$SAGE

Using the Delphi Method to Elucidate Patient and Caregiver Experiences of Cancer Care

Janet Ellis, MBBChir, MD, FRCPC[1,2,3],
Miriam von Mücke Similon, MD[4],
Melissa B Korman, BSc (Hons), MSc (Candidate)[2,3] (iD),
Sophia den Otter-Moore, BSc, MSc[2],
Alva Murray, BA, MSW, RSW[1],
Kevin Higgins, MSc, MD, FACS, FRCSC[1,3],
Danny Enepekides, MD, FRCSC, MPH[1,3],
and Marlene Jacobson, PhD, S-LP (C) reg.CASLPO[1,3]

Abstract

Objective: Identify the most salient elements of the head and neck cancer (HNC) care experience described by patients and caregivers in focus group interviews. **Methods:** Three focus groups of patients and caregivers were facilitated by research assistants and clinicians. Open-ended guiding questions captured/elicited aspects of care that were appreciated, warranted improvement, or enhanced communication and information. A four-step Delphi process derived consensus among focus group facilitators (n = 5) regarding salient discussion points from focus group conversations. **Results:** Seven salient themes were identified: (1) information provision, (2) burden related to symptoms and treatment side effects, (3) importance of social support, (4) quality of care at both hospital and provider levels, (5) caring for the person, not just treating cancer, (6) social and emotional impact of HNC, and (7) stigma and insufficient information regarding human papillomavirus-related HNC. **Conclusion:** Participants reported varying needs and support preferences, a desire for individualized communication, and to feel cared for as both a person and a patient. Findings illuminate the intricate details underlying high-quality, compassionate, person-centered HNC cancer care.

Keywords

clinician–patient relationship, communication, empathy, interprofessional education, patient/relationship-centered skills, patient feedback, patient perspectives/narratives, qualitative methods

Introduction

Head and neck cancer (HNC) carries a substantial physical and emotional burden throughout the disease trajectory (1–4). Unmet informational needs and untreated symptoms are associated with increased psychological, existential, and physical distress (5–7). Distress can reduce patients' quality of life and ability to cope with cancer (8), exacerbate symptoms, and correlates with increased Emergency Room visits and hospitalizations (5,9,10) reduced treatment compliance (11), and survival (12,13). Understanding the needs of patients with HNC is crucial.

High-quality HNC treatment requires interprofessional care and a compassionate, person-centered care (PCC) approach, including routine symptom tracking and management (14,15). PCC encourages healthcare providers (HCPs) to listen to patients' concerns and experiences, empathetically reflect on previously unconsidered values and needs,

[1] Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada
[2] Sunnybrook Research Institute, Toronto, Ontario, Canada
[3] University of Toronto, Toronto, Ontario, Canada
[4] Tel Aviv University, Tel Aviv, Israel

Corresponding Author:
Dr Janet Ellis, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Room FG13, Toronto, Ontario, Canada.
Email: Janet.ellis@sunnybrook.ca

and co-develop a plan accordingly (16). This requires effective patient–provider communication to empower patients as partners in decision-making (15,17). PCC can improve quality of life and satisfaction with care and mitigate cancer-related distress (15,18).

This project was part of a larger study that trialed a novel education model to promote PCC in HNC care by sharing reports of care experiences in interprofessional staff workshops. The patient-(and caregiver-)as-educator approach was taken (19). Experiences of care were elucidated during focus group conversations with research assistants and HCPs, which were audio-recorded and transcribed. This paper reports on the findings of a Delphi rapid assessment process, undertaken prior to transcript analysis. Focus group facilitators' perspectives of the most salient elements of focus group conversations were identified and translated rapidly to the HNC team in interprofessional workshops, highlighting actionable ways to improve compassionate PCC. Workshop teachings are described in this report.

Methods

This study was approved by the Research Ethics Board at Sunnybrook Health Sciences Centre (Reference #2057). The Odette Cancer Centre, part of Sunnybrook Health Sciences Centre, is a Regional Cancer Centre ranked amongst the top oncology care sites worldwide. The Odette Cancer Centre houses the third-largest HNC program in Canada, with an interdisciplinary team of specialists across surgery, radiation therapy, chemotherapy, oncology nursing, pathology, speech-language pathology, psychiatry, craniofacial prosthetics, dietetics, and other supportive care services.

Patients and caregivers were recruited from the ambulatory HNC clinic at the Odette Cancer Centre to participate in focus groups. Research assistants approached all patients who met the following criteria, and their caregivers, whenever they were able to do so without disrupting clinic flow: patients (or caregivers of patients) who had undergone treatment for any HNC within the prior 6–18 months, were fluent in English and at least 18 years old. Signs were also posted around the Cancer Centre, prompting interested individuals to contact the research team. Informed consent was obtained by a research assistant. Specific types and locations of tumors were not identified during the recruitment process.

