Nurse-led follow-up care
for
head and neck cancer patients

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PART I

INTRODUCTION

Chapter 1

Introduction

Cancer is a disease associated with aggressive treatments and debilitating side effects, severe physical problems and a multitude of uncertainties to face. The help of many health professionals is needed to guide patients and their families through the cancer trajectory.

For patients afflicted by head and neck cancer (HNC), the effects of their disease and medical treatment often need a high level of input from nurses; from 24-hour nursing care in hospital, to outpatient and community nursing support.[1-3] Patients often feel traumatized, both physically and psychologically, and are struggling to understand what is happening to them and how to cope. The nursing care for people with head and neck cancer concerns the management of the actual and potential responses of patients to their cancer and its treatment, and of the rehabilitation of patients back into daily life. Nowadays, cancer follow-up care is regarded as an important phase in the treatment trajectory. It is acknowledged that experienced nursing care and coordination is vital to the support of patients.[4]

This thesis addresses the role and the effects of nurse-led follow-up care for head and neck cancer patients in the first year after initial treatment has ended. By exploring and investigating this topic we aim to further enhance the knowledge-base for nurse-led cancer care and in particular for the follow-up care for head and neck cancer patients. The research findings in this thesis are intended to provide evidence-based information that can be applied in the clinical setting to enhance support and care for people with head and neck cancer.

Defining nursing

The topics in this thesis are reflected upon from a nursing perspective, and although almost everybody receives nursing care at some point in their lifetime, it is still difficult to describe and is sometimes poorly understood. Subsequently, it is not always clear what nursing could or should add to patient care. Because of this, opportunities to improve patient care are not always used to the full potential. Nurses and patients know that skilled nursing makes a difference. However, it is difficult to put into words exactly which difference, to which outcome, or how it was done. Ironically enough, the more skilful nurses are in what they do, the less likely the observer, or even the patient, will be to recognize exactly what has been done.[5]

Definitions of nursing, like nursing itself, are dynamic; nursing is constantly evolving to meet new needs and to take account of new knowledge. Defining nursing can help to put the key concepts into words, but it cannot alone accomplish what only organizational and political processes can achieve.[5] For example, it cannot determine the relationship between nurses and patients, nurses and other health professionals, or between nursing and the agencies that determine how health care is to be delivered. Nevertheless, to help interpreting the findings of this thesis in perspective we add a definition of nursing as formulated by several national nursing associations, including that of our own country, and which is also used and approved by the International Council of Nurses and the World Health Organisation.[6-10]

> *Nursing is, the use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.*

The unique contribution of nursing and other health care disciplines lies in the particular and distinctive combination of its elements and its perspective and orientation. Each discipline shares some knowledge and skills with other disciplines, and to distinguish between nursing and other disciplines one must look at the defining characteristics.

For nursing, the key characteristics have been described as follows.[8, 9]

1. A particular purpose: the purpose of nursing is to promote health, healing, growth and development, and to prevent disease, illness, injury, and disability by minimising distress and suffering, and by enabling people to understand and cope with their disease or disability, its treatment and its consequences to maintain the best possible quality of life.

2. A particular mode of intervention: nursing interventions are concerned with empowering people, and helping them to achieve, maintain or recover independence. Nursing is a process which includes the identification of nursing needs; therapeutic interventions and personal care; information, education, advice and advocacy; and physical, emotional and spiritual support.

3. A particular domain: the specific domain of nursing is people's unique responses to and experience of health, illness, frailty, disability and health-related life events in whatever environment or circumstances they find themselves.

4. A particular focus: the focus of nursing is the whole person and the human response rather than a particular aspect of the person or a particular pathological condition.

5. A particular value base: nursing is based on ethical values which respect the dignity, autonomy and uniqueness of human beings, the privileged nurse-patient relationship, and the acceptance of personal accountability for decisions and actions.

6. A commitment to partnership: nurses work in partnership with patients, their relatives and other carers, and in collaboration with others as members of a multi-disciplinary team, and where appropriate will take the lead.

The words above provide a bird's eye view of the profession of nursing and nursing care. It can be concluded that the therapeutic role of nurses is wide-ranging, encompassing many different roles including physical and technical care, advocacy, information-giving and health education, as well as complex psychological and emotional support. These skills are often needed by nurses working in head and neck oncology. The framework for the nursing of these patients must be based on a sensitive helping-trust relationship in a caring environment that allows addressing patients' changed body function and image, their changed social roles and their perspectives on health and health care, to give effective help whilst allowing the patient to choose the best action for himself at a given point in time.[11,12]

Head and neck cancer

This thesis has patients with cancers of the head and neck area as a target group. These cancers represent the sixth most common cancer worldwide.[13] In the Netherlands, there are approximately 2850 new patients each year, being 4% of all new cancer patients. According to the International Classification of Diseases, head and neck cancers occur at the following sites: lip, tongue, floor of the mouth, gum,

other oral cavity sites, salivary glands, oropharynx, nasopharynx, hypopharynx, larynx, nose and sinuses, ear and thyroid.[14]
The cells most commonly involved in head and neck cancer (HNC) are squamous epithelial cells that line the upper respiratory and gastrointestinal tract. The tumours arising from the epithelium are thus called squamous cell carcinomas.[15]

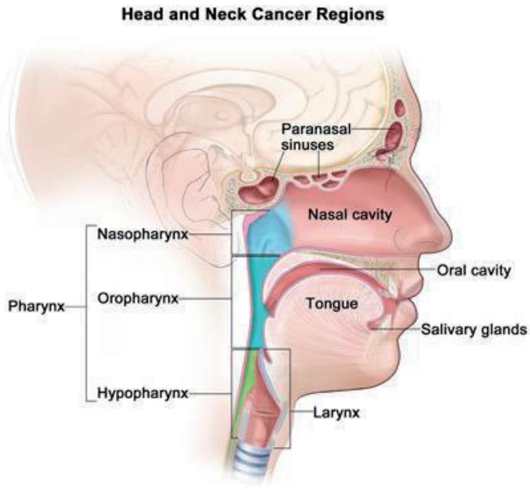

Figure 1. Head and Neck Cancer Regions

The symptoms of HNC are similar to symptoms experienced from minor disorders such as a blocked nose, sore throat, hoarse voice, earache, mouth ulcers, and swollen lymph glands. They are commonly interpreted as minor infections and treated with homemade remedies or remedies from the pharmacist. It is obvious that cancer diagnosis might be missed in the early stages of disease. Recently, referral delay has been reported for having the highest influence on mortality-rates, compared with diagnostic delay (either patient or professional delay).[16]

In the Netherlands the oral cavity and pharynx are the most common HNC sites, followed by the larynx.[17] Men are almost twice as often afflicted as women. Alcohol consumption and smoking are the strongest related etiologic factors, and in oropharyngeal cancer human papilloma virus (HPV) infection seems to play an important role.[18]

Trends show that the incidence of HNC is increasing in women explained by increased rates of alcohol consumption and smoking behaviour in the past.[19] In contrast, incidence rates in men are slightly decreasing explained by the emphasis on healthier lifestyle. Although there are several clear risk factors for HNC, it must be stated that there are also notable exceptions to the rule. Some individuals who have never abused tobacco and alcohol will unfortunately present with HNC. Nevertheless, it is a fact that the incidence of HNC increases with about 3% to 4% every year.[20] Prognosis in HNC depends very much on tumour site and size, as well as the nodal status.[21] The 5-year survival for all stages and sites of HNC in the Netherlands is about 50%. This varies from 35% for pharyngeal cancer to 60% and 70% for oral cavity and laryngeal cancer, respectively.[20] Nowadays, primary treatment for HNC aims at organ preservation. Thus, radiotherapy and chemotherapy increasingly became a part of the treatment, although surgery remains important especially in case of oral cancer. Also, laser surgery is increasingly being used either as a primary treatment modality or for palliative management.[22]

Quality of Life

Over the past decades, evaluation of quality of life (QoL) has become increasingly important in health care. The concept ‘quality of life’ has been defined in several ways, but generally, it is understood as a multidimensional construct that includes the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. In the context of cancer care, quality of life has been described as the gap that exists between one’s actual status and one’s ideal standard or otherwise as a person’s perception of his/her ability to function in meaningful areas of living after illness as compared to before illness.[23,24] This broad ranging concept is affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and environmental aspects. (WHOQOL Group 1993) As a consequence of using this broad approach, it is difficult to compare findings across studies, to draw conclusions or to make applications for clinical practice.

Therefore, starting in the early 1990's, the term 'health-related quality of life' (HRQoL) was introduced to narrow the focus to the effects of health, illness and treatment on quality of life, and not merely the absence of disease or infirmity.[25-27] It was anticipated that in this way HRQoL could be used as an additional outcome indicator of treatment.

The causal model for HRQoL from Wilson and Cleary (1995), revised by Ferrans et al. (2005), describes the conceptual distinct variables that may contribute to QoL and how they relate to one another.[25,27] The five boxes in the centre of the model are five types of measures of patient outcomes. As you move from left to right, you move from the cellular level to the individual level to the societal level. The arrows indicate the dominant causal associations.

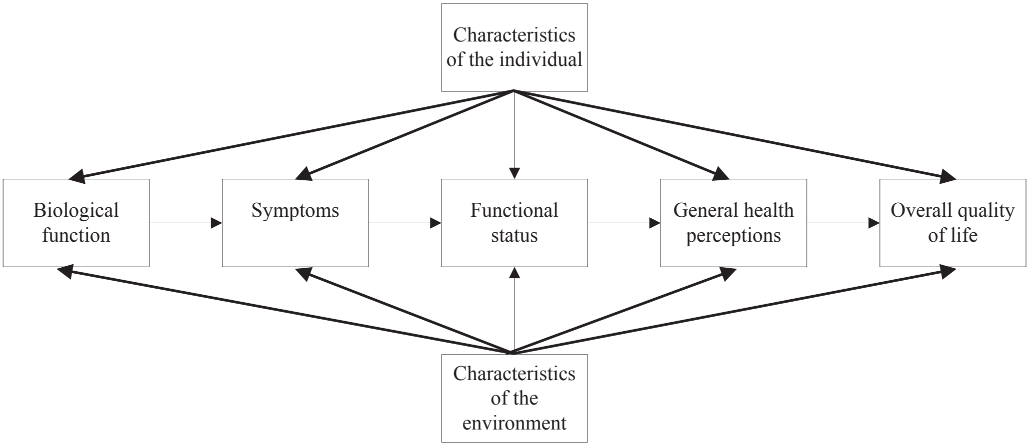

Figure 2. Revised Wilson and Cleary Model for Health Related Quality of Life

Quality of life after head and neck cancer

Any treatment for head and neck cancer has a temporary or long-lasting effect on the quality of life of patients. Impact is observed in physical, social and psychological problems and changed lifestyles.[3] Depending on the type of treatment, many patients experience problems such as oedema of the head and neck area, sores in the mouth, skin problems, xerostomia, thickened saliva, chewing and swallowing problems, trismus, changes in taste and/or smell, pain, poorly intelligible speech, and drooling.[28-30] As a consequence of these physical impairments, patients can experience depression, social anxiety, reduced self-esteem, sexual difficulties or a generalized sense of reduced quality of life.[31-33] What matters to patients are not only medical outcomes, but also social, economic and cultural consequences of illness and/or treatment.

Since the 1990's, reliable and valid HRQoL questionnaires have been developed and tested in HNC patients, and they offer clinicians a comprehensive assessment of the true outcomes of their interventions.[34] These days, a body of evidence on the change in quality of life (QoL) after HNC exists.[34] Outcomes from studies with HNC patients report a general trend with deterioration of HRQoL in the first 3 months after start of treatment followed by a gradual recovery over the following 12 to 18 months. Patients with advanced stage of disease or with recurrence or metastatic disease within a year after initial treatment report lower QoL compared to longitudinal data of disease free survivors.[35,36] Also, HRQoL outcomes at 1 to 2 years seem to reflect those at 5 year, and the general physical dimensions and consequent role functioning seem to be most affected.[37-39]

It is agreed upon that, the extent to which a patient can return to pre-illness functioning and wellbeing must be discussed by clinicians when explaining treatment to a patient.[40] Therefore, regular assessment of patients' health related quality of life (HRQoL) has become an important supplement for HNC care providers to information about local control and survival in the evaluation of treatment and (supportive) care. By regularly monitoring the quality of life of HNC patients during follow-up, accurate information is collected that should guide tailored care or intervention.

Psychosocial adjustment

Nowadays, the concept of psychosocial adjustment is considered to be a topic of central importance to the lived experience of people with cancer. The concept has been proven of value in other medical disciplines as advances in technology and treatment have resulted in a large number of patients with chronic conditions, including cancer.[41,42] Psychosocial adjustment refers to the psychological processes that occur over time as the individual and those in his social world, manage, learn from and adapt to the multitude of changes caused by the illness and its treatment. Thus, it is not just the absence of psychopathology or the end-point of coping with the global threat of cancer.[42,43] Therefore, psychosocial adjustment can be viewed as the adaptive psychosocial response of an individual to a significant life event or change.[43] Within the context of cancer as a chronic condition, it is suggested that regular psychosocial assessment could add to the quality of support for cancer patients and their families.[44] Cancer health professionals could help patients to normalize experiences that may otherwise feel overwhelming and abnormal to them, by understanding the processes involved in psychosocial adjustment and by applying communication skills that provide space for patients to talk about their experiences.[45,46]

ONGOING CARE AFTER CANCER TREATMENT

Cancer follow-up

Increasingly, cancer is viewed as a chronic condition implying complex care and a growing demand for patient-centred quality of care across the entire cancer trajectory.[47] The follow-up phase then is becoming an important step in making the transition from cancer patient to cancer survivor.[48] According to the World Health Organisation, the main goal of follow-up is to detect changes in health.[49] The ability to detect cancer recurrence and late effects is usually of great concern to patients and providers alike.[50,51] Other goals of follow-up are, prevention or early detection of other types of cancer, addressing ongoing problems due to cancer or its treatment, and checking for physical and psychosocial effects that may develop months to years after treatment has ended.

Generally, conventional cancer follow-up involves regular and frequent medical check-ups that include a review of a patient's medical history and a physical exam. Follow-up care may also include imaging procedures, blood tests or other lab checks. In general follow-up appointments are planned every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that. The total duration of follow-up can vary from about 5 years to life-long depending on type of cancer, professional guidelines or customs, patient preference.[49] See Table 1 for the guideline proposed follow-up schedule for HNC patients in the Netherlands.

Table 1. Current follow-up schedule for HNC patients in the Netherlands

	Follow-up years				
	1st	2nd	3rd	4th	5th
interval between follow-up visits (months)	2-3	3	4-6	6	6

As the number of new cancer patients together with survival rates are increasing, cancer follow-up is a much discussed topic worldwide, and of interest to health professionals as well as policy makers and health insurance companies.[13,52] The growing cancer survivor population necessitates a professional reflection on the benefits and the effectiveness of routine control schedules of many years.[47] Nowadays, conventional medically oriented follow-up schedules are questioned as regular 'screening' of treated asymptomatic cancer patients is increasingly viewed as less effective. The goals of detecting cancer recurrence in these patients are often not achieved.[47] Besides, methods used for detection of recurrent cancer may be very costly, and in the case of HNC patients medical routine screening of patients during follow-up does not add to better survival rates after treatment for disease recurrence.[53-59] Furthermore, the conventional follow-up focus on detection of cancer recurrence is viewed as suboptimal care as it does not adequately address the psychosocial needs of patients (and their families) that are of influence to their experienced quality of life.[47,48] These discussion points regarding cancer follow-up care have been acknowledged by health professionals worldwide. In an attempt to improve the quality of cancer follow-up care and to address psychosocial needs of cancer patients alternative models of follow-up care have been developed.

Nurse-led follow-up services are regularly proposed as one mean to help address the existing and future challenges in cancer follow-up. After all, nursing care is primarily directed towards helping individuals regain health, at a time when they need help doing so. Simultaneously, opportunities to develop nurse-led care have increased as role boundaries between health professionals have become more blurred, offering possibilities for joint quality improvement initiatives.[60,61]

The patients' view on cancer follow-up

In general, cancer patients describe the main purpose of cancer follow-up appointments as providing reassurance, particularly on recovery and the absence of symptoms.[47,51] HNC patients articulate specific needs in follow-up care that include speech and swallowing rehabilitation, nutritional and oral care support, physiotherapy, pain control and psychosocial help.[50] A recent exploration of the UK HNC patients' perspective on their follow-up regime showed that most patients prefer an intensive follow-up for the first year, followed by visits with a larger interval in the next two years and finally being seen according to symptoms thereafter.[62] In case of problems all cancer patients want rapid access to specialist medical care, that is, a medical specialist or a clinical nurse specialist.[51] Written information is defined as a priority, particularly, guidelines and a clear, personalised care plan, information about symptoms to look out for, how to handle them and when to contact a health professional.

Patients assume that follow-up consultations take place according to the principles of patient centeredness, and they expect health professionals to communicate in a way showing empathy and awareness of the impact of physical and psychological consequences of cancer treatment, both, for themselves as well as for their family or carers.[50,51] The possibilities of patient managed follow-up are generally viewed in a positive way especially for those patients living with the long-term side effects of treatment. The condition needed to realise this, is that patients have detailed accurate information about signs and symptoms to be aware of and rapid access to expert specialist advice if needed. In summary, patients expect services to be patient centred and systematic, specialist and holistic.[50] Essential components of high-quality follow-up care include a coordinated, multidisciplinary, and thorough approach with individualised care.[51,62]

Health care communication

It is well recognized that skilled communication is a key element of good quality care.[63, 64] On the other hand, one of the major health care complaints of patients and families concern lack of time from health providers to communicate and explain matters in a way they can understand and decide upon.[65-67] Generally, the two important functions of health care communication are to provide information and to respond to emotions.[68, 69] However, patients regularly just give verbal and non-verbal cues that signify thoughts, concerns, and feelings instead of explicitly expressing them.[70] In delivering patient-centred care, it is relevant for health care providers to address patients' cues adequately to encourage the patient to reveal beliefs about his illness and treatment, which can facilitate an effective care plan and improve the therapeutic relationship.[63] Research evidence suggests that adequate cue-responding enhances patient-centeredness of conversation and could shorten consultation length because there is a decreased need for patients to repeatedly restate their concerns.[65, 71] The HNC population adds an extra dimension to provider-patient communication skills as many patients experience prolonged and/or permanent impairment of their communication abilities for example following a laryngectomy, partial glossectomy, and radiation treatment. Therefore, the relevancy of excellent communication skills for HNC health professionals seems obvious, and has been described in the literature over the years.[72-76]

Nurse-led cancer follow-up care

With respect to the ideal cancer survivorship care discussions are ongoing as to who has to provide and coordinate follow-up care: medical specialists, primary care physicians, specialized nurses? It seems clear that we have to develop new approaches or adjust the old ones to be able to address cancer patients' and families' needs in the best possible way.[77-81]

Nurse-led cancer follow-up care generally addresses symptom assessment and management, health education and life style advice, psychosocial support, care coordination, and case management.[61, 82] During the last decade, research on nurse-led follow-up care has increased and the literature suggests a positive impact on cancer patient outcomes, mainly in the period of the first year post treatment.[60, 83-89]

However, as this still is a relatively young area of investigation there is a need for more and methodologically sound research to provide evidence on outcomes in terms of survival, patient wellbeing, and cost-effectiveness as well as on effects of nursing coordination of care and case management.[82, 90, 91]

The added value of nurse-led follow-up care is reported with respect to fewer physical problems due to better post treatment information and advice in breast cancer patients [87], high patient satisfaction and more concerns raised in telephone follow-up in colorectal cancer patients [92], less severe dyspnoea and peripheral neuropathy, better emotional functioning, and decrease of routine medical investigations in lung cancer patients.[86] Studies comparing nurse-led follow-up with physician-led follow-up also report positive outcomes regarding no differences in detecting cancer recurrence or metastatic disease in colorectal cancer patients [93], no adverse effects on health related quality of life and satisfaction with care in oesophageal cancer patients [94], and medical safety and patient satisfaction in breast cancer patients.[95] However, a systematic review of 2008 reports that there still is limited evidence to support the impact of breast cancer nurses' interventions on recognition and management of psychological distress on aspects of quality of life of breast cancer patients.[96]

With respect to nurse-led (follow-up) care for HNC patients only a small number of studies are available.[97-101] Several of these studies report beneficial effects of the tested intervention, for example on increased smoking cessation of HNC patients during treatment [100], the experienced significance of a nurse-led clinic for patients undergoing radiotherapy, with a focus on eating problems, symptom control and social and emotional support before, during and up to one year post treatment [98], a more effective management of oral and nutritional problems and more referrals to other health professionals in a comparison between nurse-led and physician-led on-treatment review for radiated patients.[101] This last study shows that specialized nurses working within the context of a supportive multidisciplinary team could manage the majority of consultations without direct medical input, even in this highly symptomatic and complex patient group. The studies from Larsson (2007) and Wells (2008) show that this form of supportive nursing care was well accepted and valued by patients, but especially before and after completion of treatment when there were no regular contacts scheduled with the health care system.

In the Radboud University Medical Centre continuous improvement of the quality of cancer care has a high priority status. More and more, patient experiences and preferences are taken into account when developing new care programs and models. Here, we refer briefly to the initiatives of e-consulting and online communities for people involved with cancer, patients and families as well as health professionals.[102-106]

Aim of the thesis

The overall aim of the thesis is to improve supportive follow-up care for head and neck cancer patients. The studies in this thesis focus on the content, form and the evaluation of care provided by specialized oncology nurses. To achieve this purpose, we answered several research questions.

Research questions

Exploration of the early post treatment phase of HNC patients treated with curative intent:

a) How do HNC patients take up health advice and instructions received during the treatment phase, and what are the influencing factors in this process?
b) What are health related quality of life outcomes, and subsequent supportive follow-up care needs one month post treatment, in advanced staged radiated HNC patients treated with curative intent?

The evaluation of an intervention:

a) What is the effect of nursing follow-up consultations added to conventional medical follow-up with regard to psychosocial adjustment and health related quality of life of patients?
b) What are the communication behaviours of nurses used in follow-up consultations to respond to patients' and partners' cues and questions?

Outline of the thesis

Chapter 2 describes a qualitative study on factors influencing the adoption of health advice or instruction by patients. To determine the content and form of a future nurse-led follow-up intervention, we had to gain insight into the patients' situation immediately after the ending of initial treatment. Therefore, patient interviews were chosen as a suitable method to start our investigation, and to learn about the patients' perspective and experiences on this theme. We interviewed twenty-one head and neck cancer (HNC) patients in a predominantly structured way using a topic list deriving from the literature, interviews with nurses and physicians, and observations of patient consultations. A thematic content analysis procedure was used to detect the relevant categories and subthemes. In this way influencing factors were analysed and categorized.

Chapter 3 concerns an analysis of HRQoL data one month post treatment in a sample of 52 radiated HNC patients with locally advanced cancer. The treatment groups studied are surgery followed by radiotherapy (n=10), conventional radiotherapy (n=21), and chemoradiation (n=21). In this study we look for differences in HRQoL scores regarding these treatment modalities, to decide on the intensity and content of supportive care needs during the first few months post-treatment, and to detect if we could further optimize the existing care. Although an extensive literature base exists on HRQoL in HNC patients from 6 months post-treatment and further, relatively little is reported on the early phase post-treatment.

Chapter 4 reports on the results of a quasi-experimental prospective trial to evaluate an intervention consisting of structured nursing follow-up consultations for HNC patients in the first year post treatment. The nursing consultations aim to provide supportive care, adequate referral and standardized assessment of actual problems and concerns. A historical control group (n=80) receiving conventional medically oriented follow-up care (without nursing consultations) is compared with the intervention group (n=80) on the primary outcomes of psychosocial adjustment and HRQoL. Besides assessing patient outcomes, data on aspects of implementation and process evaluation are collected. By using instruments such as a concerns checklist and a psychosocial distress screening instrument we aim to detect patients at risk for psychosocial maladjustment and/or severely impaired daily functioning. When this is the case, nurses are expected to adequately refer patients to other health providers and/or to advice and support them to try and prevent further worsening of problems or concerns.

Chapters 5 and 6 both address nurse-patient communication. Chapter 5 describes nurse-patient interactions, focusing on nurses' cue-responding behaviour in encounters with actors playing the role of cancer patients. The study aims at investigating nurses' cue-responding behaviours and the subsequent disclosure of concerns of patients, and the relations between those two. Video recordings of 35 interviews are coded using the Medical Interview Aural Rating Scale (MIARS). Inter-rater reliability between two coders is established, analysed, and reported in detail. The study in Chapter 6 also describes analyses of video recordings, this time of 17 real-life nursing follow-up consultations with HNC patients and their partners if present. Again, cue-responding behaviour of nurses is studied, defined and analysed in terms of adequate or inadequate communication. Nurse-patient and nurse-partner communication is analysed separately to detect for differences in nurses' responding behaviours to both. The presence of a partner (or companion) present during consultation adds another dimension to the nurse-patient communication, and is, therefore, worthwhile to investigate. The Medical Interview Aural Rating Scale is also used for coding in this study, and is integrated in the software of Observer XT 9.0, which has been developed for behavioural analyses.

Chapters 7 and 8 are the components of the discussion part of this thesis. In Chapter 7 the results of the studies are summarized followed by considerations on the main methodological issues in our studies. Chapter 8 is written as a separate paper and provides the highlights of the actual state-of-the-art for nurse-led cancer follow-up care in general, and HNC in particular. It also contains the recommendations for future research, practice and education.

References

1. Sigler BA. Nursing care of the head and neck cancer patient. Oncology 1988;2:49-53, 56, 59.
2. Penner JL. Psychosocial care of patients with head and neck cancer. Semin Oncol Nurs 2009;25:231-241.
3. Semple CJ, Dunwoody L, George Kernohan W, McCaughan E, Sullivan K. Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. J Adv Nurs 2008;63:85-93.
4. Department of Health. The Nursing Contribution to Cancer Care. London: Department of Health UK; 2000.
5. Clark J. The unique function of the nurse. Int Nurs Rev 1997;44:144-152.
6. International Council of Nurses. Position Statement. Geneva: ICN, 2003.
7. World Health Organisation. Mission and function of the nurses. Nursing in action project. Health for All Nursing Series No 2. Copenhagen: WHO, 1991.
8. V&VN (Verpleegkundigen & Verzorgenden Nederland). Beroepsprofiel Verpleegkundige. Utrecht: V&VN, 2012.
9. Royal College of Nursing. Defining Nursing. London: RCN, 2003.
10. American Nurses Association. Nursing Scope and Standards of Practice. Washington D.C. American Nurses Association, 2010.
11. Eriksson K. Caring science in a new key. Nurs Sci Quart 2002;15:61-65.
12. Austgard KI. What characterises nursing care? A hermeneutical philosophical inquiry. Scand J Caring Sci 2008;22:314-319.
13. American Cancer Society. Global Cancer Facts & Figures 2nd Edition. Atlanta: American Cancer Society, 2011.
14. World Health Organization. International Statistical Classification of Diseases and Related Health Problems (ICD-10). WHO, 2010.
15. Shah JP. Cancer of the Head and Neck. Ontario, Canada: American Cancer Society, 2001.
16. Seoane J, Takkouche B, Varela-Centelles P, Tomas I, Seoane-Romero JM. Impact of delay in diagnosis on survival to head and neck carcinomas: a systematic review with meta-analysis. Clin Otolaryngol 2012;37:99-106.
17. Dutch Cancer Registration. Figures on cancer in the Netherlands.. Available at: http://www.cijfersoverkanker.nl. Accessed May 23, 2012.
18. van Monsjou HS, Balm AJ, van den Brekel MM, Wreesmann VB. Oropharyngeal squamous cell carcinoma: a unique disease on the rise? Oral Oncol 2010;46:780-785.
19. Freedman ND, Abnet CC, Leitzmann MF, Hollenbeck AR, Schatzkin A. Prospective investigation of the cigarette smoking-head and neck cancer association by sex. Cancer 2007;110:1593-1601.
20. Dutch Cancer Registration. Available at: http://www.iknl.nl. Accessed May 29, 2012.
21. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. CA Cancer J Clin 2011;61:69-90.
22. Oncoline. Dutch Guidelines Head and Neck Cancer. Available at: http://www.oncoline.nl. Accessed May 29, 2012.
23. Calman KC. Quality of life in cancer patients-an hypothesis. J Med Ethics 1984;10:124-127.

24. Dolbeault S, Szporn A, Holland JC. Psycho-oncology: where have we been? Where are we going? Eur J Cancer 1999;35:1554-1558.
25. Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL. Conceptual model of health-related quality of life. J Nurs Scholarsh 2005;37(4):336-342.
26. Plummer M, Molzahn AE. Quality of life in contemporary nursing theory: a concept analysis. Nursing Science Quarterly 2009;22(2):134-140.
27. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995;273:59-65.
28. Rogers SN, Scott J, Chakrabati A, Lowe D. The patients' account of outcome following primary surgery for oral and oropharyngeal cancer using a 'quality of life' questionnaire. Eur J Cancer Care 2008;17:182-188.
29. Feber T. Head and Neck Oncology Nursing. First edition. London: Whurr Publishers Ltd, 2004.
30. Speksnijder CM, van der Bilt A, Abbink JH, Merkx MA, Koole R. Mastication in patients treated for malignancies in tongue and/or floor of mouth: A 1-year prospective study. Head Neck 2011;33:1013-1020.
31. Duffy SA, Ronis DL, Valenstein M, et al. Depressive symptoms, smoking, drinking, and quality of life among head and neck cancer patients. Psychosomatics 2007;48:142-148.
32. Ronis DL, Duffy SA, Fowler KE, Khan MJ, Terrell JE. Changes in quality of life over 1 year in patients with head and neck cancer. Arch Otolaryngol Head Neck Surg 2008;134:241-248.
33. van den Berg MG, Rasmussen-Conrad EL, van Nispen L, van Binsbergen JJ, Merkx MA. A prospective study on malnutrition and quality of life in patients with head and neck cancer. Oral Oncol 2008;44:830-837.
34. Rogers SN, Ahad SA, Murphy AP. A structured review and theme analysis of papers published on 'quality of life' in head and neck cancer: 2000-2005. Oral Oncol 2007;43:843-868.
35. Hammerlid E, Bjordal K, Ahlner-Elmqvist M, et al. A prospective study of quality of life in head and neck cancer patients. Part I: at diagnosis. Laryngoscope 2001;111:669-680.
36. Bjordal K, Ahlner-Elmqvist M, Hammerlid E, et al. A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. Laryngoscope 2001;111:1440-1452.
37. Rogers SN, Hannah L, Lowe D, Magennis P. Quality of life 5-10 years after primary surgery for oral and oro-pharyngeal cancer. J Craniomaxillofac Surg 1999;27:187-191.
38. Abendstein H, Nordgren M, Boysen M, et al. Quality of life and head and neck cancer: a 5 year prospective study. Laryngoscope 2005;115:2183-2192.
39. Rutten H, Pop LA, Janssens GO, et al. Long-term outcome and morbidity after treatment with accelerated radiotherapy and weekly cisplatin for locally advanced head-and-neck cancer: results of a multidisciplinary late morbidity clinic. Int J Radiat Oncol Biol Phys 2011;81:923-929.
40. Terrell JE, Nanavati KA, Esclamado RM, Bishop JK, Bradford CR, Wolf GT. Head and neck cancer-specific quality of life: instrument validation. Arch Otolaryngol Head Neck Surg 1997;123:1125-1132.
41. Weissman MM, Sholomskas D, John K. The assessment of social adjustment. An update. Arch Gen Psychiatry 1981;38:1250-1258.

42. Derogatis LR. The psychosocial adjustment to illness scale (PAIS). J Psychosom Res 1986;30:77-91.
43. Brennan J. Adjustment to cancer - coping or personal transition? Psycho-Oncol 2001;10:1-18.
44. VIKC. Richtlijn: Detecteren behoefte psychosociale zorg (National Guideline: Detection of the need for psychosocial care). VIKC (Dutch Cancer Center), 2010.
45. Osborn RL, Demoncada AC, Feuerstein M. Psychosocial interventions for depression, anxiety, and quality of life in cancer survivors: meta-analyses. Int J Psychiatry Med 2006;36:13-34.
46. Maguire P. Psychosocial interventions to reduce affective disorders in cancer patients: research priorities. Psycho-Oncology 1995;4:113-119.
47. Gezondheidsraad (Dutch Health Council). Nacontrole in de oncologie (Follow-up in Oncology). 2007/10. Den Haag: Gezondheidsraad; 2007.
48. National Cancer Policy Board USA. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington: The National Academies Press; 2006.
49. World Health Organisation. Cancer follow-up. Available at: http://www.who.it. Accessed May 29, 2012.
50. The National Cancer Alliance. Head and Neck Cancers. Patient Views and Experiences. NCA Report No.3. Oxford, UK: 2002.
51. Sheldon H, Davis A, Parsons S. Cancer Follow Up Care. Picker Institute Europe. Oxford, UK: 2009.
52. Signaleringscommissie Kanker KWF Kankerbestrijding. Kanker in Nederland tot 2020. Trends en prognoses. KWF Kankerbestrijding. Amsterdam: 2011.
53. Boysen M, Lovdal O, Tausjo J, Winther F. The value of follow-up in patients treated for squamous cell carcinoma of the head and neck. Eur J Cancer 1992;28:426-430.
54. Snow GB. Follow-up in patients treated for head and neck cancer: how frequent, how thorough and for how long? Eur J Cancer 1992;28:315-316.
55. Cooney TR, Poulsen MG. Is routine follow-up useful after combined-modality therapy for advanced head and neck cancer? Archives of Otolaryngology -- Head and Neck Surgery 1999;125:379-382.
56. Haas I, Hauser U, Ganzer U. The dilemma of follow-up in head and neck cancer patients. Eur Arch Otorhinolaryngol 2001;258:177-183.
57. Ritoe SC, Krabbe PF, Kaanders JH, van den Hoogen FJ, Verbeek AL, Marres HA. Value of routine follow-up for patients cured of laryngeal carcinoma. Cancer 2004;101:1382-1389.
58. Merkx MA, van Gulick JJ, Marres HA, et al. Effectiveness of routine follow-up of patients treated for T1-2N0 oral squamous cell carcinomas of the floor of mouth and tongue. Head and Neck 2006;28:1-7.
59. Wensing BM, Merkx MAW, Krabbe PFM, Marres HAM, Van den Hoogen FJA. Oral squamous cell carcinoma and a clinically negative neck: The value of follow-up. Head & Neck 2011;33:1400-1405.
60. Corner J. The role of nurse-led care in cancer management. Lancet Oncol.2003;4:631-636.
61. Wiederholt PA, Connor NP, Hartig GK, Harari PM. Bridging gaps in multidisciplinary head and neck cancer care: nursing coordination and case management. Int J Radiat Oncol Biol Phys 2007;69:S88-91.
62. Trinidade A, Kothari P, Andreou Z, Hewitt RJ, O'Flynn P. Follow-up in head and neck cancer: patients' perspective. Int J Health Care Qual Assur 2012;25:145-149.

