



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

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A B S T R A C T

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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

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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

(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.

Step five: For the completeness of the written material, five informational pages were written on the following topics: a) information focussing on websites for accurate additional information, b) availability of professionals after discharge, c) the consequences of alcohol use and smoking cessation (two different pages), d) and practical advice for living with a gastric tube.

Step six: A second expert group consisting of eight nurses and a Clinical Nurse Specialist (CNS) reviewed the draft version of the checklist and the written material for accuracy and feasibility and they also provided input for improvement.

Step seven: The intervention and written materials were adapted in line with the comments made by these experts. The final version of the intervention included a. instructions for the discharge interview, b. five informational pages and c. a checklist for nurses including 18 major topics and 61 detailed points, all shown in Fig. 1.

Procedure of the intervention

A few days before discharge the nurse made an appointment with the patient for the day before discharge from the hospital. Patients were encouraged to invite relatives to participate. This enabled patients to think about what they would like to know. On the day of discharge the nurse determined the educational needs based on the type of operation the patient had received and the patients' personal situation. Suitable written material was collected. The discharge interview lasted approximately 30 min and took place in a quiet room. These 'instructions' are also noted on the

front-page of the checklist, that was used to structure the interview (Fig. 1A).

The discharge interview started with the patient being given an opportunity to ask questions. This allowed the patient to receive information about the topics they identified. In addition, the nurse used the checklist to add information by discussing the major topics which are underlined in the checklist. The other more detailed points were discussed if the nurse considered them to be appropriate. The checklist is shown in Fig. 1C. The verbal information was complemented with written material that was handed out and discussed with the patient during the discharge interview.

Implementation of intervention

A single implementation strategy was used (Prior et al., 2008). Eight experienced nurses took part in an interactive educational workshop and training in how to deliver the intervention. The workshop took 1.5 h. The importance and purpose of the intervention was explained and the leading and central role of the patients' needs was emphasized. The nurses were trained in using the checklist by means of a role play and discussed the usefulness and completeness of the checklist.

Outcome

With a view to enabling a quick evaluation of the intervention, space was provided on each checklist to record comments and experiences of the patient or the nurse (see Fig. 1A, 'comments').

A Instructions discharge interview	
Preparation <ul style="list-style-type: none"> Select date and time with patient Encourage presence family Encourage bringing received written material to conversation. 	Appointments <p>Name nurse:</p> <p>Date interview:</p> <p>Family present: yes/no</p> <p>Date discharge:</p>
Provision of the educational intervention: <ul style="list-style-type: none"> Reflect on the operation and personal situation (gastronomic tube, smoking, cannula etc) Collect written materials (booklets, pamphlets, informational pages) Secure a 'quiet room' for the interview without distraction Plan adequate time (a minimal length of interview is 30 minutes) Give information by using the checklist Support verbal information with written material (hand it out during the interview) 	
Comments:	

NB: The content of this figure is used as the front-page of the checklist see Figure 1C.
NB: The lay-out of the figure is compromised for illustrative purposes.

B Informational pages	
<ul style="list-style-type: none"> Websites Disciplines Alcohol Smoking Gastronomic tube 	<ul style="list-style-type: none"> information focusing on websites for accurate additional information information concerning available professionals after discharge information discussing consequences of alcohol use and options for alcohol cessation information discussing consequences of smoking and options for smoking cessation information giving practical advice for living with a gastric tube

Fig. 1. Educational intervention.

