

# A SURVEY OF THE INFORMATION NEEDS OF PEOPLE WITH HEAD & NECK CANCER AND THEIR RELATIVES RESIDENT IN THE SOUTH WEST OF SYDNEY

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ABSTRACT

**NSW Oncology Group (NSWOG) Head and Neck**

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## **A survey of the information needs of people with head & neck cancer and their relatives resident in the South West of Sydney**

### **Aim**

To report on the results from a survey of the information needs of people with Head and Neck (H&N) cancer and their relatives.

### **Background**

H&N cancers are diverse in their aetiology and impact. In addition, groups most at-risk of H&N cancers can be clinically challenging, because many have heavy tobacco and/or alcohol use histories, are from lower socioeconomic groups and less pro-actively seek information. The delivery of accurate and comprehensible written information on disease, diagnosis, investigations, treatment, risks, side effects, prognosis and survival rate is much sought after by patients<sup>i, ii</sup>. Reviews have highlighted the secondary benefits from the quality provision of information including increased participation in decision-making, enhanced coping, increased self-esteem and confidence in living with cancer<sup>i, iv</sup>. A number of authors have highlighted the special information needs for people with H&N cancer that are distinct from other cancer groups, particularly concerning issues of disfigurement and functional challenges secondary to treatment affecting speech, swallow, sight and hearing<sup>i, iii</sup>. H&N cancers are some of the least commonly occurring, not surprisingly few studies have investigated the information needs of these patients, as well as their close relatives. At the time of application for funding to support this project there were no locally based information resources for H&N patients in NSW.

The Cancer Institute NSW Oncology Group (NSWOG) supported this identified need and determined it as a Priority Project. The mission therefore was to understand the information needs of patients and their families to determine the appropriate content and structure of information resources in order to meet these needs.

### **Method**

A consecutive series of 119 H&N patients from the Liverpool Cancer Therapy Centre were reviewed for possible inclusion in the study. Nineteen were excluded because they were deceased, medically unwell, non-English speaking or uncontactable. One hundred participants were invited to participate in the study and 69 surveys were completed and returned. Forty-eight family members and one paid carer also independently completed the same survey. Demographic and disease profile data are displayed in Tables 1 and 2.

The Information Needs Survey is a 33-item purpose designed self-report measure that evaluates the information needs of people with H&N cancer and their family members. The items were derived from the limited literature<sup>iv</sup> and the clinical experience of the project team. The items were grouped into the five domains of Disease profile, Treatment, Management of side effects, Psychosocial consequences and Survivorship. Respondents rated the items on a 4-point Likert-type scale (Very important – Not important) (see Table 3).

Ethical approval for the project was granted by the Sydney South West AHS Human Research Ethics Committee. Prospective respondents were informed of the study during a hospital visit or alternatively, mailed a letter outlining the purpose of the project, and followed up by phone. Respondents who consented to participate either completed the measure by phone interview or completed the surveys and mailed them back to the Hospital.

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## Results

The summary results are displayed on Figure 1. The percentage scores for the number of 'Most important' ratings were tabulated for each item. Mean percentage scores were then calculated for each of the five domains for both the person with H&N cancer and the family members (see Figure 1). Family members generally endorsed more items as Very Important across the five domains, however both groups displayed a very similar pattern of priorities. The patients most frequently ranked information about Disease Profile as Very important (1. Disease Profile; 2. Survivorship; 3. Treatment; 4. Side effects; and 5. Psychosocial). Family members most frequently ranked information about Survivorship as Very important (1. Survivorship; 2. Disease Profile; 3. Treatment; 4. Side effects; and 5. Psychosocial).