Three focus groups (two patients and one caregiver) of 90 to 120 min duration were conducted in September and October 2019. Focus groups were facilitated by two research assistants with experience in qualitative interviewing (SM and MBK) and three investigators (JE, MJ, and AM) with clinical experience in HNC. Facilitators asked open-ended guiding questions (Online Appendix A), targeting informational or communication needs and experiences of care. Probing questions were used to extract more detail.

The Delphi method is used to derive expert consensus regarding a defined clinical question (20). The consensus was reached using a four-step Delphi process systematically gathering anonymized reports from focus group facilitators on the most salient points of focus group conversations (Figure 1). "Salient," in this paper, refers to the intensity and frequency (prominence) of the ideas and experiences.

Each facilitator independently listed the most salient elements of the patient and caregiver experience that emerged in the focus groups, from their perspective. Lists were submitted to one facilitator (SM) to maintain anonymity. Facilitators could submit an unlimited number of items. SM consolidated the lists by identifying points most consistently noted and grouping them into categories/themes. At this stage, no points were removed. This revised list was sent back to facilitators for feedback, who were asked whether they agreed with the items included and/or felt items were missing. Feedback was requested regarding categorization and the need for clarification. Facilitators ranked the points in order of salience. Feedback and rankings were sent to SM, who updated the list accordingly. The revised list was sent to facilitators along with any outstanding points not universally listed. Facilitators were asked the same questions again and whether the suggested outstanding points should be included. Outstanding points were only incorporated with majority agreement.

Facilitators universally agreed with the final list of items. Thus, no additional rounds were conducted. After the last round, a question arose regarding the definition of one category, which was resolved through team discussion, rather than anonymous feedback.

Results

Thirteen individuals participated in the focus groups; nine patients (seven male, two female) and four caregivers (four female).

Delphi Process: Each facilitator (n = 5) sent a list of the most salient points discussed in focus groups to SM. Duplicates were consolidated, and points ranked based on frequency, resulting in a list of nine main points, or themes, with several sub-points, or categories. There was an 80% or greater consensus on seven of the nine themes after the first round of feedback. Eighty percent of the group suggested removing the ninth theme and placing it as a sub-point under another theme. Additionally, two facilitators proposed removing another initial point identified as a salient theme, and instead of placing it as a sub-point under another theme. There were also suggestions to add two subheadings beneath two of the themes. In the second round of feedback, all added subheadings were agreed upon (100% consensus) and over 80% agreed to remove the two themes that were not universally agreed upon in the previous round and to list them as categories within other themes. In the final round of feedback, further edits were made to improve readability for reporting purposes with the group consensus.