C Checklist discharge interview	
<i>The checklist is a tool to facilitate discussion of important topics with the patient during the nurse discharge interview.</i>	
<p>General</p> <p><u>Knowledge and expectations treatment</u></p> <ul style="list-style-type: none"> o results treatment, pathology report o further treatment (radiotherapy, reconstruction, dentist) o treatment plan clear? Advise: write down questions for outpatient clinic visits <p><u>Medication</u></p> <ul style="list-style-type: none"> o effect and side-effects o prescriptions <p><u>Appointments</u></p> <ul style="list-style-type: none"> o received appointment outpatient physician visit? o appointment nurse specialist; if necessary o who to contact for questions or for immediate help <ul style="list-style-type: none"> o telephone number department (refer to discharge note) <p><u>Advise and rules for daily living at home</u></p> <ul style="list-style-type: none"> o regarding activities of daily living, housekeeping, physical exercise <p>Wound care</p> <p><u>Materials, care, inspection and observations concerning:</u></p> <ul style="list-style-type: none"> o cannula, fistula, laryngectomy o gastric tube o appointment CNS o donor wound, thiersch's plastic, other wounds o nursing care plan in discharge letter <p><u>Homecare</u></p> <ul style="list-style-type: none"> o which organisation, when is the first visit o what care will be provided <p>Physical problems</p> <p><u>Swallowing & diet</u></p> <ul style="list-style-type: none"> o problems with diet/eating o possible referral to a speech therapist o dietary advice clear, what is and is not allowed o weight loss, advice to weigh once a week o possible referral to a dietician <p><u>Speech</u></p> <ul style="list-style-type: none"> o communication problems o possible referral to a speech therapist <p><u>Oral/dental hygiene</u></p> <ul style="list-style-type: none"> o problems (during radiotherapy) o significance of oral hygiene after discharge (consequences for the mouth) o prescription rinse o possible referral to a dental hygienist 	<p><u>Fatigue</u></p> <ul style="list-style-type: none"> o discuss expected duration o finding balance between relaxation and activity, exercise, 'listen to your body' <p><u>Level of consciousness</u></p> <ul style="list-style-type: none"> o drowsiness; negative influence on driving, reading, following conversations, memory o influence operation and medication <p><u>Mobility</u></p> <ul style="list-style-type: none"> o complaints neck, shoulder, arm or leg o oedema therapy o possible referral to a physical therapist <p>Psycho-social problems</p> <p><u>Change in appearance</u></p> <ul style="list-style-type: none"> o (negative) influence on self-image, selfconfidence, emotions o other possible reactions o influence on work and social contacts <p><u>Emotions</u></p> <ul style="list-style-type: none"> o uncertainty o fear of recurrence, life-threatening disease, dying o how to handle these emotions o possible referral to social worker or mental health facility <p><u>Intimacy</u></p> <ul style="list-style-type: none"> o change in personal contact (i.e. kissing) o change in sexual experiences / intimacy with partner o possible referral to specialist in sexuality <p><u>Home situation</u></p> <ul style="list-style-type: none"> o increased dependency, reduced ability to help in i.e. household maintenance o social acceptance o how to maintain social contacts and give meaning to them o discuss problems with family and friends <p>Work and finances</p> <ul style="list-style-type: none"> o (temporarily) unable to work o insurance / financial assistance o financial compensation transport to radiotherapy o possible referral to social worker <p>Source of information / support after discharge</p> <ul style="list-style-type: none"> o informational pages o brochures (available on the ward) o walk-in help centres o patient support groups (individual experiences, not always generalizable) o internet; NB not all sites are accurate, use the supplemental written information)

Fig. 1. (continued).

Methods for Aim two

The second aim of this study was to evaluate the effects of the intervention on the information needs of patients with HCN cancer and their level of satisfaction with information.

Design

The study conducted used a posttest-only design with non-equivalent groups (Shadish et al., 2002). The control group received care as usual. The intervention was then implemented with nurses receiving training and education on how to provide the intervention. Finally, the patients in the intervention group received the educational intervention from the trained nurses. Accordingly, patients gave informed consent before participation and could withdraw their consent at any time. The study was registered by the local medical ethics committee under number: 09-348/C.

Participants

Patients were included from departments of oral maxillofacial surgery and otorhinolaryngology at a Dutch academic hospital. A convenience sample was used and patients were included if they: 1) had a surgical treatment for head and neck cancer; 2) were able to read and speak Dutch. Patients were excluded if they 1) suffered from severe memory loss; 2) only underwent an endoscopy; 3) were admitted to hospital for two days or fewer.

From November 2009 to March 2010, 82 patients were screened for eligibility. Of these patients, 18 patients were excluded for not meeting the inclusion criteria and four patients declined to participate. Although 60 patients agreed to participate, 12 did not complete the questionnaire and this resulted in 48 patients being included in the study. Of these, 26 patients were included in the control group, while 22 patients were included in the intervention group.

As regards the characteristics of the included patients, more men than women participated in both the control group and

intervention group (15 compared to 11 and 15 compared to 7 respectively). The average age of people in the control group was 69, and that of people in the control group was 64 (Table 1).

