



## Educational intervention for patients with head and neck cancer in the discharge phase

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### ABSTRACT

#### Keywords:

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Information  
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Intervention

**Purpose:** The consequences of head and neck cancer (HNC) treatment have great impact on patients' lives. Despite the importance of preparing patients for the period after discharge, patients frequently experience a lack of information. Aims of the study were to develop a nurse-led educational intervention to provide information during a discharge interview and to investigate the effects of the intervention on informational needs and satisfaction with information in HNC patients.

**Methods:** A total of 48 patients participated in this quasi-experimental study. The control group ( $n = 26$ ) received standard care, which included a short interview using the patients' discharge letter dictated by the nurse. The intervention group ( $n = 22$ ) received the educational intervention, namely a discharge interview where trained nurses used a checklist to inform patients about: general information, wound-care, physical-social problems, work and finances. Effects associated with discharge interview were measured with the Patient Information Need Questionnaire (PINQ) and the Satisfaction with Cancer Information Profile.

**Results:** The findings showed that patients need information concerning: illness, treatment, side-effects, physical fitness, impact on functioning, duration of recovery time and impact on quality of life. The educational intervention had no significant effect on the informational needs or the level of satisfaction with information.

**Conclusions:** A nurse-led intervention to provide discharge information was developed however no effects on patient outcomes were found. Nurses need to use an instrument to assess the informational needs of patients prior to the discharge interview. The effects of the educational intervention need to be tested in a larger group of patients.

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### Introduction

Head and neck cancer (HNC) is the sixth most common cancer worldwide (Chin et al., 2006), representing 5% of the population of all cancer patients (Gleich et al., 2003). HNC itself may cause difficulty swallowing and eating, pain and hoarseness, depending

on the stage, localisation and size of the tumour. Lifestyle factors, such as smoking and alcohol consumption, are generally known as important determinants for developing HNC (Bagnardi et al., 2001; Zeka et al., 2003; Pelucchi et al., 2008).

The main treatment for HNC is removing the tumour by surgery, although surgery is often combined with radiation or chemotherapy (Anniko, 2006; Semple et al., 2008). Treatment leads to substantial problems in the lives of HNC patients. Generally problems identified described in literature concern three areas. Firstly, patients experience physical problems, such as pain, restrictions in speech, mastication, swallowing, shoulder function, sense of taste or smell, and breathing. Patients also describe changes in appearance, (partial) facial palsy, nausea and vomiting and fatigue

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(Trzcieniecka-Green et al., 2007; Ronis et al., 2008; Semple et al., 2008). Secondly, patients experience psychological and social problems, like reduced social activity or functioning, emotional stress, worrying about work, interpersonal relationships, day to day tasks, concerns about cancer, lack of self confidence (Björklund et al., 2008; Semple et al., 2008). Patients report being ashamed of their voice and appearance, feeling depressed, experiencing loneliness and living in uncertainty about the success of treatment (Nalbadian et al., 2001; Gradauskas et al., 2006; Trzcieniecka-Green et al., 2007; Björklund et al., 2008; Semple et al., 2008). The third area concerns, financial problems which may occur as a consequence of health care costs and or reduced physical capacity to work (Nalbadian et al., 2001; Gradauskas et al., 2006).

Given that patients experience dramatic changes in their lives after discharge, it is important to provide patients with information to prepare them for the period after discharge (Semple, 2001; Ziegler et al., 2004). Informational need has been defined as an experience of inadequate information concerning a life domain (Mesters et al., 2001). Various studies have explored the informational needs of HNC patients, showing that they prefer to receive information concerning physical problems as described above. Patients also want information on ability to work (Llewellyn et al., 2006; Semple et al., 2008), financial issues (Nalbadian et al., 2001; Gradauskas et al., 2006), social and emotional support (Llewellyn et al., 2006; Roberts et al., 2008), side-effects, duration of recovery, Quality of Life (QoL) after one-year (Llewellyn et al., 2006), symptoms of recurrence, and lifestyle factors that increase the risk of recurrence (Roberts et al., 2008).