Content of Focus Group Discussions: Seven main points were identified, with several sub-points (described below, summarized in Figure 2).
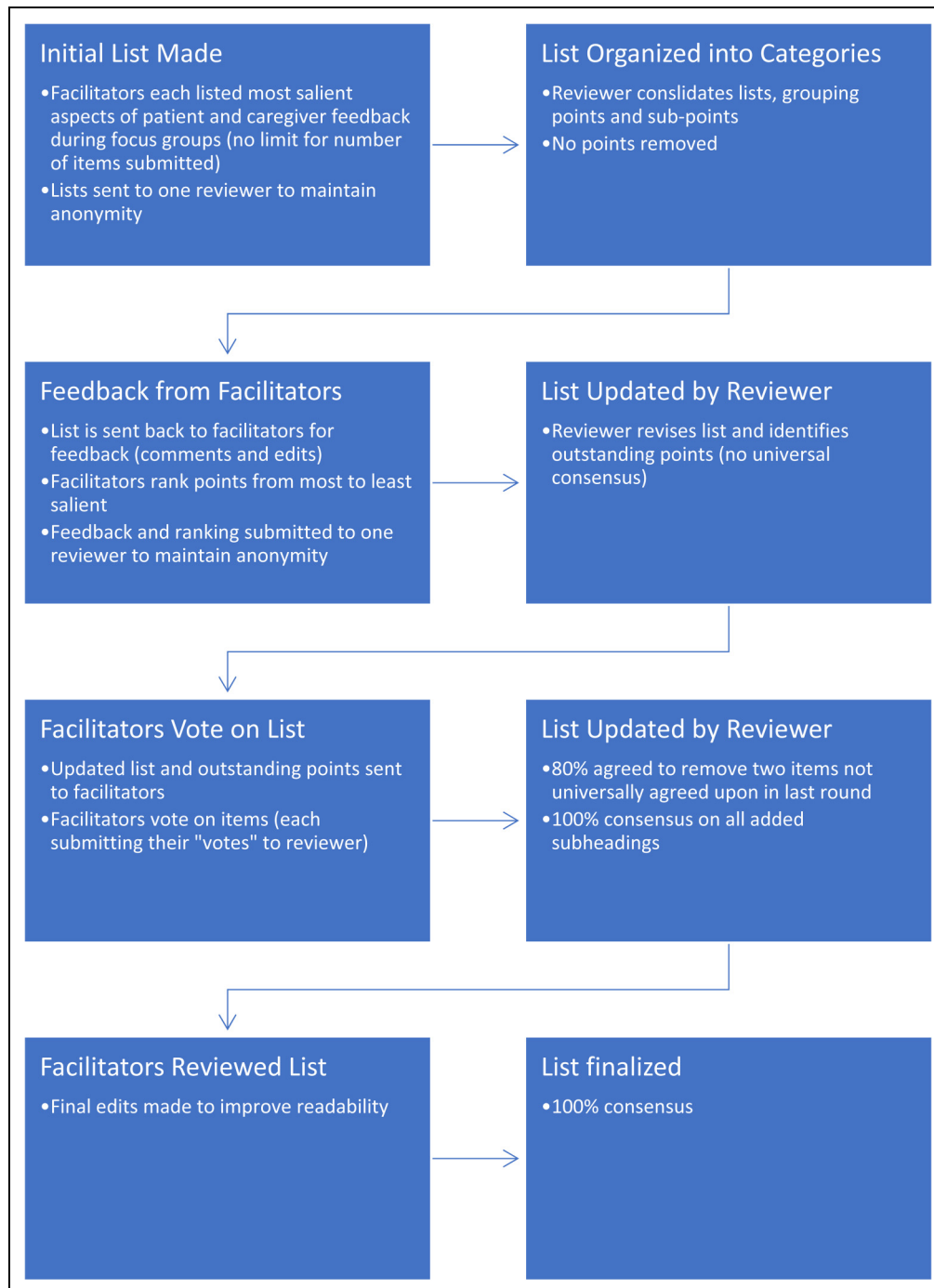
Figure 1. Stepwise description of Delphi process.

1. There were three most salient categories in the theme of ***information provision:***

Receiving Relevant Information at the Most Appropriate Time: Many participants reported receiving a large amount of information at their first oncology appointment. This was described as overwhelming and difficult to navigate. Participants voiced a preference to receive information when relevant, rather than all up-front.

Diversifying Information Provision: Patients reported receiving most information in the form of pamphlets, describing this as unengaging and difficult to organize. Participants recommended providing information in different forms of media.

Setting Realistic Expectations: Participants reported appreciating honest communication about their condition, as this allowed them to have "positive but realistic" expectations. Most participants emphasized not wanting things to be "sugar-coated."
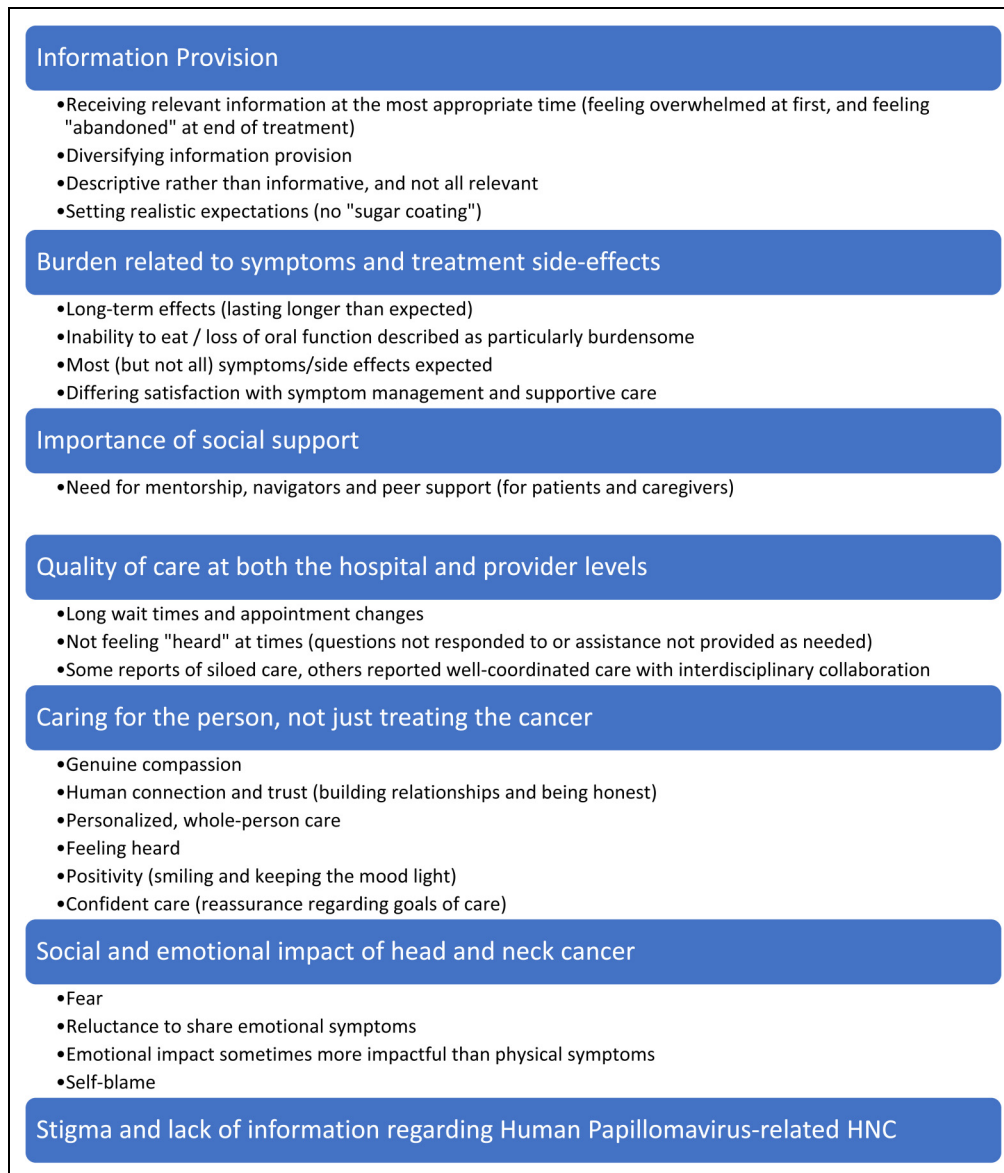
Figure 2. Seven salient themes (with sub-categories) were discussed in focus group conversations regarding patient and caregiver experience of head and neck cancer.