Procedure

Control group: During the first two and a half months, 26 participants received care as usual. Care as usual included information provided by a nurse in a discharge interview with the patient and using the patients' discharge letter which was dictated by the nurse and which provides practical information such as wound care, medication, and outpatient appointment. The content of the information provided was determined by the nurse. Most discharge interviews took place on the day of discharge. However, no specific appointment was made with the patient for the exact time of the discharge interview.

Intervention group: During the second two and a half months, 28 participants received the educational intervention from trained nurses. The educational intervention was provided as described above. The intervention enabled the nurses to give information in a structurally and timely matter. The discharge interview took place in a separate, quiet room and lasted at least 30 min. Family members were invited to attend and written material which was thought to be suitable was collected. The intervention allowed the information to be provided in a more standardized way, focussing on the needs of each patient.

Table 1
Participant characteristics.

Variable	Control (n = 26)		Intervention (n = 22)	
	n	%	n	%
<i>Gender</i>				
Male	15	57	15	68
Female	11	42	7	32
Average age	69	—	64	—
<i>Marital status</i>				
Married/cohabiting	12	46	15	68
Divorced	3	12	1	5
Single	4	15	4	18
Widowed	7	27	2	9
<i>Highest education</i>				
Primary school	2	8	2	9
Secondary school	10	39	9	41
Trade school	6	23	5	23
University	6	23	6	27
Missing	2	8	—	—
<i>Type patient</i>				
Newly diagnosed	20	77	16	73
Recurrence	6	23	6	27
<i>TN (M) status^a</i>				
T0N 1-3	2	8	0	0
T1N0	4	15	7	32
T2N0	8	31	4	18
T2, 3N0, 1	3	12	3	14
T2-4 N0-3	7	27	4	18
Missing	2	8	4	18
<i>Radiotherapy</i>				
Yes	11	42	5	23
No	2	8	3	14
Unknown	13	50	14	64

^a The TNM Classification is an anatomically based system that records the primary (T) and regional (N) nodal extent of the tumour and the absence or presence of metastases (M). (Source: www.uicc.org, retrieved at 2-25-2011).

Outcome and measures

The following characteristics of participants were collected: gender, age, marital status, educational level, patient type, tumour classification status, radiation status.

Informational needs were measured using the Patient Information Need Questionnaire (PINQ) (Mesters et al., 2001). This 17 item instrument consists of two scales, a) a disease-oriented scale including nine items to indicate the need for information on HNC and treatment, and an action-oriented scale which includes eight items to indicate the need for information on access to help and on solving practical problems. Informational need was rated by patients using four-point Likert scales. The score range for the scales is 9–36 and 8–32 respectively, with a high score implying a greater need for information. The PINQ showed good internal consistency; Chronbach's alphas were 0.88–0.92 (Mesters et al., 2001).

The satisfaction with information was measured using the Satisfaction with Cancer Information Profile (SCIP) (Llewellyn et al., 2005). This 21 item instrument focuses on HNC patients and measures satisfaction with the amount of information (14 items) using a four-point Likert scale with a range of 1–14, and satisfaction with type and timing of information (7 items) using a five-point scale with a range of 7–35. A high score reflects a high degree of satisfaction. Both scales demonstrated good internal consistency. Chronbach's alphas were 0.89 and 0.87 respectively (Llewellyn et al., 2005).

Translation

Both the PINQ and the SCIP were translated from English to Dutch using the forward and backward method (Brislin, 1970). In general the translation went well. However a few items showed some differences compared to the original version. For example, the word 'consequences' was translated with the word 'effects'. The differences were again translated using the forward and backward method and after that consensus was achieved on all items of both instruments.

Data collection

Each patient, in the control group as well as in the intervention group, was informed by the researcher or a research assistant about the study through verbal and written information 2–3 days before discharge from hospital. After an informed consent form had been signed, demographic, social and clinical data was collected from medical and nursing records. The patients received both the PINQ and the SCIP questionnaires on the day of discharge from the hospital. This gave the participants the opportunity to read the questionnaires before they received the telephone call, and simplified the process of answering the questionnaire by phone. Five days after discharge the researcher or the research assistant contacted the patient for a structured telephone interview. The active involvement of the patient meant that a better response was expected. Both research assistants were trained in administering questionnaires and Cohen's Kappa was used to evaluate interrater reliability between the researcher and the RA, which resulted in optimal agreement +1 ($p = 0.00$). However, if participants were physically unable to use a phone or objected to being contacted by phone, they were asked to fill in the written questionnaire and to return it within a week using a self-addressed envelope.

