

PATTERNS OF INFORMATION NEEDS AND AFFECTIVE DISTRESS FOR PEOPLE WITH HEAD & NECK CANCER AND THEIR FAMILY MEMBERS

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ABSTRACT

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Background and Aim

Lack of appropriate information about cancer is associated with a number of negative outcomes among patients and their families. At the time this project commenced there were no information resources on H&N cancers produced locally within NSW. The aim of the project was to survey the information needs of people with H&N cancers/family members, and to ascertain whether they experienced any associated affective distress.

Method

A consecutive series of 79 H&N patients and 52 family members recruited from the Liverpool Cancer Therapy Centre and Calvary Mater Newcastle. Respondents rated the importance (1 Very important – 4 Not important) of 33 information topics relevant to H&N cancer grouped in five domains, as well as standardised measures of distress, anxiety, depression and quality of life.

Results

The percentage of patients rating items as 'Very Important' ranged from 87% - 32% across the 33 topics. For families, the percentages ranged from 94% to 44%. Overall, family members were more likely to endorse items as 'Very important' than the patients themselves. Between-groups analysis found that family members made significantly higher importance ratings in the domains of Treatment and Survivorship, but that there were no significant differences between patients and families in the importance attributed to information addressing Disease Profile, Side effects, and Psychosocial domains. Correlational analysis found that patients with higher levels of anxiety were more likely to see information as very important. However, there was no similar pattern between information needs and depression, distress or quality of life. In contrast, there was no correlation between family member information needs and affective distress scores.

Discussion

There was a significant relationship between anxiety and the importance attributed to information needs among H&N cancer patients. Although family members attributed a high level of importance to some domains, there was no evidence of corresponding distress.