63. Bensing JM, Deveugele M, Moretti F, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. Patient Educ Couns 2011;84:287-293.
64. Epstein RM, Street RL. Patient-centered communication in cancer care: promoting, healing and reducing suffering. No. 07-6225. Bethesda, MD: NIH Publication, 2007.
65. Deveugele M, Derese A, van den Brink-Muinen A, Bensing J, De Maeseneer J. Consultation length in general practice: cross sectional study in six European countries. BMJ 2002;325:472.
66. Thorne SE, Hislop TG, Stajduhar K, Oglov V. Time-related communication skills from the cancer patient perspective. Psychooncology 2009;18:500-507.
67. Haywood K, Marshall S, Fitzpatrick R. Patient participation in the consultation process: a structured review of intervention strategies. Patient Educ Couns 2006;63:12-23.
68. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? J Clin Oncol 1999;17:371-379.
69. Schofield PE, Butow PN, Thompson JF, Tattersall MH, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. Ann Oncol 2003;14:48-56.
70. Zimmermann C, del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. Psychological Bulletin 2007;133:438-463.
71. Levinson W, Gorawara-Bhat R, Lamb J. A study of patient clues and physician responses in primary care and surgical settings. JAMA 2000;284:1021-1027.
72. Herzon FS, Boshier M. Head and neck cancer--emotional management. Head Neck Surg 1979;2:112-118.
73. Cote L. Psychosocial rehabilitation of the head and neck cancer patient. Laryngoscope 1978;88:93-94.
74. Nahum AM, Golden JS. Psychological Problems of Laryngectomy. JAMA 1963;186:1136-1138.
75. Rodriguez CS, Blischak DM. Communication needs of nonspeaking hospitalized postoperative patients with head and neck cancer. Appl Nurs Res 2010;23:110-115.
76. Roscoe LA, Tullis JA, Reich RR, Czaja McCaffrey J. Beyond Good Intentions and Patient Perceptions: Competing Definitions of Effective Communication in Head and Neck Cancer Care at the End of Life. Health Commun 2012;DOI 10.1080/10410236.2012.666957.
77. Grunfeld E. Cancer survivorship: a challenge for primary care physicians. Br J Gen Pract 2005;55:741-742.
78. Miedema B, MacDonald I, Tatemichi S. Cancer follow-up care. Patients' perspectives. Can Fam Physician 2003;49:890-895.
79. Forsythe LP, Alfano CM, Leach CR, Ganz PA, Stefanek ME, Rowland JH. Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. J Clin Oncol 2012;30:2897-2905.
80. Lotfi-Jam K, Schofield P, Jefford M. What constitutes ideal survivorship care? Cancer Forum 2009;33.
81. Signaleringscommissie Kanker van KWF Kankerbestrijding. Nazorg bij kanker: de rol van de eerste lijn. KWF Kankerbestrijding. Amsterdam: 2011.
82. Lewis R, Hendry M. A review comparing the effectiveness of nurse-led follow up for cancer with conventional care. Nurs Times 2009;105:25-27.

83. Campbell J, German L, Lane C, Dodwell D. Radiotherapy outpatient review: a nurse-led clinic. Clin Oncol 2000;12:104-107.
84. Faithfull S, Corner J, Meyer L, Huddart R, Dearnaley D. Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy. Br J Cancer 2001;85:1853-1864.
85. Brown L, Payne S, Royle G. Patient initiated follow up of breast cancer. Psychooncology 2002;11:346-355.
86. Moore S, Corner J, Haviland J, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. BMJ 2002;325:1145.
87. Beaver K, Twomey M, Witham G, Foy S, Luker KA. Meeting the information needs of women with breast cancer: Piloting a nurse-led intervention. Eur J Oncol Nurs 2006;10:378-390.
88. Howell DM, Sussman J, Wiernikowski J, et al. A mixed-method evaluation of nurse-led community-based supportive cancer care. Support Care Cancer 2008;16:1343-1352.
89. Beaver K, Williamson S, Chalmers K. Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. J Clin Nurs 2010;19:2916-2924.
90. Gilbert JE, Green E, Lankshear S, Hughes E, Burkoski V, Sawka C. Nurses as patient navigators in cancer diagnosis: review, consultation and model design. Eur J Cancer Care 2011;20:228-236.
91. Howell D, Hack TF, Oliver TK, et al. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. J Cancer Surviv 2012;6:359-371.
92. Beaver K, Campbell M, Williamson S, et al. An exploratory randomised controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. Colorectal Dis 2012;14:1201-1209.
93. McFarlane K, Dixon L, Wakeman CJ, Robertson GM, Eglinton TW, Frizelle FA. The process and outcomes of a nurse-led colorectal cancer follow-up clinic. Colorectal Disease 2012;14(5):e245-e249.
94. Verschuur EM, Steyerberg EW, Tilanus HW, et al. Nurse-led follow-up of patients after oesophageal or gastric cardia cancer surgery: a randomised trial. Br J Cancer 2009;100:70-76.
95. Koinberg IL, Fridlund B, Engholm GB, Holmberg L. Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study. Eur J Oncol Nurs 2004;8:109-117.
96. Cruickshank S, Kennedy C, Lockhart K, Dosser I, Dallas L. Specialist breast care nurses for supportive care of women with breast cancer. Cochrane Database Syst Rev 2008; issue 1.
97. Duffy SA, Ronis DL, Valenstein M, et al. A tailored smoking, alcohol, and depression intervention for head and neck cancer patients. Cancer Epidemiol Biomarkers Prev 2006;15:2203-2208.
98. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: conceptions of patients with head and neck cancer. Eur J Oncol Nurs 2007;11:49-59.
99. van der Meulen IC, de Leeuw JR, Gamel CJ, Hafsteinsdottir TB. Educational intervention for patients with head and neck cancer in the discharge phase. Eur J Oncol Nurs 2012. DOI 10.1016/j.ejon.2012.05.007.

100. Sharp L, Johansson H, Fagerstrom K, Rutqvist LE. Smoking cessation among patients with head and neck cancer: cancer as a 'teachable moment'. Eur J Cancer Care 2008;17:114-119.
101. Wells M, Donnan PT, Sharp L, Ackland C, Fletcher J, Dewar JA. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. J Clin Nurs 2008;17:1428-1439.
102. Weiss JB, Lorenzi NM. Building a shared vision for an online cancer survivorship community. AMIA Annu Symp Proc 2009;690-694.
103. Setoyama Y, Nakayama K, Yamazaki Y. Peer support from online community on the internet among patients with breast cancer in Japan. Stud Health Technol Inform 2009;146:886.
104. Head and Neck Cancer Alliance Support Community. Available at: http://www.inspire.com/groups/head-and-neck-cancer-alliance/. Accessed August 2012.
105. MacMillan Online Community for Head and Neck Cancer. Available at: http://community.macmillan.org.uk/cancer_types/head-neck-cancer. Accessed August 2012.
106. Centrum HoofdHalsOncologie Nijmegen. Online community Hoofd-Halskanker. Available at: https://www.mijnzorgnet.nl. Accessed August 2012.

PART II

THE STUDIES

Chapter 2

Discharge advice in cancer patients: post treatment patients' report

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Abstract

Background

Cancer patients are presented with advice and instructions during treatment and at discharge. Most recommendations aim at relief of physical problems, psychosocial well-being, and patients' health care behaviours. Patients often struggle to incorporate advice into daily life, and this influences symptom relief, quality of life and even longevity.

Objective

The aim of the study was to gain insight into the content and form of discharge advice to cancer patients and to determine the factors that hinder or promote the actual adoption of advice by patients.

Methods

Using a descriptive, exploratory research design, data were collected using structured interviews in a convenience sample of 21 head and neck cancer patients who had completed treatment with curative intent 2 to 6 months earlier. Descriptive statistics and a thematic content analysis procedure were used to analyse the data.

Results

Findings showed that advice or instructions received by individual patients had a range from 1 to 13, and that 17 out of 21 patients received 4 advices or more. Relevant influencing factors included patient characteristics (cognition, emotion, behaviour and social aspects) and characteristics of health professionals (content and efficacy of advice, professional attitude, behaviour and communication).

Conclusions and implications for practice

Cancer patients try but often struggle to fit the multitude and complexity of advice from health professionals into everyday life. There seems to be an excellent opportunity for health professionals to support cancer patients by further tailoring of follow-up care. Knowledge and insight into the challenges patients face post treatment will benefit both professionals and patients.

Introduction

After following cancer treatment, most patients face the challenge of coming to terms with several problems or concerns. Generally, these challenges include physical changes, work and day-to-day tasks, social functioning and interpersonal relationships, coping with feelings of anxiety, and fear of recurrence.[1-3] Toward the ending of initial treatment, that is, at discharge, patients can feel overwhelmed by the many dos and don'ts in the advice and instructions given to them by health professionals. The advice can contain short-term instructions, for example how to take care of a wound, and suggestions aiming at more long-term life style changes such as smoking cessation, dietary changes or coping with persistent fatigue. The recommendations given to patients by their health professionals during treatment and at discharge are too often misunderstood, carried out incorrectly, forgotten or even completely ignored.[4] Regularly, this has a negative impact on symptom relief, quality of life scores and even longevity.[5,6] Insight into the factors that influence the way in which patients adopt advice is of vital importance for health professionals. Patient agreement to recommendations, active patient participation in care, and the caregiver-patient relationship and communication itself, are viewed as the essential components of the advisory process.[7-9] In head and neck cancer (HNC) patients especially, the treatment and its aftermath can have a huge impact on the daily life of patients, and affects an area of the body central to a person's identity and fundamental functions such as speaking, breathing, eating and drinking.[10,11] Head and neck cancer patients have complex and often long-lasting physical and psychological needs because of the illness and the often multimodal and aggressive treatment.[12-14]

The purposes of the current study were to gain insight into the content and form of discharge advice and instructions given to HNC patients, and to determine the influencing factors on the actual adoption of advice or instructions by patients. Our ultimate goal was to use the results of the study to develop a nurse-led intervention to improve tailored follow-up care for these patients.

To develop this intervention we made use of the Medical Research Council Framework for the Development and Evaluation of Randomized Controlled Trials for Complex Interventions.[15,16] It provides an iterative view on development, evaluation, and implementation of complex interventions.

The first key element of this process, that is, our current study, is the development of an intervention based on the identification of the evidence base, identification or development of theory, and the modelling of the process and outcomes.

Methods

This study used an exploratory, descriptive approach encompassing 2 steps. First, a literature search was performed that focused on physical, psychological and social aspects and problems related to HNC and its treatment. Databases searched were: PubMed, Medline, CINAHL and PsychInfo. Key search terms used were *head and neck cancer, physical, psychosocial and psychological problems, radiotherapy, surgery, chemotherapy, informational needs, coping, adjustment*, and *quality of life*. This was followed by observation of health professionals during patient consultation. The aim of this first step was to develop an interview topic list to be used in step 2. Step 2 consisted of structured patient interviews. Permission to conduct the study was sought and obtained from the institutional review board of our hospital.

Participants

Eight health professionals participated in step 1. They were HNC-oncologists (n=2), HNC nurses (n=3), and radiotherapy nurses (n=3). In step 2, a total of 57 HNC patients, treated with curative intent in our hospital, were contacted after screening the medical files. All treatment modalities namely, surgery, radiotherapy, chemotherapy or a combination of these were included. Patients were eligible if they were 2 to 6 months posttreatment, and had routine follow-up visits at the outpatient clinic of our hospital and could read, understand and have a conversation in Dutch. Patients who had recurrence of cancer or were in the palliative phase of disease were excluded. All eligible patients received a patient information letter and were asked to return an informed consent form if they agreed to participate in the study. Thirty- one patients returned the form. The other patients (n=26) were phoned by the researcher (JdL) to find out why they had not responded. The reasons mentioned by patients or their partner/family were too ill (n=14), not willing to participate (n=10), going abroad (n=1), and deceased (n=1). During the time period of planning interview appointments, another 10 patients were excluded. The reasons were follow-up continued in another hospital (n=4), first possible moment for interview was after ending of data collection (n=4), deceased (n=1), and withdrawal from the study after giving consent (n=1). In the end, 21 patients (37%) were included and interview appointments were planned before or after routine follow-up visits at the outpatient clinic, so as not to burden patients with an extra visit to the hospital.

Setting

All participating patients were referred to the Radboud University Nijmegen Medical Centre for diagnosis and treatment of HNC. The hospital is a member of the Dutch Co-operative Head and Neck Group, a collaboration of 8 HNC centres in the Netherlands aiming for improvement of quality of care for HNC patients.[17] During the diagnostic phase, patients receive a 1-day screening at the Head and Neck Centre of the outpatient clinic of the University Medical Centre. The screening consists of several diagnostic tests, medical examinations and consultations. Outpatient oncology nurses function as case managers during that day. They have a mentoring and advisory role for patients and provide patients with oral and written information about tests and examinations. All patients also receive a personal information booklet containing relevant brochures and leaflets, and writing space for appointments, questions or notes. During the treatment phase, patients are guided by oncology nurses, for example at the radiotherapy outpatient clinic or at the clinical nursing wards.

After initial treatment, patients follow a routine control schedule for medical follow-up at the outpatient clinic for the next 5 years, in accordance with the Dutch national guidelines on HNC.[18-20] The follow-up includes a 1-time-only consultation with an oncology nurse approximately one month after ending initial treatment. Exceptions to this rule are patients treated for laryngeal cancer by means of a laryngectomy. They have regular 6- to 8- week consultations with an oncology nurse during the first year of follow-up. As such, nursing consultations, are not yet part of the aforementioned national guidelines, and are therefore unique to the setting.

ADVICE

The HNC patients referred to our hospital are confronted with advice from the first moment of contact at the diagnostic phase until the termination of the 5 years of follow-up. In the context of our present study, the term advice has been defined as all instructions and recommendations from health professionals aiming to relief or solve physical problems, to enhance psychosocial well-being by supporting coping strategies, and to influence patients' health care behaviours. The advice can cover both short- and long-term outcomes and results. When defining short-term as up to 8 weeks after treatment has ended (i.e., discharge) and long-term as from 8 weeks and further, almost all head and neck topics will contain components of both short-term instructions and long-term advice. For example, the topic of trachea stoma care contains a component of short-term instruction, namely, to learn the skills to take care of the stoma, and a long-term more advisory component regarding the psychosocial aspects of how to deal with having a trachea stoma in daily life, and in social relationships.

Data collection

During the first step of the research, with the purpose of compiling an interview topic list, a literature search was performed to get a general knowledge of problems, needs and quality of life aspects of HNC patients post-treatment. In addition, professional guidelines and protocols, patient information leaflets and brochures were studied. To complement findings from the literature search, participating health professionals were each observed during 2 occasions of individual patient consultation at the outpatient clinic in our hospital. The purpose of the observation was to see what sort of information, advice, and/or instruction was given to patients, and in what form this was provided to add to the topics derived from the literature. The second step consisted of structured interviews with HNC patients, using a topic list based on the information gathered in step 1. A draft version of the topic list was assessed and evaluated by 3 HNC nurses to make sure that essential items were included and subsequently discussed in a research group meeting. Patients involved in consultations observed in step 1 were excluded for participation in step 2.

Structured interviews

Patient interviews were conducted in a structured manner and lasted approximately 60 minutes. The topic list developed in step 1 (Table 2) was used and included 23 items. Seven questions were asked with each item.

a. Have you received any information on this topic during your treatment for head and neck cancer? (yes, no, don't know)
b. If yes, by whom? (physician, nurse, other caregiver namely..)
c. If yes, was this information given to you in written form, orally or in both ways?
d. If no, when you look back, would you have wanted information on this topic?

e. If yes, apart from the information, did you receive specific advice or instruction on this topic? (yes, no, don't know)
f. If yes, what was the content of the advice/instruction given? (open answer question)
g. If yes, were you capable of adopting the advice/instruction in daily life? What was and was not helpful to you, and which factors were of influence, do you think? (open answer question)

Questions a to c and e offered limited answering possibilities and were ticked off on the interview form. Participant answers on questions d, f and g were investigated in a semi-structured way using exploratory communication techniques. Participants were asked to reflect on and share their experiences, meanings and feelings regarding influencing factors. Specific patient statements regarding questions d, f and g, were written down verbatim on the interview form and were saved on the computer immediately afterward. All interviews were carried out by the researcher (JdL).

Analysis

Data on patient characteristics were analysed with descriptive statistics. Relevant influencing factors were derived from patients' answers to the open questions using a thematic content analysis procedure.[21] For each HNC topic, patient statements referring to positively or negatively influencing factors were grouped. Subsequently, this dichotomy was analysed searching for more differentiation. Statements with similar meaning were clustered and labels were assigned. The result then was discussed with both the research supervisor (TvA) and 1 co-author (JP) to clarify themes and to make sure that interpretation of the themes were in agreement. All influencing factors that were mentioned by more than 1 patient were reported. Factors mentioned only once were seen as potentially individual and excluded from the results.

Results

Participants' characteristics

The sample of HNC patients interviewed (n=21) was treated with curative intent and was 2 to 6 months posttreatment at the time of the interview. Stages of disease, when dichotomized, were distributed as follows: early stage (1 and 2), 52%;

advanced stage (3 and 4), 29%; and stage unknown (not reported in medical file), 19%. The main treatment modalities were surgery only and radiotherapy only. There were no major differences in male/female distribution in both the eligible group and final participant group (72%/28% vs. 76%/24%) or in mean age and age range (65, 37-90 vs. 59, 40-76 year). The demographic and clinical characteristics of participants are presented in Table 1.

Table 1. Participant Demographic and Clinical Characteristics

	No.	%
Male/female	16/5	76/24
Age, mean (range)	59 (40-76)	
Married or living with partner	15	71
Diagnosis/cancer site		
Larynx	5	24
Hypopharynx	2	9
Oropharynx	4	19
Oral cavity	10	48
Stage		
T1	7	33
T2	4	19
T3	5	24
T4	1	5
Unknown	4	19
Treatment		
Surgery only	9	43
Surgery/RT	3	14
RT only	7	33
RT/CT	2	10
Educational level		
Lower vocational education	4	19
Secondary vocational education	9	43
Higher education	5	24
University education	3	14

Abbreviations: RT, radiotherapy; CT, chemotherapy

Discharge advice: topics addressed, main source, form, and adoption of advice

In summary, participants reported a total of 136 individual forms of advice and/or instructions (mean, 6; range 1-13). Seventeen participants received 4 or more. Of 23 HNC topics, 5 were addressed in more than half of the participants. The nurse was the only and main source of advice on the topic of skin and wound care. Four topics were addressed by either the physician and/or nurse or by the nurse and/or another caregiver. Participants reported that most of the advice was given orally (n=19). Oral advice in combination with written materials was reported by 12 participants. No patients mentioned just receiving written advice. The advice on skin and wound care and on nourishment and mouth and dental care were followed best by patients. Approximately half of them reported they had been able to follow the advice on the topics of pain management and smoking cessation. The topics of intimacy/sexual functioning and the use of cosmetics for camouflage (e.g., of scars) were not addressed in advice in this sample. Details are shown in Table 2.

During the interview all participants were asked to state topics they had missed in advice. Eight patients mentioned lack of advice on 8 topics. Two topics were mentioned by more than one patient: ways to cope (n=4) and advice on dental implants (n=3). The range of topics mentioned was 1-2. Three of the topics were not listed in the interview topic list: dental implants, risk factors of cancer, and general lifestyle advice. Thirteen participants did not answer the question because they felt they did not lack any advice. Details are shown in Table 3.

Table 3. Topics Missed in Advice

Topic	In topic list	Times mentioned
Ways to cope	Yes (no. 15)	4
Dental implants	No	3
Smoking cessation	Yes (no. 5)	1
Dealing with fatigue	Yes (no. 9)	1
Risk factors cancer	No	1
How to tell my children	Yes (nos. 15 and 20)	1
General lifestyle advice	No	1
Speech therapy	Yes (no. 17)	1

Table 2. **Head and Neck Cancer-Topics Addressed, Main Source and Form of Advice, and Adopting Advice**

		Topics addressed		Main source of advice			Form of advice			
	Head and neck cancer topics	**Mostly (n = 11-21)**	**Occasionally / Never (n=0-10)**	**Physician**	**Nurse**	**Other ***	**Only written**	**Only orally**	**Written and orally**	**Taking up advice (n)**
1	Skin or wound care	17			17			15	2	17
2	Nutrition	17			10	7		8	9	13
3	Mouth and dental care	15			7	8		10	5	14
4	Pain management	12		8	4			9	3	5
5	Smoking cessation	11		6	5			10	1	6
6	Dry mouth/sticky saliva		9		9			6	3	6
7	Drinking alcohol		8	8				8		5
8	Chewing and swallowing		7		3	4		5	2	4
9	Fatigue		7	3	4			6	1	4
10	Going back to work / school		6	4	2			6		4
11	Change in taste/smell		5		4	1		1	4	4
12	Tube feeding		3		3			1	2	3
13	Eating out		3	1	1	1		3		1
14	Physical fitness / condition		3	2	1			3		1
15	Coping / anxiety		2		2			2		2
16	Participation social activities		2	1		1		2		1
17	Change of voice/hoarseness		1			1		1		1
18	Trachea stoma care		1		1				1	1
19	Clothing (trachea stoma)		1			1		1		
20	Psychological / spiritual care		1		1			1		1
21	Contact with other patients		1			1			1	1
22	Use of cosmetics									
23	Intimacy /sexual functioning									

*Dietician, speech therapist, dental hygienist

Adoption of advice and instruction: influencing factors

Two main categories and 6 subthemes were identified from the analysis of patients' interview statements. The subthemes add further refinement to the main categories (Table 4).

Table 4. Main Categories and Subthemes

Category	Subtheme
PROFESSIONALS	♦ Advice itself: content and efficacy ♦ Professionals' behaviour and attitude
PATIENT CHARACTERISTICS	♦ Cognition: perceptions, processing information ♦ Emotion: feelings, personality ♦ Behaviour: fit with daily living, behavioural change ♦ Social aspect: influence of family and social environment

PROFESSIONALS

Patients noted how professionals' contributions regularly played a key role in their effort to follow advice/instruction. This main category comprises 2 subthemes; content and efficacy of advice/instruction itself, and aspects of professionals' behaviour and attitude.

Advice: content and efficacy

An almost instant relief of symptoms or complaints, physically or mentally, was reported by patients to be the most positively influencing factor on following the advice, regardless of the complexity or strictness of it. Strong negative influence was reported when there was no noticeable effect of advice at all, or if the advice caused new problems. For example, using an ointment to relief skin burn during radiotherapy caused nausea due to the smell of the product.

> *The advice of the nurse to rinse my mouth every hour each day worked surprisingly well, so it was not difficult for me to carry out, although it was an extensive regime.(11.1)*

Sometimes, patients experienced advice as being contradictory. In such cases they were not sure what to do and sticking to the old behaviour was seen to be the most reasonable option.

> *My doctor explained to me that drinking alcohol was one of the big risk factors for head and neck cancer. After explaining this to me, he advised me not to quit drinking alcohol at once, but to keep going on drinking three to four glasses every day. I felt really confused after this message, and didn't know what to do with his advice.(1.7)*

Behaviour and attitude

Health professionals' behaviours and attitudes can have relevant impact on patients' motivation to adopt advice. Genuine human interest and contact was experienced by patients as a stimulating motivation and support to carry on with the medical treatment and to try and deal with additional problems, however difficult it sometimes was. They expressed, that with the help and encouragement of health professionals, they would finally succeed in mastering the task.

Some patients experienced little or no personal contact during their visits to health professionals. Three of them stated that this caused a negative effect on their acceptance of advice or instructions given to them.

> *The genuine human attention of my nurse for me as a person was soothing and supportive. She stood beside me all the way , even though she could not immediately solve my problems or concerns. Her presence gave me courage to hold on and to think of better times.(21.1)*

PATIENT CHARACTERISTICS

The characteristics of patients' themselves were the other key factor in relation to adopting care givers advice. This main category comprises four subthemes; cognition, emotion, behaviour and social aspects.

Cognition: perceptions, and processing information.

All patients verbalized some insight into the influence of personal cognitive aspects on their motivation to adopt advice. Factors of positive influence were verbalized as personal view on maintaining good health and independence, being convinced that the advice is going to work and that problems will be diminished, and having faith in health professionals. On the other hand, having strong convictions about health issues can have a negative influence, for example, believing that enduring pain makes you stronger or that all pain medication leads to addiction. The way in which patients process information or advice, whatever the form, can be of positive as well as negative influence. Most of the patients appreciated it when health professionals provided a detailed explanation about how to interpret and 'translate' written information and specific advice to their individual situation. An invitation to ask as many questions as possible was regarded as helpful by patients.

> *It was explained to me, again and again, why good dental hygiene is important. Formerly, I really did not know the relation between oral hygiene and head and neck cancer, but it does exist, I'm convinced of that now. I know I still need some help to comply to the new regime, but I'm getting there in the long-term, I know.(4.10)*

Emotion: feelings

The influence of emotion and personality in relation to adoption of advice was mentioned by several patients. Feelings of fear, anxiety and sometimes despair hindered patients in listening attentively to advice or to find a way to fit it into daily life. On the other hand, knowing what makes you feel happy or optimistic, and acting upon that feeling helped some patients to hold on to advice or treatment. Two patients stated, for example, that the family meals were experienced by them as moments of joy. These happy feelings "softened" the regime of the dietary guidelines they themselves had to follow, and made them more bearable.

> *Although I was not able to participate in family meals because of my tube feeding, I enjoyed it very much to sit at the table with them, watch them eat, and listen to their conversation. It gave me the courage to endure it all.(5.6)*

Behaviour: fit with daily living and behavioural change

One influencing aspect was the extent to which a fit of the advice with daily living was achieved. According to patients, the better the fit is, the better the motivation to follow the advice. The best advice was described by several patients as the one that gave instant relief of complaints, was a feasible and acceptable one, and one that was tailored to the patient's daily activity pattern.

Social aspects: influence of family and social environment

Most patients acknowledged the stimulating positive influence of partner and family members on their motivation and ability to adopt advice and often experienced it as an essential factor. Several patients stated that the role of the extended family and social network was very important. Key elements mentioned were a loving, caring, understanding homely atmosphere by which the patient felt supported during rehabilitation. Nevertheless, some patients mentioned a negative influence of either family or social contacts. Several mentioned lack of understanding for their situation from family or friends. This made them feel alone and hopeless and as a result sometimes less motivated to follow care giver's advice.

> *During my period of illness and treatment, my partner and son started smoking again. This influenced my motivation to stop smoking myself in a negative way. (2.8)*

Discussion

In general, the results confirm that during initial treatment and the first 6 months of the surveillance phase HNC patients mainly receive advice and instruction concerning the physical aspects and consequences of illness and treatment. A notable fact is that the patients in our sample regularly face the challenge of integrating 4 (or even more) individual forms of advice which require a change of behaviour in daily life either in the short or in the long-term. Nurses are indicated to be the main source of advice, followed by physicians and others, mainly allied health professionals. In most cases, advice was given orally, often complemented by written material. Sometimes, patients reported an inconsistency in the advice provided, and this was experienced as being confusing. Key factors like attitudes and perceptions in both professionals and patients, and the extent to which advice was tailored to patient's needs and the fit to the activities of daily life seemed to be of strong influence on the actual adoption of advice or instruction.

The emphasis on advice about physical problems following cancer treatment and how to deal with them is obvious. It is vitally important for all cancer patients that physical complications and sequelae of treatment are minimized to enhance recovery and rehabilitation. Nevertheless, the physical adverse effects of treatment for cancer can be evident for a significant period of time and even be permanent. Furthermore, many cancer patients face the challenge of making major lifestyle adjustments, as is obvious in our sample of HNC patients. Almost all patients in our sample underwent surgery, radiotherapy or a combination of both treatment modalities. Therefore, professionals emphasize the importance of minimizing skin and dental problems and maintaining an adequate nutritional status in patients to guide them through this phase. The importance of prevention of these problems is clearly explained to all patients and their partners or family. This could explain for the fact that advice on these topics is well adopted by patients. After the relief of surviving the illness this task can be experienced as "too much to cope with" and cause feelings of resistance, anxiety and stress. A new balance must be found as for most cancer patients life will no longer be the same as it was before the treatment. To help patients deal with this situation, a standardized and regular assessment of both physical and psychosocial concerns and needs should be an integrated part of follow-up care.[22-24]

Our study showed that psychosocial topics were not often addressed in the individual forms of advice received. This might be due to the natural emphasis on physical problems, or it could be that such issues were discussed more informally and did not result in any specific advice. However, when psychosocial advice was given, for example on coping (2 times), psychological/spiritual care (once), or contact with other cancer patients (once), it was always acted upon by the patient. It is also known that some topics, like intimacy or sexual functioning, are generally avoided in consultations because both health professionals and patients can feel too embarrassed or incompetent to discuss these. Such topics are still an underexplored area in HNC research.[25,26]

Participants mentioned nurses as their main source of advice. This can be explained by the fact that nurses are visible and approachable for patients and are increasingly assuming a coordinating role in care for HNC patients in our hospital. A possible explanation for the result of oral advice being the predominant form is that patients were interviewed up to several months after termination of initial treatment and would therefore almost certainly partly have forgotten in which form advice was given. However, when asked, patients could almost always tell in detail what the content of any advice received had been. Observation of consultations of health professionals in step 1 of this study showed just the opposite, namely, that almost all oral advice was accompanied by written material. This finding could also have been biased by socially desirable professional behaviour at the time of observation. We recommend that health professionals keep on combining oral advice with written material and that they consistently refer to the written material in subsequent patient contacts.

When we want patients to adequately process information and adopt advice, certain conditions must be met. Our search for factors influencing these conditions showed several key elements. Health professionals' behaviour and communication, and the outcome of the advice itself can be viewed as key factors. Therefore, health professionals should be aware of these aspects when trying to enhance the quality of advice and instruction in cancer patients. Several participants in our study emphasize the importance of a provider-patient relation built on an attitude of joined companionship and personal attention. Within this patient-focused professional relationship lies the opportunity to effectively tailor advice to the patients' needs, help patients make the necessary health changes, and support their self-management abilities.

Patient characteristics, like cognition, emotion, behaviour, and the social environment are other important influencing aspects in the advisory process. However, knowing what to do and putting this knowledge into practice are very different issues for many patients. Several reasons are mentioned by patients when asked, such as “can't,” “won't,” “not able to,” and “can't see why.” The traditional approach of health professionals relies on giving advice and direct persuasion. This can however, in a more or less visible way, elicit a defiant response in patients. During time pressured consultations other communication strategies may be more effective. These contain elements of empathic listening, motivational interviewing, and the non-judgmental reflection of health professionals to help patients explore their ambivalence to behavioural change. This can strengthen patient motivation and allow patients to develop their own plan to behavioural change.[27-29]

Because cancer patients regularly face major life style adjustments, follow-up care should focus on supporting patients in regaining self-control and in enhancing problem-solving skills that stimulate self-management. Specific attention to these aspects is required from (oncology) nurses, since their coordinating role and task in providing quality care for HNC patients in the aftercare continuum is becoming more distinct and noticeable.[30-32]

Strengths and limitations

In this study, several methods were used to enhance the reliability of data collection and analysis. Following each patient interview, critical reflection was carried out on the quantity of data gathered and the quality of interaction during the interview. These reflections were regularly discussed with the research supervisor (TvA) and were used to enhance the next interview. Each interview was rounded off by means of a verbal summary to the respondent, by the researcher.
Once the last interview had been conducted, a generic written summary containing a global overview of all the interviews together was sent to all participants. Participants were then invited to make supplementary remarks on this summary if they so wished, and one of them did by confirming the content of the summary. In trying to interpret the study findings it is important to recognize its limitations.

First, the use of a convenience sample of patients treated in 1 hospital could have caused some bias. Patient participation was influenced by factors such as disease severity, motivation to participate and other health and illness behavioural issues. Nevertheless, comparison of demographic and disease characteristics in both eligible and included patients showed no main differences, so it could be concluded that the participant group was a reasonable reflection of total eligible patient group. Second, data were collected by means of patient reports, and are therefore vulnerable to socially desirable answers. In an attempt to avoid this, specific questions were asked to elicit more individual statements from participants. Third, no audio taping was made because of the structured nature of interviewing the patients. Specific patient statements were written down verbatim during interviewing by the researcher (JdL), and are therefore not totally verifiable, and could be vulnerable to bias and possible individual preferences.

Recommendations for clinical practice

The study findings highlight the multifactorial complexity of following discharge advice for cancer patients and, hence, for health professionals. Characteristics of both patients and health professionals influence the way advice (and instructions) are adopted by patients. The amount of advice given to HNC patients especially, requires health professionals to apply multiple strategies and strive for coordination and alignment of health promotion activities within the multidisciplinary team. Hence, health professionals should continuously expand their knowledge, and train and refine their communicational and coaching skills to establish a supportive provider-patient relationship.

Nurses fulfil an important and often long-term coordinating role for cancer patients during the treatment and follow-up continuum. Within this role lies a superb opportunity to help and guide patients toward cancer rehabilitation. Recently, strong recommendations were made to formulate coordinated multidisciplinary rehabilitation plans for cancer patients after initial treatment.[33-35]

Because several different health professionals are involved in follow-up care for patients, this seems the proper way to fine-tune multidisciplinary health advice activities to optimize patient care and facilitate patients' autonomy. In joint collaboration with health professionals, patients can then become active participators in their own health care, and ask for services and professional care proactively when threats arise to their independence and health.

Following the results of this study, we decided to start an early intervention study to test a structured, patient tailored nurse-led follow-up intervention for HNC patients.

References

1. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. J.Cancer Surviv 2008;2:179-89.
2. Haylock PJ, Mitchell SA, Cox T, Temple SV, Curtiss CP. The cancer survivor's prescription for living. Am J Nurs 2007;107:58-70.
3. Mikkelsen TH, Sondergaard J, Jensen AB, Olesen F. Cancer rehabilitation: psychosocial rehabilitation needs after discharge from hospital? Scand J Prim Health Care 2008;26:216-21.
4. Sanderson BK, Thompson J, Brown TM, Tucker MJ, Bittner V. Assessing patient recall of discharge instructions for acute myocardial infarction. J Healthc Qual 2009;31:25-33.
5. Do KA, Johnson MM, Lee JJ, Wu XF, Dong Q, Hong WK, Khuri FR, Spitz MR. Longitudinal study of smoking patterns in relation to the development of smoking-related secondary primary tumors in patients with upper aerodigestive tract malignancies. Cancer 2004;101:2837-42.
6. Hammerlid E, Silander E, Hornestam L, Sullivan M. Health-related quality of life three years after diagnosis of head and neck cancer--a longitudinal study. Head Neck 2001;23:113-25.
7. Ajzen I (1991) The Theory of Planned Behavior. Org Hum Decis Processes 1991;50:179-211.
8. Beckjord EB, Finney Rutten LJ, Arora NK, Moser RP, Hesse BW. Information processing and negative affect: evidence from the 2003 Health Information National Trends Survey. Health Psychol 2008;27:249-57.
9. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the Health Belief Model. Health Educ Q 1988;15:175-83.
10. Murphy BA, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer: a review of the current state of the science. Crit Rev Oncol Hematol 2007;62:251-67.
11. van den Brink JL, De Boer MF, Pruyn JF, Hop WC, Verwoerd CD, Moorman PW. Quality of life during the first 3 months following discharge after surgery for head and neck cancer: prospective evaluation. J Otolaryngol 2006;35:395-403.
12. Brennan J. Adjustment to cancer - coping or personal transition? Psycho-Oncol 2001;10:1-18.
13. List MA, Bilir SP. Functional outcomes in head and neck cancer. Semin Radiat Oncol 2004;14:178-89.
14. Moore RJ, Chamberlain RM, Khuri FR. Communicating suffering in primary stage head and neck cancer. Eur J Cancer Care 2004;13:53-64.
15. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P. Framework for design and evaluation of complex interventions to improve health. BMJ 2000;321:694-96.
16. Medical Research Council. A Framework for the Development and Evaluation of RCTs for Complex Interventions to Improve Health. London: Medical Research Council, 2000.
17. Dutch Head and Neck Society (NWHHT). Web site http://www.nwhht.nl. Accessed October 25, 2009.
18. Dutch Head and Neck Society (NWHHT). Guideline Oral Cavity and Oropharynx Cancer. Version 1.4. 2004. www.oncoline.nl. Accessed October 25, 2009.

