The information needs of patients with head and neck cancer and their caregivers: A short report of instrument development and testing

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Abstract

Purpose: The study aimed to assess the reliability and scaling assumptions of an information needs questionnaire for patients with head and neck cancer (HNC) and their caregivers. 

Background: Patients with HNC have specific information needs but no tools exist that can simultaneously assess the needs among these patients and their caregivers.

Methods: The Head and Neck Information Needs Questionnaire (HaNiQ) was adapted from a validated information needs questionnaire for breast cancer patients. Participants were recruited from two regionally-defined cancer services in NSW, Australia. Internal consistency reliability was assessed using Cronbach’s alpha. Scaling assumptions, specifically item convergent and discriminant validity, were assessed using multi-trait scaling analysis.

Results: The HaNiQ showed good internal consistency reliability for both patients and caregivers (Cronbach’s alpha=0.94 for both) and scaling assumptions were met, with acceptable item convergent and discriminant validity.

Conclusions: The HaNiQ appears reliable, and would benefit from further testing.

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1. Introduction

Providing appropriate information to patients decreases anxiety and increases participation in decision-making, coping, overall satisfaction with care and confidence in living with cancer (Ankem, 2006; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Tailored, disease-specific information is also important as patient information needs (Epstein & Street, 2007) vary across cancer types.
Head and neck cancer (HNC) is one of the 10 most common cancers globally (Morris & Thomas, 2002) and patients with HNC have a number of disease-specific information needs due to impairments arising secondary to treatment (Ziegler, Newell, Stafford, & Lewin, 2004). A tool to assess the satisfaction of patients with HNC regarding the amount and level of information provided has been developed and found to be valid and reliable (Llewellyn, Horne, McGurk, & Weinman, 2006). However, this tool can be supplemented with a needs-based information instrument. A needs-based tool can be used proactively to tailor information to the expressed needs and interests of the patient, whereas a satisfaction measure is applied post-hoc to evaluate the efficacy of information already provided. Furthermore, some content areas of importance to HNC patients including the profile of the disease and specific survivorship issues were not addressed in the earlier instrument.

Despite the important role of informal caregivers (‘carers’) in providing care and support to patients (Soothill et al., 2003), research on information needs of carers of cancer patients has primarily explored the needs of spouses/partners and has been conducted in breast and prostate cancer populations (Adams, Boulton, & Watson, 2009). The valid and reliable Family Inventory of Needs (Kristjanson, Atwood, & Degner, 1995), which covers general informational needs relating to cancer treatment, has been used in HNC carer populations previously (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). To the best of our knowledge there are no instruments assessing carer informational needs specific to HNC. An instrument that can be completed by both the patients and family members has additional benefits, ensuring that the information needs of carers are also met and highlighting differential information needs of HNC patients and their carers.

This paper reports on the preliminary assessment of the reliability and scaling assumptions, including item convergent and discriminant validity, of a new measure to examine the information needs of HNC patients and carers, the Head and Neck Information Needs Questionnaire (HaNiQ).

2. Methods

2.1. Study design, sample and recruitment

A cross-sectional design was employed. The sample was derived from current or recent patients of two regionally-defined cancer services in NSW, Australia to allow for a broad range of patients. Recruitment was open to patients at all stages of the disease process, including diagnosis, treatment, post-treatment and/or palliative. Eligibility criteria were as follows: (1) a histologically confirmed primary cancer of the head and neck region; (2) age of 18 years or over at the time of diagnosis; (3) treatment at one of the two regionally-defined cancer services; (4) spoke sufficient English to complete the study measures; and (5) were not medically unwell or otherwise unable to participate. Once recruited, the patients were invited to identify a family member who could also participate. Family members also needed to be aged 18 years or older at the time of diagnosis and speak sufficient English to complete the study measures.

2.2. Study measures

An information needs questionnaire for breast cancer patients (Bilodeau & Degner, 1996; Degner et al., 1997; Luker et al., 1995) was adapted by the research team to determine information needs for patients with HNC and family members. The Head and Neck Information Needs Questionnaire (HaNiQ) contains 33 items, grouped into five domains as follows: disease profile (four items), treatment (eight items), side effects (eight items), psychosocial (nine items) and survivorship (four items). Respondents rated the importance of accessing information on each of the 33 items on a four point scale (1=very important to 4=not important). Other study measures to examine carer and patient psychological outcomes and health-related quality of life were employed but will be reported elsewhere.

2.3. Ethical approval and data collection procedures

Ethics approval was granted by the Human Research and Ethics committees of the Sydney South West Area Health Service Western Zone and the Hunter New England Area Health Service. All study participants received written information about the research and provided written informed consent prior to participation. To maintain participant confidentiality, data were de-identified prior to collation and analysis.

Prospective respondents were informed of the study during a hospital clinic visit or mailed a letter explaining the project. This was followed up by telephone by a research assistant employed by the project team. Questionnaires were completed by face-to-face or telephone interview or participant self-administration.

2.4. Data analysis

SPSS version 19.0 was used for analyses. Multi-trait scaling analysis and Cronbach’s alpha were used to assess scaling assumptions (item convergent and discriminant validity) and internal consistency reliability, respectively. Cronbach’s alpha values of 0.7 or greater were considered reliable (Streiner & Norman, 2003) and corrected item–total correlations of at least 0.3 were considered to demonstrate item convergent validity (Stewart & Ware, 1992). Items with corrected item–total correlations below 0.3 were removed from analysis (Stewart & Ware, 1992). Item discriminant validity was considered to occur when correlations between an item and its domain were significantly higher compared to correlations between an item and other domains (Ware & Gandek, 1998). Significance was defined as at least two standard errors greater than the correlation (Ware & Gandek, 1998). Because chi-square analyses identified statistically
significant ($p < .05$) differences between patients and carers in terms of perceived importance of information (Table 1), internal consistency reliability and item validity assessments were conducted for patients and carers separately.

