88 (4;1)	39	90 (4;0)	.447**	-.258
Section 8: Fear of Recurrence						
50. Fear of recurrence is common for people with HNC [†]	50	96 (4;1)				
51. Fear of recurrence disrupts daily life for people with HNC [†]	50	58(4;1)	39	85 (4;0)	.195	-.619
52. It is difficult for health professionals to recognise fear of recurrence in people with HNC [†]	50	48(3;2)	39	33(3;2)	.189	-.075
53. People with HNC require support to manage fear of recurrence	50	94 (4;0)				
54. Family members of people with HNC require support to manage fear of recurrence	50	96 (4;0)				
55. Referral options available to health professionals for managing fear of recurrence are limited [†]	50	78 (4;1)				

Note. IQD – inter-quartile deviation; HNC – head and neck cancer.

Agreement includes responses ‘agree’ and ‘strongly agree’

Statements reaching 70% agreement (consensus) are bolded.

*p<.05; **p<.01; *** p<.001; †items were recoded using the opposite scale.