19. Dutch Head and Neck Society (NWHHT). Guideline Laryngeal Cancer. Version 3.0. 2010. www.oncoline.nl. Accessed December 13, 2010.
20. Dutch Head and Neck Society (NWHHT). Guideline Hypopharynx Cancer. Version 2.0. 2010. www.oncoline.nl. Accessed December 13, 2010.
21. Krippendorff K. Content Analysis: An Introduction to its Methodology. Thousand Oaks, CA: Sage Publications, 2004.
22. Garssen B, de Kok E. How useful is a screening instrument? Psycho-Oncol 2008;17:726-28.
23. Kruijver IP, Garssen B, Visser AP, Kuiper AJ. Signalising psychosocial problems in cancer care :the structural use of a short psychosocial checklist during medical or nursing visits. Patient Educ Couns 2006;62:163-77.
24. Kugaya A, Akechi T, Okuyama T, Nakano T, Mikami I, Okamura H, Uchitomi Y. Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. Cancer 2000;88:2817-23.
25. Grant M, Krebs LU. Addressing intimacy in cancer patients. Introduction. Semin Oncol Nurs 2008;24:69-70.
26. Tierney DK. Sexuality: a quality-of-life issue for cancer survivors. Semin Oncol Nurs 2008;24:71-79.
27. Aliotta SL, Vlasnik JJ, Delor B. Enhancing adherence to long-term medical therapy: a new approach to assessing and treating patients. Adv Ther 2004;21:214-31.
28. Golin CE, Earp J, Tien HC, Stewart P, Porter C, Howie L. A 2-arm, randomized, controlled trial of a motivational interviewing-based intervention to improve adherence to antiretroviral therapy (ART) among patients failing or initiating ART. J Acquir Immune Defic Syndr 2006;42:42-51.
29. Rubak S, Sandbaek A, Lauritzen T, Christensen B. Motivational interviewing: a systematic review and meta-analysis. Br J Gen Pract 2005;55:305-12.
30. Corner J. The role of nurse-led care in cancer management. Lancet Oncol 2003;4:631-36.
31. Rowland JH. Cancer survivorship: rethinking the cancer control continuum. Semin Oncol Nurs 2008;24:145-52.
32. Wiederholt PA, Connor NP, Hartig GK, Harari PM. Bridging gaps in multidisciplinary head and neck cancer care: nursing coordination and case management. Int J Radiat Oncol Biol Phys 2007;69:S88-S91.
33. Gezondheidsraad DHC. Nacontrole in de oncologie (Follow-up in Oncology). Den Haag, Netherlands: Gezondheidsraad, 2007.
34. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. J Clin Oncol 2006;24:5112-16.
35. Ganz PA, Casillas J, Hahn EE. Ensuring quality care for cancer survivors: implementing the survivorship care plan. Semin Oncol Nurs 2008;24:208-17.

Chapter 3

Supportive care in early rehabilitation for advanced-stage radiated head and neck cancer patients

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Abstract

Objective

To investigate the health-related quality of life (HRQoL) and supportive follow-up care needs one month post-treatment for patients with advanced-stage (stage III or IV) radiated head and neck cancer (HNC) who were treated with curative intent.

Study design

An exploratory, descriptive analysis of HRQoL data obtained from three treatment groups: conventional radiotherapy (RT, n=21), surgery + radiotherapy (SRT, n=10), and chemoradiation (CRT, n=21).

Setting, subjects and methods

The head and neck oncology centre of a university hospital. Fifty-two patients completed the EORTC QLQ-C30 and EORTC QLQ H&N35 self-report questionnaires one month post-treatment. Descriptive statistics and clinically relevant differences between the groups were analysed.

Results

HRQoL outcomes between groups differed. Clinically relevant difference was observed in the RT and CRT group with respect to dry mouth, coughing, feeling ill, use of pain killers, and the use of nutritional supplements. The RT group differed from the other groups with respect to pain and swallowing. The CRT group differed from the other groups regarding role functioning.

Conclusions

HRQoL differs between RT, SRT, and CRT patients one month post-treatment. The RT- and CRT-treated patients reported higher impairment than the patients who were treated with SRT. Nutritional intake and oral function emphasize the importance of providing supportive care to radiated advanced-stage HNC patients throughout the treatment trajectory and the need for continuation during the first few post-treatment months.

Introduction

Every current treatment for head and neck cancer (HNC) places a burden on the patient, and nearly all patients experience a progressive deterioration in health-related quality of life (HRQoL) towards the end of treatment.[1,2] For most patients, these health-related complications largely disappear during the first post-treatment years.[3,4] However, if complications remain after one year, little—if any—significant improvement can be expected through the 3-year follow-up period, particularly among patients who received conventional radiotherapy as part of their treatment.[1,5]
The choice of treatment for HNC is determined by both the tumour size (stage) and location of the tumour, and these factors must be considered when interpreting HRQoL outcome.[6] Although multimodal treatment can lead to an increased prevalence of HRQoL consequences compared to single-modality treatments, the literature contains contradictory reports, particularly with respect to long-term differences (i.e., 12 months and longer).[4,7-11] HNC patients who are treated surgically can experience complications such as wound infection, microvascular flap complications, shoulder disability, swallowing and/or chewing difficulties, and aesthetic changes.[4,12] Radiotherapy can lead to complications such as mucositis, dysphagia and xerostomia, trismus and fibrosis.[5,13-15] In addition to the aforementioned radiotherapy-related complications, chemoradiation-specific complications can include infection, hematopoietic suppression, renal failure, pneumonia, the need for tube feeding, and fatigue.[8,9,16,17]

To provide on high-quality care and enhance treatment outcomes, it is important to assess HRQoL routinely throughout the treatment trajectory, address problems and complications in an early stage and discuss the short- and long-term treatment-related health consequences with the patient.[3,18] Although many studies have investigated HRQoL in HNC patients, relatively few studies provide data regarding the immediate post-treatment period; indeed, the 3- and 6-month periods are the most commonly reported short-term measurements. Therefore, we determined HRQoL at one month post-treatment to add to the short-term data and to gain insight into the problems experienced by radiated HNC patients which received different treatment. We also use these results to provide a direction for the type and intensity of supportive follow-up care within the first weeks to months in the post-treatment period.

Methods

A descriptive exploratory analysis was performed on a subset of data from HNC patients (n=160) who participated in a prospective non-randomized trial between November 2007 and February 2009 (ClinicalTrials.gov NCT01167179).[19] This trial assessed the effects of nurse-led follow-up consultations on psychosocial adjustment to illness and on health related quality of life. A usual care group (n=80), that functioned as a historical control group, was compared with an intervention group (n=80) for which nursing consultations were added to the medically oriented follow-up schedule. All patients (n=160) had completed the EORTC QLQ-C30 and EORTC QLQ H&N35 questionnaires at the baseline measurement set at 1 month post-treatment. Until that moment all patients had received usual care during treatment. As from one month, the intervention group started with the additional nursing follow-up consultations. Remaining longitudinal measurements were at 6 and 12 months, respectively. Participating patients had all been treated at the Head and Neck Centre of the Radboud University Centre for Oncology in Nijmegen, the Netherlands. All patients provided a written informed consent, and the study was approved by the Medical Ethical Committee of the district Arnhem-Nijmegen, and was conducted in accordance with the Declaration of Helsinki (CMO-nr. 2007/113).[20,21]

Sample

The patient demographic and disease characteristics are presented in Table 1. The sample consisted of 52 HNC patients with locoregionally advanced (stage III or IV) cancer who had been treated with curative intent using conventional radiotherapy (RT group, n=21), surgery followed by radiotherapy (SRT group, n=10), or chemoradiation (CRT group, n=21). The treatment that each HNC patient received was in accordance with to the guidelines of the national Head and Neck Society.[22]

Data collection

HRQoL was measured using the European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire with the Head & Neck Module (EORTC QLQ-C30 and QLQ-H&N35).[23,24] The EORTC QLQ-C30 and the EORTC QLQ-H&N35 are cancer-specific, patient-based self-report questionnaires, and the psychometric properties of both questionnaires have been tested by several studies.[25,26] The core questionnaire is composed of five functional scales, a global health status/QoL scale, and nine symptom scales. The additional head and neck module (EORTC QLQ-H&N35) contains 18 disease-specific symptom scales. A high score on the functional scales and the global health status/QoL scale represents a high functional level, whereas a high score on the symptom scale represents a high level of symptoms.[24]

Analysis

The mean scores and standard deviations of the EORTC QLQ scales were calculated in accordance with the recommended procedures in the scoring manual using SPSS 18.0.[24] Due to the small sample size and non-normal distribution of the data, the differences between treatment groups with respect to demographic and disease variables were tested using the non-parametric Kruskal-Wallis test. Clinically relevant differences between the groups were also calculated, as this adds to the meaningful clinical interpretation of otherwise aggregated mean EORTC scores. A difference of >10 points in mean EORTC scores was viewed as being clinically relevant.[27-29] An EORTC mean score of 50 was used as a threshold to detect HRQoL items that indicated worse or better functioning within the groups. A mean score of ≤50 on the function scales and global health status/QoL or and a score of ≥50 on the symptom scales was regarded as a sign of impaired function on a given scale. Because this study was exploratory in design and contained a relatively small sample size, multiple statistical testing was not considered appropriate and was therefore not performed.

Results

Our analyses revealed that the treatment groups did not differ significantly with respect to age, gender, or stage grouping (Table 1). The average of the patients (39 men and 13 women) was 56 years (range, 26-82 years). Seventy-five per cent of the patients had a stage IV tumour, and the oropharynx and larynx were the two most common tumour locations. Intensity-modulated radiation therapy (IMRT) was used in the treatment of 34 (65%) patients. Although they were not statistically significant ($p > 0.05$), the differences in tumour site between the treatment groups can be explained by the fact that the treatment variables were determined using established guidelines.[22]

Table 1. **Demographics and Disease Characteristics (N=52 patients)**

	Total	Surgery + Radiotherapy	Radiotherapy	Chemo radiation	*p*-value*
Number	52	10	21	21	
Gender					0.27
Male	39	6	15	18	
Female	13	4	6	3	
Age, years					0.40
Mean (Median)	56 (57)	58 (60)	58 (57)	53 (53)	
Range	26-82	26-82	44-75	30-75	
Cancer site					0.06
Oral cavity	9	7	0	2	
Oropharynx	15	0	9	6	
Hypopharynx	6	0	2	4	
Nasopharynx	4	0	0	4	
Larynx	15	2	10	3	
Other	3	1	0	2	
Stage [a]					0.48
III	13	1	6	6	
IV	39	9	15	15	

[a] UICC TNM Classification of Malignant Tumours 7th Edition, 2011.
*Kruskal-Wallis test

Functional scales and global health status/QoL

None of the groups had a mean score of ≤50 on either the EORTC QLQ-C30 functional scales or the global health status/QoL scale. With respect to the functional scales, role functioning was impaired in all groups, with the CRT group having clinically relevant lower scores (i.e. worse functioning) relative to the SRT and RT groups, respectively. Details are presented in Table 2.

Symptom scales

With respect to the EORTC QLQ-C30 and H&N35 symptom scales, the SRT group had mean scores of 50 points or higher for sticky saliva and weight loss, and the RT and CRT groups had mean scores of 50 or higher for dry mouth, sticky saliva, the use of pain killers, the use of nutritional supplements, and weight loss. Analyses of the clinically relevant differences between the groups revealed that compared to the other groups, the SRT group had higher (i.e., worse) scores for problems with teeth, but lower (i.e., better) scores for nausea/vomiting, dry mouth, coughing, feeling ill, the use of pain killers, and the use of nutritional supplements. The RT group had higher (i.e., worse) scores for pain and swallowing, but no lower (i.e., better) scores on any scale compared to the other groups. The CRT group had higher (i.e., worse) scores for fatigue, nausea/vomiting, appetite loss, problems with sexuality, sticky saliva, the use of pain killers, the use of nutritional supplements, and the use of a feeding tube.

Table 2. EORTC QLQ-C30 and EORTC QLQ-H&N35 Scores and Clinically Relevant Differences Between the Treatment Groups at One Month Post-treatment

	Surgery + Radiotherapy (n=10)	Radiotherapy (n=21)	Chemo radiation (n=21)	SRT vs. RT [a]	RT vs. CRT	CRT vs. SRT
	mean (sd)	mean (sd)	mean (sd)	Δ	Δ	Δ
EORTC QLQ-C30						
Functional scales [b]						
Global health status/QoL	71 (15)	72 (17)	66 (25)			
Physical functioning	80 (14)	83 (18)	74 (29)			
Role functioning	69 (22)	75 (28)	57 (36)		**+18**	**-12**
Emotional functioning	81 (25)	81 (20)	83 (21)			
Cognitive functioning	83 (15)	85 (19)	83 (17)			
Social functioning	83 (28)	84 (21)	79 (23)			
Symptom scales [c]						
Fatigue	33 (30)	32 (26)	44 (30)		**-12**	**+11**
Nausea/vomiting	8 (9)	28 (36)	19 (31)	**- 20**		**+11**
Pain	19 (20)	34 (34)	19 (18)	**- 15**	**+15**	
Dyspnoea	17 (18)	6 (18)	15 (24)	**+11**		
Insomnia	17 (28)	27 (25)	20 (21)			
Appetite loss	22 (27)	29 (40)	44 (30)		**-15**	**+22**
Constipation	17 (28)	27 (25)	20 (31)			
Diarrhoea	6 (14)	8 (15)	6 (13)			
Financial difficulties	11 (17)	13 (27)	10 (20)			
EORTC H&N35 [c]						
Pain	21 (24)	38 (25)	31 (17)	**-17**		
Swallowing	25 (25)	45 (33)	28 (26)	**-20**	**+17**	
Senses	33 (24)	41 (32)	36 (20)			
Speech	19 (27)	28 (24)	24 (24)			
Social eating	33 (36)	34 (26)	32 (27)			
Social contact	3 (6)	8 (14)	7 (11)			
Sexuality	31 (27)	29 (32)	44 (37)		**-15**	**+13**
Teeth	28 (33)	17 (32)	12 (20)	**+11**		**-16**
Opening mouth	44 (50)	27 (33)	37 (38)	**+17**		
Dry mouth	39 (25)	**63** (36)	**63** (30)	**-24**		**+24**
Sticky saliva	**50** (28)	**54** (38)	**67** (33)		**-13**	**+17**
Coughing	11 (17)	38 (36)	39 (31)	**-27**		**+28**
Feeling ill	11 (17)	27 (33)	22 (28)	**-16**		**+11**
Pain killers	33 (52)	**69** (48)	**56** (51)	**-36**	**+13**	**+23**
Nutritional supplements	33 (52)	**50** (52)	**83** (38)	**-17**	**-33**	**+50**
Feeding tube	0 (0)	0 (0)	33 (49)		**-33**	**+33**
Weight loss	**50** (55)	**56** (51)	**50** (51)			
Weight gain	33 (52)	25 (45)	17 (38)			**-16**

Abbreviations: CRT, chemoradiation; QoL, quality of life; RT, radiotherapy; SRT, surgery + radiotherapy

[a] Δ = clinically relevant difference of >10 points, indicated by bold figures.

[b] Higher score, better functioning (range 0-100).

[c] Higher score, more symptoms (range 0-100).

Discussion

The goals of this study were to gain insight into the HRQoL of irradiated advanced-stage HNC patients one month post-treatment and to determine which items should be given particular consideration in future supportive care during early rehabilitation. In the published literature, few studies have provided data regarding the early post-treatment period; therefore, it is difficult to compare our findings directly with the findings of others. Overall, the SRT group seemed to experience less of a decrease in HRQoL than the RT and CRT groups.

Function scales and global health status/QoL

With the exception of role functioning, the groups exhibited no clinically relevant differences with respect to their functional scales and global health status/QoL. Role functioning was most impaired in the CRT group relative to the other two groups. Several other studies that compared different treatment protocols have reported this same finding.[17,30,31] With respect to our CRT group, this finding could be a function of the severity of symptoms related to various aspects of nutritional intake and/or appetite loss and to the fact that one-third of the patients remained dependent on tube feeding one month post-treatment (and

Symptom scales

The clinically relevant differences between the treatment groups regarding the symptom scales pointed predominantly toward the scales that are related to nutritional intake (i.e., appetite loss, nausea/vomiting, swallowing, tube feeding, the use of nutritional supplements, and weight loss) and oral function (i.e., dry mouth, opening mouth, sticky saliva, and problems with teeth). In addition, the groups exhibited clinically relevant differences with respect to pain, coughing, and fatigue.

Problems related to nutritional intake

Several studies have reported that problems with respect to nutritional intake, swallowing, senses and impaired oral function can persist for well over a year post-treatment.[1,21,33-35] Therefore, the importance of assessing and monitoring these items early seems obvious.[36] Early supportive care—including intensive nutritional counselling by a dietician regarding maintaining body weight—led to improved nutritional status, better treatment tolerance, fewer hospital admissions, and, consequently improved treatment outcome.[37-42] Most nutritional guidance programs end within eight weeks of treatment; however, some studies have argued that patients with advanced-stage tumours—particularly patients who are treated using RT and CRT—require a longer period of dietary counseling.[38,43] This is particularly important for patients who remain dependent on tube feeding (one-third of the CRT group in our study). Indeed, prolonged tube insertion can be associated with, impaired swallowing and speech and, a decrease in overall quality of life.[44-46]

In our study, we found clinically relevant negative scores for swallowing in the RT group, with a difference of nearly 20 points compared with the other groups. This result has been well-described in irradiated patients with pharyngeal cancer, and this was the predominant tumour site in our RT group.[47] On the other hand, pharyngeal cancer was also predominant in the CRT group, although the scores in this group for swallowing were similar to the scores in the SRT group, which contained no pharyngeal cancer patients. We have no further explanation for this finding. However, dysphagia and the associated increased risks of aspiration and pneumonia are well-known problems in this patient group.[8] Therefore, an assessment of dysphagia prior to treatment and subsequent rehabilitation in patients with advanced and/or pharyngeal cancer may be an important predictor of chronic dysfunction.[48]

The health consequences of problematic nutritional intake in HNC patients have also been studied qualitatively, and reports indicate that nutritional symptoms and concerns and fatigue can have the greatest impact on the patient's attempt to achieve a normal life after treatment has ended.[49] Another study suggested that healthcare professionals who address nutritional problems in HNC patients should also talk with patients regarding their experience of the (changed) meaning of food following treatment in order to help support the patient's need to cope with changes or losses in this area.[50]

Problems related to oral function

The SRT group had clinically different scores with respect to problems with their teeth and opening their mouths. In this group, in which oral cancer was the predominant tumour site, problems with the teeth are an expected outcome, as surgical treatment routinely includes the extraction of teeth and extensive dental rehabilitation, including implants.[51] The scores are consistent with the postoperative discharge scores reported by Lee et al. for HNC patients who were treated with surgery alone.[52] The inability to bite or chew properly is a potential risk factor for the (gradual) deterioration of nutritional status and oral function and can also impact both short- and long-term HRQoL.[53] The SRT group seemed to carry a high risk, particularly in combination with a clinically higher (i.e., worse) score for opening the mouth. Hence, nutritional intake and oral function are clear points of attention for this group, and this is also confirmed by their high mean scores for sticky saliva and weight loss.

With respect to oral function, the RT and CRT groups had clinically relevant higher (i.e., worse) scores for dry mouth and sticky saliva compared with the SRT group. The mean scores for these items in both the RT and CRT groups were 10-20 points higher (i.e., worse) than in studies that reported three-month data for these same treatment groups.[5,17] Although these symptoms tend to improve over time, their impact on the patient cannot be neglected, as they are predictors of long-term weight loss.[54]

Pain and fatigue

Pain scores were highest (i.e., worse) in the RT group compared to the other two groups. We currently have no specific explanation for this finding in this treatment group, as pain is a known symptom during treatment and during the first post-treatment months in all irradiated HNC patients.[55] Pain can range from neuropathic pain to mucositis-related pain and other treatment-related pain. However, pain has been reported to be an undermanaged item in HNC patients, thus having a negative impact on all other HRQoL items; therefore, pain deserves to receive adequate professional attention.[56] Fatigue was present in all treatment groups, but scores were highest (i.e., worse) in the CRT group. Fatigue is most severe during radiation treatment and then improves gradually after treatment has ended.[57] However, because fatigue is often viewed as a general treatment-related side effect, it is perhaps not always addressed effectively. Moreover, increased levels of fatigue are tightly correlated with decreased QoL.[58]

In summary, these results support our clinical experience that prolonged intensive supportive care is warranted for irradiated advanced-stage HNC patients during the early stage of rehabilitation. In our setting, the medical routine follow-up schedule consists of twice-monthly control visits to a physician in the first year of follow-up. To provide adequate supportive care for all irradiated HNC patients during the first few post-treatment months, we recommend that patients have frequent contact with the supportive care providers within the multidisciplinary head and neck team. This care could well be organized and coordinated within the context of nurse-led clinics, encompassing specific counselling of dieticians, dental health care professionals, and other supportive care providers.[19,43,59] These contacts could be planned and guided in accordance with the severity of existing symptoms and problems, together with high-intensity contact immediately following treatment. It would be worthwhile to investigate whether such an intensified approach guided by symptom assessment can influence the general treatment outcome of HNC cancer patients.

When interpreting the results of this study, it is important to acknowledge the study's limitations. The treatment groups in this study were extracted from the cohort of a non-randomized prospective trial that was conducted in one hospital only. Consequently, we were unable to control how the groups were composed. Therefore, our relatively small sample size warrants caution in the generalization of our findings. However, despite this limitation, these results provide insight into short-term supportive care issues and differences with respect to various modalities for treating irradiated patients with advanced-stage HNC and will be helpful in improving supportive care further.

Conclusions

Our results indicate that several HRQoL items necessitate intensive supportive care at one month post-treatment for irradiated advanced-stage HNC patients, and this necessity is primarily a reflection of aspects regarding nutritional intake and oral function. The CRT and RT groups appear to have the highest need for intensive supportive care in the early post-treatment months. We argue that supportive care of these advanced-stage patient groups should be included in all phases of treatment and—depending on the severity of the symptoms—should be extended into the rehabilitation phase. A multidisciplinary head and neck team comprised of dieticians, nurses, dental health professionals and physicians is essential for incorporating this care into the treatment trajectory.

References

1. Hammerlid E, Silander E, Hornestam L, et al. Health-related quality of life three years after diagnosis of head and neck cancer--a longitudinal study. *Head and Neck* 2001;23:113-125.
2. Abendstein H, Nordgren M, Boysen M, et al. Quality of life and head and neck cancer: a 5 year prospective study. *Laryngoscope* 2005;115:2183-2192.
3. Shepherd KL, Fisher SE. Prospective evaluation of quality of life in patients with oral and oropharyngeal cancer: from diagnosis to three months post-treatment. *Oral Oncol* 2004;40:751-757.
4. El-Deiry M, Funk GF, Nalwa S, et al. Long-term quality of life for surgical and nonsurgical treatment of head and neck cancer. *Arch Otolaryngol Head Neck Surg* 2005;131:879-885.
5. Fang FM, Chien CY, Tsai WL, et al. Quality of life and survival outcome for patients with nasopharyngeal carcinoma receiving three-dimensional conformal radiotherapy vs. intensity-modulated radiotherapy-a longitudinal study. *Int J Radiat Oncol Biol Phys* 2008;72:356-364.
6. Wan Leung S, Lee TF, Chien CY, et al. Health-related quality of life in 640 head and neck cancer survivors after radiotherapy using EORTC QLQ-C30 and QLQ-H&N35 questionnaires. *BMC Cancer* 2011;11:128.
7. Alicikus ZA, Akman F, Ataman OU, et al. Importance of patient, tumour and treatment related factors on quality of life in head and neck cancer patients after definitive treatment. *Eur Arch Otorhinolaryngol* 2009;266:1461-1468.
8. Bower WF, Vlantis AC, Chung TM, et al. Mode of treatment affects quality of life in head and neck cancer survivors: Implications for holistic care. *Acta Otolaryngol* 2010;130:1185-1192.
9. Francis DO, Weymuller EA, Jr., Parvathaneni U, et al. Dysphagia, stricture, and pneumonia in head and neck cancer patients: does treatment modality matter? *Ann Otol Rhinol Laryngol* 2010;119:391-397.
10. Mowry SE, Ho A, Lotempio MM, et al. Quality of life in advanced oropharyngeal carcinoma after chemoradiation versus surgery and radiation. *Laryngoscope* 2006;116:1589-1593.
11. Hanna E, Sherman A, Cash D, et al. Quality of life for patients following total laryngectomy vs chemoradiation for laryngeal preservation. *Arch Otolaryngol Head Neck Surg* 2004;130:875-879.
12. LoTempio MM, Wang KH, Sadeghi A, et al. Comparison of quality of life outcomes in laryngeal cancer patients following chemoradiation vs. total laryngectomy. *Otolaryngol Head Neck Surg* 2005;132:948-953.
13. Netscher DT, Meade RA, Goodman CM, et al. Quality of life and disease-specific functional status following microvascular reconstruction for advanced (T3 and T4) oropharyngeal cancers. *Plast Reconstr Surg* 2000;105:1628-1634.
14. Al-Mamgani A, Mehilal R, van Rooij PH, et al. Toxicity, quality of life, and functional outcomes of 176 hypopharyngeal cancer patients treated by (Chemo)radiation: The impact of treatment modality and radiation technique. *Laryngoscope* 2012;122:1789-1795.
15. Rutten H, Pop LA, Janssens GO, et al. Long-term outcome and morbidity after treatment with accelerated radiotherapy and weekly cisplatin for locally advanced head-and-neck cancer: results of a multidisciplinary late morbidity clinic. *Int J Radiat Oncol Biol Phys* 2011;81:923-929.

16. Bucci MK, Bevan A, Roach M, 3rd. Advances in radiation therapy: conventional to 3D, to IMRT, to 4D, and beyond. *CA Cancer J Clin* 2005;55:117-134.
17. Ackerstaff AH, Balm AJ, Rasch CR, et al. First-year quality of life assessment of an intra-arterial (RADPLAT) versus intravenous chemoradiation phase III trial. *Head Neck* 2009;31:77-84.
18. Pergolizzi S, Santacaterina A, Adamo B, et al. Induction chemotherapy with paclitaxel and cisplatin to concurrent radiotherapy and weekly paclitaxel in the treatment of loco-regionally advanced, stage IV (M0), head and neck squamous cell carcinoma. Mature results of a prospective study. *Radiat Oncol* 2011;6:162.
19. de Leeuw J, Prins JB, Teerenstra S, et al. Nurse-led follow-up care for head and neck cancer patients: a quasi-experimental prospective trial. *Support Care Cancer* 2013:21(2):537-547.
20. Medical Ethical Committee Region Arnhem-Nijmegen. Available at: www.cmoregio-a-n.nl. Accessed January 15, 2012.
21. World Medical Association. Available at: http://www.wma.net. Accessed January 15, 2012, 2011.
22. Oncoline. Dutch Guidelines Head and Neck Cancer. Avalaible at: www.oncoline.nl. Accessed June 23, 2012.
23. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365-376.
24. Fayers PM, Aaronson NK, Bjordal K, et al. *The EORTC QLQ-C30 Scoring Manual (3rd Edition)*. Brussels: European Organisation for Research and Treatment of Cancer; 2001.
25. Bjordal K, de Graeff A, Fayers PM, et al. A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35) in head and neck patients. EORTC Quality of Life Group. *Eur J Cancer* 2000;36:1796-1807.
26. Bjordal K, Hammerlid E, Ahlner-Elmqvist M, et al. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. *J Clin Oncol* 1999;17:1008-1019.
27. Hammerlid E, Bjordal K, Ahlner-Elmqvist M, et al. Prospective, longitudinal quality-of-life study of patients with head and neck cancer: a feasibility study including the EORTC QLQ-C30. *Otolaryngol Head Neck Surg* 1997;116:666-673.
28. King MT. The interpretation of scores from the EORTC quality of life questionnaire QLQ-C30. *Qual Life Res* 1996;5:555-567.
29. Osoba D, Rodrigues G, Myles J, et al. Interpreting the significance of changes in health-related quality-of-life scores. *J Clin Oncol* 1998;16:139-144.
30. Pow EH, Kwong DL, McMillan AS, et al. Xerostomia and quality of life after intensity-modulated radiotherapy vs. conventional radiotherapy for early-stage nasopharyngeal carcinoma: initial report on a randomized controlled clinical trial. *Int J Radiat Oncol Biol Phys* 2006;66:981-991.
31. Vergeer MR, Doornaert PA, Rietveld DH, et al. Intensity-modulated radiotherapy reduces radiation-induced morbidity and improves health-related quality of life: results of a nonrandomized prospective study using a standardized follow-up program. *Int J Radiat Oncol Biol Phys* 2009;74:1-8.

32. Rogers SN, Thomson R, O'Toole P, et al. Patients experience with long-term percutaneous endoscopic gastrostomy feeding following primary surgery for oral and oropharyngeal cancer. *Oral Oncol* 2007;43:499-507.
33. Garcia-Peris P, Paron L, Velasco C, et al. Long-term prevalence of oropharyngeal dysphagia in head and neck cancer patients: Impact on quality of life. *Clin Nutr* 2007;26:710-717.
34. van der Molen L, van Rossum MA, Burkhead LM, et al. Functional outcomes and rehabilitation strategies in patients treated with chemoradiotherapy for advanced head and neck cancer: a systematic review. *Eur Arch Otorhinolaryngol* 2009;266:889-900.
35. Speksnijder CM, van der Glas HW, van der Bilt A, et al. Oral function after oncological intervention in the oral cavity: a retrospective study. *J Oral Maxillofac Surg* 2010;68:1231-1237.
36. Ganzer H, Touger-Decker R, Parrott JS, et al. Symptom burden in head and neck cancer: impact upon oral energy and protein intake. *Support Care Cancer* 2012;21:495-503.
37. Paccagnella A, Morello M, Da Mosto MC, et al. Early nutritional intervention improves treatment tolerance and outcomes in head and neck cancer patients undergoing concurrent chemoradiotherapy. *Support Care Cancer* 2010;18:837-845.
38. van den Berg MG, Rasmussen-Conrad EL, Wei KH, et al. Comparison of the effect of individual dietary counselling and of standard nutritional care on weight loss in patients with head and neck cancer undergoing radiotherapy. *Br J Nutr* 2010;104:872-877.
39. Capuano G, Grosso A, Gentile PC, et al. Influence of weight loss on outcomes in patients with head and neck cancer undergoing concomitant chemoradiotherapy. *Head Neck* 2008;30:503-508.
40. Ravasco P, Monteiro-Grillo I, Marques Vidal P, et al. Impact of nutrition on outcome: a prospective randomized controlled trial in patients with head and neck cancer undergoing radiotherapy. *Head Neck* 2005;27:659-668.
41. Isenring EA, Capra S, Bauer JD. Nutrition intervention is beneficial in oncology outpatients receiving radiotherapy to the gastrointestinal or head and neck area. *Br J Cancer* 2004;91:447-452.
42. Kiss NK, Krishnasamy M, Loeliger J, et al. A dietitian-led clinic for patients receiving (chemo)radiotherapy for head and neck cancer. *Support Care Cancer* 2012;20:2111-2120.
43. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: conceptions of patients with head and neck cancer. *Eur J Oncol Nurs* 2007;11:49-59.
44. Morton RP, Crowder VL, Mawdsley R, et al. Elective gastrostomy, nutritional status and quality of life in advanced head and neck cancer patients receiving chemoradiotherapy. *ANZ J Surg* 2009;79:713-718.
45. Oozeer NB, Corsar K, Glore RJ, et al. The impact of enteral feeding route on patient-reported long term swallowing outcome after chemoradiation for head and neck cancer. *Oral Oncology* 2011;47:980-983.
46. Ehrsson YT, Langius-Eklof A, Laurell G. Nutritional surveillance and weight loss in head and neck cancer patients. *Support Care Cancer* 2012;20:757-765.
47. Jaghagen EL, Bodin I, Isberg A. Pharyngeal swallowing dysfunction following treatment for oral and pharyngeal cancer--association with diminished intraoral sensation and discrimination ability. *Head Neck* 2008;30:1344-1351.

48. Patterson J, Wilson JA. The clinical value of dysphagia preassessment in the management of head and neck cancer patients. *Curr Opin Otolaryngol Head Neck Surg* 2011;19:177-181.
49. Molassiotis A, Rogers M. Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliat Support Care* 2012:1-8.
50. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *Eur J Oncol Nurs* 2011;15:145-151.
51. Pace-Balzan A, Rogers SN. Dental rehabilitation after surgery for oral cancer. *Curr Opin Otolaryngol Head Neck Surg* 2012;20:109-113.
52. Lee HF, Liu HE. Prospective changes of the quality of life for patients newly diagnosed with oral cancer during the acute stage. *Eur J Oncol Nurs* 2010;14:310-315.
53. Duke RL, Campbell BH, Indresano AT, et al. Dental status and quality of life in long-term head and neck cancer survivors. *Laryngoscope* 2005;115:678-683.
54. Petruson KM, Silander EM, Hammerlid EB. Quality of life as predictor of weight loss in patients with head and neck cancer. *Head Neck* 2005;27:302-310.
55. Epstein JB, Wilkie DJ, Fischer DJ, et al. Neuropathic and nociceptive pain in head and neck cancer patients receiving radiation therapy. *Head Neck Oncol* 2009;1:26.
56. Whale Z, Lyne PA, Papanikolaou P. Pain experience following radical treatment for head and neck cancer. *Eur J Oncol Nurs* 2001;5:112-120.
57. Jereczek-Fossa BA, Santoro L, Alterio D, et al. Fatigue during head-and-neck radiotherapy: prospective study on 117 consecutive patients. *Int J Radiat Oncol Biol Phys* 2007;68:403-415.
58. Sawada NO, de Paula JM, Sonobe HM, et al. Depression, fatigue, and health-related quality of life in head and neck cancer patients: a prospective pilot study. *Support Care Cancer* 2012;20:2705-2711.
59. Wells M, Donnan PT, Sharp L, et al. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. *J Clin Nurs* 2008;17:1428-1439.

Chapter 4

Nurse-led follow-up care for head and neck cancer patients: a quasi-experimental prospective trial

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Abstract

Purpose

The aim of this study was to compare conventional medical follow-up with follow-up containing additional nursing consultations regarding the psychosocial adjustment and health related quality of life (HRQoL) of head and neck cancer patients.

Methods

Using a quasi-experimental design, patients were enrolled consecutively into two groups. Experimental care covered six 30-minute bimonthly nursing follow-up consultations during the first year posttreatment. Data were collected at posttreatment months 1 (baseline), 6 and 12 for both groups.

Results

The intervention group was significantly worse at baseline, based on two of the seven adjustment scales and on the majority of HRQoL scales. However, their outcome at 6 and 12 months was consistent with that of the group which received conventional follow-up. Thus, the intervention group had a larger improvement in scores, and this was significant for one of the seven adjustment scales and 19 of the HRQoL scales at 6 and 12 months, respectively. Most of the differences in HRQoL scales were clinically relevant at 6 months.

Conclusion

These results suggest that nurse-led consultations for patients with head and neck cancer have a positive effect, primarily with respect to HRQoL. Nurse-led follow-up leads to a similar psychosocial adjustment as conventional follow-up, even among patients who showed worse performance at the start of follow-up. Thus, nurse-led follow-up may be a cost-effective way to improve follow-up care for this patient group.