Data analysis

Concerning aim one: the experiences of patients and nurses with the intervention were analysed using thematic content analysis (Polit and Beck, 2008). Practical information was compared with information on content and the number of negative and positive comments was counted.

Concerning aim two: patients' characteristics, informational needs and satisfaction with information were analysed using descriptive statistics. The group differences on baseline characteristics were evaluated using the Mann–Whitney test. The normality of the data was measured with the Shapiro–Wilk test. Since the data was not normally distributed and the sample was relatively small, the Mann–Whitney test was conducted to analyse the effect of the educational intervention. Finally, a post-hoc power analyses was performed. A p -value equal to or less than 0.05 was considered significant. The data was analysed using Statistical Package for the Social Sciences (SPSS), version 17.

Results

Aim one

Intervention development

A nurse-led educational intervention was developed to provide HNC patients with information for the period after discharge, see Fig. 1. The intervention was provided in addition to care as usual and included instructions for the discharge interview, written informational pages and a checklist to structure the information provided by nurses.

Comments from nurses and patients concerning the intervention used

Of the 28 discharge interviews conducted with the nurses, the nurses registered, in 25 interviews, their own comments and experiences, or those of the patient, with regard to the educational intervention. In eight cases, the comments were purely practical, for example: “supplied information leaflets” or “conversation went well”. The comments in the other 17 interviews contained information about the content of the intervention. Thirteen of the comments were positive and emphasised that the discharge interview was helpful in structuring the information and that both the patients and the nurses found it to be a pleasant experience. One patient remarked that she missed this kind of education in the interview the last time she was admitted to the hospital. There were four less positive comments, for example: “it was already clear to the patient” or that the interview was difficult because “the patient did not want to let his emotional guard down”. Both these comments were made by a nurse. No comments were made which indicated a need to modify the structure or elements of the checklist or the discharge interview.

Aim two

Sample characteristics

There was no significant difference between the groups with respect to the demographic, social and clinical data. In the intervention group questionnaire data was collected from nine patients by telephone and 13 returned the questionnaire by post (for the control group this was 15 and 11, respectively). No significant differences in responses were found.

Effect of the intervention

Data collected using the PINQ was normally distributed for the ‘disease-oriented’ scale ($p = 0.07$) and was not normally distributed for the ‘action-oriented’ scale ($p = 0.02$). The Cronbach's alpha was 0.92 for the ‘disease-oriented’ scale and 0.79 for the ‘action-oriented’ scale. No significant differences were found between the control and intervention group for either the ‘disease-oriented’ scale ($p = 0.98$) or the ‘action-oriented’ scale ($p = 0.44$), see Table 2. No significant differences in responses by telephone or questionnaire were found.

Table 2

Differences in informational needs and satisfaction with the received information between the control group and the intervention group.

	Control group (<i>n</i> = 26)		Intervention group (<i>n</i> = 22)		
	Mean	Std. deviation	Mean	Std. deviation	Effect size (ES)
<i>Informational needs – PINQ</i>					
Disease oriented scale	21	7.6	21.1	8.6	0.01
Action oriented scale	14.9	5.2	15.9	5.5	0.19
<i>Satisfaction with information – SCIP</i>					
Amount of information	9.5	3.7	8.5	4.2	0.25
Type and timing information	27.3	4.5	26.9	5.1	0.08

Data collected using the SCIP was not normally distributed for the ‘amount of information’ scale ($p = 0.005$) and the ‘type and timing information’ ($p = 0.002$). The Cronbach's alpha was 0.86 for the ‘amount of information’ scale and 0.87 for the ‘type and timing’ of information scale. No significant differences were found between the control and intervention group for either the ‘amount of information’ scale ($p = 0.39$) and the ‘type and timing information’ scale ($p = 0.74$), see Table 2. No significant differences in responses by telephone or questionnaire were found.

Post-hoc power analyses

The post-hoc power analysis showed an effect size of 0.01 with a power of 0.05 for the ‘disease-oriented’ scale and an effect size of 0.19 with a power of 0.1 for the ‘action-oriented’ scale of the PINQ. For the SCIP the post-hoc power analysis showed an effect size of 0.25 with a power of 0.14 for the ‘amount of information’ scale and an effect size of 0.08 with a power of 0.06 for the ‘type and timing information’ scale.

Discussion

This study described the development of a nurse-led educational intervention and determined the effect of this intervention on the informational needs and satisfaction with information in Head and Neck Cancer (HNC) patients.