The literature shows that HNC patients who are unsatisfied with the information received experience high levels of fear and depression, and low QoL (Edwards, 1998; Mesters et al., 2001; Semple et al., 2008). Patients' level of satisfaction with the received information can be improved by providing information in the identified areas (Jackson et al., 2001). To prepare the patient for the period after discharge, it is important to give the patient adequate information before discharge. However, the literature does not report any effective intervention that meets the informational needs of HNC patients after discharge. Nevertheless, literature exists concerning the manner in which HNC patients would like to receive information. Patients prefer to receive verbal and written information and they want to be informed at the right time, on the right place and by a professional on an individual basis (Llewellyn et al., 2005; Pollock et al., 2008). During the hospital stay, it can be difficult for patients to comprehend the received information and to consider it as meaningful (Newell et al., 2004; Llewellyn et al., 2005). It has, however, been reported that the meaning becomes apparent during the recovery period at home (Henderson and Zernike, 2001; Newell et al., 2004). Furthermore, the provision of information about the combination of the problems to be expected is of great importance to HNC patients (Björklund et al., 2008).

Many different health care professionals, including social workers, nurses or doctors provide information to patients in all stages of the disease and recovery. However, studies show that nurses are important for providing information and support, and for coordinating the care (Whale, 1998; Beaver et al., 2006; Eades et al., 2009). For example, a RCT showed that a nurse-led follow-up provided more continuity of care and that the nurses were better able to detect psychological problems than doctors in the case of breast cancer patients (Baildam et al., 2002). Furthermore, Henderson and Zernike (2001) emphasised that nurses must provide relevant and useful discharge information to surgical patients.

In conclusion, HNC patients face all kinds of difficulties after treatment and there is an indicated need for comprehensive

information and thorough preparation. An effective and efficient nurse-led educational intervention that meets the informational needs of the patient is the next step in the care for HNC patients (Newell et al., 2004; Llewellyn et al., 2005, 2006; Pollock et al., 2008; Semple et al., 2008). The aims of this study were firstly to develop a nurse-led educational intervention to provide information for the period after discharge, and secondly to investigate the effect of the intervention on the informational needs and level of satisfaction with the information among HNC patients.

## Method

### *Methods for Aim one*

The first aim of this study was to develop an intervention focussing on how to provide information to patients with HCN cancer.

### *Design*

The intervention was developed using a seven step procedure, which included searching the literature for cancer patient interventions and tailoring the intervention to the needs of patients with HCN cancer.

### *Intervention development*

Step 1. A literature search for educational interventions for cancer patients. A structure was needed for the intervention on how to provide information to patients. Two studies were found in the literature which described educational interventions for cancer patients (Keller, 2006; Mueller and Glennon, 2007). One of these studies described an intervention using a specific topic list to provide structural information in breast cancer patients (Keller, 2006), while the other study described an intervention using a checklist to provide structural information to patients who were receiving chemotherapy (Mueller and Glennon, 2007). In these interventions nurses provided verbal and written information during a 30–45 min structured conversation with each patient. In addition, the checklist and topic list were used to ensure that the information provided was complete and consistent. Nurses found the checklist helpful and it made them feel confident when providing information (Mueller and Glennon, 2007). Based on these two studies, the format of a checklist was adopted for this study.

With a view to adapting the topics of the checklist for HNC patients, the following steps were undertaken by the researcher and two research assistants, both of whom were fourth year nursing students and experienced in caring for HNC patients.

Step two: Interviews were conducted with experts in the care and treatment of HNC patients. The experts included a social worker, dietician, physical therapist, outpatient clinic nurse and a specialist nurse. They were asked to indicate what information they provide during the hospital stay, which problems, from their perspective, were experienced by patients at home and which professional should be assigned to manage these problems.

Step three: All existing and relevant written material from the departments of oral maxillofacial surgery and otorhinolaryngology was collected. In addition, a nurse from another hospital specialised in caring for HNC patients was consulted concerning their provision of discharge information.

Step four: All the information gathered was categorized and a draft version of the checklist was created with six sections, namely general, wound care, physical problems, psycho-social problems, work and finance and sources for additional information/professional help.

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