Introduction

It is generally accepted that regular posttreatment surveillance is important for the general well-being of cancer patients, for the management of (late) complications, and for detecting recurrence of cancer in an asymptomatic stage.[1] It is also recognized that long-term routine follow-up in head and neck cancer (HNC) patients does not lead to improved survival and is inefficient at detecting recurrence.[2-4] For HNC patients, a rigid one-size-fits-all approach of follow-up is questionable, and there is currently an ongoing professional debate to determine the optimum duration and content of follow-up care.[4] However, other goals of follow-up care, (e.g., management of (late) complications, evaluation of treatment and psychosocial care) remain crucial and are being increasingly recognized as an important standard of care for cancer management.[1]

Specialized nurses are frequently considered as the appropriate professionals for assuming a role in cancer follow-up.[5-7] With regard to cancer populations such as breast, lung, prostate, colorectal and oesophageal cancer patients, nurse-led care has been found to be acceptable, appropriate and effective, and does not adversely affect patient quality of life compared with standard follow-up care by clinicians.[8-12] In a study of nurse-led follow-up for HNC patients undergoing radiotherapy, positive effects were found with respect to attendance at follow-up visits and no differences regarding health related quality of life (HRQoL) scores compared with physician appointments.[6]

In recent years, the Head and Neck Oncology Centre at our institute tested an integrated care program for HNC patients. The results suggested improvement, particularly with respect to information and psychosocial support.[13] Upon confirming the results by interviews with 21 HNC patients regarding the management of their discharge advice and posttreatment care, it was decided to start the current study.[14] In this trial, we compared predominantly medically oriented follow-up (i.e., conventional care) with follow-up that was expanded using structured nursing consultations (i.e., experimental care), focusing on supportive care and simple medical control checks. We hypothesized that the experimental care would result in improved patient outcomes on psychosocial adjustment and HRQoL relative to conventional care.

Materials and methods

Study design and setting

This quasi-experimental prospective single-centre study was conducted at the Radboud University Centre for Oncology in Nijmegen, the Netherlands. The study was a full-scale pilot in accordance with the guidelines of the Medical Research Council (MRC) Framework for the Evaluation of Complex Interventions.[15,16] A comparison group (*n*=80) and (after providing a training for nurses) an intervention group (*n*=80) were recruited consecutively. Ethical approval was obtained from the regional Medical Ethical Committee (CMO-nr. 2007/113), and the study was conducted in accordance with the Declaration of Helsinki.[17, 18]

Participants

The eligibility criteria for the study were as follows: informed of a HNC diagnosis (but no other cancer); to be treated with curative intent; to be able to speak, write and understand Dutch; and be cognitively able to provide informed consent. Exclusion criteria included overt psychopathology, alcohol addiction, and/or a life expectancy of less than 6 months. HNC patients who attended a weekly screening session were identified and approached by oncology nurses. For this purpose, the nurses used a written scenario. All participants provided a written informed consent. Patients were recruited to the comparison and intervention groups from November 2007 to July 2008 and from January 2009 to February 2010, respectively. A total of 170 eligible patients were asked to participate. Ten patients refused: six were not willing to participate, two preferred physician follow-up only, and two declined for other reasons.

The nurse participants were registered nurses currently working as legal registered oncology nurses. All of the nurses were female, (mean age 43 years) with a mean experience in the HNO field of 11 years (range 6-20 years). Nurses were eligible if they had indicated a willingness to receive training and supervision and to have their performance evaluated on a regular basis.

One nurse unexpectedly withdrew from the study. A new nurse was recruited and individually trained and instructed by the researcher. Subsequently, this nurse participated in the supervision, coaching and video recording as planned.

To compensate for this delay, the recruitment period for the intervention group was extended by 2 months.

Procedure

CONVENTIONAL CARE

The participants in the comparison group received conventional care that consisted of a 5-year routine control schedule with six bimonthly 10-minute visits to a head and neck surgeon in the first year posttreatment in accordance with national guidelines.[19] Nursing follow-up care consisted of ad hoc problem-based contacts except for patients who underwent a laryngectomy, who received standard nursing consultations during the first 6 months posttreatment in parallel with the medical control visits. Patients who were treated with surgery alone all had one standard wound control visit with a nurse; patients who were treated with radiotherapy had one to six ad hoc nursing contacts during the first 6 months posttreatment. For the duration of the study, there were no changes in conventional care.

EXPERIMENTAL CARE

The intervention consisted of six 30-minute nursing follow-up consultations in the first year posttreatment. A standardized protocol was used for this purpose. Nursing consultations were conducted in parallel with and preceding the medical routine control visits and included a needs assessment based upon the biopsychosocial model. [20] The aim of consultation was to give advice and support to patients (and their partners) addressing the physical and psychosocial consequences of treatment. To increase patient focus and active participation during consultations, patients completed a 13-item checklist prior to each consultation.[14, 21-23] Every 3 months, patients were screened for psychosocial problem areas using a specific questionnaire.[24]

During the consultations, the nurses also performed simple medical checks including inspection of the tracheal stoma, cannula and speech valve (if applicable), and oral cavity, and palpation of the neck and lymph nodes.

Training of nurses

Before recruiting patients to the intervention group, nurses participated in two 3-hour training sessions for the following items: 1) information regarding the biopsychosocial model and 2) performing a consultation using exploratory communication skills. Training sessions were developed and delivered in collaboration with a clinical psychologist (author J.P.). Also, two head and neck surgeons delivered a 2-hour training session regarding how to perform simple medical checks.

During the intervention period, nursing supervision meetings were planned every 2 months led by a clinical psychologist (J.P.). The aims were to share experiences from consultations, provide collegiate support, and address issues that obstructed execution of the intervention. Individual coaching of nurses was offered by the researcher by attending several consultations followed by reflective conversations afterwards.

Outcome measures

The primary outcomes were psychosocial adjustment and HRQoL. Psychosocial adjustment can be viewed as “the adaptive psychosocial response of an individual to a significant life change” [25] and was assessed using the Psychosocial Adjustment to Illness Scale – Self Report (PAIS-SR), a 46-item self-report measure that assesses changes in seven domains. A mean PAIS-SR T-score of 50 is the average score for each domain, meaning that patients with this score adjusted neither better nor worse than a mixed cancer reference group, whereas a score lower than 50 indicates better adjustment. The PAIS-SR is well validated and has been used in previous studies of HNC patients.[26-28] Here, we used the validated Dutch translation.[29]

HRQoL can be defined as; “a state of physical, mental and social well-being and not merely absence of disease or infirmity”.[30] HRQoL was measured with the European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire with additional Head & Neck Module (EORTC QLQ-C30 and QLQ-H&N35).[31,32] These are cancer-specific patient-based self-report questionnaires, and the psychometric properties of both have been tested thoroughly in several studies.[33,34] The core questionnaire was composed of five functioning scales, a global health status/QoL scale, and nine symptom scales. The additional H&N35 module contained 18 disease-specific symptom scales. All EORTC scores were transformed to a 0-100 scale in accordance with the procedures in the scoring manual.[32] A high score for the functional scales and for the global health status/QoL scale represents a high level of functioning, whereas a high score on a symptom scale represents a high level of symptoms.

Data collection

Data were collected from November 2007 to March 2011. Patient demographic and disease-related characteristics were retrieved from patient records. Questionnaires were delivered 1, 6 and 12 months after treatment. The baseline moment of the 1-month posttreatment questionnaire was set to a week before the first nursing consultation. To increase patient compliance in returning questionnaires several steps were taken, including postage-paid return envelopes, a postal reminder after one month, and, if necessary, a repeat postal reminder 1 month later together with a new set of questionnaires.

Statistical analysis

SPSS 18.0 was used to analyse the descriptive data. Baseline differences between groups with respect to sociodemographic and disease characteristics were tested using χ^2 test. Data were analysed on an intention-to-treat basis. To account for the similarity of each measurement within patients, a linear mixed model for repeated measurements was applied to analyse the effect of nurse-led follow-up consultations on the primary outcome variables. These models also account for missing data (provided that the missing data were missing at random). The SAS software package (version 8.2) was used to fit the models. Intervention and time (as well as their interaction) and the adjustment factors tumour location, size of the tumour (stage I, II vs. stage III, IV), treatment modality, living without a partner, and education (high vs. other) were included in the model as fixed effects. Differences between groups at baseline, 6, and 12 months, and differences in change from baseline to 6 and 12 months were estimated from this model. An unstructured covariance matrix was fitted.

To facilitate the interpretation of scores of differences in changes from baseline, the frequency of clinically relevant changes was analysed. A clinically relevant change in PAIS-SR was defined as a change of 1 standard deviation (10 units) in mean T-score compared to the preceding measurement.[26] For the EORTC, a clinically relevant change was defined as change of 10 points in mean scores.[35] No formal power calculation was performed, as this study was an exploratory trial. The sample size was determined by taking into consideration the number of patients lost due to recurrence of cancer and/or death.

Treatment fidelity

Several measures were taken to strengthen treatment fidelity in this study.[36] All of the nurses had similar levels of education, which is relevant when group training is provided. During training, standardized materials and role playing were used. To minimize the drift of skills after training, supervision meetings and individual coaching sessions were offered for the duration of the intervention period. To help the nurses and to improve delivery of the intervention as intended, we used a standardized consultation protocol. Additionally, video recordings of consultations were used to verify the actual professional performance (results will be reported elsewhere), and the researcher maintained contact with nurses several times per week to monitor intervention delivery, and to serve as a consultant.

Results

Demographic and disease characteristics are shown in Table 1. Both, educational level and treatment modality differed significantly between groups. No explanation other than coincidence was found to account for the difference in educational level. During the recruitment period of the intervention group, there was an increase in chemoradiation treatment for patients with stage III or IV malignancies. Consequently, more patients in the intervention group received this treatment, and this accounts for the difference in treatment modality between groups.

Response rate

At 12 months, 124 patients (78%) had returned their mailed questionnaires. The reasons for nonresponse were distributed as follows for the intervention and comparison groups, respectively: recurrence of disease, 4/4; death, 10/4; withdrawal from study, 2/1; other reasons, 5/6 patients. The number of non-responses was distributed evenly between the groups at 6 and at 12 months, with the exception of “death” (at 6 months, eight and two patients had died in the intervention and comparison groups, respectively).

Table 1. Demographic and Disease Characteristics per Group

	Intervention group (*n*=80)	Comparison group (*n*=80)
Gender		
Male	54 (67.5)	60 (75)
Age, years		
Mean [range]	58.4 [22-86]	59.2 [30-83]
Marital status		
Living with partner	56 (70.9)	58 (73.4)
Occupational status		
Employed	52 (67.5)	43 (55.8)
Educational level[a]		
High	29 (36.3)	14 (18.2)
Medium	19 (23.8)	22 (28.6)
Low	32 (40.0)	41 (53.2)
Caucasian race	79	80
Cancer site		
Larynx	14 (17.5)	23 (28.8)
Hypopharynx	7 (8.8)	1 (1.3)
Oropharynx	15 (18.8)	10 (12.5)
Oral cavity	32 (40.0)	34 (42.5)
Other	10 (12.5)	10 (12.5)
Stage (UICC – 2011)		
I	24 (30.0)	30 (37.5)
II	19 (23.8)	22 (27.5)
III	10 (12.5)	7 (8.8)
IV	24 (30.0)	12 (15.0)
No stage	2 (2.5)	0
Treatment modality [a]		
Surgery only	34 (42.5)	50 (62.5)
Surgery + Radiotherapy	11 (28.8)	9 (22.5)
Radiotherapy alone	23 (13.8)	18 (11.3)
Chemoradiation	12 (15.0)	1 (1.3)
Laser surgery	0	2 (2.5)

Figures in parentheses are percentages

[a] Significant difference between the groups ($\chi 2$ - test)

Table 2. Mean (SD) Scores of PAIS-SR and EORTC QLQ-C30 / EORTC QLQ-H&N35 at Baseline, 6 and 12 Months (n=160)

	Baseline (SD)		**6 months (SD)**		**12 months (SD)**	
PAIS-SR [a]	**intervention group**	**comparison group**	**intervention group**	**comparison group**	**intervention group**	**comparison group**
Health care orientation	54 (10) *	50 (8)	51 (8)	49 (9)	52 (9) *	48 (8)
Vocational environment	62 (7)	59 (7)	57 (7)	56 (7)	54 (7)	54 (7)
Domestic environment	46 (9)	44 (9)	43 (9)	42 (9)	42 (9)	41 (9)
Sexual relations	49 (9)	47 (9)	46 (8)	47 (9)	46 (8)	47 (9)
Extended family relations	49 (8)	50 (8)	49 (7)	52 (8)	49 (7)	49 (7)
Social environment	51 (15) *	45 (15)	43 (15)	43 (13)	42 (14)	42 (13)
Psychological distress	49 (10)	46 (10)	45 (10)	45 (10)	45 (11)	43 (10)
Total adjustment	50 (11) *	46 (12)	44 (12)	44 (13)	43 (13)	42 (12)
EORTC QLQ-C30						
Functional Scales [b]						
Physical functioning	71 (23) *	86 (17)	83 (17)	86 (16)	86 (17)	87 (16)
Role functioning	54 (32) *	75 (27)	79 (26)	81 (24)	81 (27)	85 (25)
Emotional functioning	80 (24)	83 (18)	84 (19)	85 (19)	82 (23)	85 (18)
Cognitive functioning	81 (23)	87 (19)	88 (17)	87 (17)	87 (20)	86 (21)
Social functioning	76 (25) *	88 (22)	91 (15)	90 (16)	90 (19)	91 (21)
Global health /QOL	64 (23) *	76 (17)	77 (16)	80 (18)	81 (18)	80 (17)
Symptom scales [c]						
Fatigue	46 (29) *	29 (23)	24 (21)	25 (23)	19 (25)	22 (24)
Nausea/vomiting	15 (29) *	7 (15)	3 (13)	4 (13)	3 (13)	4 (10)
Pain	35 (29) *	18 (22)	15 (22)	14 (23)	12 (22)	15 (22)
Dyspnoea	19 (26) *	9 (18)	10 (20)	14 (23)	12 (21)	12 (19)
Insomnia	29 (29)	23 (29)	20 (28)	18 (25)	19 (30)	18 (25)
Appetite loss	29 (35) *	12 (24)	13 (23)	9 (19)	7 (17)	8 (21)
Constipation	21 (30) *	10 (19)	8 (21)	6 (14)	7 (18)	6 (15)
Diarrhoea	10 (23)	7 (17)	5 (15)	6 (16)	4 (11)	8 (18)
Financial difficulties	10 (25)	8 (15)	7 (17)	8 (20)	8 (22)	7 (15)
EORTC QLQ-H&N35						
Symptom scales [c]						
Pain	38 (24) *	25 (22)	15 (16)	15 (14)	14 (17)	14 (18)
Swallowing	37 (30) *	20 (21)	4 (18)	11 (16)	9 (19)	10 (15)
Senses	29 (30) *	16 (20)	17 (24)	14 (21)	18 (26)	15 (23)
Speech	29 (27) *	17 (20)	12 (21)	8 (15)	11 (19)	10 (19)
Social eating	34 (27) *	16 (21)	15 (18)	9 (19)	10 (19)	9 (17)
Social contact	12 (18) *	6 (11)	6 (10)	4 (9)	5 (12)	3 (8)
Less sexuality	31 (35)	20 (29)	19 (26)	20 (29)	19 (27)	15 (23)
Teeth problems	15 (28)	23 (31)	15 (28)	17 (27)	11 (24)	12 (24)
Opening mouth	43 (35) *	24 (31)	17 (29)	14 (23)	11 (21)	10 (21)
Dry mouth	47 (36)	44 (30)	41 (33)	38 (35)	38 (34)	33 (33)
Sticky saliva	47 (38) *	33 (34)	34 (32)	23 (32)	25 (32)	22 (29)
Coughing	33 (33) *	20 (26)	16 (23)	20 (30)	20 (26)	15 (25)
Feeling ill	28 (33)	18 (26)	6 (17)	12 (24)	7 (22)	9 (18)
Use of pain killers	63 (49) *	43 (50)	29 (46)	24 (43)	22 (42)	22 (42)
Use of nutritional supplements	44 (50) *	22 (42)	22 (42)	13 (34)	9 (28)	8 (27)
Use of feeding tube	15 (36)	6 (24)	3 (18)	0 (0)	3 (18)	2 (12)
Weight loss	56 (50) *	26 (44)	16 (37)	17 (38)	15 (36)	13 (33)
Weight gain	13 (34) *	29 (46)	26 (44)	35 (48)	27 (45)	34 (48)

‡ $p<0.05$ (significant at this level, t-test for independent samples)

a PAIS-SR: Compared to a mixed cancer reference group, scores > or < 50 indicate worse or better adjustment, respectively. b EORTC: Higher score, better functioning (range 0-100). c EORTC: Higher score, more symptoms (range 0-100)

Psychosocial Adjustment

The baseline mean scores for the PAIS-SR (Table 2) were significantly worse in the intervention group for the domains of health care orientation, social environment and total adjustment (p =<0.05). At 6 months, no significant differences were observed between groups; at 12 months, health care orientation differed significantly between groups (p=<0.02), although the difference never exceeded 1 standard deviation.

Table 3 shows the results from the mixed model analysis. No significant difference between groups was detected in the change from baseline in PAIS-SR scores at 6 and 12 months, with the exception of the domain of social environment, in which the intervention group had significant worse scores at baseline (p=<0.05) but a 7.8 point (95%-CI=2.3, 13.2) and 6.7 point (95%-CI=1.3, 12.2) larger improvement than the comparison group at 6 and 12 months, respectively.

Analyses of clinically relevant changes are presented in Table 4. Nearly equal numbers of patients in both groups had improved by at least 1 standard deviation at 6 and 12 months. With respect to deterioration, however, at 6 months, more patients had deteriorated in the intervention group than in the comparison group. The largest difference was in the domain of social environment, with twice as many deteriorated patients in the intervention group as in the comparison group (27 vs. 13 patients, respectively). At 12 months, the number of deteriorated patients was approximately equal between groups.

Table 3. Differences in Change From Baseline (i.e., 1 Month After Medical Treatment) at 6 and at 12 months

	Baseline		**6 months**		**12 months**	
	score	(*p* value)[a]	Change from baseline (95%CI)[a]	*p*-value*	Change from baseline (95%CI) [a]	*p*-value*
PAIS-SR						
Health care orientation	2.6	(0.12)	-0.6 (-3.6,2.5)	0.71	0.0 (-3.1,3.2)	0.98
Vocational environment	2.7	(0.03)	-0.7 (-3.2,1.9)	0.59	-2.4 (-5.0,0.2)	0.07
Domestic environment	2.8	(0.09)	-1.8 (-4.7,1.2)	0.24	-2.4 (-5.4,0.6)	0.12
Sexual relations	0.7	(0.65)	-2.0 (-4.8,0.7)	0.15	-2.4 (-5.4,0.5)	0.11
Extended family relations	-1.0	(0.39)	-0.6 (-3.5,2.1)	0.64	0.3 (-2.2,2.9)	0.80
Social environment	5.1	(0.04)	-7.8 (-13.2,-2.3)	0.01	-6.7 (-12.2,-1.3)	0.02
Psychological distress	3.6	(0.07)	-1.8 (-5.1,1.5)	0.29	-1.2 (-4.5,2.2)	0.49
Total adjustment	3.3	(0.13)	-3.6 (-7.5,0.4)	0.07	-3.5 (-7.5,0.6)	0.09
EORTC QLQ-C30						
Functional Scales						
Physical functioning	-13.1	(0.00)	11.3 (4.3,18.4)	0.00	12.7 (5.8,19.7)	0.00
Role functioning	-17.8	(0.00)	21.1 (9.8,32.5)	0.00	17.3 (4.1,30.4)	0.01
Emotional functioning	-5.6	(0.18)	1.0 (-5.8,7.7)	0.77	1.0 (-6.0,8.0)	0.78
Cognitive functioning	-5.2	(0.21)	4.4 (-2.7,11.4)	0.22	5.9 (-1.3,13.1)	0.11
Social functioning	-12.4	(0.01)	12.9 (4.9,21.0)	0.00	11.5 (1.9,21.0)	0.02
Global health status/QOL	-10.4	(0.00)	8.7 (1.1,16.3)	0.02	12.1 (4.6,19.7)	0.00
Symptom scales						
Fatigue	15.5	(0.00)	-17.6 (-26.8,-8.3)	0.00	-19.2 (-29.1,-9.3)	0.00
Nausea/vomiting	9.3	(0.03)	-8.9 (-16.0,-1.9)	0.01	-10.3 (-17.9,-2.7)	0.01
Pain	16.7	(0.00)	-14.4 (-24.1,-4.7)	0.00	-17.9 (-27.7,-8.1)	0.00
Dyspnoea	9.7	(0.02)	-15.2 (-24,-6.4)	0.00	-10.8 (-19.1,-2.5)	0.01
Insomnia	5.2	(0.37)	-3.2 (-14.0,7.5)	0.55	-3.3 (-14.1,7.5)	0.55
Appetite loss	12.8	(0.02)	-10.4 (-20.6,-0.2)	0.04	-17.0 (-27.3,-6.7)	0.00
Constipation	14.3	(0.00)	-9.7 (-18.8,-0.7)	0.04	-12.2 (-21.2,-3.3)	0.01
Diarrhoea	2.5	(0.52)	-2.5 (-9.9,4.8)	0.50	-6.8 (-15.8,2.1)	0.13
Financial difficulties	3.0	(0.43)	-2.9 (-10.3,4.4)	0.43	-1.5 (-0.9,6.3)	0.71
EORTC QLQ-H&N35						
Symptom scales						
Pain	12.2	(0.01)	-11.2 (-19.5,-3.0)	0.01	-13.1 (-22.5,-3.7)	0.01
Swallowing	17.7	(0.00)	-12.2 (-21.5,-2.8)	0.01	-18.3 (-27.1,-9.4)	0.00
Senses	10.2	(0.02)	-9.6 (-17.1,-2.1)	0.01	-11.5 (-20.1,2.8)	0.01
Speech	13.3	(0.00)	-4.6 (-12.3,3.1)	0.24	-10.1 (-18.6,-1.7)	0.02
Social eating	17.1	(0.00)	-10.9 (-19.0,-2.9)	0.01	-17.2 (-26.3,-8.2)	0.00
Social contact	7.0	(0.02)	-4.5 (-9.5,0.6)	0.09	-5.1 (-10.2,-0.1)	0.05
Less sexuality	10.0	(0.09)	-11.5 (-21.8,-1.3)	0.03	-8.8 (-20.7,3.2)	0.15
Teeth problems	-7.5	(0.19)	10.3 (-3.5,19.3)	0.17	10.2 (-0.9,21.4)	0.07
Opening mouth	15.6	(0.01)	-15.0 (-27.9,-2.2)	0.02	-18.4 (-30.6,-6.2)	0.00
Dry mouth	-2.0	(0.75)	0.4 (-8.8,9.5)	0.94	3.5 (-7.7,14.7)	0.53
Sticky saliva	8.0	(0.21)	-4.0 (-16.1,8.0)	0.51	-8.7 (-20.9,3.5)	0.16
Coughing	13.6	(0.01)	-13.8 (-24.7,-2.9)	0.01	-6.1 (-16.8,4.6)	0.26
Feeling ill	10.7	(0.05)	-13.8 (-24.6,-2.9)	0.01	-10.5 (-20.6,-0.4)	0.04
Use of pain killers	20.7	(0.03)	-16.2 (-38.1,5.7)	0.15	-19.4 (-41.9,3.2)	0.09
Use of nutritional supplements	19.8	(0.02	-12.8 (-30.3,4.6)	0.15	-21.0 (-38.5,-3.5)	0.02
Use of feeding tube	9.3	(0.12)	-5.4 (-18.0,7.2)	0.40	-6.8 (-19.2,5.5)	0.27
Weight loss	25.3	(0.01)	-27.3 (-47.0,-7.6)	0.01	-25.4 (-47.4,-3.5)	0.02
Weight gain	5.4	(0.49)	6.6 (-13.1,26.3)	0.51	10.3 (-10.6,31.1)	0.33

* $p<0.05$ (significant at this level)

[a] Negative values for differences favour the intervention group

Table 4. Clinically Relevant Changes (Better or Worse) in Both Groups at 6 and at 12 Months

	6 months				**12 months**			
	improved		deteriorated		improved		deteriorated	
	i-group *n* (%)	c-group *n* (%)	i-group *n* (%)	c-group *n* (%)	i-group *n* (%)	c-group *n* (%)	i-group *n* (%)	c-group *n* (%)
PAIS-SR [a]								
Health Care Orientation	6 (9)	7 (10)	11 (17)	6 (8)	3 (5)	8 (12)	4 (7)	11 (17)
Vocational environment	4 (6)	1 (1)	17 (26)	11 (15)	1 (2)	4 (6)	9 (15)	7 (11)
Domestic Environment	6 (9)	8 (11)	10 (16)	6 (8)	3 (5)	7 (11)	6 (10)	9 (14)
Sexual Relations	5 (8)	2 (3)	11 (18)	2 (3)	4 (7)	2 (3)	7 (12)	5 (8)
Extended Family Relations	9 (15)	11 (16)	8 (13)	7 (11)	4 (7)	4 (6)	6 (11)	13 (20)
Social Environment	9 (14)	14 (20)	**27** (41)	**13** (15)	8 (13)	7 (11)	8 (14)	12 (18)
Psychological Distress	6 (9)	8 (11)	16 (25)	11 (16)	6 (10)	8 (12)	8 (14)	9 (14)
Total Adjustment	7 (11)	11 (15)	23 (35)	17 (24)	5 (8)	8 (12)	9 (15)	15 (23)
EORTC QLQ-C30 [b]								
Functional Scales								
Physical functioning	**30** (48)	**13** (19)	10 (16)	8 (11)	15 (25)	7 (11)	5 (9)	4 (6)
Role functioning	**39** (63)	**28** (41)	11 (18)	16 (23)	16 (27)	21 (33)	10 (17)	10 (16)
Emotional functioning	14 (23)	15 (21)	10 (16)	13 (19)	9 (15)	10 (16)	8 (14)	10 (16)
Cognitive functioning	**20** (32)	**9** (13)	13 (22)	11 (16)	13 (22)	12 (19)	10 (17)	12 (19)
Social functioning	26 (43)	19 (27)	8 (13)	13 (19)	12 (20)	12 (19)	11)20)	11 (17)
Global health status/QOL	**32** (52)	**20** (29)	6 (10)	10 (14)	15 (25)	12 (19)	6 (10)	14 (23)
EORTC QLQ-C30 [b]								
Symptom Scales								
Fatigue	42 (68)	34 (49)	**6** (10)	**22** (31)	22 (37)	23 (36)	9 (16)	9 (14)
Nausea/vomiting	15 (24)	9 (13)	1 (2)	4 (6)	4 (7)	5 (8)	2 (3)	6 (9)
Pain	**38** (61)	**25** (36)	7 (11)	15 (21)	15 (25)	17 (26)	**7** (12)	**17** (27)
Dyspnoea	**19** (31)	**6** (9)	6 (10)	13 (19)	5 (8)	9 (14)	5 (9)	8 (13)
Insomnia	21 (33)	20 (29)	8 (13)	13 (19)	11 (19)	12 (19)	10 (17)	12 (19)
Appetite loss	**23** (51)	**13** (19)	5 (8)	9 (13)	11 (19)	6 (9)	3 (6)	7 (11)
Constipation	19 (31)	11 (16)	5 (8)	6 (9)	9 (15)	4 (6)	3 (5)	5 (8)
Diarrhoea	6 (10)	8 (12)	4 (7)	5 (7)	5 (8)	4 (6)	3 (5)	8 (13)
Financial difficulties	5 (8)	6 (9)	6 (10)	4 (7)	3 (5)	6 (9)	4 (7)	5 (8)
EORTC QLQ-H&N35 [b]								
Symptom scales								
Pain	**38** (61)	**26** (38)	1 (2)	7 (10)	9 (15)	9 (14)	7 (12)	7 (11)
Swallowing	**35** (56)	**25** (36)	7 (11)	9 (13)	13 (22)	10 (16)	5 (9)	11 (17)
Senses	**33** (53)	**19** (27)	7 (11)	11 (16)	14 (24)	14 (22)	9 (16)	11 (17)
Speech	**42** (67)	**31** (44)	4 (6)	8 (11)	11 (19)	8 (12)	11 (19)	14 (22)
Social eating	**34** (54)	**19** (27)	3 (5)	3 (4)	**16** (27)	**5** (8)	6 (10)	9 (14)
Social contact	15 (24)	11 (16)	3 (5)	6 (9)	8 (13)	4 (6)	2 (3)	4 (6)
Less sexuality	**21** (34)	**10** (14)	7 (12)	10 (15)	11 (21)	10 (19)	8 (16)	5 (9)
Teeth problems	11 (18)	15 (22)	12 (20)	9 (14)	10 (17)	11 (18)	7 (12)	2 (3)
Opening mouth	**31** (50)	**20** (30)	6 (10)	6 (9)	12 (20)	11 (17)	5 (9)	6 (9)
Dry mouth	22 (35)	20 (29)	12 (19)	6 (9)	12 (20)	15 (23)	10 (17)	7 (11)
Sticky saliva	27 (44)	23 (33)	7 (11)	9 (13)	11 (19)	9 (14)	6 (11)	9 (14)
Coughing	**26** (42)	**16** (24)	8 (13)	13 (20)	4 (7)	11 (17)	11 (19)	8 (13)
Feeling ill	**29** (47)	**18** (27)	4 (7)	6 (9)	3 (5)	8 (12)	5 (9)	5 (8)
Use of pain killers	26 (41)	20 (29)	4 (6)	7 (10)	7 (12)	7 (11)	3 (5)	8 (12)
Use of nutritional supplements	**19** (30)	**8** (11)	4 (6)	2 (3)	10 (17)	4 (6)	4 (7)	2 (3)
Use of feeding tube	9 (14)	4 (6)	2 (3)	0	1 (1)	0	1 (2)	1 (2)
Weight loss	**26** (41)	**12** (17)	2 (3)	6 (9)	7 (12)	4 (6)	7 (12)	3 (5)
Weight gain	5 (8)	8 (12)	11 (19)	12 (18)	7 (12)	6 (9)	9 (16)	5 (8)

i-group intervention group, *c-group* comparison group. Bold figures indicate a difference of ≥10 patients between groups.

[a] PAIS-SR: figures based on a change of at least one standard deviation.

[b] EORTC QLQ-C30 & H&N35: Improvement by at least 10 points (better QOL and functioning or fewer symptoms).

Health Related Quality of Life

For most of the EORTC scales, baseline mean scores were significantly worse (p=<0.05) for the intervention group (Table 2). At 6 and 12 months, the mean scores were not significantly different between groups. At 6 and 12 months, differences in scores with respect to changes from baseline were significantly larger for the intervention group for many of the EORTC scales (Table 3). This was the case for 3 of the 5 functional scales, for global health status/QOL, for 6 of the 9 generic symptom scales, and 9 of the 18 specific head and neck scales at each time point. The most robust clinically relevant changes (i.e., a change of 10 points or more on a given scale) occurred at 6 months (see Table 4). For many items, more patients improved in the intervention group than in the comparison group. A difference of 10 patients or more (in favour of the intervention group) was observed for 3 of the 5 functional scales, for global health status/QOL, for 3 of the 9 generic symptom scales, and for 11 of the 18 specific head and neck scales. The largest difference between groups was seen with respect to fatigue at 6 months and for pain and social eating at 12 months, both differences favouring the intervention group.

Aspects of treatment fidelity

To determine to which extent the intervention was executed as planned, several aspects were evaluated. Patient participation in nursing follow-up consultations was deemed to be good; 480 consultations were planned, and 389 (81%) were realized. In addition, 70% (n=56) of the patients attended all consultation sessions. The reasons for failing to attend a consultation included: recurrence of disease and/or death (n=14), planning errors (n=5), withdrawal from study (n=2), and other causes (n=3). In 49% (189) of consultations nurses independently performed medical checks, 154 of which were verified by a physician (Table 5). In 37% (145) of the consultations, the nurses did not execute medical checks, but rather asked a physician for this task. This latter group of consultations was for laryngeal patients, as the required laryngoscopy had to be performed by a physician: thus, to minimize patient burden, nurses asked the physician to perform the other medical control checks as well. In 14% (55) of the nursing consultations, it was unclear whether (and how) medical checks were performed, as registration information was missing. The nurses themselves reported that the majority of consultations could be performed adequately within 30 minutes, and they reported an increase in work satisfaction, as they were now (in their words) “finally doing what I’m trained for”.

Table 5. Medical Control Checks by Nurses During Nursing Consultations (389 Consultations)

	Laryngeal patients	All other HNC patients	no.	%
Independent	1	34	35	9
Independent + checked by physician	5	149	154	40
Not executed, asked physician	145	0	145	37
Missing (performance not registered)	42	13	55	14
Total	193	196	389	

Figures are number of consultations

Discussion

Cancer follow-up is shifting slowly from the detection of recurrence towards the management of several aspects of cancer survivorship. Specialized oncology nurses are increasingly embedded in a multidisciplinary cancer care team to provide symptom management and supportive follow-up care. Several reviews have suggested that this care has the potential to add quality to cancer care and decrease costs; however, there is currently a paucity of sound economic evaluation research.[37,38] Substituting nurses for doctors is a potential next step in cancer care, but additional research is needed before nurse-led follow-up care can be considered equivalent to physician-led follow-up care in terms of survival, recurrence, and cost-effectiveness. Patient perspective with respect to follow-up care seems to be shifting as well. In a recent survey in the UK, when 263 HNC patients were asked, “who they would like to contact in a system based on patient-reporting problems and requesting appointments,” 45% (118 patients) stated a preference for a clinical nurse specialist.[39]

The results of our study show that nurse-led follow-up had positive effects on HRQoL, although effects were small and were not statistically significant. In the intervention group, in patients who were initially worse at baseline, psychosocial adjustment and HRQoL scores at 6 and 12 months reached same levels as in patients in the comparison group, which had received conventional care.

Therefore, the differences in the changes in scores from baseline between groups were significantly larger for the intervention group, and this effect was primarily in the HRQoL scores. More clinically relevant changes were more observed in the intervention group at 6 months for many of the disease-specific and generic HRQoL scores.

Patients in both groups experienced few significant problems with psychosocial adjustment (PAIS-SR). In a study by Vickery et al., a total adjustment score at 6-18 months posttreatment of 47-51 was reported.[28] In both our study groups, scores were lower, suggesting improved overall adjustment. Greer et al.[40] applied the PAIS-SR in a prospective design and tested a psychological therapy intervention in 174 patients, 9 of whom were HNC patients. In this randomized trial, no significant differences between groups persisted at the 4-month follow-up, with the exception of the domain of psychological distress. The mean total adjustment score in the experimental group was 50. At baseline (1 month post treatment), our intervention group reported minor disturbances in adjustment; therefore, possibilities for improvement were perhaps somewhat limited. The domain of health care orientation showed a small but significant difference in mean scores at 12 months in favour of the comparison group. This domain concerns the patient's perspective regarding health and health care. No explanation for this difference can be given except perhaps increased "health care awareness" among patients in the intervention group as a result of nurse-patient conversations causing a slightly more critical score in this domain. Because we did not measure pretreatment scores, it is unclear whether (and to what extent) any psychosocial adjustment had occurred during the course of treatment. It would be interesting, however, to determine how adjustment scores in disease-free HNC patients will develop over the coming years. This is particular important for patients with a permanent impairment and/or long-term symptom burden.