Next, the possibility that specific information concerns were more important for one of the two groups was investigated. The response scores for each item were collapsed into a dichotomous variable (Very important vs other responses) and a series of chi-square analyses were conducted to investigate whether there were any between-groups differences. Significantly more family members than people with H&N Cancer thought it was Very important to have information about the following:

- (i) The goals of treatment (92% vs 77%;  $\chi^2 = 4.6$ );
- (ii) Ways of managing eating/drinking to maintain nutritional intake (80% vs 62%;  $\chi^2 = 4.0$ );
- (iii) Stress management (61% vs 39%;  $\chi^2 = 5.6$ );
- (iv) Staying well after the treatment is finished (80% vs 62%;  $\chi^2 = 4.0$ ); and
- (v) When cancer cannot be cured and needing palliative care (88% vs 67%;  $\chi^2 = 6.3$ ).

All differences were significant at  $p < 0.05$ .

There were also trends to significant ( $p < 0.10$ ) for another four items (items 6,7,12,19). Once again, for each of these items, more family members thought that it was Very important to have information than the people with H&N Cancer.

## Discussion

Surprisingly, despite the many psychosocial issues that arise with H&N Cancer, respondents ranked information about Disease and Survivorship most highly. A likely reason for this may be the severity of physical symptoms that arise from the disease itself and effects of treatment. Survivorship is also a major concern possibly due to challenging long-term side effects that are often ongoing as well as anxiety about disease recurrence. Similar results were found in a study of women<sup>ii</sup>. Around time of diagnosis they wanted information about the extent of their disease, prognosis, likelihood of cure and treatment options. Information needs on psychological effects were identified later on during the treatment phase. Examples of the first five information needs identified by patients with cancer are summarised in another study<sup>v</sup>. They are: likelihood of cure and prognosis, details of treatment regimens, side effects of treatment, extent of disease, safe-care and changes of returning to normality. These findings are consistent with those of this study.

Although patients and family members showed a similar pattern of priorities in information needs, the results showed that family members endorsed more items as "Very Important" across all five domains. This could be that the majority of patients are male (78%) and many are in married/de facto relationships (68%). This reflects the major concerns of the female carers.

That psychosocial needs were ranked the lowest out of the five domains may suggest that psychosocial needs are well met. This is unlikely however as there is a dearth of support services for H&N patients and their carers.. A literature review<sup>iii</sup> found that medical problems of H&N cancer patients improved with time but most psychological ones including anxiety and anger deteriorated markedly.

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That study showed that the psychological impact of disfiguring disease is becoming more widely recognised, however there are issues about who can provide professional support to deal with those experiencing anxiety and depression and that counselling services were often inaccessible and inappropriate<sup>iii</sup>.

### **Conclusion**

We intend to explore the issue of timing of information needs from demographic data collected as part of this study as part of ongoing work by this project group. Since commencement of this project NSW Cancer Council has published a written information resource for H&N cancer patients. We would intend to use our results to evaluate this resource and determine whether all the needs identified are addressed.

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<sup>i</sup> Semple, C. J., & McGowan, B. (2002). Need for appropriate written information for patients, with particular reference to head and neck cancer. *Journal of Clinical Nursing*, 11, 585-593.

<sup>ii</sup> Wolf, L. (2004). The information needs of women who have undergone breast reconstruction. Part II: Information giving and content of information. *European Journal of Oncology Nursing*, 8, 315-324.

<sup>iii</sup> Ziegler, L., Newell, R., Stanford, N., & Lewin, R. (2004). A literature review of head and neck patients information needs, experiences and views regarding decision-making. *European Journal of Cancer Care*, 13(2), 119-126.

<sup>iv</sup> Ankem, K. (2006). Use of information sources by cancer patients: results of a systematic review of the research literature. *IR Information Research*, 11(3), April 2006. Available at: <http://InformationR.net/ir/11-3/paper254.html>

<sup>v</sup> Mills and Sullivan (2000) cited in Chau, I., Legge, S. & Fumoleau, P. (2004). The vital role of education and information in patients receiving Capecitabine (Xeloda). *European Journal of Oncology Nursing*, 8(Supplement 1), S41-S53.