With regard to the study's first aim, a nurse-led educational intervention was developed and comments of nurses and patients were overall positive. In general the nurses found the intervention helpful in structuring information. One patient remarked that she missed this kind of education in the interview the last time she was admitted to the hospital. With regard to the study's second aim, the intervention had no significant effect on the informational needs and had no effect on the level of satisfaction with information.

Several steps were undertaken during the development to strengthen the educational intervention, such as reviewing the literature and using other known interventions. In addition, only experienced nurses carried out the discharge interviews, and they received interactive training and feedback on the content and utility of the checklist. Furthermore, the use of validated questionnaires specific to the HNC patients strengthened our study (Mesters et al., 2001; Llewellyn et al., 2006). Given the method used for translation and that fact that the translation went well, we believe that the Dutch versions are equivalent to the originals.

It is possible that the development process and the content of the educational intervention may not have been strong enough to lead to significant results. The post-hoc power analyses showed

a low effect size on both scales of the PINQ and the SCIP, assuming that the intervention needs to be improved. Furthermore, nurses who performed the intervention were only trained once and the knowledge of the nurses including the intervention fidelity was not measured. Only the 'amount of information' scale of the SCIP showed an effect size of 0.25 which can be considered as a small effect (Cohen, 1988). The associated power of 0.14 is low, but with a bigger sample size the results of the 'amount of information' scale might have been significant. However, a similar discharge intervention with one contact and small sample size ($n = 50$) improved outcome of cardiac patients (Ozcan et al., 2010). We assume that a combination of improving the intervention and enlarging the sample size should be undertaken to gain significant results on both the informational needs and satisfaction with information. Finally, one may question whether the educational intervention provided upon discharge can produce results five days later.

In connection with the data collection, telephone interviews were conducted with a good interrater reliability. Telephone interviews are a recommended strategy for assessing whether patients need further information (Henderson and Zernike, 2001), are widely used and are considered to be appropriate and efficient (Waterman et al., 1999; Polit and Beck, 2008). Nevertheless, the authors question whether the participants in this study evaluated the information they received as intended, in order to prepare themselves for the period after discharge. During each telephone call it was emphasised that the focus would be on the information given with regarding to the period after discharge, received in the period after the operation. Nevertheless, several participants gave the impression that they were evaluating information received during the whole hospital admission. In addition, 50% of the patients in this study were not willing or able to receive a telephone call because of difficulty speaking. No differences in the outcome of the PINQ and the SCIP were found between responses by telephone interviews or self-report questionnaires. Offering options such as face-to-face interviews or internet surveys may be a more efficient way of interviewing patients with HCN and should be considered in future research with this group of patients.

The characteristics of our sample are similar to other studies previously conducted with the same questionnaires (Mesters et al., 2001; Llewellyn et al., 2006). Furthermore, the participants in our study are equally satisfied with the information received as the participants in the study by Llewellyn et al. (2006). However, our control group was more satisfied than the intervention group, although the results were not significant. By contrast, participants in our study reported less informational needs than reported by Mesters et al. (2001) with a score of 21 versus 28 on the 'disease-oriented' scale and a score of 15 versus 20 on the 'action-oriented' scale, respectively. It is possible that the relatively low average score in our study made it more difficult to measure the effect of the intervention because more participants already felt that they had received sufficient information.

There is some evidence to indicate that actively involving the patient and caregiver in the provision of information can have clinical benefits (Smith et al., 2009). One can assume that actively involving patient and caregiver in information provision may also be beneficial for cancer patient. This, however, needs to be further investigated. We recommend that nurses in clinical practice use the PINQ as a standard assessment tool to evaluate the patients need for information prior to the discharge interview and to provide the patient with information prior to discharge based on this assessment. In this way the intervention can be tailored even more effectively to patients' needs.

Further research focussing on the intervention should adopt a model for intervention developments, for example 'The Utrecht model' (Meijel van et al., 2004). A model can be used to develop the

intervention in more detail. In particular, the experiences of nurses as providers of information and patients as recipients of the intervention can generate useful data. We also suggest expanding the intervention, where possible, to include a planned follow-up with the patient to evaluate the given information and to provide more information as necessary. This has been shown to be effective in a review by Smith et al. (2009). In addition, new methods of how to supply information, for example a web based computer program can be considered (Hoffmann et al., 2004). This needs to be further explored for HNC patients. Although there is a lack of studies focussing on these new methods with HNC patients, one can assume that using web based interventions may be beneficial because HNC patients often have difficulties with verbal communication. However, patients need to have access to a computer and skills in how to use one.