The EORTC questionnaire combined with the H&N35-module is a sensitive instrument for detecting differences in this patient population. The results of the HRQoL scores were more disparate than those of the PAIS-SR. Although there were no differences in mean scores between groups at 6 or 12 months, clinically relevant changes were more prevalent in the intervention group, thereby supporting the results of the mixed model analyses. In agreement with other HNC studies, the largest improvement in HRQoL scores in both groups occurred in the first six months posttreatment.[41,42]

In considering these findings, it is important to acknowledge the study's limitations. A key issue is the study design, which lacked randomization; thus, possible confounding factors may have influenced the results. The quasi-experimental design also limited the possibility of assessing causality. Due to practical and organizational limitations, conducting a randomized controlled trial was not feasible. Specifically, contamination was a potential problem, due to a small nursing staff (three nurses). Thus, a quasi-experiment (pre-test, post-test) with a historical control group was the best alternative.

In conclusion, oncology nurses can contribute considerably to further development and advancement of follow-up care for HNC patients. Although our single institution setting and some methodological disadvantages limit the findings, our results imply potential value and suggest improved outcomes for HNC patients. The nurse-led model that we used can be readily modified for use in other (cancer) patient populations. Future research regarding nurse-led follow-up care for HNC patients should focus on improvement of the intervention program, and on continued evaluation of patient's outcomes, including HRQoL. A possible multi centre implementation study of this nurse-led program combined with a thorough economic evaluation would provide valuable additional information for cancer follow-up care.

References

1. Dutch Health Council. Follow-up in Oncology. The Hague, Netherlands: Gezondheidsraad, 2007.
2. Ritoe SC, Krabbe PF, Kaanders JH, van den Hoogen FJ, Verbeek AL, Marres HA. Value of routine follow-up for patients cured of laryngeal carcinoma. Cancer 2004;101:1382-89.
3. Merkx MA, van Gulick JJ, Marres HA, Kaanders JH, Bruaset I, Verbeek A, de Wilde PC. Effectiveness of routine follow-up of patients treated for T1-2N0 oral squamous cell carcinomas of the floor of mouth and tongue. Head Neck 2006;28:1-7.
4. Joshi A, Calman F, O'Connell M, Jeannon JP, Pracy P, Simo R. Current trends in the follow-up of head and neck cancer patients in the UK. Clin Oncol 2010;22:114-8.
5. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: Conceptions of patients with head and neck cancer. Eur J Oncol Nurs 2007;11:49-59.
6. Wells M, Donnan PT, Sharp L, Ackland C, Fletcher J, Dewar JA. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. J Clin Nurs 2008;17:1428-39.
7. Wiederholt PA, Connor NP, Hartig GK, Harari PM. Bridging gaps in multidisciplinary head and neck cancer care: nursing coordination and case management. Int J Radiat Oncol Biol Phys 2007;69: S88-91.
8. Montgomery DA, Krupa K, Cooke TG. Alternative methods of follow up in breast cancer: a systematic review of the literature. Br J Cancer 2007;96:1625-32.
9. Cox K, Wilson E, Heath L, Collier J, Jones L, Johnston I. Preferences for follow-up after treatment for lung cancer: assessing the nurse-led option. Cancer Nurs 2006;29:176-87.
10. Anderson B. The benefits to nurse-led telephone follow-up for prostate cancer. Br J Nurs 2010;19:1085-90.
11. McFarlane K, Dixon L, Wakeman CJ, Robertson GM, Eglinton TW, Frizelle FA. The process and outcomes of a nurse led colorectal cancer follow up clinic. Colorectal Dis 2012;14(5): e245-e249.
12. Verschuur EM, Steyerberg EW, Tilanus HW, Polinder S, Essink-Bot ML, Tran KT, van der Gaast A, Stassen LP, Kuipers EJ, Siersema PD. Nurse-led follow-up of patients after oesophageal or gastric cardia cancer surgery: a randomised trial. Br J Cancer 2009;100:70-6.
13. Ouwens MM, Hermens RR, Hulscher MM, Merkx MA, van den Hoogen FJ, Grol RP, Wollersheim HC, Marres HA. Impact of an integrated care program for patients with head and neck cancer on the quality of care. Head and Neck 2009;31:902-10.
14. de Leeuw J, Prins JB, Merkx MA, Marres HA, van Achterberg T. Discharge advice in cancer patients: posttreatment patients' report. Cancer Nurs 2011;34:58-66.
15. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P. Framework for design and evaluation of complex interventions to improve health. BMJ 2000;321:694-96.
16. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 208;337:a1655.
17. Medical Ethical Committee Region Arnhem-Nijmegen Web site www.cmoregio-a-n.nl. Accessed January 15, 2012.

18. WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. (2008). Web site http://www.wma.net. Accessed January 15, 2012.
19. Dutch Head and Neck Society (NWHHT). Guidelines for Head and Neck Cancer. Web site www.oncoline.nl. Accessed: November 7, 2011.
20. Engel GL. The biopsychosocial model and the education of health professionals. Ann NY Acad Sci 1978;310:169-87.
21. Devlen J, Maguire P, Phillips P, Crowther D. Psychological problems associated with diagnosis and treatment of lymphomas. II: Prospective study. BMJ 1987;295:955-57.
22. Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. Pall Med 1997;11:283-90.
23. Uitterhoeve R, Bensing J, Dilven E, Donders R, Mulder P, van Achterberg T. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. Psycho-Oncol 2009;18:1060-68.
24. Garssen B, De Kok E. How useful is a screening instrument? Psycho-Oncol 2008;17:726-28.
25. Brennan J. Adjustment to cancer - coping or personal transition? Psycho-Oncol 2001;10:1-18.
26. Derogatis LR, Derogatis MF. PAIS & PAIS-SR. Administration, scoring & procedures manual - II. Towson, Maryland, USA: Clinical Psychometric Research Inc., 1990.
27. Ramirez MJ, Ferriol EE, Domenech FG, Llatas MC, Suarez-Varela MM, Martinez RL. Psychosocial adjustment in patients surgically treated for laryngeal cancer. Otolaryngol Head Neck Surg 2003;129: 92-97.
28. Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. Head Neck 2003;25:289-96.
29. Bekkers MJ, van Knippenberg FC, van Dulmen AM, van Den Borne HW, van Berge Henegouwen GP. Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: a 4-year follow-up. J Psychosom Res 1997;42:235-44.
30. World Health Organization. The Constitution of the World Health Organization. Chronicle 1 p 29 (1947). www.who.int Accessed: November 7, 2011.
31. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85:365-76.
32. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A. The EORTC QLQ-C30 Scoring Manual (3rd Edition). Brussels: European Organisation for Research and Treatment of Cancer, 2001.
33. Bjordal K, de Graeff A, Fayers PM, Hammerlid E, van Pottelsberghe C, Curran D, Ahlner-Elmqvist M, Maher EJ, Meyza JW, Bredart A, Soderholm AL, Arraras JJ, Feine JS, Abendstein H, Morton RP, Pignon T, Huguenin P, Bottomly A, Kaasa S. A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35) in head and neck patients. EORTC Quality of Life Group. Eur J Cancer 2000;36:1796-807.

34. Bjordal K, Hammerlid E, Ahlner-Elmqvist M, de Graeff A, Boysen M, Evensen JF, Bjorklund A, de Leeuw JR, Fayers PM, Jannert M, Westin T, Kaasa S. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. J Clin Oncol 1999;17:1008-19.
35. King MT. The interpretation of scores from the EORTC quality of life questionnaire QLQ-C30. Qual Life Res 1996;5: 555-67.
36. Bellg AJ, Borrelli B, Resnick B, Hecht J, Minicucci DS, Ory M, Ogedegbe G, Orwig D, Ernst D, Czajkowski S. Enhancing treatment fidelity in health behavior change studies: best practices and recommendations from the NIH Behavior Change Consortium. Health Psychol 2004;23:443-51.
37. Lewis R, Hendry M. A review comparing the effectiveness of nurse-led follow up for cancer with conventional care. Nurs Times 2009;105:25-27.
38. Goryakin Y, Griffiths P, Maben J. Economic evaluation of nurse staffing and nurse substitution in health care: a scoping review. Int J Nurs Stud 2011;48:501-12.
39. Trinidade A, Kothari A, Andreou Z, Hewitt RJD, O'Flynn P. Follow-up in head and neck cancer: patients' perspective. Int J Health Care Qual Assur 2012;25:145-49.
40. Greer S, Moorey S, Baruch JD, Watson M, Robertson BM, Mason A, Rowden L, Law MG, Bliss JM. Adjuvant psychological therapy for patients with cancer: a prospective randomised trial. BMJ 1992;304:675-80.
41. Hammerlid E, Silander E, Hornestam L, Sullivan M. Health-related quality of life three years after diagnosis of head and neck cancer--a longitudinal study. Head Neck 2001;23:113-25.
42. Abendstein H, Nordgren M, Boysen M, Jannert M, Silander E, Ahlner-Elmqvist M, Hammerlid E, Bjordal K. Quality of life and head and neck cancer: a 5 year prospective study. Laryngoscope 2005;115:2183-92.

Chapter 5

Cue-responding behaviours of oncology nurses in video-simulated interviews

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Abstract

Aim

This paper is a report of a study to describe nurse-patient interactions, i.e., nurses' cue-responding behaviour in encounters with an actor playing the role of patients.

Background

Patients with cancer seldom express their concerns directly but express cues instead. Few studies empirically investigated nurses' cue responding behaviour and the subsequent influence of disclosure of cues and concerns.

Methods

In this descriptive observational study, conducted from April 2004 to June 2004, five oncology nurses interviewed an actor playing the role of a patient with cancer. Each nurse performed seven different interviews (n=35); these were videotaped and subsequently rated for cue responding using the Medical Interview Aural Rating Scale. Mixed model analysis was used to investigate the relation between cues and cue responding.

Findings

Half of the patients' cues were responded to with distancing behaviours. The other half of the cues were either explored (33%) or acknowledged (17%). In 16% of these responses, nurses used open directive questions. One out of four open directive questions were used as a distancing response, suggesting that open directive questions are not used to explore or acknowledge cues of patients. Cue responding influenced subsequent expression of concerns and emotions, i.e., disclosure of a concern is two times higher after exploration or acknowledging of a preceding cue than after a distancing response.

Conclusion

Cue responding is a valuable concept which can contribute to our understanding of optimal ways of communicating. Cue responding behaviour facilitates the disclosure of worries and concerns of patients. Further research is needed to assess the clinical relevancy of cue responding.

Introduction

Patients seldom express their concerns and emotions directly and spontaneously, but instead express indirect cues that something is worrying them. [1, 2] A core skill for nurses is therefore to recognise cues of patients that are clinically relevant, but not directly expressed.[3] Patients' cues are typically embedded in dialogues that take place throughout the nursing hours of a day, i.e., during bedside care, on admission or at discharge interviews and even during 'social talk'. Nurses therefore, have many opportunities to pick up cues of patients, which may lead to the recognition of those needing emotional support. Distancing from cues, on the other hand, may result in leaving patients leave patients with unrecognized emotional sorrow or psychological problems, and may prevent them from receiving the care they require. It is frequently observed that nurses overlook patients' social and emotional needs, focusing instead on physical care.[4-7] It has been observed that only 20 - 55% of existing patient concerns are adequately identified, which are predominantly related to physical symptoms.[4-6, 8] Studies have shown that nurses often use blocking behaviour (ranging from 55% to 75% of occasions), thus avoiding subjects that are emotionally charged, rather than encouraging patients to express their concerns.[9] In a recent descriptive study[10], which aimed to identify problem areas in care for patients receiving chemotherapy, professional caregivers (medical oncologists and oncology nurses) and patients alike reported that affective communication, in particular, is in need of improvement. Other studies suggest that patient outcomes, such as satisfaction with care and quality of life, are most affected by the emotional dimension of communication.[11, 12] Improving the emotional dimension of nurse-patient communication in cancer care is thus clearly a relevant area for research.

Background

Our study was developed to investigate a specific area of the emotional dimension of provider-patient communication: responding to cues about worries and concerns. A review of the literature[13] identified two advanced observation instruments that are capable of methodological identification and coding of cues expressed by patients and provider responses. Both instruments are specially developed for the oncological setting and are suitable for research into patient-nurse communication: the Cancer Research Campaign (CRC) Utterance by Utterance rating scale[9, 14] and the Medical Interview Aural Rating Scale (MIARS).[15]

The CRC scale was developed from a number of theoretical insights, including Bandura's Social Cognitive Learning Theory[16, 17], Hobson's conversational model of psychotherapy[18, 19] and Davenport *et al.*'s [20] and Goldberg *et al.*'s [21] work on cues. The MIARS grew out of the Utterance by Utterance rating scale as a shorter and less complex rating system developed to assess nursing communication skills in encounters with patients with cancer.

In the MIARS [15], the basic unit of observation is each turn of speech, for both nurse and patient. Patients' turns can be coded as cues and concerns. In 2005, the *European Association of Communication in Health Care* (EACH) reached consensus on the definition of 'cue' and' concern'.

A cue has been defined as:

> *"... a hint, which might be an expression or signal, mostly verbal but also nonverbal, which indirectly indicates an issue of presumed importance for the patient and implies an emotion, worry or uncertainty that the patient would like to bring up, or a move to another topic, that should demand an exploration from the provider".*

A concern is described as:

> *"... a verbal expression, which explicitly indicates an issue of importance for the patient".* [22]

The MIARS distinguishes three levels of patients' cues, depending on the extent that feelings are disclosed. A phrase from a patient that hints at a worry or concern, is coded as a level 1 cue.[15] An expression that explicitly mentions worry or concern is coded as a level 2 cue, and a clear expression of emotion (e.g., anger or crying) is coded as level 3.[15] Each turn of a nurse can be coded according to its function and form. Function includes whether the cue is explored (by eliciting, clarification or an educated guess), acknowledged but not explored (by an empathic statement, reflection or checking) or distanced from (for instance, by inappropriate reassurance, premature advice or switching focus).[15] Form includes morphological aspects of the turn, i.e. taking into account if the turn contains a directive open question, a screening question, a negotiation question or summarizing. A directive open question, as opposed to a closed question that can be answered with a simple 'yes' or 'no', requires a more elaborative response (You say you are worrying - in what way?).

Screening questions ask if there are concerns, worries, problems, thoughts or issues of presumed importance, which are not yet discussed. Negotiation questions refer to asking consent from a patient about the process of the discussion (Do you agree if we close this part of the discussion and continue to talk a bit more about how you are coping with the side-effects of the treatment?). Summarizing refers to a response from a nurse that summarizes information, concerns or feelings which are expressed in preceding turns of the current discussion, with the intention to give feedback to the patient.[15]

Although the potential influence of cue responding on the perceived quality of nurse-patient communication has been acknowledged, relatively little is known about how nurses' respond to emotional cues of patients and the subsequent influence on the further expression of cues and concerns. Therefore, in this study, we attempt to describe cue-responding behaviour in oncology nursing using the MIARS as the most appropriate instrument for this purpose.

The study

Aim

The aim of this study was to describe nurse-patient interaction, i.e. nurses' cue-responding behaviour in encounters with an actor playing the role of patients.

Design

A descriptive observational study was conducted, using videotaped discussions with an actor playing the role of oncological patients. The data were collected from April 2004 to June 2004.

Participants

Registered Nurses from a medical oncology inpatient clinic of a large teaching hospital in the Netherlands were asked to participate in the study. Seventeen of 35 nurses were eligible for study participation, i.e. were employed as a Registered Oncology Nurse (a legal qualification in the Netherlands) with a 0.6 to 1.0 job assignment. Four nurses declined to participate because videotaping of their performance distracted them from their work. Of the remaining 13 nurses, five were randomly selected for actual participation.

These five nurses were female, between 40 and 48 years of age, with a median of 15 years (range 5-18 years) experience in oncology nursing.

Data collection

Instrument

In this study, we used 'turns' as the unit of observation. A turn is everything a current speaker says before the next speaker takes over.[23] Two reviewers (RU and JdL) independently coded the videotapes. We classified patients' turns of speech using the *Cues* class of the MIARS, showing whether the turn was neutral (level 0), or whether it contained a cue. When a cue was present, we classified it into one of three levels, depending on emotional intensity (column 1, Table 1). We coded nurses' turns of speech in different ways: first, in terms of the function as a response to the patient's turn of speech and, secondly, for its form. The *Function class* refers to the degree of adequacy of the cue-response, and can either facilitate or inhibit further disclosure of emotion (see column 1, Table 1). The *Function* class consists of the following elements: cue acknowledgement and cue exploration, composing adequate cue-responding behaviour, and distancing from cues which is distinguished as inadequate cue-responding behaviour. The *Form* class measures behaviours for which clear evidence of impact on patient disclosure has been established: i.e. use of open directive questions, screening, summarizing and negotiation.[9, 21, 24]

To obtain a complicated data set in an accessible way and to ease coding procedures, we incorporated into the MIARS classes into OBSERVER VIDEO-PRO software.[25] This software enables direct coding while observing the videotaped nurse and patient behaviour and without transcribing the discussions. The validity of this software when used with the MIARS has been demonstrated.[26] To ensure consistent coding between the two raters, both received training in the use of the OBSERVER VIDEO-PRO software.[25] This one-day training consisted of an introduction to the configuration of the MIARS, becoming familiar with the description of the relevant patient and nurse behavioural classes and elements, and coding rules and coding process using the OBSERVER data entry module. The reviewers practised coding until questions and uncertainties using the system were resolved.

Table 1. Patient and Nurse Behavioural Elements of the Medical Interview Aural Rating Scale (MIARS)

Behavioural elements of MIARS	Frequencies *n* (%)	Degree of agreement
Patients' cue-emission behaviour:		
Cues[†]		
Level 0 (neutral expression)	311 (33)	0.77
Level 1 (expression that hints worry or concern)	370 (39)	0.72
Level 2 (expression that mentions worry or concern)	132 (14)	0.50
Level 3 (clear expression of unpleasant emotion)	145 (15)	0.80
Nurses' cue-responding behaviour[‡]:		
Function class[†]:		
Adequate response – exploration and acknowledging	319 (50)	
Exploration:	*209 (33)*	0.73
Eliciting	*62*	*0.62*
Clarification	*73*	*0.61*
Educated guess	*74*	*0.57*
Acknowledging	*110 (17)*	0.56
Empathy	*37*	*0.55*
Reflection	*24*	*0.36*
Checking	*47*	*0.48*
Inadequate response – distancing:	321 (50)	0.78
Factual clarification	*34*	*0.44*
Inappropriate reassurance	*25*	*0.67*
Premature advice	*38*	*0.55*
Passing the buck	*15*	*0.40*
Switching focus	*171*	*0.64*
Blocking	*37*	*0.26*
Form class[§]:		
Directive question	154 (16)	0.79
Screening	19 (2)	0.71
Negotiating	47 (5)	0.81
Summarizing	8 (<1)	0.78

[†] Elements are mutually exclusive
[‡] Classes are not mutually exclusive
[§] Elements are not mutually exclusive

Inter-rater reliability data on the behavioural elements of cue-acknowledgement, cue-exploration and cue-distancing has been published by Heaven and Green[15], while unpublished data are available in Schofield[27] and Fletcher[28]. Heaven's work shows intra-class correlation coefficients (ICCs) of reliability for cue-acknowledgements of r=0.71 (95% CI 0.60 – 0.82), and r=0.77 (95% CI 0.67 – 0.86) and r=0.71 (95% CI 0.59 – 0.82) for cue exploration and distancing respectively. These studies all took place in a single centre and it is therefore important to confirm the reliability of the MIARS in studies conducted in other centres.

In the present study, inter-rater reliability coefficients (κ) for the coding of the cues and functional class were 0.74 (95% CI: 0.70-0.78) and 0.76 (95% CI: 0.71 – 0.80), respectively. A coefficient (κ) between 0.60 and 0.80 is accepted as good agreement.[29]

The level of agreement between both raters regarding coding of the separate elements of the *cues, function and form* class, where events of specific behaviours can only be coded as present, was estimated as the probability that the second rater would agree with the first rater. This method is independent of the number of observations in which both observers would code a specific behaviour as not present.[30, 31] These reliability data are displayed in the 'Degree of agreement' column of Table 1. In relation to the elements of the *cues* class, the highest probability of 0.80 was found for level 3, and the lowest probability of 0.50 for level 2. For the elements of the *functional* class (i.e. exploration, acknowledging and distancing), probabilities ranged from 0.78 for distancing to 0.56 for acknowledging ('Degree of agreement' column, Table 1). At the level of actual nurses' cue-responding behaviour the degree of agreement of single elements of the different behavioural classes is notably lower than the agreement value of the classes themselves ('Degree of agreement' column, Table 1). The elements 'reflection', 'passing the buck' and 'blocking' clearly stand out, with levels of 0.36, 0.40 and 0.26, respectively. The ICC for the overall cue-responsiveness score, using the two-way mixed effects model of consistency and single measure statistic, was 0.78 (95% CI: 0.59 – 0.88). According to Fleiss[32], ICC values above 0.75 represent excellent reliability.

Procedure

During the data collection, nurses' interviews with an actor playing the role of patients were videotaped. We used a single professional actor, experienced in simulating interviews, to play the role of a patient with cancer. Elaborate, standardised scripts were used to ensure that the actor enacted the same patient role during each nurse encounter. The content of the scripts was based on cases that experienced oncology nurses (N=10) brought to a meeting to discuss distinguishing characteristics of nurse-patient conversation in oncology care. At the end of this meeting, different scripts were composed relating to a middle-aged female patient and subsequently checked for realistic content. These scripts were studied by the professional actor and subsequently discussed and practised until she was able to perform the scripts consistently. This procedure was used to reduce patient variation and improve comparability of the nurses' performance.

For each participating nurse, seven conversations were scheduled. Each nurse performed the same sequence of seven conversations, played by the same actor according to the different scripts. Prior to each interview, nurses were given a short description of the patient's history and given an opportunity to ask questions for clarification of the description. Subsequently, they were asked to discuss the patient's present concerns for approximately 10 minutes. They were informed that, after 10 minutes, videotaping would terminate. The video-recording was performed with no researcher present and the discussion took place in a patient room at an oncology outpatient clinic. This process produced 35 videotaped discussions of approximately equal length.

Ethical considerations

As no real patients were involved in this study, approval of the ethics committee was not required. However, we did inform the ethics committee about the study and received a letter stating that they had no objection to the study. The study was approved by the administration of the division of internal medicine and by the chief physician and the head nurse of the ward involved. Participation was voluntary and nurses' oral and written consent to participate in the study was obtained. The professional actor who played the part of the patient was paid for her contribution. Nurses were informed that the patient was an actress.

Data analysis

We performed sequential analysis to investigate how nurses responded to patient cues and how patients reacted to nurses' responses. Sequential analyses traced sequences of specific patient and nurse behaviour and resulted in a matrix, in which each cell contained the frequency with which a specific type of behaviour followed another. Every interview contained several cues, and every nurse had an opportunity to respond to several of these cues. As a result, there were two levels of variability. At the highest level, there were differences between the nurses and differences between the interviews (variation between nurses and interviews). At the lowest level, there were differences between the cues and responses per nurse and per interview (variation within nurses and interviews). These two levels of variability made it necessary to analyse the relationship between the two variables using a two-level (mixed) model. Such a model requires inclusion of the highest levels as random factors, while the other variables are included as fixed factors. In our analysis, we therefore included the random factors of nurse and interview.

For analysis of the responses, the dependent variable was ‘response’ (adequate vs. inadequate) and the fixed factor was ‘preceding cue’ (levels 2 and 3 vs. level 1). To estimate the ratio between the responses, a multiplicative link function (i.e. log link function) was used, with Bernouilly distribution for the dependent variable.[33, 34] A similar approach was used for analysis of the patient’s reaction of the subsequent nurse response. In this case, the dependent variable was ‘cue level’ (2 and 3 vs. 1) and the fixed, independent variable was ‘previous response’ (adequate vs. inadequate).

Results

Nurses’ behaviour

Description of nurses’ cue-responding behaviour

Of the scheduled 35 interviews, three interviews were cancelled because nurses were not available to perform the interview. One videotaped interview was inaudible because of equipment failure and therefore excluded from our analysis. The two reviewers (RU and JdL) rated the remaining 31 interviews.

Each interview contained a median number of 20 cues (minimum 9 cues to maximum 30 cues). The ‘Frequency’ column of Table 1 shows the distribution of behavioural elements of the MIARS across patients and nurses. One-third of the patient turns involved neutral expressions by the patient (level 0). Approximately one-third (39%) of patient turns were expressions that signalled worry or concern (level 1), and another third of the turns mentioned worry or concern (14% cue level 2) or clearly expressed unpleasant emotion (15% cue level 3). Thus, in the 31 interviews 647 cues were given.

The elements of the *Function* class, i.e. adequate (exploring and acknowledging) and inadequate responses (distancing), were evenly distributed. About 32% of the 647 cues were explored, 17% were acknowledged and 50% were responded to with distancing behaviours. The most prevalent inadequate response to patient cues was switching the focus away from cues: 53% of the 321 inadequate responses were classified as such. The extracts shown in Figure 1 illustrate adequate and inadequate responses of nurses to patients’ cues.

We also coded nurses’ turns in the *Form* class of the MIARS (see Table 1). A minority of the turns could be coded with elements of this class: namely, 16% of nurse turns were coded as open directive questions, 2% as screening, 5% as negotiating, and less than 1% of the nurse turns were coded as summarizing. A vast majority (77%) of the turns was coded as miscellaneous. Turns that were coded as ‘open directive questions’ were predominantly (52%) used in combination with ‘exploring’ or ‘acknowledging’. Open directive questions were also used in combination with ‘distancing’ in 21% of the cases.

Figure 1. Nurses’ Responses to Patients’ Cues Coded With the Medical Interview Aural Rating Scale (MIARS).

	Inadequate responses to cues of patients:	**MIARS coding**
P	…and treatment – I just don’t know. On the one hand I think, ‘Yes, I go along with treatment’ but, on the other hand, my children will see my suffering, the hair loss, the sickness – and I am afraid they will take a distance.	Cue-level 2
N	You have two girls, how old are they?	Distancing
P	I feel sad, so sad, so angry and sad. I am angry at everyone who can walk out of here.	Cue-level 2
N	You say that you’re sad…I just saw your family leaving. How was their visit?	Distancing, open directive question
P	I am afraid, terribly afraid of dying, letting go (crying). Where an I…? Uuh…it is a black hole, and then I think…	Cue-level 3
N	Did you talk about this with a priest?	
P	I feel down, worrying what is hanging over my head, and yes I have no appetite either, and stabs of pain…	Cue-level 2
N	And, the pain…Is it under control?	Distancing
	Adequate responses to cues of patients:	
P	I don’t have a choice really. When I don’t do it (treatment), the I surely…and then I think, ‘What am I inflicting on them?’ (the patients’ children)	Cue-level 1
N	So, actually you are worried about how this affects your children?	Exploring
P	I just can’t handle it this way, on my own, and it makes me afraid that I’ll lose control.	Cue-level 1
N	Listening to you, I have the idea that you feel that you’re on your own and that you feel that you need support to cope better with what’s going on.	Acknowledging
P	I can’t stop crying. I’m in panic all the time.	Cue-level 2
N	What exactly brings about this feeling of panic/	Exploring, open directive question

Sequences of nurse –patient behaviour

Mixed model analysis shows that the proportion of adequate responses to cues with level 1 is equal to the proportion of adequate responses to cues with levels 2 and 3, with a ratio of 1.02 (95% CI: 0.82 – 1.24). Table 2 shows that half the cues with level 1 and levels 2 and 3 are responded to adequately. Table 3 shows the number of sequences of the nurse responding to a preceding cue and the reaction of the patient. The chances that patients clearly express an unpleasant emotion, raise a worry or concern (cue levels 2 and 3) is about two times higher after an adequate response than after an inadequate response, with a ratio of 1.92 (95% CI: 1.40 – 2.64).

Table 2. Number of Nurses' Responses to the Different Levels of Patients' Cues

	No response	Adequate response (exploration and acknowledging)	Inadequate response (distancing)
Level 0	319 (100)	-	-
Level 1	-	191 (50)	191 (50)
Level 2	-	69 (51)	67 (49)
Level 3	-	76 (52)	70 (48)

Figures in parentheses are percentages

Discussion

Cue-responding is an exciting new concept in communication research. The concept concurs with the sequential nature of communication. Analysis of sequences of patients' cue emissions and providers' responses provides empirically-based insight in how patients and providers influence one another. Our current study shows that patients are clearly responsive to adequate responses of nurses to their cues, and suggests that there is a case for teaching nurses adequate cue-responding skills.

A strength of this current study lies in the use of an actor playing the role of the patient, as this reduces patient variations and improves comparability of the nurses' performance. At the same time, the use of an actor may alter nurses' behaviour towards displaying 'ideal' behaviour. We have no indication that this phenomenon actually occurred, especially as our findings reflect those of Heaven [8], which were based on real encounters. The sample of nurses was randomly selected but small, which may impede generalization of the findings.

Table 3. Number of Different Cue Levels After Adequate and Inadequate Response of Nurses

	Cue level 0	Cue level 1	Cue level 2	Cue level 3
No response	192 (56)	115 (33)	22 (6)	15 (4)
Adequate response (exploration and acknowledging)	28 (9)	134 (42)	79 (25)	76)24)
Inadequate response (distancing)	108 (33)	136 (42)	29 (9)	54 (17)

Figures in parentheses are percentages

One-third of the patients' cues in this study were explored, one-sixth acknowledged, while in half, the nurses, in one way or another, distanced themselves. Only recently, as sequential analysis has become feasible, has cue-responding gained importance as a relevant outcome measure in patient–provider communication research. [35] There are, therefore, few studies with which to compare our findings. The two studies that investigated cue-responding in patient-nurse communication showed similar results regarding the use of distancing behaviours.[8, 36] This reveals that there is room for improvement. Similar to the study of Heaven[8], we also found that 50% of the cues were responded to adequately. Yet the percentage of cues that were adequately responded to by either exploration or acknowledging were reversed in comparison to Heaven.[8] They found that 29% of the cues were acknowledged and 12% of the cues were explored. The most used distancing behaviour in our study was 'switching the focus' away from the cue. This means that, although attention is paid to something the patient said, it is not directed to the part with the emotional tie, i.e. not to the part that contains the issue of presumed importance for the patient. Another important finding is that nearly one quarter of the 'open directive questions' in this study were used as inadequate responses to patients' cues, showing that open directive questions are not always appropriate. These findings reflect those of Fletcher[28], who showed that open directive questions used as a response to cues were three-and-a-half times more likely to elicit further disclosure than those not related to a patient cue. Consequently, communication training should not focus on teaching the use of 'open directive questions' *per se*, but should consider matching the patients' preceding turn as an important directive. The limited use of negotiation, screening questions and summarizing was in line with the findings of Heaven.[8]

Sequential analysis of the data does not provide evidence about the influence of the emotional level of cues on the subsequent response of the nurse. This finding is inconsistent with what is generally assumed[37-42] and empirically supported by others[43, 44], i.e. that higher emotional cue levels are related to the use of distancing behaviours. However, our findings agree with those of De Valck [45], who found no correlation between level of expressed emotion and the communicative reaction of the provider.

A key finding of our study is that cue-responding influences the expression of concerns and emotions. The chance of an expression of cue levels 2 and 3, after an adequate response, is one-and-a-half to two-and-a-half times higher than after an inadequate response from the nurse. This outcome has clinical value because it demonstrates that patients are clearly responsive to adequate responses to their cues from nurses. This confirms that there is a case to teach nurses adequate cue-responding.

Our study raises several questions that could be examined in future research. Although this is an observational study, the findings suggest the relevancy of training nurses in the use of cue-responding behaviour. Examining whether the use of open directive questions, screening, negotiation and summarizing to explore or acknowledge preceding cues could be improved by training would be of great value. This is especially the case, as our study showed that these behaviours are seldom used, although it is known that they encourage disclosure of concerns. For instance, a recent study [24] showed that screening questions like ‘What else?’ or ‘Are there any other concerns that you want to discuss?’ improved further disclosure of concerns and reduced patients’ anxiety. As this study does not address the clinical relevancy of provider cue-responding, we also recommend that future research should study the value patients assign to the cue-responding behaviour of nurses, and which improvement in cue-responding are perceived as meaningful by patients. Another interesting topic for future research would be whether nurse-patient communication differs between European countries, and between European and non-European countries in terms of adequate and inadequate responses.

The current study identifies cue-responding as an important skill for nurses in cancer care. We identify the teaching of cue-responding skills as an important aim of communication skills training and propose cue-responding as an appropriate skill in and of itself.

Even in the context of *information provision* or *patient education*, cue-responding skills are necessary, especially as cue-responding provides an opportunity to acknowledge emotional distress of patients that may hinder their understanding of information being given. Because of limited resources in current health care, and the high cost of communication training, as a first stage, we recommend careful evaluation of the effectiveness of such a training program. We emphasize that such a training program should address the problem of transferring learned behaviour to practice by incorporating transfer strategies into the training programme.[8, 43, 46-49]

Conclusion

Sequential analysis of strings of patients' cues and nurses' responses allows inferences to be made about how nurses and patients influence one another. Sequential analysis contributes to our understanding of optimal ways of communicating with patients with cancer. This study showed that adequate cue-responding behaviour from nurses facilitates the disclosure of worries and concerns by patients. This method for analysing nurse-patient communication has satisfactory reliability indices and would support the future use of the MIARS in research on nurse-patient communication in cancer care.