2.   There were two most salient categories in the theme of **burden related to symptoms and treatment side effects**:

Long-Term Effects: Most participants reported being informed about symptoms and side effects, including the potential for chronicity. Nonetheless, they were shocked and upset by the lasting impact of their treatment 6-to-18 months later, right up until attending the focus group. Many symptoms discussed were locoregional though some unexpected symptoms were described, for example, fainting and shoulder pain. Facilitators observed excitement in the group about having the space and opportunity to openly discuss common experiences with a group of peers.

Differing Satisfaction With Symptom Management and Supportive Care: Some participants reported that their symptoms were managed well and felt satisfied with their care. Others said they would have benefitted from supportive care services or that the most appropriate resource was not offered. Some participants were offered, but did not access or were not satisfied with, supportive care services, feeling that others might need the services more or that attending would be an additional burden.

3.   **Importance of Social Support**

Patients and caregivers frequently noted the benefit of peer support, mentorship, and navigators during treatment and recovery, and described social support as essential after

treatment, partly due to losing the sense of security associated with being surrounded by HCPs through treatment. Some patients connected with peers in clinic waiting rooms, others turned to friends or family with similar experiences.

4. ***Quality of Care at Both the Hospital and Provider Levels***

This theme was characterized by patients' reports of both positive and negative care experiences impacting their well-being. These reports were comments regarding the quality of care rather than medical treatment. At the systems level, patients and caregivers reported appreciating having their schedules accommodated when making appointments, and how quickly treatment started after diagnosis. Overall, patients and caregivers reported experiencing high-quality, professional care, specifically appreciating when their needs and values were accommodated.

At times, participants felt that their quality of care was compromised. At the systems level, examples were related to respect for time, for example, long wait times and last-minute appointment changes), having needs addressed (e.g., requests on the nursing line not answered), and coordination of care. At the provider level, incidents of incorrect tests, referrals, and diagnoses were distressing to participants.

5. There were two main categories in ***Caring for the person, not just treating cancer***:

Genuine Compassion: Overall, participants reported valuing the compassionate care they received. When asked what compassionate care meant to them, several described it as caring for the whole person, not just the cancer. Participants valued *personalized* and holistic care, specifically appreciating when HCPs took the time to get to know them.

Human Connection and Trust: Participants valued providers taking the time to actively listen to their concerns and respond to questions. Some participants reported appreciating when clinicians would smile, keep the mood light, make eye contact, and use humor and physical touch. Participants highlighted HCPs who were perceived as confident and capable, as well as caring.