In summary, this study responded to the need for a comprehensive intervention to meet the informational needs of HNC patients (Semple et al., 2008; Chen et al., 2009). A structured approach to determine informational needs was used and a nurse-led intervention to provide information was developed. However, no significant effects were found. Further development of the intervention and furthermore comprehensive research is needed to investigate its effects in a larger group of patients.

Conflict of interest statement

None declared.

References

- Anniko, M. (Ed.), 2006. Ear-, Nose- and Neck Diseases, Head and Neck Surgery. Liber AB, Stockholm.
- Bagnardi, V., Blangiardo, M., Vecchia, C.L., Corrao, G., 2001. A meta-analysis of alcohol drinking and cancer risk. *British Journal of Cancer* 85 (11), 1700.
- Baildam, A., Keeling, F., Noblet, M., Thomson, L., Bundred, N., Hopwood, P., 2002. Nurse led follow up clinics for women treated for primary breast cancer: a randomised controlled trial. *European Journal of Cancer* 38, S136.
- Beaver, K., Twomey, M., Witham, G., Foy, S., Luker, K.A., 2006. Meeting the information needs of women with breast cancer: piloting a nurse-led intervention. *European Journal of Oncology Nursing* 10 (5), 378–390.
- Björklund, M., Sarvimäki, A., Berg, A., 2008. Health promotion and empowerment from the perspective of individuals living with head and neck cancer. *European Journal of Oncology Nursing* 12 (1), 26–34.
- Brislin, R.W., 1970. Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology* 1 (3), 185–216.
- Chen, S.C., Tsai, M.C., Liu, C.L., Yu, W.P., Liao, C.T., Chang, J.T., 2009. Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nursing* 32 (6), 473–481.
- Chin, D., Boyle, G.M., Porceddu, S., Theile, D.R., Parsons, P.G., Coman, W.B., 2006. Head and neck cancer: past, present and future. *Expert Review of Anticancer Therapy* 6 (7), 1111–1118.
- Cohen, J., 1988. *Statistical Power Analysis for the Behavioral Sciences*, second ed. Hillsdale, NJ.
- Eades, M., Chasen, M., Bhargava, R., 2009. Rehabilitation: long-term physical and functional changes following treatment. *Seminars in Oncology Nursing* 25 (3), 222–230.
- Edwards, D., 1998. Head and neck cancer services: views of patients, their families and professionals. *The British Journal of Oral & Maxillofacial Surgery* 36 (2), 99–102.
- Gleich, L.L., Collins, C.M., Gartside, P.S., Gluckman, J.L., Barrett, W.L., Wilson, K.M., et al., 2003. Therapeutic decision making in stages III and IV head and neck squamous cell carcinoma. *Archives of Otolaryngology–Head & Neck Surgery* 129 (1), 26–35.
- Gradauskas, P., Rubikas, R., Saferis, V., 2006. Changes in quality of life after esophageal resections for carcinoma. *Medicina (Kaunas, Lithuania)* 42 (3), 187–194.
- Henderson, A., Zernike, W., 2001. A study of the impact of discharge information for surgical patients. *Journal of Advanced Nursing* 35 (3), 435–441.
- Hoffmann, T., Russell, T., McKenna, K., 2004. Producing computer-generated tailored written information for stroke patients and their carers: system development and preliminary evaluation. *International Journal of Medical Informatics* 73 (11–12), 751–758.
- Jackson, J.L., Chamberlin, J., Kroenke, K., 2001. Predictors of patient satisfaction. *Social Science & Medicine* 52 (4), 609–620.