References

1. Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM (2002) Oncologists' reactions to cancer patients' verbal cues. Psycho-Oncol 11: 47-58
2. Suchman AL, Markakis K, Beckman HB, Frankel R (1997) A model of empathic communication in the medical interview. JAMA 277: 678-682
3. Eide H, Quera V, Graugaard P, Finset A (2004) Physician-patient dialogue surrounding patients' expression of concern: applying sequence analysis to RIAS. Social Science and Medicine 59: 145-155
4. Farrell C, Heaven C, Beaver K, Maguire P (2005) Identifying the concerns of women undergoing chemotherapy. Patient Educ Couns 56: 72-77
5. Heaven CM, Maguire P (1997) Disclosure of concerns by hospice patients and their identification by nurses. Pall Med 11: 283-290
6. Hill KM, Amir Z, Muers MF, Connolly CK, Round CE (2003) Do newly diagnosed lung cancer patients feel their concerns are being met? European Journal of Cancer Care 12: 35-45
7. Parle M, Jones B, Maguire P (1996) Maladaptive coping and affective disorders among cancer patients. Psychological Medicine 26: 735-744
8. Heaven C, Clegg J, Maguire P (2006) Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. Patient.Educ.Couns. 60: 313-325
9. Maguire P, Faulkner A, Booth K, Elliott C, Hillier V (1996) Helping cancer patients disclose their concerns. European Journal of Cancer 32A: 78-81
10. Uitterhoeve R, Duijnhouwer E, Ambaum B, van AT (2003) Turning toward the psychosocial domain of oncology nursing: a main problem analysis in the Netherlands. Cancer Nursing 26: 18-27
11. Bensing J (1991) Doctor-patient communication and the quality of care. Soc Sci Med 32: 1301-1310
12. Ong LM, Visser MR, Lammes FB, de Haes JC (2000) Doctor-patient communication and cancer patients' quality of life and satisfaction. Patient.Educ.Couns. 41: 145-156
13. Caris-Verhallen W, Timmermans L, van DS (2004) Observation of nurse-patient interaction in oncology: review of assessment instruments. Patient.Educ.Couns. 54: 307-320
14. Booth K, Maguire P, Hillier VF (1999) Measurement of communication skills in cancer care: myth or reality? Journal of Advanced Nursing 30: 1073-1079
15. Heaven CM, Green C (2001) Medical Interviewing Aural Rating Scale. Psychological Medicine Group, Christie Hospital, Manchester, 2001.
16. Bandura A (1986) Social Foundations of Thought and Action: A Social Cognitive Theory. Prentice-Hall, Englewood Cliffs, USA
17. Parle M, Maguire P, Heaven C (1997) The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. Soc Sci Med 44: 231-240
18. Goldberg DP, Hobson RF, Maguire GP, Margison FR, O'Dowd T, Osborn M, Moss S (1984) The clarification and assessment of a method of psychotherapy. Br J Psychiatry 144: 567-575
19. Maguire GP, Goldberg DP, Hobson RF, Margison F, Moss S, O'Dowd T (1984) Evaluating the teaching of a method of psychotherapy. Br J Psychiatry 144: 575-580

20. Davenport S, Goldberg D, Millar T (1987) How psychiatric disorders are missed during medical consultations. Lancet 2: 439-441
21. Goldberg DP, Jenkins L, Millar T, Faragher EB (1993) The ability of trainee general practitioners to identify psychological distress among their patients. Psychol Med 23: 185-193
22. Del Piccolo LD, Goss C, Zimmermann C (2005) The Third Meeting of the Verona Network on Sequence Analysis. Finding common grounds in defining patient cues and concerns and the appropriateness of provider responses. Patient.Educ.Couns. 57: 241-244
23. Sandvik M, Eide H, Lind M, Graugaard PK, Torper J, Finset A (2002) Analyzing medical dialogues: strength and weakness of Roter's interaction analysis system (RIAS). Patient.Educ.Couns. 46: 235-241
24. Lienard A, Merckaert I, Libert Y, Delvaux N, Marchal S, Boniver J, Etienne AM, Klastersky J, Reynaert C, Scalliet P, Slachmuylder JL, Razavi D (2006) Factors that influence cancer patients' anxiety following a medical consultation: impact of a communication skills training programme for physicians. Ann Oncol 17: 1450-1458
25. Noldus LP, Trienes RJ, Hendriksen AH, Jansen H, Jansen RG (2000) The Observer Video-Pro: new software for the collection, management, and presentation of time-structured data from videotapes and digital media files. Behav.Res.Methods Instrum.Comput. 32: 197-206
26. Fletcher I, Heaven C, Maguire P, Dunn G (2004) A comparison of traditional vs. computerised methods of rating communication skills. Elsevier, City.
27. Schofield M (2003) Reducing the occurrence of blocking behaviours by health care professionals in cancer care. University of Manchester, City.
28. Fletcher I (2005) Patterns of verbal interaction between health professionals and cancer patients. University of Manchester, City.
29. Altman DG (1991) Practical Statistics for Medical Research. Chapman & Hall, London
30. How do I measure observer agreemtn when only positive observations are recorded? (2006). http://www-users.york.ac.uk/~mb55/meas/nonos.htm October 10, 2006
31. Markus H, Bland JM, Rose G, Sitzer M, Siebler M (1996) How good is intercenter agreement in the identification of embolic signals in carotid artery disease? Stroke 27: 1249-1252
32. Fleiss JL (1986) The Design and Analysis of Clinical Experiments. John Wiley & Sons, New York
33. Greenland S (2004) Model-based estimation of relative risks and other epidemiologic measures in studies of common outcomes and in case-control studies. Am J Epidemiol 160: 301-305
34. Zou G (2004) A modified poisson regression approach to prospective studies with binary data. Am J Epidemiol 159: 702-706
35. Bensing J, Zandbelt L, Zimmermann C (2003) Introduction. Sequence analysis of patient-provider interaction. Epidemiol Psichiatr Soc 12: 78-80
36. Wilkinson S (1991) Factors which influence how nurses communicate with cancer patients. J Adv Nurs 16: 677-688
37. Bensing J, van Dulmen S, Tates K (2003) Communication in context: new directions in communication research. Patient Educ Couns 50: 27-32

38. Fallowfield L, Jenkins V (1999) Effective communication skills are the key to good cancer care. European Journal of Cancer 35: 1592-1597
39. Heaven CM, Maguire P (1996) Training hospice nurses to elicit patient concerns. Journal of Advanced Nursing 23: 280-286
40. Kruijver IP, Kerkstra A, Bensing JM, van de Wiel HB (2000) Nurse-patient communication in cancer care. A review of the literature. Cancer Nursing 23: 20-31
41. Maguire P, Pitceathly C (2002) Key communication skills and how to acquire them. BMJ 325: 697-700
42. Maguire P, Pitceathly C (2003) Managing the difficult consultation. Clin Med 3: 532-537
43. Booth K, Maguire PM, Butterworth T, Hillier VF (1996) Perceived professional support and the use of blocking behaviours by hospice nurses. J Adv Nurs 24: 522-527
44. Razavi D, Delvaux N, Marchal S, De Cock M, Farvacques C, Slachmuylder JL (2000) Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. Psychooncology 9: 293-302
45. De Valck C, Bruynooghe R, Bensing JM, Kerssens JJ, Hulsman RL (2001) Cue-responding in a Simulated Bad News Situation: Exploring a Stress Hypothesis. J Health Psychol 6: 585-596
46. Baldwin TT, Ford JK (1988) Transfer of training: a review and directions for future research. Personnel Psychology 41: 63-105
47. Butler L, Degner L, Baile W, Landry M (2005) Developing communication competency in the context of cancer: a critical interpretive analysis of provider training programs. Psychooncology 14: 861-872; discussion 873-864
48. Saks AM, Belcourt M (2006) An investigation of training activities and transfer of training in organizations. Hum Resour Manage 45: 629-648
49. Salas E, Cannon-Bowers JA (2001) The science of training: a decade of progress. Ann Rev Psychol 52: 471-499

Chapter 6

Nurse-patient communication in follow-up consultations after head and neck cancer treatment

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Abstract

Background: Adequate provider-patient communication is viewed as an important aspect of good quality (cancer) care, supports patients' stress control, and can positively influence health outcomes.

Objective: To describe nurse-patient communication in consecutive follow-up consultations after head and neck cancer, with or without a partner present.

Methods: A descriptive observational study of 17 video recorded, coded, and analyzed consultations of 10 head and neck cancer patients and six partners; on 7 patients two consecutive consultations were recorded.

Results: About 25% of patients' and partners' emotional cues were adequately responded to by nurses. In almost 75% nurses responded to cues using distancing behaviors. The majority of informational questions of both patients and partners were adequately answered to. Analyses of consecutive visits showed no significant differences for patients' and partners' cue-emission and for nurses' responsive behaviors between visits 1 and 2.

Conclusion: Nurses adequately respond to informational questions from patients and partners. However, they seem to be less observant of and able to address emotional cues. Communication on nurse-patient-partner interaction deserves further research in a much larger sample and over a longer time period.

Implication for practice: Nurses' awareness of the importance of adequate cue-responding is vital, as is the choice to 'unlearn' the predominant distancing behaviors. The needs and the role of the patients' partner in consultations, and managing consultations ask further attention in professional practice and training.

Introduction

Dealing with cancer is challenging for patients, families, and health care providers. The cancer trajectory often generates a great deal of fear and uncertainty, and patients (and their families and partners too) often experience feelings of low mood and worry during the diagnosis and treatment phase or afterwards.[1] After treatment for head and neck cancer (HNC) many patients experience physical and psychosocial problems that affect their lifestyle and quality of life significantly.[2] Impairments in communication abilities are common in this patient group, either in the acute phase or in the long-term (e.g., in the case of a total laryngectomy, a (partial) glossectomy, or as a consequence of (chemo)radiotherapy).[3, 4]
Cancer follow-up, among other things, aims at supporting patients and their informal caregivers to handle the aftermath of treatment and to address their individual needs. In this light, appropriate patient centred communication is recognized as an important aspect of high-quality care, may help patients to control stress from disease and treatment, and may enhance psychosocial adaptation.[5-7]

Patient-centred communication includes eliciting and understanding the patient's perspective, concerns, needs, feelings and functioning, and offers patients and their family the opportunity to participate in the conversation.[8] In this way, understanding and partnership could be improved in health care relationships. Adequate patient-centred communication is regarded as a tool to positively influence health outcomes such as adherence [9], health care utilization [10] patient satisfaction [11] and symptom resolution.[12] Two important functions of patient-centred healthcare communication are providing information and responding to emotions.[13] Communication skills that facilitate these functions are behaviours that support the conversation by providing space and by avoiding inhibiting behaviour which are said to reduce space and have a discouraging effect in interaction.[14] Previous studies have demonstrated that adequate responses to emotional dimensions of communication may encourage patients to disclose their perspectives on illness and treatment.[15, 16] If emotional needs and concerns of patients are not acknowledged and dealt with they may become persistent or begin to affect functioning and delay rehabilitation.[16] However, the patient's emotion-oriented affective needs are seldom presented directly and spontaneous but as an indirect hint or cue of an underlying feeling.[6]

With respect to cancer follow-up, services, including nursing consultations, are expanding to meet the needs of an ever growing cancer population.[17] The follow-up phase is viewed as an important step in making the transition from cancer patient to cancer survivor.[18] In this light, addressing both medical and psychosocial needs of patients (and their families) is important. During the last decades, the added value of nurse-led cancer follow-up care has been reported for different cancer populations with respect to symptom management, patient satisfaction, emotional functioning, and medical safety.[19] Regarding the HNC population, research results of nurse-led follow-up care are still very limited, but positive results have been reported on symptom management, psychosocial support and medical safety.[20-22]

Oncology patients attending a consultation are often accompanied by family members. Because caring for a family member with cancer can be burdensome, high levels of worry or distress up to 30% in family caregivers, and up to 40% in case of HNC have been reported.[23-25] The problems of family caregivers may affect the basic provider-patient relationship in consultations in several ways: negatively, by limiting patients' involvement and discussing the partners' own concerns, or positively, by encouraging the patients' disclosure of worries and assertiveness and thus improving the patients' verbal participation.[26-28] Still, relatively little is known about the presence of a third party on the dynamics of exchanges in discussions.[29]

As a consequence of the disease or the treatment, almost all HNC patients are known to go through a period of impaired or painful speaking and audibility. In this situation, health professionals managing these patients are challenged to adequately address patients' communication needs and to support them. No studies on communication were detected with HNC patients (and partners) as the sole study group.

Therefore, the purpose of this study was to explore the content and form of nurse-patient communication in follow-up consultations with head and neck cancer patients with or without a partner present. We focused on the emotional cue-emission, and the informational questioning of patients and partners, and the subsequent nurses' responding behaviours. We were interested if there were noticeable changes in the nurses' cue-responding behaviours over time in a situation where the same nurse and the same patient (and partner if present) met regularly. For this reason, we decided to film two consecutive encounters and describe possible differences.

Methods

This study was conducted using an observational design, and as part of a larger study. (ClinicalTrials.gov ID NCT 01167179). The aim of the original quasi-experimental study (n=160) was to compare conventional medical follow-up with follow-up containing additional nursing consultations (6-8 consultations in the first year post-treatment) regarding the psychosocial adjustment and health-related quality of life of head and neck cancer patients. The experimental group (n=80) participated in the additional nursing follow-up consultations, and patients from this group patients were approached for video recording.[22] The conceptual framework underlying the nursing consultations was based upon the biopsychosocial model and the use of exploratory communication skills as an important aspect of patient centred communication.[13, 30] Video recordings were made of nursing follow-up consultations with HNC patients treated with curative intent, and their partners, if present. The focus of observation was on the cue-emission of patients and partners, and the subsequent cue-responding behaviours of nurses. Data were collected between March and September 2010 at the outpatient clinic of an oncology centre of a university hospital in The Netherlands. The Regional Ethics Committee was informed and consented to the video study emphasizing to pay careful attention to the patients' privacy and integrity. (CMO 02102009) [31]

Patient and partner participants

HNC patients in the experimental group of the original study were considered to be eligible to participate in the video study if: consultations were scheduled between March and September 2010 (evaluation period of nursing consultations in the original study), they had attended at least one nursing follow-up consultation prior to video recording (the first consultation was used to explain about the nursing follow-up consultations and to establish a therapeutic relationship), there was no recurrence of disease at the moment of recruitment (patients with recurrent disease were excluded from nursing follow-up consultations due to the start of new treatment and/or palliative care).

Every eligible patient was approached either by telephone or during consultation by one of the nurses participating in the original study. Information on the video study was provided on paper as well as explained verbally, and patients were asked to decide on participation before the next consultation, 6-8 weeks later. Patients were not asked upfront if a partner would be present during consultations. Hence, partners were involved when naturally present at the moment of consultation. Written informed consent was obtained from all participating patients and partners and included information on, the voluntariness of consent and participation and withdrawal at any time, guarantee that care would not be affected when consent was refused, use of recordings for research purposes only and guaranteed anonymous reporting or results, who would see the tape, how the tape would be stored and for how long, and that a signature was needed. Video recordings were made at the outpatient clinic of the Head and Neck Centre in a consultation room equipped for this purpose. In this room, two cameras were fitted almost invisibly in the walls, and were connected to recording equipment in another room.

Nurse participants

All registered oncology nurses (n=3), employed at the Head and Neck Centre were once more asked for consent to videotape several of their follow-up consultations. Preceding the start of the larger study, encompassing these video recordings, the nurses had provided a written consent. The nurses, all female, had a mean experience in head and neck oncology of 11 years (range 6-20). Prior to the start of the implementation of nursing consultations within the original study (approximately 6 months earlier), the nurses had attended a short training workshop of two three-hour sessions, provided by a clinical psychologist (JP) and a researcher (JdL). The workshop comprised two main topics: 1) patient assessment using the perspective of the biopsychosocial model, and 2) how to execute an effective patient centred consultation using exploratory communication skills. During one year post training, nurses were offered 2-monthly reflection sessions, at least three moments of individual coaching-on-the-job, and e-mail consultation by the clinical psychologist on nurses' request, to enhance knowledge transfer from training to daily practice. At the time of this video study, nurses had almost 6 months of experience with performing nurse-led follow-up consultations.

Measures

The Medical Interview Aural Rating Scale (MIARS) was used to code the video recordings. This scale was developed for the oncological setting and was directed at providers' communication related to disclosure of cues and concerns.[32] In the general oncology setting, this instrument has been used previously to study nurse-patient interaction.[33-35] In the MIARS, each turn of speech is used as the unit of observation, and is coded for both provider (nurse) and patient (or partner). A turn of speech is everything a speaker says before the next speaker takes over. Patient or partner cues are coded on three levels to record the extent to which feelings or concerns are disclosed. Cues on Level 1 are indirect hints at a worry or concern but lack an exact content. Example: “They want me to go back to work, but…I don’t know…I don’t have a choice really, have I?” Cues on Level 2 refer to the mentioning of worry or concern. Example: “I feel really sad, and I worry about the future.” Cues on Level 3 are a clear expression of emotion, i.e., crying, shouting. Neutral expressions were also coded, and refer to verbal utterances of patients that contain no cues at all. Example: “Yesterday, I had an appointment with my physician.”

The provider behaviours are coded for both form and function. The form or morphologic aspects of the turn are defined as a directive open question, screening question, a negotiation, or a summarization. The function of the nurse response is coded as behaviours providing space, i.e., cue explored (by eliciting, clarification or an educated guess), and cue acknowledged but not explored (by an empathic statement, reflection, checking, or minimal encouragement such as humming), or behaviours reducing space, i.e., cue distanced from (by inappropriate reassurance, premature advice or switching focus).

The MIARS coding scheme was integrated in the specialized software of The Observer XT 9.0. [36] This software enables direct coding while observing the videotaped consultation and without transcribing the discussions. Validity of the Observer XT software in combination with the MIARS has been demonstrated. [37] Furthermore, the coding scheme was expanded with a category to code the questions of patients and partners. This category was subdivided in questions on information regarding medical, practical, and lifestyle issues. Nurses’ responses to questions were coded as adequate (if the answer was clearly related to the question, addressed all aspects more or less detailed, or if the nurse would say she would come back on it later), or inadequate (when the answer was unclear or confusing, not related to the topic, or not addressing the topic at all by ignoring it).

Coding reliability

To ensure the reliability of coding of the videotaped consultations, inter-rater reliability was established on six (35%) recordings. Two researchers (JdL and RU) with previous coding experience using the Observer XT software separately coded six consultations. Inter-rater reliability coefficients were determined for the coding of patients’ and partners’ cue-emission and nurses’ cue-responding behaviour using

Cohen’s Kappa (κ). With respect to cue levels 1 and 2, coefficients were 0.64, and 0.81 respectively. Cue Level 3 was not coded because it was not present in the selected recordings, hence, no coefficient was calculated. Regarding nurses’ cue responses, coefficients for behaviours providing space and behaviours reducing space were 0.65 and 0.79 respectively. Coefficients between 0.60 and 0.80 are generally considered as good inter-rater agreement.[38]

Analysis

Descriptive statistics were used to analyse the demographic and disease characteristics of the patient sample. Frequencies and percentages of MIARS codes and the coded informational questions were used to calculate nurses’ responses to patients’ and partners’ cues and questions. The amount of cue responding was calculated for each coded consultation by totalling nurse behaviours providing space (exploration, acknowledgement and minimal encouragement) minus the number of behaviours reducing space (distancing) divided by the total number of cue responses per conversation. The outcome ranges varies from -1 to 1, and figures higher than 0.0 indicate more cues were responded to with behaviours providing space than behaviours reducing space.

Results

Sample characteristics and response rate

Demographic characteristics of all participants, patients, partners and nurses are shown in Table 1. Disease characteristics of patients were retrieved from the hospital information system. All patients and partners approached for video recording agreed. The total sample of patients and partners consisted of 16 people, 10 patients and 6 partners. At the time of video recording, patients were two to eight months post treatment and disease free.

Video recordings

Of the total of 20 scheduled video recordings, 17 recordings, from 10 patients, were coded and analysed. Details are presented in Table 2. All consultations lasted between 20 and 30 minutes. Two consecutive consultations of one patient were always executed by the same nurse.

Table 1. Characteristics of Participants

	Patients	Partners	Nurses
Age			
Mean	58	unknown	43
Range	45-69	unknown	33-49
	n	n	n
Gender			
Male	5	3	0
Female	5	3	3
Marital status			
Married	8	6	2
Single / Widowed	2	0	1
Occupational status			
Employed	8	1	3
Unemployed	2	5	0
Educational level[a]			
High	3	unknown	3
Middle	4	unknown	0
Low	3	unknown	0
Caucasian race	9	6	2
Diagnosis/site of cancer			
Larynx	3		
Hypopharynx	2		
Oropharynx	3		
Oral cavity	2		
Stage grouping			
I	3		
II	1		
III	2		
IV	4		
Treatment			
Surgery only	2		
Surgery + Radiotherapy	2		
Radiotherapy only	4		
Chemoradiation	2		

[a] International Standard Classification of Education (ISCED), 2011; UNESCO.
High: bachelor, master, doctoral; Middle: lower and upper secondary; Low: primary education.

Table 2. Details of Video Recordings

Recordings scheduled	20
Recordings not usable (technical error, cancelled visit, disease recurrence)	3
Recordings usable for coding	17
Specification	
Patient/partner recordings of two consecutive visits	10
Patient/partner recording of one visit	1
Patient alone recordings of two consecutive visits	4
Patient alone recording of one visit	2
Recordings per nurse (n=3)	
Nurse 1	5
Nurse 2	5
Nurse 3	7

Patients’ and partners’ cues and questions, and nurses’ responses

The average number of cues/questions of patients was calculated over all consultations. For partners this was calculated only for those consultations where a partner was present (11). Patients expressed 1.4 times more cues (patient-cues M = 5.7, SD = 4.2; partner-cues M = 4.1; SD = 3.6) and expressed 1.2 times less questions (patient-questions M = 2.1, SD = 2.1; partner-questions M = 2.5, SD = 2.0) than partners. Overall, analyses of all consultations (17) showed that patients’ turns consisted of 70% neutral expressions, 25% cues and 5% questions. For partner turns these percentages were 64%, 28% and 8%, respectively. The majority of emotional cues were at Level 1, 125 of the 149 patient cues and 48 of the 49 partner cues, respectively. Level 2 was coded for 23 of the 149 patient cues and for 1 of the 49 partner cues, respectively. A Level 3 cue was coded once, for a patient turn. Details are presented in Table 3.

Patient cues on Level 2 or 3 were also coded according to their content. A total of 24 cues at Level 2 or 3 were expressed by patients. The concerns mentioned more than once were: dealing with emotions (6), general physical complaints (5), dry mouth / sticky saliva (2), impaired smell/taste (2), speech difficulties (2), and other concerns (2). On one occasion a patient’s partner expressed a cue on Level 2 in the category of ‘other concerns’.

Nurses’ responses to emotional cues were classified as either providing space (i.e., cue acknowledged with or without exploring), or reducing space (i.e., cue distanced from). The distribution in nurses’ responses providing space or reducing space to patients’ and partners’ cues was 28% vs. 72%, and 20% vs. 80%, respectively. Nurses’ responses to patients’ and partners’ informational questions were predominantly adequate, in 81% and 73% of the cases, respectively (Table 3).

Table 3. Frequencies of Patients' and Partners' Cues and Questions, and Nurses' Responses in All 17 Video Recordings

Elements of coding	Patients (n=10)		Partners (n=6)	
	no.	%	no.	%
Patients' and partners' cues and questions				
Neutral expressions	421	70	114	64
Emotional cues: total	149	25	49	28
Level 1 (hint of worry or concern)	125	21	48	27
Level 2 (mentioning of worry or concern)	23	4	1	<1
Level 3 (clear expression of emotion)	1	<1	0	0
Informational questions: total	31	5	15	8
Medical info	16	3	8	5
Practical info	14	2	7	4
Lifestyle info	1	<1	0	0
Nurses' responses to emotional cues [a]				
Providing space				
Cues acknowledged and explored	16	11	9	18
Cues acknowledged but not explored	25	17	1	2
Reducing space				
Cues distanced from	108	72	39	80
Nurses' responses to informational questions				
Adequate response	25	81	11	73
Inadequate response	6	19	4	27
Form class				
Directive open question	15	3	0	0
Screening	12	2	0	0
Negotiating	3	<1	0	0
Summarising	0	0	0	0
Form otherwise	571	95	178	100

[a] Calculated as % of all nurse responses to Level 1, 2 and 3 emotional cues or questions

The overall mean amount of cue-responding (all consultations, all nurses together), was calculated at -0.46 (SD 0.42; range -1.00 to 0.55). Also, an overall amount of cue-responding per nurse was calculated. Scores were -0.37, -0.54, and -0.61 for nurses 1, 2 and 3, respectively. Furthermore scores per nurse for responding to patients' and partners' cues separately were calculated. The amount of cue-responding to patients' cues per nurse was -0.42, -0.30, and -0.63, and for responding to partners' cues this was -0.77, -0.41. and -0.90, respectively. These scores were all below zero, indicating that more cues were responded to with behaviours reducing space rather than behaviours providing space. Details are presented in Table 4.

In the *Form class* of the MIARS the majority of nurses' turns regarding patients' and partners' cues were coded as 'form otherwise', in 95% and 100%, respectively. The term 'form otherwise' refers to nurses' utterances containing small talk to keep the conversation going but not actively exploring the topic. 'Directive open questions' and 'screening' were coded in 3% and 2% of responses to patients' turns, and not at all in reaction to partners' turns. The response of 'summarizing' was not coded at all, and 'negotiating' was coded three times (<1%) as a reaction to a patients' turn.

Table 4. Amount of Cue-Responding Overall and Per Nurse in Consultations With/Without a Partner Present [a]

	Mean	(SD; range)
All consultations and nurses' behaviours together		
All consultations	-0.46	(0.42; -1.00, 0.55)
To patient cues (overall)	-0.29	(0.60; -1.00, 1.00)
To partner cues (overall)	-0.68	(0.34; -1.00, -0.14)
To patient cues with partner present	-0.48	(0.59; -1.00, 1.00)
To patient cues without a partner present	-0.43	(0.34; -1.00, 1.00)

Per nurse (n=3)	Nurse 1 Mean (SD;range)	Nurse 2 Mean (SD;range)	Nurse 3 Mean (SD;range)
All consultations	-0.37 (0.49;-1.00, 0.33)	-0.54 (0.24; -0.86,-0.29)	-0.61(0.31; -1.00,-0.14)
To patient cues (overall)	-0.42 (0.20; -1.00,-0.30)	-0.30 (0.25; -1.00,1.00)	-0.63 (0.24; -1.00,-0.14)
To partner cues (overall)	-0.77 (0.35; -1.00,-0.20)	-0.41 (0.20; -0.60,-0.14)	-0.90 [c]
To patient cues with partner present	-0.64 (0.27; -1.00,-0.43)	-0.27 (0.84; -1.00,1.00)	-0.66 (0.04; -0.69,-0.64)
To patient cues without a partner present	-0.21 (0.13; -0.11,-0.30)	-0.33 [b]	-0.60 (0.43; -1.00,-0.14)

[a] Calculation of amount of cue responding: ((number of behaviours providing space(i.e. exploring, acknowledging, minimal encouragement) minus (number of behaviours reducing space (i.e. distancing)) / total number of cue responses. Scores higher than 0.0 indicate that more cues were responded to with behaviours providing space than with behaviours reducing space.

[b] Only one consultation without a partner present, so no SD and range could be calculated

[c] Only one consultation with a partner present, so no SD and range could be calculated

Differences in consecutive consultations with or without partner present

For seven patients video recordings were made of two consecutive nursing consultations with a time interval of eight weeks. Five of these patients attended both consultations with their partner. The mean patient cue-emission in consultations with or without a partner present, and calculated for both visits together was 9.5 and 8, respectively (Table 5).

When comparing consultations 1 and 2 with regard to the increase or decrease of patients' and partners' cue-emission, some small differences were present. Four (of the 7) patients expressed more cues (range, 1-4) in visit 2 of which in three cases a partner was present. Consequently, 3 patients expressed less cues (range, 1-7) in visit 2 of which in two cases a partner was present. One partner (of the 5) expressed more cues in visit 2, and 3 partners expressed less cues (range, 1-3). One partner did not express any cue during visits.

Nurses' responses providing space to patients' cues in a situation with a partner present increased in one (of the 5) consecutive consultations, remained the same in 3, and decreased in one occasion. In consecutive consultations without a partner present one (of the 2) consultations remained the same and one showed a decrease. With regard to nurses' responses reducing space to patients' cues, 2 consultations showed an increase, one remained the same and 2 showed a decrease. In the consultations without a partner present both consultations showed a decrease in nurses' responses reducing space. (Table 5).

Table 5. Patients' Cue-Emission and Nurses' Cue-Responding in Consecutive Consultations of Patients (n=7) With a Partner Present (n=5) and Without a Partner (n=2) Present.

	Cues Patient		Nurse Response PS		Nurse Response RS		Cues Partner		Nurse Response PS		Nurse Response RS	
	Visit 1/2	Change	Visit 1/2	Change	Visit 1/2	Change	Visit 1/2	Change	Visit 1/2	Change	Visit 1/2	Change
Partner present	no.		no.		no.		no.		no.		no.	
Patient 2	6 / 10	↑	4 / 6	↑	0 / 5	↑	0 / 0	-	NA		NA	
Patient 3	4 / 1	↓	0 / 0	-	2 / 1	↓	6 / 3	↓	0 / 0	-	5 / 2	↓
Patient 4	5 / 7	↑	2 / 2	-	5 / 5	-	8 / 6	↓	1 / 3	↑	4 / 4	-
Patient 5	15 / 8	↓	2 / 0	↓	12 / 8	↓	5 / 4	↓	1 / 1	-	3 / 3	-
Patient 6	18 / 21	↑	4 / 4	-	15 / 18	↑	1 / 3	↑	0 / 0	-	1 / 3	↑
Total	48 / 47		12 / 12		34 / 37		20 / 16		2 / 4		13 / 12	
Mean	9.6 / 9.4						4 / 3.2					
No partner present												
Patient 1	12 / 11	↓	4 / 4	-	7 / 5	↓						
Patient 7	4 / 5	↑	3 / 0	↓	4 / 2	↓						
Total	16 / 16		7 / 4		11 / 7							
Mean	8 / 8											

Abbreviations: NA, no cues expressed by partner, thus, no nurse cue-response; PS, providing space; RS, reducing space.
Change: ↑ increase, ↓ decrease, - no change. Figures represent absolute numbers

Discussion

This observational study assessed head and neck cancer patients' and partners' cue-emission and informational questioning, and nurses' responses to these cues and questions in videotaped real-life nursing follow-up consultations. The main findings showed that nurses responded to a quarter of patients' and partners' cues with exploring behaviours which are known to provide space. Hence, three quarters of all cues were responded to using distancing behaviours known to reduce space. The vast majority of informational questions, on the other hand, were answered to adequately. There were small differences with regard to increase or decrease of patients' and partners' cue-emission and of nurses' responding behaviours in case two consecutive consultations were compared.

It remains difficult to compare studies on provider-patient communication due to differences in conceptualization, measurement, coding, population and context. Looking at studies that have nurse-patient communication in non-simulated oncological settings as their scope, the means for patients' cue-emission per consultation vary between three and fourteen. [34, 39-41] With a mean of five, the number of patients' cues in our study seems to be at the lower end side of this spectrum. Also, in our study, the percentage of nurses' responses providing space and reducing space differs from that of other studies using the MIARS. [34, 40, 42, 43] These studies showed an almost equal distribution in adequate and inadequate responses to patients' cues, whereas in our study the distribution is one- versus three-quarters, respectively. Our study showed that indeed the majority of patients' and partners' cues are mere hints at worry or concerns (Level 1), and this is more in line with other studies. [44] This finding emphasizes the potential advantage of nurses' responsiveness to patients' and partners' cues, which may lead to more identification of actual concerns (at Level 2 or 3), and a more patient-centred approach.

A part of the explanation for the relatively lower number of cue-emission could be that patients were disease-free at the moment of follow-up consultation after being treated with curative intent, and experienced less problems. Although some of them still suffered from serious side-effects of cancer treatment this was not reflected in a heightened number of cues at the different levels. Since responses providing space and the accompanying morphological elements that explore communication were not applied very often by nurses, this could have been of influence on the number of cue-emissions by patients and partners, as both components are found to be interconnected.[44] Nurses frequently responded to an emotional cue of a patient or partner by giving information. Providing information can serve as a reassuring response to an emotional cue and should therefore perhaps not always be considered as distancing behaviour. However, it is also known that strong emotions can produce narrowing of attention as a result of which information may only be heard partially and/or may not be understood fully, unless emotions are taken care of first.[45] Emotional distress is very common in cancer patients, but patients show individual differences in emotional responses and subsequently to nurses' responses to patients' cues.[1,44]

It is also suggested that professional care givers' provisions of space for further exploration of a cue do not occur at random and are influenced by individual characteristics, psychophysiological reactions to emotional behaviours as well as aspects of the ongoing interaction.[46] The way in which these phenomena are intertwined is not clear yet, and is in need of further research.

A finding of our study was that the number of cues expressed by patients and partners in consecutive visits showed small differences. The total number of patients with consecutive visits though, is too small to point out a trend or pattern. The same applies to the partners' cues and the nurses' responses. The analyses of the content of the patients' cues at subsequent visits showed that the majority of problems present in visit one were also there in visit two. This underlines the fact that HNC patients (and their partners) experience significant problems over the first year post treatment, that take a longer time to resolve than in the eight weeks between consultations.

Another finding was the fact that the amount of cue-responding of the individual nurses between consultations 1 and 2, and with or without a partner present showed only small differences. The amount of cue-responding remained below zero for all nurses. After nurses had established a therapeutic relationship with the patient (and partner) in the consultation preceding video recording, we had assumed a gradual increase in amount of cue-responding in nurses over consultations. However, as we did not measure the cue-responding skills of nurses prior to the start of consultations this limits a further explanation of this finding.

Within the process of exchanging information other aspects besides verbal communication are of influence and must be acknowledged. Whilst interpreting and coding the video recordings using the MIARS, nonverbal communication by patients, partners and nurses was taken into consideration.

Although, in our small study no predominant negative or positive influence from the presence of a partner in consultations was found, we want to point out that managing triadic communication in an effective and empathetic way requires specific communication skills, such as explaining the rules and order of conversation. In the context of nursing consultations this is an important theme to further study in future research.

Limitations

When interpreting the results of this study the following limitations must be noted. The small sample size of 3 nurses, 10 patients, and 6 partners does not allow for statements regarding generalisability of findings in spite of the fact that the patients' and partners' cues and the provider response patterns observed are likely to be recognizable. Results must be viewed in the light of a first attempt to try to gain insight in nurse-patient-partner communication in HNC follow-up consultations.

During coding, mainly verbal behaviours were considered in analysis, although we did listen to voice tone and looked at non-verbal behaviours of both patients, partners and nurses. It is known that these behaviours may also influence the meaning of spoken language and subsequently add to adequate or non-adequate cue-responding. As we did not measure patient and partner satisfaction with consultations formally (by questionnaire or interview) we only have informal evaluation statements from patients and partners during consultations. These verbal reports were all positive about the support experienced from the nurses, but possibly slightly biased by the situation.

People who know that they are being filmed are susceptible to act and talk in a socially desirable way. This phenomenon may have influenced patients, partners and nurses. And although patients, partners, and nurses, when asked, all stated they forgot there was a camera present, it is known that people can underestimate their camera awareness and the influence of the video recording on their behaviour. [47, 48] A strength of this study is that inter-rater reliability on the coding of patients' and partners' cues and nurses' responses reached good levels, but would have been further strengthened by more observations of Level 3 cues. Selection bias of patients by nurses was minimized by providing clear instruction for inclusion and by careful monitoring by the researcher. Although the participating available nursing staff was limited we could not detect any significant variation in outcomes linked to individual nurses.

A point worthwhile to argue is that of the effect of the training workshop for nurses preceding the start of nursing consultations and approximately six months before video recordings were made. We had assumed (on the base of the nurses' working experience in oncology) that a concise workshop with a focus on explorative communication skills and including role play, would put these experienced nurses in the required consultation ‘mode’. We deliberately planned video recordings at a time that nurses had about 6 months experience with several real life consultations and had participated in one or two supervision sessions. It was expected that by that time they would have become accustomed to conducting a consultation based on the expected communication style. An explanation we discussed for not finding the expected results was that perhaps we underestimated the effort it takes for a person to modify existing professional behaviour into new performance. Actually, almost all health care professionals, including nurses, use distancing communication tactics internalized over the years. Yet, literature reports that participation in reflective meetings and supervision can be of support to professionals who aim to change this behaviour.[42, 49] However, it might be that the planning of supervision sessions in our study was not frequent enough (every eight weeks), and that more daily support was needed, also for these experienced nurses.

Conclusions

This study added to further insight in nurse-patient-partner communication in a sample of HNC patients, and showed that adequate cue- and question responding remains challenging for oncology nurses. They seemed to be more skilled in and tended to respond to informational questions of patients and partners than in addressing and exploring emotional cues. Also in highly motivated nurses, it is not that straightforward to change existing communicative behaviour, and this requires an intensive approach containing supervision and refection sessions as well as guidance in daily practice.

Practice implications

Nurses involved in follow-up consultations with HNC patients should acknowledge the importance of having excellent communication skills in order to invite patients (and partners if present) to disclose cues and concerns that might otherwise hinder adequate rehabilitation into cancer survivorship. Nurses should also be aware that professional distancing behaviours are not always the most appropriate ones in the context of follow-up consultation, in which emotional needs are seldom presented directly by patients. Ongoing professional training and clinical supervision may be helpful for nurses to further improve on their communication skills. However, it must be acknowledged that behaviour change is complex and requires further investigation.

References

1. Carlson LE, Bultz BD. Cancer distress screening. Needs, models, and methods. *J Psychosom Res.* 2003;55(5):403-409.

2. Abendstein H, Nordgren M, Boysen M, et al. Quality of life and head and neck cancer: a 5 year prospective study. *Laryngoscope.* 2005;115(12):2183-2192.

