

# Perceived unmet supportive care needs and determinants of quality of life among survivors of head and neck cancer

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## KEY MESSAGES

1. The most common unmet need among head and neck cancer survivors was having a hospital staff member with whom they could discuss their condition, treatment, and follow-up. Patients were eager to know more about disease prognosis, symptom management, how to improve their health, and how to access information and healthcare or social services.
2. Optimism, education, co-existing diseases, number of symptoms experienced, household income, eating ability, social support, perceptions on whether the cancer was under control, and the time required to travel between home and hospital may directly and/or indirectly impact quality of life in terms of psychological, physical, and/or health system information domains. These factors accounted for 64% of the variance

in the total Functional Assessment of Cancer Therapy–Head and Neck score.

3. Providing the information that head and neck cancer survivors want is a significant factor in fulfilling their psychological needs and improving overall quality of life.

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## Introduction

Head and neck cancer (HNC) is prevalent in Hong Kong; most patients are middle-aged males aged 45-64 years who are likely to be the breadwinner of the family.<sup>1</sup> With advancements in cancer screening and treatment, the number of HNC survivors is increasing.<sup>1</sup> Nevertheless, HNC patients are reported to experience high levels of distress throughout the disease trajectory and after completion of treatment. This may be detrimental to their health and in turn increase the burden on healthcare services.

A systematic review examined the unmet supportive care needs (SCNs) of patients at different points across the cancer trajectory.<sup>2</sup> Unmet SCNs identified at the post-treatment stage included health information, physical and daily living needs, psychosocial concerns, sexuality, and communication. Nonetheless, work to identify the unmet SCNs among HNC patients is limited. This study aimed to (1) identify the most common perceived unmet SCNs of HNC survivors, and (2) examine the mediating role of perceived unmet SCNs in the relationship between quality of life (QoL) and patient characteristics.

## Methods

This study was conducted from January 2012 to

September 2013. Approval was obtained from the hospital's research ethics committee. A mixed-design method consisting of a quantitative cross-sectional design (phase I) and a qualitative descriptive approach (phase II) was used. In the phase I study, 285 Chinese patients were recruited, and common unmet SCNs were identified using a structured questionnaire. A purposive sub-sample of 53 people was invited to the phase II study that involved a 45-to-60-minute face-to-face interview. The details of the methodology have been reported elsewhere.<sup>3</sup>

Skewed continuous and normal-like distributed variables were presented as median (interquartile range) and mean±standard deviation (SD), respectively. Categorical data were presented as frequencies (percentage). Path analysis was used to examine the relationship between demographic and clinical characteristics, perceived unmet SCNs, and QoL.

## Results

In the phase I study, the response rate was 89.1%. The mean patient age was 55.3 (SD, 12.3) years. Most patients were male (76.8%), married (82.1%), with a secondary education (67.3%), unemployed (63.5%), and with a middle or high household income (60.5%). Of the patients, 51.9% were diagnosed with stage III

cancer. The mean period since diagnosis was 8 (SD, 3.8) months and the mean period after treatment was 4.5 (SD, 3.4) months. The most common cancer type was pharyngeal cancer (73.3%). Half of all patients had undergone combined radiotherapy and chemotherapy. The three most common symptoms were dry mouth (95.4%), altered taste (82.8%), and fatigue (76.1%). Patients rated their eating ability as moderate (mean±SD, 6±2.4).

In the phase II study, 40 males and 13 females participated. Most were married (83%) and had a secondary education (78.3%). About half were still in employment (49.1%) and had a middle household income (50.9%). Their stage of disease varied from I to III, and most had nasopharyngeal carcinoma (71.7%) and had received combined cancer treatment (84%).

The ten most common unmet SCNs were (1) having a hospital staff member with whom to discuss their condition, treatment, and follow-up (41.1%); (2) being informed of the approaches to getting well (40.5%); (3) being informed that the cancer was under control (30.5%); (4) being informed of test results at the earliest (29.1%); (5) financial assistance for patient expenses (24.6%); (6) more choice of physicians to consult (23.6%); (7) fear of cancer spreading to other sites (20.0%); (8) being cared for like a person (20.0%); (9) concern that they had no control over treatment outcome (19.3%); and (10) 24-hour telephone support and advisory services (19.3%).<sup>4</sup> The top three needs were related to the health system and information domain.

#### **Having a hospital staff member with whom to discuss their condition, treatment, and follow-up**

Most participants supported the view that having a designated healthcare professional would be helpful. In particular, they were eager to know more about disease prognosis and symptom management, how to improve health, and how to access information and healthcare or social services. Nonetheless, participants noted that under the existing public healthcare system they had difficulty in finding help, as they were allocated to a different physician or nurse at each consultation.