6. ***Social and Emotional Impact of HNC***

Many participants emphasized the significant psychosocial and emotional burden of HNC, reporting that fear and anxiety emerged at different points across the illness trajectory. For some, these feelings were most significant when first diagnosed; for others, it was after treatment ceased. Both patients and caregivers voiced the desire for more psychological support. However, many patients felt reluctant to share emotional symptoms with their oncology HCPs and caregivers, and some self-referred to psychology or social work, rather than discussing their needs with their primary HCPs. Appropriateness of psychological support received

was also discussed (e.g., needing support from psychiatry rather than psychology).

7. ***Stigma and Lack of Information Regarding Human Papillomavirus (HPV)-Related HNC***

By chance, three out of four participants in one focus group were diagnosed with HPV-related HNC, so this was a dominant topic of conversation. Patients and caregivers with HPV-related HNC expressed unique informational and psychosocial needs. Some patients chose not to share their diagnosis with friends and family, reporting feelings of guilt and stigma. Similarly, caregivers reported guilt related to their partners' HPV, feeling that the cancer was "their fault." Most reported receiving minimal information, expressing a need for more information about the HPV diagnosis, particularly concerning intimacy and broader implications for their health and their partners' health.

Discussion

Focus groups illuminated many factors impacting the patient and caregiver experience of care, resulting in actionable recommendations for improving future PCC. PCC promotes flexibility in the timing, amount, and method of information-sharing based on patient preferences, addressing individual *informational needs* thereby increasing their understanding and information retention.

Patient-Centered Communication improves informed medical decision-making, patient satisfaction, treatment adherence, and medical outcomes (21). People with cancer, specifically HNC, often want maximal information about their illness and prognosis (22). Unfortunately, many have inaccurate illness understanding (23). HCPs often underestimate informational needs and struggle with communicating poor prognosis or "bad news," (24) possibly due to insufficient training (22). The present study revealed a desire for HCPs to be "positive but realistic" when discussing their prognosis and long-term burden of treatment. Patients appreciated a sense of optimism but wanted accurate expectations for preparing ahead.

Many patients struggle to navigate information about their illness, sometimes due to *emotional barriers* such as feeling anxious or overwhelmed at the prospect of integrating information, or *scalable barriers* related to the constant accumulation of information (25). When receiving excessive information up-front, patients face *temporal barriers* including insufficient time to learn and organize the information (25). To address these barriers, participants in the present study recommended ongoing information provision, highlighting what is *currently* relevant to the individual. This might maximize patients' ability to benefit from the information provided, thus overcoming *functional barriers* (25).

Information can also be personalized according to the individual's type of cancer. Participants with HPV-related HNC voiced the desire for more information about HPV.

Oncologists may lack sufficient training in providing HPV-related counseling (26). Confusion and misinformation can contribute to stigma, negative emotions, poor illness understanding, implications for relationships and intimacy, and decreased compliance with follow-up and disclosure of HPV status to partners (27). Distress about being HPV-positive decreases when informational needs are met (28). Finnigan and Sikora (29) developed a guideline for counseling patients with HPV-related HNC, addressing major areas of patient concern. Referrals to other support services can help address this issue (27).

Participants also highlighted informational needs post-treatment, when appointments are less frequent. Long-term contingency planning and expectation-setting may benefit patients, given the lasting impact of some HNC-related side effects (i.e., impaired eating, speaking, and tasting). Though HCPs may be wary of discussing anticipated side effects while patients are doing "well," reminders can help patients prepare for harsher symptoms toward the end of, or after, treatment. Patients may appreciate being reminded of how to access support and information related to side effects.

Finally, participants recommended diversifying the *form* of information provision, that is, using different media (including *discussion*), rather than mostly written pamphlets. Discussion may help to increase the quality of patient-centered communication, by allowing patients to ask questions and request further information, where needed. This would overcome barriers that prevent *patients from addressing their own informational needs*, reported in this study and the literature, such as feeling that there is not enough time in the clinic to ask questions, reluctance to bother HCPs, or believing that HCPs will not be able to provide answers or solutions (30).

Understanding the* individual's *psychosocial needs and preferences for support might improve the quality of PCC and system efficiency, as individuals reported differing needs and desires related to psychosocial support at different points in their illness trajectory. Ongoing assessment of patients' psychosocial needs over the course of treatment with judicious timing of referrals to psychosocial resources might increase patients' likelihood of accepting such support. Many patients are reluctant to share emotional symptoms and psychosocial issues are under-discussed in cancer care (31), as confirmed in this study.

Barriers to discussing distress in appointments and accessing specialized support include lack of psychosocial evaluation, time, resources, and awareness of helpful resources (32–34). Methods of increasing psychosocial care and greater resource utilization might include providing simple pathways of referral to oncologists, reminding teams to use symptom screening (35,36), increasing knowledge of resources, and appreciation for the importance of psychosocial support in cancer treatment and recovery.