### 3. Results

A consecutive series of 149 patients from the two services were reviewed. A total of 44 did not meet the inclusion criteria resulting in 105 patients invited to participate. Seventy-nine surveys (75% of invited) were completed and returned. In 23 cases, HNC patients either did not nominate a carer, or the carer could not be contacted, did not return the survey forms or declined to participate. Fifty-six carers (either family members or paid carers) participated, but four carers completed surveys where the patient did not and so were excluded from analysis.

Most patients were male ($n=63$, 80%) and the average patient age was 62.7 years (SD 11.9). A majority of patients were married ($n=53$, 67%). Patients mostly had squamous cell carcinomas ($n=60$ or 78%), and tumours were located most commonly in the oropharynx ($n=26$ or 35%), followed by the larynx ($n=12$ or 16%), oral cavity ($n=11$ or 15%) and skin ($n=11$ or 15%). Tumour stage could not be assessed in several cases ($n=16$ or 20%); the largest group had stage IV cancer ($n=29$ or 37%), while 16 patients (20%) had stage I, 7 (9%) had stage II and 11 (14%) had stage III. Treatment information was available for 76 patients; 43 received radiotherapy (RT) as their primary treatment (30 with concurrent chemotherapy), 18 received RT postoperatively (2 with concurrent chemotherapy), 2 received palliative RT and 13 had surgical intervention alone.

In contrast, family members were predominantly female ($n=45$, 86%). Most were related to the patient through marriage (patient’s spouse: $n=39$, 75%; patient’s adult child: $n=7$, 14%; other: $n=6$, 11%).

#### 3.1. HaNiQ reliability and item validity results: patients

All items save two had correlations of at least 0.3 with their own domains and no items had significantly higher correlations with other domains than with their own domains, although 23 had non-significantly higher correlations. The two items with correlations of <0.3 with their own domains came from the disease and psychosocial domains.
As per recommendations (Stewart & Ware, 1992), these items were removed from analysis and all analyses conducted once more.

Following removal of these two items, the Cronbach’s alpha for the overall questionnaire was 0.94 and alpha coefficients for domains ranged from 0.67 to 0.91. No corrected item–domain correlations fell below 0.3; just one item had a significantly higher correlation with another domain than with its own domain, and 12 items had non-significantly higher correlations. Furthermore, the two domains from which items were removed showed improvements in internal consistency reliability (disease: 0.63 to 0.67; psychosocial: 0.89 to 0.91).

3.2. HaNiQ reliability and item validity results: carers

All items save two had correlations of at least 0.3 with their own domains and five items had significantly higher correlations with other domains than with their own domains, with 18 having non-significantly higher correlations. The two items with correlations of <0.3 with their own domains were from the disease and survivorship domains.

Following removal of these two items, the Cronbach’s alpha for the overall questionnaire was 0.94 and alpha coefficients for domains ranged from 0.73 to 0.89. No corrected item–domain correlations fell below 0.3 and just two items had significantly higher correlations with other domains than with their own. Thirteen items had non-significantly higher correlations with domains other than their own. Furthermore, the two domains from which items were removed showed improvements in internal consistency reliability (disease: 0.70 to 0.73; survivorship: 0.81 to 0.89).

3.3. Patient and carer information needs

As Table 1 shows, the majority of patients and carers rated most items as ‘very important’: of the 30 items, only six were rated by <50% as ‘very important.’ More carers than patients saw items as ‘very important,’ with carer percentages exceeding patient percentages in all but three of 30 items. All items for which there were significant differences in terms of information needs were also items in which carer ratings exceeded patient ratings.

4. Discussion

For both family members and patients, the HaNiQ showed good internal consistency reliability and scaling assumptions were met, with acceptable item convergent and discriminant validity. As the HaNiQ was administered to family members and patients separately, and because this study has identified different information needs between these groups, separate administration of the questionnaire is recommended for future work. Consistent with studies in different cancer populations (Booth, Beaver, Kitchener, O’Neill, & Farrell, 2005; Gonzalez & Stepan, 2006) as well as other studies with HNC patients (Ziegler et al., 2004), patients in this study prioritised information about the disease and treatment while psychosocial concerns were comparatively less important. Carers also seemed to have more information needs (as indicated by percentages rating needs as ‘very important’) than patients, broadly consistent with previous work showing that carers tend to seek information more proactively than patients (James et al., 2007). The findings of greater informational need as well as previous findings of carer unmet needs exceeding patient unmet needs (Soothill et al., 2003) and levels of concern (Harrison, Haddad, & Maguire, 1995) underscore the importance of addressing carer informational needs (Morris & Thomas, 2002).

4.2. Recommendations for future research

The HaNiQ needs to be tested in a larger sample of HNC patients and carers, with assessments of validity such as criterion and construct validity undertaken. Examining the differences among different types of carers (i.e. spouse versus adult children) given the focus on spouses in the literature (Adams et al., 2009) would also be of interest. The next stage of research would be to use the HaNiQ to guide the development of interventions to address the information needs of HNC patients and carers, and to test the effectiveness of these interventions.

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References