#### **Being informed of the approaches to getting well**

Most participants emphasised the need for information about how to get well, particularly they wanted more information about Chinese dietary regimens. They wanted more information about the 'specific types of food to be avoided'.

#### **Being informed that the cancer was under control**

Many participants were worried about disease

recurrence. Nonetheless, only those with high information needs wanted to be informed about whether the cancer was under control or diminishing, so that they could stop worrying.

#### **Mediating role of unmet needs in the relationship between patient characteristics and quality of life**

The final path model (RMSEA=0.02, SRMR=0.038, CFI=0.99, NNFI=0.98, and AGFI=0.94) showed that QoL of HNC survivors could be directly and/or indirectly affected by factors including attitude towards life, education, co-existing diseases, somatic symptoms, household income, eating ability, social support, perceptions on whether cancer was under control, and the time required to travel between home and hospital.<sup>5</sup> These factors directly and/or indirectly affect the psychological, physical and/or health system information domains, and accounted for 64% of the variance in the total Functional Assessment of Cancer Therapy–Head and Neck score.<sup>5</sup> The mediating effect of the physical aspect of SCNs was identified in the relationship between attitude towards life, number of symptoms, travelling time, perceptions on whether cancer was under control, and social support. Health system information and psychological needs were also found to mediate the association between QoL and the attitude towards life score, number of symptoms, education, co-existing diseases, and travelling time.<sup>5</sup>

## **Discussion**

One year after cancer treatment, HNC survivors had unmet SCNs in various domains. The three most prevalent unmet SCNs were in the health system and information domain, with >30% of participants reporting moderate or high unmet needs.<sup>4</sup> This indicates that Hong Kong hospital support services might have paid insufficient attention and support to HNC survivors. Currently, services for HNC patients in Hong Kong public hospitals mainly focus on supporting those who are at the pre-treatment or treatment stage, with support provided by the Cancer Patient Resource Centre, advanced practice nurses, and volunteers. These resources are rarely utilised by HNC survivors. Possible reasons may be related to poor access and insufficient referrals. Videos of nasal washing are available for nasopharyngeal carcinoma patients after treatment, but this is not sufficient for HNC survivors with a range of persistent and distressing symptoms.

In this study, we revealed the mediating effect of physical aspects of SCNs in the relationship between clinical characteristics of HNC survivors and QoL. These characteristics included less social support, longer time required to travel between home and hospital, uncertainty about whether cancer was

under control, experience of more symptoms, and a pessimistic attitude. This implies that meeting the physical needs of HNC survivors can be an effective strategy to improve their QoL. It was interesting to identify the relationship between psycho-socially related constraints and physical needs. Although survivors were relatively pessimistic with limited social support, their overall QoL can be improved if their physical needs are met.<sup>5</sup>

Moreover, the health-system and information may indirectly mediate the association between specific backgrounds of HNC survivors and their QoL. HNC survivors experienced less fear and distress when they were provided with information about their disease, diagnosis, treatment, or related follow-up issues. Those with a higher educational level, a co-existing disease, more cancer symptoms experienced, and a more pessimistic view appeared to benefit more when their psychological needs were met. These findings indicate that healthcare professionals should be encouraged to provide HNC survivors with information on all aspects of the disease in order to alleviate their fear and anxiety and improve overall QoL.

## Conclusions

HNC survivors in Hong Kong have unmet SCNs. The three most prevalent unmet SCNs were in the health system and information domain. The association between certain characteristics of HNC survivors and their overall QoL was mediated by SCNs.

Efforts should be made to develop a multi-dimensional supportive care system for cancer survivors. The integration of needs assessments may guide healthcare professionals towards identifying the actual needs of HNC survivors. The establishment of a nurse-led clinic to provide patient-centred survivorship care should be considered. An experimental study to examine the effectiveness of survivorship care interventions to improve the QoL of HNC survivors is recommended.

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Results of this study have been published in:

(1) So WK, Choi KC, Chan CW, et al. Perceived unmet supportive care needs and determinants of quality of life among head and neck cancer survivors: a research protocol. *J Adv Nurs* 2013;69:2750-8. 4.

(2) So WK, Wong CL, Choi KC, et al. A mixed-methods study of unmet supportive care needs among head and neck cancer survivors. *Cancer Nurs* 2017. Advance online publication. doi: 10.1097/NCC.0000000000000542.

(3) So WK, Choi KC, Chen JM, et al. Quality of life in head and neck cancer survivors at 1 year after treatment: the mediating role of unmet supportive care needs. *Support Care Cancer* 2014;22:2917-26.

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