Not all patients reported a desire for formal support; common reasons included already receiving informal help elsewhere or a preference for self-management of distress (37).

Physicians should focus interventions on those willing to accept support (37). Both patients and loved ones reported positive views regarding peer support. Some described benefitting from connecting with others in waiting rooms or sharing their experiences with friends with previous cancer experience and receiving mentorship from their peers. Others noted the desire for peer support through their treatment, stating a formal peer support program would be a useful addition to the cancer centre. Despite the large interest in peer support expressed by participants, previous research shows low engagement in peer support when available (38,39). Barriers to engagement in peer support include stigma, lack of awareness, limited time, and the emotional burden of discussing disease (40), though, peer support might actually help to mitigate stigma. Most peer support programs tend to reach middle-aged, educated women without advanced cancer (41).

Peer supporters can help to inform and educate patients and their loved ones, reduce anxiety, increase a sense of empowerment, and may improve quality of life and coping (42–45). Some studies showed no change in health-related quality of life or distress (46,47), possibly reflecting different patient preferences regarding peer support and its delivery (e.g. group or individual). This underlines the importance of HCPs having some time to listen to and understand individuals' needs, preferences, and coping methods, so that they can help patients and their loved ones access support most suited to them. HCPs need to be aware of available supports, including peer support to recommend the most appropriate resources.

Feeling cared for as a person, not just a patient, was described by many when discussing positive experiences of care. On a hospital level, this was characterized by streamlined and coordinated care, considering the individual's schedule, making treatment accessible and convenient. On an individual provider level, participants appreciated those who acknowledged their unique challenges and provided tailored "whole-person" care. Participants defined compassionate care as genuine and authentic—characterized by the perception that HCP truly cared for them as a person. Some actionable ways for HCP to show compassionate care identified during this study include clinicians taking time to introduce themselves and connect to patients and caregivers by sitting down, making eye contact, listening attentively, asking follow-up questions, and using physical touch (e.g., hand on the shoulder). Understanding compassionate care from the patient and caregiver perspectives can enable HCPs to provide high-quality care. Not only does compassionate care decrease distress and improve patient satisfaction, but also has benefits for clinicians such as increased job satisfaction and retention (48,49).

Limitations and Future Research

There are several limitations of this study. Firstly, the experiences described may not be generalizable due to the limited sample size. However, salient elements of the HNC experience identified echo those noted in related studies. The sample size

and methodology taken also did not allow a thorough between-group comparison of patient and caregiver reports. Future work with larger sample sizes might consider exploring the similarities and differences in experience and needs between these groups. Similarly, the sample included a large proportion of patients (and caregivers of patients) with HPV-related HNC, potentially limiting the generalizability of some findings to other sub-populations. Future research exploring the specific needs of varying sub-populations could lead to the creation of guidelines for personalizing care based on the specific form of an individual's cancer.

Finally, there is a risk of bias in the Delphi method, due to facilitators' previous knowledge and experiences. Methodological guidelines for the Delphi Method were followed (50); facilitators submitted feedback anonymously. One facilitator consolidated and refined all feedback to limit group bias. Finally, the panel of facilitators came from different professional backgrounds and had different levels of experience or familiarity with HNC. Future work will report on the similarities and differences between findings of the Delphi process versus the thematic analysis of focus group transcripts.

Conclusions

Our findings present seven salient themes capturing the experiences of HNC care for patients and their caregivers. Listening to the perspectives of patients and caregivers allowed us to identify three overarching recommendations to improve patient care—**using patient-centered communication, seeking to understand the individuals' psychosocial needs and preferences for support, and aiming to make patients feel cared for as a person, not just a patient**—all of which relate to the practice of PCC. The experiences of patient and caregiver participants in our study presented in the context of a review of relevant literature establishes a solid foundation for proposing concrete strategies to address these areas of concern during cancer care.

Authors' Note

Findings were previously presented in poster format at the Sunnybrook Clinical Innovation through Impact Expo (2020) and the American Psychosocial Oncology Society Conference (2020).

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

ORCID iD

Melissa B Korman https://orcid.org/0000-0002-5526-2804

Supplemental material

Supplemental material for this article is available online.