3. Jacobi I, van der Molen L, Huiskens H, van Rossum MA, Hilgers FJ. Voice and speech outcomes of chemoradiation for advanced head and neck cancer: a systematic review. *Eur Arch Otorhinolaryngol.* 2010;267(10):1495-1505.

4. Johansson M, Ryden A, Finizia C. Self evaluation of communication experiences after laryngeal cancer - a longitudinal questionnaire study in patients with laryngeal cancer. *BMC Cancer.* 2008;8:80.

5. Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *Br J Cancer.* 2003;88(5):658-665.

6. Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer.* 2001;84(8):1011-1015.

7. Zimmermann C, del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol Bull.* 2007;133(3):438-463.

8. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med.* 2005;61(7):1516-1528.

9. van Dulmen S, Sluijs E, van Dijk L, de Ridder D, Heerdink R, Bensing J. Patient adherence to medical treatment: a review of reviews. *BMC Health Serv Res.* 2007;7:55.

10. Mauksch LB, Dugdale DC, Dodson S, Epstein R. Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. *Arch Intern Med.* 2008;168(13):1387-1395.

11. Uitterhoeve R, Bensing J, Dilven E, Donders R, deMulder P, van Achterberg T. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-Oncol.* 2009;18(10):1060-1068.

12. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract.* 2000;49(9):796-804.

13. de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient Educ Couns.* 2009;74(3):287-294.

14. Del Piccolo L, de Haes H, Heaven C, Jansen J, Verheul W, Finset A. Coding of health provider talk related to cues and concerns. Manual 2009. European Association for Communication in Health Care (EACH). Available at: http://www.each.nl. Accessed October, 2011.

15. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol.* 1999;17(1):371-379.

16. Schofield PE, Butow PN, Thompson JF, Tattersall MH, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol.* 2003;14(1):48-56.

17. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. *CA Cancer J Clin.* 2011;61(2):69-90.

18. National Cancer Policy Board. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington: The National Academies Press; 2006.

19. Lewis R, Neal RD, Williams NH, et al. Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review. *J Adv Nurs.* 2009;65(4):706-723.

20. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: conceptions of patients with head and neck cancer. *Eur J Oncol Nurs.* 2007;11(1):49-59.

21. Wells M, Donnan PT, Sharp L, Ackland C, Fletcher J, Dewar JA. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. *J Clin Nurs.* 2008;17(11):1428-1439.

22. de Leeuw J, Prins JB, Teerenstra S, Merkx MA, Marres HA, van Achterberg T. Nurse-led follow-up care for head and neck cancer patients: a quasi-experimental prospective trial. *Support Care Cancer.* 2013;21:537-547.

23. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer.* 2003;39(11):1517-1524.

24. Ross S, Mosher CE, Ronis-Tobin V, Hermele S, Ostroff JS. Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer.* 2010;18(2):171-178.

25. Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans CR. Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope.* 2007;117(2):238-241.

26. Eggly S, Penner LA, Greene M, Harper FW, Ruckdeschel JC, Albrecht TL. Information seeking during "bad news" oncology interactions: Question asking by patients and their companions. *Soc Sci Med.* 2006;63(11):2974-2985.

27. Karnieli-Miller O, Werner P, Neufeld-Kroszynski G, Eidelman S. Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinics encounters. *Patient Educ Couns.* 2012;88:381-390.

28. Street RL, Gordon HS. Companion participation in cancer consultations. *Psycho-Oncol.* 2008;17(3):244-251.

29. Roter DL. Observations on methodological and measurement challenges in the assessment of communication during medical exchanges. *Patient Educ Couns.* 2003;50(1):17-21.

30. Engel GL. The biopsychosocial model and the education of health professionals. *Ann.N.Y.Acad.Sci.* 1978;310:169-187.

31. Medical Ethical Committee Region Arnhem-Nijmegen. Medical Ethical Committee Region Arnhem-Nijmegen. Available at: www.cmoregio-a-n.nl. Accessed January 15, 2012.

32. Heaven CM, Green C. *Medical Interviewing Aural Rating Scale*. Psychological Medicine Group Christie Hospital Stanley House Manchester; 2001.

33. Heaven C, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient Educ Couns.* 2006;60(3):313-325.

34. Uitterhoeve R, Bensing J, Dilven E, Donders R, deMulder P, van Achterberg T. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-Oncol.* 2009;18(10):1060-1068.

35. Uitterhoeve R, de Leeuw J, Bensing J, et al. Cue-responding behaviours of oncology nurses in video-simulated interviews. *J Adv Nurs.* 2008;61(1):71-80.

36. Noldus LP, Trienes RJ, Hendriksen AH, Jansen H, Jansen RG. The Observer Video-Pro: new software for the collection, management, and presentation of time-structured data from videotapes and digital media files. *Behav.Res.Methods Instrum.Comput.* 2000;32(1):197-206.

37. Fletcher I, Heaven C, Maguire P, Dunn G. *A comparison of traditional vs. computerised methods of rating communication skills*. International Conference on Communication in Healthcare 14-17 September 2004. Bruges, Belgium.

38. Altman DG. *Practical statistics for medical research.* London: Chapman & Hall; 1999.

39. Jansen J, van Weert JC, de Groot J, van Dulmen S, Heeren TJ, Bensing JM. Emotional and informational patient cues: the impact of nurses' responses on recall. *Patient Educ Couns.* 2010;79(2):218-224.

40. Kennedy Sheldon L, Hilaire D, Berry DL. Provider verbal responses to patient distress cues during ambulatory oncology visits. *Oncol Nurs Forum.* 2011;38(3):369-375.

41. Oguchi M, Jansen J, Butow P, Colagiuri B, Divine R, Dhillon H. Measuring the impact of nurse cue-response behaviour on cancer patients' emotional cues. *Patient Educ Couns.* 2011;82(2):163-168.

42. Heaven C, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient Educ Couns.* 2006;60(3):313-325.

43. Heaven CM, Maguire P. Training hospice nurses to elicit patient concerns. *J Adv Nurs.* 1996;23(2):280-286.

44. Uitterhoeve R, Bensing J, Dilven E, Donders R, Mulder P, Van AT. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-Oncol.* 2009;18(10):1060-1068.

45. Najmi S, Kuckertz JM, Amir N. Attentional impairment in anxiety: inefficiency in expanding the scope of attention. *Depress Anxiety.* 2012;29(3):243-249.

46. Finset A. "I am worried, Doctor!" Emotions in the doctor-patient relationship. *Patient Educ Couns.* 2012;88:359-363.

47. Hargreaves PN, Peppiatt R. Is videotaping of consultations acceptable to patients attending a hospice day centre? *Palliat Med.* 2001;15(1):49-54.

48. Penner LA, Orom H, Albrecht TL, Franks MM, Foster TS, Ruckdeschel JC. Camera-related behaviors during video recorded medical interactions. *J Nonverbal Behav.* 2007;31(2):99-117.

49. Uitterhoeve R. *Nurse responsiveness to emotional cues of cancer patients. Development of a training program.* [thesis]. Nijmegen: Radboud University; 2009.

PART III

DISCUSSION

This part of the thesis contains two chapters.
In Chapter 7 the results of the studies described in Chapters 2 to 6 are summarized, and issues concerning the methodology are discussed. Next, Chapter 8 provides an integrated overview of the evidence for nurse-led cancer follow-up care, the existing points of debate, and the recommendations for research, clinical practice, and education.

Chapter 7

Summary of results and methodological considerations

Introduction

Supportive follow-up care for cancer patients is regarded as an essential component of the cancer treatment continuum. The overall aim of this thesis was to study the improvement of supportive follow-up care for head and neck cancer patients by focusing on the content and form, and by evaluating follow-up care provided by specialized oncology nurses. This thesis comprehends the following themes: an exploration of the early posttreatment situation including the taking up of advice by patients and supportive care needs; an evaluation of the effects of nurse-led follow-up consultations on the patient's psychosocial adjustment and quality of life; and in-depth analyses of nurse-patient communication behaviours. Both qualitative and quantitative research designs were applied to study the research questions of this thesis. This chapter contains the summary of the results and the methodological considerations.

Take-up of advice and supportive care needs

The chapters 2 and 3 of this thesis were dedicated to the exploration of the early posttreatment situation regarding head and neck cancer patients treated with curative intent. In Chapter 2 the patients' views on factors influencing the adoption of advice provided by the many health professionals during the treatment trajectory were explored. Interviews were conducted with 21 patients (and their partners if present) who were between 2 and 6 months posttreatment. The findings showed that patients often received several types of advice at the same time (up to a number of 14), which often consisted elements requiring life style changes. Patients regularly struggled to fit these advices into daily life. They reported that characteristics of health professionals, such as empathy and skills to find creative solutions for patients' everyday problems, were of crucial importance in succeeding on this task. Patients also acknowledged that their own personality and perspective on health and health care were of influence in the adoption of the health professionals' advice. Results further suggested that the professionals' awareness of these factors and their influence on the way information is processed by patients, offers opportunities for improvement of practice.

Regarding this interview study, we aimed at investigating and acknowledging patients' experiences by using a structured interview topic list as well as explorative communication techniques. Because of this predominantly fixed-response nature of the interview, it was decided not to make audio recordings. This often is regarded as a disadvantage especially with respect to the reliability of the analysis of patients' statements on open ended questions, which could not be quantified.[1] Therefore, statements of patients were written down verbatim during the interview, and were saved in the computer immediately after finishing the interview. Several other measurements were taken to enhance reliability and validity: a trained interviewer, feedback from patients on a written summary of their individual interview, and regular reflective discussions on findings of the thematic content analysis with the research supervisor.

Furthermore, response bias is said to be inevitable when interviewing patients.[1] We tried to minimize this by emphasizing and explaining patient anonymity and by creating a neutral and non-judgmental but friendly atmosphere during interviews.[2] Our structured interview approach, combined with giving room to patients to elaborate on their answers, gave focus in the conversation as well as acknowledgement of patients' experiences. For that reason, we have no concrete indications of results being influenced by response bias.

Selection bias, of course, is another threat to the validity of interview findings. In our study, we approached 57 eligible patients of which 21 (37%) agreed to participate. Beforehand, we excluded patients with overt psychiatric disease and/or alcoholism, because of anticipated higher prevalence of cognitive impairments in these participants. The most common reasons for nonparticipation were, feeling too ill or not being willing to participate; this involved 24 patients in total. Thus, there clearly was some selection. On the other hand, several patients who were interviewed still experienced severe complaints and symptoms of their disease and treatment, but they did want to participate. Therefore, not only patients who had an uncomplicated posttreatment phase were interviewed, and this to a certain extent diminished the influence of this bias.

The findings of this interview study provided insight in the multitude of challenges and tasks with which patients were left at the end of treatment. This did already give us some idea of the possible needs for supportive (nursing) care. The study in Chapter 3 further explored this theme by assessing health related quality of life (HRQoL) outcomes 1 month posttreatment. The data of 52 patients with locally advanced cancer (stages III or IV), who all had radiotherapy as a component of treatment were analysed. Patients with locally advanced cancer commonly undergo aggressive cancer therapy. As a consequence they tend to experience more severe symptoms and complaints, i.e. more impairment of HRQoL than patients with stage I/II cancers.[3] There were differences in HRQoL scores between the three treatment groups of surgery-radiotherapy (SRT, n=10), radiotherapy alone (RT, n=21), and chemoradiation (CRT, n=21). Overall, the SRT group seemed to experience the least impairment on HRQoL, except for problems with teeth, when compared with the other groups. The RT group and CRT group reported the greatest impairment on HRQoL scales, mainly on the symptom scales related to nutritional intake (appetite loss, tube feeding, use of nutritional supplements, weight loss) and oral functioning (swallowing, dry mouth, sticky saliva, opening mouth). The clinically relevant differences between treatment groups predominantly pointed toward these scales. The CRT group had a lower score (i.e., worse) for role functioning compared to the other groups. This could be related to symptoms with respect to nutritional status and oral function, as one-third of CRT patients were still dependent on tube feeding and all but four used nutritional supplements. Also, in the RT and SRT group, nutritional supplements were used by half and one-third of patients, respectively. The results emphasize the importance of intensive and, if deemed necessary, prolonged supportive care in the first few months of follow-up on problems mainly related to nutritional intake and oral functioning.

The major drawbacks of this study were the small sample size and the fact that the treatment groups were extracted from a cohort of a prospective non-randomized trial, as a consequence of which there was no control on the homogeneity of the groups. Nonparametric analyses of demographic and disease variables did not show any significant differences between groups. However, it must be noticed that cancer sites clearly differed between groups due to the guideline instigated treatment protocols. For example, there were no patients with oral cavity cancer in the RT group, and no pharyngeal cancer patients in the SRT group. Because of the study’s purpose and the small sample size, performing any advanced statistics was not considered suitable. In spite of these limitations, the results provided information on the supportive care needs of these treatment groups. The results for the SRT group, however, may be biased by the small size of this group (n=10) meaning that they could either be better or worse when analysed in a larger sample.

In trying to compare our results with the literature we noticed that, although many studies report on HRQoL in HNC patients and on measurements during and immediate posttreatment, not many papers actually report figures on these data. Concerning our research question, we would have welcomed more data in the literature to compare our findings with.

Evaluation of nurse-led follow-up care

Chapter 4 evaluated the effects of nursing follow-up consultations on psychosocial adjustment and health related quality of life (HRQoL) in the first year posttreatment in a cohort of 160 head and neck cancer patients. In a prospective non-randomized design, a historical comparison group which had received convential (medically oriented) follow-up care was compared with an intervention group receiving convential care supplemented with additional nursing consultations. The intervention group had lower baseline functioning, yet had scores similar to those of the comparison group at one year post treatment. Thus, the intervention group had a larger improvement in scores. This turned out to be significant for one of the seven PAIS-SR scales, namely social adjustment, and for 18 of the 33 HRQoL scales at 6 and 12 months respectively. However, with respect to HRQoL scales, the 6 and 12 months effects were found for largely different HRQoL scales. Most of the differences in HRQoL scales were clinically relevant at 6 months, but not at 12 months. The results suggested some effects of nursing consultations, mainly on aspects of HRQoL.

With respect to the trial design, a randomized controlled study with the nurses and patients being randomly allocated to the intervention and comparison condition would have been superior. However, this was not a feasible design in our setting because of the limited number of available nurses who meet frequently in various treatment-related meetings. Contamination between both conditions would have been the result. A quasi-experimental non-randomized approach with a historical control group being the comparison group was considered the most appropriate alternative. However, this design limited us in making causal inferences, and consequently, the two groups were likely to differ on some characteristics. Also the confounding factor of history could not be controlled for. There was indeed a difference in the variables of treatment modality and educational level between groups. In the intervention group, which was recruited almost one year after the comparison group, more patients were treated with chemoradiation according to the latest guidelines for head and neck cancer. Also more patients in this group were categorized having a ‘higher’ educational level, for which we could find no explanation other than coincidence. Nevertheless, our design provided us with pre-test data, which allowed for comparison of groups at baseline, and subsequently to account for the possible effect of these differences in the development of the statistical model.

In general, almost all head and neck cancer patients approached were very willing to participate in this study. We estimated that about 225 eligible patients had to be asked to include the necessary 160 participants needed. Eventually, after approaching 170 patients we already reached our target number, a response percentage of 94%. We concluded that because oncology nurses were the recruiters, and they were carefully instructed on how to invite patients, this may have been of influence.

To determine the primary outcomes of this study, we used well validated self-report measures, namely the PAIS-SR and EORTC QLQ C30 + H&N35 questionnaires. These instruments offer an easy and inexpensive possibility to gain insight into the patient’s perceived psychosocial adjustment and HRQoL which is not presented by clinical and laboratory data. The PAIS-SR, which measures psychosocial adjustment to illness, was not specific to our population of head and neck cancer patients. To compare scores we used the PAIS norm group of ‘mixed cancer patients’, which best seemed to match our sample. Also, we used the Dutch validated version of this questionnaire.[4] The baseline measurement in our study was set at one month posttreatment and before the start of nursing consultations. Of the seven PAIS domains, social environment showed a statistically significant difference between groups at 6 and at 12 months, favouring the intervention group. To compare our results with other prospective studies we used those of Cain et al. (1982) and Greer et al. (1992), which both used the PAIS-SR in a sample of cancer patients.[5, 6] These studies evaluated psychological counselling sessions (group and individual sessions) during eight weeks of cancer treatment in gynaecological and mixed cancer patients, respectively. The posttreatment PAIS-SR measurements showed no statistically significant differences except for the domains of health care orientation in the study of Cain et al., and for psychological distress in the study of Greer et al. We regard the PAIS-SR as a valid instrument for measuring psychosocial adjustment, although in hindsight, having pretreatment adjustment measures could have added to more insight in the overall psychosocial adjustment course during the treatment trajectory.

Worldwide, monitoring and measuring cancer patients' psychosocial adjustment is regarded important.[7, 8] Nowadays, in many health care settings in the Netherlands the Distress Thermometer is increasingly used by health providers to detect and address the patient's psychosocial status and experienced disease burden. This user- and time-friendly instrument has been found valid and acceptable as a rapid screening instrument and studies indicate that it could be used to monitor change in psychological distress over time.[9,10] A trial to further confirm these results is currently ongoing in our hospital (Clinialtrials.gov NCT01091584).

A combined multidimensional and disease-specific instrument like the EORTC QLQ-C30 questionnaire and the additional head and neck module (EORTC QLQ-H&N35) offers detailed and specific information about health areas which are affected by disease and which may change through health interventions and long-term care.[11] When results are analysed for clinically relevant differences, the meaningfulness of the patient's improvement not only is of interest to health professionals but could be discussed with the patient and add value to the provider-patient relationship and communication about treatment and rehabilitation.[12,13] The EORTC questionnaires have been used in many cancer studies. Reference values are available for different cancer populations, including HNC patients, and for certain predefined characteristics, in particular cancer stage and site.[14] Therefore, we regarded the EORTC instrument and the additional cancer specific module a valuable tool for determining the course of changes in HRQoL in HNC patients. In case of a small sample size (Chapter 3), when advanced statistics are not applicable, the EORTC still allows for calculating clinically relevant differences on the aggregated mean scores which provide clinical valuable information.[15,16] In recent years, promising initiatives were developed to help clinicians to provide patients with information on the likelihood of QoL improvements compared with the patient's current status.[12,17]

Nurse-patient communication

Adequate patient centred communication is viewed as a key quality component of health care.[18,19] In the chapters 2, 3, and 4 nurse-patient communication was an essential part of post-treatment care. Therefore, the chapters 5 and 6 of this thesis focused on the exploration and analysis of the content and form of nurse-patient communication, and zoomed in on nurses' cue-responding behaviours. Adequate cue-responding is hypothesized to help optimize the interaction between providers and patients and has the potential to enhance mutual understanding of different perspectives. Chapter 5 described a study of conversations between oncology nurses and actors playing the role of cancer patients. The cue-responding behaviours (adequate vs. inadequate) of nurses and the influence of responses on subsequent expression of cues by the patient were investigated. For this purpose, 35 videotaped conversations between nurses and an actor in the role of patient were coded using the Medical Interview Aural Rating Scale (MIARS). Another aim of the study was to establish inter-rater reliability of coding with the MIARS. All video recordings made were used for this purpose and were coded independently by two researchers. Results showed high coding reliability. About half of the nurses' behaviours to emotional cues were coded as inadequate, i.e. distancing responses. The emotional level of the cue did not determine the subsequent response of the nurse. However, when a nurse responded to a cue with adequate behaviour, i.e. exploring and acknowledging, this doubled the chance for the expression of concerns and emotions by the patient.

In Chapter 6 we focused on real life nurse-patient communication in nursing follow-up consultations with head and neck cancer patients. Again, the MIARS was used to code video recordings. Analyses of findings showed that a quarter of patients' and partners' utterances contained cues of an emotional nature, and in 28% of these nurses responded with exploring and acknowledging behaviours providing room for further disclosure. In 72% of the nurses' reactions, these cues were responded to with distancing behaviours in which 'switching the focus' was coded in more than 50% of the occasions. There were some small differences in nurses' responses to cues from patients in consultations with or without a partner present. The vast majority of patients' and partners' informational questions were adequately answered to by nurses. Findings suggested that there seemed to be room for improvement in nurses' explorative communication skills.

Both of our studies focused on the analyses of nurses' responsiveness to patients' (and partners') cues and informational questions. The MIARS coding scheme was built around the concept of cue responding, and accordingly other aspects of the natural nurse-patient communication have been ignored in analyses. This does not imply that they did not add to the conversation or to the patients' and partners' experience with the conversation.[20] Patients themselves also have control over when they disclose emotional material.[21] And if nurses manage dialogues to keep off certain topics, maybe patients do as well. However, in a recent study, nurses' cue-responding was found to be related to patients' satisfaction with the conversation.[22] In our study in real-life consultations we did not formally measure patient satisfaction with the conversation as this was not defined as an outcome measure. And although the patients and partners stated to be satisfied with the consultation, when asked by the nurses, response-bias likely has influenced (part) of these statements. Patients said that they felt that the nurse was really helpful and caring during consultations, and that concerns could easily be discussed with the nurse. Also, several of them stated that they experienced that the nursing consultations added value and were complementary to the medical consultations.

One of the advantages of using the MIARS for coding communication and cue-responsiveness is its reliability which was confirmed in other cancer studies.[22-24] Another advantage is that the MIARS coding scheme can be easily integrated into the user friendly software of Observer Video-Pro [25], that allows for direct coding and subsequent analyses of video recordings without writing transcriptions. Nowadays, there is a varied choice in coding instruments, which is a good development for this kind of research.

In our studies, we used videotaping. This provides a richness of data and can capture the uncensored content and interactions of a consultation, especially when conducted in a setting fitted for the purpose (hidden camera, remote recording in the study in Chapter 6). During video recording special attention had to be given to aspects of confidentiality and privacy of subjects, and to the storing and analyses of recordings.[26] Potential threats to the interaction were the camera-related behaviours of patients, partners or nurses. These tend to occur most often in the very early stages of interaction, and it has been suggested that people underestimate their camera awareness and its influence on their behaviour.[27] In our study in real-life consultations (Chapter 6), patients and nurses commonly said they forgot they were being video recorded. Yet, in some of the video recordings, some camera-related behaviour was noticed: a patient and/or partner looked at the camera in 5 cases, 2 patients and 1 partner talked about the camera, and 1 partner whispered about the position of the camera. All these behaviours happened during the first few minutes of consultations, but we cannot assess how this could have influenced our findings.[27]

Generalization

All patient participants in our studies were recruited from one oncology centre of a university hospital in the eastern part of the Netherlands. Nearly all participants (patients, partners, and nurses) were of Caucasian race. Other oncology centres in the Netherlands, for example in the western part of our country, have a more diverse ethnic patient and employee population. As there are known differences between cultures on perspectives of health and healthcare, ways of coping and communication about disease and emotions, it is plausible that our findings are less applicable to non-Caucasian head and neck cancer patients. However, there were no noticeable differences in general findings regarding HRQoL and psychosocial adjustment compared to the known literature. The advantage of the nurse-led model we used, to develop and organize the follow-up consultations in Chapter 4, was that it has a generic design that could be readily modified for use in other (cancer) patient populations.

References

1. Kvale S, Brinkmann S. Interviews: learning the craft of qualitative research interviewing. 2nd [rev.] ed. Los Angeles: Sage, 2009.
2. Streubert HJ, Carpenter DR. Qualitative research in nursing. Advancing the humanistic imperative. 2nd ed. Philadelphia,USA: Lippincott Williams & Wilkins, 1999.
3. Bjordal K, Ahlner-Elmqvist M, Hammerlid E, et al. A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. Laryngoscope 2001;111(8):1440-52.
4. Bekkers MJ. Psychosocial adaptation to stoma surgery: a controlled study. Thesis. Universiteit Utrecht, 1993.
5. Cain EN, Kohorn EI, Quinlan D, et al. Psychosocial benefits of a cancer support group. Cancer 1986;57:183-9.
6. Greer S, Moorey S, Baruch JD, et al. Adjuvant psychological therapy for patients with cancer: a prospective randomised trial. BMJ 1992;304(6828):675-80.
7. NCCN (National Comprehensive Cancer Network). Clinical Practice Guidelines in Oncology: Distress Management. Version; 2011. Available at: http://www.nccn.org.
8. VIKC (Dutch Cancer Center). Richtlijn: Detecteren behoefte psychosociale zorg (National Guideline: Detection of the need for psychosocial care). VIKC: 2010.
9. Tuinman MA, Gazendam-Donofrio SM, Hoekstra-Weebers JE. Screening and referral for psychosocial distress in oncologic practice: use of the Distress Thermometer. Cancer 2008;113(4):870-8.
10. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychologic distress in ambulatory cancer patients. Cancer 2005;103(7):1494-502.
11. Abendstein H, Nordgren M, Boysen M, et al. Quality of life and head and neck cancer: a 5 year prospective study. Laryngoscope 115(12):2183-92.
12. Sloan JA, Frost MH, Berzon R, et al. The clinical significance of quality of life assessments in oncology: a summary for clinicians. Support Care Cancer 2006;14(10):988-98.
13. Cocks K, King MT, Velikova G, Fayers PM, Brown JM. Quality, interpretation and presentation of European Organisation for Research and Treatment of Cancer quality of life questionnaire core 30 data in randomised controlled trials. Eur J Cancer 2008;44(13):1793-8.
14. Scott NW, Fayers P, Aaronson N, et al. EORTC QLQ-C30 Reference Values. European Organisation for Research and Treatment of Cancer. Brussel, Belgium: 2008.
15. Osoba D, Rodrigues G, Myles J, Zee B, Pater J. Interpreting the significance of changes in health-related quality-of-life scores. J Clin Oncol 1998;16(1):139-144.
16. King MT. The interpretation of scores from the EORTC quality of life questionnaire QLQ-C30. Qual Life Res 1996;5(6):555-67.
17. Cleeland CS, Sloan JA, Cella D, et al. Recommendations for including multiple symptoms as endpoints in cancer clinical trials: A report from the ASCPRO (Assessing the Symptoms of Cancer Using Patient-Reported Outcomes) Multisymptom Task Force. Cancer. 2012.
18. Bensing JM, Deveugele M, Moretti F, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. Patient Educ Couns 2011;84(3):287-93.

19. de Boer D, Delnoij D, Rademakers J. The importance of patient-centered care for various patient groups. Patient Educ Couns November 2011. DOI 10.1016/j.pec.2011.10.002.
20. Jarrett NJ, Payne SA. Creating and maintaining 'optimism' in cancer care communication. Int J Nurs Stud 2000;37(1):81-90.
21. Jarrett N, Payne S. A selective review of the literature on nurse-patient communication: has the patient's contribution been neglected? J Adv Nurs 1995;22(1):72-8.
22. Uitterhoeve R, Bensing J, Dilven E, Donders R, et al. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. Psycho-Oncol 2009;18:1060-8.
23. Heaven C, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. Patient Educ Couns 2006;60(3):313-25.
24. Uitterhoeve R, de Leeuw J, Bensing J, et al. Cue-responding behaviours of oncology nurses in video-simulated interviews. J Adv Nurs 2008;61(1):71-80.
25. Noldus LP, Trienes RJ, Hendriksen AH, Jansen H, Jansen RG. The Observer Video-Pro: new software for the collection, management, and presentation of time-structured data from videotapes and digital media files. Behav Res Methods Instrum Comput 2000;32(1):197-206.
26. General Medical Council Guidelines. Making and using visual and audio recordings of patients. Available at: www.gmc-uk.org/guidance. Accessed January 16, 2011.
27. Penner LA, Orom H, Albrecht TL, Franks MM, Foster TS, Ruckdeschel JC. Camera-related behaviors during video recorded medical interactions. J Nonverbal Behav 2007;31(2):99-117.

Chapter 8

Nurse-led follow-up care in cancer; what is known and what is needed

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Submitted

Introduction

The impact of cancer and treatment on health and quality of life of patients is substantial.[1] Therefore, the goals of cancer follow-up are multiple. They include the evaluation of treatment and detection of recurrence but should also address psychosocial support. Such support is preferably guided by regular assessment of health related quality of life.[2] Conventional models of care, including traditional medical routine follow-up schedules, regularly fail to meet the needs of supportive care and surveillance of a still growing cancer survivor population.[3-6] Consequently, this has caused a growing strain on outpatient follow-up services, and there is an interest as well as an urgency to redesign existing follow-up and services.[7] Such care redesigning is aimed at supporting patients to manage the clinical and psychological sequelae of cancer treatment, to keep costs of care under control, and to make efficient use of the existing health care work force.[8,9] In general, the trends with respect to alternative follow-up approaches are to reduce long-term secondary care based follow-up, to further develop primary care follow-up, and to evaluate models in which allied health professionals and nurses are in the lead. Furthermore, alternative follow-up care often aims to increase patient-initiated contact combined with educational supported self-management.[5,10,11]

Subsequently, since the 1990's nurse-led cancer services have expanded considerably, encompassing pretreatment-, therapy- and follow-up trajectories.[12] In 2001, a literature review from Loftus et al. highlighted the evolving role of nurse-led clinics since the year 1990.[13] The paper, in particular focused on the nursing skills used and patient needs which could be met by nurses working in these clinics. In 2003, Corner published a review on the existing evidence to support doctor-nurse substitution in the context of cancer services, which was followed in 2009 by a systematic review from Lewis et al. who compared nurse-led versus physician-led follow-up for cancer patients encompassing the literature from inception until 2007.[14,15]

With our paper we aim to provide an update of the state of affairs by highlighting the literature on nurse-led cancer follow-up care of the past five years. Furthermore, we specifically focus on the population of head and neck cancer (HNC) patients, which has been understudied with respect to nurse-led follow-up care and, hence, underreported in the literature.

Our purpose is to provide input for further development of research, clinical practice and education on nurse-led follow-up cancer care.

The cancer patient's view on follow-up care

In a recent series of focus group meetings with cancer patients (breast, gynaecological, and prostate cancer) in the United Kingdom, their views and perspectives on cancer follow-up care were investigated. Also, a separate group meeting was held with people who had cared for a partner, friend or parent with cancer.[6] All patients considered the main purpose of follow-up appointments as providing reassurance, particularly on recovery and absence of symptoms. In case of concerns, rapid access to specialist medical care was viewed as very important. For patients, care access could be either to the cancer consultant or a clinical nurse specialist. Also, accurate information about what to expect during follow-up care, help with returning to work and financial problems following treatment were considered significant. Psychological support needs were considered greatest around the time of diagnosis and initial treatment. These needs were related to support with the changes to everyday life, physical changes, and support for the effects on relationships with family. Patients suggested that support received at this time affected their psychosocial support needs during follow-up care; although this was depend on how successful the recovery process had been. All these points were also stated by the group of carers.[6]

Head and neck cancer patients' views on follow-up care are largely similar to the findings for other cancer patients as described above.[16-18] A specification these patients add is that, primary care professionals, physicians as well as others, need to be educated about HNC patients' post-treatment needs so that they can take an active role in follow-up care. In a recent survey among 263 HNC patients in the United Kingdom, patients stated that, in a traditionally scheduled follow-up system of intensive visits during years 1 and 2, visits were too frequent. Issues addressed at medical follow-up often overlapped those addressed by the allied healthcare professionals involved. A majority of these patients (73%) were in favour of a less intensive follow-up system in which they could also initiate visits themselves. Almost half of them stated that in such a system they would like to contact a specialized nurse first. It was suggested that, because of the important role the patients ascribed to allied healthcare professionals and specialized nurses, a shift of responsibility towards these professionals could be made in the follow-up process, with a very low chance of missing patients with a suspected recurrence. [18]

Nurse-led cancer follow-up care

Nurses play an essential role in supporting cancer patients to manage disease-related problems, in monitoring patients' responses to the health care system's interventions, and in coordinating patient care. Gradually, it is recognized how nurses have become part of multidisciplinary cancer teams with cancer specialists and allied health professionals.[12] This participation often implies the extension of roles and responsibilities, and the taking on of some functions of doctors to further improve service provision, and to reduce costs.

A steadily growing number of studies address the topic of nurse-led cancer follow-up care, and evidence is beginning to emerge on the effectiveness of these initiatives. A systematic review of Lewis et al (2009) reported on comparative studies and economic evaluations of nurse-led versus physician-led cancer follow-up. Seven studies that met the inclusion criteria were detected, of which four were randomized controlled trials. The cancer populations studied were breast, prostate, lung, and ovarian cancer patients. In the studies, no statistically significant differences were detected in survival, detection of cancer recurrence or psychological morbidity.

Regarding HRQoL measures and patient satisfaction, results differed between studies, with an equal number of studies showing statistical differences or no differences. In a group of lung cancer patients, the nurse-led follow-up group (i.e. telephone follow-up) had better emotional functioning and less neuropathy at 12 months than those in a doctor-led follow-up group.

With respect to patient satisfaction it was found that lung cancer patients valued the convenience of nurse-led telephone follow-up. Also, statistically significant more patients in the nurse-led group were able to die at home rather than in a hospital or a hospice, and this was highly valued on the satisfaction scale. In a study of breast cancer follow-up (i.e., patient-initiated vs. conventional hospital scheduled follow-up), no significant differences were found between groups for HRQoL. Regarding patient satisfaction, a statistically significantly greater number of patients in the conventional hospital follow-up group than in the patient-initiated group reported reassurance and being checked as advantages. However, more women in the patient-initiated group reported convenience as an advantage compared to those receiving conventional follow-up.

One study showed the cost of nurse-led follow-up to be less than that of physician-led follow-up, but no statistical comparison was made.[15]

Our update of the literature focusing on outcomes of nurse-led cancer follow-up care from February 2007 (end date of included literature in the review of Lewis et al) to September 2012 was performed in the databases of Medline, Medline in progress, PsychInfo, CINAHL, and the Cochrane database of systematic reviews. Keywords used were: nurse-led, nurse-led clinic, nursing clinic, follow-up, cancer, and outcomes of care. The studies found, addressed the patient populations of prostate[19-21], colorectal[22-27], ovarian[28], oesophageal[29,30], and breast cancer[31-34]. Four of the studies had a randomized design.[22,27,30,33] In six of the studies nurse-led telephone follow-up was evaluated or compared with traditional hospital follow-up, and was reported as having a high patient satisfaction and convenience aspect, as well as saving costs of care and waiting time for patients.[19-21,23,28,31]

In the studies where nurse-led follow-up was compared with physician-led follow-up, outcomes indicated uncompromised medical safety and detection of cancer recurrence with cancer follow-up; while HRQoL and patient satisfaction were equal or slightly better.[25-27,30] In contrast with studies conducted before 2007, more results were reported on economic evaluations or cost-effectiveness.[21,24,25,27,29,31-33]

Lower costs for nurse-led care were described with respect to medical costs, for example less blood test taken and less diagnostic tests ordered.[29,30] However, the total costs of nurse-led care were either not significantly lower [25,29], or did not differ compared to physician-led follow-up.[27]

With respect to nurse-led follow-up care *for HNC patients*, results of research are very limited. The importance of nurse-led care for this patient group has been emphasized with respect to symptom management, tobacco and alcohol cessation, patient and family health education and care coordination.[35] Several studies described projects which implemented nurse-led or nurse-coordinated care to improve HNC patient outcomes. More specifically, these studies looked at using a case management model[36], nurse-led on-treatment care[37], introducing a supportive nurse-led clinic[38], and evaluating nurse-led follow-up consultations.[39]

Wiederholt et al (2007) discuss the necessity and the role of a head and neck oncology nurse coordinator at a single institution in bridging gaps across the continuum of care, and enhancing the overall quality of patient centred HNC care. And although no scientific data are provided, a positive effect of this role is described for the coordination of consultations, the assessment of patient needs and providing patient education, symptom management, and for facilitating an outpatient support group.[36]

The studies of Larsson (2007) and Wells et al (2008) focused on the effects of a supportive nursing care clinic for HNC patients treated with radiotherapy. Larsson's qualitative study, investigated how HNC patients conceived the significance of a supportive nursing clinic before, during, and after completion of radiotherapy. Nurse-led care was complementary to the regular care, and the aim was to improve patients' nutritional status and life situation by providing nutritional care, symptom control, and social and emotional support. The main findings were that this care met patients' needs for safety and security, which were experienced as especially important before and after completion of treatment when there were no other regular contacts with the health care system.[38]

Wells (2008) studied the on-treatment care for HNC patient undergoing radiotherapy. Medical review was compared with nurse-led review on HRQoL, symptom management, and patient satisfaction with care. There were few significant differences in HRQoL between groups, mainly related to cancer site (laryngeal, non-laryngeal). Patient satisfaction with care did not differ. Yet, oral and nutritional problems were better managed in the nurse-led group, as was pain. Nurses more frequently referred patients to other professionals of the multidisciplinary team. Patients' general practitioners were satisfied with the improvement in timely and adequate information exchange of the nurses. As a result of this study, the clinical protocol for reviewing HNC patients undergoing radiotherapy was adjusted and review clinics are now conducted by a specialized nurse.[37]

In the study of De Leeuw et al (2013) patients who attended conventional medical follow-up consultations were compared with patients who also had additional bimonthly nursing supportive care consultations. During the first year post-treatment, both groups were monitored on the primary outcomes of psychosocial adjustment and HRQoL. Some small but statistically non-significant positive effects were detected for HRQoL in the intervention group at 6 and 12 months. However, this group scored more negatively at baseline and was shown to have larger clinical relevant changes than the comparison group, meaning that patients in this group had improved more on HRQoL. As a part of this study, nurse-patient communication was also investigated. Communicative behaviours of nurses responding to verbal emotional cues from patients – and their partners if present - were analysed as either adequate (i.e. exploring or acknowledging the cue) or inadequate (i.e. answering to the cue with distancing behaviour).