- Keller, J.S., 2006. Implementation of a prechemotherapy educational intervention for women newly diagnosed with breast cancer. *Clinical Journal of Oncology Nursing* 10 (1), 57–60.
- Llewellyn, C.D., McGurk, M., Weinman, J., 2005. Striking the right balance: a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer. *Psychology, Health & Medicine* 10 (2), 180–193.
- Llewellyn, C.D., McGurk, M., Weinman, J., 2006. How satisfied are head and neck cancer (HNC) patients with the information they receive pre-treatment? Results from the satisfaction with cancer information profile (SCIP). *Oral Oncology* 42 (7), 726–734.
- Meijel van, B., Gamel, C., Swieten-Duijffes van, B., Grypdonck, M., 2004. The development of evidence-based nursing interventions: methodological considerations. *Journal of Advanced Nursing* 48 (1), 84–92.
- Mesters, I., Borne van den, B., Boer de, M., Pruyn, J., 2001. Measuring information needs among cancer patients. *Patient Education & Counseling* 43 (3), 253–262.
- Mueller, P.S., Glennon, C.A., 2007. A nurse-developed prechemotherapy education checklist. *Clinical Journal of Oncology Nursing* 11 (5), 715–719.
- Nalbadian, M., Nikolaou, A., Nikolaidis, V., Petridis, D., Themelis, C., Daniilidis, I., 2001. Factors influencing quality of life in laryngectomized patients. *European Archives of Oto-rhino-laryngology* 258 (7), 336–340.
- Newell, R., Ziegler, L., Stafford, N., Lewin, R.J., 2004. The information needs of head and neck cancer patients prior to surgery. *Annals of the Royal College of Surgeons of England* 86 (6), 407–410.
- Ozcan, H., Yildiz Findik, U., Sut, N., 2010. Information level of patients in discharge training given by nurses following open heart surgery. *International Journal of Nursing Practice* 16 (3), 289–294.
- Pelucchi, C., Gallus, S., Garavello, W., Bosetti, C., La Vecchia, C., 2008. Alcohol and tobacco use, and cancer risk for upper aerodigestive tract and liver. *European Journal of Cancer Prevention* 17 (4), 340–344.
- Polit, D.F., Beck, C.T., 2008. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Lippincott Williams & Wilkins, Philadelphia.
- Pollock, K., Cox, K., Howard, P., Wilson, E., Moghaddam, N., 2008. Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. *Supportive Care in Cancer* 16 (8), 963–973.
- Prior, M., Guerin, M., Grimmer-Somers, K., 2008. The effectiveness of clinical guideline implementation strategies: a synthesis of systematic review findings. *Journal of Evaluation in Clinical Practice* 14 (5), 888–897.
- Roberts, K.J., Lepore, S.J., Urken, M.L., 2008. Quality of life after thyroid cancer: an assessment of patient needs and preferences for information and support. *Journal of Cancer Education* 23 (3), 186–191.
- Ronis, D.L., Duffy, S.A., Fowler, K.E., Khan, M.J., Terrell, J.E., 2008. Changes in quality of life over 1 year in patients with head and neck cancer. *Archives of Otolaryngology–Head & Neck Surgery* 134 (3), 241–248.
- Semple, C., 2001. The Role of the CNS in Head and Neck Oncology. In: *Nursing Standard*, vol. 15(23). Royal College of Nursing (Great Britain): 1987, pp. 39–42.
- Semple, C.J., Dunwoody, L., Kernohan, W.G., 2008. Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. *Journal of Advanced Nursing* 63 (1), 85–93.
- Shadish, W.R., Cook, T.D., Campbell, D.T., 2002. *Experimental and Quasi-Experimental Designs for Generalized Causal Inference*. Houghton Mifflin Company, Boston New York.
- Smith, J., Forster, A., Young, J., 2009. Cochrane review: information provision for stroke patients and their caregivers. *Clinical Rehabilitation* 23 (3), 195–206.
- Trzcieniecka-Green, A., Bargiel-Matusiewicz, K., Borczyk, J., 2007. Quality of life of patients after laryngectomy. *Journal of Physiology and Pharmacology: an Official Journal of the Polish Physiological Society* 58 (Suppl 5(Pt 2)), 699–704.
- Waterman, H., Leatherbarrow, B., Slater, R., Waterman, C., 1999. Post-operative pain, nausea and vomiting: qualitative perspectives from telephone interviews. *Journal of Advanced Nursing* 29 (3), 690–696.
- Whale, Z., 1998. Head and neck cancer: an overview of literature. *European Journal of Oncology Nursing* 2 (2), 99–105.
- Zeka, A., Gore, R., Kriebel, D., 2003. Effects of alcohol and tobacco on aerodigestive cancer risks: a meta-regression analysis. *Cancer Causes & Control* 14 (9), 897–906.
- Ziegler, L., Newell, R., Stafford, N., Lewin, R., 2004. A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making. *European Journal of Cancer Care* 13 (2), 119–126.