References

1. Korsten LHA, Jansen F, de Haan BJF, Sent D, Cuijpers P, Leemans CR, et al. Factors associated with depression over time in head and neck cancer patients: A systematic review. Psycho-Oncology. 2019;28(6):1159-83.
2. Molassiotis A, Rogers M. Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. Palliat Support Care. 2012;10(3):197-204.
3. Misono S, Weiss NS, Fann JR, Redman M, Yueh B. Incidence of suicide in persons with cancer. J Clin Oncol. 2008;26(29):4731-8.
4. Kam D, Salib A, Gorgy G, Patel TD, Carniol ET, Eloy JA, et al. Incidence of suicide in patients with head and neck cancer. JAMA Otolaryngol Head Neck Surg. 2015;141(12):1-8.
5. Korman M, Moore S, Goldberg L, Ellis J. How and why we address distress in oncology. Sunnybrook Hotspot. 2019;21(1):1-3.
6. Carlson L, Angen M, Cullum J, Goodey E, Koopmans J, Lamont L, et al. High levels of untreated distress and fatigue in cancer patients. Br J Cancer. 2004;90(12):2297-304.
7. Li J, Girgis A. Supportive care needs: Are patients with lung cancer a neglected population? Psycho-Oncol. 2006;15(6):509-16.
8. Shim EJ, Mehnert A, Koyama A, Cho SJ, Inui H, Paik NS, et al. Health-related quality of life in breast cancer: A cross-cultural survey of German, Japanese, and South Korean patients. Breast Cancer Res Treat. 2006;99(3):341-50.
9. Wagner-Johnston ND, Carson KA, Grossman SA. High outpatient pain intensity scores predict impending hospital admissions in patients with cancer. J Pain Symptom Manage. 2010;39(2):180-5.
10. Nipp RD, El-Jawahri A, Moran SM, D'Arpino SM, Johnson PC, Lage DE, et al. The relationship between physical and psychological symptoms and health care utilization in hospitalized patients with advanced cancer. Cancer. 2017;123(23):4720-7.
11. Ayres A, Hoon PW, Franzoni JB, Matheny KB, Cotanch PH, Takayanagi S. Influence of mood and adjustment to cancer on compliance with chemotherapy among breast cancer patients. J Psychosom Res. 1994;38(5):393-402.
12. Hjerl K, Andersen EW, Keiding N, Mouridsen HT, Mortensen PB, Jørgensen T. Depression as a prognostic factor for breast cancer mortality. Psychosomatics. 2003;44(1):24-30.
13. Faller H, Bülzebruck H, Drings P, Lang H. Coping, distress, and survival among patients with lung cancer. Arch Gen Psychiatry. 1999;56(8):756-62.
14. Gagliardi AR, Stuart-McEwan T, Gilbert J, Wright FC, Hoch J, Brouwers MC, et al. How can diagnostic assessment programs be implemented to enhance inter-professional collaborative care for cancer? Implementation Sci. 2014;9(1):4.
15. Hansson E, Carlström E, Olsson L-E, Nyman J, Koinberg I. Can a person-centred-care intervention improve health-related

quality of life in patients with head and neck cancer? A randomized, controlled study. BMC Nurs. 2017;16(1):1-12.

16. Towle A, Bainbridge L, Godolphin W, Katz A, Kline C, Lown B, et al. Active patient involvement in the education of health professionals. Med Educ. 2010;44(1):64-74.

17. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care—ready for prime time. Eur J Cardiovasc Nursing. 2011;10(4):248-51.

18. Dean M, Street RL. A 3-stage model of patient-centered communication for addressing cancer patients' emotional distress. Patient Educ Couns. 2013;94(2):143-8.

19. Towle A, Godolphin W. A meeting of experts: The emerging roles of non-professionals in the education of health professionals. Teach Higher Educ. 2011;16(5):495-504.

20. Wood L, Bjarnason GA, Black PC, Cagiannos I, Heng DYC, Kapoor A, et al. Using the Delphi technique to improve clinical outcomes through the development of quality indicators in renal cell carcinoma. J Oncol Pract. 2013;9(5):e262-7.

21. Swenson SL, Buell S, Zettler P, White M, Ruston DC, Lo B. Patient-centered communication. J Gen Intern Med. 2004;19-(11):1069-79.

22. Wittmann E, Beaton C, Lewis W, Hopper A, Zamawi F, Jackson C, et al. Comparison of patients' needs and doctors' perceptions of information requirements related to a diagnosis of oesophageal or gastric cancer. Eur J Cancer Care. 2011;20(2):187-95.

23. Sivendran S, Jenkins S, Svetec S, Horst M, Newport KB, Yost KJ, et al. Illness understanding of oncology patients in a community-based cancer institute. J Clin Oncol. 2017;35-(15_suppl):e21605.

24. Andreassen S, Randers I, Näslund E, Stockeld D, Mattiasson A-C. Family members' experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer. Eur J Cancer Care. 2005;14(5):426-34.

25. Unruh KT, Pratt W. Barriers to organizing information during cancer care: "I don't know how people do it." AMIA. Annual Symposium Proceedings. 2008;2008:742-6.