In almost 75% of uttered emotional cues, nurses responded using distancing behaviours. In the vast majority of informational questions of patients/partners, responsive behaviour of nurses was adequate. With respect to the main goals of nursing consultations, i.e. adequate assessment and clarification of patients' (and partners') problems and concerns, empathic and understanding acknowledgement, and adequate referral, explorative communication skills were regarded of vital importance. It was concluded that there was room for improvement in nurses' communication skills, to help further develop nurse-led care.[39]

In summary, there is a scarcity in studies with respect to nurse-led (follow-up) care for HNC patients. More research on this theme is needed. There clearly seems to be a promising opportunity to improve the quality of care for this patient population. The several models of care evaluated in the studies discussed above, may further add to the development and evaluation, and the careful embedding of nurse-led care in all phases of the treatment trajectory.

What is needed to further develop nurse-led cancer follow-up care?

The studies on nurse-led cancer follow-up care showed that for patients the end of active treatment is by no means a final stage. Rather, it is the start of new phase of regaining normalcy in daily life and of long-term adjustment toward cancer survivorship. Many patients will benefit from professional nursing support which can help them make this transition. In reflecting on the studies on nurse-led cancer follow-up care, they suggest utility and versatility of this care for cancer patients, but also that more research and organizational investment is required to maximize their contribution. More research on nurse-led cancer follow-up care in general and in particular with respect to HNC patients seems important. Although follow-up care has been recognized as a critical issue in most national cancer reports [4,40,41], it has also been acknowledged that there is an absence of research on good practice, on guidelines for service provision and on the general lack of attention outside the medical treatment context. So, there is some urgency for an increase of research data and for the development of organized and coordinated approaches to follow-up care. The development of new alternative cancer care models including nurse-led initiatives should therefore be placed on the national policy priority list.

RESEARCH

Continued research on nurse-led cancer follow-up care is in need of studies with a rigorous design and substantial sample sizes. Research addressing this topic warrants instruments for assessing needs and health-related outcomes for use with follow-up and long-term cancer survivors, and methodology for evaluating (new) care models. Regularly, no statistically significant differences in patient outcomes were detected when comparing nurse-led care with conventional (physician-led) care.[25,30,39] This lack of statistical significance is not the same as 'no difference' in functional outcomes. Moreover, calculating clinically relevant differences adds value to statistical analyses in showing differences in functional status of patients. An increase in functional status could well be of clinical (and potentially economical) importance.[43,43] In potential, this could be a useful approach when analysing patient outcomes of nurse-led follow-up care. However, in the case of comparing nurse-led versus physician-led care, it sometimes is questioned if research should assume that the outcomes of nursing and medical care are equivalent. As the objectives of both professions are not either, it is sometimes suggested that outcomes of care should be studied separately for both disciplines.[44,45]

It is important to calculate costs and cost-effectiveness when introducing or redesigning care models. But as research showed, nurse-led follow-up care is not necessarily less costly than the conventional (medical) follow-up, i.e. longer consultation time or more frequent patient contacts. What we do not know at this moment is, if short-term costs of nurse-led care are offset by lower costs (of health care and social care) and health benefits gained in the longer term. And if we would know, and it turns out these benefits come at an additional cost, are they worth paying for? Future research which measures long-term costs of nurse-led care (in sufficiently powered studies) could provide part of the answer to this question.

CLINICAL PRACTICE

To further strengthen the quality and continuity of cancer follow-up care and nurses' roles, we would suggest starting with a comprehensive nursing assessment immediate post-treatment. This assessment may then be integrated in the survivor care plan of the patient. Survivor care plans are strongly recommended a handhold for patients, and as the base for individually tailored nurse-led follow-up care.[4,46] Nurse-led follow-up care could then be adjusted and planned according to patients' needs and preferences (i.e., telephone, e-mail, eye-to-eye) as described in this care plan, and could also empower patients to take an active role in their own follow-up management, to the extent that they desire. A structured care plan could also guarantee that no patients will be missed in follow-up and that patient data could be collected for use in future research.

The use of a follow-up care plan also presents an opportunity for collaboration with primary care providers in the community setting as they are expected to take care of long-term cancer survivors.[40] In case of HNC – and this being a relative rarity in primary care practice – there is a lack of knowledge of the disease and its problems among general practitioners as well as community nurses.[17] Therefore, we would suggest further development or the start of professional collaboration between expert services from cancer centres and workers in the community setting. Oncology nurses could fulfil a pioneering role in developing these initiatives.

Besides establishing nurses' roles in follow-up care, we would also suggest to introduce a model of structured nurse-led cancer care encompassing the total treatment trajectory of patients. Research has shown that patients have supportive care needs all through the treatment trajectory.[38,37] The actual ongoing development of nursing case management in cancer care offers a possibility to realize a further quality improvement of patient care.

The future expansion of nurse-led cancer care services demand a critical review of the existing professional skills mix. If deemed necessary, modifications must be made with respect to the required nursing competencies and responsibilities following new nursing roles.

EDUCATION

Almost all nurses will come in contact with cancer patients or cancer survivors during their careers. Therefore, it is suggested that all nurses – not only those specializing in cancer care – have knowledge and skills sufficient to ensure they are competent and confident to deal with people affected by cancer. Nursing schools should offer cancer curricula covering the total cancer care trajectory, including follow-up and long-term survivorship issues. It is also important to underline the versatility of the cancer care field at the start of a nursing career, as this will contribute to attract motivated and well educated new nurses, who will we be able to further develop the quality of cancer nursing care. This is also a

challenge for (cancer) nursing associations and (cancer) nurse leaders too, who must ensure that cancer workforce needs are properly scoped and skills deficits are tackled effectively.
Whatever the situation for nursing consultation is, nurse-patient communication will always be the fundament of the therapeutic relationship. We argue that additional training for nurses would be useful. Particularly, the training of explorative communication skills, and more specifically training in addressing patient statements containing emotional cues. As is known, emotions can block or narrow the patients' (and may be the nurses') cognitive ability to process information[47]. Hence, the subsequent distancing nursing behaviour could limit the so called 'teachable moments' within a consultation. To support nurses in using an exploring communication style, and to promote transfer of training, we advise to set up regular reflective meetings or guided supervision sessions. If requested, a communication refreshment course could also be useful, on the condition that the transfer of skills to daily nursing practice is accommodated by supervision sessions. Without them, learned skills have been shown to have little effect on clinical practice.[48,49]

All this cannot be realized without effective nursing leadership. Many nurses occupy key leadership positions in cancer services, mainly in the frontline clinical services. The strengthening of leadership is of crucial importance to further develop service efficiency and quality improvement. The definition of goals in generic national cancer programs alone is not enough if cancer nurses are not involved at the national level. By using the infrastructure of nursing associations and by establishing cancer nursing networks at a local, regional and national level a significant contribution could be made to support the national cancer program and to further engage in other national level work. This infrastructure also has to be reflected in health care organizations where nurses then can effectively contribute to meet the future demands of cancer care in joint collaboration with other health care providers.

In conclusion, further development of general nurse-led cancer care services and follow-up care in particular contains promising opportunities for the improvement of cancer care. The current evidence has shown that nurse-led services are applicable for almost all cancer populations. However, more research on nurse-led cancer care, preferably embedded in national cancer care programs, would further determine its clinical impact and effectiveness. Initial nursing education should use the current evidence to develop state of the art curricula on cancer care to motivate nursing students for this domain of care. In closing, there is an urgent need to develop or modify cancer services as quickly as possible. The steadily increasing number of patients together with the demands to continuously improve the quality of cancer care makes this a topic of the utmost importance.

References

1. Kjaer TK, Johansen C, Ibfelt E, et al. Impact of symptom burden on health related quality of life of cancer survivors in a Danish cancer rehabilitation program: A longitudinal study. Acta Oncol 2011;50:223-32.
2. National Cancer Institute. Follow-up Care After Cancer Treatment. Available at: http://www.cancer.gov/cancertopics/factsheet/Therapy/followup. Accessed May 12, 2012.
3. American Cancer Society. Global Cancer Facts & Figures 2nd Edition. Atlanta: American Cancer Society, 2011.
4. Gezondheidsraad (Dutch Health Council). Nacontrole in de oncologie (Follow-up in Oncology). Den Haag: Netherlands, 2007.
5. Davies NJ, Batehup L. Cancer follow-up: towards a personalised approach to aftercare services. Macmillan Cancer Support, UK, 2009.
6. Sheldon H, Davis A, Parsons S. Cancer Follow Up Care. Oxford, UK: Picker Institute Europe, 2009.
7. Rowland JH. Cancer survivorship: rethinking the cancer control continuum. Seminars in Oncology Nursing. 2008;24:145-52.
8. Howell D, Hack TF, Oliver TK, et al. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. J Cancer Surviv 2012;6:359-371.
9. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol 2006;24:5117-24.
10. Kate W, Ziv A. Patient choice in cancer follow-up. Eur J Oncol Nurs 2006;10:5-7.
11. National Cancer Policy Board. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington: The National Academies Press, 2006.
12. Gilbert JE, Green E, Lankshear S, Hughes E, Burkoski V, Sawka C. Nurses as patient navigators in cancer diagnosis: review, consultation and model design. Eur J Cancer Care 2011;20:228-36.
13. Loftus LA, Weston V. The development of nurse-led clinics in cancer care. J Clin Nurs 2001;10:215-20.
14. Corner J. The role of nurse-led care in cancer management. Lancet Oncol 2003;4:631-36.
15. Lewis R, Neal RD, Williams NH, et al. Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review. J Adv Nurs 2009;65:706-23.
16. Offerman MPJ, Pruyn JFA. Quality care criteria for patients with head and neck cancer. (Goede zorg voor mensen met kanker in het hoofd-halsgebied: kwaliteitscriteria gezien vanuitde patient). Utrecht: Patientenverenging NSvG en Stichting Klankbord, 2009.
17. The National Cancer Alliance. Head and Neck Cancers. Patient Views and Experiences. NCA Report No.3 ed. Oxford, UK: The National Cancer Alliance, 2002.
18. Trinidade A, Kothari P, Andreou Z, Hewitt RJ, O'Flynn P. Follow-up in head and neck cancer: patients' perspective. Int J Health Care Qual Assur 2012;25:145-49.
19. Anderson B. The benefits to nurse-led telephone follow-up for prostate cancer. Br J Nurs 2010;19:1085-90.

20. Leahy M, Krishnasamy M, Herschtal A, et al. Satisfaction with nurse-led telephone follow up for low to intermediate risk prostate cancer patients treated with radical radiotherapy. A comparative study. Eur J Oncol Nurs 2012. DOI 10.1016/j.ejon.2012.04.003.
21. Shaida N, Jones C, Ravindranath N, et al. Patient satisfaction with nurse-led telephone consultation for the follow-up of patients with prostate cancer. Prostate Cancer Prostatic Dis 2007;10:369-73.
22. Beaver K, Campbell M, Williamson S, et al. An exploratory randomised controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. Colorectal Disease 2012;14(10):1201-9.
23. Jefford M, Lotfi-Jam K, Baravelli C, et al. Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. Cancer Nurs 2011;34:E1-10.
24. Jeyarajah S, Adams KJ, Higgins L, Ryan S, Leather AJ, Papagrigoriadis S. Prospective evaluation of a colorectal cancer nurse follow-up clinic. Colorectal Dis 2011;13:31-38.
25. Knowles G, Sherwood L, Dunlop MG, et al. Developing and piloting a nurse-led model of follow-up in the multidisciplinary management of colorectal cancer. Eur J Oncol Nurs 2007;11:212-23.
26. McFarlane K, Dixon L, Wakeman CJ, Robertson GM, Eglinton TW, Frizelle FA. The process and outcomes of a nurse-led colorectal cancer follow-up clinic. Colorectal Dis 2012;14:e245-49.
27. Strand E, Nygren I, Bergkvist L, Smedh K. Nurse or surgeon follow-up after rectal cancer: a randomized trial. Colorectal Dis 2011;13:999-1003.
28. Cox A, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. Nurse led telephone follow up in ovarian cancer: a psychosocial perspective. Eur J Oncol Nurs 2008;12:412-17.
29. Polinder S, Verschuur EM, Siersema PD, Kuipers EJ, Steyerberg EW. Cost comparison study of two different follow-up protocols after surgery for oesophageal cancer. Eur J Cancer 2009;45:2110-15.
30. Verschuur EM, Steyerberg EW, Tilanus HW, et al. Nurse-led follow-up of patients after oesophageal or gastric cardia cancer surgery: a randomised trial. Br J Cancer 2009;100:70-76.
31. Kimman ML, Dirksen CD, Voogd AC, et al. Nurse-led telephone follow-up and an educational group programme after breast cancer treatment: results of a 2 x 2 randomised controlled trial. Eur J Cancer 2011;47:1027-36.
32. Kimman ML, Dirksen CD, Voogd AC, et al. Economic evaluation of four follow-up strategies after curative treatment for breast cancer: results of an RCT. Eur J Cancer 2011;47:1175-85.
33. Sheppard C, Higgins B, Wise M, Yiangou C, Dubois D, Kilburn S. Breast cancer follow up: a randomised controlled trial comparing point of need access versus routine 6-monthly clinical review. Eur J Oncol Nurs 2009;13:2-8.
34. Cruickshank S, Kennedy C, Lockhart K, Dosser I, Dallas L. Specialist breast care nurses for supportive care of women with breast cancer. Cochrane Database Syst Rev 2008;1.
35. Kagan SH. The influence of nursing in head and neck cancer management. Curr Opin Oncol 2009;21:248-53.

36. Wiederholt PA, Connor NP, Hartig GK, Harari PM. Bridging gaps in multidisciplinary head and neck cancer care: nursing coordination and case management. Int J Radiat Oncol Biol Phys 2007;69:S88-91.
37. Wells M, Donnan PT, Sharp L, Ackland C, Fletcher J, Dewar JA. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. J Clin Nurs 2008;17:1428-39.
38. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: Conceptions of patients with head and neck cancer. Eur J Oncol Nurs 2007;11:49-59.
39. de Leeuw J, Prins JB, Teerenstra S, Merkx MA, Marres HA, van Achterberg T. Nurse-led follow-up care for head and neck cancer patients: a quasi-experimental prospective trial. Support Care Cancer 2013;21:537-547.
40. Signaleringscommissie Kanker van KWF Kankerbestrijding. Nazorg bij kanker: de rol van de eerste lijn. Amsterdam: KWF; 2011.
41. Signaleringscommissie Kanker van KWF Kankerbestrijding. Kwaliteit van kankerzorg in Nederland. Amsterdam: KWF; 2010.
42. Funk GF, Karnell LH, Smith RB, Christensen AJ. Clinical significance of health status assessment measures in head and neck cancer: what do quality-of-life scores mean? Arch Otolaryngol Head Neck Surg 2004;130:825-29.
43. Guyatt GH, Ferrans CE, Halyard MY, et al. Exploration of the value of health-related quality-of-life information from clinical research and into clinical practice. Mayo Clin Proc 2007;82:1229-39.
44. Cullum N, Spilsbury K, Richardson G. Nurse led care. BMJ 2005;330:682-83.
45. Farrell C, Molassiotis A, Beaver K, Heaven C. Exploring the scope of oncology specialist nurses' practice in the UK. Eur J Oncol Nurs 2011;15:160-66.
46. Morgan MA. Cancer survivorship: history, quality-of-life issues, and the evolving multidisciplinary approach to implementation of cancer survivorship care plans. Oncol Nurs Forum 2009;36:429-36.
47. Najmi S, Kuckertz JM, Amir N. Attentional impairment in anxiety: inefficiency in expanding the scope of attention. Depress Anxiety 2012;29:243-49.
48. Heaven C, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. Patient Educ Couns 2006;60:313-25.
49. Uitterhoeve R. Nurse responsiveness to emotional cues of cancer patients. Development of a training program. Thesis. Radboud University Nijmegen, the Netherlands; 2009.

Samenvatting

Kanker is een ziekte die vaak gepaard gaat met agressieve en afmattende behandelingen, vervelende en soms langdurende bijwerkingen, en ernstige fysieke problemen of beperkingen. Veel kankerpatiënten voelen zich fysiek en psychisch getraumatiseerd en worstelen om te begrijpen wat er met hen gebeurt en hoe hiermee om te gaan. Voor mensen met hoofd-halskanker heeft de behandeling bijna altijd gevolgen voor functies als spreken, eten, drinken, slikken, kauwen, ruiken of proeven. Deze beperkingen vragen over het algemeen om aanpassing van leefstijl en dagelijkse gewoonten. Veel verschillende zorgverleners zoals artsen, verpleegkundigen en paramedici zijn dan ook betrokken bij de zorg en begeleiding van deze patiënten.

Nadat een in intentie genezende behandeling voor kanker is afgerond, begint een periode van herstel en het weer oppakken van de draad van het leven. Tijdens deze fase (follow-up) zijn er regelmatige routinecontroles in een ziekenhuis om de effecten van de kankerbehandeling te evalueren en eventuele beperkende gevolgen en bijwerkingen te verminderen of te behandelen. Diverse landelijke rapporten uit de laatste tien jaar vestigen de aandacht op het belang van goede medische, paramedische en verpleegkundige ondersteunende zorg in de kanker follow-up.

De studies in dit proefschrift richten zich op de inhoud, vorm en evaluatie van verpleegkundige zorg in de follow-up periode, voor mensen die werden behandeld voor hoofd-halskanker. We starten met een verkenning van de situatie van de patiënt kort na afronding van de initiële kankerbehandeling, in het bijzonder factoren die het opvolgen van gezondheids-en leefstijladvies beïnvloeden en de behoefte aan ondersteunende zorg (hoofdstuk 2 en 3). Daarna beschrijven we de opzet en evaluatie van een interventie bestaande uit verpleegkundige follow-up spreekuren (hoofdstuk 4), met als belangrijkste uitkomstmaten *psychosociale aanpassing* en *kwaliteit van leven* van patiënten. Een belangrijk kenmerk van goede patiëntenzorg is de kwaliteit van de communicatie tussen alle betrokken partijen. In dit proefschrift krijgt de specifieke verpleegkundige-patiënt communicatie ruim aandacht in hoofdstuk 5 en 6.

Samenvatting hoofdstukken

Hoofdstuk 1, de introductie, beschrijft de achtergrond van het proefschrift. Het specifieke verpleegkundig perspectief, van waaruit de studies zijn uitgevoerd, wordt geschetst. Belangrijke begrippen *zoals kwaliteit van leven* en *psychosociale aanpassing* aan ziekte worden uitgelegd en in de context van de follow-up fase geplaatst. Het begrip *kanker follow-up* en de actuele professionele discussiepunten worden beschreven. Daarnaast is er aandacht voor de kijk van de patiënt op diverse aspecten van follow-up, gevolgd door een beschrijving van het belang van adequate en bij het perspectief van de patiënt aansluitende professionele communicatie. Tot slot wordt de rol van de oncologieverpleegkundige in de follow-up besproken.

Hoofdstuk 2 beschrijft een kwalitatieve studie waarin 21 patiënten individueel worden geïnterviewd over de beïnvloedende aspecten bij het opvolgen van gezondheids-en leefstijladvies en instructies van zorgverleners. Interviews vonden plaats twee tot zes maanden na een in opzet genezende behandeling voor hoofd-halskanker. De resultaten laten zien dat patiënten regelmatig meerdere en diverse typen van advies of instructie tegelijk, of in korte tijd, krijgen (tot wel 14 adviezen), waarvan een deel vraagt om leefstijlverandering. Dat laatste is niet gemakkelijk, en patiënten geven aan te worstelen met het vinden van manieren om adviezen in te passen in het dagelijks leven. Wat hen hierbij helpt zijn empathische, meedenkende en aanmoedigende zorgverleners, die zich verdiepen in de individuele situatie van de patiënt. Patiënten verwoorden dat de eigen kijk op gezondheid en gezondheidsbevorderend gedrag een belangrijke rol hierbij speelt, in het bijzonder bij het verwerken van de informatie van zorgverleners. Deze studie toont (opnieuw) het belang van het professioneel bewustzijn van de, soms complexe, interactie van deze beïnvloedende factoren bij het geven van gezondheids –en leefstijladviezen aan patiënten.

Hoofdstuk 3 geeft inzicht in de behoefte aan ondersteunende zorg, een maand na beëindiging van de initiële kankerbehandeling, in een groep van 52 patiënten, allen gestadieerd met grotere tumoren (T3 of T4) en met conventionele radiotherapie als een component van de behandeling. De geselecteerde behandelmodaliteiten in deze studie zijn: chirurgie-radiotherapie (SRT), radiotherapie (RT) en chemoradiatie (CRT). Het doel van deze cross-sectionele vragenlijststudie is het in kaart brengen van domeinen van KvL die om meer intensieve en langer durende zorg en begeleiding vragen, en de verschillen hierin tussen de geselecteerde behandelmodaliteiten. De resultaten laten zien dat er klinisch relevante verschillen zijn tussen de groepen, waarbij de SRT-groep relatief de minste beperkingen rapporteert. De beide andere groepen (RT en CRT) rapporteren sterke beperkingen op de domeinen van voedsel-en vochtinname en gerelateerde domeinen zoals kauwen, slikken, droge mond, taai slijm en beperkte mondopening. Deze resultaten benadrukken het belang van intensieve monitoring en continuering van ondersteunende zorg gedurende de eerste maanden van de follow-up fase voor deze specifieke groep hoofd-halskankerpatiënten.

Hoofdstuk 4 rapporteert over de resultaten van een prospectief niet-gerandomiseerd experiment met 160 patiënten. Een interventiegroep (n=80) wordt vergeleken met een historische controlegroep (n=80), die ’zorg zoals gebruikelijk’ kreeg. Deze studie evalueert het effect van gestandaardiseerde verpleegkundige follow-up spreekuren voor hoofd-halskankerpatiënten in het eerste jaar na een, in intentie, genezende behandeling. De belangrijkste uitkomstmaten zijn *psychosociale aanpassing* en *kwaliteit van leven* (KvL). De verpleegkundige spreekuren bieden ondersteunende zorg bij symptoommanagement en psychosociale problemen, waarbij zorgen en klachten gestructureerd worden geïnventariseerd en besproken met patiënten. Doel hiervan: zelfmanagement – en controle bij de patiënt bevorderen, stimuleren tot het oppakken van de draad van het leven, desgewenst adequaat door te verwijzen naar bijvoorbeeld psychologische hulp of kankerherstelprogramma’s, en het bekende ‘luisterende oor’ te bieden. De resultaten van deze studie laten zien dat de interventiegroep start met slechtere baseline scores (meetmoment: 1 maand na behandeling) dan de controlegroep, maar dat op de 12-maanden meting de scores niet meer verschillen. Dit betekent dat de interventiegroep een grotere verbetering laat zien in de tijd, alhoewel deze niet als statistisch significant kan worden aangemerkt. Tijdens de 6-maanden meting zijn er klinisch relevante verschillen te zien tussen de beide groepen, met name in de KvL-symptoomschalen, ten faveure van de interventiegroep. De methodologische beperkingen van het ontwerp van deze studie staan oorzaak-gevolg uitspraken niet toe. Het is echter wel interessant verder te bestuderen wat de verschillen tussen de beide groepen heeft doen ontstaan.

Hoofdstuk 5 beschrijft hoe vaak verpleegkundigen communicatief adequaat en inadequaat reageren op signalen van emotionele spanning in patiënten. Een acteur speelt in deze studie de rol van patiënt. Onderzocht wordt in hoeverre het emotionele niveau van de signalen van een patiënt bepalend is voor de reactie van de verpleegkundige en omgekeerd of de soort reactie van de verpleegkundige (adequaat of inadequaat) van invloed is op het emotionele niveau van de reactie van de patiënt. De Medical Interview Aural Rating Scale (MIARS) wordt gebruikt om de 35, op video opgenomen, gesprekken te coderen. Op deze codering wordt een interbeoordelaarsbetrouwbaarheidsanalyse uitgevoerd die als 'hoog' wordt vastgesteld. De resultaten tonen dat verpleegkundigen op de helft van de signalen van emotionele spanning van patiënten inadequaat reageren. Meestal is dat door het (deels) negeren van de emotionele betekenis van het signaal. Het emotionele niveau van een signaal is niet bepalend voor de daaropvolgende reactie van de verpleegkundige. De reactie van de verpleegkundige beïnvloedt wel het emotionele niveau van de daaropvolgende verbale expressie van de patiënt. Een adequate reactie van de verpleegkundige leidt tot een verdubbeling van de kans op een expressie van zorgen of emotie door de patiënt, in vergelijking met een inadequate reactie van de verpleegkundige.

Hoofdstuk 6 beschrijft een tweede studie over verpleegkundige-patiënt communicatie, gesitueerd in de poliklinische (niet-gesimuleerde) setting en met verpleegkundige follow-up spreekuren als context. In deze studie wordt ook de communicatie met een eventueel aanwezige partner tijdens het spreekuur gecodeerd en geanalyseerd. De Medical Interview Aural Rating Scale (MIARS) wordt wederom gebruikt om 17, op video opgenomen consultaties, te coderen en analyseren. Een analyse van de interbeoordelaarsbetrouwbaarheid, op de codering van de gesprekken wordt ook in deze studie als 'hoog' aangemerkt. De verpleegkundigen in deze studie reageren adequaat op emotionele signalen van patiënten en partners in ongeveer een kwart van de voorkomende gevallen. Er zijn geen opvallende verschillen in reacties van verpleegkundigen op signalen van patiënten of die van partners. We concluderen dat er verbetering van het reageren op emotionele signalen van patiënten en partners door verpleegkundigen mogelijk is. Tevens stellen we vast dat het veranderen, en 'ontleren' van al veel langer bestaand professioneel (communicatief) gedrag lastig en moeilijk is, ook al zijn verpleegkundigen voorafgaand aan de studie kortdurend getraind. Verder behoeft de interactie en communicatie in de patiënt-partner-zorgverlener context meer onderzoek. De aanbevelingen van deze studie zijn gericht op regelmatige bijscholing op het gebied van communicatie en op het bevorderen van reflectieve praktijkvoering bij oncologieverpleegkundigen door het invoeren van reflectie- en casuïstiekbespreking in de klinische praktijk.

Discussie

Hoofdstuk 7 beschrijft de onderzoeksresultaten van de diverse studies in samenhang met de methodologische beschouwingen.
Hoofdstuk 8, ten slotte, is geschreven in de vorm van een separaat artikel en beschrijft de actuele stand van zaken van ontwikkelingen en effecten van verpleegkundige follow-up voor kankerpatiënten in het algemeen en voor hoofd-halskankerpatiënten in het bijzonder. Dit hoofdstuk bevat tevens de aanbevelingen voor (vervolg)onderzoek, de klinische praktijk en onderwijs.
Deze worden als volgt samengevat:

ONDERZOEK

- Vervolgonderzoek wordt aanbevolen, specifiek over ‘klinisch relevante verschillen’ in uitkomsten van follow-up zorg wanneer bijvoorbeeld verpleegkundige en medische zorgmodellen worden vergeleken.
- Vervolgonderzoek naar kosten en kosteneffectiviteit van de verschillende soorten follow-up zorg (verpleegkundig, medisch) is relevant. Momenteel is nog onbekend of de kortetermijnkosten van verpleegkundige follow-up zorg (die niet *per se* lager zijn dan die van medische follow-up) worden gecompenseerd door lagere gezondheidszorgkosten op de langere termijn. Dit vraagt om studies met een groot aantal proefpersonen.

KLINISCHE PRAKTIJK

- Beschouw de follow-up fase als een volwaardige ‘behandelfase’, en start deze fase door met iedere hoofd-halspatiënt een individueel nazorgplan te formuleren. Zet oncologieverpleegkundigen in om hierin de regierol te vervullen.
- Organiseer verpleegkundige follow-up spreekuren voor hoofd-halskankerpatiënten in het eerste jaar van follow-up, zodat adequaat kan worden ingespeeld op behoeften aan ondersteunende zorg van patiënten en ontsporing van problemen wordt verminderd of voorkomen.
- Overweeg verpleegkundige spreekuren voor hoofd-halskankerpatiënten in te voeren in het gehele behandelcontinuüm. Patiënten en naasten hebben niet alleen tijdens de follow-up periode behoefte aan ondersteunende zorg.
- Nieuw zorgaanbod voor hoofd-halskankerpatiënten brengt nieuwe taken en verantwoordelijkheden voor oncologieverpleegkundigen met zich mee. Dit vraagt om een kritische beschouwing en evaluatie van de bestaande

professionele functiemix, en waar nodig aanpassingen in het licht van de gewenste professionele kwaliteit.

ONDERWIJS

- Omdat bijna alle verpleegkundigen tijdens hun werk in aanraking komen met (ex)kankerpatiënten is het van groot belang dat initiële beroepsopleidingen een gedegen curriculum over kankerzorg aanbieden. Het totale behandelcontinuüm moet daarin aan bod komen, inclusief follow-up zorg, secundaire preventie, leefstijlbegeleiding en langetermijnoverleving. Het is tevens een goede gelegenheid de veelzijdigheid van het werken in de kankerzorg aan bod te laten komen en zo gemotiveerde en goed opgeleide toekomstige oncologieverpleegkundigen aan te trekken.
- De basis in ieder patiëntencontact is adequate communicatie. Twee studies in dit proefschrift tonen aan dat hierin nog verbetering valt te behalen. Met name op het vlak van explorerende gesprekstechnieken en meer specifiek in het reageren op signalen van emotionele spanning of zorg van patiënten. Regelmatige en aanvullende training voor verpleegkundigen gebaseerd op de laatste inzichten wordt aanbevolen.
- Omdat emoties, in welke vorm dan ook, communicatie beïnvloeden of zelfs blokkeren bevelen we aan, om voor oncologieverpleegkundigen reflectie- of supervisiebesprekingen te organiseren, waar in een veilige omgeving werkervaringen uit de dagelijkse praktijk van de kankerzorg besproken kunnen worden. Op deze manier wordt reflectieve praktijkvoering ondersteund en dat zal de professionele verpleegkundige-patiënt communicatie ten goede komen.

Afsluitend

Al het bovenstaande is lastig, zo niet onmogelijk te verwerkelijken zonder effectief (klinisch) verpleegkundig leiderschap. Veel verpleegkundigen bekleden sleutelposities binnen de kankerzorg, zeker sinds de invoering van het casemanagement binnen de oncologie en van functies als die van verpleegkundig specialist of – consulent. Het behouden en versterken van deze leiderschapsposities is belangrijk om de kwaliteit, effectiviteit en efficiëntie van het zorgaanbod verder te ontwikkelen.

Daarnaast is de zichtbaarheid en positionering op regionaal en landelijk niveau van belang, in netwerken, belangenorganisaties en bijvoorbeeld nationale kankerprogramma's. Hierbij is de infrastructuur van een nationale beroepsvereniging relevant om in dit streven te faciliteren. Die zichtbaarheid van (oncologie)verpleegkundigen zou ook weerspiegeld moeten worden op alle niveaus in de gezondheidszorginstellingen zelf. Op die manier kan het meeste rendement worden verkregen uit de samenwerking met andere disciplines om de kankerzorg verder vooruit te brengen.

De conclusie van dit proefschrift is, dat oncologieverpleegkundigen veilige en kwalitatief verantwoorde follow-up zorg geven aan patiënten die zijn behandeld voor hoofd-halskanker. Vervolgonderzoek over deze zorg zou gezien de nationale ontwikkelingen, goed passen in het nationale kankerprogramma, zodat op grotere schaal de klinisch relevante effecten kunnen worden vastgesteld en passende onderzoeksmethoden kunnen worden aangewend. De gestaag groeiende kankerpopulatie en de vraag naar kwalitatief excellente kankerzorg maken nieuwe modellen voor zorgaanbod noodzakelijk en geven tegelijk enige urgentie mee aan dit onderwerp.

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> *Je moet leren om de dingen te begrijpen die je niet snapt,*
> *Je moet begrijpen dat er ook dingen zijn die je niet snapt,*
> *Je hoeft niet alles te weten, het is genoeg te begrijpen*.

Zonder mensen tekort te willen doen beperk ik me tot het noemen van hen die een bijzondere rol hebben gespeeld.

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Het altijd steunend thuisfront. Marcel.

Curriculum Vitae

After high school graduation Jacqueline de Leeuw started her career in health care when she began her training to become a Registered Nurse at the University of Applied Sciences in the city of Nijmegen. Subsequently, she worked as a nurse in psychiatry, in the care for the mentally handicapped, and in hospital care. In the university hospital of the Radboud University Nijmegen Medical Centre she worked in the medical specialties of neurology, internal medicine, general surgery/traumatology and surgical oncology. Over the years she obtained a bachelor's degree in Health Management and in Education, and she combined her nursing work with the function of clinical nurse teacher. In the meantime she obtained her Master of Science degree in Nursing at the University of Cardiff, UK/Utrecht University of Applied Sciences. Her dissertation addressed the topic of transfer of learning in nursing students in the Netherlands. In the year 2000 Jacqueline switched to a job as a nursing policy advisor of the Neurosensory Cluster of the Radboud University Nijmegen Medical Centre. From there on plans for carrying out nursing research developed. From 2006 to 2012, she worked as a PhD student (half-time) on the project described in this thesis. Until this day, Jacqueline has always been involved in policy groups and associations that strive for the advancement of nursing practice and nurses' roles in health care. Currently, she is the chairperson of the working group of Oncology Nurses of the Radboud University Nijmegen Medical Centre Oncology Centre, and a board member of the Dutch Nursing Association (V&VN). Also, she is a scholar at the European Academy of Nursing Science (EANS). As from September 2012, Jacqueline holds a position as an expert nurse at the department of Otolaryngology – Head and Neck Surgery at the Radboud University Nijmegen Medical Centre.