26. Fakhry C, D'Souza G. Discussing the diagnosis of HPV-OSCC: Common questions and answers. Oral Oncol. 2013;49(9):863-71.

27. Chu A, Genden E, Posner M, Sikora A. A patient-centered approach to counseling patients with head and neck cancer undergoing human papillomavirus testing: A clinician's guide. The Oncologist. 2013;18(2):180-9.

28. Waller J, McCaffery K, Kitchener H, Nazroo J, Wardle J. Women's experiences of repeated HPV testing in the context of cervical cancer screening: A qualitative study. Psycho-oncology. 2007;16(3):196-204.

29. Finnigan JP, Sikora AG. Counseling the patient with potentially HPV-related newly diagnosed head and neck cancer. Curr Oncol Rep. 2014;16(3):1-8.

30. Henselmans I, Jacobs M, van Berge Henegouwen MI, de Haes HCJ, Sprangers MA, Smets EM. Postoperative information needs and communication barriers of esophageal cancer patients. Patient Educ Couns. 2011;88(1):138-46.

31. Fagerlind H, Kettis Å, Glimelius B, Ring L. Barriers against psychosocial communication: Oncologists' perceptions. J Clin Oncol. 2013;31(30):3815-22.

32. Fagerlind H, Lindblad ÅK, Bergström I, Nilsson M, Nauclér G, Glimelius B, et al. Patient–physician communication during oncology consultations. Psycho-Oncology. 2008;17(10):975-85.

33. Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. Psycho-Oncology, 2001;10(2):103-13.

34. Kam LYK, Knott VE, Wilson C, Chambers SK. Using the theory of planned behavior to understand health professionals' attitudes and intentions to refer cancer patients for psychosocial support. Psycho-Oncology. 2012;21(3):316-23.

35. Greenhalgh J. The applications of pros in clinical practice: What are they, do they work, and why? Qual Life Res. 2009;18-(1):115-23.19105048

36. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. J Clin Oncol. 2016;34(6):557-65.

37. Baker-Glenn EA, Park B, Granger L, Symonds P, Mitchell AJ. Desire for psychological support in cancer patients with depression or distress: Validation of a simple help question. Psycho-Oncology. 2011;20(5):525-31.

38. Owen JE, Goldstein MS, Lee JH, Breen N, Rowland JH. Use of health-related and cancer-specific support groups among adult cancer survivors. Cancer. 2007;109(12):2580-9.

39. Sherman AC, Pennington J, Simonton S, Latif U, Arent L, Farley H. Determinants of participation in cancer support groups: The role of health beliefs. Int J Behav Med. 2008;15(2):92-100.

40. Van Uden-Kraan CF, Drossaert CHC, Taal E, Smit WM, Bernelot Moens HJ, Van de Laar MAFJ. Determinants of engagement in face-to-face and online patient support groups. J Med Internet Res. 2011;10(4):13.

41. Walshe CE, Roberts D. Peer support for people with advanced cancer: A systematically constructed scoping review of quantitative and qualitative evidence. Curr Opin Support Palliat Care. 2018 Sep 1;12(3):308-22.

42. Hu A. Reflections: The value of patient support groups. JAMA Otolaryngol Head Neck Surg. 2017;156(4):587-8.

43. Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. Soc Sci Med. 2006;62(10):2565-76.

44. Vakharia KT, Ali MJ, Wang SJ. Quality-of-life impact of participation in a head and neck cancer support group. JAMA Otolaryngol Head Neck Surg. 2007;136(3):405-10.17321868

45. Schou I, Ekeberg O, Karesen R, Sorensen E. Psychosocial intervention as a component of routine breast cancer care-who participates and does it help? Psycho-Oncol. 2008;17(7):716-20.

46. Toija AS, Kettunen TH, Leidenius MHK, Vainiola THK, Roine RPA. Effectiveness of peer support on health-related quality of life in recently diagnosed breast cancer patients: A randomized controlled trial. Support Care Cancer. 2018;27(1):123-30.

47. Giese-Davis J, Bliss-Isberg C, Wittenberg L, White J, Star P, Zhong L, et al. Peer-counseling for women newly diagnosed with breast cancer: A randomized community/research collaboration trial. Cancer. 2016;122(15):2408-17.

48. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician–patient communication to health outcomes. Patient Educ Couns. 2008;74(3):295-301.

49. Sinclair S, Norris JM, McConnell SJ, Chochinov HM, Hack TF, Hagen NA, et al. Compassion: A scoping review of the healthcare literature. BMC Palliat Care. 2016;15(1):6.

50. Biondo PD, Nekolaichuk CL, Stiles C, Fainsinger R, Hagen NA. Applying the Delphi process to palliative care tool development: lessons learned. Support Care Cancer. 2007;16-(8):935-42.